

What you don't know will hurt the patient

Cross-cultural clinical medicine and communication with ethnic minority patients

Morten Sodemann

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with ethnic minority patients

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1. Introduction

All humans are built the same way. We consist mostly of water, fat, and protein, and we all carry around 39 billion bacteria. We also have 99 % of our DNA in common, which leaves very little room for variation. It is often said that the genes 'load the gun' but the living conditions determine whether the gun is fired. The points where we differ are our upbringing and social living conditions, the environment, and the scope of collective preventive measures against illness and social catastrophes. Over the last few decades, our knowledge has greatly increased about the influence of the environment on how genes are expressed and how many genes are expressed (epigenetics). The conditions under which our grandparents were raised affect their grandchildren's risk of illness. Negative experiences during childhood increase the risk of chronic illness, mental illness, and early death as an adult.

The most important issue is not which illness the person has, but rather which person has the illness. When you as a health professional meet a new patient for the first time, an automatic and rapid process starts up with the purpose of placing the patient into a known frame of understanding: *'What kind of patient is this? Do I like the patient? Strange patient? Clever informer? Competent? Annoying? Do I respect the patient? Can I trust the patient? What illness is the patient trying to describe?'* To this end, we as health professionals draw on a motley hybrid collection of experiences stitched together by prejudices, stereotypes, implicit bias, our own experiences of illness, experiences with previous patients, illness theory, and the hidden learning gained from colleagues over the years. This assembly of experiences is sorted depending on your energy, mood, and blood sugar at that very moment - and you choose among your experiences based on the first-hand impression of the patient.

This model, however, does not always work for most of the health professionals in the current Danish healthcare system, whose experiences have been developed and refined based primarily on a life in Denmark and with patients born and raised in Denmark. Thus, health professionals get into trouble when they encounter patients who have lived as nomads in the desert between Iraq and Kuwait all their lives; when they encounter adult patients who started working in the rice fields when they were five years old, were seamstresses at the age of 10, and canoed through dead bodies that was floating in the water as a 13-year old; or when they encounter a nuclear physicist from Iran who cannot remember his own name after eight years of imprisonment and daily torture. *'You have to understand how it is not to be understood in order to understand it'*, a patient from West Africa once told a nurse who tried to understand why the patient declined tuberculosis medication. For this reason, it has been a goal of the Migrant Health Clinic (MHC) to try to describe what the health professional has to understand 'in order to understand it'.

Intercultural dilemmas in cross-cultural medicine are diverse, and the solutions are seldom simple:

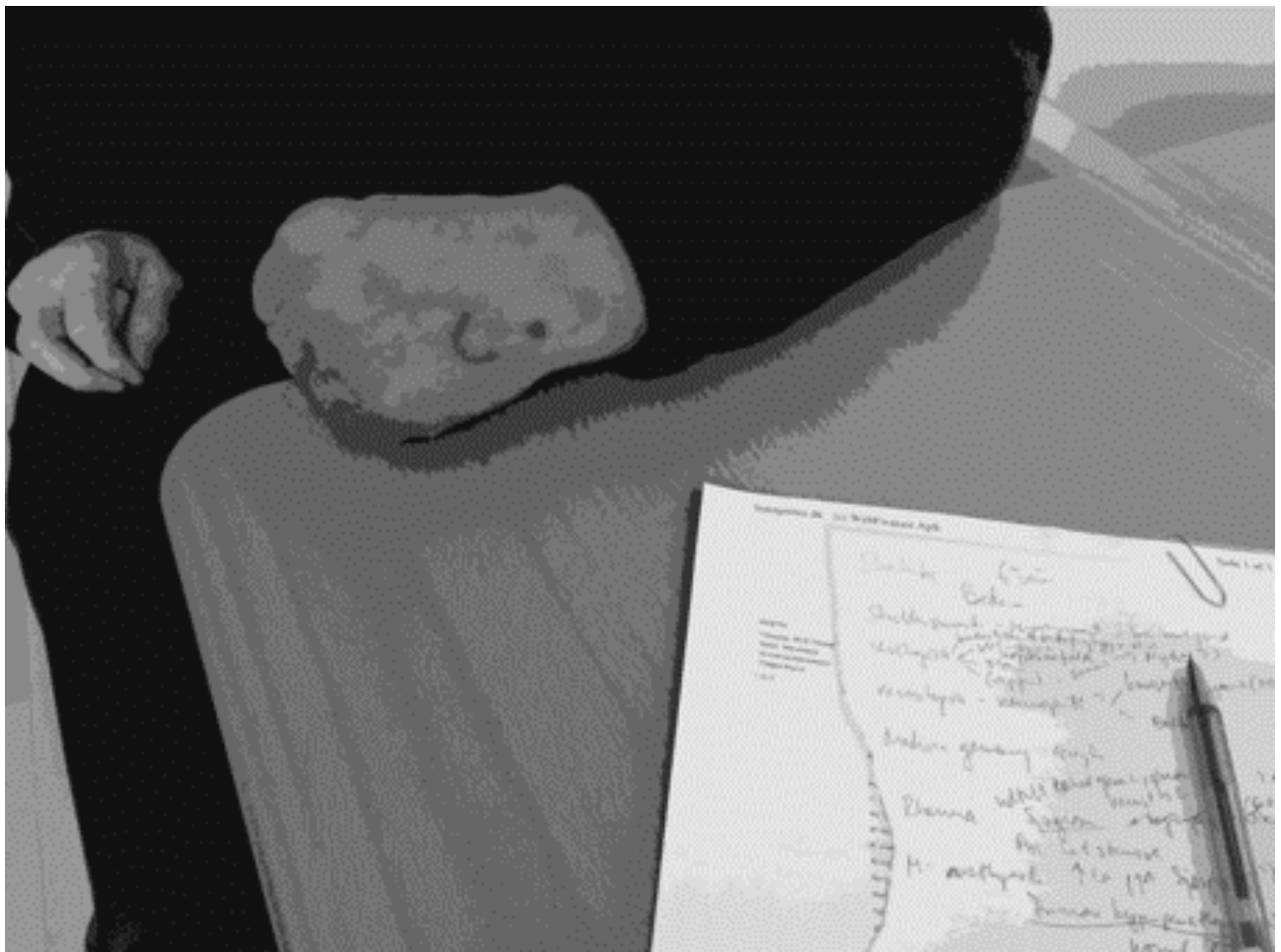
- The legitimate needs of migrants and refugees for cultural sustenance and recognition are seldom fulfilled - and maybe even rejected.
- Specific experiences with diagnostic issues, misdiagnoses, and misunderstood symptomatic manifestations reduce the confidence in and use of the healthcare system ('ethnic pains' etc.).
- Symptoms may be an expression of an intercultural discomfort or chronic homesickness/sorrow because of what has been lost, or they may be caused by deeper unfulfilled expectations of Denmark - expectations that have never been discussed with or agreed upon by the patient.
- It is hard to understand the extreme stress of having experienced severe trauma and at the same time having to live alone with this trauma in a country where you neither speak nor understand the language.

- Compliance issues, which may considerably limit treatment options, are often caused by unrecognised layman's comprehension of illnesses or misunderstood information on illness or treatment.
- The poor economy that migrant families often suffer can influence a number of choices that have consequences for health and treatment. The health professional's lack of understanding regarding the link between poverty and disease management can essentially limit the patient's options.
- A different - many might say patriarchal - concept of the relation between the sexes and between generations and of contacts with the doctor, can derail the routines of the healthcare system and make health professionals give up.
- Health professionals often have a very broad exemption from liability in meetings with patients who are migrants/refugees, which is in sharp contrast to the general requirements for patient involvement and mutual decision making, and this can lead to some less desirable (or less tenable) clinical decisions.
- Options are lacking for grief management after a death, e.g. through visiting arrangements or timely washing of the dead person at the hospital.
- The (current) sky-high fee for interpreter assistance in hospitals limits the exchange of important information and questions and can lead - understandably - to mistrust.
- Health professionals can react by getting stressed or feeling inadequate when they are confronted with strong emotional expressions, violent trauma, incomprehensible symptoms, or clearly hopeless situations. Professional inadequacy may lead to irritation and outbursts of anger, which worsens the relationship with the patient and relatives.
- Complicated family backgrounds and opaque decision-making processes make the usual process of care difficult. The distribution of family roles, including who really influences the decisions (e.g. an older family member in the home country), is only partially visible.
- Refugees experience more critical social events than health professionals are used to, and these very often lead to violent identity crises, doubt about future prospects, rootlessness, and a feeling of emptiness that borders on a schizophrenic state.
- Insecure and unhealthy housing conditions and a fragile work situation with a high risk of accidents influence and maintain a high risk of illness.
- Tightening of immigration rules and uncertainty about future residency demoralise the immigrants' self-care, increase their risk of illness, and lower compliance (e.g. relating to language school, smoking cessation, weight loss, or medical treatment). There is a constant see-saw between going home to uncertainty and staying in Denmark in uncertainty - their soul is in their homeland, but their body is in Denmark.
- Language challenges and social segregation processes affect the risk of illness and health behaviour in ways that health professionals are unaware of.
- Children of adult war refugees have particular hidden challenges that get overlooked in the healthcare system as these children are in many ways more adapted in both culture and language.

This book is not a substitute for medical or surgical textbooks. The book deals with everything that we don't know about patients from a different background compared to patients we are familiar with. As the Danish poet Piet Hein put it: 'Knowing what you do not know - is, however, a kind of omniscience'. This book is intended to highlight the known unknowns about migrant health and hopefully through that insight to awaken a professional curiosity among health professionals in their encounter with refugees, migrants and ethnic minority patients. It is about everything that we forget, overlook, ignore, misinterpret, minimise, or simply give up on. And then there are the small things that are rare, strange,

and which we are not used to. Regard it as a book that is perhaps primarily about experiences collected while examining and treating patients of immigrant background, but which is basically about how many things become understandable when you understand the patient and their background - regardless of whether the person was born in Sweden or Somalia. We have most of the body in common, we have most illnesses in common - but, it is the life story, the social events, resources, trauma, actions, the help we receive, and the social consequences that determine whether we get ill, how we become ill, how we live with the illness, and how long we live with it.

The cross-cultural encounter is an extremely complicated four-way intersection between the foreign and different, the overt threat to professional competence, the idealisation of the victim role, and the dehumanisation/devaluation of the human being. Furthermore, this intersection is light-regulated by constantly shifting legislation, complicated requirements from social authorities, poor economy, language requirements, and the public rhetoric. Thus, besides having to understand the individual patient's life, you also have to understand the often less visible, external factors that influence their life, body, and soul in exile.



2. Body and soul in exile

2.1. The baggage and circumstances of exile

The number of armed conflicts is increasing around the world, and the number of UN refugees reached its highest ever level in 2013. Most refugees are victims of crises such as brutal regimes, civil war, anarchy, and famine. They have often been put in danger due to their ethnicity, religion, or political conviction. They may have endured persecution, torture, rape or abduction, or they may have witnessed a killing. Many arrive after dangerous travels and detention in refugee camps. They have lost their relatives, social networks, homes, belongings, and work. Between 30 and 70 % of refugees have faced severe traumatic experiences and have developed signs of chronic post-traumatic stress disorder (PTSD) of various types and severity.

Refugees flee for many different reasons. In some contexts, it may be important to know the most common types of refugees and the reasons for their flight. There are two basic types of refugees that we should be aware of, as these can affect our understanding of the individual refugee: 1) the pre-emptive refugee who perceives the danger and leaves the area while it is still possible to do so in an orderly fashion. Often the entire family flees together and manages to take essential belongings with them. These refugees are typically well educated and more affluent and have a functioning network that may assist them, and they can afford to pay for a secure escape route. 2) The acute refugee whose flight is seldom well prepared. They typically flee when the danger has reached its peak, and they must leave behind the few belongings they have and are forced to contend with insecure and dangerous escape routes without any protection. It is often during the flight that the refugee experiences the greatest helplessness and vulnerability. This group is often completely unprepared, shocked, and disoriented when they arrive at the host country. They have no strategies for the future besides getting away from war and uncertainty (1-3). For this group of refugees, it is often only when calm sets in when in the host country that they fully realise the loss and finality of their decision. At this point, many refugees become apathetic and begin to feel helpless about their lives, while others become manic or aggressive in their frustration over feeling powerless and lacking the ability to act or communicate (4). For a comprehensive review of the types of refugees and escape routes, please see Kunz, *The Refugee in Flight: Kinetic Models and Forms of Displacement* (5, 6).

Many children fleeing from war experience multiple traumas including exposure to armed conflict, displacement, loss of close adults, loss of safety, and continued severe mental stress (7). New social contexts in the host country may present new physical and emotional risks for children. In recent years, there has been increasing recognition of the close association between the physical/mental health of children and negative childhood experiences and later illness as adults, which manifests as developmental disorders that have their source early in life (8). An extensive review and launch of a biological model created a plausible connection between early hardship during childhood and increased vulnerability and susceptibility to later illness and early death (9). Understanding how these models relate to the health of refugees is but one of many arguments for interventions to reduce long-term damage from armed conflicts. By way of example, increased awareness, a heightened state of alertness, and distrust are typical behavioural and cognitive reaction patterns when children are faced with high levels of threat (10). Even if the reactions are rational adaptations to threats and uncertainty, they increase the risk of developing negative relations with others, including those who might be able to help them (11). This limits the possibility of creating potentially beneficial interventions for children. Their risk of developing chronic illnesses as adults is also increased by the higher likelihood of impulsive behaviour, reward-oriented personality, and unhealthy lifestyle choices, which may lead to obesity and alcohol and drug addiction (12). A review of the health risks among migrant populations from 2015 by Rook et al. revealed

that the migration process itself seems to increase the risk of illnesses such as type 1 diabetes or multiple sclerosis (13).

No refugee can imagine how life will be in the host country. The refugee's strategy is to escape from the insecurity, persecution, and war, not to live as a minority in some faraway country. This implies that many situations in the host country will be first-time experiences entailing unfamiliar problems, which only adds to their stress and uncertainty. Being a refugee equates to living through massive and extensive losses. It is a grief process that can be expressed in various ways, depending on the person's culture. Such existential pain is frequently expressed through body language or symptoms because these are the only things that are available, understandable, or acceptable in one's environment. The real story is horrible and cannot be shared with others. Consequently, several less painful life stories are constructed, which one needs to keep track of with regards to oneself and one's spouse, children, family, and friends and the authorities. If, at the same time, one experiences that one's language, culture, life history, and person are discredited, there is only one direction - isolation and a tightening of the cultural wrapping. Values from one's home country become more important. Clothes, ceremonies, and events are prioritised in one's daily life, and the inner values and defence mechanisms are reinforced in an attempt to re-establish an identity. This results in situations where contact or a real conversation with a professional might have been available, but instead, all manner of other agendas must be handled before the key service can be attended to. If the professional is not aware of the many identity and security-building processes at play, then the conversation becomes brief, imprecise, and unsuccessful.

2.2. Health and risk of illness among immigrants, refugees, and migrants

In 1974, physicians Klebak and Kabel described in *Ugeskrift for Læger* [a Danish weekly medical journal] four serious cases where children (infants) of foreign workers were hospitalised with severe dehydration and infection. This occurred after multiple failed attempts to contact the healthcare system. Three of the children died less than 12 hours after hospitalisation, while the third one recovered after it was discovered that the child had a gluten allergy. In the article, the doctors recommended that foreign workers be offered access to social services on the same terms as other Danes, that professional health interpreters be trained and used, and that targeted healthcare services be created for this population group (14). Magistrate judge Fanny Hartmann later commented on the case in the same journal:

All four of the foreign worker families ... had received good information ... and had used this information in the prescribed manner. They contacted their doctor, but it did not save their lives. In three of the cases, the on-call GP utterly failed. They would have been treated differently had they lived on up-scale residential streets in Copenhagen. These particular medical cases indicate that the Copenhagen health care system has some enormous cracks which the socially weakest users of the system - including many foreign workers - risk falling into (15).

In a critical article in the newspaper *Land and Folk* from 1974, the Danish Health Authority is confronted with the chain of events, but as an office manager concludes, 'The article in *Ugeskrift for Læger* is not well suited as a basis for sensational articles ... the chain of events reveals a failure in communication due to language difficulties rather than a failure of the healthcare system' (16). Language and communication are not considered services that the healthcare system is responsible for, but rather as an irritating condition that the healthcare system has no influence over. This family's experience and the comments from doctors and officials very accurately describe the challenges that ethnic minority patients are faced with - language barriers, lack of information, and social inequality create a very unfortunate interplay, and no one is willing to take responsibility for the consequences. Language barriers have not been perceived as a failure in the healthcare system, and this is still the case.

Not much has changed in the 43 intervening years because in 2017 two children of Congolese refugee parents died from acute liver failure after the family had apparently eaten poisonous mushrooms. The family sought medical help several times, and yet the Danish Patient Safety Authority and Region Zealand concluded in two independent investigations that no medical error had been committed in the case (17). Just as in 1974, no interpreter had been used in this acute situation and the family had sought medical help several times before the children were finally admitted, only to die a few hours later.

Social inequality exists in healthcare, but language barriers and the life situations of minorities amplify the negative effects of short education, weak social network, and social exclusion. This leads to a type of social inequality in healthcare that is more complex than what we usually see. Doctors often have to deal with ambiguity and uncertainty and are to a certain extent trained to deal with this, but not all of them are happy about it. Many doctors are challenged far beyond their competencies and what their personalities can handle (18). Interviews with refugees/immigrant patients often feature ambiguous or uncertain symptoms that are often further complicated by language barriers, while the patient's fear of not being understood may distort the medical history. Traditionally, we have talked about culture clashes and the need for cultural competencies to reduce contrasts, yet it is more likely a clash between routines. Routines and rituals surrounding illness are deeply rooted in humans, but they are learned during childhood and are thus coded in one's mother tongue. To achieve mutual understanding in doctor-patient communications with migrants requires professional curiosity, cultural sensitivity, and a good interpreter. As doctors, we tend to limit our thinking of the life and situations of refugees/immigrants to their Danish life - that starts when they get a health insurance card. As a consequence, we are implying that the life history, social events, physical and mental trauma, war experiences, accidents at work, severe courses of illness, and neglect during childhood in the home country are of no interest in a Danish context. We probably do this because we either do not believe that we are capable of understanding the patient's experiences, or because we do not believe we can use the information in the clinical decision process - that perhaps these elements would interfere with diagnosis and treatment. We might even have a tendency to perceive *the cultural aspect* as misleading and irrelevant to the doctor's objective assessment of the patient's symptoms. By removing the cultural aspect, the physician can treat the case in a neutral way to the benefit of both patient and doctor. However, precisely by knowing- or unknowingly ignoring the importance of the patient's life prior to Denmark, we plant the seed for many misunderstandings between patient and doctor. When we fail to understand the patient's beliefs, circumstances, and motivations, the symptoms become strange, ambiguous, and irrational and the patient ends up becoming even more of a stranger to us. On the other hand, if we try to understand the patient from a complete life-historic perspective, then the strange and irrational become understandable. All humans are rational according to their own terms. To understand patients, we must understand their terms. To understand refugees/immigrant patients, we must understand their lives before they arrived in Denmark and the causes and risks of migration, as well as how life as a minority person in Denmark influences language, body, and soul.

Migration has a wide variety of causes, and the migration process entails many different phases. Each cause of migration is associated with a particular set of health-related strengths and risks. Moreover, the pre-migration phase, the migration itself, the integration phase, and the post-integration phase are each associated with risks of illness and often long-term health consequences. The health of migrants is shaped by their experiences and circumstances in their home countries, during transit/migration/flight, in the host country, and in their current situation - and in some cases, also during repatriation to their home country (19, 20). The conditions for self-care, self-regard, identity and future perspectives change throughout these phases of migration. The structures that normally protect most people against serious physical or mental illness disappear and can reappear with new actors and new social rules in unfamiliar circumstances that require one to renegotiate one's role in social contexts as both a human and a patient. Ambiguous requirements are stressful and easily lead to low self-esteem, anxiety,

and depression: you have to be in an extremely weak position to obtain asylum, yet you must keep strong enough to keep your fragmented family together. You have to be strong to deal with the Danish language and job market, but weak enough to have your residence permit extended or to apply for early retirement benefit.

The concept of a *healthy migrant effect* has existed for many years. This concept arose when people wondered why South American migrants working in the southern US were in relatively good health compared to the local population. This phenomenon was then studied in Europe, initially with the theory that it was the healthy people who fled or migrated to Europe, and simultaneously assuming that the ill, and in particular older, refugees/migrants returned to their home countries (21). However, a large Danish registry study from 2014 found no such healthy migrant effect (22), and those who migrated back to their home countries showed no particular tendency toward illness (23). What was found, however, were great social differences - and differences in illness types - between ethnic groups and reasons for migration. Several Danish studies have shown that refugees and immigrants who come to Denmark from non-Western countries have a longer average lifespan than ethnic Danes and that the difference is primarily due to cancer, alcohol-related illnesses, and illnesses related to smoking (24, 25). The same trend has been found in other European countries (26). Thus, the so-called healthy migrant effect is much more telling of the health profile of the local population than it is of the migrants' health (27). Additionally, later studies have shown that disease risk among migrants, including cancer, diabetes, and cardiovascular disease, increases very quickly and in some cases even surpasses the risk for ethnic Danes (28, 29).

A large European registry study demonstrated that in different European countries, the same ethnic minority group had very different survival rates following cardiovascular disease and cerebral infarction. And, in this case, the Danish healthcare system did not score the highest (30). Social inequality in terms of access to prevention, treatment, and rehabilitation also affects ethnic minorities, but it is aggravated due to lack of knowledge and information, language barriers, negative professional relations, and the healthcare system's narrow scope and lack of ability to adapt (31). When doctors receive continuing education in cross-cultural competency, it improves mutual doctor-patient understanding and, to a certain extent, the quality of treatment experienced by the patient (32). Published studies describe the advantages of using professional interpreters in terms of strengthening communication (to avoid errors and improve understanding), use of the healthcare system, treatment results, and patient satisfaction (33). Other studies have shown that the use of interpreters can improve compliance, reduce hospital stays, and prevent medication errors (34). Considering the increasing requirements for patient inclusion, mutual decision-making, and improved patient safety, it is disturbing to see how rarely interpreters are used in the healthcare system (35-37). More and more evidence indicates that migration is an independent social determinant of illness and health. It is noteworthy that migration in itself is a risk factor for chronic illnesses such as cardiovascular disease and diabetes in addition to the well-known socio-economic factors (38). However, migration is also a risk intensifier that potentiates the effect of other social factors. For example, Palestinian refugees in Denmark are three times more at risk of developing diabetes than the same ethnic group in Lebanon. Body weight increases quite fast after migration from rural to urban areas and after transnational migration (e.g. to Europe). Professor Charles Agyemang has researched this issue in an admirable study of body weight among Ghanaians in rural areas and after they moved to the capital Accra, as well as among Ghanaian migrants in the Netherlands (39).

Besides language as a social barrier, many other factors hamper or influence the doctor-patient communication and can have a negative effect on the encounter (40). Thus, although refugees/immigrants from non-Western countries have a longer average lifespan, they also have worse self-reported health than the majority population in European countries, and this is further aggravated by social factors (41, 42).

If you ask migrants about the barriers they encounter in the healthcare system, the replies are quite consistent across the world: access to healthcare, poor relations with the doctor, incomprehensible treatment/advice, and unfulfilled expectations.

In terms of access to healthcare, a common barrier is that many migrants are not familiar with the family doctor system and do not know that it is the gate to the healthcare system. Moreover, the wait involved in getting a consultation with a specialist is incomprehensible when, in the home country, you could have been seen directly by a specialist the very next day (for a fee). It is hard for migrants to figure out where and how to seek help regarding a specific problem, including outside normal office hours (43). Transport may pose a challenge, particularly for patients with PTSD, and transport expenses can take up to a large portion of the integration benefit. Making an appointment with the doctor over the phone might be stressful due to language barriers, and consultations often depend on the ability or willingness of family members to assist. The prospect of getting a prescription that one cannot afford can also be a barrier (44). Language barriers are naturally a widespread problem (45-47) and having to use family members as interpreters because physicians seldom order an interpreter is stressful and suboptimal. At the same time, patients may have issues that they are unwilling to discuss in the presence of a stranger, i.e. the interpreter (48, 49). After seven years of living in Denmark, 15 % of refugees still feel the need to use an interpreter. In the experience of the MHC, however, the percentage of those needing an interpreter is considerably higher as many patients are either not aware of the misunderstandings that occur, or they are ashamed of their poor language skills (31, 50, 51).

While encountering and navigating the healthcare system can be a considerable challenge, refugees/immigrants also encounter more subtle obstacles. Doctors' styles of interaction and the level of information they provide vary greatly depending on the patient's educational level, social class, appearance, sex, and language competency. In communications with ethnic minority patients, physicians show less empathy and are less involved with these patients in comparison with other types of patients (52).

In some European countries, refugees/immigrants are covered by special legislation that limits and guides social and health-related situations. When European countries were ranked according to a *Migrant Integration Policy Index*, which described integration policy and social and health related conditions for migrants, it was found that migrants in Europe experience less inequality in both health legislation and social mobility in countries that are considered to be multi-cultural (highest score: UK, Spain, Italy, Sweden) than in more mono-cultural countries (lowest score: Austria, Denmark) (53). Socially vulnerable people can easily end up living in the same housing areas, partly for financial and social reasons and partly because they have been socially excluded everywhere else. The families of the four severely ill children from the case of 1974 where three children died, all lived in the area of Copenhagen that was most in need of demolition, and their fathers were all unskilled labourers. Disadvantaged neighbourhoods are characterised by a lack of public infrastructure, which includes having a general practitioner. Social structures in disadvantaged neighbourhoods lead to unsuitable health behaviour, multimorbidity, and social epidemics of symptoms and disease, while neighbourhoods with a homogeneous minority population protect their psychologically vulnerable residents (54).

The relatively modern distinction between immigrants/migrants and refugees is interesting in that it helps to ensure protection and limits assaults on population groups who are in very insecure situations. It is also very problematic; however, as the emphasis on vulnerability tends to minimise the refugees' actual strengths, flexibility (resilience), and drive - and the distinction does not adequately describe the degree of diversity across migrant and refugee groups. Traditionally, refugees are individuals who have escaped from armed conflicts or persecution, while migrants are assumed to mainly migrate to improve their lives through better education or job opportunities. The reality is more complex, and the two groups overlap: migrants are increasingly moving to other countries because of political and social unrest, and a considerable number of them have experienced persecution, chronic armed local conflicts, or organised violence. On the other hand, many refugees flee from very poor economic circumstances,

collapsed infrastructure, lawlessness, no life prospects, and (increasingly) climate changes that cause hunger and poverty (55).

Between one-third and one-half of refugees coming from war zones have faced serious experiences of war. For most refugees, these experiences have a major effect on their daily lives: insomnia, anxiety, memory problems, heightened alertness, and learning difficulties. These can periodically affect work, language learning, family life, and self-care. War traumas stay inside the body and act as a 'noise channel' that distorts the body's signals and interrupts communication with the surrounding world. The consequences of mental traumas in parents can be transmitted to their children, who develop anxiety, stress, and social isolation (56). There is even evidence that war traumas can continue over several generations where grandchildren of Jewish and Vietnamese grandparents display symptoms that resemble those of PTSD.

Most refugees flee *from* something rather than *to* something. In Denmark, however, refugees often encounter the opposite attitude: refugees leave their home country to come to Denmark. They are not assessed by their need for protection but rather by an assumed need for welfare. As a refugee, you must earn your ordinary rights - and as a patient or social client, you have to be humble and grateful. As of this writing, a large body of legislation aims to redefine the need for protection into a permanent 'temporary status' where all steps and services are oriented toward repatriation. Socio-economic tightening reflected in interpreter fees, ceilings for social security allowances and child benefits, and the introduction of a repatriation benefit have resulted in new levels of poverty, which primarily impacts refugees and immigrants (57). Directly against these intentions, however, refugees remain in Denmark, as the alternative in their home country is much worse than poverty in Denmark. At the same time, the Danish Aliens Act has been tightened so much that a lot of time is spent either applying for an extension of a residence permit or anxiously awaiting the answer. Society's unclear demand for gratitude for the charity of the welfare state prompts refugees to use the social and healthcare systems in undesirable ways. Language, residency status, identity, finances, and illness create a new and complex clinical reality for doctors and patients. Patients adopt an intelligent compliance behaviour where medical advice is weighed against the family's budget, they prioritise the most important consultations because they cannot afford transportation, and they cancel operative procedures because they cannot afford an interpreter.

Although economic collapse, war, unrest, or natural catastrophes hit everyone in some way, they do not have the same effect on everyone. Similarly, not everyone chooses to flee or to stay and fight the circumstances. The choice between migrating/fleeing or staying may also be an expression of personality (58). It is not quite random who migrates voluntarily or who chooses to flee rather than stay. Migration researchers have studied the characteristics of the Danes who migrated to America from 1850 to 1900 when close to one in 10 Danes sought new pastures on the other side of the Atlantic. They were more disheartened than hungry, but they were poor and had miserable futures as labourers. However, other mechanisms also played a part. Researchers classified Danish first names according to how much individuality or collective thought these names mirrored at the time. Those who migrated to America were more likely to have names that reflected individuality, while those who stayed in Denmark had names that reflected collective thought.

Sociologist Zygmunt Bauman speaks of a *mobility hierarchy* in which there are two different ways of migrating. One is the forced cosmopolitan or vagabond (the migrant), and the other is the free and rich global citizen of the world. If you come from a Western country and are well off, you are entitled to cross borders and be mobile without having to justify your actions or stand in line. If you are a poor person from an African country, the situation is quite different: you have to sneak around in the world, you have to defend your existence, and you have to stand in line at the counter. According to Bauman: 'Some inhabit the globe; others are chained to place' (1344).

It was once said: *'Culture is what a butcher would have if he were a surgeon.'* Doctors learn to use evidence, biomedical explanatory models, strict instructions, and rigorously developed guidelines.

Unfortunately, we have no manuals for conversations with patients of non-Danish ethnic background. It is prejudiced and meaningless to speak of a manual for Somalis with diabetes or Bosnians with Bechterew's disease. Norwegian professor of anthropology Thomas Hylland Eriksen explains why the culture concept in itself is meaningless and only serves to hide the diversity that is vital to understanding another human being:

The world does not consist of defined cultures. It consists of more than five billion people, who in varying degrees have been marked by different cultural forms and traditions that both overlap and show great individual variation. Purity and clear-cut limits are figments of the imagination created by victims of overly strict potty training. The world is impure and consists of a myriad of grey zones (59).

The culture concept is an obstacle to understanding. It is not ethnicity that creates the barriers facing doctors and patients. Barriers arise when our professional inquisitiveness fades, when we as doctors encounter something we think we cannot understand, and when our attention to the diversity of human circumstances and lives is blurred by the language barrier that we still refuse to reduce through the use of professional interpreters. The result is poorer disease management, overlooked and misunderstood symptoms, unnecessary side effects, and complications that could have been avoided. However, the result is also the omission of vital information on smoking cessation, mammograms, and lifestyle changes, and doctors failing to refer patients to rehabilitation after heart attacks and cancer because it is too difficult to explain or because the doctor assumes that the patient will go to rehabilitation on their own.

2.3. The doctor's role in discrimination

Professor Raj Bhopal put ethnicity, migration, and xenophobia into perspective in the *Lancet* prior to the First World Congress on Migrant Health in Edinburgh in 2017: 'Racism and xenophobia are among the most dangerous threats to public health, with death rates that cannot be equalled even by the deadliest contagion. Racism and xenophobia are surely on a par with climate change as a threat to health' (60). Discrimination due to ethnicity is a cause of illness that we refuse to acknowledge (61). Although over 10 % of the world's population are migrants, willingly or by force, migration is an independent social determinant of health risk, even after accounting for the usual socio-economic risk factors. Stereotypes, antipathies, and implicit and explicit bias fly under the radar in the doctor's clinical decision processes, but the evidence is clear: discrimination is part of a migrant's daily life, including in the healthcare system (62). When doctors frequently write something like, 'it has been hard to get a complete medical history, which has also been a challenge at the hospital', and it later turns out that interpreters were never used and the documented medical history was far from the truth, then there is plenty of room for improvements to reduce inequality. Having said that, some urban areas are marked by *super-diversity*, a concept that emphasises a level and a kind of complexity that surpasses anything previously experienced. Super-diversity is characterised by 'a dynamic interplay of variables among an increased number of new, small and scattered, multiple-origin, transnationally connected, socio-economically differentiated, and legally stratified immigrants who have arrived over the last decade' (2008 - 2018) (63). More than 80 different nationalities exist in some cities. Thus, we may need to develop an understanding and some techniques that are independent of specific knowledge of the concepts held by individual ethnicities about health and illness.

Most, but not all, doctors generally follow an ethic, which demands that all patients receive medical treatment regardless of their ethnicity, social status, or residency status. Doctors do not necessarily think that the laws and policies defining the rights of immigrants are relevant to clinical practice. Nor do many doctors believe that life histories, war traumas, and the psychosocial situations of refugees are needed for the examination and treatment of trivial illnesses. Yet, migrant status and exile conditions

have an enormous influence on the physical and mental health of immigrants because these factors affect all situations in life - not just health directly but also schooling, work, education, family life, basic rights, security, and prospects for the future. Thus, they also affect self-care, motivation, and perspective (64). In many cases, several traumatic incidents may have interrupted the person's daily life over an extended period of time (65). A recent meta-analysis of 181 studies involving more than 80,000 adult refugees and others who were affected by extensive armed conflicts showed that cumulative exposure to trauma was a strong predictor of PTSD and, especially, depression (66). People who were assigned legitimate, permanent status in another country had a lower risk of PTSD than those without legitimate grounds for residence, which indicates that a positive and safe environment can help to buffer the effects of trauma and promote recovery. This aligns with another meta-analysis on the mental health of refugees, which found that favourable conditions in the host country, such as access to employment and suitable housing, limit the negative effects of war traumas (67). A Canadian study showed that most adults and children with legitimate grounds for permanent residence as refugees adapt well, even despite having experienced very extensive war trauma (68, 69). In contrast, negative post-migration conditions can disproportionately affect the health of refugees and sometimes irreparably. Known stress factors that may affect integration and health among newly arrived refugees include language difficulties (70), the experience of cultural differences (71), lack of recognition of personal/professional qualifications, loss of social support (72), experienced discrimination (73), or a combination of factors (74).

Doctors have a variety of competencies, many of which are acquired during their training. With increasing patient contact, however, they develop new competencies that are more random and individual. It can often be an advantage to first find out which person has the illness and then find out what illness the patient has, but for some physicians, it is like a guessing game that the doctor mistakes for a complicated, cognitive diagnostic process based on medical experience. What the doctor has actually learnt to do is to guess what type of person the patient is, what the patient's needs are, and what the patient can understand or manage or be willing to accept. Here, the doctor builds on a toolbox consisting of prejudices, stereotypes, personal values, language and educational concordance, and social codes. Or simply: a cultural diagnosis that is part of the clinical decision process on equal footing with the theoretical and clinical knowledge. That mechanism is likely a condition that patients have to live with and negotiate with their doctor. Doctors, however, have a professional responsibility that patients do not have, and the doctor's task is to be able to use cultural knowledge to get the culture out of the consultation room.

Doctors need to know how personal values, biases, and cultural analyses play out in the interaction with the patient. It is equally important that decision-makers, managers, and planners in the healthcare system are able to incorporate cultural and ethnic contexts into models for structural changes or the introduction of new technologies (75). If the structure and conditions for employees in the healthcare system are appropriate, then culture and ethnicity will not feature so highly in individual doctor-patient communications (76). Generally, *the science of human factors* in the clinical context is an expanding and necessary field of research to enable workflows, technologies, and processes to be adapted to human behaviour on both sides of the doctor's desk (77). This article on human factors describes the multifaceted ways in which patients' values and backgrounds can confuse the doctor, and vice versa.

Compared to patients without language barriers, refugees have a different course in the healthcare system and benefit less from the examinations and treatment plans within healthcare (78-80). There are more medication errors, and patients' issues, worries, and needs are not always taken seriously; the healthcare system thus loses valuable trust (81-83). Access to the healthcare system is often skewed either through the on-call doctor/emergency room or through primary hospital admission to the wrong department. Admissions are often more acute and of longer duration, and there are more readmissions (84). There are medical errors, and complications are more serious; pain relief is less optimal, and sedative psychotropic drugs are more frequently used (85). More unnecessary examinations are ordered,

and routine examination programmes take longer than usual, while relevant examinations are more frequently omitted (80, 86). Infant and maternal mortality rates are higher, and the causes of death in many ethnic groups have a completely different pattern from those of the local population. Doctors obtain informed consent less frequently, and they only order an interpreter in one of three conversations where it is needed (87, 88). Even with diseases where treatment and rehabilitation are firmly established and well defined, such as diabetes and heart attack, ethnic minority patients have poorer disease management, higher mortality, and less benefit from rehabilitation (89). A study of routine minor surgical procedures (e.g. gallbladder removal) showed that ethnic minorities were more likely than other patients to have the procedure carried out by a doctor who was still in training (90).

Not uncommonly, stereotypes and bias influence the doctor's clinical judgement, and this affects the quality of treatment and the potential for rehabilitation to a degree that many doctors are not aware of (89). Doctors are often completely unaware of how fundamental cognitive mechanisms can affect their judgement and clinical decision-making processes (91). In a modern healthcare system, many factors influence the doctor's cognitive resources or opportunities to use these, such as time pressure, guidelines, information overload, and inappropriate workflows. Ethnic minorities rarely participate in satisfaction surveys and are as a rule excluded from research projects due to the anticipated language difficulties. This contributes to maintaining a culture barrier in doctor-patient communications.

There is room for improvement, and cultural clinical competencies are one of the cornerstones in eradicating the inequalities that arise when refugees/immigrants encounter the healthcare system (92). Already in 1978, Kleinman pointed this out in his ground-breaking article on doctors' lack of knowledge about 'moral and existential values' when stating that biomedical practice should be based more on 'the moral world of human experience.' However, despite the extensive literature on the subject since 1978, doctors largely receive no information about the situations and life experiences of refugees and immigrants and how these affect clinical practice.

2.4. The noisy-channel effect

George Mike said, '*A refugee is a person who has lost everything except his accent*' (1346). An accent may prevent refugees from living an anonymous life, even if it is only two or three words that cause problems. But an accent and a hybrid language can also be a kind of 'noise channel' that may fool the listener. The linguist Edward Gibson calls it *the noisy-channel effect* (93). Gibson recounts - a little surprisingly - that Henry Kissinger (former American Secretary of State and non-native English speaker, who came from Germany) told Arianna Huffington (a Greek immigrant and entrepreneur/writer who later founded The Huffington Post) that she should not worry about her accent, 'because you can never, in American public life, underestimate the advantages of complete and total incomprehensibility.' By using the noisy-channel effect to understand bilingual 'loudspeakers', you may perceive the 'errors' in the language of non-ethnic Danes as a noisier language model than the native loudspeaker model. The listener expects more errors and is, therefore, more disposed to consider that a bilingual speaker is saying something sensible when they are really saying something incoherent, inappropriate, or ambiguous. However, if an ethnic Dane says something inappropriate, the listener is more likely to accept it literally, because they know that their language model has less noise. Kissinger advised Huffington that listeners and readers would be very likely to give her the benefit of the doubt because of her accent. For the doctor, it may be a case of unknowing bias where you assume that the patient's medical history is more meaningful than it actually is - and thus you may act based on a 'noisy' patient's story. In other words, doctors may settle for a fragmented, imprecise medical history because they imagine that somewhere the story probably makes sense. Thus, doctors may act on an incomplete or incorrect medical history without the patient realising this as they are seldom invited to edit their medical history.

2.5. Copy-paste story and crosstalk

The health professional's task of turning a medical history given by a refugee/immigrant into a cohesive and easily understood narrative that is 'understandable' in a wider Danish health professional context is far more extensive than just turning a simple conversation into text that can be separated from the local context in which it was experienced. Doctors/nurses who experience the unfamiliarity of refugees/immigrants lack knowledge and competencies. This makes them dependent on the 'common' but completely prejudiced knowledge that we call folk wisdom and on implicit bias towards social, cultural, and language values. In the absence of relevant tools, an interpreted medical history is created in which medical values concerning the validity and importance of the refugee's medical history can influence which symptoms are documented in the medical record and thus become 'the medical history of the patient.' Consequently, patient records are largely built on procedures that are influenced by generally accepted, but undocumented assumptions about language, national identity, and communicative competencies - which may lead to violations of patients' rights, medical errors, and unnecessary conflicts. The processed version of the patient's story is distributed as the person's narrative, and with each retelling it becomes more simplified and processed by other professionals' personal biases and ends up becoming an altered story (in the same way that a short sentence whispered from one student to the next in a class of 25 students ends up being a completely different and somewhat bizarre sentence for the last student). The process is continuously influenced in its language, content, and concepts by the different interpreters who recount the story - through their different dialects, sparse empathy, varying knowledge of the original cultural context, and very different language skills - so that the original story is given a peculiar, unreal, and illogical taint that will always stick to the refugee. You create an artificial and meaningless abstract of the refugee's story that is easy to remember and recount, but that essentially never makes sense (94). The problematic nature of these communications can be traced back to the form of late modern communication, characterised by asymmetrical power balances (great variation in knowledge between sender and receiver), several concurrent communicators with competing agendas, multiple languages (jargon, professional language, idiomatic phrases, grey zone language, dialects), and hybridised speech and interaction (mixture of concepts from several languages). Others have called this complex communication 'cross-talk' (95).

The sad part is that, due to language powerlessness and ignorance about the content of the story, refugee/immigrant patients end up by acquiring and adapting to the documented story. In other words, the patient becomes the medical history that the healthcare system has given them because it is easier and because it is the only thing the patient can do.

2.6. Understanding humans who move between cultures

Going from refugee to immigrant is a complex process that is influenced by many expected factors, but a significant proportion of the barriers are organisational, administrative, and legislative (96). Fleeing is associated with massive social changes and various risk and stress factors. These include uncertainty about the future, social and economic problems, language isolation, discrimination, and redefinition of the psychological self-image. These factors can influence the mental well-being of refugees by increasing the risk of re-traumatisation and the development of stress, anxiety, and depression (97-99). The health of migrants is influenced by their pre-migration socio-economic and ethnic backgrounds, health state, histories, and the quality of and access to healthcare services. The circumstances of the migration and the social and health-related factors in resettlement further influence health, and post-migration health determinants include the type of work refugees are expected to perform in the host country, their living conditions and language skills, their level of contact with family and ability to acquire new social networks, and their access to health and social services. The 'ecological space' that the refugees travel through increases the complexity of their health risks. The migration existence is often filled with fear

of the unknown, anxiety about the fate of family they left behind, and a feeling of threatened loss - a condition that has been described as a type of cultural death (100). Others choose to tackle the demands and pressures of their surroundings by putting all their energy into ensuring the well-being of the family, which is a type of alternative survival strategy (101). Chronic anxiety, homesickness, and isolation hinder psychosocial well-being and lead to depression, migraine, and disabling neurogenic pain. The complex relation between physical and mental health gets disturbed by differing attitudes and ideas of the concept of illness, which do not get commented upon or negotiated between the doctor and the patient. Family relations are interrupted by differences between family members in their speed of adaptation, language learning, and health situations.

Case 1

A 39-year-old man from the Middle East is referred due to chronic knee and back pain, unusual sensory disturbances in his legs, and chest pains. Additionally, the patient has compliance issues with his hypertension medication and he is concurrently being assessed for sleep apnoea. Despite guidance, the patient has not succeeded in losing weight. In the first conversation at the MHC, he appears to be very ambitious on his own behalf, but he has severe dyslexia and has problems with memory and concentration. His wife experiences severe anxiety attacks and bursts of anger and is very accusative with regard to their poor financial situation. The man finds intimate relations with her to be a challenge. The patient feels guilt and shame over not being able to support his family in Denmark, as he had promised when the family was reunified. The patient has nightmares, flashbacks, and does not dare answer the phone or watch TV. He is afraid of water, electricity, darkness, ice, and loud noises. When he lost his father as a 13-year-old, he was taken out of school and sent out to find a job. The patient has been in prison for quite a time - the most repugnant thing he has ever experienced. The patient believes it is the worst place in the world to be. They torture people and let them go again, but the prisoners are unable to live their lives again because they have suffered such violations that nobody would believe them if they talked about it. The patient has been suspended by his arms, his genitals have been electrocuted, and he has been blinded by duct tape for several days in a basement. He has been exposed to severely degrading mental torture, he has slept in ice water, and he has deliberately been nearly drowned on several occasions. He got a job at a building site, but to be allowed to stay there, he had to make himself available sexually for the other men. He got the impression that this is what adult men did and that it was normal for older men to have sexual intercourse with young boys. Every morning he has to look himself in the mirror and tell himself that he is totally normal, but he feels guilt and shame for what has happened, and he blames himself. Now he is worried about his children in Denmark, and he has seen some of the same types of men in Denmark. He has heard that sexual abuse of children is very prevalent in Denmark.

The patient is referred to trauma and torture management, which gives him greater control over his symptoms and a better understanding of his emotions and how to avoid being overpowered by them. An MRI scan of his back reveals several herniated discs in his neck and lumbar area and spinal stenosis of the neck. Due to PTSD, the patient has difficulty giving a consistent picture of his pains, and he is considered unlikely to benefit from surgery as the pains are characterised by long-term hypersensitivity and neurogenic pain. The patient is satisfied with the explanation for his pains and sensory disturbances. The lack of weight loss is due to the patient's comfort-eating throughout the night, and it is hoped that with a better understanding of his condition, he may be able to reduce his self-medication with food. The patient does not have sleep apnoea, and his sleep has improved following a corrective procedure for a crooked nasal septum. The patient's wife has been referred for treatment. In cooperation with the patient and his wife, a report is forwarded to the municipality to apply for support for his wife and the children at home. His wife did not know about the sexual violations in his childhood nor of his imprisonment. She has changed her behaviour at home after being informed about this in broad terms.

Comment: *A typical case in which somatic symptoms are distorted by an altered experience of pain due to PTSD and exacerbated by stress at home, a poor financial situation, poor prospects for the future, low self-esteem, and sexual abuse during childhood. Information is not necessarily shared within families, especially if it is unpleasant, even when it could be crucial to healthier family relationships.*

The concept *culture encounter* is often used in situations where the balance of power is very unequal. For human encounters that have a more equal footing, we use concepts such as interaction, exchange, co-creation, etc. In post-colonial studies, the concept of ‘translation’ is often applied to communication between cultures because it better facilitates an openness towards the circumstances and contexts of minorities, while simultaneously focusing on hybrid co-creation, creativity, negotiation, and transformation rather than integration and assimilation (102). When you translate, you are always left with a ‘remainder’. This is the element of resistance or untranslatability, which prevents the translated text from becoming a faithful copy of the original but always contains a disquieting element of something rewritten or altered. In other words, something new. In the world of literature, this creative element brings about world literature, because the text is lifted out of its own context into ever new frameworks in an endless chain of new interpretations, new times, and new places. In the world of migrants, you are dealing with a very elementary survival strategy. The migrant’s survival depends on this ability to renew or reinterpret their own existence, including their past and future (102).

The persisting health inequalities affecting ethnic minorities is a serious health issue that requires a diverse and multidisciplinary approach. There are many indications that inequality is largely conditional on social circumstances and improved finances, living conditions, and legislation. However, increasing evidence suggests that a disproportionate part of the inequality is created and maintained by the healthcare system. Training of employees within the healthcare system, including hospital owners and managers, in clinically relevant and documented cultural competencies can alleviate many of the factors creating the inequalities that are inherent in the surrounding community (103-105).

In the final analysis, the only tool the physician has, and the only salvation for the patient, is language. Everything else is secondary. As human beings, we become members of a community through language, which makes the world understandable and meaningful - not least in the event of illness (106). Our lives and situations become real through language. We become visible and meaningful as persons through language, both as doctors and as patients. We let ourselves get easily distracted and disturbed by unexpected signals. Things we do not understand, we try to make sense of through prejudice and convenient assumptions about the patient. The individual experiences such generalisations as disempowerment and dehumanisation (107). The mastering of a language is important for the individual’s ability to speak up against or to clarify the generalisations they meet, but that is something that few refugees/immigrants are able to do. If the patient cannot explain their way out of a generalisation, they feel powerless and demoralised. Generalisations cause people to vanish physically and mentally from the conversation. ‘*A real doctor seeks the human being*’, Franz Kafka said. However, how do you seek the human being when you do not speak the same language and have very divergent routines regarding health and illness? This is what this book is about.

This book builds extensively on clinical experiences from the MHC at Odense University Hospital. It is a textbook about doctors’ blind spots and learned professional biases - about everything ‘we didn’t realise, we didn’t know’ about the health of refugees/immigrants - and about how you, as a doctor, can prepare yourself for the unexpected and the ambiguous in a professional and inclusive way. It is a textbook that will hopefully awaken professional curiosity about the life story as a clinical tool and will sharpen the doctor’s motivation to understand the multi-faceted contexts of patients, thereby allowing the doctor to create lasting solutions together with the patient.

3. Concepts and definitions

In this book, the overall target patient group comprises those who identify themselves as belonging to an ethnic minority. Table 1 presents more or less well-defined categories of ethnic minorities.

Table 1. Definitions of various categories of ethnic minorities.

Group	Definition
Internally displaced (IDP)	Pressured to flee but has not crossed a country border to get to safety. Lives in the homeland.
Asylum seeker	A person who seeks protection and whose case is being processed.
Refugees	People who have fled involuntarily from an area of conflict and have attained a formal status as a refugee by a government or the UN refugee programme UNHCR.
UN-mandate refugees	Refugees who have obtained refugee status under the UN mandate via UNHCR.
Migrant (previously ‘immigrant’)	No formal definition, but an international migrant is often considered to be a person who moves from their usual country to another country in order to settle down for a brief or extended period of time regardless of cause or grounds for residency. In other contexts, it is also termed a ‘newcomer’. Descendants are not considered to be migrants (but belong to the ethnic group they identify themselves with).
Undocumented migrant	A person who due to an unauthorised arrival, rejection of asylum, or visa expiration does not have a documented legal residence permit.
Ethnic minority	The social group that a person indicates they belong to or identify with due to culture, language, religion, origin, or physical attributes connected to the group. All human beings belong to an ethnic group.
Majority population (‘background population’)	The population used for comparison with ethnic minorities.
Non-ethnic Dane	Child of a migrant (descendant). Previously called a second-generation immigrant.
Hyphenated identity	Considered an attempt to identify simultaneously with two different ethnicities, e.g.: Danish-Somali, Danish-Arabic, Danish-German.

3.1. Migration phases

The factors influencing the health and quality of life of refugees are usually divided into three phases: pre-migration, transit/flight, and post-migration. In our experience in a Danish context, however, a further phase - integration - should be added. Integration is required by Danish law, and its course is important to the subsequent life in Denmark. Table 2 shows the most significant factors in each phase.

Table 2. Factors that influence the physical and mental health of refugees at different phases.

Phase	Factor
Pre-migration (home country)	<ul style="list-style-type: none"> • Potential traumatic experiences <ul style="list-style-type: none"> ○ Singular, multiple ○ Discrete or continuous
	<ul style="list-style-type: none"> • Living conditions <ul style="list-style-type: none"> ○ Socio-economic circumstances ○ Family situation ○ Position and affiliations (ethnic, religious, social, political)

	<ul style="list-style-type: none"> • Personal story <ul style="list-style-type: none"> ○ Weakness, vulnerability ○ Protective factors, resilience
Transit/flight	<ul style="list-style-type: none"> • Direct flight to the host country vs. transit stay <ul style="list-style-type: none"> ○ Refugee camp (internal/transit country) ○ Transit country <ul style="list-style-type: none"> • Undocumented ('illegal') vs. official vs. family/friends • Finances, access to healthcare, school • Detainment due to refugee status • Official/unofficial travel documents <ul style="list-style-type: none"> ○ Payments to smugglers, financial consequences • Traumas during the flight <ul style="list-style-type: none"> ○ Family separation, disappearance ○ Flight with infants/small children, pregnancy ○ Exploitation by smugglers ○ Extreme poverty ○ Extreme helplessness ○ Long-lasting feeling of marginalisation, being trapped, doubt, uncertainty ○ Hunger, internment ○ Violations by persons of authority (border guards, refugee camp guards) ○ Rape, robbery, assault
Integration & adaptation	<ul style="list-style-type: none"> • Whole family arrived vs. partial vs. alone • Experience of interview/interrogation • Reception from others of the same ethnic group • Contact with the Danish society, integration officers • Health problems • (Functional) illiteracy • Physical-mental disabilities • Uncertain basis for residency, doubt about residency basis for parts of the family • Language <ul style="list-style-type: none"> ○ PTSD, anxiety, uncertainty with cognitive effects ○ Varying language acquisition ○ Family structure is affected ○ Parent role is changed ○ Language failures • Children's well-being • Different adaptation/integration speed • High or wrong expectations, disappointments
Post-migration	<ul style="list-style-type: none"> • Extended uncertainty regarding basis of residency • Repeated police interviews/interrogation reinforces anxiety and uncertainty • Fear and uncertainty <ul style="list-style-type: none"> ○ Fear of being sent back ○ Requirement of language acquisition ○ Requirement of job, activation, work ability testing ○ Continuing uncertainty about safety of relatives in the home country or in third countries ○ Problems with adaptation to own ethnic group in the host country, sharpened or strange cultural requirements ○ Fear that affiliations with former social networks, religious/political groupings will cease • Living conditions <ul style="list-style-type: none"> ○ Loss of social identity in several areas (provider, family, parent, resource person) ○ Limited access to work, education, healthcare system, social authorities ○ No family, family reunification, separated, single ○ No functioning networks ○ Poverty ○ Extreme private debt ○ Continued experience of marginalisation and discrimination is internalised ○ General integration challenges: language, work, support, identity, cultural barriers, hidden codes, navigation difficulties, system competencies, strategy difficulties

In the refugee debate, politicians, media, and opinion leaders tend to be very specific and focused on contrasts, attitudes, and prejudice. Knowledge is not always the basis for people's understanding of migrants and refugees. Most often, the causes of migration and flight are more complex and intertwined. The many specific 'visual' ideas of migration, together with the many theories about migration, can lead to an over-explanation that does not apply to the individual refugee. Neither Marx' economic theories nor climate change can independently explain why a Congolese chooses to flee to Europe in a leaking rubber dinghy after a deadly chase through the Sahara (108). Often, both individual and structural factors are at play at the same time, alongside the possibility of escape, political circumstances, and family pressure.

The stress and trauma factors in exile are often just as powerful as the stressors that existed in the home country (1). Failed language courses, split families, divorces, children doing poorly, lack of education, terror attacks, media focus, and unfulfilled ideas of the refugee existence in the host country may equal the difficult experiences in the home country - at least in perception - and increase the risk of demoralisation and depression (109-113). Table 3 outlines the various types of reactions to encounters between minority and majority cultures (adapted per 114).

Table 3. Different types of cultural adaptation and cultural exclusion.

		The importance of maintaining cultural identity and characteristics	
		Yes	No
Relation to the surrounding society is important	Yes	Integration Cultural sensitivity Acceptance of diversity	Assimilation One-sided adaptation
	No	Separation Enforced or chosen by oneself	Marginalisation Exclusion and discrimination

Many have criticised Berry's division as crude and inapplicable. Others feel that cultural adaptation is an ongoing struggle and negotiation between the past and the present, between country of origin and home country where identity is constantly challenged and changes into a hybrid identity that is not necessarily the best version of the person (115). Many refugees choose different appearances depending on the context where the ethnic heritage may be toned up or down depending on what is most effective in their experience (116). The adaptation of migrants has many psychological facets that are in turn linked to a diverse range of social, material, and cultural factors (117). The - often politically driven - simplified focus on 'integration' actually prevents a constructive understanding of the thoughts and actions of the individual refugee/immigrant. By limiting the meaning of ethnic identity to pure demographic properties (barriers), the identity is reduced to stereotypes that hide the individual's fundamental values about illness and health from the surroundings, including the healthcare system (118). Refugees as a group have been made into a single collective object: a redundant population group. They have been reduced to a collective patient group with deviant and incomprehensible morbidity that prevents integration. The refugee feels the generalisation and typecasting but lacks the communication tools to speak up against the trend - instead they internalise it: they develop the symptoms that are expected, and they isolate themselves in the way that is expected.

The refugee responds to the integration pressure from society by selecting out certain aspects of the country's customs and at the same time resisting change to meaningful and value-laden aspects of their identity. You feel lost, lonely, and insecure in the host country, and this loss of identity is compensated for by seeking reassurance and meaning in the routines, customs, and values of the home country. This causes a constant clash of values - 'culture shock' - and withdrawal attempts. In the worst case, it

leads to social and psychological de-compensation. The lack of language tools amplifies the feeling of incompetence and lack of autonomy. In some cases, the social and personal identity do not even harmonise. In certain settings, the refugee can maintain a positive personal identity, but in others, they experience a downgraded, wrong, or invisible social identity. The book *The psychology of culture shock* describes a somewhat odd view of acculturation based on the idea that various cultural syndromes exist, which when encountered either facilitate or prevent integration: cultural complexity, strict versus loose cultures, and individualistic versus collectivist cultures (120). For example, people in strict cultures place great value on security and predictability. This causes problems with integration of refugees from loose cultures, who will be unfairly regarded as unreliable and undisciplined. People from less complex societies will be considered rude, lazy, and disrespectful in more complex societies. The contact points between collectivist cultures and individualistic cultures are more complicated but also give rise to psychological reactions that can affect health.

Table 4. Stages in integration and their psychological patterns (120).

Stage	Roles of professionals and support persons	The refugee's task	Treatment issues
Early phase (1-6 months after arrival)	Teacher, guide, resource person	Getting to know the surroundings, contact with the home country, meeting other refugees	Disorientation, dejection, anger, guilt, shame
Destabilisation (6 months - 3 years)	Teacher, psychological support, resource person, psychoeducation	Acquiring survival tools, learning the language, adjusting to new values regarding expectations, gender, and relationships, developing networks	Hostility, resistance, rejection, stress
Experimentation, stabilisation	Counsellor, psychoeducation	Choosing flexible cultural adaptation, marital adaptation, maintaining relationships, new parent roles	Fear of failure, isolation, feeling defeated, identity crisis, authority crisis
Return to normal life (5-7 years)	Counsellor, psychotherapist	Maintaining flexible cultural adaptation, developing realistic goals and expectations, strengthening self-confidence, lasting personality changes	Rigidity, conservatism, generational conflicts, stress, hopelessness
Decompensation (7-12 years)	Crisis intervention	Survival strategies, changing identity, preventing isolation, developing new strategies; connecting past, present, and future	Psychosis, personality disorders, re-traumatisation, existential crisis, family breakup

In a newer model from 2018, Salman Türk describes the emotional phases in migration using Jung's individuation concept (the process of getting to know yourself in youth). Türk compares the migrant's integration process as a repeat of the gradual exposure and shaping of the 'me' during one's youth (121). This model is interesting because many refugees at the MHC are unhappy with - some even tired of - 'the hybrid version' of themselves that has been created after their arrival in Denmark; see Figure 1 below.

The cultural formative process has a number of features in common with the processes that influence adolescence when identity is shaped:

- Daring to start something new

- Replacing family relations and cultural connections
- Considerable changes to past understanding of culture, values, and gender relations
- Pivotal changes in the meaning of one's person, work, hierarchies, religiosity, and authority
- Urges to move or overstep social limits/norms
- Different perceptions of the self towards other people
- Stress endurance relating to the tension between the 'me' and the foreigners in the host country
- Enduring constantly new learning processes
- Increased vulnerability to psychological problems
- Endurance and coping with great emotions such as love, need, insatiability, existential anxiety, liberation, grief, loss, fascination, and euphoria
- Dissolution of the psychological ego-structure
- Recreation of self-image, new identity (bi- or multicultural)
- Redefinition of roles and options
- Restraining fantasies of omnipotence (visions, utopia, longings, wishes - false memories), aggressive unrealistic thoughts of self-realisation
- The social (re-)birth through fantasies of omnipotence (being 'stronger, more beautiful, smarter than everyone else') as a narcissistic regulation that protects against impending fiasco, disappointments, guilt, shame, thoughts of failure/catastrophe, low self-worth, and meaninglessness - a violent urge toward self-realisation. 'The dream of going from paper-boy to millionaire'.
- Creating and maintaining a distinct separation between fantasy and reality (self-reflection)
- Contrast between family and culture as an integration incentive and challenge

Figure 1. Emotional phases of the flight and integration processes.

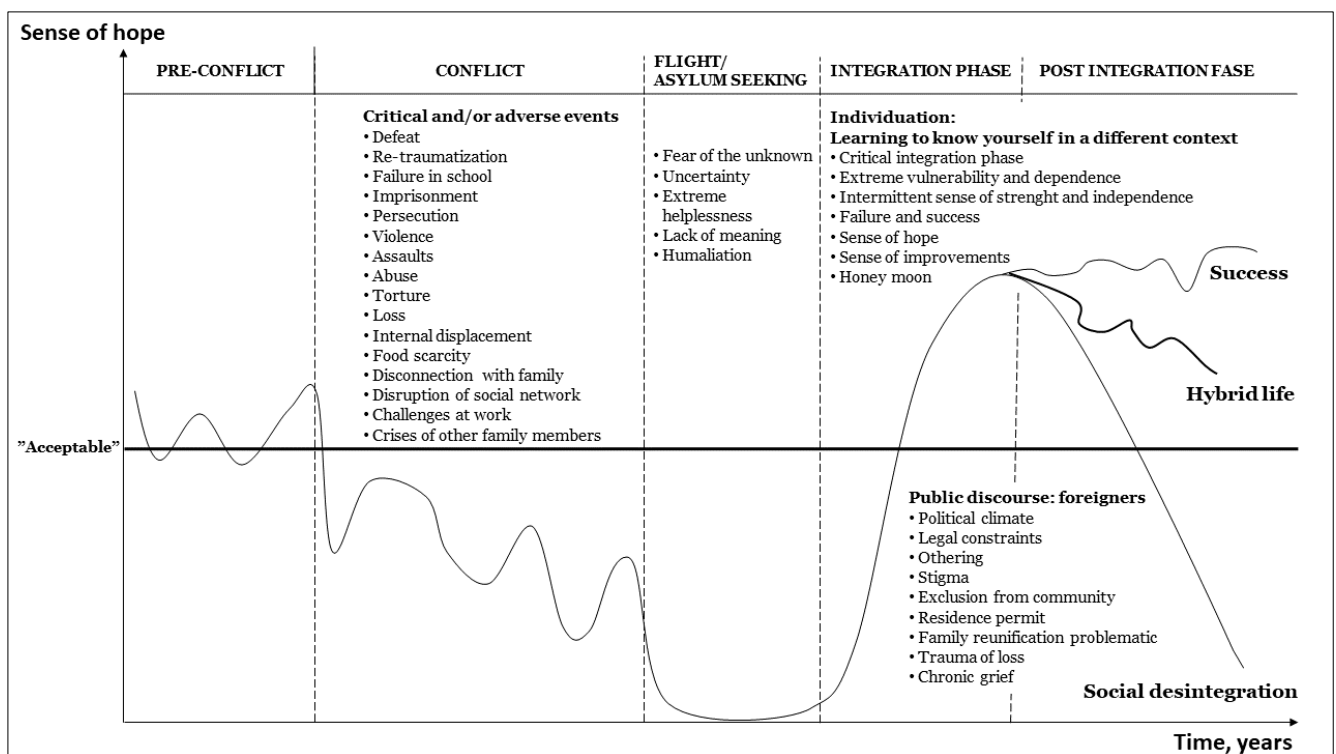


Figure 2 describes the elements of the migrant's 'youth', in which they once again must get to know themselves (individuation) in a new social context.

The cultural 'youth' in the migration process: How you become aware of your self

'At home'		'Abroad'	
3. Individuation: Migration	<ul style="list-style-type: none"> • Original culture • Homeland, nation, mother tongue 	<ul style="list-style-type: none"> • Culture of host country • Foreign, other country, other language 	3. Individuation: Migration
2. Individuation: Youth	<ul style="list-style-type: none"> • Family • Closeness, Tradition 	<ul style="list-style-type: none"> • Culture of host country • New homeland, new nation 	2. Individuation: Youth
1. Individuation: Birth	<ul style="list-style-type: none"> • Primary security 	<ul style="list-style-type: none"> • Family • Other closeness, hybrid tradition 	1. Individuation: Birth

Figure 2. Differences and similarities between the identity development (individuation) in the home country and in the host country.

Just like young people, the migrant has to (partially) break the relationship to the family and parents in order to find new friends. This presents a unique opportunity to review one's past (what will I take with me, and what will I avoid), and the future may be regarded from a new, more individual point of view in which a re-orientation of culture and values is possible. There may be changes in relational ties, gender relationships, religiosity, work, and decision processes. Just like young people, migrants have a need to renew, change, test limits, move limits, and try to manoeuvre through unfamiliar social contexts in which they have to learn new rules, roles, and language. Just like young people, migrants live in a constant adaptation (acculturation) stress between the 'me' and the foreign/new. They slowly develop a new third 'me' and their final identity in the new framework. Great emotions need to be displayed, tested out, formed, and controlled in relationships, just as the fear of collapse, fiasco, and social exclusion threatens the identity. Fear of separation and grief due to what has been lost (the safe family, the home country) are always waiting in the wings. The new and more open relations and action spaces outside the family strengthen the possibility of creating a new self-image in step with the nuancing of one's self-image. However, the danger is that in the euphoria and fear of failure, a new 'wrong' hybrid identity is created, which neither the person nor the surroundings can come to terms with (121).

Integration processes are synergistically linked to the stress factors of the migration/flight process in the concept *acculturative stress* (123). When you travel to a new country, you often encounter dramatic and overwhelming cross-cultural contact points and experiences that lead to psychological reactions. Climate, language, food, clothes, religion, and values all - and often at the same time - challenge the refugee and demand some psychological/behavioural answer. These cultural differences may be accepted, understood, interpreted, or rejected, and the refugee either can live with them or be overwhelmed by them (124). Especially the latter mechanism seems to be the case for refugees with trauma, chronic illness, great losses, or chronic grief. An impending threat of collapse - of ability to act, overview, coping strategies, morals, motivation, lifeblood - is experienced by most refugees, but only a few decompensate completely. According to Gonsalves, there are four steps in a cognitive/behavioural breakdown: failed personal integration/adaptation, familial disintegration, isolation, and existential crisis with demoralisation and identity decay. Danger signals are as follows:

- Overwhelmed by the (minor) demands of reality
- Thoughts/actions/vacuum are filled with old problems that gain unrestrained new life
- Feels split between the exile's choices and the major changes in surroundings
- Incipient near-psychotic experiences, hearing voices, total vegetative isolation
- Loss of employment, failed language courses, divorce, municipal stress
- Broken family structures with new channels of command and unfamiliar generational issues
- Addiction, intermittent suicide ideation, utter indifference

A Swiss study of 104 refugees 10 years after they received their residence permit found that a large proportion of them had difficulties settling in the host country, based on a wide range of integration goals. On average, each refugee had almost 10 post-migration challenges (see Table 5, adapted per (125)). These were primarily psychological issues such as PTSD, anxiety, and depression that were associated with the integration challenges; 87 % of the refugees had experienced torture or other traumatic abuse, and 80 % had been in immediate danger of death. It took on average 7.7 years for the refugees with PTSD to start treatment.

Table 5. Post-migration challenges among 104 refugees in Switzerland ten years after their first residence permit.

Post-migration challenge	Percent (N=104)	
Loneliness, boredom, isolation	84.3	
Worries about the family in the home country	80.6	
Unable to travel home in the event of a family catastrophe in the home country	79.4	
Difficulty learning the second language	75	
Separation from large parts of the family	72.1	
Employment issues	69.6	
Problems communicating/making oneself understood/be heard	63.1	
Fear of being returned to the home country	56.7	
No possibility of borrowing money	56.7	
Temporary or bad housing	52.9	
Not enough money for food, rent, and clothing	52.4	
Discrimination	49.0	
Anxiety about not getting treatment if ill	44.7	
Conflicts with the caseworker or authorities	39.4	
Problems with interviews in connection with extension of residence permit	36.5	
Fear of not being recognised as a refugee	33.7	
Ethnic conflicts in the host country	25.5	

3.2. Generational differences in the approach to illness, coping, and diagnoses

There are very large differences in whether, how, and when different ethnic groups adapt to the host country's understanding of illness, behaviour in the event of illness, and diagnostic picture: the effects of integration, assimilation, separation, or marginalisation apply to the area of healthcare (41, 126-129).

Whoever is the first to flee/arrive in the host country can also influence the further course, even if the health consequences are complex (130, 131) (132). Some ethnic groups resemble the majority's illness patterns after one generation (e.g. Bosnian refugees to other European countries) while other groups only approach after several generations in the host country (a few African groups, some Asian, and Middle Eastern groups in European countries) (24, 133-137). There are differences in self-perceived health between ethnic minority groups and between generations in Denmark, but it seems that socio-economic circumstances play a large role - again, however, for some ethnic groups more than others (42). The same influence of socio-economic status on self-perceived health through several generations within ethnic minorities has been found in, for example, Sweden and England (138, 139).

A German study took a closer look at what happens to illness perception, illness behaviour, and coping strategies through four generations of Turkish immigrants (140). In this study, the 4th generation was defined as persons born in Germany to parents who migrated to Germany before they were aged 12. Regarding mental illness, psychosomatic diagnoses and clinical depression were more common in the 1st generation than in the 4th generation, while personality disorders, eating disorders, and schizophrenia were more common in the 4th generation. First generation Turks in Germany more frequently attributed external causes to their illness than did the 4th generation, just as the 1st generation more frequently felt they had no control over the illness and had no influence on the treatment. Additionally, the 1st generation had considerably less general understanding of their illness. Both generations largely attributed their illness to stress, exhaustion, and family problems, in contrast to the German majority population. The 4th generation thought more about strategies in relation to their illness and acted more independently in getting help, caring for themselves, etc. Regarding patience with the illness, however, there were no generational differences. The 1st generation sought more often religious solutions for their illness, while coping strategies such as humour and rejection were both frequent in the 4th generation, who also more frequently chose to use alcohol and other substance abuse for coping - along with mental blindness and avoidance behaviour.

3.3. Cross-cultural vulnerability

At the MHC, around 25 % of the patients are men. This under-representation of men does not mean they are less vulnerable or that there are fewer patients in this group - on the contrary, they have shorter life expectancy than the women and do not consult a doctor even when they should. The male patients at the clinic have a different and more complex vulnerability than that of the women, which is typically more evident and thus easier to treat. There is a lot of professional experience with women's vulnerability, but very few are familiar with the men's vulnerability in a clinical context. This is a major problem in the efforts for equal and fair treatment. We see in the clinic that this patient group has well-hidden vulnerabilities that doctors and social workers do not pick up, and it is often the *discovery* of exactly that hidden vulnerability that explains and contributes to the solutions in a clinical context. This also means that the ability to find and articulate this hidden vulnerability is a competence that most doctors, nurses, and social workers could improve.

Language is a chapter in its own right, and it plays a hidden but very special role for refugees. Language is closely connected to culture and strengthens the ability to navigate in a culture no matter whether it is from the home country or the host country (141, 142). Language and culture are hard to separate, and language has been described as both the strength of the culture and its tool. If you do not understand the stimuli around you, such as the language, you cannot read the code of the culture. Without language certainty and scope, the experience of understanding is weakened, and even everyday events may be incomprehensible (143). When the codes of everyday life are incomprehensible, then anxiety, uncertainty, and lack of cohesion are amplified. This can affect the ability to navigate in places like the healthcare system, and influence the way in which the refugee tackles symptoms or understand the doctor's advice. Very few studies examine patients' actual language and reading skills, but the few that

exist paint a clear picture: up to one-half of the people questioned feel that they need interpreter assistance in certain situations, and just as many are dissatisfied with the way they get information from the doctor (78, 87).

Although refugees often indicate some of the same barriers and conditions, their importance is different for each of them. The most important conditions are language isolation, complications with residence permits, financing the family and daily life, discrimination and exclusion from social life, and access to the job market. These factors lead to loneliness, frustration, overload, and feelings of lacking co-determination, of being unfairly treated, and of being trapped in Denmark. Often it is this trapped feeling that is crucial to health because it demoralises and strips patients of hope and motivation in relation to self-care, medical examination, and treatment. The conditions that refugees have to relate to and survive in, and the significances they assign to these conditions, create a feeling of meaninglessness and lack of coherence - experiences that are poison to people who already have a high risk of anxiety and depression and to patients with PTSD. The outcome is determined by the patient's own mastering strategies, whether a functioning and effective network exists, their social capital, and how society treats them.

Studies show that the impact on mental health depends on the resources the immigrant has available and how risk and stress factors are handled (98). It is a common idea that people judge risks in the same way regardless of ethnicity. This is far from the case, however, and - more importantly - ethnic minority migrants are much less willing than the majority population to take a risk or to enter situations of low risk (144). Experiencing control over one's own life and a cohesive existence are examples of important resistance resources in relation to whether immigrants develop cultural adaptation stress or other symptoms (99). When you lose everything that makes life secure and safe and then lose your language, your ability to navigate, and your drive, then you lose control of your life. A key element of PTSD is a feeling of extreme helplessness. This feeling can be more severe and last longer when you end up in a completely different country, long after the experiences that sparked the trauma and flight. It is one of the most serious and significant basic circumstances for refugees - and unfortunately, it is a problem that is both overlooked in the host country and affects whether the refugee finds a tolerable role in the host country. The effect on the mental health of immigrants depends on the conditions and challenges the immigrants encounter, but also what resources they can draw on. The human capital stays in the home country and does not travel with the refugee - as opposed to trauma (145, 146). The stress of migration may be so disturbing that the migration process adds a completely new level to the life cycle in the form of multiple concurrent crises. The feeling of great loss, a lack of language, and culture clashes can lead to serious adaptation issues and may throw the refugees and their families into chaos, unsuitable impulsive decisions, and constant imbalance (147). It is in this minefield that the doctor and the healthcare system have to meet the individual immigrant patient and learn how to organise health promotion and treatment of illness.

3.4. Children and family

Many refugees come from countries and cultures with strong family ties and an emphasis on family-based values. This can make it very hard at a later point to navigate in a society that emphasises the individual's independence and decision-making ability. It may provide conditions that amplify anxiety, and certain types of personality disorders can become problematic outside the safe framework and handling strategies of the family. In many cultures, it is inconceivable to say, *'I think...'*, until one is older and has children of one's own; attempts to include the patient in the treatment decisions may be directly anxiety-provoking.

Children of immigrants are often caught in the crossroads between the second language and the parents' mother tongue and the values that are simultaneously broken. Ethnic youth are caught in a

crossfire of unhealthy habits from their minority cultures and acquired unhealthy habits from the parents' host country. The parents consider whole milk healthy and a sign of wealth, while the young people like Coca Cola. The result is a very high intake of energy and obesity.

Children pose a particular challenge in cross-cultural clinical contexts. Not only have many been raised in troubled areas with poverty, chronic conflicts, and violence, they are also exposed after their flight to long stays in asylum centres and uncertain prospects for the future. A Danish study of asylum children found that 35 % of children aged 4-15 had signs of mental illness. The same study found that the children also had several physical symptoms, low self-assessed quality of life, and a weak social network (148).

In Sweden, a so-called *resignation syndrome* has been described among asylum children whose families are waiting on a residence permit. Children that live under unbearable life conditions may develop life-threatening depression-withdrawal symptoms known as *Pervasive Refusal Syndrome* (PRS). This also applies to children in traumatised asylum-seeking families. The children improve when the family's underlying fear and hopelessness are relieved by a permanent residence permit, and their traumas are addressed (149).

However, the challenges do not stop here. When the children have obtained a residence permit, a long and obstructive integration process begins in which they have to find their own new identity and create social relationships while also maintaining the norms and values of their home country. Yet, it is often the children, who learn the language and system competencies the fastest, and thereby acquiring a new ambiguous role in the family. As young adults, many migrant children complain that they skipped childhood. See chapter 2, *Body and soul in exile*.

A study of 46 migrant children examined at the School Psychiatric Centre in Copenhagen in 1992 concluded that most of the children had significant psychosocial issues. Studies found that it was often more important to look at the system around the child's problem rather than the child's immediate problem. Cultural circumstances are important, but you have to be careful not to overestimate the significance of cultural factors as cultural pseudo-explanations can easily overshadow the real problems and thus prevent proper diagnosis and appropriate treatment (150). It is important that the people who are involved in the problems are included in the treatment. These could be the child, the child's family, teachers, and school psychologists, and any others involved. This could indicate that in many cases, you should focus on the overall system around the child and not just the parents, the child, and any cultural values. However, in a chapter on immigrant children in a child psychiatry textbook from 1988, Gretty Mirdal concludes that 'family therapies seeking open, direct, and crystal-clear communication are in many cases not desirable for immigrant families' (151). Additionally, Gretty Mirdal explains that, 'Immigrant children's identity formation is hampered by poor language skills, cultural isolation, low-status parents, and at times a hostile attitude from the environment towards foreigners. This can result in the child adopting society's negative view of minority groups as a part of their own self-assessment.' In 1984, a Swedish social paediatrician found that immigrant children more often than ethnic Swedish children had 'nervous symptoms, contact difficulties, and too low or unrealistic self-perception' (152). Not much has happened in this area in the many years since then.

The Danish suburban core family with mum, dad, two children, a dog, and a car is very different from the multi-generational immigrant family living under one roof. Children from other societies can issue from monogamous, polygamous, or polyandrous relationships, be from blended families, or be children on loan or adopted. Concepts like brothers, sisters, cousins, uncles, aunts, and grandparents that have well-defined meanings in the Danish context may have quite diverse meanings in other contexts. In some societies, dead members are still part of the family. Psychiatrists, family therapists, educators, and social workers can easily get the impression that foreign family structures are pathological, deviant, and harmful to children because they are not familiar with them.

The close ties between generations in extended families means that ‘family stories’ and ‘family traumas’ can transfer to younger generations as myths and can have a negative influence on health, self-care, and concepts of illness. Symptoms may be ‘inherited’ as a social legacy from generation to generation. By way of example, some grandchildren in Japan and Israel have been found to have inherited their grandparents’ traumas. Some family stories are linked to certain types of families that have a higher risk of psychosomatic disorders, eating disorders, or personality disorders (153).

The extended family favours behaviour that binds the family together with other family members at the expense of behaviour where the individual family member goes their own way. This means that children are raised to be close to the family and to conform, cooperate, do their duty, have close ties, be grateful, and be very dependant. This upbringing may collide with the values that ethnic Danish children are brought up with, and many children vacillate their entire life between two incompatible family lives and often have to live a silent double-life. The value-clash between generations is inevitable, and guilt and shame are central challenges among children and youth in migrant families. The problem, and thus the solution, lies within the family. The smallest unit is the family, and the individual is regarded as a part of the group and not as a strong ego motivated to go its own ways towards autonomy. Access to the patient via the Danish civil registration number (CPR number) collides with the fact that health issues are seldom related to the CPR number but to the family.

The power structure in the family is disturbed soon after arrival in the host country. Some family members learn the language quickly while others take longer. Some achieve system competencies faster than others and become the natural family advocates, social workers, interpreters, and coordinators. These processes do not respect traditional family structures: girls take over leader roles while the older members become dependent on their children and lose their natural authority, which is only maintained as a *pro forma* structure by the children.

The superior ability of the children to adapt and learn the language and culture of the host country often creates a divide between the immigrant parents and their children. The children experience many conflicts in both spheres and to some degree must live an exhausting double-life. Their immigrant parents fear that the children distance themselves from their innate values and behavioural patterns. Language acquisition occurs at various speeds, and this can change the family dynamic if the power structure shifts when someone in the family masters Danish better than others do - the roles shift, and the hierarchy falters (1). The older family members typically have to rely on the youngest children’s quickly developing navigation skills and their understanding of many of the social codes. It can be very hard to maintain a parent role with such skewed and reverse dependency, and the lack of a work connection worsens the isolation (101, 154). Family stress and generational conflicts can be the early stages of low self-esteem, increasing feelings of guilt, and psychosocial morbidity among immigrant children (12). If, at the same time, the adults do not know how to ‘read’ non-verbal communication, then even every-day communication with the municipality or hospital may become a hopeless guessing game for all parties (1). Since 2007, Swedish migration research has attempted to define a group of refugee children/youth by what they called resignation syndrome caused by unresolved grounds for residency following a long asylum process (apathetic refugee children) (155-157). Large differences exist between European countries in terms of how negatively the behaviour patterns and conditions of the host country affect the health of refugees, but there is no doubt that the Western way of life for most refugees will be detrimental to their health (158). There is probably a certain selection in who migrates, but the idea of the healthy migrant (that the healthiest migrate) is absurd in this context (159, 160). The ‘healthy’ effect does not make sense in a context where blameless refugees have to settle into a cultural context marked by excessive alcohol consumption, loneliness, cigarette smoking, traffic accidents, and individual focus. In Denmark, refugees/immigrants live longer than ethnic Danes do, but the joy is short-lived when you realise that the causes of death are the only reason for this paradox: refugees smoke less, drink less alcohol, and only seldom commit suicide relative to ethnic Danes. However, they have a 2-3 times excess mortality

from infections and cancer caused by infection, and excess mortality among infants, just as maternal mortality is higher among ethnic minorities. Additionally, the cause of death varies greatly among ethnic minorities (137). Refugees/immigrants are not particularly 'healthy', but they step into a very *'unhealthy'* context when they arrive in the host country. In France, the situation is different because the local population has a different risk behaviour, and the difference in mortality between immigrants and ethnic Frenchmen is very small (161, 162).

Refugees' identities must be recreated in the host country, and in contrast to returned veterans who only need to get back to society, social networks, and family, the family members of refugee families need to renegotiate their identities in a completely new country in new frameworks with new values and codes they have not yet decoded (163). It is expected that women do not appear weak because then they cannot take care of children and food. The more or less distinct 'machismo' of men leads to delayed contact to the doctor and quick rejection of attempts to talk about or process emotions and experiences (97).

The social reception in the host country is important for health. Those who have 'time' to receive new refugees are initially 'those who get paid for it' (immigration workers, caseworkers) and after that 'those who have time' - typically other refugees. It seems that the 'refugees who have time' are actually those refugees who themselves have lost their network in the host country due to poverty, marital problems, illness, or ethnic disputes (154). In some contexts, this can lead to a skewed socialisation in a relatively isolated subculture or an environment where system competencies and language skills are insufficient to support an integration process. The involuntary and unintended social isolation may also increase the risk of depression (1). Another aspect, which leads back to health professionals, is that on a less conscious level we can show empathy, compassion, and understanding for the refugees' situation in their home country, while we simultaneously perceive the refugees as an intolerable burden on the healthcare system and society: they are poor people in danger in their home country and irritating expensive problem patients in the host country. This could be seen in connection with the Irish Potato Famine where Irish people living in the US at first saw their fellow countrymen as victims in their home country and sent generous amounts of food and money. When the same Irishmen crossed the Atlantic to live in poverty in Boston, however, they were considered hordes of insufferable parasitic tax burdens washing ashore from Europe (164).

Post-migration factors are critical to the development of PTSD and the severity of symptoms. The lack of social network, loss of cultural ties, and lack of access to professional support are stronger risk factors than traumas for the development of depression (112). Sleep disorders are almost four times as frequent among refugees as among other people, and they affect concentration, memory, and learning ability and reduce self-assessed health (165).

Unfortunately, many workers in the health and social sectors choose to disqualify the patient's language, ethnicity, and life story from the professional assessment of health issues, treatment needs, and support needs.

3.5. The chronic flight

Many refugees have less than one hour to pack and flee. Their luggage is often light, but besides their language, accent, and life story, they also carry a life filled with unpleasant or downright horrific experiences. Most of them have fled more than once, have had to hide for months together with strangers, and many only remember a life in flight. Not flight towards something, but flight away from chaos, guns, and bullets. Some refugees internalise the thought of flight and the flight as a solution. This means that their first reaction to uncertainty, ambiguity, or failure is flight - also in Denmark.

'Man cannot stand a meaningless life,' said the psychoanalyst Carl Jung. Fleeing is doing something, and doing something is meaningful. In the Danish context, it is considered a bad nomad strategy to 'shop around' or move restlessly from apartment to apartment, from city to city, and it is assumed

that the family is 'resource poor' or is indeed a nomadic family. However, it can often be a human expression for a life of flight: the world is an unsafe place if you stay too long in one location.

The thought of flight spreads throughout the family and becomes a part of the family's options, even among the children. A boy born and raised in Denmark said, *'I am looking forward to find out how peace looks like,'* while a mother who had experienced both her children and themselves as parents being tyrannised by a group of youngsters on mopeds asked us, *'How do you flee from Langeskov [small Danish town]? In Somalia, I would know, but here in Denmark, I do not know who to pay to help me flee.'*

Refugees have fled a lot - often their whole life - and flight as a way out is an automatic option and a safe way out of difficult situations. You flee from public offices, from the doctor, from the language school, and from the Danish town if the challenges you meet are too big (166). It is important that workers in the health and social sectors are aware that the patient's own circumstances often better explain an incomprehensible pattern of action than our (poor) imagination, which is largely based on fragile prejudices and stereotypes built on Danish assumptions.

3.4. The blind paths of exile

Figure 3 below gives a small insight into the inherent pitfalls of refugee life. The figure is not an expression of how all refugees are affected, but it shows the many negative factors that are theoretically at play at all stages of refugee life. The group of refugees stranded in the health and social sectors is often also stranded personally in a linguistic and network sense to such an extent that they have found it safest to disguise themselves in a vegetative isolated state they never come out of, and they live exclusively through their children and spouse. The double burden of illness comes into play because the home country's diseases and mental breakdowns were brought along in the suitcase, while the Western lifestyle and the sedentary everyday life of the exile increase the risk of obesity, hypertension, diabetes, and heart disease. The refugees' particular problem is that many factors play out simultaneously, and this is a mechanism that doctors, for example, often overlook. A number of things are happening simultaneously in several social contexts, which together threaten to disqualify the refugee's language, culture, and life story. This can deprive them of morality, courage, and self-care and can result in a higher risk of illness and disinterest in caring for themselves.

The experience that the world is a dangerous place and that you cannot trust anyone will be extra harmful to health because you also lose your language, identity, self-esteem, and ability to act. You become functionally disabled and dependent on help - a need that is usually not recognised professionally, and even if it was, the necessary help does not exist. The patient's need for help turns into a defeat because they do not know where to ask for support, and if they do ask, they experience rejection or a lack of understanding. If you have a health problem, the easiest strategy is to hide at home, not ask for help, and wait for a miracle. Many refugees with health problems or disabilities also experience stigmatisation in their own minority group: they feel physically and verbally imperfect, and this reinforces the tendency not to talk about health issues, even to those most close to them. This stigma is often more strongly expressed and in a different form than they are used to from their home country (167). Strong family ties, social communities, and greater tolerance for deviations in a society are factors that are assumed to have a positive effect on living with mental illness in one's own country. With migration, however, several of these protective factors disappear and are replaced by a very unfortunate and harmful exclusion (168, 169). Unfortunately, it appears that the internalisation of stigma and the stigma of being treated for a mental disorder are the clearest predictors of altered health behaviour when seeking help (170). Stigma is all-encompassing and pervasive by disrupting several domains of life simultaneously (structural resources, knowledge, social networks, opportunities for action, coping strategies), and it corrodes health and self-esteem (171). Stigma in the close environment that refugees depend on will increase their insecurity and prevent them from manoeuvring socially in the way they are used to, which results in lost

control functions. The only way to protect yourself is to keep quiet and not communicate with family or friends - and certainly not with doctors or caseworkers.

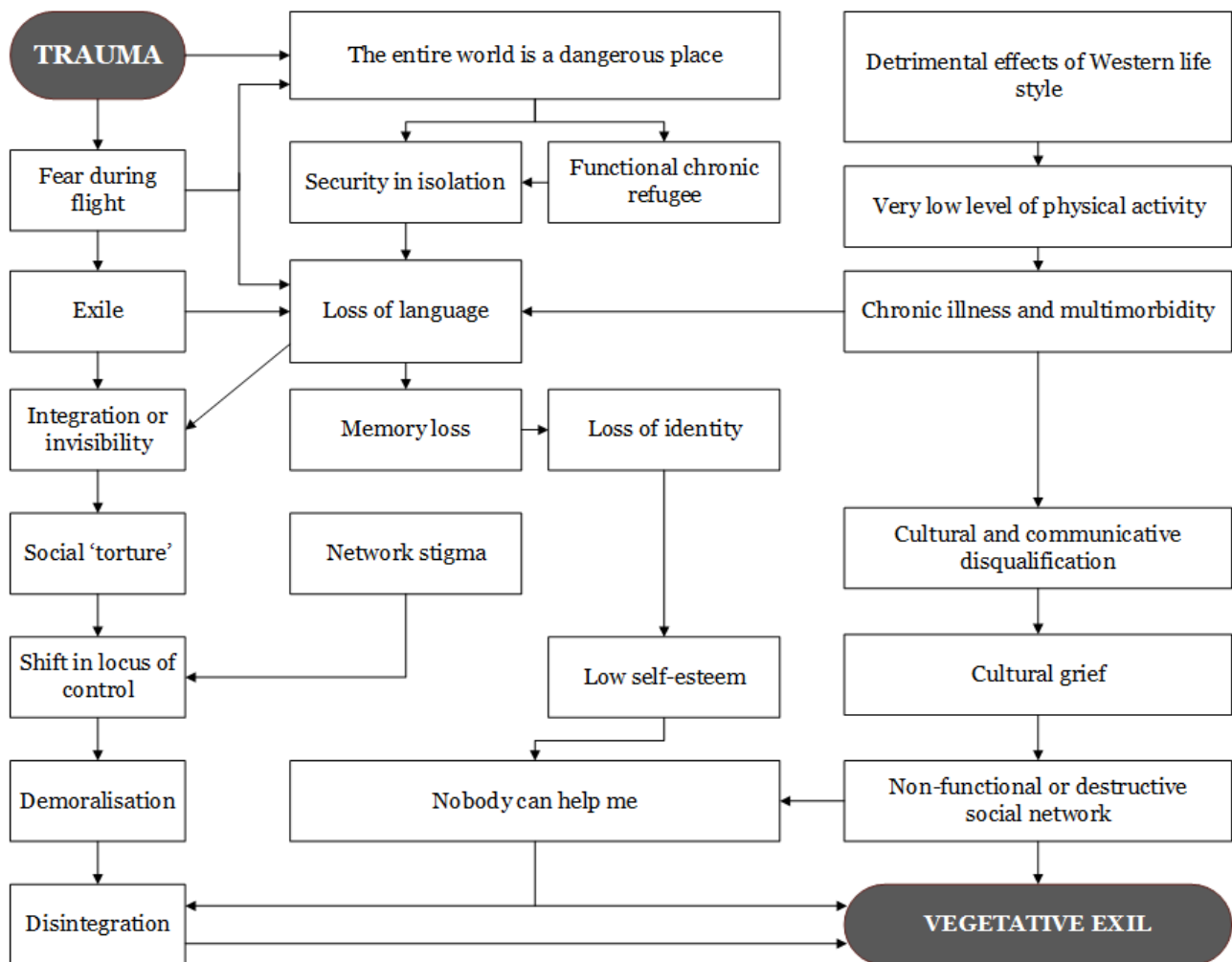


Figure 3. Pathways to vegetative life in exile.

3.5. Four penalty points in the mental driving license

Despite well-documented poor access to prevention, treatment, and after-care, very few studies have explored the barriers to accessing the healthcare system and the reasons for discrimination in Denmark and the Nordic countries (172). Social differences in health and disease are well documented. However, the basic conditions of refugees/immigrants are often ignored in health contexts. Being a refugee immediately gives you four penalty points in your mental driving license: **Self-esteem** is challenged, the **social safety net** is undermined, **stress management** is compromised, and the **life strategy** was lost during the flight. Conditions such as poor or no schooling, early neglect, great responsibility at a young age, violent war experiences, extreme helplessness during flight, paralysis of action, hidden suicidal thoughts, uncertainty about the state of family members, dependence on weak networks, and loneliness are all exacerbated by uncertain future prospects, unclear grounds for residence, suspicion, anxiety, insecurity, and distrust, maintained by a constant language barrier in all aspects of life. After settlement outside the home country, a language gap quickly emerges within the refugee family between children and parents, thereby compromising the natural mutual support of a family. The only social contact that remains is often in relation to public authorities, on which there is an increasing dependence. A social worker expressed this succinctly: ‘The family’s only network in DK consists of those “who get paid for

it". Whether you like it or not, it places a lot of responsibility on the shoulders of the health professionals who meet ethnic minority patients. If you want to be professional, you must first help clean up and create coherence.

3.6. Social suicide

Many people are torn between tradition and religion on the one hand and progress and modernity on the other. It is a fundamental human conflict that has always kept generations on their toes. However, this eternal duality places refugees in an artificial conflict because they are being pressured to take sides. Instead of being a ubiquitous general human challenge known in both Libya, Liberia, and any small Danish town, it is turned into a conflict in which the host country requires a definitive choice to be made. Refugees cannot see the interaction as enriching and are torn between the demands from their own ethnic minority group to maintain the identity and tradition of the home country and the natural need for an identity in Denmark. The political and social environment of exile forces them to constantly choose sides ('if you are not with us, you are against us'). This inevitably stresses them and results in many choosing to resign themselves to what they know (tradition and religion) but in a frustrated, demoralised isolation. The pressure on refugees to choose sides ends up having the direct opposite effect than intended. Ethnic Danes commit suicide when pushed beyond the edge of accumulated demands and unsolvable problems. Hard-pressed refugees, on the other hand, do not have this way out, as suicide is socially completely unacceptable. Instead, they choose to isolate themselves and vegetate in a state that, seen from the outside, resembles a functional social suicide. The suicide is not due to extreme hopelessness but due to extreme communicative, physical, and psychological paralysis due to the forced choice between two identities that they cannot reconcile.

3.7. Post-traumatic stress and feeling unwell

One of the biggest barriers in the conversation with immigrant patients is that doctors often fail to incorporate the basic conditions of the refugees/immigrants in their dialogue, information, studies, and treatment. Health professionals find it difficult to understand and include the lives of ethnic minority patients *before* they came to the host country. This often leads to failed examination programmes, low quality of treatment, medical errors, and ineffective health education measures (51, 173, 174). Current life conditions and concerns are rarely in focus during the planning of clinical examinations, but these aspects can influence the patient's participation if the purpose is not entirely clear (175, 176). Basic rules and rights may be side-lined when ethnic minority patients encounter the health service because we forget their situations. Fear of touching, taboos, irritation, and reluctance, as well as lack of respect and suspicion of relatives easily gain the upper hand and can threaten both the quality of treatment and patient safety (78, 177).

Post-traumatic stress syndrome (PTSD) and related conditions are overlooked problems but are often invisible players or opponents in a clinical context and should also be known to doctors working in somatic health fields (51, 78).

PTSD causes memory and concentration difficulties that lead to PTSD patients understanding, processing, and storing knowledge in ways that hinder language learning. PTSD can affect the ability of refugees to learn and use new knowledge, such as information about prevention and disease (178). Sleep, pain, and worries affect the ability to concentrate during conversations, including those with the doctor. Refugees do not know many of the codes that explain the language or the concepts we use, and the doctor's professional terms may be misunderstood without the doctor noticing. Feelings and thoughts are best and most confidently expressed in the native language, so if an interpreter is not used, the doctor may be missing important information. PTSD patients have a particular need to express themselves accurately and to be understood. Therefore, interpreter assistance can help to create calm, security and

trust. Women with PTSD and short or no schooling are particularly vulnerable when learning new things and they are often socially challenged in more areas than men. PTSD patients very easily lose their Danish language skills if they are exposed to breaks in their routine or social/physical/psychological events. A need for interpreter services can easily arise, for example, during illness. If the doctor is not aware of this fact, important information can be missed, leading to compliance problems that are incomprehensible to the doctor (178-180).

Patients on high alert look for information in the brain (cortex) differently than calm patients do. Even if new knowledge has been stored appropriately in the cortex, it can be difficult to access when one is on high alert and anxious. If the patient is very afraid, access to 'adult and rational' thought and analysis may be completely blocked, and the patient may suddenly appear immature in their thought processes - the primitive and less rational areas of the brain, below the cortex level, are in control. Verbal and non-verbal signals are over-interpreted and distorted, making the patient appear untrustworthy, immature, and with low self-esteem. Patients in fear focus on a few impressions that seem important to the anxiety, and new knowledge or new tasks are either ignored or provoke more anxiety. Adults with PTSD can find it difficult to be 'present' in a conversation with the doctor. They have difficulty treating linguistic ambiguities and discussions or doubts as anything other than anxiety-inducing situations, e.g. in relation to issues that require participation from the patient (181, 182). As a result, the patient may have very negative hospital experiences that compromise their opportunities for continued learning (183). Due to trauma, refugees do not have an overview of what has happened. They remember random images, have gaps in their awareness, and suddenly may recall something that does not match what they have described previously. This may be interpreted as if the patient is not telling the truth. If the patient tells a disjointed story, the patient is perceived as untrustworthy, and the risk is that a valid patient history is rejected. Fragmented and disorganised memory especially around the trauma can keep PTSD patients in a situation where they cannot start a course of examination and treatment, e.g. for a somatic illness, until a targeted PTSD treatment aiming at a better memory structure has first been initiated (184, 185).

How patients experience time depends on a wide range of factors, including grief and depression, as well as the more extensive processes at play in chronic PTSD or psychosis. Nevertheless, it is important to incorporate differences in time perception in the clinical process, and it can probably be used to assess overall functional level and quality of life in a similar way to self-perceived age (272). It is often necessary to have professional patience when complicated memories in a medical history need to be retrieved and located sensibly. Just as there are many languages in a bilingual conversation, so too are many points in time and perceptions of time: the time sequence of the trauma that subsequently became traumatic and led to illness; the sequence in which the patient chooses to describe events to the doctor; the sequence the patient chooses to apply in the clinical context; and the sequence in which the doctor chooses to see and document the events. An anthropological thesis from 2011 describes from qualitative interviews how diabetes patients' perception of time may be very far removed from that of health professionals - time blurs, days go by without plan or purpose (273). Time is seen as nostalgia and boredom - some have called it cultural mourning. Unfortunately, the interviews do not elicit how the perception of time relates to the life stories and the psychosocial events that mark it. Undoubtedly, however, the smooth transition from cultural mourning to the effect of actual traumatic experiences, unproductive sleep, nightmares, and re-experiences, as well as orientation and memory problems, strongly impact self-care and time perception. This includes diabetic patients, and this knowledge should be basic knowledge for all doctors and nurses who encounter ethnic minorities.

Bilingual people often switch back and forth between their languages consciously and unconsciously. Additionally, different languages often refer to time differently. For example, Swedish-English speakers refer to physical distances: *'Take a short break,'* while Hispanics refer to physical amounts and volume: *'Take a small break.'* The researchers asked native Swedish speakers, who also spoke Spanish,

to estimate how much time had passed while they were looking at a line that slowly grew across a screen or a container that was slowly filled. Participants were asked to use the word *duración* (Spanish for duration) or *tid* (the Swedish equivalent). When asked about the Spanish word, bilinguals based their estimates on volume related to a container being filled in. When asked for the Swedish word, they changed mind-set and suddenly gave time estimates as a range, referring to the line on the screen rather than volume.

Unproductive sleep, splitting, dissociation, and difficulties remembering or concentrating are PTSD-related factors that can affect anamnesis and compliance in unpredictable ways. Varying elements of anxiety, depression, personality disorder, flashbacks, voice-hearing, and borderline psychotic conditions can be in play simultaneously and can easily confuse the clinician (186). Some PTSD patients display changes in emotional expression and behaviour in the form of indistinct or ambiguous body language, no facial expressions, loud voice, and being too watchful, which gives an outward impression of disorganisation. Severe and long-term PTSD symptoms with memory problems are also associated with large 24-hour variations in blood pressure (187).

Traumatic events overwhelm the normal human defence systems that give people a sense of control, context, and meaning. Traumatic experiences are extraordinary because they destroy the normal adaptations people make when faced with challenges in life. Trauma confronts people with extreme helplessness and violent fear, which triggers a sustained disaster response. PTSD patients are afraid of making decisions, starting something new, or taking a risk. They are afraid of being humiliated (again) or rejected, and they fear making decisions or mistakes that could trigger unpredictable and ambiguous situations (188). Trauma wears the patient's self-esteem and self-confidence down, and many PTSD patients are at high risk of not being able to acquire knowledge, such as about their body, health, and illness, due to their feelings of guilt, shame, and responsibility for the trauma (189). For refugees, everyday worries include financial problems (e.g. paying rent or getting money for food), problems with children (e.g. risk of pregnancy and absence from school), health problems (e.g. worries, anxiety symptoms experienced as an expression of a dangerous life-threatening or debilitating illness), and problems feeling unsafe and unprotected from dangers and accidents. In our clinical work, we have found that refugee patients have many such concerns and that they respond frequently and forcefully to them. They find it difficult to stop worrying and have much mental and somatic suffering caused by these concerns as in a vicious circle. When refugees have these 'episodes of concern,' they also tend to trigger uncontrolled re-experience of war, disaster, or torture trauma, as well as pronounced disastrous thinking that directly affects their perception and judgement, even in completely mundane everyday situations in school, on the bus, in parenting, or in the doctor conversation (178, 190). In this condition, inappropriate decisions are very easily made, including about their own health or treatment, and it is important not to judge patients on their decisions without knowing their specific circumstances. It is often small things that breaks the camel's back at the doctor's office, at school, or at the municipal office. Even small misunderstandings can have very, very, large consequences. How to use a contact book at school can cause major conflicts, a quick remark from the doctor may be understood as mockery, and a fleeting remark from a fellow passenger on the bus gets internalised and contributes to the feeling that the world is a very unsafe place. On top of that, patients' losses are not appreciated: friends, homeland, culture, and language. It is very difficult to make it important at the municipal services office and in the healthcare system. The experience of a total rejection and disqualification of the life story and language contributes to the demoralisation of the patient - nothing matters. What starts as a necessary and normal mourning of one or more losses slowly slips into melancholy, powerlessness, and indifference, even when you get a serious diagnosis and an illness that requires your full attention.

The usually protective social networks do not work as they do in the home country. Ethnic minority communities need to find new ways of defining themselves. New needs arise that social networks must learn to tackle, and problem solving in minority environments is challenged almost daily with unfamiliar

challenges (legislation, organisational changes, altered educational requirements) that they do not control and often barely understand the background for. Parents and social networks can compensate for patients with PTSD as long as they (parents and social networks) themselves are able to handle the pressures of their own situation. Tightening refugee laws, caps on social security benefits, and changing rules for family reunification reduce the resilience of social networks and thus their ability to help and support a patient with PTSD. It can be difficult for the outside world to distinguish between general/expected mental stress and severe psychological strain, and patients can fluctuate between the two conditions without being detected (191).

Immigrant environments that previously were able to deal with and absorb members with PTSD who have high stress levels or social phobia can lose their buffering effect. This puts patients with PTSD and their families in a vulnerable and uncontrollable situation, which is often described as the same extreme helplessness and the same severe loss of control that was the very reason they fled their home country. Even small legal changes regarding education, social security benefits, and residency grounds or an occupational injury can shift the balance from tolerance and resilience to exclusion and extreme vulnerability.

The distinction between what is extreme adversity and what is trauma can have different meanings in different ethnic contexts, as has been demonstrated recently among Ethiopian refugees in England. Thus, it is important that doctors do not rely only on trauma definitions that are rooted in a Western understanding but can also professionally handle the inclusion of the social, political, religious, and economic framework in which the experiences occurred (192). Figure 4 below shows the elements that together control and characterise when and how past trauma can be experienced and expressed (190):

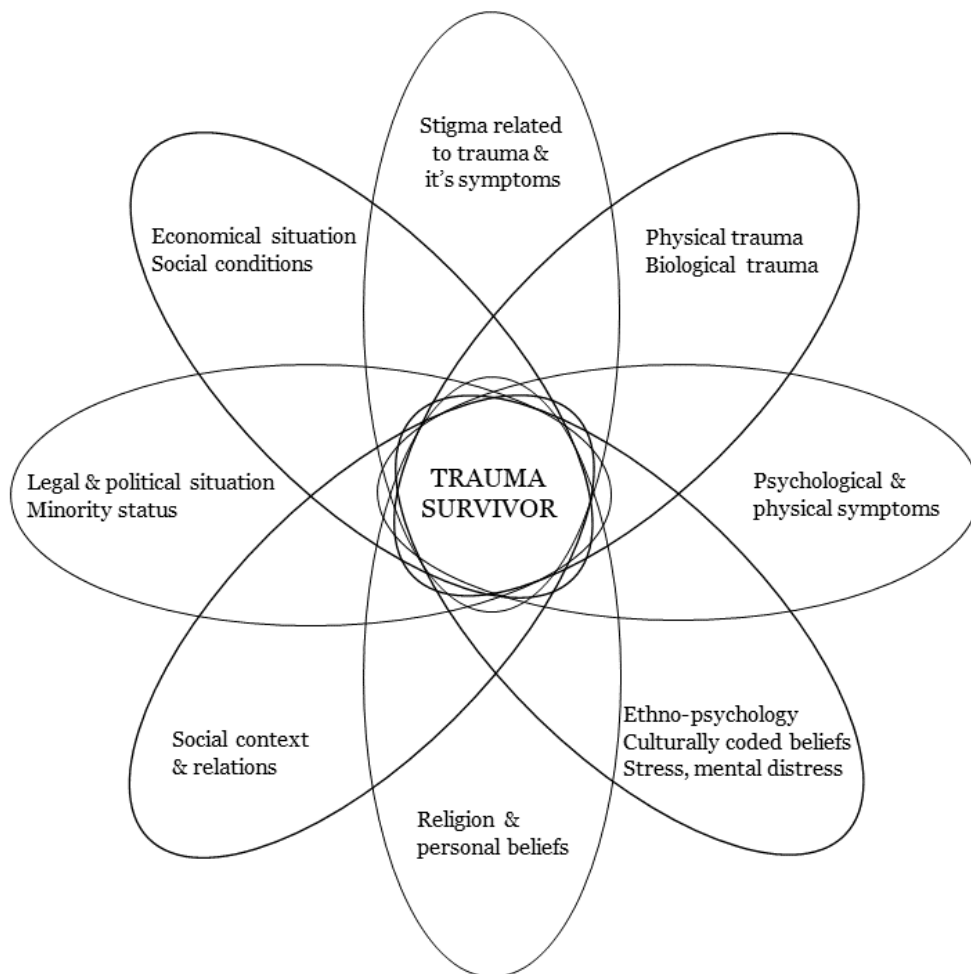


Figure 4. Factors that can influence whether and how a mental trauma is expressed.

3.8. Stereotypes hinder the conversation

When Walter Lippmann introduced the concept of stereotypes in his book *Public Opinion* (1922), he defined stereotypes as mental concepts - images in the brain (*pictures in our heads*) - that control the way we perceive the world. He argued that stereotypes are necessary for our ability to orient ourselves in the world. The real world is 'in every way too big, too complex, and too fleeting for direct acquaintance between people and their surroundings. Therefore, humans construct a pseudo-reality that is a subjective, attitude-coloured, and simplistic mental image of the world'. The crucial problem occurs when openness disappears, because absolutes and stereotypes are not flexible enough to capture the real people who populate the world. It is an important point that when you move around in the world, you do not meet 'cultures', you meet people (1345). The further away the doctor is from the patient's actual life, the easier it is to maintain stereotypic ideas about the patient. Lippmann called for 'keeping them (stereotypes) light and modifying them willingly'.

As humans, we live the most diverse lives. But paradoxically, people everywhere think that their way of seeing things is the only natural and right thing for people, and that other ways are reprehensible or erroneous. Each human being lives egocentrically rooted in their own historical moment, in their society, and their physical environment, in short: **locked inside a bubble of their own experienced reality and in their own knowledge**. There is nothing wrong with this, but it must not affect the doctors' clinical decision-making capacity. In a doctor-patient conversation, the doctor is the professional expert, and the patient is 'an expert in his own life', as it is often expressed. It is the doctor, however, who as a representative of the health service has the task of, 1) capturing and 'translating' the patient's experiences with his body and mind into a formulation and sense that is operational for the healthcare system, and 2) communicating this professional assessment and plan to the patient.

In a study of how the professionalism of teaching was influenced at Danish and Norwegian universities depending on which language was used in the teaching, it was found that if the teaching was done in English, then the academic content was lowered, questions were not clarified, humour disappeared, too much time was spent explaining common words, and there was no discussion. As a starting point, every doctor-patient conversation contains an element of cultural differences and language barriers, regardless of ethnicity, but there are also many other, more elusive factors at play, as shown in figure 5.

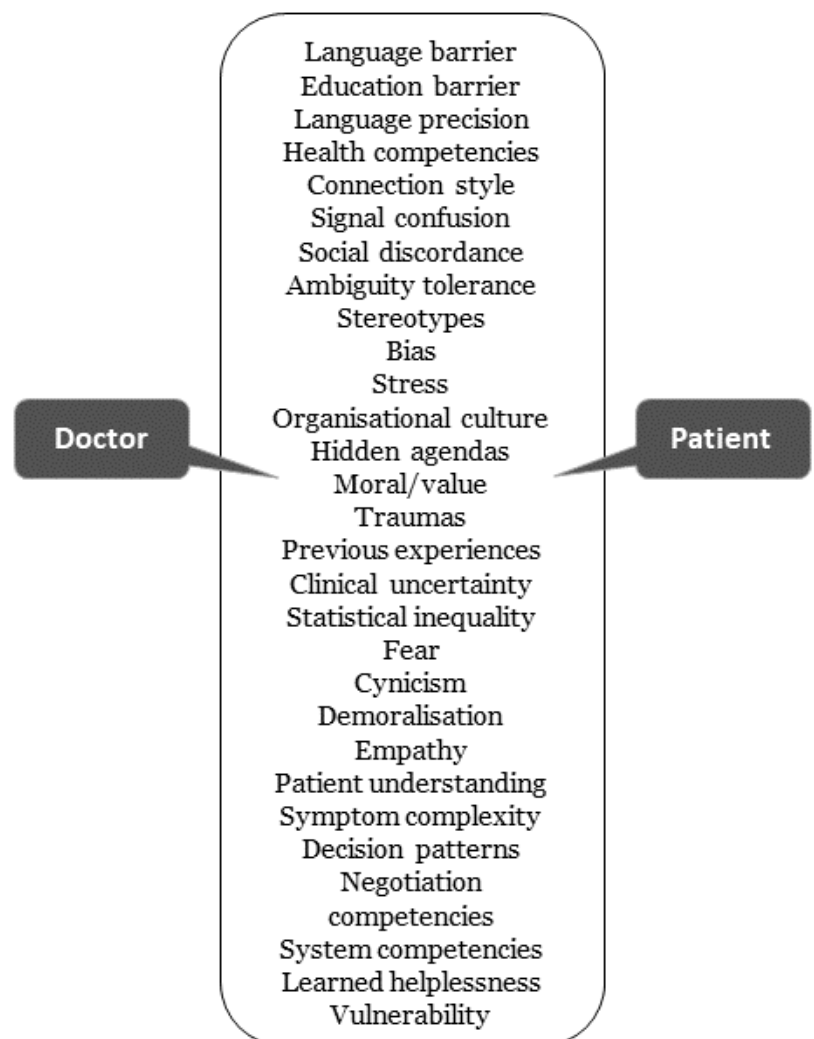


Figure 5. Potential barriers in intercultural conversations.

The conversation between a doctor and a patient must move, remove, replace, exchange, and process information. The aim of the conversation is to reduce uncertainty and clarify ambiguities on both sides of the table. Uncertainty is lack of knowledge - the difference between the knowledge needed to understand a patient and the knowledge the doctor/healthcare system already has about the patient (and vice versa) (193). Ambiguity means that there are many concurrent and divergent understandings of a situation. There is widespread confusion and lack of understanding and the conversation is characterised by mutual stress that obscures the full view (194, 195). It is difficult to ask questions and the framework and premises of the situation are so poorly defined that the answers are difficult to use. Patients do what they do best: describe what they feel and share their needs, anxiety, and worries. It is the task of the health professional, in this case the doctor, to wrestle with the many invisible and fleeting factors in the conversation so that it becomes an informative, meaningful, and calming procedure that reduces some of the uncertainty or doubt that existed at the start. In the diagnostic-clinical process, doctors often fail to notice the fleeting factors and thus may not capture the full diagnostic picture. The conversation is not a precision machine. We interpret, experience, and respond to ambiguity and uncertainty individually, and one has to be professionally aware of that. When it comes to ambiguity and uncertainty, we are very different in our professional responses and action patterns, and we must learn to take that into account so as not to destroy the diagnostic process (195). Doctors who have low tolerance for ambiguity are more likely to withhold unclear or negative examination results, feel uncomfortable with difficult conversations, order unnecessary blood tests, and experience negative feelings towards vulnerable patients (18).

3.9. Language in the clinical context

Language does not only communicate explanations and understandings - about illness for example - it also shapes and forms perceptions about the body and about illness. Opinions and concepts are processed and provide an overall understanding in the mother tongue *but not necessarily in the second language*. Many common words and concepts relating to diseases in the mother tongue do not exist in the second language, and if you are ill, it causes anxiety if you cannot express yourself precisely.

Important core cultural values about disease can be encoded in the first language in such a way that it requires very skilled interpreters for it to be understood in the second language. Language and conceptualisation in the first and second languages are critical in the doctor-patient context when it comes to language barriers. Migration involves loss of language (especially everyday language and dialect), attitudes, values, social structures, normal life strategies, options for action, and support networks. The language, the mother tongue, will often be the only item remaining that gives the refugee identity, security, and peace of mind (196). For particularly fragile refugees with war trauma and no school education, their mother tongue is the only sure means of communication, and attempts to change such a fundamental element of an otherwise chaotic and unsafe refugee life is associated with fear and high alertness. As a result, both their own cultural identity and conformity with the new culture are being eroded simultaneously, leaving a refugee in an unconstructive linguistic no-man's land. Many of the patients who are referred to the MHC have ended up in a linguistic limbo and have given up on language, body, health, and social interaction. It is a humanly costly condition centred on lost language and consequent lost identity. A loss that affects patients' ordinary human drives, their motivation, and their self-care - a condition reminiscent of demoralisation.

3.10. Recipe for misunderstandings: the interpreted conversation

Refugees can lose their 'voice' both literally, in re-animations of their words, and symbolically, as they are reduced to being spectators to the reconstruction of their own identities. In many cases, their voice is the refugee's only tool to justify an application/request. However, the way in which their often very

complex social experiences are captured and understood into bureaucratically manageable narratives is indicative of convoluted and messy multi-discursive processes for representation and assessment of the refugee's original narrative and experiences. They are administrative processes of a formal character, but on the few occasions when they are the subject of scientific communication and cross-cultural analysis, they turn out to be bizarre, pointless, and arbitrary, with no respect for the individual (197, 198).

Many problems that arise in connection with interpreting by public authorities are assumed to stem from cultural differences or the interpreter's general lack of competence, but instead they stem from hidden differences in language ideologies and ignorance about how language is used in different cultures. One of the most important routines in the refugee process is the discourse on reporting, which effectively blurs the distinction between written and oral language and the de-naturalisation of the 'spontaneous' spoken language in interpreter-mediated conversations. The initially vivid, association rich narrative, supported by additions, elaborations, clarifications, and anecdotal memories, is reduced to a neutral impersonal decision-making report that cannot reflect the person's unique history in its diversity, thereby depriving the history - and thus the refugee - of its legitimacy and credibility. As soon as there is a language barrier where the patient has to speak through a third person or has to speak in a language other than their mother tongue, the power balance of the conversation changes, which diminishes the patient's opportunities for dialogue and to correct or counter generalisations and ambiguities in the conversation (199). If the health professional is not aware of this power shift, the certainty of the diagnosis may be compromised, and the quality of treatment is threatened. A critical reflection on language and the nature and function of multilingualism and the consequences of language use is necessary to enable the interpreter to work in a way that can negotiate power relations and achieve an approximate linguistic parity. Such reflection should be part of the education of both interpreters and doctors. Doctors receive no training in the language ideologies of the interpreted conversation, and interpreters are trained to do one thing: to faithfully and directly translate what the doctor says, and only that, without respect for the patient's language, background or needs (200). An interpreter policy that puts uniformity and management first may look like a fair form of communication. Unfortunately, that is not the case. While standardisation is institutionally valued and expected, a very high degree of variation exists because the patient, the interpreter, and the doctor try to bring human and individual aspects into the conversation (201).

Intercultural communication misunderstandings result when the parties involved in the conversation pursue uncontrolled communication strategies that are not shared by the other parties and that lie below their level of awareness. To avoid intercultural disturbances, the meta-communicative attention of those involved in the conversation need to be increased. This applies especially to those in positions of power (police, doctors, nurses, educators, teachers, lawyers, civil servants, etc.) (95).

Hofstede and others have, among other things, suggested familiarising yourself with six cultural variables through which communication should be filtered (202, 203):

1. Power distance: how far is it up through the power structure? Flat versus vertical power structure
2. Avoidance of uncertainty: tendency to take risks, face the unknown, tolerate ambiguity
3. Individualism versus collectivism
4. Masculinity/femininity: goal achievement/results-oriented versus equality and focus on relationships
5. Short-term/long-term orientation: reward now, traditions, pride versus reward later in life/second life (stubbornness, savings, and flexibility)
6. Forbearance, indulgence versus restraint

The linguistic and social strength needed to assert yourself and be visible in a specialised hospital system is often absent, and when health workers are not aware of how language and language usage can

affect the patients' visibility, then the unequal 'power' situation becomes an invisible barrier. Insecure and frightened patients fall back into their mother tongue, express themselves in vague terms, are difficult to understand and difficult to treat. Unsure doctors and nurses have a hard time remaining patient and listening. The experience of strange events or unexpected actions on the part of the doctor leads to uncertainty and a lack of confidence in the doctor on the part of the patient. Distrust has been shown to be linked to low patient satisfaction, poor compliance/adherence to study programmes and treatments, lower self-assessed health, less willingness to seek professional help, and poorer quality of interactions with the general practitioner and other health workers (204, 205).

Language is a key resource as it is a prerequisite for avoiding ending up in clinically unusable generalisations. Explanations and reasons are essential for positioning oneself in a conversation, but the prerequisite is still that someone is listening. Ethnic minorities have less mastery of the nuances of language and concepts, so misunderstandings can easily occur, yet it is a condition for intercultural communication. Both doctors and patients tend to use generalities when they lack words or knowledge. Combined with a busy everyday life where time is a scarce resource, this gives little room for acknowledgement, and stressed or anxious patients feel confirmed in their feelings of being marginalised (107).

Figure 6 below shows a model for how and where interpreter assistance can contribute to reducing health inequalities (103):

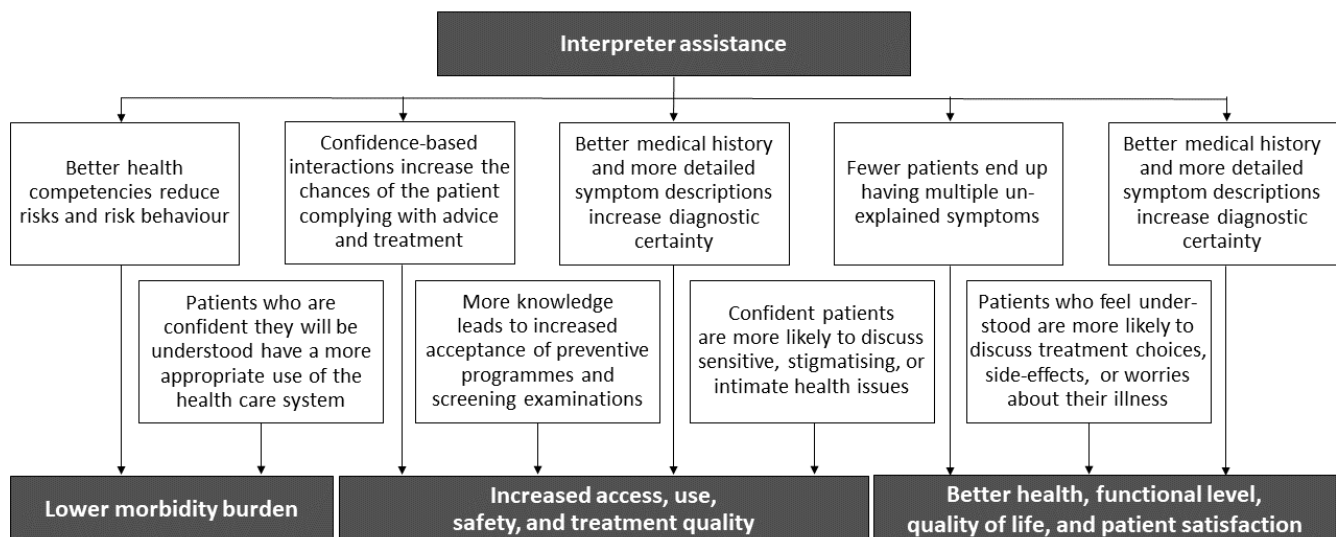


Figure 6. Benefits of interpreter-assistance.

3.11. The cultural X-ray vision

Culture is a laundry list of items so mixed in colour that when washed together, the clothes become pale and dull (206). The culture ghost is often pulled into the doctor-patient context. Without admitting it, doctors automatically think 'culture' when something happens in a patient conversation that they do not understand, or if the patient's inner logic appears incomprehensible. There are pictures in the minds of both doctors and patients with cultural icons when you experience incoherence or lack of comprehension in a situation. *'Those pains must be a cultural-ethnic expression'*, the doctor thinks, while at the same time the patient thinks, *'He (the doctor) does not understand what I feel anyway, and I do not want to try to explain it again for the umpteenth time'*. Religion and ethnicity also get a seat in the consultation room: *'She has a sore ear, but she wears a headscarf and they will not take that off, so I might as well not examine it'*, the doctor might think, while the patient complains, *'Why does the doctor never examine me when I say I have a sore ear? Is he a doctor or not?'*

The paradox is that it takes knowledge of culture, religion, and ethnicity to get them out of the consultation room again. Ultimately, they are less important in the doctor-patient conversation that should primarily be about basic symptoms, experiences, feelings, needs, information, and plans - when everything that makes noise and distorts the conversation is peeled away.

A culture that embraces the interwoven patterns of human behaviour, such as language, communication, customs, habits, beliefs, and values, is important in health. Cultural, social, and family influences play an important role in the formation of attitudes and ideas on health, disease, and treatment. Thus, the early establishment of a good patient-provider relationship is key to uncovering any cultural beliefs or values that may prevent or affect treatment, e.g. acceptance of insulin therapy or surgery. Although cultural components can vary among different populations, values may be the same among some minority groups (207-209). A good example of complex cultural values are body ideals. Ethnic English mothers considered slim children to be a sign of health, while Asian, Caribbean, and African migrants in England considered that overweight children represented healthy children (210). It seems that viewpoints change and become more complex as children get older (211). Among women in some ethnic groups, being overweight is considered to be a sign of fertility, and it may be associated with beauty in other groups (212). A link between a thinner body ideal and educational/social status among Arab women is likely, yet women were more critical of men's weight than women's weight (213).

It is impossible to manoeuvre in the soup of ethnicity, culture, and religion without knowing both one's own culture and ethnicity and those of the patient - through which the doctor and the patient together can achieve professionalism and humanity and reach the core of the doctor-patient conversation: what does the patient feel, and how can the doctor help? You have to acquire cultural-ethnic X-ray vision by understanding how these elements unfold in the field between disease and health - how they work and their consequences - to be able to respond to them, take them into account, and guide them out of the consultation room. There are many good recent sources on these topics in a Danish clinical context (214-217).

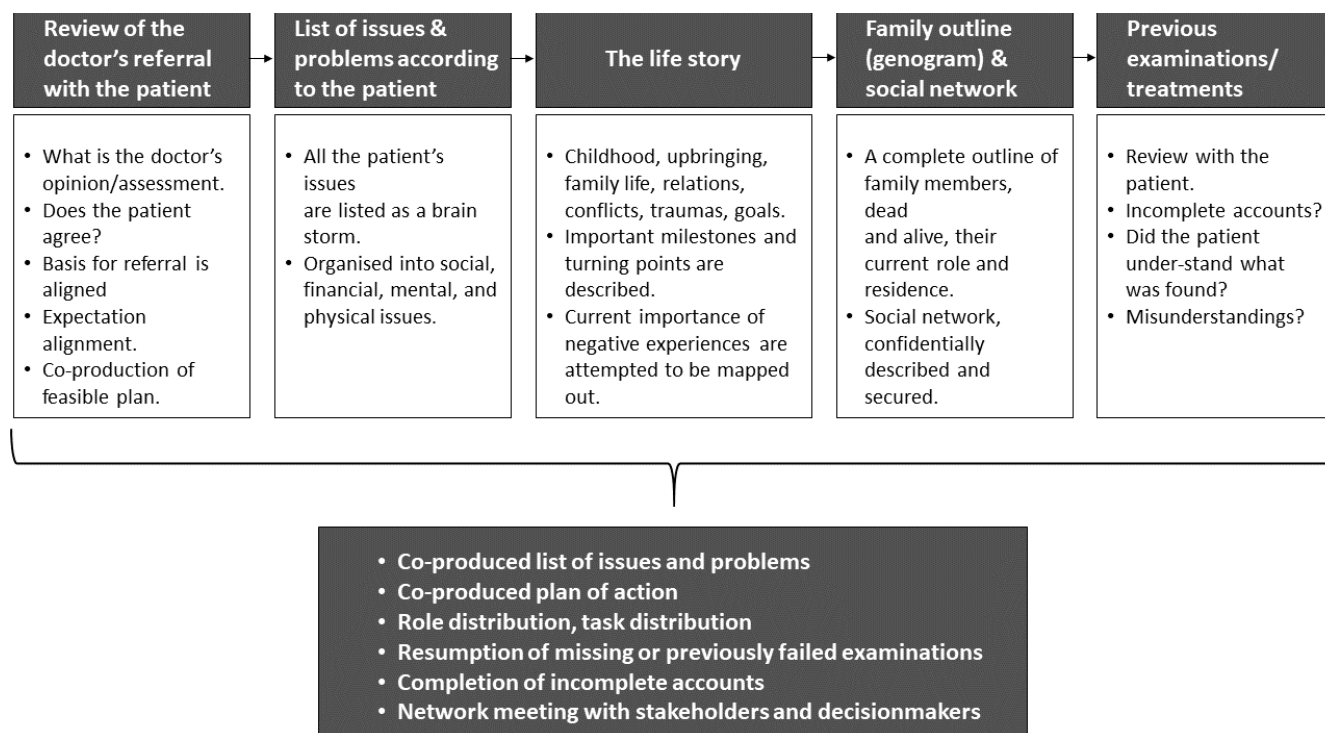
Assessing the seven cultural dimensions ranging from environment, economy, technology, religion/worldview, language, and social structure to the more commonly known dimensions such as family structure and individual and cultural beliefs and values requires that one understands culture as a system of factors that have a clear and important purpose rather than being an exotic collection of characteristics.

3.12. The life story as a clinical tool

Health professionals often find it difficult to understand and include the lives of ethnic minority patients **before** coming to the host country. This often leads to failed examination programmes, low quality of treatment, medical errors, and little effect from health education measures (51, 173, 174, 218). Respect for the whole life story by listening to it and actively using it in the professional meeting to help the patient to greater self-awareness and self-care must be at the heart of all those dealing with ethnic minorities (215, 219-221). The clinical potential of a patient-centred life story angle in the clinical doctor-patient conversation is well described (51, 173, 174, 220, 222). For example, a Swiss study found that refugees from the former Yugoslavia often had underlying somatic complaints even though the immediate symptoms were psychological in nature (222). Furthermore, 78 % in the same patient group found that their disease had been triggered by traumatic experiences and subsequently characterised by biomedical and psychological factors. The most surprising thing about the study was the large number of psychosocial and psychological causes of somatic symptoms, which only emerged by systematically guiding the conversation towards seeking such explanations in the patient.

Together with the list of problems and the family tree, the life story is a tool for drawing up a common list of issues and a common action plan based on the patient's own preferences.

Figure 7. Basic tools for mutual decision-making in complex patient conversations with cross-cultural issues.



3.13. Stigma and the imperfect human being

In many countries, psychiatric disorders are associated with stigma, and it is often difficult for patients to be allowed to receive treatment because the family does not give permission. Psychiatric disorders are a sign of weakness and a self-inflicted condition (223). Similarly, other health problems are more stigmatising than we are used to in ethnic Danish contexts, such as urinary and faecal incontinence, which are described by some patients as worse than HIV/AIDS (82). An attempt to downplay the incontinence problem may have the unintended effect of the patient perceiving the doctor to be ignorant and disrespectful. The relationship between psyche and body can be difficult to understand let alone accept and will always pose a clinical challenge if it is not actively incorporated into the understanding of the patient (215, 224). Disabled members of ethnic minority families, with even very small and invisible disabilities, are pushed into double minority status and must live in isolation partly because of social stigma and partly because of self-imposed isolation due to shame about 'not being a perfect human being' (78, 225). A doctor who is not aware of the disability or the consequences may overlook important causes of poor self-care or may only perceive unexplained patient behaviour. *'It is very difficult to keep a family in Denmark,'* said a patient, *'there are so many rules you do not know, and we are constantly unlucky and get hurt.'* For many refugee families, it feels like a fulltime job just to survive. The children live double lives between two cultures and have many homework assignments, while the elderly pose a hidden but very great challenge for the younger members of the family (226).

3.14. Need to know basis

It is not particularly difficult to consider the refugees' circumstances, but many doctors do not realise how large and important a role the patient's circumstances play in relation to self-care, health, and disease. This holds especially for patients who have language barriers and who grew up in a cultural context

that is very different from the Danish one. It is not clinically productive to pretend that the patient's life only began on the day they set foot on Danish soil. If the doctor ignores or downplays the language barrier, the patient will experience a feeling of being disqualified in their ancestry, upbringing, culture, and language. In doing so, the doctor sets a condition for the conversation that the patient has no chance to change - and thus the patient's only way out is to protect themselves. Patients do this by: 1) teaching themselves the doctor's code language, i.e. presenting only one symptom and asking only one question, 2) by saying 'no' if they have not understood the doctor's information, 3) by providing the doctor with information only on a 'need to know basis', i.e. the doctor will have to ask if the doctor wants to know something, and 4) by saying 'yes', but thinking 'no' because the doctor still does not understand what it is about. Unfortunately, neither the doctor nor the patient notices until much later. The patient thinks, *'The doctor's question does not help me'*, and again the doctor feels powerless and confirmed in thinking that immigrant patients do not listen to what the doctor says.

3.15. Health competencies: Good food for the sick

It is important that doctors inform themselves about ethnic and social differences concerning ideal body image in relation to self-care and metabolic syndrome. It is not useful to assume that all peoples in the world have the same perception of what body weight is ideal and what a healthy body looks like. There are ethnic differences in treating BMI as a risk factor (e.g. the BMI score for overweight is lower for Asians than for others), and there are significant differences between ethnic groups in reporting (BMI-defined) overweight as (ethnically/culturally defined) overweight, which can give rise to serious and harmful misunderstandings (227-229). In many societies, the connection between disease and diet and body appearance is pivotal. In resource-poor areas, it is essential that you can afford energy-rich food and that you can eat. The only sign that you are not poor or sick is that you eat - and eat 'well'. If you are sick, you should eat even better in the form of fatty milk with sugar, rice fried in oil, and fatty meat. If you have been told that you are sick and have high blood pressure, diabetes and a bad heart, then you should eat 'expensive' food with ample energy content. The dietitian's advice and the doctor's admonitions bounce off like Teflon on the patient's eardrums: Danish doctors do not know what is good when you are sick. If you are thin, you are both very sick and very poor, and it has social consequences in terms of recriminations, stigma, and isolation. It is thus better to maintain the illusion of prosperity and health by eating well and ignoring the Danish dietary advice.

Much is therefore accomplished in a conversation if the doctor and patient together clarify what the patient is afraid of and what aspect of the disease, examination, or treatment the patient is uncomfortable with or does not understand. It is our experience that some patients:

1. Do not dare tell the doctor that they are afraid, or why
2. Say 'yes' but think 'no'
3. Do not know which department they have been referred to in the hospital
4. Do not know that there are different types of doctors with specialty knowledge
5. Do not know what the doctor's plan is
6. Do not expect to get help
7. Do not count on the doctor being able to understand the patient's needs
8. Assume that the doctor has not understood the patient's needs
9. Do not expect the help received to work
10. Assume that all information flows freely
11. Are already unambitious in terms of examination and treatment and rarely expect success

If the doctor pro-actively addresses the patient's doubts and anxiety, it will be easier to plan and conduct examinations and treatment.

In an attempt to create a foundation that can support patient-centred examination and treatment, the concept of health literacy has gained ground and has become health competencies (*sundheds-kompetencer*) in Danish. There is good evidence that a patient's individual knowledge, motivation, and ability to seek out and use information are essential elements of the patient's health literacy (230, 231). More and more people want to contribute with definitions, and the health literacy model is now so inclusive and complex that it is too comprehensive for health education and makes no sense at all in clinical practice (232). Unfortunately, health literacy depends on two key competencies - numeracy and literacy - that have nothing to do with the tasks of the health service. None of the models of health literacy focuses on those patients who cannot read or do arithmetic. The health service assumes a minimum ability to read and do arithmetic at a certain level, otherwise health literacy does not work. The concept has become a bureaucratic and research-oriented product that places a large proportion of patients outside the room - they are not included in the model.

It is especially the health competencies of ethnic minority patients that are affected by the lack of cultural clinical competencies of doctors and the healthcare system (233-236). In a cross-cultural context, the concept reveals an underlying stereotype that is of particular importance for the ethnic minority patient's encounter with the healthcare system. The concept actually masks professional uncertainty and a reluctance to touch; they are rather an expression of an academic and political need for calm, order, and regularity than of patient's actual needs. Shifting the blame to the patient strengthens the doctor's and the health service's concept of where the main problem and responsibility for cross-cultural patient meetings lies: it is with the patient, who needs to know more, act more, and fit in better to the healthcare system. Unfortunately, their strategy fails because it is meaningless in conversations with linguistic, cultural, and psychological barriers, which is often the case in meetings with immigrant patients. Most patients want respect, responsiveness, and understanding on their own terms. For most health professionals, low health literacy means that the patient's ability to understand and follow the doctor's instructions is affected. For the patient, the problem is that the doctor does not know how to meet the patient where they are. Whether the patient's health skills increase depends to a large extent on how effective and adapted the doctor's communication is (237). For example, diabetes management is directly influenced by how the patient experiences the doctor's communication skills (238). Knowledge of social determinants and other non-medical factors are elements of patient involvement that are increasingly being included in what is called *critical health literacy* (239).

As noted above, patients do what they do best: they say what they sense and feel with the words and understanding they have of their body, disease, and health. The concept of health literacy is fundamentally misunderstood and has therefore been given an incorrect and unconstructive focus. In the healthcare system, we cannot change each individual patient much, and it would also be megalomaniac to think that we could. On the other hand, we can do a great deal about the way the healthcare system interacts with patients. It is the doctor who is the health professional in the relationship, while the patient is a professional patient on his or her own terms. Thus, the situation can be reversed: it is the health literacy of the doctor and the health service that is sub-optimal. It is the doctor's ability to understand the patient's needs and to adapt this information that is affected. Thus, it is the competencies of the doctors and the healthcare system that need to improve - then the patients' health competencies will also improve.

3.16. The ordinary in a foreign place: the cultural X-ray vision

When working with refugee/immigrant patients, you gradually discover that most problems that are perceived to be 'culturally based' turn out to be generally human shaped by the vicissitudes, values, and relationships of life.

Case 1

A 30-year-old woman from a country in the Far East was referred with epilepsy-like psychogenic or culture-based seizures. The patient is under medical care but there is no satisfactory seizure control. A functional element and poor medicine compliance are suspected. No full anamnesis has been recorded. The patient arrives with her spouse, and an interpreter is used. It soon turns out that in the past only an interpreter who speaks a different language than the patient has been used (two very different languages are spoken in her country, and the interpreter did not master the other language). The patient has had 10 years of schooling in her home country, quickly got a job in Denmark and started at Adult Education but stopped again in both places. She could previously speak Danish but has lost the language again. Says that she has now been told that she has had epileptic seizures since childhood, but that her mother (who still lives in her home country) would only tell about it now that her daughter is in Denmark. She lost a cousin who died of epilepsy, and her mother was afraid it would spread if it was talked about. The mother has said that the patient often bit her tongue and the mother had to use a spoon to prevent tongue bites. She had many seizures at night, and she is still afraid to sleep. Furthermore, the mother has said that the patient has two kinds of seizures: one type is regular tonic-clonic convulsions, and the other is an absence-like condition that is sometimes accompanied by foaming about the mouth and faecal incontinence. The husband says that after starting medical treatment, the patient only has seizures 1-2 times a week, but that she is very forgetful and extremely tired. The patient confirms the husband's description and says that she is very upset, ashamed and feels guilty towards her former workplace, the language school, adult education course, her husband, and in particular their children. She does not feel she can become a normal person again with her illness, and it was a big personal defeat for her that the doctor took away her driver's license. She stopped working because she was afraid of falling and hitting herself and she often worked all alone. She stopped her adult education course because she felt she needed more help than the others and was slowing down the class. She felt ashamed about this, and it has contributed to her depressive thoughts. She is afraid to go out alone with the children in case she has a seizure, and she feels like a bad mother. The patient says she has *'difficulty rooting for herself'*. She feels like a weak and abnormal human being who is only a burden. It is probably not psychogenic pain, but rather misunderstandings that arose with the first interpreter who did not speak the patient's language. The patient had an understandable and relatively uncomplicated temporary stress reaction based on the diagnosis and the social consequences of the disease. The patient was referred to psychologist help for processing the disease. These were not psychogenic or cultural seizures but rather complex epilepsy, and the patient will be further assessed regarding surgical treatment of her epilepsy.

Comment: *The importance of using interpreters who speak the patient's language (and not just another language from the same country) cannot be overstated. Prejudice and bias interfere with doctors' decision-making processes by derailing general medical considerations and replacing them with vague ideas of 'cultural symptoms' or 'psychosomatic behaviours'. It is always important to make sure that the patient agrees with the version of medical history that the doctor perceives and documents, so that misunderstandings and untraceable generalisations can be corrected. A lack of vigilance to ensure the best conditions for achieving a correct medical history compromises patient safety, but in the long term it creates an unnecessary vulnerability in the patient, who often does not have the ability to amend the medical history if it is incorrect, superficial, or very inaccurate. Through frameworks, approaches, and interactions, doctors can very easily create vulnerability in the patient. There is a greater risk in the presence of a language barrier, but there are general human consequences. In reality, anyone can become unnecessarily vulnerable if doctors are not sufficiently sensitive to the patient's competencies, language level, preferences, and style of interaction (240).*

3.17. Ethnic cough

Inherently, doctors understand (and patients expect) that we look at and assess patients objectively and without prejudice, in that we use biomedical observations from the objective examination combined with blood tests and other para-clinical examinations to make a diagnosis and a treatment plan. Research suggests that this is a completely unrealistic and incorrect way to view the doctor-patient meeting (241, 242). Van Ryn has described the areas where there is evidence of discrimination that lacks medical evidence: osteoporosis treatment/prevention, education on smoking cessation, reduction of excessive alcohol use, referral for mammograms, advice on breastfeeding, pain management, referral for dialysis, referral for coronary angioplasty, recommendation for kidney transplantation, and psychiatric treatment (79). The many non-medical factors at play when the doctor makes a clinical decision are documented in a number of test lab studies, e.g. in a study where an actor-patient had a long-term cough and was a smoker but possessed various combinations of social characteristics: 192 doctors were tested, and a clear tendency was evident where younger patients were told that the coughing was psychosomatic, and referral to X-ray or smoking cessation depended largely only on social (non-medical) factors (243).

It is well documented that compliance and adherence are linked to the patient's experience of the doctor-patient conversation, the doctor's empathy, and whether the patient has been listened to. A study in which independent observers encoded 150 doctor-patient conversations found that non-medical factors such as the patient's gender, age, and ethnicity significantly affected the doctor's interaction with the patient in several areas: non-verbal communication, empathy, courtesy, respect, and especially the type and amount of information given to the patient (241). In addition, the following factors were shown to influence the doctor's decisions regarding treatment: the doctor's moral notions of the patient's right to treatment (whether the patient 'deserved' it), the doctor's stereo-typical view of the patient's supposed (lack of) social network or cognitive ability, and the doctor's expectation of patient compliance (86, 244).

3.18. Immigrant inertia and statistical inequality

In the real world, many factors are often in play simultaneously. Some factors cannot be changed here and now, while other factors are important to observe as conditions in the interaction between ethnic minorities and the healthcare system. Just as it is a fact that older people have more disabilities and more need of a doctor than younger people, it is also a fact that language barriers, together with differences in perceptions of illness and health, create a basic inequality that can ultimately be impossible to completely offset - in some contexts it is called a statistical inequality. The ethnic inertia is the overall expression of a number of factors that only come into play in intercultural fracture surfaces, e.g. in the immigrant patient's encounter with the hospital. It is the inertia that arises when you are afraid, uncertain, insecure and at the same time distrust the healthcare system's capabilities while also having to balance your personal needs, family needs, and the hospital's rules and structure. A simple examination, a trivial medical treatment, or a choice between three treatment options can become a lengthy negotiation and understanding process where the patient must convince both himself and the family and maintain contact with the hospital while negotiations are ongoing. Acute doubts may arise about needs and possible complications on the very day of the examination or surgery, which, in the absence of access to advice and guidance, often result in the planned action being rejected or the patient staying away entirely. You could become overpowered by a sudden feeling of guilt about leaving children and spouses alone in Denmark if you do not wake up after the minor but necessary knee surgery, and it gets postponed indefinitely. It is important that neither inertia nor statistical inequality become factors that contribute to worsening inequality in access to and impact of healthcare. Furthermore, knowledge of this inertia and the structures that can reduce it appears to be economically viable (245).

3.19. The veil in the clinical space

As doctors, we must recognise that we can do very little to change patients' behaviour. They do what they do best, and it is our job to translate this into useable and acceptable clinical practice. This task is difficult, but it is not made easier if the patient does not read or speak much Danish. If additionally, much of the codes, rules, and information that exist are not freely exchanged between doctor and patient, then the cultural veil becomes totally opaque. In this case, it is important that the doctor has a toolbox that can provide a degree of cultural X-ray vision and can preserve professionalism. It is important to remain calm: usually, the doctor has not understood something, and the patient has not understood something. The first must be the professional question you always ask yourself as a doctor, while the latter is solved by systematically questioning the patient with the aim of understanding what the patient has not understood. It is also important to rid the clinical space of the noise that may confuse the conversation: religion, scarves, gender, war, and cultural codes. Most problems perceived as cultural or religious are in fact quite common everyday problems, family clutter, poor finances, loneliness, issues with self-esteem, communication problems, uncertainty, and lack of knowledge. The most frequent tasks at the MHC include:

- Problems understanding the patient's perception of disease
- Patient rejection of well-indicated treatment/low compliance
- The doctor asks for a cultural analysis of the patient's health problem/compliance
- Family conflicts around illness and health in relation to the individual patient
- Social and economic issues
- Self-perceived discrimination as the cause of communication problems
- Diagnostic problems partially due to 'poor co-operation'
- Medically unexplained symptoms, suspected cultural cause
- Perception of culture as the cause of the pathological picture/compliance

In the meeting with the individual patient, you have to reduce anxiety, reduce stressors, and process disease concern while building trust, knowledge, and ability to act independently. On a larger scale, it is about detecting and documenting structural barriers and increasing the system's competencies and sharpening the employees' cultural X-ray vision. In the report, *Thank you for making a better version of me*, the tasks are described in detail and the underlying causal relationships are described (78).

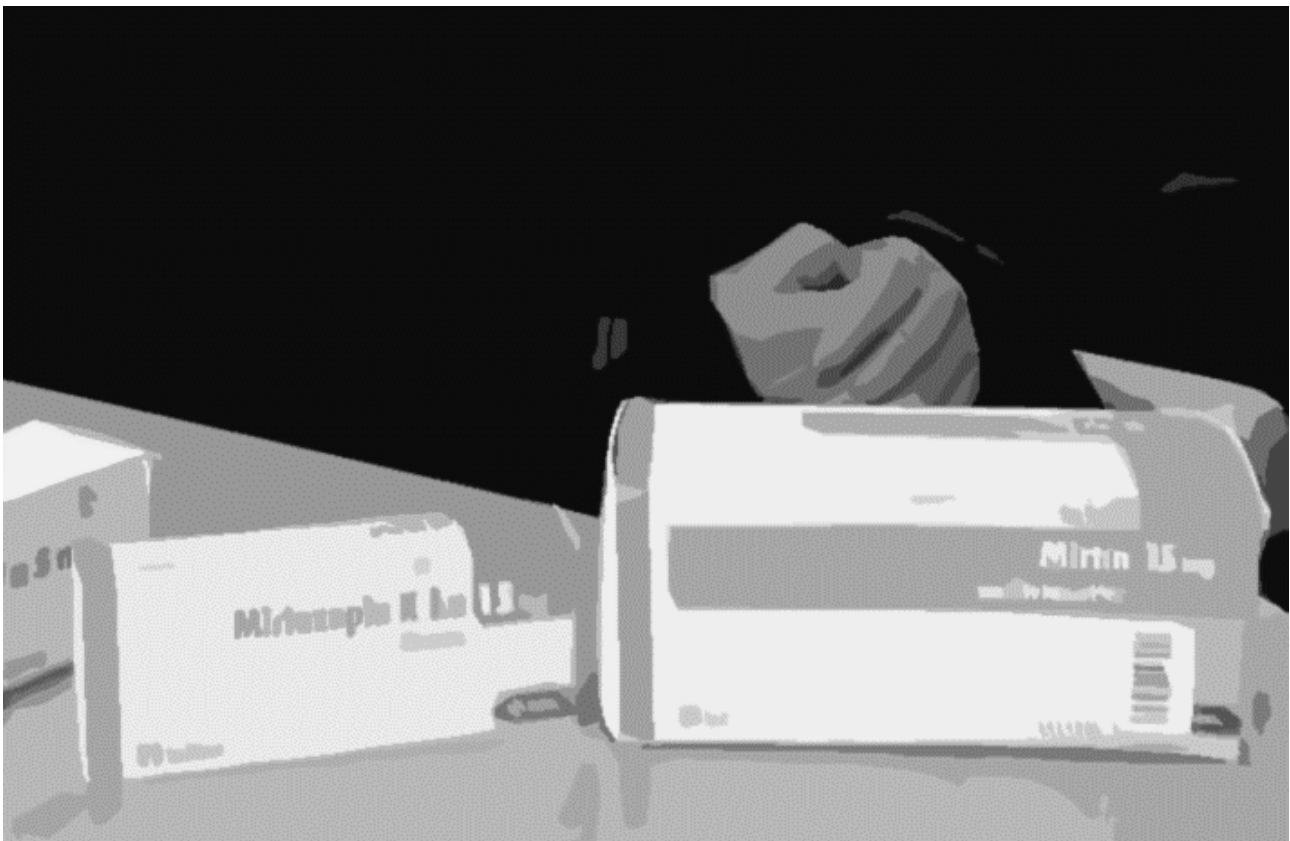
3.20. Professional disqualification

In the experience of the MHC, some healthcare workers consider the fact that immigrant patients (and citizens) do not speak the **language** and lack **system competencies** to be an acceptable excuse not to do what is normally expected of health professionals. It may be believed that the immigrant patient's 'shortcomings' absolve us of a generally accepted professional responsibility, and we convince ourselves that our medical knowledge is insufficient to understand or treat immigrant patients: the professional disqualification (78, 246). In any case, the decision on what to do is up to the individual, and is not subject to any documentation requirements, compliance with quality models, or specific objectives. The Danish quality model does not contain guidelines for courses of treatment that require a lot of resources and time. However, resources and time are just two of many aspects that must be taken into account ahead of time in the public sector. It should not be up to the individual health professional to decide based on mood, discretion, or the will of individual department managers, whether to spend extra time and resources on the socially vulnerable patient.

Jonas Christoffersen, Director of the Institute for Human Rights, wrote in a feature article in the Danish newspaper *Politiken*, 'Authorities at various levels are not equally good at thinking about the rights of individual citizens. Unfortunately, the side effect is that some of society's most vulnerable

groups, who need their rights the most, cannot fully benefit from these rights.' Hospitals, regions, and municipalities must realise that ensuring equality in public services is not up for discussion. This requires a pro-active effort to address the weak points where inequality arises in organisations, and it requires changes in the organisations and the competencies of the employees. In relation to ethnic minorities, this would mean improving clinical ethnic competencies.

Disqualification of the importance of the refugee's life history, language, and trauma in a clinical context reinforces the cultural, religious, and ethnic explanation models that doctors in their despair try to push down onto the conversation. This framework we set up for the conversation forces us to behave unprofessionally, and the diagnostic process is likely to have a sad and demoralising outcome for both parties. Doctors as well as the healthcare system as an organisation must learn to have cultural X-ray vision. It is often more important to find out which patient has the illness than finding out which illness the patient has, as Virchow put it.



4. Cross-cultural clinical problem areas

4.1. Background

According to Statistics Denmark, immigrants and their descendants made up 13 % of the population in Denmark on 1 January 2018 (247). The proportion of immigrants is 10 % and of these 58 % are from non-Western countries. There are large geographical differences, with 39 % of non-Western immigrants in Ishøj, 19 % in the capital overall and 6 % in Rebild municipality. Over the past 30 years, the number of non-Western immigrants has increased fivefold. In 2017, 22 % of live-born children were born to mothers who were immigrants or descendants of immigrants.

4.2. Mortality

Ethnic minorities in Denmark generally have higher morbidity than the majority population, but the morbidity patterns are not quite the same and the differences between ethnic groups are greater than the difference between ethnic and non-ethnic Danes (248). The difference between register-based morbidity and self-reported morbidity often gives a false picture because self-perceived and treatment-requiring health problems are mixed together (248).

The same lower mortality rate for ethnic groups has been found in neighbouring Scandinavian countries, but it has not been possible to demonstrate a 'healthy worker effect', which is often a convenient explanation for the unexpected find (249). Furthermore, there are significant differences between Western and non-Western migrants and between people with different residency types, and this is not always accounted for in analyses. Non-Western adult migrants have significantly lower mortality rates than ethnic Danes and Western immigrants, notwithstanding the large variation between ethnic groups. This presents a false picture of reality, however, because non-Western immigrants overall have significantly lower mortality rates for cancers, cardiovascular diseases, and lung diseases (and accidents) although some ethnic groups are close to ethnic Danes in this context. Because refugees often smoke less and consume less alcohol than ethnic Danes (who drink and smoke considerably more than the populations of other European countries), the refugees in Denmark have 'artificially' better survival statistics than most Danes (250). The diagnoses where refugees have excess mortality are typically acute and chronic infections (tuberculosis, HIV, hepatitis) and the cancers associated with these illnesses. If non-Western immigrants had the same tobacco and alcohol consumption patterns as ethnic Danes, they would have a significantly higher mortality rate than ethnic Danes. Additionally, the infections that contribute to the high mortality among non-Western immigrants can be both prevented and treated. One should be aware of the large differences regarding smoking (and alcohol and drug abuse) between ethnic groups, which is why analyses should always take ethnic differences into account (251).

4.3. Morbidity

A comparison of mortality rates from myocardial infarction and cerebral thrombosis for the same ethnic minority groups across European countries will show striking differences where the Danish healthcare system does not excel (26, 30). Similarly, pregnant Turkish women in Denmark have a higher risk of stillbirth and neonatal death than in other European countries (252). Compared to the other Nordic context, Denmark has lagged behind as we have experienced declining life expectancy. Although immigrants are often, at least initially, relatively healthy compared to the majority population in the host country, available data suggest that they tend to be more vulnerable to certain infectious diseases, occupational diseases, injuries, mental health problems, diabetes, and poor mother-child health. Some groups may be at particular risk of non-communicable diseases due to obesity and insufficient physical activity. Legal rights may need to be extended, but the healthcare system also needs to become more

migrant-friendly in other ways - for example, by reducing language and cultural barriers, improving ethnic clinical skills among health professionals, and increasing health literacy among refugees/immigrants (253).

A higher incidence of cardiovascular disease has been found among Turkish and Pakistani immigrants compared to ethnic Danes, while the risk of myocardial infarction was only higher for Turkish men and Pakistani men and women; there were no differences when comparing to Yugoslavian immigrants or Turkish women (254). The risk of developing diabetes is considerably higher among Turkish (18.9 %) and Lebanese (19.8 %) immigrants than among ethnic Danes (3.6 %), and there is a greater risk of poor diabetes management in these minority groups (255). Both Lebanese and Turkish immigrants are more at risk of developing diabetes in the host country than in their home countries (256). The incidence of diabetes is higher among non-Western migrants compared to the background population, and it increases faster among migrants; the increased prevalence can thus be partly explained by increased incidence (29). Clear guidelines exist for treatment of diabetics with statins, but Pakistani, Turkish, and Yugoslav patients were less frequently put onto statin treatment after the start of anti-diabetic treatment than ethnic Danes (257). In a Swedish diabetes study (type 2), ethnic minority patients were less often treated with insulin and were less often referred to specialist wards for assessment than ethnic Swedish diabetes patients (258). Adults of ethnic origins other than Danish and their adult descendants have poorer self-assessed health conditions than the majority of ethnic Danes - an effect that is amplified by socio-economic factors (42). Despite well-documented poor access to prevention, treatment, and after-care, very few studies have been done on the barriers within the healthcare system and the reasons for unequal *outcomes* in Denmark and the Nordic countries (172).

In some cases, barriers to access may be due to a lack of specific medical skills required to treat illnesses that are particular to ethnic minority groups. These can include illnesses such as hemoglobinopathies (i.e. sickle cell anaemia among people of West African origin and West Indian descent, and thalassemia among populations from southern Asia and the Mediterranean), and PTSD among refugees from armed conflicts or natural disasters (259). It may also concern specific parasitic infections that present with many or diffuse organ manifestations such as strongyloidiasis, cystic echinococcosis, and dwarf tapeworm. Familial Mediterranean fever is a difficult diagnosis, and treatment and control require good communicative characteristics based on ethnic competencies (260). Many generalised parasitic and bacterial infections are accompanied by characteristic rheumatic manifestations, but this connection is often overlooked (261). Finally, the investigation and treatment of lactose intolerance may be problematic for ordinary doctors because the random and individual clinical picture may be complicated by language barriers. Access to medical expertise for diseases seen almost exclusively among minorities is often compromised because the expertise is not needed in the general population. On the other hand, diseases such as cystic fibrosis, sarcoidosis, and coeliac disease are relatively rare in some ethnic minority groups. These examples reflect the varying needs for certain medical competencies when treating ethnic minority groups. Even when the need is small, however, the healthcare system should take note that different population groups may still be at risk and that their risk profile may change over time, especially with regard to the conditions associated with living conditions, lifestyle, and environmental factors, as well as genetic factors.

Finally, equal access to effective emergency medical care is a challenge, partly because there are a number of inescapable economic costs associated with language barriers, especially outside regular hours, but just as much because discussions on equality in this context are more easily influenced by political, administrative, and economic arguments than by purely medical and ethical considerations (262, 263). An Australian hospital study demonstrated a link between the staff's prejudices and perceptions of patients and language barriers and their choice of hospital services. In particular, employees appeared to have unconscious thought processes that were based on non-health professional feelings such as not liking differences, fear of differences, intolerance of differences, fear of competition for

sparse health finances, suppressed hostility toward differences, or general disregard for differences (264).

An analysis of the causes showed that in Denmark there has been a great deal of reluctance to reduce and prevent inequality in healthcare, with regard to both healthcare policy and social policy, and the analysis specifically points out the lack of targeted specialty care for refugees/immigrants in the Danish healthcare system (265).

Registry studies from comparable countries have found significant differences in perinatal health between social strata, ranging from premature birth to low birth weight, birth complications, congenital disorders, neonatal and infant mortality - differences that varied according to time period and ethnic group (266). Some ethnic groups (Somali, Turkish, and Pakistani) have a higher perinatal and infant mortality rate than that of ethnic Danes (267).

4.4. Cancers

Ethnic minority women are offered - or accept - less cervical, breast, and bowel cancer screening compared to ethnic Danish women. Ethnic differences and educational level play a large role but do not explain all the differences (268-271). Inequality often exists in the use of various cancer prevention services, such as HPV vaccinations and cervical smears (272).

Ethnic minority Danes have lower incidences of the following cancers: ear-nose-throat, breast, pelvic, lung, testicular, and colorectal cancer (273-275). In the same study, ethnic minorities had higher incidences of cancers associated with chronic infections (e.g. hepatitis B and C, HIV) than ethnic Danes did.

4.5. Pregnancy and childbirth

There is a higher incidence of mental illness among pregnant women of ethnic origin other than Danish (276). Pregnant refugees/immigrants suffer more frequently from anaemia than ethnic Danish pregnant women (277). While premature birth is more frequent within certain ethnic minorities, ethnic minority groups as a whole have more low birth weight babies than ethnic Danes (278). The frequency of serious perinatal events among refugees/immigrants is significantly higher than among ethnic Danes (279).

4.6. Hospitalisations

No studies have been carried out in Europe, but in the United States a number of studies have examined the term *avoidable hospitalisations* and found that ethnic minorities are admitted without a specific reason considerably more often than others or were hospitalised because they had received inadequate treatment in the primary sector (280). In England, patients with language barriers were more often found to be admitted to the wrong ward, discharged too quickly, and readmitted more than other patients.

Refugees/immigrants, especially relatively new arrivals, more often use emergency medical assistance for relatively non-acute conditions, and they pay more visits to their doctor than other Danes. This is especially pronounced for refugees/immigrants with little or no schooling. Although they pay more visits to their doctor, they are still less satisfied with the quality of treatment, and both parties attribute this to communication difficulties, sparse understanding of the cultural context, and conflicting perceptions of the roles of the doctor and the patient. The limited ethnic competencies of health workers and the patients' knowledge, experiences, and expectations affect patients' satisfaction and comfort in the healthcare system as well as their incentive to use the system again (281-285). A Danish study from 2020 showed that compared to other Danes, ethnic minorities had longer waiting times for a number of routine interventions such as cataract surgery and prostate hypertrophy (286). The study also showed a

social and geographical bias concerning who uses the treatment guarantee to be treated in the private healthcare system, also among ethnic minorities.

4.7. Discrimination and health

Stress has become increasingly recognised as one of the key social determinants of health, and persistent discrimination leads to stress (287-289). Continuous discrimination due to skin colour or ethnicity can lead to a condition with symptoms resembling PTSD (290). A European study of depression risk among ethnic minorities found that social and economic vulnerability in combination with ethnic discrimination was the more likely cause of a higher risk of depression in the group (291). When someone perceives themselves ('the I') as a direct target of discrimination, it harms their mental health in the long term. Discrimination based on skin colour/ethnicity and actual racism affects the mental and physical health of minorities through subtle and hidden mechanisms. Although science has shown the existence of prejudices, stereotypes, and hostile attitudes between ethnic groups and their often implicit and automatic nature, relatively little is known about their impact on health. Experiencing discrimination and differential treatment in society in general can affect health in several ways depending on how you respond to the experience as well as on age, gender, ethnicity, connection to the labour market, basis for residency, identity, and social network. A fundamental analytical challenge is the link between discrimination and socio-economic conditions. Many studies have indicated that lifelong experience of ethnic discrimination prevents individuals from accumulating the social capital needed for education and work (292, 293).

Several reviews have found that discrimination was associated with the following health issues: poor self-reported health, multi-disease, smoking, alcohol consumption, drug abuse, overweight, cardiovascular disease, diabetes, sexual dysfunction, loneliness, and sleep disorders (288, 294). Also found was a correlation between discrimination and increased HIV risk behaviour, delay in doctor visits, and lower adherence to preventive health services such as cancer screening, smoking cessation, and dietary guidelines. A correlation between discrimination and poorer physical and mental health was found in a study from Finland (295), while discrimination and xenophobic comments experienced at the workplace among Spanish migrant workers and ethnic minorities in England were associated with worse mental health and lower quality of life than that of the majority population (296, 297).

An interesting cross-European study (Germany, the Netherlands, and Sweden) of young people from minority backgrounds found that xenophobia experienced on social media and discrimination experienced in nightlife, public transportation, or from police/security guards was associated with an increased risk of psychosomatic symptoms (298). Children appear to be generally more sensitive to discrimination from a health point of view than adults, and the duration of exposure is a key factor (299). A study among Turkish migrants in the Netherlands showed that a high level of structural discrimination in society affected their group identity and led to poorer physical and mental health (300). There is a need for studies in this field to use intersectoral research approaches since power, identity, discrimination, and sexism have very different expressions (301).

4.8. Health assessment of newly arrived refugees

In practice, there is no broad healthcare reception of refugees in Denmark. Even in the case of refugees accepted through the quota system where there is some legal basis for a targeted healthcare review, the reception is sporadic and half-hearted in most parts of the country (302). A basic health screening of UN refugees effectively disappeared when the screening was turned over to the municipalities and family doctors in the mid-1980s (303). Several later studies suggest that it has not been an appropriate decision (302, 304). Similarly, the Norwegian Health Inspectorate concludes in their report on the health-related

reception of refugees in the municipalities that newly arrived asylum seekers, refugees, and family members for reunification risk not getting necessary healthcare because the municipalities do not provide them with information about the healthcare system. In many municipalities, the overview of new arrivals is too poor to ensure sound tuberculosis control. Municipalities are also paying too little attention to other infectious diseases. New arrivals who are mentally ill are also affected by the failure to receive psychiatric care (305). A recent commentary in the *European Journal of Public Health* recommends health screening of newly arrived refugees because it not only benefits the refugees but also society (306).

Health professionals in the host country later find it difficult to understand and consider the lives of ethnic minority patients *before* they came to the host country, which often leads to failed examination programmes, low-quality treatment, medical errors, and poor results from health education measures (51, 173, 174, 218). Current life conditions and concerns are rarely the focus when planning examinations; however, they may impact on patients' participation in clinical examinations if the purpose of these is not entirely clear (175). The significance of the life story in treatment and adherence is well documented (51, 173, 220, 307, 308).

Case 1

A 46-year-old woman asks her doctor to be referred to the MHC due to diffuse pain and fatigue. Her doctor writes, 'Since arriving in Denmark complained of pain, fatigue, and night sweats. Examined at several local hospitals without success. Has iron deficiency and takes iron supplements. Can no longer do her cleaning job.' Her doctor believes that the patient's complaints are real and without mental superstructure. The patient herself states that she is mentally strong, but that she is physically tired. In the course of three conversations, the patient is asked to tell her life story. The patient has endured many violent experiences since the age of 12. She had to escape through the desert while heavily pregnant. She has nightmares and flashbacks but has chosen to believe that they do not mean anything. She spoke with a psychologist upon her arrival to Denmark, but he said for the patient to be strong and that everything would be all right. The husband is severely mentally affected by war experiences, has diabetes and kidney failure (is currently on dialysis), and was fired from his job due to too many sick days. After that, the husband experienced additional mental decline and is now behaving like a child, whereas he had previously been able to take care of the children so that the patient could go to work. The patient experiences increasing memory issues and stress at home, and she is losing her Danish language, which the children make fun of, 'then I have to put on a metal shirt'. A son with mental issues is in prison, and the patient has decided to forget him. She is happy with her life in Denmark, but pressure from family, her husband, and the municipality as well as pain cause her to give up on doing anything about her situation. The patient feels like a single mother of nine where before she had eight children, but she does not get any understanding from the caseworker, who very persistently ignores the MHC's request for her to be activated more gently and gradually. In addition to pain in her hands, feet, and back, the patient has urinary incontinence and a pronounced bleeding disorder. An MRI scan of the back shows a spinal disc herniation that explains her back and leg pain. The patient is lactose intolerant but does not remember the information from the dietary guidelines. She is also found to have asthma, which is the cause of her chest pain. Gastroscopy finds pronounced reflux. Her neck pain is caused by disc herniation in the cervical spine. Her headaches are caused by chronic sinusitis based on a CT scan of her sinuses. It turns out that the patient's daughter, who has two young children, has a severe connective tissue disease, which means the patient often has to assist her as well. The patient has requested help for her daughter, but this has been rejected. She has applied for a pension but was denied. She applied for cash benefits but was denied when the husband received a small insurance payment after being diagnosed with chronic kidney disease. That money was given to a son who is going to study in the United States, but the municipality still refuses to hand out any cash assistance. The patient is referred to trauma and torture treatment with

good results. With consent from the patient, the social worker at the clinic contacts all actors in her municipality to inform them of the patient's situation. The patient feels locked in place and paralysed and has suicidal thoughts, although these are not specific.

Comment: *The vast majority of studies on the health of ethnic minorities focus on patient-perceived access and barriers in their encounter with the healthcare system, self-perceived health, living conditions, culture and lifestyle, consumption of healthcare (including emergency room visits and hospitalisation rates), diagnoses, and genetics. However, there are no studies of the professional barriers that patients of other than Danish ethnic backgrounds encounter in the Danish healthcare system - also called 'treatment provider bias' (309). Immigrants lack basic system competencies; they are more frequently lonely than ethnic Danes and are functional singles who lack the social network we expect to see around citizens and patients in general (310). When at the same time the health service and the social services are unable to adapt their services to the socially disadvantaged, it is very likely that patients' hospital treatments are either never started or are delayed or stopped inappropriately.*

Case 2

A 41-year-old patient checks in at a local health centre with a friend. A few days earlier, the patient had participated in an interpreter-assisted health education programme at the health centre that had discussed the symptoms of PTSD among other things. The patient feels sick and believes that her symptoms match what was explained in the programme, i.e. she falls asleep at 5 a.m., one hour before the family gets up; she has many bad dreams and pain in her bones, and she wonders if it is cancer. She cannot stand turmoil and noise and is afraid someone is hiding in the closets. She constantly sees pictures of her little boy who died in Somalia. In her home country, she went to high school and was educated as a teacher. She lost a 2-month-old son because they could not get medical assistance. When the soldiers came, they dug up the grave looking for gold and jewellery, so she had to bury the child again. Many of the children were wounded by the soldiers and still suffer physically, which reminds the patient of the war. She fled to a camp in Kenya and then one in Ethiopia and arrived in Denmark where she was quickly got a qualification. She experienced her neighbour's apartment burning, which also torched the patient's apartment that then burned down completely with all her belongings. This meant that the patient no longer dared to sleep at night. The patient's parents died in a grenade attack without the patient managing to contact them in the home country. In connection with a visit abroad, she got stomach pains again. The patient had had these for a while, but the doctor had not really understood that. The patient underwent acute surgery for ovarian cancer. She experiences many complications, and chemotherapy was hard on her. She has a hard time talking about the past, but she loosens up when talking about her children, who are doing well in school, and trust is built through many conversations. Due to her traumatic background, which is revealed while she is being treated for cancer, the patient is referred to the MHC. She has been checked annually for cancer, but she has murmurs in her stomach and is afraid. A hospital check is quickly arranged, which calms the patient. She cannot talk to her family or friends about her cancer, but she is happy to be able to speak with the nurse. Grants are being sought for rent after the patient lost her wallet, which contained one month's rent. The patient is referred to trauma and torture treatment with good results. She is forgetful and has a hard time remembering appointments, so she gets support to be reminded of her appointments. A case officer is contacted about housing relocation. The move seems to reduce her stress, and the patient gets better sleep at night with calming music. She is supported in her application for financial assistance to move. She is granted early retirement and would like help with writing down her life story so that others might learn from it.

4.9. Problem areas seen in the Migrant Health Clinic

While research into the health of ethnic minorities is mainly concerned with inequality in disease risk and access to the healthcare system, the patients who are referred to the MHC reflect a jungle of clinical issues that are confused or overshadowed by bad experiences as well as social, language, financial, and knowledge challenges, including mental problems such as anxiety and depression as well as war trauma, PTSD, and personality disorders. Table 6 lists the issues most frequently faced by the referred patients.

Table 6. Problem areas observed at the MHC 2008-2018.

<ul style="list-style-type: none"> • Primary social problems • Severe illness anxiety • Multiple unexplained symptoms • Chronic pain • Back problems • Palliative care, death, and dying • Care coordination within the hospital area • Compliance in cancer diagnosis and treatment • Overlooked cognitive loss • Diminished sight and hearing as a communication failure • Fertility, family planning, new parents • Conflicts/disputes about the cause of illness or about treatment (anger aimed at the healthcare system) • Clashes between understandings of illness • Family pressure regarding fertility, health, pension • Work-related illnesses and accidents at work • Early burnout, e.g. adults who started to work at an early age (6-7 years old) • Consequences of other accidents (traffic, assault, violence) 	<ul style="list-style-type: none"> • PTSD (including the whole family being affected), secondary traumatisation • Newly arrived refugees (less than 3-4 years stay) • Non-refugees (working migrants, family unification) • In Denmark: victims of violence, accidents, PTSD contracted in Denmark. • Elderly migrants • People who obtained family unification but are now divorced • Previous child soldiers, previously forced soldiers • Adults who were sexually abused as children • Severe, chronic dental conditions, dental injuries • Obesity with musculoskeletal pain • Personality disorders with somatic illnesses or somatic symptoms • Physical and mental disabilities, relatives of persons with physical/mental disabilities • Severe obesity • Repeat referrals
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4.10. Inequalities in the quality of treatment

Studies on the quality of the clinical care experienced by ethnic minority patients are sparse, especially within the hospital services, but there are several studies from general practice (311). The same applies to studies on the link between treatment quality and literacy/health literacy (health competencies).

A number of studies point directly or indirectly toward the impact of professional barriers and bottlenecks in core areas of the hospitals: specialised examinations, treatment, relief, and information for patients regardless of social status, education, or origin. Several studies have been conducted on ethnic minority patients with language barriers (312). It takes longer to complete the examinations, the hospital stay lasts longer, and ethnic minority patients were given intravenous medication and fluids more frequently than other patients (313). Women of minority ethnic origin receive hormone therapy in

hospital less frequently than other women, regardless of language barriers (314,315). In palliative pain treatment for cancer, only 1/3 of ethnic minority patients received the recommended doses according to guidelines. There were large differences between ethnic groups, indicating that the greater the language barrier, the less the guidelines were followed (316, 317). Ethnic minority patients were less likely to return for a scheduled check-up at the hospital after their discharge; they were more likely to stop a commenced medical hospital treatment than other patients were; and they more frequently used the emergency room instead of the treatment ward after their discharge (318). Type 2 diabetes patients with language barriers improved markedly in their diabetes regulation when they were offered an interpreter for all conversations (319). Even after correcting for other risk factors (smoking, social status, education, BMI, income), there are large ethnic differences in many countries in diabetes mortality, complication rates, kidney failure, and treatments, which are not addressed (320). A multivariate analysis of which factors influence how well people with diabetes control their blood sugar levels found that language barriers and ethnicity were independent risk factors for poor diabetes management after controlling for other socio-economic and therapeutic factors (321). Ethnic minority patients with mental health problems were more frequently admitted for treatment if they had conversations that involved interpretation services or bilingual doctors and nurses (322). Patients with language barriers had a considerably harder time explaining their own diagnosis, treatment, and follow-up plan at the hospital (323). Patients with language barriers complained twice as frequently as other patients that they were unsure of the possible side effects and complications of their treatment. Patients with language barriers who felt they had been given too little information on side effects were also more likely to stop the treatment or to take the medication in smaller doses (324). In a German survey of gynaecology consultations, 50 % of Turkish women understood the information they received, while 90 % of ethnic German women understood the information from the gynaecologist. The study also found that the less German the patients were able to speak and the less they already knew about gynaecological diseases, the less they got out of the information from the gynaecologist (325, 326). A US study investigated whether patient knowledge and understanding of their diagnosis and treatment depended on the presence of language barriers, whether interpreters were used for the conversation, or whether they thought an interpreter should have been present. In this study, 67 % of those who did not need an interpreter felt that they had good or very good knowledge of their illness; among those who had brought an interpreter to the interview, 57 % said they had good knowledge of their illness, while 38 % of those who thought they *should* have had an interpreter but did not have one, felt they had good knowledge (327).

In videotaped conversations between patients with and without language barriers and their doctors, it was found that patients with language barriers asked fewer questions of the doctor and were less often encouraged by the doctor to ask questions about illness, examination, or treatment than other patients (328). Patients with language barriers mention fewer symptoms than other patients, and in particular, insomnia, anxiety, or sadness are not mentioned spontaneously in general questioning. Traumatic experiences, confinement, torture, or dead/missing family members were consistently not mentioned by patients with language barriers and only came to light when interpreters were used. The description of the latter experiences required a vocabulary and command of language that virtually none of the patients possessed (322).

A study of 2400 patients who had been admitted to a hospital emergency department found that many more patients with language barriers than other patients were dissatisfied with treatment quality, patient information, and follow-up, and they were less likely to let themselves be admitted to the same place again (329).

Patients with language barriers tended to rate the quality of the doctor-patient conversation more negatively than did patients without language barriers. The areas that received particularly negative assessments were explanations, showing respect, meeting the patient's needs, the interview process, and agreements regarding follow-up (330).

As ethnic minorities perceive barriers in their relationship with their family doctor, they tend to use the emergency telephone number to gain access to healthcare. Different perceptions of risk affect people's behaviour, and risk perceptions can be so far removed from those assumed in the Danish health campaigns that the campaigns miss the target group or are experienced as exclusionary by the target group (331). Ethnic minorities lack knowledge of existing health services and ask for a more general introduction to the structure of the healthcare system. Although the healthcare system is streamlined and efficient, it does not suit first-generation immigrants who do not know the language and are socially isolated. An unfulfilled need for an interpreter leads to insecurity and distrust as well as a lack of knowledge about examinations and treatments (332-334). The main problems perceived by patients are language barriers and a lack of respect on the part of the doctor (335). Language and the removal of language barriers are also crucial to patients' trust in staff (336). The staff finds that language barriers cause the level of information provided to be inferior to that which is provided to other patients (332). Staff tend to generalise based on individual bad experiences: *'Somalis are like that'*, *'interpreters are not good enough'* etc. (334). Patients experience that the doctor is not listening and that they are not being included in the decision-making (333).

Generalisations in the healthcare system cause groups of people to be regarded as homogeneous (cumbersome). It depersonalises the individual and furthers an experience of being trouble-some and 'in the way' (Gormsen 1998). Mette Breinholdt describes very nicely the *heart sink patient* in a post in the blog section of the Danish medical journal *Ugeskrift for Læger* (337).

4.11. Inequality in clinical decisions

Evidence suggests that doctors overuse epidemiological findings in individual contexts, which prevents them from including individual information in the clinical decision process and reinforces the marginalisation of ethnic minorities in doctor-patient conversations (243). Additionally, doctors' differential diagnostic considerations are highly influenced by their perception of the ethnic affiliation of the patient. The diagnoses the doctor focuses on are selected partly based on non-medical indicators such as assumed ethnicity and the application of general epidemiological findings regarding the individual patient, without sufficient inclusion of the conditions and needs of the specific person (338). It is worrisome that the doctor's diagnostic quality can be influenced by irrelevant factors such as in the diagnosis of breast cancer and depression, but what is particularly strange and thought-provoking is that the higher the patient's education level, the more confident doctors feel about their diagnosis (339, 340). A study of doctors' decision-making processes found that the more diagnostic or therapeutic options the doctors were faced with (or confronted themselves with), the more uncertain they become and the more likely they were to choose not to treat or to choose the simplest treatment, and the more likely they were to opt for a safe, 'conservative' diagnosis. The study points out that when patients present multiple complex problems, doctors should be aware that they risk choosing inappropriate and incorrect diagnoses and treatments (341).

Evidence also suggests that doctors, often unknowingly, convey non-medical social values into the doctor-patient conversation, which can have a decisive impact on the patient's adherence to treatment, the quality of treatment, and the treatment outcomes. These may be moral values such as the need to make an effort to get a reward, self-support, self-care, education, and the acquisition of information; or it may be that the doctor clearly signals lower expectations of the success of examinations, treatment, or ability to follow check-ups due to education, ethnicity, lack of networks, or other stigma (342, 343).

Examples of areas where we lack Danish studies on the importance of ethnicity include hypertension control, cerebral thrombosis, writing prescriptions, diabetic retinopathy, kidney insufficiency, cardiac insufficiency, consequences of meningitis, and stroke (344). One Dutch study of thrombolytic

treatment after cerebral thrombosis showed large ethnic differences in access and efficacy (345). Another Dutch study identified large ethnic differences in the control of diabetes type 2 measured by HbA1c (346).

If not attended to, language barriers can affect the doctor's way of recording the medical history and make it difficult to get a coherent story that makes sense medically; the story often ends up having many information gaps that can lead to misdiagnosis (347). Illnesses that are difficult to diagnose due to multiple organ involvement and slow development over many years (e.g. the connective tissue disease lupus) are diagnosed much less often among ethnic minorities (348). A Canadian population study of nearly 37,000 people showed that a PTSD diagnosis (adjusted for socio-economic factors and other mental illnesses) was significantly correlated with increased risk of cardiovascular disease, lung disease, chronic pain conditions, gastrointestinal diseases, and cancer. The PTSD diagnosis was also linked to suicide risk, physical and mental disability, and low quality of life (349).

Figure 8 below is a simplistic overview of detected mechanisms of inequality in healthcare among ethnic minorities.

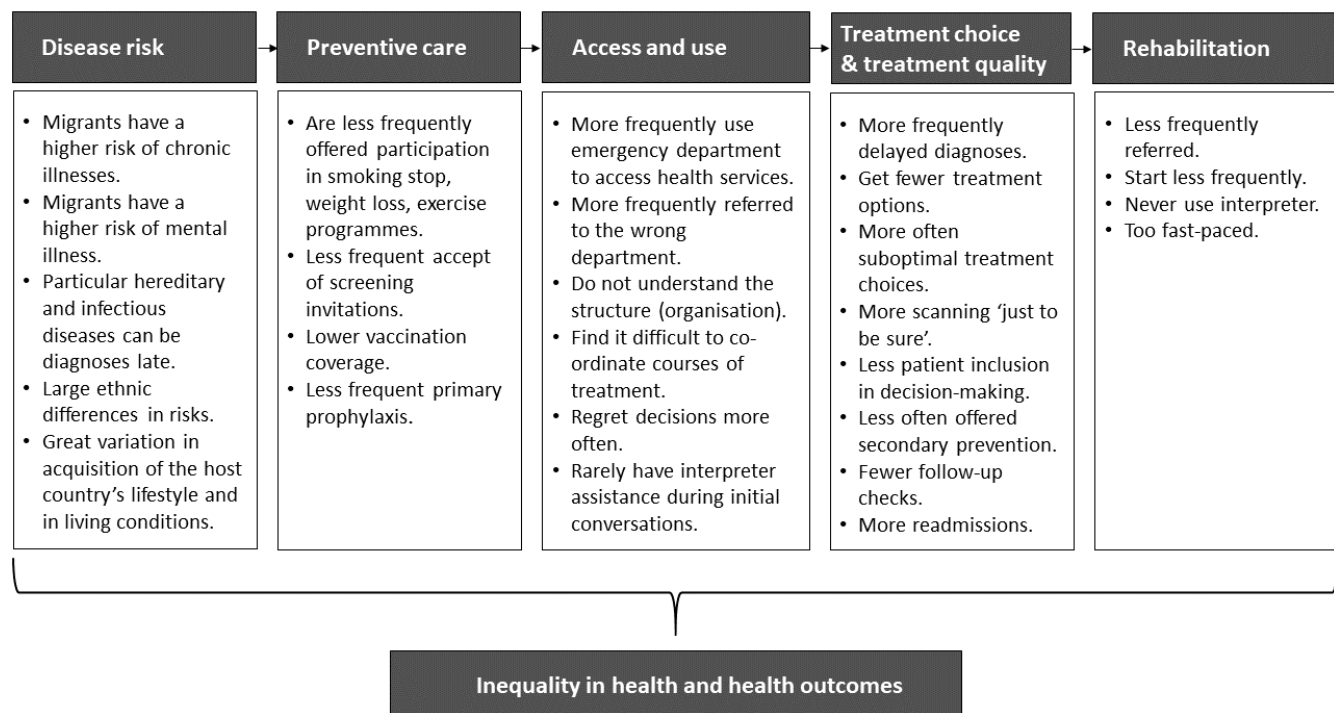


Figure 8. Mechanisms that can create inequality in health among ethnic minorities.

4.12. Children and childhood

Higher rates of stillbirths and infant mortality have been found among certain ethnic minority groups (Turkish, Pakistani, and Somali), while other ethnic groups had the same incidence as the majority population (Lebanese and Yugoslav) (252, 279, 350, 351). There is also a higher incidence of congenital disorders among ethnic minorities (351). Suboptimal breastfeeding is more frequent among ethnic minorities - some more than others (352). Infant mortality (up to five years) is significantly higher among ethnic minorities in Denmark, which could not be explained by socio-economic differences (353). With regard to the causes of death among children, an over-mortality rate exists among immigrant children

in the following diagnostic groups: accidents, congenital disorders/malformations, metabolic and hereditary diseases, and cancer (353). Diseases directly caused by parents being closely related by blood are significantly higher among ethnic minorities and are highest among the children of Pakistani or Turkish parents (354). A Scandinavian review found that ethnic minority children/adolescents generally had poorer health than majority children in the following areas: diabetes, obesity, dental status, psychological challenges, and quality of life, and that this could not be explained solely by social differences (355). It is questionable whether ethnic minority children have higher morbidity than ethnic Danish children (356). There are indications that migrant parents go to the doctor with their sick children less often than ethnic Danish parents, but several studies indicate a higher morbidity among immigrant children (357, 358). Moreover, the differences between ethnic groups were so large that in some cases they were greater than the difference from children of the majority population. Immigrant children clearly have fewer cases of middle ear inflammation than do ethnic Danish children - probably because they are placed in day care later than ethnic Danish children (359). Minority children are more likely to lack vitamin D and have poorer dental status than ethnic Danish children (360, 361). Refugee children are less frequently vaccinated according to current guidelines and participate less in child examinations performed by the family doctor (362).

4.13. Clinical blind spots

Several studies suggest that the clinical ethnic competencies in the Danish healthcare system are deficient. In a study of age-standardised mortality rates per 100,000 for cardiovascular disease, ethnic minorities of Polish descent residing in Denmark had a mortality rate of 630, while an ethnic minority of the same lineage residing in France had a mortality rate of 150. For people of Turkish descent in Denmark and the Netherlands, the figures were 439 against 231, and the figures for people of Pakistani descent were 500 in Denmark but only 350 in Scotland. The same pattern was observed for persons of Chinese or former Yugoslav ancestry. The same pattern of higher mortality in Denmark was also found for cerebrovascular disease (162).

Refugees/immigrants live longer than ethnic Danes because they smoke less or start smoking later than ethnic Danes, drink less alcohol, and have a lower suicide rate. Nonetheless, immigrants from non-Western countries in Denmark have a massive over-mortality rate due to infections and cancers caused by infections (137, 363). These infections (e.g. tuberculosis, HPV, chronic hepatitis, and HIV) are both preventable and treatable.

Language barriers, prejudice, and lack of knowledge among patients and health professionals are probably the main causes of discrimination. For example, migrants go later to their doctor, regardless of socio-economic factors (364). While the mechanisms that create the link between language, language barriers, and health are unknown, the consequences of language barriers are clear: lower compliance, higher morbidity, more medical errors, more serious complications, and higher mortality rates in preventable and treatable diseases (51, 78, 180, 363).

In the daily clinical life with ethnic patients, health professional bias in the form of stereo-typing, prejudice, and 'cognitive short-cuts' plays a part in clinical decisions, especially regarding *whether* to launch an examination programme, under whose *area* the examinations are to be conducted, the choice of *examinations*, the choice of *treatment complexity*, how many trials are used to achieve success, and the *duration* of outpatient *follow-up*. The core areas in which we most often experience undesirable patient events are shown in Table 7. On the other hand, the extent to which health professional bias is allowed to unfold varies widely between hospitals, hospital departments, and family doctors. The unpredictability of the pattern complicates the establishment and retention of appropriate patient programmes in treatment chains as some links in the 'chain' are weak or too quickly give up in an otherwise well-planned programme.

Table 7. Medical findings at the MHC. Patients referred have long-term undetermined health and/or compliance issues.

Medical assessment of the primary problem	Percent (N=134)
Overlooked social, financial, or psychological issues of great importance during illness/examination/treatment	31.5
Overlooked or ignored health problems	25
Misinterpreted or misjudged symptoms/illnesses	18
Illnesses that require special clinical-ethnic competencies (e.g. hereditary blood disorders, Familial Mediterranean fever, certain psychiatric disorders, urinary and faecal incontinence)	5.7
Unsolved or worsened health issues due to lack of hospital coordination	5
Special support needs in connection with complex or serious compliance problems, including examinations for life-threatening illness	4.6
The patient lacks key information/knowledge on treatment/medication/illness	4.8
Omitted examination/treatment for unprofessional medical reasons or due to lack of professional knowledge/insight	3.2
The examination programme is not commenced or completed not solely due to language barriers (e.g. no interpreter; the patient lacks information about the plan and what is expected)	2.0
Second opinion	0.2

4.14. Symptoms that are frequently missed or misinterpreted

The consequence of many blind spots in the conversation with the ethnic minority patient is that essential health conditions are overlooked. MHC's clinical studies show that almost one-third of the referred patients have unrecognised social, economic, or mental health problems that are central to the patient's symptom picture, compliance failure, or unresolved chronic condition (Table 7). One in four patients has a definite unrecognised health condition, while one in five has a health condition that was incorrectly assessed or misinterpreted.

Examples of diseases and health problems in refugees/immigrants that very frequently, cause doctors diagnostic problems, often because of unclear or weak symptomatology or language barriers, see Table 8.

Table 8. Examples of diseases and health problems in refugees/immigrants that frequently cause diagnostic problems for doctors.

<ul style="list-style-type: none"> • Asthma • Bleeding disorders • Bursitis • Chronic sinusitis • Connective tissue diseases • Constipation • Familial Mediterranean fever • Hereditary blood disorders • Hiatus hernia • Hidden shrapnel/war injuries and occupational injuries/accidents (including occupational anaesthetic from the home country) 	<ul style="list-style-type: none"> • Ischaemic heart disease • Lactose intolerance • Minor physical disabilities • Partner violence • Personality disorders and schizophrenia • Physical consequences of torture • Physical mutilation committed by family member • PTSD • Sexual dysfunction • Somatic anxiety • Spinal stenosis • Urinary incontinence
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Table 9 shows other examples of how symptoms/diseases have been misinterpreted by a doctor (and patient).

Table 9. Examples of missed or misinterpreted symptoms and diseases in 134 patients referred to the MHC with long-term unresolved health and/or compliance issues.

Cause of referral and subsequent diagnosis at the MHC are in parentheses.

Culture shock (spinal tuberculosis)	Shoulder pain (benign lump in humerus)
Dementia (PTSD)	Shoulder pain (hung up during torture)
Impaired cognitive function (PTSD)	Kidney transplant with poor compliance
Repeated accidents at work (PTSD)	Ten acute hospitalisations (Familial Mediterranean fever)
Pain in the feet and knees (consequences of torture)	Role model dropping all jobs and roles (blood clot)
Operated for carpal tunnel syndrome (neurogenic pain due to PTSD)	Migraines (tooth abscesses, chronic sinusitis, Sjogren's syndrome)
Fatigue, migraines, muscle and joint pain (sarcoidosis, kidney failure, nerve inflammation, diabetes)	Three acute hospitalisations with arm pain (blood cancer)
Fatigue, pain on swallowing, muscle soreness, trembling (hormone lump in the parathyroid gland)	Back pain (discus prolapse with lasting paralysis)
Fibromyalgia and depression (PTSD, undergone feigned execution three times)	Not taking blood pressure medication regularly (kidney disease)
Back pain (accidents at work)	Pain in the neck and sensory disorders (congenital malformation of the spinal cord)
Back pain (shrapnel in the back)	Stopped taking blood-thinning medication after heart attack because pain continued (broken rib)
Back pain (stool incontinence after anal torture)	Insulin diabetes stopped taking insulin (child soldier re-traumatised when he had children of his own)
Shoulder pain (hung up during torture)	Off work sick and changed mentally (re-traumatised by flooding in basement)
Pensioner with two bouts of meningitis (head trauma with defective meninges, knocked down and tortured)	Schizophrenia (asthma)
Refused gynaecologic examination (raped by doctors at a hospital in home country)	Fatigue (asthma)
Violent reaction to scanning (kept hidden as a child in water tank)	Violent symptoms without explanation (constipation)
Young man, frequent admissions (Familial Mediterranean fever, father with PTSD and anxiety)	Stomach pain – somatising (ovarian disease, lactose allergy, diabetes, bladder polyps)
Menopause (hormone lump in the parathyroid gland)	Ethnic pain (rheumatoid arthritis)
	Diffuse symptoms (strongyloides infection)

<p>Ethnic pain (cancer of the liver, breast, abdomen, lung)</p> <p>Leg pain (spinal stenosis)</p> <p>Diffuse pain (polymyositis)</p> <p>Neck pain (thoracic outlet syndrome)</p> <p>Restless legs (asthma)</p> <p>Back pain (anal fistulas resulting from torture)</p> <p>Tiredness, diffuse symptoms (recent myocardial infarction and affected heart function)</p> <p>Changed mentally after first child (previous child soldier)</p> <p>Depression, tiredness, and feeling sick (blood cancer)</p> <p>Ethnic muscle pain (polymyositis and side effects of cholesterol-lowering medication)</p> <p>Tiredness (iron deficiency anaemia)</p> <p>Childlessness (congenital sex gene defect)</p> <p>The patient complains that his penis is too small (impotence due to poor finances)</p> <p>Unexplained abdominal pain (lactose intolerance)</p> <p>Unexplained abdominal pain (severe constipation due to PTSD memory failure)</p>	<p>Leg pain (grenade injuries)</p> <p>Diffuse abdominal pain (fibroid in uterus)</p> <p>Diffuse abdominal pain (lactose intolerance)</p> <p>Diffuse abdominal pain (dwarf tapeworm)</p> <p>Lower back pain (faecal incontinence)</p> <p>Somatisation and pension wish (work-related injury with heavy lifting as a child in the home country)</p> <p>Functional ethnic attacks (epilepsy from Takayasu syndrome)</p> <p>Psychosis with hearing voices (tinnitus with machine sound)</p> <p>Pain in the legs (erythema nodosum)</p> <p>Unexplained anaemia (heterozygote thalassemia)</p> <p>Pain during intercourse (mutilated after gang rape in home country, but spouse does not know)</p> <p>Pain in the breasts (mother had both breasts removed due to cancer)</p> <p>Urinary incontinence but examinations are normal (forgetting toilet visits due to PTSD memory failure and exposed to water deprivation as torture)</p>
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4.15. Diagnostic uncertainty

Patients with other ethnic ancestry in Denmark have a higher hospitalisation rate in the cardiology department for suspicion of heart attack, but as a group, they have the same frequency of heart attack as ethnic Danish patients (365). Ethnic minority patients are hospitalised due to language barriers and diagnostic uncertainty more frequently 'as a precaution' in the cardiology department when complaining of slightly diffuse pain in the chest region. A Dutch study showed that ethnic minority patients were admitted five times more frequently with diffuse pain conditions (abdominal or joint pain) than the local population, although they were less often hospitalised with specific medical problems (366).

Many unwritten rules exist, and ethnic Danes have learned most of them. However, even banal explanations or plans are often misunderstood because patients of other ethnic origin do not know the 'codes'. It may be obvious to the doctor and the majority of ethnic Danish patients that a back surgeon cannot assess shoulder pain. However, if the patient is unaware of the different departments in a hospital or cannot easily distinguish a doctor from a nurse, does not know which ward they are in or that there are different types of doctors, then misunderstandings and disappointments will quickly occur. This, in turn, causes the patient to become distrustful, which the doctor will experience as a confirmation that

immigrant patients are dissatisfied, difficult, and time-consuming. The solution is to remove anxiety, misunderstandings, and stereotypes and to replace them with simple questions that ensure the patient and doctor agree on the plan.

Evidence suggests that doctors apply epidemiological findings in individual contexts, which prevents them from including individual information in the clinical decision process, and thus reinforces the marginalisation of ethnic minorities in doctor-patient conversations (243). Additionally, it has been established that the doctors' differential diagnostic considerations are highly influenced by the doctor's perception of the ethnic affiliation of the patient. The diagnoses that the doctor focuses on are selected partly based on non-medical indicators such as assumed ethnicity and the application of general epidemiological findings regarding the individual patient without sufficient inclusion of the conditions and needs of the specific person (338). A big part of the problem is that doctors often fail to realise how their own (medical) culture affects their clinical decision-making skills, but unfortunately gender, age, social status, educational level, and ethnic discordance/concordance between doctor and patient do directly affect the doctor's clinical decision-making with regard to examination, treatment, and information level (and whether the patient understands and trusts the doctor) (246, 338, 367, 368). Although doctors do not believe they are categorising both socially and linguistically in the clinical patient situation, it occurs as part of an unconscious and sophisticated individualisation strategy. In addition to starting with the individual patient from whom they are sitting across, doctors also 'read' their patients using a social radar that records the patient's physical and mental appearance, interaction, and language (369).

The memory of patients with PTSD is intermittently affected very strongly. Patients from refugee-producing countries often have violent experiences that have a somatic expression causing them to go to the doctor, but patients find it difficult to share these experiences with the doctor and at the same time, it is difficult for Danish doctors to understand them in a somatic context (370). Edith Montgomery has demonstrated in her studies here in Denmark how patients with war/torture experiences and PTSD are often seen as unreliable informants because their memory and recollections can be very differently composed depending on external impressions, stress level, and general condition. Thus, patients with PTSD and somatic symptoms are at risk of being either rejected or misunderstood by health professionals. This has clinical implications and is a real problem in the anamnestic doctor-patient conversation whose focus is on chronology and contexts where the history given by PTSD patients can vary from time to time as a kind of 'snapshot' of their memory that day.

Some medical consultations can end up with the exact opposite of their intention if the doctor is unaware of the needs that uncertain patients with language barriers may have. The question of the importance of patients' trust in the doctor in relation to compliance is not very well researched, but studies suggest that patients with language barriers often express the need to build trust in the doctor before they can and will listen to the doctor's advice and guidance. Especially in regard to invasive procedures, distrust of the doctor can lead to patients perceiving the doctor's information as being inconsistent, vague, and imprecise (371). Uncertain patients with language barriers would like to be persuaded by the doctor before agreeing to invasive examinations, surgeries, or treatments with potential side effects. If the doctor fails to pick up on this need and respond with appropriate explanations, the patient will refuse an otherwise justified and necessary examination.

A study in general practice assessed how frequently patients regretted a decision they had previously made with their doctor, based on the validated scales *Decision Regret Scale* (DRS) and *Decisional Conflict Scale* (DCS). A very simple version of the DCS scale is available for patients with low literacy rates (*Decisional Conflict low literacy scale*) (372). There is also a more complex *Regret and Disappointment Scale* that involves a retrospective assessment of a decision with multiple personal angles and an assessment of the guilt element (373) - see overview in Table 10.

Table 10. Three different methods for assessing the patient's level of agreement or satisfaction with a decision and its consequences.

Decision and regret scale	Answer options	Decisional conflict scale (low literacy)	Answer options	Regret and disappointment scale	Answer options
It was the right decision.	<i>Strongly agree</i>	Do you know what your options are?	<i>Yes (=0)</i>	I am sorry about the decision.	<i>Strongly agree</i>
I regret my decision.	<i>Agree</i>	Do you know the advantages of each option?	<i>Uncertain (=2)</i>	I wish I had made a different decision.	<i>Agree</i>
I would make the same decision again.	<i>Neither agree nor disagree</i>	Do you know the risks and side effects of each option?	<i>No (=4)</i>	It would have been better for me if the things I had no influence over had had a different effect.	<i>Neither agree nor disagree</i>
The decision caused me a lot of difficulties.	<i>Disagree</i>	Are you aware of which advantages are the most important?	<i>The total is divided by 2 and multiplied by 25</i>	I feel responsible for the decision not being right.	<i>Disagree</i>
It was a wise decision.	<i>Strongly disagree</i>	Are you getting enough help from people around you to make the right choice?		I am satisfied with the decision based on the result.	<i>Strongly disagree</i>
	<i>Not sure</i>	Are you able to choose without being under pressure from others around you?		I would have been much better if I had chosen differently.	<i>Not sure</i>
		Have you had enough help in making your decision?			
		Are you now aware of what the best choice is for you?			
		Are you totally sure of what the best choice is for you?			

The study showed that while 43 % of patients did not regret the decision, the rest had regretted it to some or to a very pronounced degree (374). Pronounced regret was clearly linked to a high DCS score. Decision conflict occurs when there is a high degree of risk, anxiety, loss, or serious side effects, or if the patient's life values are threatened by a choice. The DCS scale measures patient uncertainty and whether the patient feels they are not included or their needs lack recognition. Decision conflicts can also occur when the patient cannot follow the doctor's clinical decision-making process.

Care should be taken to use a concept such as health literacy in intercultural contexts, as it is more often a necessary bilateral learning process for both the patient and the health professional in a trans-cultural, culturally sensitive framework (375, 376). Often, the doctor needs more patient competencies than the patient needs health skills. Culturally based health perceptions are also dynamic and change over time as Carruth observed in Ethiopia where she found changing and diverse health routines rather than static perceptions of disease and health (377). Concepts and values regarding illness should be understood and discussed with the patient, even if it challenges medical standards (378, 379).

A simple series of questions for self-reflection after a difficult conversation that did not go exactly as planned could be:

- How well did I listen to the patient?
- How well did I understand how the patient felt?
- How well did I check whether the other one understood what I said?
- How supportive was I of the patient's perceptions and ideas?
- How curious was I in terms of seeking out other options/explanations with the patient?
- How much more do I have in common with the patient after compared to before the interview?

4.16. Inappropriate patient care

The main factors that most frequently contribute to diagnostics and treatment not being started or being stopped prematurely are shown in Table 11. While most doctors probably recognise the individual points, it may not be so clear to the individual doctor that these factors are often at play simultaneously for a small group of patients. Most of the patients that are referred to us can say, *'the doctor's questions didn't help me,'* meaning that with our standard way of asking patients, we do not fully get what the problem really is. Also, we do not go directly to what it is that patients are afraid of in connection with their symptoms, examinations, or the proposed treatment. It is well documented that in only 50 % of conversations do doctors ensure that the patient understands the plan and knows who to contact if symptoms worsen or other problems occur.

Ethnic minority patients go through countless well intentioned attempts to examine and treat, that are stopped too early because hospital departments do very little to inform their patients. It is also typical for some departments to discontinue patients the first time they fail to show up. Departments that reschedule patients instead of discontinuing them often find that patients will show up the second time. Some departments have a policy whereby they only see the patient once and then draw up a plan that can involve the local hospital, radiology department at a third hospital, the family doctor, private specialists, and subsequent rehabilitation in the municipal sector. The patient is given the task of reporting at a specified time if, for example, the scan shows stones in the gallbladder or rehabilitation does not have the expected outcome. These treatment plans will almost certainly end without success because the patients lose track of the various strands. We have seen patients who have waited over 12 months for a lung X-ray that the local hospital mistakenly failed to request as planned by the university hospital. Patients with language barriers lack the ability to detect this themselves or to draw attention to it.

The underlying circumstances of refugees/immigrants are not taken into account when discussing the quality of treatment, self-care, and equality in health.

Table 11. Key points in hospital care where the examination or treatment of ethnic minority patients is often not started, is prematurely interrupted, or is unsuccessful.

Experiences from the MHC 2008-2013.

Conversations where:

- the patient's basic concern and anxiety is not addressed
- the patient is not sure whether the doctor has understood
- the patient has not understood the plan and its purpose
- the patient rejects the plan without the doctor trying to talk about the patient's reasons
- the patient has symptoms that are prematurely perceived as being ethnic or culturally related and without a somatic basis
- the patient expresses symptoms of common health problems in a different and an unfamiliar way from what the doctor is used to and the doctor consequently misinterprets them as either a rare disease or a somatisation

Examination processes:

- where the patient is not aware of what symptoms are examined in which department
- involving psychological interviews or psychiatric assessment (finances, long waits)
- where the patient has a completely different plan from that of the doctor (e.g. the patient suspects cancer, while the doctor thinks it is asthma)
- where imprecise medical formulations are perceived as the doctor's diagnostic uncertainty
- where the doctor starts diagnostics on an uncertain basis
- where the patient thinks that the doctor is 'guessing' (because the reason is not explained by the doctor)
- where doctors express themselves differently about the importance and consequences of the same symptom (e.g. osteoarthritis with moderate disc prolapse)
- that the patient associates with particularly severe discomfort due to previous confinement, prolonged hiding during escape, prison stays, (invasive) torture, or rape in hospitals in the home country
- that involve several hospitals
- that involve both privately practising specialists and hospital departments
- that include many preparations for the patient (diet, drinks, medications, pre-examinations, medication breaks, schedules)
- that take place during Ramadan (including certain treatments)
- that are perceived by the patient (by others) as a 'cheap and simple' examination that will reveal nothing (ultrasound versus MRI scan)

Treatment courses involving:

- a period of testing treatment efficacy, but with vague objectives, before forwarding for further examinations or treatment
- a period of testing the results of rehabilitation, but with vague goals

- outpatient checks within the same department but taking place in different locations due to space limitations
- different doctors who express slightly different attitudes to efficacy and side effects – anxious patients who do not understand the overall plan try to pick up signals from different doctors
- private actors, municipality, and hospital (vision, hearing, ear doctor, psychiatrist, dermatologist, private X-ray clinics, shoe inserts, dental treatment)
- several departments simultaneously without the patient understanding the relationship or differences between the individual treatments

Departments:

- where there is a sharp separation between the individual areas of specialisation/outpatient clinics in the ward that the patient does not understand (shoulder/knee, degenerative disorders/immunological disorders, arrhythmia/cardiac insufficiency, etc., asthma/lung cancer).
- where 1st time no-show automatically results in termination of investigations or treatment
- that require completion of long questionnaires before the first visit
- where patients experience being scolded/blamed for a lack of self-care
- with a very long waiting period where it is unclear to the patient why they have been referred
- that consistently fail to use interpretation services
- that do not accept family members as interpreters in situations where no interpreter has been requested
- that have no clear routines regarding the booking and use of interpretation services
- with sparse patient information
- with very short phone hours
- where decisions with clinical consequences are made at too low a competency level
- with standard letters that are easily misunderstood (hospital mergers where geography is assumed to be known)
- that has a special booking policy (e.g. the patient must call a specific phone number before a certain date and within a certain period of time to confirm an already scheduled time)

4.17. Examples of frequent clinical misunderstandings in everyday life

1. The doctor as the absolute authority

A patient is referred to the vein clinic at the local hospital because of varices in her legs. Here, the plan is to give the patient support stockings and to consider surgery as an option. It is clear from the medical journal that the patient is to be called for a follow-up after a couple of months to assess the effect of the support stockings. Five months later, an employee at the MHC calls the vein clinic as the patient has not been called in as agreed. The patient suffers from PTSD and has a hard time getting an overview of her

treatment. The department apologises for not having scheduled the patient and reschedules her on our request. The patient shows up at the MHC to get information on her case. The patient reports that the doctor informed her that she could not get surgery but that she has to use the support stockings. The journal entry is reviewed with the patient. It says the patient could be offered surgery but probably would not be motivated to do so and that is why they would attempt the support stockings for starters. This message surprised the patient as she had understood that she was not a candidate for surgery. No interpreter was present during the conversation with the surgeon, and the patient was only a moderate speaker of Danish. The patient considered the doctor as an authority and the information from the doctor to be the final decision, not as a subject for discussion. The doctor failed to ensure that the patient had understood the information and did not consider that many minority patients perceive the doctor as an authority not to be argued with.

Comment: *Ethnic minority patients frequently decline surgery because they perceive the doctor's emphasis of one option with its potential complications as a clear message from the doctor not to accept surgery.*

2. Carrier or unwell?

A 42-year-old female patient who had been referred to the MHC turned out to be a carrier of hepatitis B. When the patient went to the dentist, she was asked about contagious illnesses, and she informed them that she was a carrier of hepatitis. The dentist reacted by refusing to treat the patient due to the danger of infection. The dentist even informed the patient and her husband that the illness was a sexually transmitted illness. The husband got angry with the patient and requested an immediate divorce, as he did not want to be married to a woman who had a sexually transmitted illness. The MHC had to have many conversations with the couple before they could accept the natural history of the illness as a childhood infection in many countries, and the rest of the family were vaccinated.

Comment: *Clinical cultural competencies are important and should be linked to detailed know-ledge of illnesses that are frequent among refugees/immigrants. Professionals who overreact and make treatment decisions on limited evidence can create unnecessary doubt and distrust. Communication is not just the relaying of knowledge - the knowledge must be correct and precise and always be put into context.*

3. Broken ribs

A 45-year-old woman was referred to the MHC for a second opinion due to persistent pain in her chest and thorax. She had been examined several times at her local hospital with no result. Three months earlier, the patient had had a cardiac arrest and received CPR several times during the ambulance transport from her home to the hospital. She was transferred to the university hospital due to heart failure. She developed respiratory difficulties, was put on a ventilator, and developed Adult Respiratory Distress Syndrome (ARDS/white lungs). The patient was in intensive care for six weeks and recovered. Post-discharge, she complained of persistent thoracic pain. Her son was used as interpreter as a professional health interpreter was not used. A review of her medical record and the course of treatment revealed that four of her ribs had been broken during the CPR and that this was the source of her pain. With help from a professional interpreter, the cause and the benign nature of the pain was explained to the patient. The patient then explained that she had experienced pains similar to the current ones for one year prior to her cardiac arrest. On closer questioning, however, these were established to have been due to angina pectoris. The patient believed that the long period of intensive care at the hospital had been useless because the pain had returned, and the interpretation by the son had been insufficiently precise for the personnel at the hospital to see the connection. The patient was given four different types

of pain medication, including morphine. The patient chose to stop taking this pain medication once she understood the source of the pain.

Comment: *A pain anamnesis requires precision and thus interpreter assistance in the case of a language barrier. Even the best analgesics will not work when based on the wrong medical history. Information is medication saving.*

4. Who prescribes medication and why (caseworker, family doctor, neighbour, family)

A 57-year-old man with diabetes, cardiovascular disease, spinal stenosis, and chronic obstructive lung disease (COPD) is referred to the MHC due to failure to comply with medication and difficulty walking. The patient speaks and reads Danish and has lived in Denmark as a refugee since 1985. Every day, the patient takes 15 different medications and until recently he has administered and followed his treatment himself. He is being referred because he has begun to forget to take his medication and has expressed low quality of life. It turns out that several changes have occurred in his life. He got divorced and his children do not want to have any contact with him because he now has a new and younger spouse. This has caused him stress and he has begun to forget things, including his medication. A home nurse is assigned to help him remember to take his medicine, but the patient will only take his heart medication. When asked why he will only take the heart medication, the patient explains that the municipal caseworker has said he should remember to take his heart medication because it is very important. His family doctor said the diabetes medication was most important, but the patient himself felt he was most ill in the heart. His new pregnant spouse was most afraid that his 'smoker lungs' would become a problem when he played with the new baby. The patient was upset about having to go to the lung ward because he had felt they had a very negative attitude toward COPD due to his smoking. However, the patient was very fond of the contact nurse in the cardiac outpatient clinic, and she helped him with many of his problems and always had time to talk. The patient admitted this was the reason it was very important to him that he maintained a good relationship with that particular nurse, and now that he was so stressed and forgetful, he chose to focus on the heart disease and the helpful cardiac nurse. He was also dissatisfied that the municipality sent him a home carer twice a day to put on support stockings; he found it degrading and felt that he had been excluded from the decision. The patient had heard that the municipality had an iPad for patients with diabetes so that they could help him without having to come to his home, and he had heard from a friend that you could get a special device that enabled you to put on support stockings yourself.

Comment: *Patients are easily 'trampled' by well-meaning family members, doctors, and nurses, resulting in their own needs drowning in a host of actions that can end up with the patient feeling humiliated and neglected. Patients unconsciously prioritise good relationships and compassion and are less impressed by professional arguments if they are not supported by good relationships. Patients with multiple illnesses prioritise the illness that is accompanied by the best relationship and the least reproach.*

5. Ugly and bad breasts

A female patient talked about a series of medical consultations at the hospital where she had several surgical procedures that she still does not know the reasons for. She described the hard times she had when she divorced her husband, lived alone with three young children, and had to make ends meet on the 7.000 DKK cash benefits she received. On top of that, she was told she had breast cancer. The patient had just started language school and was not good at Danish (nor did she speak English). The patient said that she had only just learned to say things like, 'My name is...', and 'Hi, how are you?' Her language level was not sufficient to understand a medical conversation in Danish, but she was willing to practise.

The patient remembers one particular conversation at a time when she had attended Danish language school for two months but still needed an interpreter. There was no interpreter for the interview. The patient was trying to explain to the doctor that she did not understand what the doctor was saying, but the doctor did not stop the conversation and did nothing to help or minimise the language problems. She also asked the nurse who was present what the doctor meant, but the patient did not understand what the nurse was saying either. The doctor continued the consultation, so the patient asked for the doctor's explanation to be written down on a piece of paper. At this time, the patient had only understood from the doctor's interview that she had 'bad breasts'. The doctor wrote a note in Danish, and when the patient got home, she sat down at her computer to Google translate what was on the note from the doctor. That is when she found out that the doctor had been talking about breast cancer, and the patient recalls that the internet said it was a dangerous and deadly cancer. The patient's world collapsed. She had to deal with it all on her own (divorced and family-reunited without anyone but her sick, elderly mother in Denmark). She thought the children were too small to be told, so she sat alone and cried. She had no social network in Denmark to assist her. She did not dare tell her mother because she felt it was embarrassing and undignified to talk about her breasts when her mother was severely ill herself. Later, she again had 'something' removed from her breast, but she does not know what it was as everything happened again without an interpreter. She does not know what they did - only that her breasts became ugly from it. Spontaneously, the patient tells a similar story about her mother. In Denmark, her mother had an entire eye removed and still, neither the mother nor the daughter knows why. Again, it was because they could not understand what the hospital staff were saying - no interpreter was ever used. Now, the mother stays inside all the time as she feels embarrassed about the eye and thinks it looks ugly. Just a hole is left, and the daughter says she can understand why the mother does not want to go out. She says that in their home country it makes you less dignified when you are sick, especially when it is visible. The patient concludes by saying that it is very easy to be misunderstood in Denmark because you are in a foreign country, with a foreign language and a foreign system. The patient says it is the worst at the doctor's office and at the hospital - things go wrong there all the time.

Comment: *Always use an interpreter when the patient does not speak Danish. Patients look for information on the internet and from neighbours, but they are not prepared for the answers, nor can they discern the importance of the answers or assess their relevance to their own situation. It is important to ensure that patients understand what has been talked about and what has been agreed upon. In most patient conversations, the patient's only contribution is a, 'hmmm' - but that does not mean acceptance. Take nothing for granted when a language barrier exists: check, cross-check, and end by asking the patient to tell you what was discussed and what the plan is. Always have a backup plan, a plan B, for patients who are at obvious risk of later questioning what was discussed at the doctor conversation (a name, a phone number). Patients are often unsure where to turn when in doubt about a diagnosis, treatment, or follow-up plan.*

4.18. Errors due to lack of an interpreter

1. Where is his belly button?

Together with his mother, a boy is admitted to the children's ward with bleeding stomach ulcers. The child's mother and father have severe PTSD following persecution, torture, and escape from their homeland, and the mother is referred to the MHC. The couple now have a residence permit in Denmark and have lived in the country less than 4 years. Both parents speak a little Danish but usually have an interpreter when they have appointments at the municipality and in the healthcare system. They have three children together who are all well integrated and fluent in Danish. Prior to the eldest son being admitted to the children's ward with bleeding ulcers, the boy was sent home several times from the emergency

room as no immediate cause of the abdominal pain was found. On the day of the admission, the mother and her boy had gone to the emergency room but were sent home again. At night, the boy's condition had deteriorated, and he had to be rushed by ambulance and receive emergency surgery for bleeding ulcers - again without the use of an interpreter. The contact nurse at the MHC was contacted by the mother via text message on the third day of the admission. The mother could not understand what had happened to her son. For three days, the staff had chosen not to order an interpreter as it was considered that the son and the parents spoke sufficient Danish and that everybody understood what had happened. It turns out that the sick boy himself had been used as an interpreter, which had created a conflict between the boy and the parents since the boy had difficulty speaking clearly and easily got throat pain when he spoke because of the gastric tube. The mother expressed that she was very nervous about her son's condition, and because that they had been rejected several times prior to the admission, she was uncertain whether the doctors knew what was wrong with her son. The mother asks the contact nurse at the MHC, 'You say he has bacteria in his stomach - can it infect the rest of us in the family? Can it spread to his intestines? I can't see his belly button, has it been cut away?' The father, who speaks only a few single words of Danish, has been used as an interpreter by the department. The mother says that the boy becomes very angry when he has to interpret for his parents, at which point the boy says, 'No mum, but yesterday when I had a snake (tube) down my throat, it hurt so much every time I spoke.' The nurse at the MHC sets up telephone interpretation. The boy is relieved of this responsibility, and the mother gets the opportunity to ask relevant and needs-oriented questions regarding her son's health situation. The interpretation services that are provided appear to reduce the stress of the pressured parents, who are now getting answers to the many questions that they had not been able to ask earlier. It is important to ensure that both parents are able to follow what is happening as well as ask questions and get involved in the medical history. Often one of the parents is considered to be Danish-speaking while the other, who understands even less Danish, is completely excluded from the conversation and unable to contribute to the medical history. This can have serious consequences in situations where the parents have different perceptions of the child's situation or condition.

Comment: *Always use an interpreter when needed by relatives, and children should never interpret no matter how convenient it may be. Without an interpreter, it is almost impossible to detect misunderstandings and disagreements until they have turned into a conflict or serious mistrust. Small or brief conversations do not necessarily equate to simple conversations, and brief conversations may require an interpreter as much as longer conversations do. Parents are important in the paediatric ward, and both parents must be consulted simultaneously and with an interpreter so that everyone is part of the conversation and can ask important questions. It is not always the one who speaks a little Danish who has the most important questions or the best insight. Spouses do not necessarily inform each other. As a health professional, do not assume you know what patients and relatives might be worried about - ask them instead of guessing. Incomprehensible rejections in the healthcare system can lead to fundamental doubt about competencies and distrust of the staff.*

4.19. Failure to inform the patient and interpreter

1. They've taken a chunk of meat from my strange life

The patient was referred by her family doctor when her mental health deteriorated following her mother's death in January 2013. The patient grew up in a harmonious family that worked as farmers. The patient has eight years of schooling and reads and writes in her native language. The patient has extremely violent experiences from her home country where family members have been killed and she herself has been gang-raped by seven men. The patient has given birth to seven children who were sent to Denmark by other family members. The patient came later and her spouse even later. It took five

years to get the parenthood of the children recognised, and the process caused mistrust of the Danish authorities. The patient has severe PTSD, has been seen by a psychiatrist, and was referred to the department for trauma and torture treatment. The spouses are no longer living together, and the patient is alone with her seven children aged 10–24 years, with the four youngest still living at home with her. The patient is on high alert and is afraid that others in her ethnic group might think she is mentally ill or disabled, and she is afraid that her ‘secret’ will get out. The patient was referred to the gynaecology department in January due to vaginal bleeding and uncertainty whether it originated from the urethra or the vagina. The patient comes to the first nurse consultation at the MHC and appears upset and is crying. It turns out that the patient has recently been in a gynaecology department that had allegedly taken a large lump of meat out of her ‘strange life’ as the patient had understood it. [Note: ‘strange life’ (‘underlige liv’ in Danish) is a misunderstanding of the Danish word ‘underliv’ referring to the female reproductive organs.] The patient had the idea that a large amount of meat had been removed, and she was concerned whether there was ‘anything left’. The patient is reassured when the doctor’s dictated notes are replayed and explained through an interpreter. The notes state that a (small) biopsy had been taken from her cervix. The interpreter had not understood the nature of the procedure and subsequently stated that the doctor had spoken very quickly and mechanically. The interpreter had not been able to translate everything and did not have the time to make sure that the patient had understood the procedure. The patient said she got flashbacks of the mass rape and tensed up during the procedure.

Comment: *Know the patient’s ‘larger story’ (background, life story) and the patient’s ‘smaller story’ (the current personal account). Had the gynaecology department read the referral notes closely, they would have seen that she was a severely traumatised patient with, among other things, a mass rape in her past, and they could have adjusted the procedure accordingly. Rape is a frequent occurrence in war, but talking about it is taboo, and patients do not mention it unless it is addressed directly. Before the conversation, it is important to briefly inform the interpreter about the purpose of the communication and the scope of any procedure. Patient consent is a consent and requires that the patient is fully informed of their situation.*

4.20. Incorrect assumptions

The little daughter of Zaynab and her husband was forcibly removed from the home because Zaynab was assessed as having paranoid schizophrenia and deemed unable to take care of her daughter. The municipality did not take the father’s ability to parent into account during the case handling, which is unclear on this point. Zaynab had many gastrointestinal symptoms and was psychologically very affected by the forced removal of her child. Zaynab was referred to the MHC where she had conversations about once a month. The clinic arranged for an examination of parenting ability by a psychologist, and an employee at the clinic participated in the ‘Forceful Removal Committee’ as a support person.

Zaynab was monitored by the outreach psychosis team of district psychiatry where she was interviewed once a month. She was started on anti-psychotic treatment. At one point, when Zaynab was on vacation in a neighbouring country to her home country, she consulted a psychiatrist who assessed that she suffered from depression. He gave her anti-psychotic medication, which she took for some months. During a home visit by an employee from the clinic, Zaynab says, ‘I have a secret,’ whereupon she shows a big shopping bag filled with medication. ‘I have not been taking my anti-psychotic medication for a year, but I bought it.’ Zaynab knew that presentation of a prescription at the chemist can be checked, so she bought but did not take her medication. Afterwards, Zaynab asked if she was mentally ill, which the clinic employee denied. Zaynab had otherwise told the Danish psychiatrists that she took the medication they had prescribed, and they considered the treatment to be working well. When asked why she told her secret to the clinic employee, she answered, ‘I trust you. It is better that you tell the doctors.’ Following a new examination, the forced removal was lifted, and the little girl came home from her foster

family. The marriage did not last, and Zaynab and her daughter moved close to her parents in another part of Denmark. The husband stayed in the same town as Zaynab and has visiting rights every 14 days.

Comment: *Cases where there are barriers of language and understanding require a high degree of rigour and care. The language barrier should be minimised by always using an interpreter, and both social workers and family workers need to be very sure of their observations - any doubts should be clarified openly and transparently. Medication is not necessarily taken, even if purchased. Patients will go to great lengths to avoid humiliation and to maintain a good relationship. The fear of side effects and stigma can overshadow professional arguments.*

4.21. Misconceptions, gossip, and rumours

Rumours can lead to false ideas about illness and health. This problem is likely greater among minorities due to the absence of the usual channels for adjusting and discussing informal information. A Norwegian survey of Pakistani women showed that the fear of rumours contributed to the women not daring to participate in activities such as municipal rehabilitation (380). Rumours in the minority context apparently arise in situations marked by uncertainty and unpredictability and where suitable information is missing in the mother tongue, as was recently observed during the H1N1 epidemic and most recently during the COVID-19 pandemic of 2020 (381, 382). Rumours may also arise when there are special interests in conserving traditional values. Many undesirable rumours concern illness and behaviour in connection with illness. Rumours create anxiety and result in avoidance behaviour for fear of getting exposed to information of uncertain origin and information that is hard to understand.

When the swine flu epidemic, later renamed H1N1, was threatening in 2009, a number of rumours arose in immigrant circles concerning the illness and the vaccine. The Danish Health Authority had not prioritised the preparation of information packages in foreign languages, and it was hard to get valid information through other channels. In this vacuum of panic and lack of information, rumours quickly appeared in Denmark. An information meeting with an interpreter present was arranged in the Vollsmose neighbourhood of Odense, and here the following rumours came to light: 1) the name of the illness proved that it was created by the Americans to kill Muslims, 2) all other Danes got vaccinated but not the immigrants, which proves that they wanted the immigrants to get sick and die, and 3) the internet had information on the vaccine that stated it was based on swine protein, so Muslims could not receive it. The Danish Health Authority subsequently maintained that they could not support the cost of targeted campaigns.

Vaccination for girls against the human papilloma virus (HPV) was introduced in Denmark in 2006. It turned out there was a particularly low vaccination uptake among ethnic minorities, and it was extremely low within certain groups. Zeraiq organised a series of focus groups among Arabic women and girls and found that while the mothers got their health information from Arabic TV channels, their daughters obtained hybrid information from Danish and Arabic sources, and clearly a doubt existed among both generations as to what was the correct information (383). In other ethnic groups, it was demonstrated that it was the lack of official Danish information in particular that led to many hybrid ideas that primarily followed this logic: the Danish Health Authority clearly announced that the vaccine should be administered prior to a girl's sexual debut, so many mothers reasoned that the vaccine was not relevant for their daughters but only for ethnic Danish daughters. Others accepted the information but understood the message to be that the Danish Health Authority recommended that the girls be examined to see if they had had a sexual debut before they could get the vaccine. As the Danish Health Authority did not clearly explain the meaning of their message, the mothers imagined that the girls would have to get examined by the doctor, and during this examination the doctor might break the hymen (which was their experience from their home country). Consequently, many mothers opted for their daughters not to get the vaccine.

Comment: *It is important to monitor inappropriate health information that flourishes in minority circles. It is critical that central information is available in foreign languages, especially regarding epidemics where there is a risk of spreading harmful misinformation.*

4.22. Complexity and problem categories

The experiences from resolving issues for complex patients with immigrant background have led to new understandings of how illness develops and how it is understood, determined, and treated. Illnesses develop in and are shaped by social contexts that interact with biology and gain their final expression - for better or for worse - in their encounter with the healthcare system. For the patient, however, a 'second life' reality emerges with the secondary illness, i.e. the social 'illnesses' that follow the physical/mental illness: disability, loss of function, practical burdens, cognitive loss, social deprivation, poverty, and loneliness. See Figure 9.

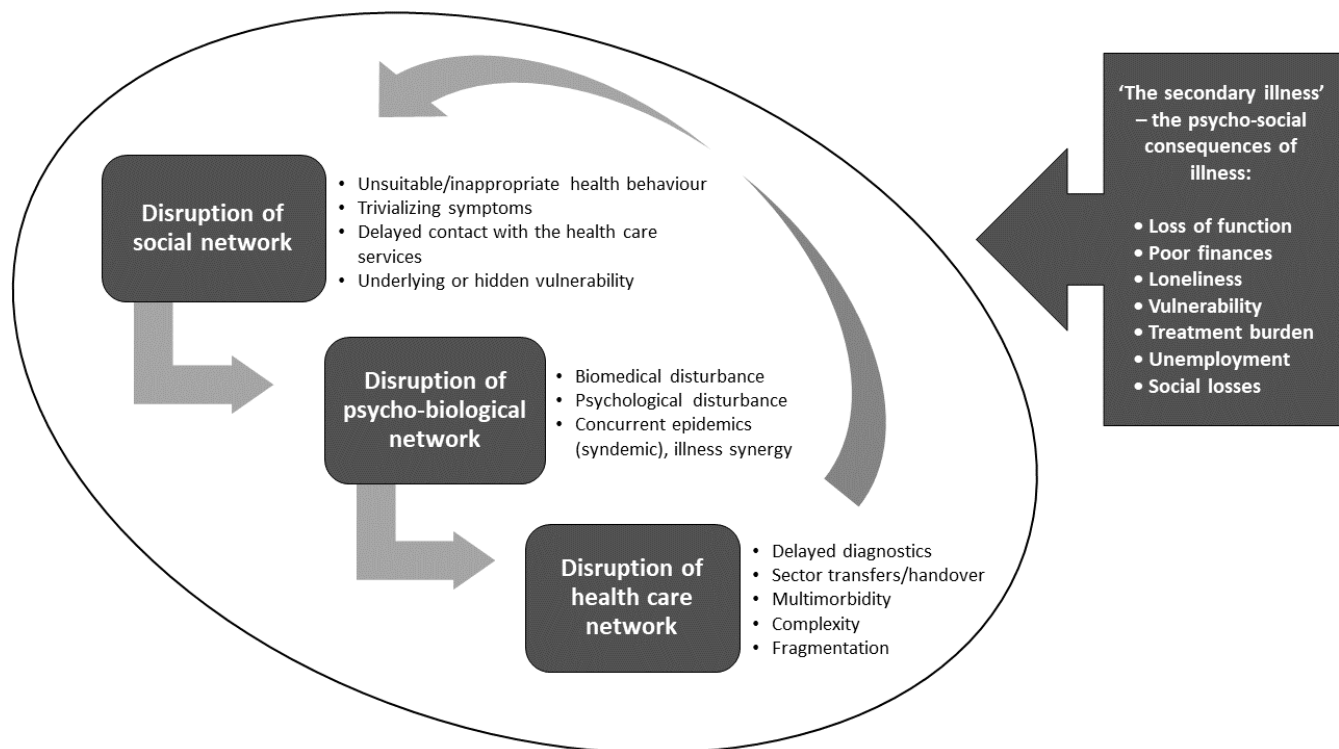


Figure 9. Framework of understanding in regard to refugees/immigrants and other vulnerable patient categories at the MHC.

It is particularly important to understand the vulnerability that can hide in the 'secondary illness', i.e. every illness gives rise to a series of issues that the patient might perceive as illness: the derived health issues and the social, financial, and psychological consequences of the illness.

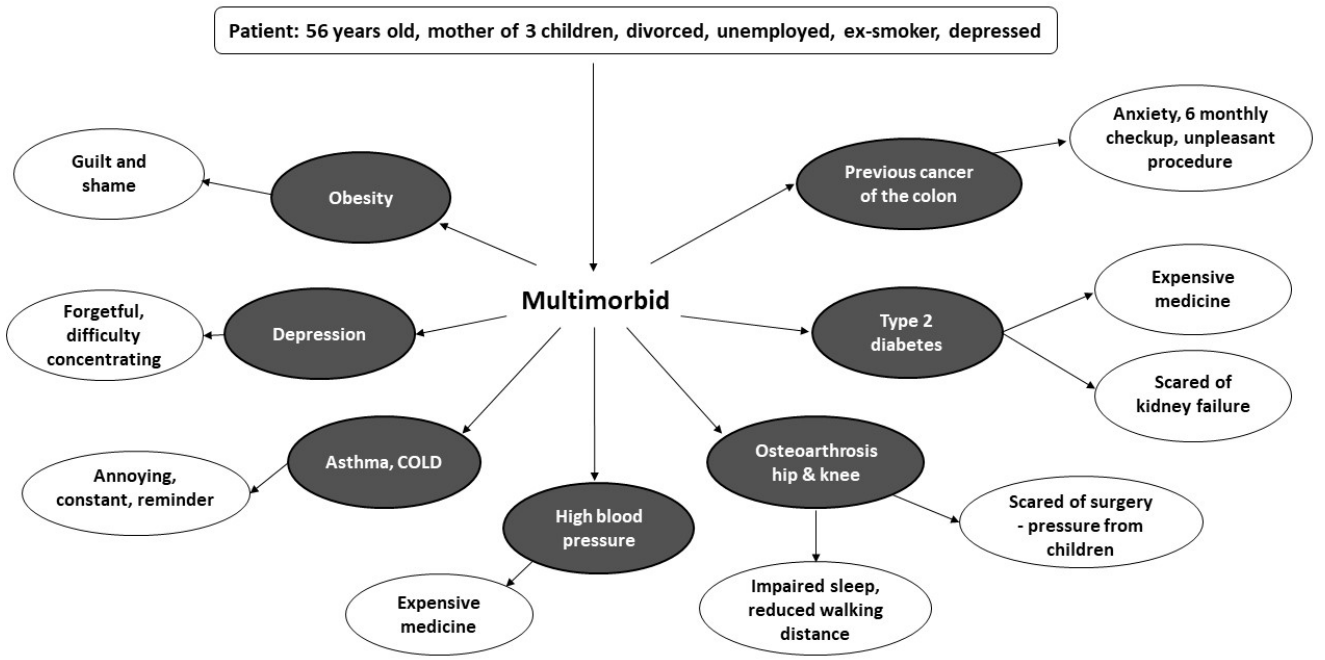


Figure 10. Illnesses and their derived health issues.

In working with multi-diseased and complex patients, a problem-oriented approach is clinically more practical and is also patient-inclusive because the focus is on the patient’s experiences, burdens, and preferences. As a result, a dynamic model has emerged of categories of complex patients that all require the same level of effort but present very different types of complexity - see Figure 11.

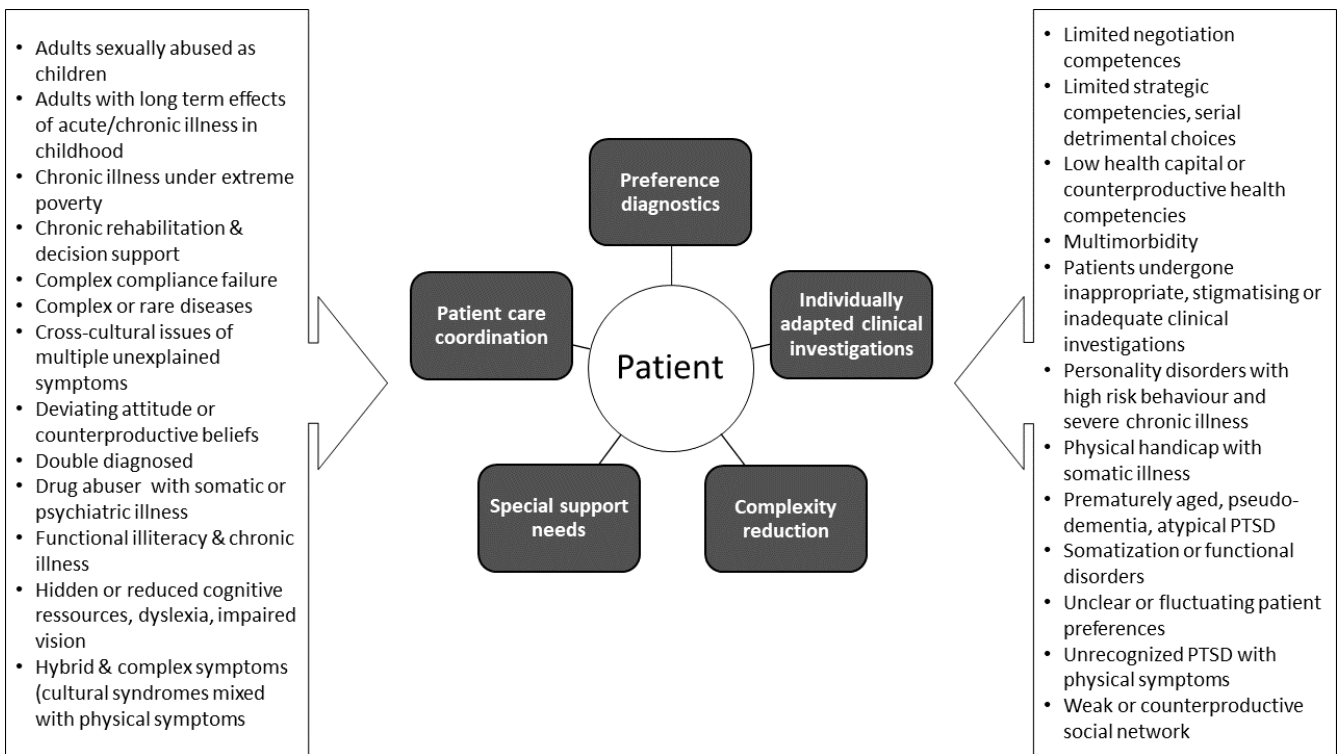


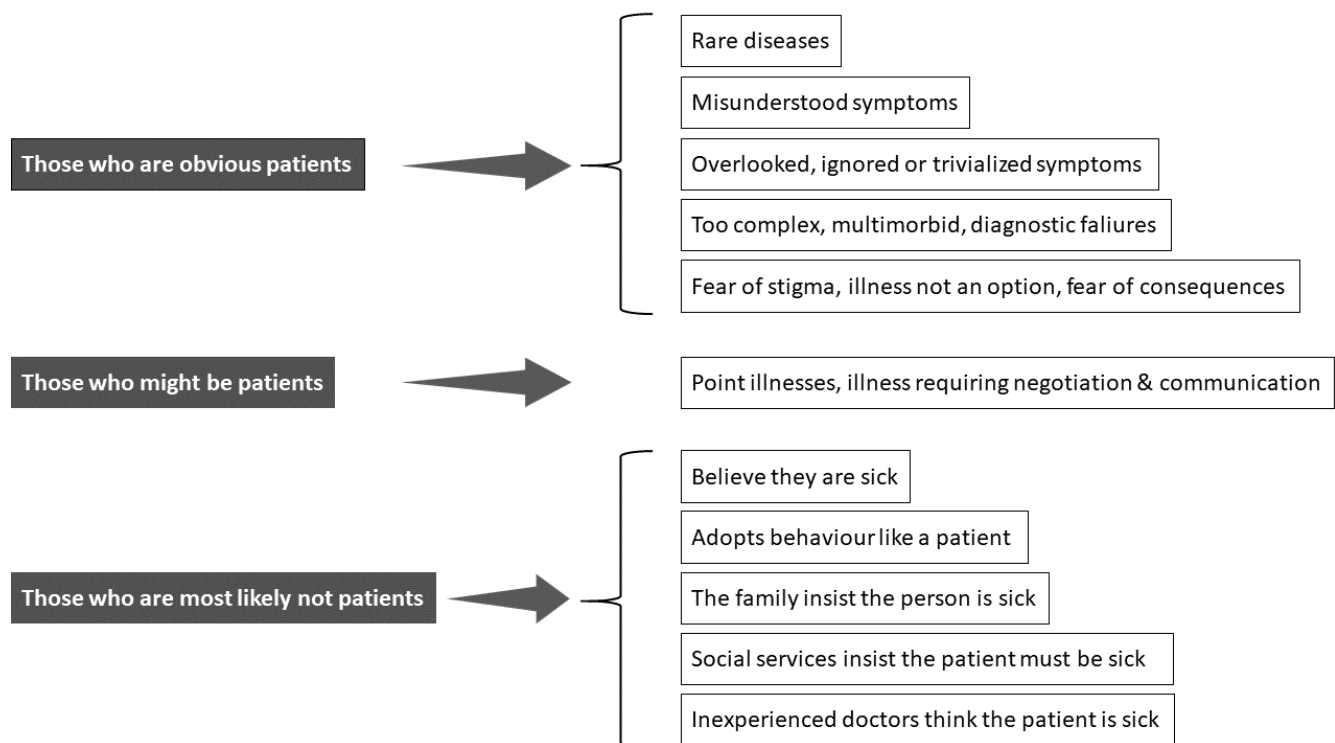
Figure 11. Types of complexity among patients referred to the MHC.

Some of these categories are already known, but many will find such categories as ‘accident-prone’, ‘poor negotiation competencies’, ‘inappropriate beliefs’, or ‘counterproductive network’ to be new and provoking, and similarly categories such as ‘patients who have been wrongly diagnosed’ or ‘pre-maturely aged’.

Among the patients referred to the MHC, there are three broad diagnostic groupings. Firstly, there are the patients who clearly have an illness, but they have either been misunderstood, are too complex, or the diagnostic process has stopped prematurely due to communication problems or ordinary organisational errors/omissions. Some of these patients do not want to be sick, and they try to hide or minimise their symptoms (cancer, mental illness, or disability). Others do not know that their symptoms are signs of illness. Secondly, there are the patients who are probably ill - typically patients with symptoms that could very easily be categorised as insignificant or ‘culturally determined’, i.e. illnesses with discrete symptoms from several organ systems or symptoms that appear and disappear, like asthma, cancer, or autoimmune illnesses (rheumatoid arthritis, sarcoidosis, etc.). Thirdly, there is a mixed group of patients who probably do not have anything wrong with them but have an acquired behaviour that resembles that of a patient. They may be subjected to social illness criteria, or their symptoms may have been made out to be an illness by a caseworker or by doctors, leading to their internalisation over time as an illness. Finally, some people have acquired a patient role as a way of maintaining contact with the family and the authorities. See Figure 12.

Figure 12. Patient categories. MHC.

(Point illness means illnesses that require a given number of symptoms from a list of fixed symptoms e.g. Lupus erythematosus or rheumatoid arthritis).



The MHC has compiled a series of diagnoses and procedural codes that reflect the complex nature of the patients' problems see Table 12.

Table 12. Diagnoses and procedures that are frequently used at the MHC.

Action diagnoses	Post-traumatic stress reaction Complex long-term/chronic non-malignant pain Complex compliance failure Significant psycho-social issues
Additional diagnoses	Poor compliance Treatment coordination and cross-sectoral effort Interdisciplinary intervention for the purpose of improving illness insight and self-care Previous postponement due to particularly violent experiences
Procedure codes	Evaluation of psychological causes and risk assessment Training in problem-solving regarding daily life Socio-medical options Referral to rehabilitation for trauma and torture survivors Care coordination Cross-sectoral approach Interdisciplinary diagnostics and treatment Interdisciplinary intervention Interpreter assistance Collaboration with the primary sector Contact with relatives

4.23. Cases

The following is a description of clinical problem areas based on a series of anonymised cases from the MHC.

Case 1

A 57-year-old woman from an Asian country who had obtained family unification when she was 37 years old was referred due to inexplicable pains in her head, back of the neck, shoulders, and lower back, as well as her knees and calves. She also experienced sensory disturbances in her hands, and she wanted to lose weight. Her life story reveals that the patient lost her little finger traumatically during an argument with her brother, who cut it off. She had a very early debut in the workforce at the age of six. She worked on the family's farm until she was 12, whereupon she worked in the family's restaurant for 20 years. She met her first Danish husband at the restaurant and obtained family unification in Denmark where she worked for 10 years at a plant nursery and then six years doing cleaning jobs at night. One

evening, she fell on a slippery floor, hit the back of her head, and was unable to get up for the rest of the night until she was found the next morning. After the fall, she developed anxiety symptoms and chronic pain in the back of her neck. She was on a one-year leave to take care of her first husband, who had cancer, until he died. A few years later she was fired while she was on sick leave following ear-nose-throat surgery. She received a small compensation for the wrongful dismissal, but she does not dare work alone anymore and gets anxiety attacks in closed spaces. Her then 10-year-old daughter was abducted by some residents in her apartment block, who kept her daughter captive for 10 days until the police found her. This was an incident the patient never recovered from, but because the father had died, she did not dare show that her anxiety symptoms had worsened for fear that the municipal child services would take away her child. The daughter was affected by the abduction and developed self-harming behaviour, and the municipality hired a mentor for the patient. When the child turned 18, the mentor stopped and that was a great loss to the patient, who developed pressing suicide thoughts because her mentor had been her only confidante. She purchased pills on the internet and attempted suicide, but when she was brought to the hospital, she said that she had taken too many diet pills to lose weight. Her new husband disappeared and was gone for three days. Only when the patient contacted the hospital for the third time, was she told that the husband had died. The hospital had not informed her as a relative, but two of his children from a former marriage had been informed of his death. MRI scanning of her knee showed severe osteoarthritis, but the patient was afraid of dying during surgery. Heart and lung examinations were normal. MRI scanning of her head showed pronounced thickening of the mucous membranes of the sinuses. Asked why she was considering suicide, she said she never had a good day in her life; it was too hard to raise her children by herself in a country she did not belong in; that the first husband was nice but he died, and the municipality sent a competent mentor which they took away from her again. It turned out the mentor had talked her out of committing suicide several times. The patient was referred for knee surgery, psychiatric treatment, and was treated with nasal steroids for her chronic sinusitis. The accident at work was reported.

Comment: *At first view, this is a relatively straightforward type of referral covering a chronic pain issue and a long-term sickness leave. Her life story, on the other hand, indicates a more complex collection of problems that weave the past and the present together with an accident at work, that has traumatised the patient, who has developed an unrecognised condition of anxiety. The pain has several causes that need to be separated: accident at work and chronic sinusitis. The patient's shame over her wasted life and the grief over the loss of her first husband have drained her interest in life and self-care.*

Case 2

A 42-year-old female refugee from Afghanistan was referred with chronic lower back pain and tingling paraesthesia in her lower limbs. She sees a privately practising psychiatrist due to anxiety. She explains that she has improved after beginning municipal rehabilitation, and the conversations with the psychiatrist have helped so that she can now feel happy about small things. She describes having developed thoughts of catastrophes and constant unspecific anxiety that has taken over her life. Her lower back pain started when she lifted something very heavy in her home country. A recent epidural block has helped somewhat. The patient is restless while at the same time she is demonstratively expressing that she is doing better. When directly questioned about any important problems in her life that she has not talked about or has difficulty talking about, the patient breaks down. She says that she cannot tolerate her parents, even though she should be able to. The patient asks if she may tell her story, and when this is confirmed, she says that her father was a compulsive gambler and an alcoholic and that her mother was temperamental and depressed, never happy. Her childhood was full of physical and psychological violence from both her parents, and the patient was very angry with both of them. She wishes she could

love them, but she cannot. In particular, she talks about repeated unpleasant incidents from when she was eight years old, and her mother sent her shopping every day to a place where many men groped her in a very abusive way. Her mother said it was her own fault for being condescending, and she was told she had to learn to be chaste and not tell anyone. Since then, sexual activity has been shrouded in guilt and impurity for the patient. Her current husband and father to her children has been unfaithful to her in Denmark - with his previous fiancée. The patient always thought she had a dirty and ugly body, and the acquired guilt has been further reinforced by her husband's infidelity. The patient did not want her psychiatrist to know anything about these aspects of her life, but she was willing to talk about it at the MHC. The patient explained that she had a clear sense that her pain and sensory disturbances were related to her childhood, but in her view, there was no way she would talk about it. After more conversations at the Clinic, the patient chose to tell her psychiatrist about her childhood experiences.

Comment: *The patient's physical symptoms had a psychological explanation that the patient was aware of, but it was in a context that was unacceptable to talk freely about. The combination of physiotherapy and conversations with the psychiatrist normalised the context for the patient and made it possible for her to speak about other, more sensitive conflicts in her life. The patient put into words the physical discomfort of her own and her husband's body and was able to go back to the psychiatrist with a clearer idea of what the psychiatrist could help her with. It is often unacceptable to express mental unease, and a connection between psyche and body is completely unacceptable ('if the body is strange, then I am crazy'). A joint effort from somatic care and psychiatry (and physiotherapy) can improve the patients understanding of the body's functions.*

Case 3

A 50-year-old man from Afghanistan was referred for pain treatment due to persistent pain after a work-related cervical fracture of C3. The referral also reports that the wife has taken early retirement and has PTSD, and that they have two disabled children. The patient is uneducated but has worked for 15 years as an officer in the Afghan army. In connection with his life story, the patient is calm and imprecise about his time in the army. When asked if he had seen things that people should not experience or if he had physically experienced the war himself, the patient breaks down. The cause of his work-related fracture of the neck vertebra was that he fell over a piece of meat when cleaning a slaughter room that looked like a room in which he was once locked up. After the fall, he experienced frequent flashbacks, and lately he has begun having nightmares of people who are crying for help. The patient says that many of his soldier colleagues perished in a fire caused by arson when they were stationed in an area controlled by the Taliban. Their screams are mixed in with the screams of his co-prisoners, who he remembers from the time he was imprisoned by the Taliban. He hardly sleeps at all and cannot manage simple decisions; he is restless and constantly vigilant at the smallest sound; he cannot watch TV, and he does not dare walk outside alone. He cannot remember, he cannot concentrate, and he feels like a frightened animal. He says that he started having long 'films' that ran while he was cleaning at the slaughterhouse and that this might have been the reason he fell and hit his head and the back of his neck. At the end of the interview, the patient says that he is nervous because he has just received a letter from his municipality that they are going to terminate his work support. The reason given was that he had been on a short vacation in London over Christmas with one of his daughters. In their letter to the patient, the municipality stated that he had thereby proven that he was able to sit down for 1½ hours and that he could be together with other people and thus should be able to perform a job. The patient had been persuaded by his daughters to travel even though he was very much against it. His daughters felt that it would be good for their father to get away from home. It was hard for him to say no, and he travelled to London with his daughter for three days between Christmas and New Year. It was an uncomfortable trip for him, but he did it to make his disabled daughters happy, and now the travel has put him in a situation where his

trustworthiness and honour are threatened. He has had specific suicidal thoughts but had second thoughts due to the situation of his children and wife. The patient was referred to an occupational health assessment, and a compensation case was initiated. The patient was also referred for treatment for PTSD.

Comment: *Lack of insight and understanding of the challenges that face people who are traumatised by war can lead to loss of self-care and demoralisation in parenting roles and the job market. The senselessness of war may in these cases merge with the experienced senselessness of the demands from the municipality. Pain, anxiety, and mental pressure prevent/influence the person's contact with the environment and their own body. In such cases, it is necessary to prioritise stress reduction and to create long-term psychosocial support in collaboration with the municipal caseworker (who does not know the patient's back-story).*

Case 4

A 42-year-old Syrian male refugee is referred with chronic pain in his lower back and sensory disturbances. He also suffers from hypertension and obesity and is being investigated for sleep apnoea. He has previously been diagnosed with spinal stenosis and two herniated discs, but due to the duration of the symptoms, the patient was referred to rehabilitation. Blood tests show low MCV, slight anaemia, and increased calcium levels. The patient feels that the pain has taken over his body and that he can no longer manage the pain. He has sexual problems, and the wife accuses him of wanting to get divorced. He says he is in 10th grade at the language school but has developed memory and concentration difficulties. He does not dare watch TV. When asked if he has violent experiences in his past that may be hard to think or speak about, the patient answers that he does, but he does not want to talk about them because of 'culture'. He says he is always afraid and does not think he can survive one more year this way. He stays far away from electricity, switches, and water. He is told that the doctor and the interpreter are obligated to maintain confidentiality, whereupon the patient says that he lost his father when he was 13 years old and was then taken out of school and sent to work at a construction site. In order to be allowed to work there, he had to make himself available sexually to the older men. For years he believed that this is what men did to each other. He feels guilt and shame over what happened and feels it was his own fault. Now he worries about his own children getting exposed to the same kind of men in Denmark. He says that as a young adult he was imprisoned and subjected to torture by electricity to his genitals, nearly drowned, submerged in ice water, and hung up blindfolded while others were tortured. Most of all, he wishes to get a job so that he can take his mind off his thoughts. His nightly breathing problems are caused by anxiety in connection with nightmares, and he often sits up most of the night eating to lessen the effect. The sleep apnoea test is cancelled, and the patient is referred for treatment for PTSD. He is offered conversations concerning food and exercise, and his wife is invited for conversations together with the patient about their marital relationship. The patient had a harmless heterozygous beta-thalassemia and a very low level of vitamin D for which he was treated. Prior to the referral, no interpreters were being used during doctor consultations, but the patient wishes to use an interpreter in the future.

Comment: *A systematic approach is needed for patients with complex and multiple issues. The life story is a good frame of reference for recreating structure and separating the clinical and psychological problems from each other. Anxiety that is expressed physically and sexual issues can be hard to get clarified, but they are so frequent that they should be part of every conversation with refugee patients.*

Case 5

A 49-year-old female refugee of Asian background was referred due to functionally and culturally conditioned sensory disturbances. For more than 10 years, the patient has had sensory and strength disturbances in her extremities, intermittent difficulty swallowing, periodic breathing difficulties, and abdominal pain. She had a thyroid adenoma removed to no effect. Transient enlarged lymph nodes in the mediastinum suggested sarcoidosis, but this could not be confirmed. Suspected autoimmune hepatitis was rejected clinically although no liver biopsy was performed. Persistent eosinophilia led to suspicion of schistosomiasis infection, but the treatment did not help. Via her life story, it emerges that the patient started working in the family rice fields at the age of six. Ethnic violence in the country broke out and government soldiers often came by the fields, and the patient experienced many violent assaults from the soldiers. When the family arrived in Denmark as refugees, the patient's daughter developed an anxiety condition requiring treatment, which demanded the patient's full attention for a number of years. When the daughter began improving, her mother - the patient - began having intrusive thoughts and uncontrollable re-experiences of the violations she and her family had suffered. Sensory disturbances and anxiety were amplified by an increased state of alarm, but the patient did not have the courage to speak to her doctor about it, and her husband did not know of the violations, so she decided to remain silent. The patient had not previously been examined rheumatologically, and it turned out she had a connective tissue disease and PTSD. The patient was referred for treatment of both conditions.

Comment: *Symptoms and their origins easily become unclear in the presence of language barriers. If you do not attempt to get precise descriptions of pain and what it means to the patient, then complex but explainable conditions end up in a tangled group of 'functional disorders' - a diagnosis that patients with language barriers have a hard time negotiating themselves out of. This functional nature is, however, created solely by a lack of thoroughness on the part of health professionals and the far too little use of interpreters for important conversations about the origin and meaning of symptoms.*

4.24. Somatic symptoms: clinical cases with clinical ambiguity, misinterpretations and delayed diagnostics

Prejudices, omitted use of an interpreter, and sparse anamneses frequently contribute to somatic symptoms being missed, wilfully ignored, or misinterpreted. This chapter describes a series of clinical cases that illustrate the importance of a detailed anamnesis. Doctors often miss the social causes of acute hospitalisations, and it cannot be stressed enough that social circumstances are just as important in diagnostics and treatment as nerve reflexes and heart sounds. When the doctor has achieved an overview of all the problem areas, i.e. physical, social, and financial problems, then the tasks are as follows:

1. Understanding, what has been misunderstood by the doctor? By the patient? By the family?
2. Helping the patient separate the different problems
3. Helping the patient understand how the individual problems affect their health and social life
4. Creating solutions together - including prioritising problems that require immediate action and those that can wait

Case 1

The patient is referred to the MHC with 'poor compliance' relating to her treatment for hypertension that had previously been well-controlled. The patient is referred for ultrasound scanning of her kidneys, which shows pronounced chronic kidney changes that could explain her hypertension, and a malignancy

is suspected in one of her kidneys. A CT scan of her kidneys is ordered, but the patient did not receive the letter with the appointment until the day after the test, and the patient does not know what to do about getting a new appointment, as she is uncertain about which department ordered the scan. The department that ordered the test does not follow up on the examination, so the MHC asks the department to reorder the examination. The examination that is performed due to suspicion of cancer is carried out with a delay of 3½ months.

Comment: *Ethnic minority patients with language barriers are characterised faster than other patients as having ‘poor compliance’, but unfortunately, the causes have not been carefully examined. Prejudice and convenient assumptions easily replace usual objective clinical decision processes. The expectations of hospital departments that the patients are fully informed about the background for their referrals or examinations are seldom met by patients who only speak a little Danish. The doctor should be alert when a patient goes from having been ‘compliant’ to being ‘non-compliant’, what changed - the patient or the illness?*

Case 2

This is a 53-year-old patient who struggles financially (high medicine costs) and has PTSD, rheumatoid arthritis, urinary incontinence, chronic sinusitis, and diabetes. She fled her home country at the age of 19 after both her parents had been killed in front of her and she was raped on top of their bodies; her son got lost during her flight. She talked about her experiences to the psychologist at the asylum centre upon arrival as well as to the integration caseworker. The patient remembers the caseworker saying she would speak to the psychologist about treatment. This did not happen. She has begun forgetting to take her diabetes medication due to bad memory - she thinks it is because of her PTSD. She is given devices to remember to take her pills, and a neighbour agrees to support the patient in using them. The severe incontinence caused by her many childbirths and female genital mutilation is treated with medication and pelvic floor exercises, and financial support for adult diapers is applied for. As the patient gains an overview of her situation, it turns out that she is mainly troubled by the numerous side effects of the medication for her rheumatoid arthritis. The MHC informs the treating rheumatology department at her local hospital of the side effects, whereupon the treatment is changed to one without side effects. A small debt relief and a payment plan is worked out for medication at the pharmacy. The patient no longer felt it was the PTSD-symptoms that were the cause, rather, it was the side effects of the medicine that had confused her. The patient is awarded an early retirement benefit, and then she asks to be discharged from hospital care, *‘Now I feel better mentally and bodily; my finances are also better’*.

Comment: *It can be hard for patients with multiple diseases to work out where their symptoms come from, and PTSD can also confuse the body signals. In this case, it was the side effects of medication, which became clear, as the other problems were resolved. In complex clinical situations, it is often a good strategy to begin by solving the easy issues first. This creates space for the harder and more ambiguous symptoms.*

Case 3

This 55-year-old patient from a West African country has diabetes, high blood pressure, high cholesterol count, obesity, and diffuse muscle pain. She speaks a language that only few people speak, so her son, aged 17, is often used as an interpreter. Three years prior to the referral to the MHC, the patient was assessed by a rheumatologist, who determined that the pain must be due to cholesterol-lowering medication, and it was recommended that the patient stop the treatment. The patient’s hospital care was considered finished shortly afterwards, and she was referred to her own doctor for follow-up. The patient says that stopping the medication failed to alleviate the pain, and now the pain had increased so much

that her functional ability was severely limited. At the MHC, the patient had unchanged elevated muscle enzymes and was consequently referred for rheumatology assessment. Here, the patient was found to have signs of polymyositis, which the patient had presumably had all along as the previous examination also showed elevated enzymes. The patient was started on treatment, but this had no marked clinical effect. The patient was referred to interpreter-assisted dietary guidance with a view to losing weight, but this had no effect, reportedly because the patient's pain prevented exercise. The patient's husband reports as a curiosity that the patient's date of birth is incorrect. According to her personal ID number, the patient is 55 years old, but in reality, the patient is 67 years old (i.e. 12 years older). The mistake occurred when the husband was applying for family unification and simply gave a random age for his wife. The biological age of the patient fits with the age of her first-born child, whom she had when she was 17. This error may have influenced the risk assessment and differential diagnostics, and it explains why the patient more easily tires than her (previous) peers despite relevant treatment of her polymyositis. The patient's true age is 67 years, which was later confirmed by a birth certificate from her home country. It turns out that the patient had been having many nightmares of her traumatic experience in her home country and that she gained mental relief by eating at night, which was the actual reason that the patient did not lose weight.

Comment: *The importance of establishing the most correct medical history cannot be overstated. Non-medical preconceived ideas and affinity for easy solutions can delay correct diagnosis. You often see a complex mixture of common illnesses, misunderstandings, and intermingled multiple causes that prevent a balanced clinical decision process. It is often advantageous to be very specific in getting the patient's symptoms described - it is not fruitful to assume that the documented symptoms are actually the real symptoms. This case illustrates the importance of a systematic approach and the usefulness of obtaining a complete list of issues.*

Case 4

A 32-year-old man who is a keen sportsman and socially very active in clubs. In the course of a few months, he loses his functional ability almost entirely, stops doing sports, loses his Danish language, is fired, and has to use a walker. His wife, who is a college student, has to act as interpreter and coordinator. There have been many visits to the doctor, and the municipal caseworker is pressing for a return to employment. He is referred to the MHC. An interpreter is used, and the patient explains that he suddenly experienced that he could not physically stand playing football; he got out of breath and had a tight sensation across his chest; he felt old, lost his sex drive, and isolated himself. He had nightmares and uncontrolled re-experiences in the daytime of the torture he suffered in his home country. An electrocardiogram indicated an infarct of the posterior heart of older date. The patient was referred to the cardiology department and for trauma and torture treatment.

Comment: *There is a risk that cognitive bias delays correct diagnosis when the doctor does not obtain a full and detailed medical history. Delayed diagnosis generally occurs when the person - in the doctor's view - does not 'fit' the diagnosis, and it happens more frequently with young adults, women, ethnic minorities, and older people. The life experiences of the patient will always affect how the symptoms are experienced and expressed.*

Case 5

A 53-year-old woman is referred with migraines over 10 years, no muscle strength, pain in all joints, and depression. She can no longer handle the children and is despairing. Her own doctor writes, 'Nothing found physically, normal blood tests, seen by private neurologist and gynaecologist.' At first, the patient is referred to the neurology department, which in turn refers her to the MHC. It turns out that the patient

has clear PTSD symptoms (saw her niece getting killed by soldiers, became re-traumatised when a male assistant, who looked like the soldier who killed her niece, started at the kindergarten where she worked). The patient has suicidal thoughts and has made several close attempts, but she has not talked about it. She is referred for trauma and torture treatment. Diffuse pain in her thorax turned out to be tumours in her chest cavity due to sarcoidosis (connective tissue disease in the skin, kidneys, nerves, and lungs) in combination with a very high level of calcium in her blood, which can explain her depression, tiredness, and headaches. The reduced kidney function can also contribute to tiredness and muscle soreness. Additionally, the patient has type 2 diabetes and neuritis due to the sarcoidosis disease.

Comment: *Systemic illnesses and illnesses with varying expression over time in ethnic minority patients are often connected to misunderstandings and misinterpretations by the doctor. Illnesses that require negotiation skills and language proficiency can also lead to misdiagnoses and unnecessary patient suffering.*

Case 6

A 41-year-old woman is referred with pain throughout her body, migraines, and poor compliance in relation to her treatment for thyroid metabolic disorder. The hospital and family doctor have given up. The patient is referred to the MHC. The patient suffered from severe panic disorder and night-mares (insomnia), hereditary eye disorder that the patient misunderstood would blind her, hereditary blood disease with anaemia (thalassemia), chronic allergic sinusitis that caused her migraines, urinary incontinence that led to social isolation and depression, and lactose intolerance that caused stomach discomfort. The patient also suffered from type 2 diabetes.

Comment: *It is important to have ongoing discussions with the patient about their illness concerns so that any misunderstandings can be cleared up. Patients with language barriers seldom manage to talk about all their health issues, and if the doctor is very 'controlling', it may lead to the patients synthesising all their health issues into one problem. This can prevent the doctor from detecting the existence of several different problems. It is important to be open to the possibility of new health issues.*

Case 7

A 34-year-old woman is referred with diffuse pain and anxiety attacks. The referral read: 'Diffuse pain, anxiety attacks, many contacts with the emergency department, on sick leave from adult education.' The patient informs the MHC that she has diffuse pain, but there is another kind and much stronger pain in her left arm. The pain in her left arm has been so heavy on two occasions that she fainted at home and had to call the emergency number (she was admitted acutely twice and sent back home with no plan). The patient is being stalked by her ex-husband, with verbal threats of murder and violence, but she does not dare file a complaint because her Danish residency was obtained through family unification. Chaotically poor finances as the ex-husband has gambled all the family money away. She attends adult education classes and cannot keep up due to memory and concentration difficulties, but she does not want to quit. She has urinary incontinence, haematuria, and pain in her abdomen. X-ray shows a fracture of her left upper arm and osteolytic metastases due to myelomatosis. The patient is referred to the gynaecology department for her urinary incontinence where they discover uterine fibroids as the reason for the gynaecological complaints and blood in the urine. The patient has been imprisoned and tortured in her home country, and she has a chronic personality disorder with severe anxiety elements, which requires that the patient get special support during the course of her cancer treatment.

Comment: *Diffuse pains are perceived as excessive in the presence of language barriers. Acute pains that require repeated contact to the hospital should always lead to closer examination. Social factors always affect how symptoms are experienced and should be actively sought out in the medical journal.*

There should always be a clear plan of action for following up vague symptoms - especially in the presence of language barriers.

Case 8

A 44-year-old Asian woman is referred to the MHC with increasingly frequent sick days due to pains in her lower back and the threat of getting fired. She has worked continuously since she came to Denmark in 1988. She has become increasingly sad, is withdrawn, and isolates herself from others including the family. She is married to a man from another country, which causes family conflicts. She tells the Clinic that she snapped a few years ago when the Danish town she lives in experienced serious flooding due to very heavy rain. All the basements in the area were flooded, including her own, and everybody was talking about it. The patient explains that she began having uncontrolled re-experiences from her childhood, when they saw corpses floating in the rivers. Also, later during her flight away from her home country, they were practically canoeing in corpses. She was convinced that corpses were floating in her own basement and in the streets of her town in Denmark. The patient had had to flee alone with her younger sister, and they never found their parents again. This torments the patient. Several of the patient's own children are very sick with epilepsy and an unsightly skin disease. The husband is unaware of the patient's experiences in her home country. The patient has abdominal pains that affects her sex life unacceptably. The MHC discovers that the patient has symptoms of PTSD as well as chronic liver inflammation and pronounced urinary incontinence. She is referred to the gynaecology department for assessment, and they find a large uterine fibroid.

Comment: *PTSD symptoms may appear decades after the primary trauma, and this should always be kept in mind. PTSD can hide somatic illnesses, and it requires an active and systematic questioning technique to bring these out.*

Case 9

A 38-year-old man from the Middle East who has lived in Denmark for 25 years and has worked until half a year prior to the referral to the MHC. He speaks and writes in Danish. He complains of pain in his back and radiating pain in his arms and legs. He was seen by privately practising neurologists and rheumatologists, psychiatrists, psychologists, and orthopaedic surgeons and was eventually diagnosed with fibromyalgia. He was fired from work due to too many sick days. He has been referred to the MHC as he has changed behaviour, sleeps in his car, is short-tempered, and isolates himself. It turns out that he has undergone feigned execution twice in his home country, first when he was aged 15 and again when he was visiting his home country at the age of 25. The first feigned execution occurred when he and a friend were pushed out from the top of a high-rise building in his home country. He was blindfolded, and he hears his friend's screams as the friend is pushed out over the edge by the soldiers, while the patient himself is spared. The patient is re-traumatized when he gets hit by a sofa in Denmark that was tossed out from a balcony. He gets a work-related injury from a heavy iron plate that crushes him into a wall. The foreman makes little of it, however, and the incident does not get reported. The patient forgot about it due to his many nightmares in which he hears his friend screaming, and he only remembers the work incident when he tells his life story. He has neuropathic pain as a result of chronic PTSD. He is referred for trauma and torture treatment, and on the basis of an occupational health assessment, he is awarded compensation. The patient has no signs of fibromyalgia.

Case 10

A 37-year-old man was referred with diffuse pain complaints in his whole body, particularly in the back of his neck. 'Hard to activate', wrote his own doctor. An ordinary objective examination shows that the

patient has an underdeveloped left arm that is shorter and has less muscle mass than the right arm. He became sick when he was six years old in his home country, after which he could not use his arm. This is very likely the result of polio (the patient lived in an area that had no vaccination campaigns due to war). The patient is ashamed of his disability, which would be visible in the jobs the municipal job centre tries to get the patient to participate in. In his previous job at a pizzeria, it was not hard to hide his disability. He always hides his arm in long-sleeved clothes. The pains in the back of his neck are likely due to his efforts to hide his disability at work.

Case 11

A 32-year-old woman with sensory disturbances in her left leg for over 6 years, back pain, and leg cramps for 3 years, primarily in her left leg. An ordinary X-ray of her spine was normal, and the patient was told it had to be exercised away. The patient continued to work as a seamstress and performed back exercises, but the symptoms got worse and she developed muscle weakness in one leg. MRI scanning of her back indicated a neurinoma in the medulla, which had now resulted in lasting neurological damage to the medulla and was too widespread to remove without causing further damage to the patient. The patient had worked as a seamstress since she was seven years old in her home country. The patient was not immediately informed of access to patient complaints or insurance by the examining department. The patient limps and is in pain. The patient was fired from her job as an assistant to her disabled younger sister, as the municipality could not be responsible with regard to the patient's mobility and the physically heavy tasks required to help the younger sister. The patient speaks perfect Danish.

Comment: *Persistent back pains must be sorted out and treated according to current guidelines even in cases of language barriers. Particular attention should be paid to ensuring that the anamnesis is correct and kept up to date - with an interpreter.*

Case 12

A 47-year-old woman from Northeast Africa who speaks a little Danish and has never been to school. Referred by her local doctor due to heart problems fear of the proposed heart surgery. The patient's primary heart problem is mitral stenosis/insufficiency alongside beginning aortic stenosis, and severe aortic insufficiency. Her mitral stenosis was treated with catheter dilatation in 1997, and in 2006 she was recommended for triple heart valve surgery. She did not show up for surgery, however, and has since been unwilling to have any operations. The patient says that she stayed away because she gets more ill every time she speaks to the cardiologists. She felt that they only made her more scared rather than more comfortable. The patient has experienced a steeply declining functional ability; with a current walking distance of 150 m, she gets very tired and is no longer able to do her own shopping or house cleaning. Her husband of the same age died unexpectedly four years earlier. It was assumed to be cardiac arrest as he apparently had not been sick. This was a big blow to her and her children as he had been responsible for the practical things at home and their income. The heart surgeons recommend surgery, but the patient still does not dare. She says, however, that she would not mind if the MHC was present during the conversations with the heart specialists and if the MHC can talk to her children about it. The patient is called in for a so-called risk interview with a representative from the MHC, but she gets second thoughts and avoids the appointments. A home visit is arranged with a doctor and a nurse as well as an interpreter. Here it turns out that her children disagree on whether the mother should undergo surgery. Apparently, the oldest son is now the head of the family, and he is the person who is most against the mother's surgery. The children are more traumatised by the loss of their father than had been reported. When asked directly if anyone else in the family is included in the decision making, the patient mentions that her 67-year-old mother in their home country may be the one who has the most say. The patient herself would like to have the operation, but her mother has prohibited it because the patient is at risk

of dying, which would leave her four children homeless in a foreign country. The surgeons estimate that the patient has less than two years left to live without the surgery. A conversation is held with the mother in the home country and the children, and a family care worker is appointed by the municipality. Arrangements are made for the patient's sister, who lives in another Scandinavian country, to come and take care of the children while the mother undergoes surgery.

Comment: *It is always important in cases of serious illness to clarify who makes the decisions around the patient: who takes part in deciding and who decides the most? It is not always the case that the head of the family lives close to the patient or even in Denmark. A collective cross-sectoral effort for support of the children calms the patient, who then accepts the life-saving operation.*

Case 13

A 31-year-old man from East Africa came to Denmark at the age of 17 as an unaccompanied refugee. He is referred due to non-epileptic seizures and unusual behaviour. In the conversation, he appears to be smiling but is incoherent. The friend who has come with him explains that the patient cannot take care of himself and that he has been to the language school and done practical training but could not handle it. He cannot remember things and has a hard time understanding simple messages. In simple tests, the patient cannot remember, combine, or perform simple tasks (like folding an A4 size paper twice). He has been in the army but not in combat, only training. He fled due to the prospect of a very long military service. Scanning of the cerebrum reveals multiple infarcts, and scanning of the carotid vessels shows a rare autoimmune arteritis as a partial cause of the infarcts together with the blood disease, polycythaemia vera. He is started on relevant treatment in two hospital departments. The municipal job centre finds it difficult to adapt their offers to him, disagrees that he belongs in the category of older disabled persons, and rejects a neuropsychological examination of the patient. The municipal mentoring is stopped, after which the patient fails to appear for check-ups on his treatment at the rheumatology and haematology departments. He suffers from severe chronic headaches, but there is a two-year wait for assessment at the headache clinic.

Comment: *The diagnosis was delayed as it was initially assessed that the patient was an 'uncooperative' and 'foolish' young man. It appears that the boy has lost his cognitive resources because of the many infarcts. The sequence of actions shows how the interests of the municipality do not always match the needs of the healthcare system - and that of the patient. Compliance from patients with cognitive loss is a chronic support task for the municipality, but in practice, it is very hard to establish support for young patients. In this particular case, regular network meetings take place, but the establishment of a steady mentor arrangement has never materialised, and the patient has yet to receive a cognitive test.*

Case 14

A 39-year-old man from East Africa is referred with suspected drug abuse/drug psychosis and HIV infection. The patient only speaks Swahili and a few words of English. He has been hospitalised acutely numerous times with the ambulance doctor assessing him as being unconscious and under the influence of drugs. He has been frequently admitted from the emergency department, but he most often leaves the ward early the next morning. None of the conversations with him have had interpreter assistance. With a Swahili interpreter present, the patient says he has been divorced and has to pay for his ex-wife's apartment and child support. He works three different jobs to handle this, two in the daytime and one as a newspaper deliverer late at night. He has moved into a home for men where a group of men smoke hash and play loud music at night, so in reality, the patient never sleeps. He appears malnourished and has a low BMI. He has a negative HIV test and never takes drugs, nor does he drink alcohol. Further

details of what exactly happens to the patient before he is found unconscious reveal that the patient suffers from narcolepsy, for which he is referred for treatment. His finances are sorted out, and he finds a new and inexpensive room to rent.

Comment: *Deficient social and seizure history-taking as well as cultural prejudice delays diagnosis and treatment.*

Case 15

A 37-year-old Danish-speaking woman from North Africa is referred with complaints related to several organ systems, chronic migraine, indigestion, stomach pain, tiredness, and a feeling of being overwhelmed as well as lower back pain and difficulty standing or walking for any length of time. Her own doctor writes that the patient wants long-term sick leave due to pressure from her caseworker to find work. The patient would like to have an interpreter at the first consultation. She grew up in a refugee camp and does not remember anything from her childhood except grenades, mutilated corpses, and destruction. She has felt increasingly under pressure after a divorce, and she feels lonely and overloaded with five children of which two are less than four years old. She has been experiencing increasing and specific nightmares about her childhood and is now being pressured by her municipal caseworker to start working. She cannot sleep and has started to comfort-eat at night. She shows clear symptoms of PTSD as well as memory and concentration difficulties. Additionally, she has symptoms of asthma (her housing is humid), chronic urticaria, allergic rhinitis, chronic sinusitis, urinary and faecal incontinence, and a clinical suspicion of cervical (not lumbar) disc prolapse. She has homozygous lactose intolerance, which explains her indigestion, and anaemia due to excessive bleeding. She has gastritis and is helicobacter-positive. She has Haglund's deformity (of the heel), which partially explains her difficulty to do jobs requiring a lot of standing. She is referred to treatment for PTSD, and a new employment programme is adapted to her functional level. Social challenges and somatic symptoms may be combined with previous experiences without the patient herself being fully aware of the connection.

Comment: *It is not uncommon for problems to get mixed up together, thereby hiding the individual health issues. This case illustrates the importance of a systematic approach and the usefulness of obtaining a complete list of issues.*

Case 16

A 59-year-old man with type 2 diabetes who has had a personality change with increasing apathy and severe physical and psychological loss of function after a cardiac arrest and stent-treated LAD stenosis a year and a half prior to the referral. A previous psychiatric assessment for depression was inconclusive, as the patient did not feel depressed.

He is referred for assessment at the MHC where he expresses great worries about his two adult daughters, who are fleeing their home country with small children. The patient explains that he used to be part of a team that dug out dead people from bombed houses and drove them to the hospital. The uncertain plight of his daughters has made these experiences come back to him during the day and as nightmares at night. He reveals very annoying auditory and olfactory hallucinations stemming from his tasks in his home country. A strategy is discussed with the dementia clinic, who deems this to be depression, but the patient again rejects this, commenting, *'Medication will not bring my daughters to safety.'* He shows signs of PTSD and re-traumatisation, and commences treatment for these.

It turns out that his wife is mostly worried about the fact that the patient frequently faints and hurts himself falling. The patient describes vertigo and loss of consciousness. He is referred to the Fall Clinic where they find hypotension, high salt excretion, and orthostatic hypotension as well as benign

paroxysmal positional vertigo. He begins treatment with hydrocortisone (for adrenocortical insufficiency) and treatment for positional vertigo with immediate results. MR scanning indicates multiple white matter lesions of the brain. At the same time, the wife is being examined for possible cancer, which puts additional pressure on the couple. The patient gets some home aids, and the couple's worries diminish as the patient's symptoms are explained, his treatments take effect, and the wife is found not to have cancer. After the wife's worries about the patient's condition have lessened and the daughters simultaneously gain residence permits in another European country, the patient's stress symptoms disappear.

Comment: *It can be hard to determine what is cause and what is effect in complex cases like this one, so it is important to keep all avenues open rather than fixating on one particular suspicion. The importance of a detailed anamnesis, in which relatives are also included, cannot be overstated. Often, the treatment consists of a combination of medication, information, and stress reduction.*

Case 17

A 53-year-old man from the Middle East is referred with fatigue and unexplained universal pain. He has been hard to place into the workforce, and the municipal caseworker pressures the family doctor for a clarification. The patient has not had an interpreter at previous consultations. During the first examination, it is noted that the patient is limping, he cannot climb stairs, and he has difficulty standing up from a sitting position. He suffers from hair loss and annoying itching in his scalp.

The patient is unable to spell his own name after seven years of schooling in his home country. He describes a severe learning disability since childhood. Blood tests show signs of immune activation, and the patient has a positive QuantiFERON test, minimal lung infiltration of older date, and very high levels of creatine kinase in his blood. A few acid-proof rods are found in the patient's sputum. Although this is interpreted as tuberculosis with myopathy, a 6-month anti-tuberculosis treatment does not improve the tiredness, muscle weakness, or creatine kinase levels. Due to the pronounced musculoskeletal symptoms, an MRI scan of the spine is performed, and this indicates axial arthritis, while a dermatology examination reveals psoriasis of the scalp. Upon completion of tuberculosis treatment, the patient begins a biological treatment of psoriatic arthritis with axial involvement. The patient has slight cognitive impairment, which together with a lack of interpreter assistance has delayed a clarification of the patient's symptoms. However, with the help of an interpreter and a systematic review of issues carried out at the patient's pace, a constructive anamnesis was achieved and gave rise to two diagnoses for further examination. The muscle symptoms are presumably due to autoimmunity and are reflected in both of the patient's conditions.

Comment: *Patients who are difficult to place in the workforce should be carefully examined both somatically and psychologically, including an evaluation of cognitive functions. Symptoms that persist should be examined using more specific biochemistry and imaging diagnostics.*

Case 18

A 39-year-old man is referred with sweats, tiredness, stomach pain, headaches, and unusual pain in his lower extremities following a shooting trauma to his foot in his home country. He had an extensive treatment course at the pain clinic, but this was stopped after the treatment options were exhausted. He is being treated by a neurologist with oxygen and lithium for Horton's headache. One child has been forcibly removed for unknown reasons, and he does not want to talk about it. He is examined for PTSD, but the suspicion is rejected. There is suspicion of a functional disorder.

The patient has multiple traumas in his background (e.g. he has seen his sister be killed), and he has symptoms of PTSD, but he declines to participate in screening or treatment.

The patient has lactose intolerance, and the stomach pain is frequently caused by his consumption of milk products, even though he is aware of the connection.

Blood tests show unmeasurable amounts of vitamin D and high levels of TSH. The patient is recommended to increase vitamin D intake and is referred to the endocrinology department where they find subclinical autoimmune myxoedema that requires treatment.

Comment: *Men can have thyroid disorders, but these are easily overlooked. Careful questioning techniques (see the section on PTSD) can often reveal traumas and PTSD symptoms. The patient's perception of pain is certainly influenced by PTSD symptoms as well as neuropathic pain in his lower extremities. One can hope that over time, the patient will become motivated to get treated for PTSD before he is examined for a functional disorder.*

Case 19

A 46-year-old refugee from the Middle East is referred with unexplained universal pain. He has previously been treated for torture damage and PTSD. Now, he feels that symptoms have returned in a different way and are worse. He has been hospitalised a number of times for stomach pain. He was referred to the neurology department where he did not show, at which point he was discharged for further treatment as it was not felt that torture pain belonged in neurology. He was referred to the infectious diseases department but stays away, which is interpreted as meaning that the patient's symptoms are no longer present. The patient has symptoms matching Familial Mediterranean fever and has a family history of this condition. The diagnosis is confirmed by evidence of gene mutations. He is referred for renewed treatment of PTSD as he suffers from massive neuropathic pain that arises from his navel and moves distally; this is a result of electrical torture.

Comment: *A precise anamnesis for patients in pain is crucial. Existing diagnoses are not necessarily explanatory. Familial Mediterranean fever is a frequently overlooked diagnosis in patients with other diagnoses, or when the pain is considered psychogenic.*

Table 13. Clinical cases: Learning points.

- Importance of a detailed and thorough medical history cannot be overstated.
- Poor compliance/adherence can be poor communication.
- Social events often make patients change their behaviour from compliant to non-compliant.
- It can be hard for patients to distinguish their symptoms themselves without active assistance.
- Always think of the usual - but be prepared for unexpected connections.
- 'Ethnic pain' does not exist - all pain has a social meaning and an origin in learnt pain perception.
- Somatoform/'functional' conditions are rare and often have a non-functional background.
- Symptoms have a social function and may be formed by others than the patient.
- The patient's preferences are always important, but especially so in the presence of language barriers.
- Cognitive impairment can be hard to identify (for social and linguistic reasons), but it should always be considered.
- Cultural preconceptions and prejudices can get in the way of correct and timely diagnosis.

4.25. Key cross-cultural clinical competencies

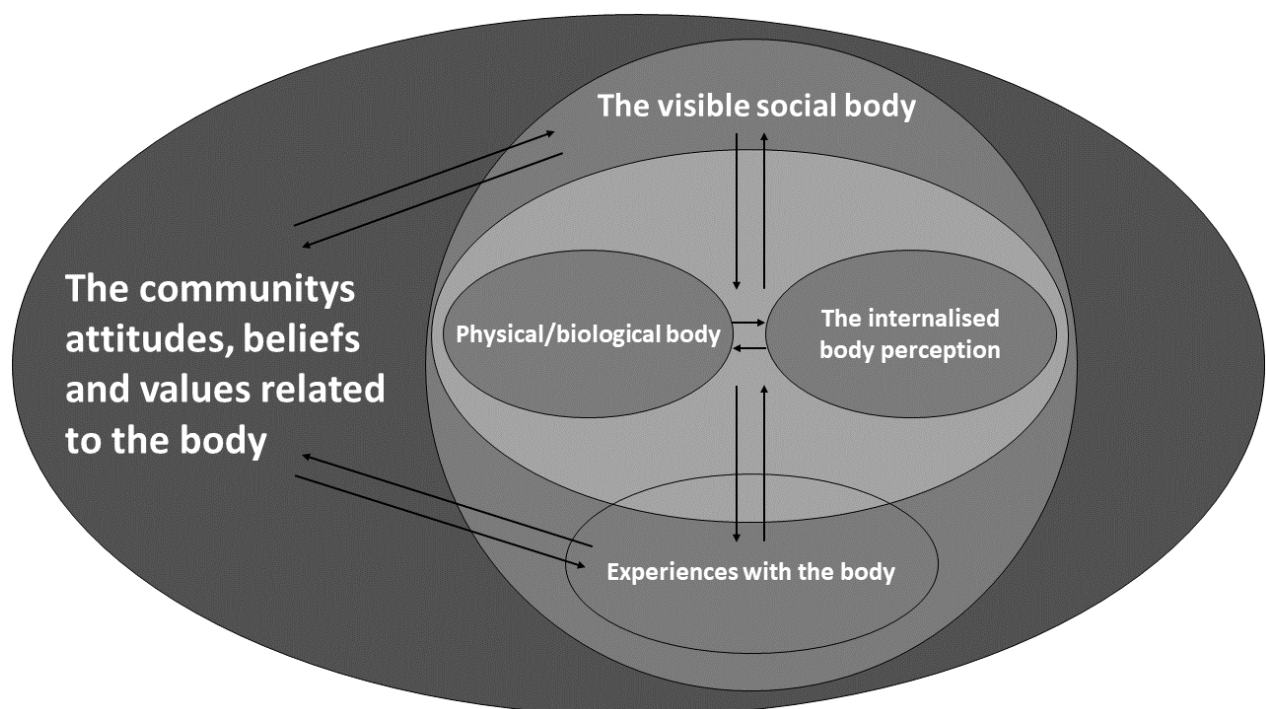
1. The experience and meaning of symptoms are coded in the mother tongue - use an interpreter to understand their social context.
2. All roads lead to pain. Pain is a clinical end-point. What is interesting clinically is the individual patient's roads to pain. There can be many concurrent but clinically independent pains. Separate them out.
3. Do not minimise symptoms or experiences based on your own values. Begin with the patient's perception regardless of your own attitude.
4. All symptoms have a source and a significance. Patients describe what they feel. Some patients are good at describing it, while others are less able to do so. In any event, it is your task to create clarity and make sense of the symptoms together with the patient.
5. Most often, patients have common illnesses, but unbroken language barriers and a lack of diagnostic diligence make them 'exotic'. Avoid confusing yourself: use an interpreter and use your true professional curiosity.



5. Pain, symptoms and somatisation in a cross-cultural perspective

People have three interconnected body universes: the individual, physical biological body given at birth; the psychological, internalised body perception; and the social body that is shaped by the society in which one grows up. The social body is key to body perception. It frames the perception of physical symptoms and psychological processes, their social function, and the consequences they have or may have for the individual (and secondarily, for the family and relatives). The social body is governed by one's environment: pain, appearance, clothes, attitudes, illness, health, and beauty ideals. Pain, however, occurs primarily in the individual body. From a physiological viewpoint, pain signals tissue damage or physiological malfunction. Pain is felt when harmful internal or external substances affect nerve endings. Because it is perceived as a biological phenomenon, pain can be surrounded by ideas that it is unrelated to culture and thus can easily be objectified and even 'corrected' or calibrated depending on cultural factors. Pain is composed of several elements in addition to the immediate involuntary feeling of pain and reflex withdraw reaction. How one expresses the pain, removes the cause of the pain, seeks help to dull or remove the pain, and chooses from whom to seek help depend on social and cultural factors, as does the social significance of the pain. Pain resulting from internal damage is 'private' and requires the person to inform the outside world of it, but many societies deem it unacceptable to openly admit to pain (384). Social norms and a complex decision-making process determine whether the pain should be 'public'. See Figure 13 (385).

Figure 13. The social significance of pain and its complex formation.



Expressions of pain in connection with pelvic floor instability after childbirth, menstruation, or irregular bleeding depend partly on the common conversation topics and paradigms within one's social circle, which Zola already noted in 1966 (386). In many societies, pain is considered a sign of bad luck, a personal weakness, a human failure, or a punishment that must have a sociological cause: *'Why me?'*

What have I done? Is it something my family did? Thus, patients may feel the need for a distressing solution such as self-mutilation or asking the doctor to cut the pain away, or they may seek alternative treatment options outside of biomedicine. Pain is only one type of suffering out of a broader spectrum of misfortune and accidents, all of which entail a type of suffering that requires healing, rituals, buying forgiveness, and fraternisation with evil. Zola found that the perception of pain, its form, and the response it elicits are culturally determined. Some societies expect an extravagant, theatrical, and emotional expression of pain expression whereas other societies value stoic calm, verbal restraint, and underplayed pain expressions. Non-verbal pain expressions also reflect cultural patterns: immobilisation, lack of facial expressions, grimacing, unrest, agitation, grunting, crying, screaming, or specific gestures such as hitting oneself or an object.

Pain can be expressed differently within the same ethnic group depending on whether one lives in the home country or the host country, and first- and second-generation immigrants can have different pain expressions that are often hybrids. The amount of attention one gets depends on how well the pain expression 'matches' the social context in which the patient seeks help. If the mismatch is too great, the patient gets no or only negative attention. The pain connected with birth naturally has a strong cultural significance. In some societies if the mother screams, it is an expression of unfaithfulness, while in other societies the release of heavy pain during delivery is thought to increase the woman's reproductive power; the louder she screams during delivery, the stronger the next child will be (387). Consequently, pain has more than just the immediate and momentary significance measured by health professionals with numbers or happy-unhappy smileys on a visual analogue scale. A pain scoring a high of 10 may in 15 minutes be reduced to 5 when the family comes to visit. In many contexts, however, pain expressions are an investment in strength or social capital or can guard against exclusion or evil forces. Ideas about the organs of the body may also elicit unfamiliar pain expressions. In some societies, the heart fills the entire chest so that any sensation above the navel constitutes heart pain. Rites of passage often involve painful routines where pain is necessary to mark the passage into a new social identity (e.g. child to adult, girl to woman). Publicly visible pain by means of torture, random violence, or summary punishment is part of a dictatorship's identity. Chronic pain differs from acute pain in that acute pain creates immediate contact and reaction with the outside world, whereas chronic pain isolates the person. Chronic pain is something one lives with in private; it is invisible and must be negotiated and constantly renegotiated.

5.1. Pain language

Pain can make us all vulnerable. Even though it may be a demanding task for the nursing staff, it is crucial to take the necessary time to understand the unique ways in which each individual patient is vulnerable. Conversations about pain are complex for several reasons. The conversations are experienced as demanding and frustrating negotiations containing many hidden agendas and factors on the part of the patient as well as the health professional (388). It is hard to appreciate the sufferings of another human being, and pain often results in patients demanding fast solutions: surgery, analgesia. We may get tired, angry, uncommunicative, or silent, or we may shout. No matter the reaction, we are vulnerable, but we also make ourselves vulnerable by displaying signs of weakness, by showing that we have been pushed to the limit and just need some care and a sympathetic response, or merely the symbolic gesture of someone else acknowledging the problem by offering a painkiller and a glass of water.

Very often, people lack words for pain, as it is a feeling that is hidden from others. Hidden feelings can be a strength short-term if one can analyse the pain without interruption (and much of one's mental attention is occupied by pain) but a vulnerability long-term as pain may become more unbelievable the longer it lasts. Pain that is difficult to express in words typically takes longer for the patient to talk about it out loud. Pain appears and is experienced in our consciousness as a reaction to an external influence,

and its significance is worked out in specific social contexts and relations with family, friends, and colleagues (389) (390). The body's unclear danger signals become meaningful and of consequence through conversations with others: *'What does it mean? Is it serious? What should I do about my pain? It is something other people have experienced?'* As American professor of literature, Elaine Scarry wrote in 1985 in her ground-breaking review of various social sufferings, 'So, for the person in pain, so incontestably and unnegotiably present is it that 'having pain' may come to be thought of as the most vibrant example of what it is to 'have certainty', while for the other person it is so elusive that 'hearing about pain' may exist as the primary model of what it is 'to have doubt'.' Scarry believes that pain resists language. Pain actively destroys language and takes the patient back to a pre-language state, to the sounds and cries a human being makes before language is learned - sounds that put the health professional in a difficult dilemma of listening with empathy but without understanding, and then having to measure the 'sound' of the patient's pain (391). A basic ethical dilemma for health professionals is that they lack the necessary communication skills to sufficiently understand the quality and strength of the patient's pain. At the same time, the health professional is expected to provide solutions to the patient's pain relatively quickly. In desperation, the health professional attempts to get the patient to grade the pain with a visual analogue scale from 1-10, but pain is an *appeal* - a cry to the surroundings for recognition and a conversation - not an invitation to assign it a number. The pain cannot be reinterpreted or recoded. It can be described directly, and the description may be nuanced and rendered probable through the narrative about it when 'developed' together with the health professional (392-394). The pain must be assessed based on its function in that it starts mental processes within the listener (the health professional) rather than on its lack of language precision (395). The health professional must be aware that a patient's pain expression elicits thoughts and feelings within the health professional - thoughts and feelings that can influence clinical judgement and the professional interpretation of the patient's expression: *'Can I trust the patient? Is the patient likeable? Is this a pain I know myself? Is the patient a reliable informant?'* (396).

Just as patients experience pain through a hybrid filter of their own experiences, social values, and the others' expectations, doctors perceive the patient's expression of pain through a corresponding hybrid filter composed of knowledge, experience, prejudices, and cognitive bias. If a doctor dislikes the patient and considers the patient to be unreliable and incompetent, then the patient's lack of language precision only seems to confirm that the patient has less pain than they actually have (397). Unfortunately, lack of language precision is worsened by common language barriers and the different functions of pain (398). As Milan Kundera states in his novel *Identity*, 'Pain doesn't listen to reason, it has its own reason, which is not reasonable' (399). People hit by pain are dragged into a land of no language that cuts the person off from external reality (391, 400, 401). People clamour for sense and context, especially when hit by illness and pain, and in reality, we are all just one diagnosis away from our entire existence changing in an instant (143, 402). When people are not assisted in understanding the body's noisy language of pain and making their feelings understandable, they become extremely vulnerable. Health professionals can reduce the vulnerability of patients and citizens by offering themselves as a negotiation partner in the patient's fight with the body in assigning meaning and value to symptoms. Unfortunately, health professionals often misread the patients' existential cries for help as cultural noise and as irritating, irrational patient characteristics that require no further dialogue or professional insight (36). Doctors miss 80 % of the social causes of hospitalisations, and patients who are regarded as strange or difficult are not encouraged to elaborate on their symptoms or the real reason behind their appeal to the healthcare system (403-408).

The dilemma of the health professional is that the patient often has an immediate and hidden reason for seeking help. There are four clinical situations that should raise suspicion that the patient is contacting the healthcare system for a non-biomedical reason. Firstly, some of these patients seem to be unduly affected by their symptoms. Asking the patient what they imagine could be the reason for their

illness might make the visit much more understandable. Secondly, it should raise suspicion if the patient is not looking for a diagnosis, so the question here would be how the patient was hoping to be helped. Thirdly, patients who express dissatisfaction with the help they have received could have been misunderstood concerning their real motivation for seeking help. Fourthly, patients who report in without any changes in their clinical condition should be asked about any current life changes or important social events (409).

To the health professional, the patient's fear of pain is a condition that the patient must learn to live with. The more noise the fear of pain makes in the conversation, the more health professionals are exposed to their own fear of failure and inadequacy (391, 410). In fact, the health professional becomes personally vulnerable when meeting with frightened patients. Patients get scared and have a harder time handling the pain experience if the health professional is visibly uncertain; the health professional gets scared if the patient expresses overwhelming fear of suffering from a serious illness due to pain or other symptoms. The ethical dilemma for the individual health professional is that for practical documentation purposes the healthcare system has defined pain on a scale of 1-10 or as 10 different smileys, but the scale does not help the patient verbally express what the pain is and what the fear of it is. Pain is not a simple mechanical biological phenomenon; it is a complex sociological transaction resulting from a negotiation process with friends and family, and it often ends in a doctor-patient conversation that includes many different aspects and types of information (411).

The language people develop around illness is highly personal; it is acquired from the first time a human being becomes aware of illness at the age of three to four and is expanded upon each time one gets ill, experiences a new symptom, or discovers how to tackle illness (412-416). Language philosopher Wittgenstein showed that as children get older, they learn to substitute the *feeling* of pain with the *word* pain. However, the function and (social) meaning of the word is coded early in childhood before language acquisition seriously sets in, and it depends on the reaction of parents/the environment and the support we get in managing the pain experience. We learn how to have a stomach ache before we learn how to say 'stomach'; we learn the feelings of being sad and afraid long before we can put them into words (417). The language of pain is imprecise, almost chaotic, and it is closely linked to fear and physical discomfort, but we learn it only gradually (418). Patients need time and stillness to translate the internal chaos into a controlled and socially acceptable adult language and thus garner the respect of the health professional and recognition of the symptom. It is important for patients to have witnesses to their pain and loss of function, primarily among friends and family and secondarily within the healthcare system (390, 419-422). Health professionals are witnesses to the patients' pain but not always in the same soothing manner as co-patients and relatives are (423). The pivotal point as a witness is whether you are an attentive or inattentive witness, as psychiatrist Judith Hermann writes in her book *Trauma and Recovery* about victim and witness roles:

Witnesses, as well as victims, are subject to the dialectic of trauma. It is difficult for an observer to remain clear-headed and calm, to see more than a few fragments of the picture at one time, to retain all the pieces, and to fit them together. It is even more difficult to find a language that conveys fully and persuasively what one has seen. Those who attempt to describe the atrocities that they have witnessed also risk their own credibility. To speak publicly about one's knowledge of atrocities is to invite the stigma that attaches to victims (424).

The patient and the health professional who witnesses the patient's trauma history both risk having suspicion thrown at them, being considered untrustworthy, or being stigmatised. When you as an employee of the healthcare system offer yourself as a witness, you silently risk listening to a story that can have serious consequences both for the patient and for yourself as a professional. You cannot delete a story once you have heard it. The question is how you will perceive and act on the story as a professional because a regard for patient as well as your own credibility is at stake. Nurses who inflict pain on patients may end up in an ethical dilemma because the pain they inflict may be considered poor care or

lack of technical know-how, and the result is that health professionals may doubt the quality of their own professionalism (425). Prejudices and the requirements of professional objectivity (e.g. the visual pain scale from 1-10, nutrition scores, body mass index, or suicide screening) prevent the health professional from recognising the pain-relieving effect of listening. On the other hand, a good patient conversation - where the patient feels the engagement of an empathetic doctor, the patient is invited to share thoughts and feelings, and the doctor frequently asks for the patient's assessments of the options (426, 427) - is like good music. It soothes and influences other mental functions such as language and mobility, and it gives rewards and dependency - the brain wakes up and wants more (428-431). People tend to seek further contact with those whose voices are familiar and with whom they associate something pleasant (432). Areas of the brain that are connected with chronic pain are also closely connected to areas of the brain that regulate rewards, and thus the coupling between a pleasant conversation (partner) and pain reduction is more probable (433).

A noteworthy study from 2016 entitled 'Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites' found that half of the doctors believed that Afro-Americans had thicker skin than white Americans and were therefore able to withstand more pain. The more the doctors believed the false assumptions, the more they adjusted (reduced) their assessments of pain in Afro-American patients, and the more they deviated from standard pain management (434).

The 2003 ground-breaking article 'The Unequal Burden of Pain' describes inequality in pain management within the healthcare system (85). Inequality exists in how health professionals perceive the significance of pain to the patient, how patients are objectified through measurement, and how patients are treated in all clinical contexts (surgery, acute care, palliative care, chronic pain care). This inequality applies to all types of pain and seems to have multiple causes: communication, bias, prejudice, generalisations, opaque clinical decision processes, access to pain management, and different approaches to professionalism. Despite the overwhelming evidence, the same pattern was found six years later in an article on ethnic disparities in pain management (435). The consistent barrier lies in the doctor-patient relationship: patients with language barriers experience a less empathetic response from the doctor and fewer good relations, they get less information, and they are less involved in mutual decision-making (436). Pain does not descend from Heaven, nor does it emerge out of nowhere. Pain appears and is experienced in our consciousness as a reaction, and the significance of it is worked out in specific social contexts and relations with family, friends, and colleagues (389). But just as incontestable and unnegotiable it is for the person in pain to 'have pain', just as elusive is it for another person (such as a doctor) to 'hear about the pain' (437).

Generally, there are many factors that create asymmetry in the doctor-patient communication about pain (Table 14):

Table 14. Common barriers between doctors and patients in understanding pain.

Based in part on experiences from the MHC (411).

Patients: 'Why don't they tell it like it is?'	Doctors: 'Why don't they hear it like it is?'
Lack of ability to express or communicate the pain	Preferences for other and more 'objective' measuring methods than the patient's own
Fear of expressing an unwanted worsening of a condition or illness	The doctor's institutional insensitivity

Fear of more unpleasant treatment or taking on a 'pathetic patient role'	Personal attitudes towards pain
Needing to get/maintain control over the illness	Lack of empathy or sympathy
Playing a culturally acquired role	Personal nuances/preferences
Experienced loss of self-care/loss of control	Bias, stereotypes, preconceived ideas
Experienced scepticism/rejection on the part of the doctor	Incompetence, poor clinical judgement, antipathies, clear value formulation
Afraid of the doctor, experiences with derogatory interaction style, lack of recognition	Lacking awareness of own (doctor's) role Conscious intimidating style
Conscious attempt to cheat to obtain treatment	Critical evaluation, clinical overview, and objectivity
Mental health problems or illnesses that affect memory and how symptoms are experienced	Lack of knowledge about pain and mental disorders
The doctor's questions do not help (or no questions are asked)	A 'shutting down' style of interaction or conversation The patient is regarded as poorly educated/from low social strata and is not invited into a dialogue
Cultural differences in how pain is expressed	Doctors' cultural preconceptions: 'Blacks have thicker skin, so they can withstand more'

Every society has its own expressions and concepts of grief, pain, and misery. In a society where emotional outbreaks, psychological problems, depressive thoughts, anxiety, and guilt are not socially acceptable in the public sphere, they may be substituted by physical expressions to attain contact and recognition (439, 440). But how the unacceptable feelings and thoughts are somatised, and the degree to which they are accepted, vary from society to society (441). Physical pain with a psychological basis is acceptable in places like China, whereas in the Western European healthcare system the somatisation of feelings is regarded as an expression that patients lack psychological insight (low level of metallisation) or are unable to intellectualise or verbalise their feelings (442). In Mediterranean countries, the phenomenon is totally different: in societies that are much more explicitly physical in everyday interactions and where body language says more than verbal communication, it is quite normal to express psychological problems as physical phenomena (443). In most societies, the body and the soul are not as sharply separated as they are in the Western scientific understanding of health, and in those societies, it is natural for the entire body to communicate physical symptoms (444). Pain can be a cry for help for women who live in societies where they are mostly the ones who help others. In such cases, pain may also be a physical expression of a mental need for relief. Turkish women in Denmark called it 'tightness', while Iranian women in Turkey call it 'heart discomfort' (445, 446). Pain may be regarded as a catalogue or an index of illness, as a symbolic expression of a psychological conflict, as a specific psychopathology, as an imprecise expression of discomfort, as a metaphor for an experience, as a positioning in the social network, or as a form of social protest/commentary (447). Most patients, however, would probably consider this an over-interpretation - patients just want to get help and attention in the way they have learned gets the best result (448).

Kipling syndrome is an expression professionals use to describe when there is too much focus on cultural differences while power differences and the importance of prejudice and ignorance in the doctor-patient relationship are ignored (449). The expression is based on the quote from the author Rudyard Kipling: 'East is East, and West is West, and never the twain shall meet.' When the power relationship between patient and therapist is trivialised or made invisible and there is excessive focus on cultural differences (and excessive requirements of cultural competencies), employees in the health services begin to doubt their own professional competencies, which then get replaced with inappropriate prejudices and generalisations about pain (450). Culture sensitivity is about competencies in seeing/hearing when and where cultural differences are important in the course of illness. Health professionals also need to know about differences and similarities - thus they need to know their own pain culture (451). Many employees in the healthcare system are liable to think that culture is irrelevant social 'noise' brought along by patients. Doctors and nurses are most comfortable with grateful, pain-free patients; when patients complain loudly of their pain, it might be interpreted as an expression of the staff's professional insufficiency. Staff feel powerless when encountering a patient who expresses physical pain through sounds rather than precise language or the pain scale. Animals make sounds, but humans verbalise. The patient with pain elicits emotions in the health professional as an animal at the subjective mercy of emotions (410). Stereotypes are frequently applied by the health professional when pain is accompanied by too much sound or the wrong sound.

Marie Louise Tørring examined pain management and ethnicity in Italy and Denmark and found many similarities in the way patients were generalised: 'typical woman', 'whiner', 'old', 'teen-ager', 'emotionally charged', 'strange', 'hysterical', 'spoiled', 'third-degree burn', 'drug addict' (452). Objectification, indifference, and alienation are spiced with subtle frowning or direct rebuke when the staff feel that the patient has played up or dramatised the pain. Tørring notes:

The doctors let interpretation of pain-behaviour be part of a certain knowledge hierarchy about the patient's physical and mental condition and socio-cultural background. A frequent pain interpretation concerned the scope or degree of bodily injury. The therapists used their knowledge of third-degree burns inconsistently and ambivalently (452).

In some cases, the doctors lauded the patient for their pain endurance, and in other cases they hushed patients whom they considered to be hysterical Southern Italians (*'The further south you go, the more they wail,'* as one doctor said.) The Italian burns specialist explained to Tørring that pain evaluation was only necessary in Northern Europe because the patients do not scream when they hurt, whereas Italian patients express themselves clearly. The Danish burns specialist felt the opposite - that you had to assess the pain using an objective scale because as a doctor you cannot feel another person's pain. In reality, however, anthropologist Tørring noticed that the employees, in direct contravention of the objective intention, applied the pain scale with the patient to negotiate the pain intensity downwards by putting words into the patient's mouth. Tørring explains that therapists do not have a neutral view of the pain but recognise the patient's pain by using their own material and relating it to the context of which the patient is a part. The doctor can only understand the patient's pain by understanding it as a first-hand impression that covers a broad section of material such as childhood memories, life situations, cultural expectations, myths, definitions, observed emotions, the physiology of the musculoskeletal system, and so on. In order to interpret, explain, or understand another person's feelings, the doctor automatically links to this material, and this is the process that constructs an understandable and meaningful model for the patient's experience at the doctor. This way of understanding pain is called sympathy, a knowing compassion rather than the indiscriminate compassion contained in the concept of empathy. The same criticism may be directed at the doctor's idea of the (objective) clinical view. Doctors do not have a neutral view of the pain but recognise patients' pain by using their own experiences and knowledge and their own material and relating this to the context and the circumstances from which the patient and the pain come. Doctors have greater empathy/understanding of the pain experienced by a patient who belongs

to the same social group or the same ethnic group as themselves (453, 454). While we are deeply and empathetically engaged in listening, soothing, and relieving discomfort in our own social group, research indicates that only perverse pleasure is felt toward the pain experienced by members of other social groups (455). To protect themselves and to hide a threatening professional 'failure', the doctor is capable of making a conscious empathy disconnect (456-458). This can happen when the therapist encounters a patient who:

1. fails to respond to the pain management promised or expected
2. fails to remain in the patient role
3. develops complications
4. is unlikeable
5. is boring
6. has few characteristics in common with the doctor
7. has low compliance

Unfortunately, a patient's pain is not formed solely by experiences and socially acceptable expressions of pain. The patient's pain experience becomes increasingly influenced by medical devices, equipment, drugs, guidelines, and paradigms, which often pose additional 'communication' challenges to refugees/immigrants.

Pain expression and pain understanding require mutual insight and negotiation. This may require the doctor to accept unfamiliar pain expressions and meanings, and the patient to change their concept of the connection between pain, body, and psyche. People are not very inclined to accept changes in their perception of reality, however, as that would entail unacceptable ambiguity and uncertainty, which ultimately leads to anxiety (459). Frames of understanding are like toothbrushes - everyone has their own, and it is completely unthinkable to use someone else's toothbrush. Pain does not have the same function for the sadist as it does for the masochist. Pain expressions in connection with childbirth have strong cultural ties. In some ethnic groups, it is proof of unfaithfulness if the mother screams during the delivery, especially if it is the mother-in-law and sisters-in-law who attend to the birth, whereas in other ethnic groups the pregnant woman is expected to clearly express her pain to show that she is fighting for her child as a good mother. Many reactions to pain have equal value: silence, withdrawal, weeping, shouting, rationalising, emotional distress, anger, change of tone, and panic. Believing that pain is only expressed in one way leads to incorrect management. Illnesses are surrounded by undesirable metaphors that worsen and extend the pain (and in some cases, make it chronic). When we say that pain is evil, it is a primary metaphor that creates a string of secondary metaphors: you have to fight pain, pain is like knives, pain attacks, we have cutting pain, and pain needs to be knocked down. When we say *knife*, we get an image of a dangerous, sharp weapon as well as an accompanying known type of pain. We absorb our metaphors, and they shape our pain perception and the doctor's handling of the patient. The primary metaphor pulls a string of secondary metaphors that slowly get internalised while making us weaker, more vulnerable, and more pain-ridden. Other metaphors objectify and create helplessness: one 'goes under the knife' or 'the surgeon cuts out the bad part'. The pharmaceutical industry is thrilled with our war metaphors about 'fighting illnesses', 'breaking the fever', 'protecting yourself against' infections, and 'the fight against' cancer (169). The anthropologist Clifford Geertz said, 'the problem of suffering is, paradoxically, not how to avoid suffering but how to suffer, how to make of physical pain, personal loss, worldly defeat, or the helpless contemplation of others' agony something bearable, supportable - something as we say, sufferable.' (460). In 1934, Dr. Gordon wrote in the medical journal *Canadian Medical Association Journal*:

There is no royal road to this knowledge, but patience, perseverance, and observation will carry us far along the two rails of honesty and kindness. There is one method, which will certainly fail. We cannot enter the mind of another by burglary, and the method of the third

degree or of mental burglary is not the means of access. An invitation to you as a friend is much more satisfactory than a visit as a police officer ... (1350)

All patients are informants, but some patients are better informants than others. How good an informant the patient is depends on how good the doctor is at bringing out the patient's perspective and experiences using the patient's own words. All humans are rational according to their own terms. It is the doctor's ability to uncover these terms that turns patients into 'good informants'.

In his book on the traumatised refugee, Peter Elsass describes the potential in the often overlooked extra therapeutic space (461). You lose a therapeutic option when the patient desperately seeks an explanation in the family and the life story, but the therapist sticks to the individual approach, 'Often, it is some very specific circumstances like a death in the family, the dissolution of a marriage, political changes in the home country, which the therapist fails to notice.' In this way the therapist fails to understand the pain according to the patient's system of significance and thereby loses a therapeutic entry into, for example, pain management.

There are many concepts in Danish that describe the pain experience: sore, throbbing, shooting, burning, deep, hidden, stinging, electric, knifelike, stabbing, smouldering. Common language characteristics of pain descriptions have been identified across a variety of languages (462). Verbs are used that describe: 1) physical action and the destruction of the structure of the object by means of tools: shoot, cut, scratch, prick, stab, drill through, hammer, 2) destruction of the structure of the object by hand: scratch, squeeze, hurt, hit, 3) soft deformation of the object: pressure, gnaw, dilate, spin, grow, make numb, tighten, 4) verbs that designate fire: burning, flaming, and 5) descriptors of motion: swimming in, being pursued/plagued by pain. The metaphors the patient uses depend on the feeling of causation that is connected to the pain, i.e. whether the person feels the pain as a result of an external influence or whether it is an organ that is behaving abnormally/strangely. Externally induced pain gets described by externally induced metaphors (stab, cut, burn, etc.), whereas pain stemming from an organ that is behaving abnormally is described by metaphors where the organ becomes the active part (sound, dilate, grow, move, pressure). The degree to which metaphors are used in different languages and in different social strata varies widely. However, metaphors allow an opportunity for equality and creative interactions within the communication between doctors and patients. The significance of metaphors lies not in their representation, but rather in how they represent actions and life approaches. A conversation about the significance of a metaphor may expose or narrow the contrast between the patient's basically irrational illness experience and the doctor's despairing assumption of a sort of rationality in the patient's illness experience.

Doctors see pain primarily as a physiological phenomenon, whereas social scientists believe that socio-cultural and psychological factors play an equally important role in the pain experience and how people react to it. Beecher was one of the first doctors to show that the significance of pain influenced the perception of and the reaction to pain (463). He found that despite clearly serious tissue damage, soldiers wounded during WWII had conspicuously little pain in connection with their injuries. He noted that the wounded men were not in shock and that their strong pain expression when a drip was inserted indicated that they were totally capable of feeling pain in other parts of the body. The wounds of the battlefield were numb, but wounds from the hospital resulted in pain. Beecher concluded that the soldiers did not feel the pain from their wounds because their perception was influenced by the advantages they expected to gain by leaving a life-threatening existence in the trenches of the battlefield.

A widespread, but incorrect, idea exists among laymen, medical students, and interns that there are biological differences between refugees/immigrants and Western Europeans. This idea indicates the existence of ethnic discrimination in the assessment of the patient's pain perception and consequently in the pain management provided. Studies have shown that 50 % of medical students and interns have

an idea that black Americans 'have thicker skin' than white Americans. When following up on their actual clinical behaviour, it was found that doctors who had this misconception unknowingly rated the pain intensity lower for black patients than for white patients (464).

1. Pain as a social construct

The concept of 'ethnic pain' is frequently applied by doctors in clinical contexts, although often indiscriminately and unthinkingly with the danger of compromising patient safety (36, 465, 466). 'Ethnic pain' is not a distinct and well-defined pain with its own diagnosis code or well-described pathology; it mostly serves in day-to-day life to relieve the doctor of diagnostic responsibility. In reality, it is a generalisation of unexplained pain in patients with brown eyes, scarves, and accents. If you as a doctor indiscriminately accept your own ethnic standpoint and personal values as the measuring stick of the world, then a blind spot will emerge. This blind spot becomes a measure for everything - the mind-set behind the concept of 'normal' pain (as opposed to so-called 'ethnic' pain) is the same mind-set that believes in the existence of a 'normal' race that is biomedically and behaviourally rational. No humans are without ethnicity, however. No humans have grown up without cultural values and social experiences of pain. Every human being has ethnic pain, if you have to use this odd mind-set. The Italians think Danes are strange because they do not clearly express their pain. African doctors think Danish patients are difficult because they lie completely still even when they are in pain. The concept of ethnic pain is mostly an expression of professional insufficiency - some might add that it is an expression of cross-cultural laziness, but how did it get to the point where doctors make a diagnosis whose only characteristic is that it lacks cause, pathology, symptoms, and treatment?

Generally speaking, it is hard to describe symptoms. One learns how to vomit, have an earache, or cut oneself with a knife at the age of three or four years old. Illnesses and symptoms are experienced as feelings and are stored in a language that is still very imprecise. Yet, it is the same language that gets used when one as an adult has to describe transient, unclear but dangerous symptoms. Something gets lost in the precision when one has to describe symptoms in words. As one patient said, *'My pain has no words, so it doesn't need any interpreter.'* It is challenging to set precise words on vague feelings and unfamiliar pain. Authors and painters make a living describing what most people cannot personally describe in words - most patients are not a modern Shakespeare or Picasso and have to wrestle with the frustration of seeing themselves reduce complex feelings into crude linguistic stick figures for the doctor. How can a life-long disorder be described in a few words? When words cannot be found, a scream, cry, whimper, snap, or hiss may be closer to what one feels than our inadequate language. Maybe a panic reaction, an affective reaction, or desperate gesticulation is closer to the pain than the doctor's visual analogue scale with the idiotically simplistic, irritating yellow smileys. To make matters worse, the doctor starts going into detail, *'Is it murmuring, throbbing, buzzing, pricking, burning, or cutting? Is it a soreness or a pain?'* Soreness does not exist in many languages and needs to be negotiated, but who decides what soreness is called in Somali? Symptoms and their values are coded during childhood in a different kind of language than the adult language. Patients are speaking in an adult language about symptoms and feelings that have been encoded at the age of three years old - and in a foreign language - via an interpreter.

Many people would like to oversimplify conversations with immigrant patients as culture clashes, but in truth, the clash lies between routines and rituals that do not mix. Who decides what routines are valid in the doctor-patient communication? We let ourselves be influenced by the unfamiliar ways of expressing and understanding pain, and our methods for handling these are often to label the patient's symptoms as strange, alienate the patient, objectify the complaints of pain, automatically subtract an 'ethnic factor' when we have to assess how bad the pain is, and refer to it as *ethnic pain*. There are many differential diagnoses for ethnic pain, but they very likely cover the same need for distancing on the part

of the health professional. Over time, they have been described in highly stigmatising ways, such as those shown in Table 15.

Table 15. Stigmatising names for illnesses.

<ul style="list-style-type: none"> • Nostalgia syndrome • Rootlessness syndrome • Homesickness syndrome • Guest worker syndrome • Foreigner's stomach syndrome • Mediterranean syndrome • Bosporus syndrome • Mama mia syndrome 	<ul style="list-style-type: none"> • Spaghetti deficiency syndrome • Bibi-itis • Ethnic pain • Ethnic pain style • Culturally expressed symptoms • Cultural pain syndrome • Certificate illness
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Already in 1984, Gretty Mirdal attempted to stop this stigmatising style of 'diagnosis' without much success (467, 468). The use of humiliating patient descriptions is still a huge problem, as noted by the English doctor Ali Fizzah in a 2020 article in the *British Medical Journal*; he described the term 'Bibi-itis', which supposedly designated a middle-aged Asian woman with exaggerated subjective complaints, backed up by few objective findings. (469). This is a dangerous (and contagious) trend of clinical stereotyping about the causality of illnesses. Fizzah describes examples of patients who were referred due to suspected culturally conditioned functional symptoms, which in one case turned out to be a spinal tumour while another patient went on to develop Guillain-Barré syndrome.

In a very readable classic from 1952, Zborowski analyses the pain expression of four distinct US ethnic groups (470, 471): the Jewish patient, the Italian patient, the Irish patient, and the 'Yankee' patient, also termed 'the old American' (in the terminology of the day, this referred to a white protestant patient whose grandparents grew up in the USA). An individual of the latter group was regarded as a 'neutral' pain patient, a 'patient you could understand' and which constituted the majority among the patients. At first, the doctors were asked to describe the pain management of each patient type:

- **Irish style** ('Can handle much pain,' no feelings, high pain threshold)
- **Italian style** ('Exaggerates pain,' full of feelings, low pain threshold, easy to satisfy)
- **Jewish style** ('Exaggerates pain,' full of feelings, low pain threshold, hard to satisfy)
- **Old American style** (protestant, white) ('Majority pain expression,' neutral expression!)

The doctors admitted that they would always unofficially subtract an ethnic factor when they recorded the patients' pain statements in the medical records - regardless of the ethnicity (unless they were *old Americans*). Zborowski then interviewed a large number of patients about pain:

- **Jewish patient:** A more forward and significance-oriented experience of pain, pessimistic attitude, the doctor does not know everything, provokes worry and care in their social network by describing the pain clearly. Sound level does not express pain intensity, but it creates an atmosphere and a necessity to focus on the cause/pathology, i.e. fast and effective treatment. Very worried about a future with pain, distrusts help and pills. The male role less expressed at the hospital. Uneasy at the hospital.
- **Italian patient:** A here-and-now experience of pain, uses the illness to provoke sympathy in their social circle, is not ashamed of attracting and getting attention. Not very sceptical or worried as long as they get help. The male role is very expressed at the hospital (postures). Uneasy at the hospital.

- **Old American patient:** No reason to cry or groan loudly, wants to cooperate, plays the role of an objective informant who calmly describes the location, type, frequency, and intensity of the pain through words. Admits to crying and groaning outside of the healthcare system. More optimistic of possible healing. Mechanistic attitude towards the body: get it fixed. Leaves it to the professionals to apply their know-how. The pain lessens with the number of examinations, blood tests, doctors, and injections. Would like to go to the hospital - the hospital takes away the pain.
- **Irish patient:** Considered to be a more stoic and persistent version of old Americans, but otherwise resembles them.

Zborowski found that uniform reactions to pain in different ethnic groups do not reflect the same attitude towards pain. Uniform reactions to pain in different ethnic groups have different functions and purposes in different cultures. The variation in pain perception within the same ethnic group is due to age, gender, education level, socio-economic factors, and degree of religiosity. Work function and future outlook also play a key role (e.g. the significance of spinal osteoarthritis depends on whether one is an office worker or a steel worker). Finally, he found that pain management is learned at an early age; as a child you learn to scream loudly when you are hurt, or you learn to shut up and bottle up the pain. He found no discernible difference in pain intensity, but wide ethnic differences in experienced fear in connection with pain and wide differences in the background and intention of putting a clear sound on the pain experience. Both the Irish and old American patients admitted that outside of the hospital they could put sound to the pain and get the entire family to provide sympathy and care. Over time, the Italian and Jewish patients adapted their pain experience to the 'Yankee' model.

In 1966, the sociologist Zola showed that ethnic differences in pain and pain management were mostly a reflection of the social differences regarding what makes a patient go to the doctor and what they handle in other ways (386). It is not the believed aetiology that guides behaviour, but the acquired social patterns. He showed, for example, that Irish Americans described pain/irritation in the ear-nose-throat area as a specific and limited dysfunction of that area, whereas Italian Americans described a diffuse general dysfunction without attempting to limit it to an organ or an area. The Irish were less irritated by localised pain, whereas Italians felt more irritated. The Irish tried to tone down or deny their condition, whereas the Italians accepted and embraced the illness. Overall, for the same condition, the Italians had more symptoms and dysfunctions and a larger part of their body was involved when compared to the Irish Americans. A detailed study from 1984 compared five ethnic groups in the USA. Using the concepts of the time, it was found that their pain experience was the same, but the factors influencing the experience varied widely (472). For black Americans it was the degree of 'biomedical acculturation', for Irish patients it was the degree of social assimilation, for Italian patients it was the duration of the pain, and for Jewish and Puerto Rican patients it was the degree of accompanying mental stress. Across the ethnicities, it seems that the degree of acquired 'catastrophe thinking' mediates a (small) part of the ethnic differences (473). Ethnic differences have also been shown in terms of *Locus of Control*, i.e. the self-experienced degree and type of control you have over any situation or illness (474). Ethnic differences also exist in how inclined one is to accept that somatic symptoms are expressions of a basic depression and which somatic symptoms are expressed in a depression. All ethnicities have somatic components in a depression, but these components differ (475).

In a study of ethnic differences in symptom presentation in the case of AMI (acute myocardial infarction), no ethnic differences in pain intensity were seen. However, large ethnic differences existed in which symptoms received most attention and the level of anxiety connected to the pain. The pain was identical, but some people were more afraid of the pain than others, and school education was a considerable anxiety-modifying factor (476). The balance between the various characteristic symptoms of AMI varied according to ethnicity. For example, ethnic minorities had 50 % less chance of mentioning chest

pains when hospitalised for AMI (477). Some ethnic groups express themselves more in pain terms, while others focus on shortness of breath, and yet others primarily refer to chest pressure. Patients who express symptoms differently or with a different focus than we do are perceived as different. It is the same illness and the same experience, but with different cultural focus on the individual symptoms. Algorithms and guidelines have been compiled for the Yankee model, but it fails with other patients. Other studies indicate that ethnic characteristics of pain expression get regulated up or down depending on the patients' experiences and needs (164).

New studies have shown how the pattern of pain handling as adults is established in childhood (478, 479). Negative experiences during childhood lead to bad sleep, lower mood level, and increased pain experience as an adult. (480). Patients with no resilience let the pain win - the pain filled the whole day and took over all activity. In contrast, optimism and a feeling of some degree of control increased patients' resilience. The source, experience, and resulting treatment of pain depend on the person's life story, negative experiences, and resilience. What we perceive as 'ethnic pain' is in reality the long-term effect of traumatic experiences during childhood. Vulnerability and resilience factors may help explain the connection between early hardship and future pain symptomatology. However, with the social and legal tightening of rules concerning refugees, mediators such as optimism and a feeling of control become more important in the pain experience. Doctors should be aware of the undesirable but close link between childhood trauma, loss of control in adulthood, and pain management. To the doctor, the pain appears as somatisation or as 'ethnic pain'. When seen in a *life course perspective*, however, they make sense, and the life story can assist in giving the pain a meaning the patient can live with. By way of example, Swedish researchers have found that Iraqi refugee women connect their pain directly to dependency upon the society, authorities, and family. Due to a discontinuity in the healthcare system, they experience having to repeatedly describe their trauma and explain their symptoms whereby the healthcare system becomes a pain-maintaining rather than a healing function (481).

Immigrant patients and their relatives often find dealing with hospital departments to be a challenge. They should not have to consider the context. If you grow up as child number six out of eight, you learn already at the age of two or three to fight loudly for your rights. Popular ideas that you have to and should care for the sick can put social pressure on relatives, 'What will people say if we do not show up to support Uncle Ahmed in the hospital?' You are a bad person if you do not help the sick, and bad people are expelled and do not go to Paradise. As a human being, you are given your body as a gift from God, and you have to take care of and protect it - and do so visibly. You are a bad person if you cannot protect your body against pain. Maybe there is a valid fear of not getting the help you expect, which may increase the pain experience, or you may have experienced that you do not get anything unless you do it yourself. These are common human reactions to broad social requirements. Finally, a culture may exist among male relatives that 'if it works, it works.' People are pushing to get help, demanding examinations and treatments, and authorities are challenged - until the personnel establish frameworks and rules (often too late). Most of the conflicts in hospitals are actually not based on cross-cultural conflicts, but on intra-cultural disagreements concerning patient understandings, inclusion of relatives, communication style, and development of relationships. Uncertainty on the part of health professionals is quickly interpreted by the relatives as ambiguity and a lack of rules.

Somalis became ill when they arrived in Denmark at the end of the 1980s and the start of the 1990s. The weather was cold; it was dark and always foggy. A bad mood combined with shoulder, neck, and lower back pains was called *Boofis*, which meant a combination of grief, myths, and muscle pain that no one could do anything about. *Boofis* also means a hard inflated balloon just before it bursts. An Afghan patient with muscle pain and a headache got tired of the Danish healthcare system and sought help at a private hospital in Teheran using 10,000 DKK that she had partly saved up and partly borrowed. The money only covered an X-ray of her skull. The doctor evaluated the image and gave her a

prescription for an injection with the diagnosis: 'Danish illness', i.e. the pain immigrants get in Denmark due to the cold air and the hostile feelings towards immigrants.

In other words, we are all 'ethnic'; we all have pain, but its significance, how afraid we are of it, the idea of what help we get, and the future outlook for pain are encoded early in our language-cultural world. Everybody has ethnic pain and thus, the concept is meaningless in a clinical context. Ambiguity and uncertainty are something we as health professionals introduce - by being ambiguous and uncertain. Drop the reluctance to deal with it. Be curious and ask.

2. Approach

Inadequate knowledge of anatomy and bodily functions, together with traditional perceptions of pain (e.g. magic, curse, punishment), has a significant impact on the diagnosis of pain among migrants. The pain experience is often considered very holistic in that it relates to the whole body rather than being limited to a certain part of the body. Over time, limited access to psychologically adapted treatment often leads to diffuse pain. The ailing body expresses its condition in broad and complex terms - social, collective, economic, related to the migration history, psychological, and cultural - which the doctor has difficulty translating into diagnosis and treatment. An individualised multi-disciplinary and culture-sensitive approach, preferably at a reduced pace and with less emphasis on biomedical details, is necessary for effective pain management of patients with a traditional background. Try to create a framework in which the patients themselves are allowed to explain their terms and experiences through their life story and accompanying narratives (482).

It is important to professionally witness the pain and seek an appropriate way to recognise its significance to the patient. For example, it is effective to categorise pain in other ways than the visual analogue scale of numbers or smileys. Instead, try to get the patient to assign their own number, or concept, to the pain to achieve a patient-defined starting point. Another strategy would be to help the patient divide the body into parts - a virtual 'CT scanner' where you review the body in layers and describe the pain in that layer. Try to downplay irritation with the way the pain is expressed and instead focus on its origin, meaning, and function for the individual patient. This approach provides more clinical options - and more ways out for the patient, not only in terms of understanding but also in relation to the patient's surroundings. After having attempted to treat 10 patients from the MHC, a pain specialist stated, *'Even if we made them pain-free, they wouldn't feel it.'* The goal is not freedom from pain, but freedom from the pain of having such agonising, unexplained pain. The main task is to help patients understand their pain and learn how to get a little better at dealing with it.

Attempts at generalisations, stereotyping, or downplaying based on the false notion that there are particular 'ethnic' pains with an over-dramatised expression only contribute to the creation of just that: dramatic patients (483). We are all 'ethnic', and we express pain that could be perceived as deviant in another society or foreign social context. Ethnic pain does not make clinical sense other than being an expression of intellectual laziness, ethnocentrism, and professional inadequacy.

5.2. Culture-borne syndromes

1. Meaning systems and views of humanity

Our human and world-views blend philosophy, religion, politics, and experience and are shaped through social networks. Our values, attitudes, and behaviour characterise the way we behave during illness. The culturally borne conditions also involve explanations and decisions about illness and health. The healthcare system has objectivity as a basic value, and this has traditionally implied that patients' cultural significance systems can be perceived as disruptive to the doctor's clinical decision-making processes.

In Western medicine, the patient's culturally embedded framework of understanding is ignored. Health in the West equals being free of symptoms. Individuals are responsible for their lifestyle and thus their health. From a non-Western perspective, health is a harmonious balance in the person (body and soul) and relates to living, absent, and deceased family members - often also in relation to nature and more spiritual relationships. In a non-Western context, mental health is part of the holistic perspective and represents a harmonious balance in the relationship between the individual and the entire outside world. In the West, mental health is the individual's ability to adapt to the majority and the social/cultural reality. In non-Western understanding, there may be religious significances to illness, such as illness is an ordeal from God or an expression of God's will. Illness can be a sign of disorder in bodily fluids or in social relationships, and illness can be evil spirits, evil eyes, or troubled souls of the deceased within the social network or family. Illness, health, resilience, and weakness are often described in distancing or protective metaphors rooted in local and societal conceptual forms.

Only few concepts of illness are universal. Explanatory systems can vary within the same ethnic group and even within the same patient over time and can depend on current and past experience with disease. However, stereotypes, prejudices, and generalisations are frequently used as convenient shortcuts when health professionals have to interpret a foreign perception of *illness*. Stereotypes caricature and freeze iconic images and characteristics, and they label paternalistic immigrant patients as victims of their 'culture', 'religion', and 'traditions'. The individual's illness expression is subject to a (postulated) overarching culturally enforced expression. Prejudices are acquired simplistic attitudes that facilitate categorisation and diagnosis. Generalisations are a way of streamlining diagnostics through a polarisation that positions the patient by force and neutralises sociocultural factors that could bring the patient's individual needs and experiences into play. Finally, ethnocentric delusions of health professionals can impose an imprecise or inappropriate assumption on the patient: immigrant women are 'dependent' on their husbands as a type of personality disorder; unfamiliar expressions of pain turn into 'ethnic pain'; and unexplained symptoms are perceived as 'cultural expressions of functional disorder'. As a group, doctors can have the self-image of being part of a zero culture - and act as such, overlooking the fact that their own values, strengths, weaknesses, and idiosyncrasies affect their style of interaction. This prevents them from understanding symptoms on the patients' terms.

2. Cultural syndromes

At the time of this writing, more than 50 years have passed since culture-bound syndromes were first proposed as illness groups. At that time, mental illness and its related syndromes were very affected by geographical boundaries and delineated socio-cultures. For example, *taijin kyofusho* (extremely severe social phobia) in Japan and *dhat* syndrome (fear of loss of sperm) in India have long been referred to as cultured syndromes in international diagnostic criteria, such as the International Classification of Diseases (ICD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM).

Now it is time, as Ventriglio et al. have proposed, to rethink cultured syndromes. Ventriglio et al. have underscored the irony that 'culture-bound' syndromes are becoming smaller and less culturally rooted and may break traditional boundaries due to intercultural influences (484). This can be directly attributed to globalisation, industrialisation, and urbanisation. Modern society's 'perception of suffering' has changed; cultures no longer remain within their borders but affect and inspire each other, including with regard to new symptoms, and thus hybrid global syndromes (485). Postmenstrual syndrome (PMS) has widely varying symptom expressions in different cultures (in some societies it is not known as a syndrome) and is highly disputed as a culture-bound syndrome (486). Anorexia nervosa is perceived by some as a culture-bound syndrome, along with bulimia. Anorexia and bulimia occur in some communities but not in others (487, 488). While anorexia has a stable prevalence in Western Europe, the incidence of bulimia has decreased (489). Chronic fatigue syndrome is another Western culture-bound syndrome that some, in trying to find a more politically correct term, are now trying to call

Systemic Intolerance to Physical Activity Syndrome - as an umbrella term for patients with chronic, debilitating, and unexplained fatigue (490). In Japan, you now see a pattern they call *hikkiomori* ('modern depression'), depression symptoms that seem inspired by European perceptions (491). In Sweden, an epidemic has been seen among children in asylum centres who develop a Resignation syndrome comparable to a catatonic, depressive, dissociative state without a perception of pain (492).

Over time, post-migration factors contribute to stress maintenance, and the patient may end up in a chronic stress-driven condition that is increasingly characterised by physical symptoms such as chest pain due to muscle tension, tension and turmoil in the body, headaches and muscle tension in the neck and shoulder areas, and severe choking sensations. Other reactions include joint swelling, joint stiffness, muscle soreness/weakness, profuse sweating, digestive problems, a frequent urge to urinate, and sexual dysfunction. The psychological and behavioural symptoms can include aversion, restlessness, irritability, loss of appetite, difficulty sleeping, anxiety, and depression. To varying degrees, patients of their own free will - or when pressured by relatives - develop hybrid explanation models involving *illness* concepts and causes from the homeland, such as the Somali *boofis*, *walli* and *jinni*, the Arab *djinn*, the East African *cenn* who are offended war victims or war spirits, or *kiyang-yang* in Guinea-Bissau in West Africa (493-498). Anthropologists in particular have argued that the mental health problems of refugees should be viewed under a broad umbrella of varying expressions of mentally distressed people (484). Concepts related to mental strain have been explored in various sociocultural contexts and include experiences as diverse as *nervios*, *susto*, *llaki*, *ñakary*, *ihahamuka*, *open mole* and *khyâl attack* (499, 500). The diagnostic system DSM has an appendix with culturally-based syndromes - formerly referred to as 'rare, unclassifiable collective and exotic psychotic syndromes'. Table 16 (468) shows a number of examples of this type of syndrome:

Table 16. Culture-borne syndromes according to the DSM-IV

<ul style="list-style-type: none"> • Amok • Ataque de nervios • Bilis/colera/muina • Bouffée délirante • Brain fag • Dhat • Falling-out/blacking out • Ghost sickness • Hwa-byung 	<ul style="list-style-type: none"> • Koro • Latah • Lokura • Mal de ojo • Nervios • Pibloktoq • Qi-gong psychotic reaction • Rootwork • Sangue dormido 	<ul style="list-style-type: none"> • Shenjing shuairo (neurasthenia) • Shenkui • Shin-byung • Spell • Susto • Taijin yofusho • Zar
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As Mirdal points out, it is striking that the syndromes originate primarily from Latin American, Japanese, and Chinese contexts, probably because these were the countries the authors knew little about. The list is arbitrary, and the eligibility criteria are unclear, just as one could easily supplement the list from virtually all the other countries of the world (467, 468, 501). Mirdal surveyed 75 Turkish women and writes:

The image, the metaphor that Turkish women used to denote their condition, was 'sikinti' Ninety-two percent of the women had somatic grievances and 56 percent complained of sikinti. The word 'sikinti' comes from the Turkish siki = tight or narrow, and it conveys a negative feeling of unease, psychosomatic discomfort, anguish, boredom, and cheerlessness. The emotional correlates of bodily tightening were feelings such as anxiety, sadness, worry, melancholy, irritability, vulnerability, excessive sensitivity, touchiness, etc. The sikinti concept had a third aspect besides the physical and the mental, namely the cultural.

The word communicates a condition that is obvious to all those who speak the Turkish language. It is obvious to everyone that *sikinti* corrodes body and soul, that one becomes vulnerable to all sorts of physical illnesses when one is *sikilmis*, and that *sikinti* can interfere with the rhythm of the heart and the functioning of the stomach (502).

Mirdal sought out the same Turkish women 20 years later (45 of the 75 women) and found that the term 'sikinti' was no longer used so widely but had been replaced by 'stress' in a Danification of their original concept (503). Mirdal goes on to explain why illness concepts can be difficult to translate:

In Arabic, for example, there are approximately 20 different words that denote being possessed by spirits or jinn. For example, jinn is included in the word *mecnun*, which means both in love and mentally ill. Thinking about emotions and disturbances in Arabic implies you automatically 'also think of' jinns and spirits, which of course is not possible in Danish. On the one hand, it is impossible in translation to reproduce the way in which jinns are embedded in the body and in the language, and on the other hand, patients are reluctant to talk to us professionals about these topics. Arabic-speaking patients are not so insensitive than that they cannot perceive that psychologists and psychiatrists in the West have a somewhat strained relationship with spirits. Therefore, it makes no sense to talk about such models of explanation with the psychologist and the doctor, just as one does not so much like to talk about assumptions about being struck by the evil eye or other curses (503).

A common feature of these concepts is that they are multifaceted, whereas the causes and understandings of them are a combination of social, physical, and psychological phenomena. In collaboration with Arabic-speaking health professionals, Kienzler has tried to describe 13 different terms in Syrian Arabic for suffering from psychological strain (379). Misunderstandings can easily arise if you do not have an open-minded dialogue. For example, being 'stressed' in Russian can have the meaning that you are busy, in a good way. Some languages have no term similar to the Danish word 'stress' - either you are normal, or you are crazy ('lost') as was found in a survey of immigrants in England where mental strain was expressed as objective stressors, such as housing conditions, finances, residence permits, or untreated symptoms (43). These patients had observed that interpreters often translated in a stigmatising way by, for example, changing the statement '*I feel depressed*' to '*I feel like I've gone crazy*' in the translation. Somali patients explained that they do not know the 'stress' concept because there are no doctors in Somalia - all of Somalia was stressed as a country (by war), but that was different. If you express depression in Somalia in any way, you are 'crazy' ('mad') or *Wa wa shee* in Somali; you are either crazy or you are normal. Stress, depression, and anxiety make no sense in Somali, and without a mutual dialogue, too much meaning will be lost if one tries to 'force-fully' push the patient into one of these categories. In some Arab cultures, *afiya* is the target of treatment. *Afiya* is physical, mental, and spiritual human well-being - unlike *sihha*, which is an expression of the physical health universe where *illness* must be eliminated completely. *Afiya* means that *illness* is an ordeal, a test, and *afiya* requires more extensive 'treatment' in the form of social, political, and religious reforms in the society (504). Likewise, it is important to understand that there may be several subtypes of *jinn*, not all of which are associated with something unpleasant. According to Islam, every human being has a personal positive companion *jinn* called *qarin*, as well as two angels (505). Originally (i.e. pre-Islam), *qarin* was a kind of muse for poets. Some patients may have conversations with their *qarin*, which is not the same as the voice hearing of PTSD or psychoses.

Culture can influence the development of somatic symptoms ranging from the first sensation to the actual clinical presentation (506). An understanding of each of the following three elements is necessary to put a given symptom into an appropriate context:

1. The language and linguistic expressions used to describe the symptom

2. The illness and health perceptions used to interpret the significance and severity of the symptom
3. Culturally sanctioned illness behaviour used to present the symptom to other people in order to gain understanding, care, and treatment

The dualistic Western concept that man consists of a psyche and a body quickly falls short when one tries to understand migrants' symptoms. Western biomedical scientists have learned to categorise symptoms that have no biomedical explanation as 'psychosomatic' symptoms. However, this category covers a particularly diverse group of symptom complexes that are difficult to understand, explain, prevent, or treat based on simple biomedical models. Psychosomatic illness additionally requires a linear causality between psychological factors (personality, character, hereditary conditions, conflict management patterns, learned coping strategies and emotional register) and specific symptoms or physical changes. Encounters with the healthcare system and health professionals may over a long period of time expose the person to such a degree that certain symptoms and their professional importance are internalised by the person in a symbiotic process (507). As globalisation and migration increase, more and more clashes will occur between the world's widely different perceptions of illness and health. These discordant illness presentations (from a Western health science perspective) are typically referred to as *culture-borne syndromes*. A number of older and slightly newer culture-borne syndromes have been identified and may be important to know (121, 153, 508-510):

Table 17. Overview of selected culture-borne syndromes

Spirit possession - the African continent	Aggressive behaviour syndromes: 'road rage', trolley rage - conflicts among road users or customers in supermarkets
<i>Jinn, zar, cen, dybbuk</i> - African, Jewish, and Islamic countries - possession by a restless soul from a (often violent) dead person	Violent behaviour syndromes: serial killers, child abuse, mobbing, intimate partner violence, granny bashing, misogyny, xenophobia
<i>Amok</i> - orgy of violence against humans or animals	Dependency syndromes: workaholism, shopaholism, gambling addiction, sex addiction, internet addiction
<i>Hsiehping</i> - state of trance through possession by a deceased person	Energy loss syndromes: burn out, stress, yuppie flu, ME, fatigue syndrome, fibromyalgia, post-infection fatigue
<i>Koro</i> - shrinking or theft of genitalia	Various syndromes: refugee children, school refusal, ADHD
<i>Dhāt</i> - loss of semen through urine	Non-specific exile syndromes: <ul style="list-style-type: none"> • <i>Boofis</i> - exile stress with demoralisation and chronic pain among Somali refugees • <i>Upridosh</i> - possession among migrants from Bangladesh in London with mental impact, refusal to eat, muteness, crying, yelling, and 'disrespectful behaviour'
<i>Mal de ojo</i> - illness caused by a person giving a malevolent glare	Anorexia, bulimia
<i>Latah</i> - sexually challenging conduct, puts oneself in dangerous situations (Malaysia, Japan, Africa, Russia)	Climate depression
Voodoo death - curse leading to illness and death (Caribbean)	High blood/low blood - blood gets high or low depending on what you eat and drink (low-skilled workers in the South, USA)

<i>Shinkeishitsu</i> - anxiety condition with compulsive actions (Japan)	Migrating navel - stomach aches, nausea, vomiting, dizziness, fatigue. Seen in 'hard life', paralysis of action, hopelessness (Middle East)
<i>Kitsune-tsuki</i> - possession by a fox spirit (Japan)	Burning liver - depression, deep grief. Seen in privation, loss, and relationship issues (Middle East)
<i>Windigo</i> - obsessive urge to eat human flesh (India, Canada)	'Back pain' - relationship issues, conflicts, problems with identity/role, 'hard life', often in connection with sexual problems
<i>Susto</i> - fear, loss of the soul (South America)	Black/cold wind - pain throughout the body, grief, conflicts, privation, exhaustion, resignation, lacking recognition by the family, 'hard life' (Southern China)
<i>Narahtiyе qalb</i> - heartache	Anxiety - guilt, shame, grief, privation, headache, lump in the throat, difficulty swallowing, claustrophobia, respiratory distress, tendency to sweat, feeling of alarm, fear
<i>Dil ghirda hai</i> - sinking heart	<i>Karabasan</i> - nightmares, grief, privation, irritation, broken heart, guilt, shame, uncertainty (Latin America)
<i>Ataque de nervios</i> - South America	Dissociative hair pulling (women) - anxiety, panic, shame, loss of chastity, sexual conflict (Middle East)
<i>Amafufunyana</i> - South Africa, hysteria and uncontrolled behaviour with suicide attempts, often in epidemics and with the possession of spirits from other ethnic groups simultaneously	Psychogenic fainting fits/cramps - trauma, anxiety, extreme stress reaction (Middle East)
<i>Ukuthwasa</i> - South Africa, reaction to violent incident, a healing syndrome	<i>Taijin Kyofusho</i> - extreme social phobia (Japan)
<i>Sangue dormido</i> /Sleeping blood - after physical trauma/broken bones the living blood flows out to the skin and become sleeping blood, which paralyses the person (Cape Verde)	<i>Hikkiomori</i> - 'modern' depression, symptoms inspired by European depression expressions not previously seen in Japan
<i>Boofis</i> - isolation, grief, action paralysis, shyness, muscle pain, fatigue, feeling overwhelmed, 'bad air'	Upgiving/resignation syndrome - primarily seen among children in Swedish asylum centres (Sweden/refugees)
<i>Gato pegal</i> - children with congenital deformities or severe disability, children born with or developing peculiar looks (undernourishment/malnutrition due to illness) (Guinea-Bissau)	Systemic intolerance of physical activity syndrome - a new (according to some more politically correct observers) variation of chronic fatigue syndrome; chronic debilitating fatigue that is inexplicable
Brain fag syndrome (brain exhaustion syndrome) - a combined depression-anxiety-stress-like syndrome observed among students in Nigerian high school prior to exams	<i>Fallen fontanelle, caída de fontanelle, caída de la mollera</i> - seen as a syndrome in infants in Latin America and West Africa. A biomedical expression for dehydration; however, it is assigned a series of symbolic health significances
<i>Hwa-Byung</i> - 'Fire illness' or 'Anger syndrome', strong feeling of injustice, violation, humiliation (Korea)	Münchhausen/Münchhausen by proxy (factitious syndrome) - knowingly self-inflicted (or on another person) symptoms by means of toxic or physical injury
<i>Piblokto</i> - seizures of bizarre behaviour (screaming, yelling, running amok, undressing in public spaces) (Es-kimo communities)	<i>Windigo</i> - delusion of being possessed by a man-eating monster (indigenous peoples of Canada)
Addicted to anabolic steroids and struggles with body image	Various delusions: <ul style="list-style-type: none"> • Clerambault's delusion/ erotomania / stalking - believes that a well-known person is in love with them • Cotard's delusion - everything is lost including one's organs • Hysterical pseudo-dementia

The hallmark of these syndromes is that they are phenomenological, and on closer inspection they can often be linked to biomedical illnesses and syndromes. Many of them can probably only be treated by a combination of treatments, some of which will be outside the healthcare system (e.g. *jinn*, which may involve the efforts of an imam in addition to psychiatric treatment - if this is needed) (511). With globalisation and the limitless flow of information on the internet, the geographically isolated exotic syndromes of the past have been replaced by boundless modern hybrid syndromes that are not bound by culture but are constantly shaped and dynamically adapted by different cultures simultaneously all over the world.

Case 1

A 37-year-old man from a country in central Africa is referred with a short presentation: 'Multiple African symptoms. Previous attempts at diagnosis have been made.' Up until the current referral, the patient had been spoken to in English, or else a French interpreter had been used (French was the patient's second language). The patient's native language was Swahili. The patient had reportedly been complaining for several years that his penis had shrunk and was now far too small. Several independent specialists had assessed it as normal in size, which caused the patient to become angry and lose confidence in doctors in Denmark. With a Swahili interpreter, however, it became clear that the patient with the 'small penis' believed that two women had caused his previously normal genital organ to shrink because they had cheated him out of a large sum of money. He knew that in his home country he could have a special ceremony performed that would harm the women and give him a normal-sized genital organ again, but he had not managed to find anyone in Denmark who could perform the ritual. He was advised to report the women to the police if he believed they had done something illegal. The women were convicted, and the patient reported that his genital organ subsequently returned to normal.

Comment: *This patient's syndrome is similar to the koro syndrome. Moreover, it is widely believed that eating a certain kind of food or dealing with 'ghosts' can cause one's genitals to rapidly shrink. In several cases, there have been koro epidemics in which men were convinced they were victims of infectious diseases that caused their penises to shrink. The hysteria is sparked by rumours. It lasts from a few days to several months and often affects thousands of men. The 'victims' are very troubled and experience sweating, palpitations, and insomnia. They often place clamps or cords around the organ or make family members hold the penis until it is possible to be treated by native healers or medicine men. Women can also be afflicted and can believe that their breasts and vaginas are being pressed into the body (512). During a koro epidemic in the island nation of Singapore in 1967, thousands of inhabitants (both men and women) were afflicted, prompting the government to declare the island a disaster area (513).*

In 1982, an epidemic broke out in northern India. The panic was widespread, and authorities decided to drive around the area with loudspeaker cars to reassure residents. Authorities also measured the anxious men's penises to prove that they had not shrunk (514, 515).

Case 2

A 38-year-old woman from a country in southern Africa was referred with unexplained pain. The text of the referral read:

Since 2010, she has had chronic pain in the form of a burning sensation throughout her body, in her skin and radiating to her muscles. In the past, the pain only appeared when she was at home. When the family moved two years ago, the pain disappeared, and she therefore suspects that the house was cursed.

In the interview at the MHC, the patient elaborates on her description of the pain through her life story and problem list, *'Pain in the knees and hands; it feels as if the body is burning inside.'* The patient says that it dates from 1 October 2010. It happened suddenly. The patient says she remembers that there had been a death in the family at the same time. It was her sister's child who died in the homeland.

Comment: *A 'curse' does not come by itself or for no reason. It is vital that the doctor looks for further explanations than the one immediately offered. One should look for the source of the causes and give the patient time to explain the context.*

Case 3

A 35-year-old woman from a Kurdish area of the Middle East is referred from the psychiatric ward where the patient was judged not to have a psychiatric illness. However, they expressed uncertainty about the assessment and ended the investigation due to 'complicated health problems as well as linguistic and cultural difficulties.' The patient had first presented one and a half years before this referral when she had undergone acute psychiatric hospitalisation due to increasing symptoms of anxiety and psychosis. In the department of trauma and torture survivors, the patient was diagnosed with PTSD but with psychotic traits. The patient hears second- and third-person voices that speak disparagingly to her. The characters who speak are women of huge size with very long hair. They grab the patient and scare her. The patient's family and friends have mentioned that the patient could be the victim of a spirit and that there are ceremonies that can stop the possession. However, the spouse is afraid of seeing the patient as possessed and would rather choose 'science' as treatment, as he expressed it. The patient is assessed over several interviews at the MHC with an interpreter. It is determined that the patient has regular psychotic symptoms that should be treated in the psychiatric context, and she is therefore referred back to the psychiatric ward.

Comment: *The diagnostic balancing act between jinn-like conditions, PTSD with personality change (and dissociation), and psychotic mental illness is difficult and most often requires close collaboration between specialists. In this case, the symptoms initially sounded jinn-like but turned out to be regular psychotic symptoms (probably related to the patient's PTSD).*

3. Somatisation

Somatisation is a complicated concept to define. Some definitions emphasise the presence of several complaints in different areas of the body and a fear of having a serious physical disorder in the absence of objective physical/biochemical findings. Other definitions describe physical complaints as manifestations of a hidden psychiatric illness. The concept of somatisation has its origins in Freud's work, which proposed the idea of conversion as a main mental defence mechanism. Today, somatisation is often considered 'a tendency to experience and communicate somatic distress in response to psycho-social stress and to seek medical help for it' (1347). Somatisation is most often associated with depression and anxiety conditions. Physical manifestations of somatisation can be described through the number, severity, and degree of loss of function, ranging from only one or a few transient symptoms at one end, to having several severe symptoms over a long period of time and therefore meeting the diagnostic criteria for an actual somatoform disorder. Somatisation has traditionally been perceived as a pattern of reaction seen primarily among ethnic minorities. Older studies (often small case series) showed that in some countries, patients suffering from depression or anxiety had somatic pain-like complaints. This applies, for example, to China, South America, India, and Nigeria (442, 516).

A 2019 review of 38 cross-sectional studies on somatisation among migrants found that migrants with somatisation more frequently had mental health challenges, an increased need for contact with the healthcare system, and more socio-economic challenges due to migration and/or PTSD than migrants

without a somatisation diagnosis. It turned out that specific individual traits mediate the link between somatisation and migration. The prevalence and context of somatisation were found to vary across ethnic groups, depending on variation in the causes of migration, stress exposure/trauma, differences in illness understanding, mastery, and other individual factors. None of the studies have examined language barriers as an explanatory factor, which is striking when language barriers have proven to be a key clinical challenge when exploring unexplained symptoms among ethnic minorities (517).

Distinguishing between the very rare culture-bound syndromes and the frequently misunderstood patient symptoms is a challenge for any doctor. The combination of unclear symptoms and a tendency to exoticise symptoms one does not understand creates fertile ground for a widespread perception of somatisation among ethnic minority patients. Culture-specific diagnoses (see section on culture borne illnesses in the current chapter) cover a different group of diseases with syndrome compositions that are unique to certain ethnic groups. While general medical conditions localised to specific geographic regions or genetic groups have historically been included in the culture-specific diagnoses, the term is now primarily used to refer to mental health conditions. In the eighteenth century, researchers had already identified differences in *illnesses* based on the geographical origin of the patients. In 1733, George Cheyne, a Scottish physician practising in England, wrote *The English Malady*, a book about ailments that he felt were more common among Englishmen (518). He attributed the disorders of depression, nervous traits, melancholy, and hypochondria to the cultural factors of poor diet, 'way of life', and geographical factors including the foggy English weather. For a number of reasons, doctors tend to (over-)interpret unusual presentations of normal *illnesses* as cultural expressions, inherited weaknesses in certain peoples, rare tropical diseases, medically unexplained symptoms, or functional disorders. The combined influence of language barriers and the cognitive bias of the doctor is a disadvantage for immigrant patients who lack the communicative strength to challenge the clinical and psychosocial generalisations they experience. The result is that the symptoms are misdiagnosed or ignored and remain 'unexplained' from the patient's point of view; from the doctor's point of view, they are expressions of somatisation (517). Examples of blind spots in bilingual doctor-patient communications can be seen in Table 18.

Table 18. Examples of blind spots in bilingual doctor-patient communications.

Patient factor	Clinical significance
<p><u>Learning the rules and playing the game:</u></p> <p>Acceptance of the doctor's social codes and acquisition of the language of the health professional. Afraid of the doctor and afraid of stressing or irritating the doctor.</p> <p>Offers the doctor information only on a <i>need-to-know</i> basis. Patients will go to great lengths to avoid (what they consider) humiliation. Makes many assumptions about doctors' ability to understand a problem or symptom. Respects, but does not trust the doctor.</p>	<ul style="list-style-type: none"> • The patient presents only one symptom and asks only one question. No interaction, no answers, no information - or only 'neutral' information exchange. • Fearing that the doctor will not understand the problem or situation, it is better to be silent than to show vulnerability since the doctor (perhaps) may downplay concerns that feel humiliating. Hesitant in addressing difficult, sensitive issues. • Patients are willing to change and formulate their story, omit information, highlight 'favourable' and suppress 'dangerous' or sensitive information that may require details that they are not willing to share with the doctor. Accepts an unwanted clinical trial or treatment to 'play along'.

	<ul style="list-style-type: none"> • In many cultures, respect for doctors is taken for granted, but trust only enters the picture if the help is clear - no help, no trust. This can be confusing for some doctors who misinterpret respect as being an expression of the patient's acceptance of the doctor's skills and plan.
	<ul style="list-style-type: none"> • The patient does not provide spontaneous information. • The patient may withhold important clinical information because it is not considered relevant and does not attempt to discuss it with the doctor.
<p><u>Illness symptoms and illness concepts</u></p> <p>Concepts of disease are encoded and rooted in one's native language and are perceived in a different social context and mind-set than that of the doctor (host country).</p>	<ul style="list-style-type: none"> • Has difficulty explaining symptoms to the doctor and can completely avoid mentioning it to the doctor (heat/heat syndromes, e.g. <i>Koro</i> syndrome, <i>jinn</i>). • Bilingual patients often need interpreters' help when they become ill because illness concepts are rooted and formed in childhood in their native language and they lack a 'Danish' vocabulary in the field of illness. • The conversation is too simple and contains too little information in the second language. Important details are omitted or missing. The clinical history lacks detail, and misunderstandings or inaccuracies are not corrected by the patient because the patient does not recognise them.
<p><u>Shame, fear, stigma, and taboo</u></p> <p>Shame due to lack of Danish language skills. It is shameful to ask for an interpreter. Shame due to health problems and the patient dares not mention it to the doctor (or stigmatised).</p> <p>Ashamed of poverty/economic situation or action paralysis. Ashamed of putting themselves/family in an unsustainable situation because of their illness.</p> <p>Considers it unacceptable to have detailed knowledge of body parts, their functions, and excretions.</p> <p>Mental illness is a disability or a taboo. Fear of stigma and social isolation.</p>	<ul style="list-style-type: none"> • Simple health complaints or severe warning signs are not mentioned (incontinence, blood in the urine, diarrhoea, weight loss, cough (TB stigma)). Socio-economic reasons for compliance problems are overlooked (cannot afford medicines). • Talking about organs such as 'kidneys', 'liver', or 'gallbladder' does not make sense to the patient. The patient feels uncomfortable discussing diseases involving 'unclean' organs such as kidneys, urinary bladder, and reproductive organs. • Symptoms that point to, e.g. HIV or tuberculosis are not mentioned as these illnesses are associated with extreme stigma that can be extra severe in minority environments. • Will not mention or discuss mental health issues, does not want psychiatric evaluation or medication.

The link between ethnicity and somatisation has since been refuted, including by Kleinman himself, who later found that with better diagnosis in China, the link disappeared (519). In Latin America, there turned out to be a different weighing of psychological and somatic symptoms than what western psychiatrists were used to, i.e. the importance of symptoms differed (520). Researchers have also shown interest in the idea that somatisation was linked to socio-cultural status. People with little schooling or from poorer social strata reportedly had to express their emotional or mental health problems through somatic complaints - most often, pain. The logic was that they lacked the linguistic skills to describe their feelings and symptoms. A diagnosis for this purpose was invented, *alexithymi*, which described a condition with a 'narrow emotional level of function' accompanied by a 'limited and lacklustre life'; in other words, a dull patient (521, 522). A lack of relevant specific concepts in some languages, such as Farsi, has contributed to the linking of culture with somatisation (523). In Asian cultures, emotional interaction is socially unacceptable, and expressing feelings or mental health problems is a sign of weakness (524). In Arab cultures, mental illness is a familial shame, a punishment expressed through an inherited psychological weakness that affects the whole family and thus shows a weak morality and causes mutual recriminations within the family (525). Mental health problems are therefore deliberately expressed in somatic terms to avoid social exclusion. This is a double stigma, as seen in a wide range of cultures where pain is used as a proxy term for mental health problems (526). Experience of racism/social exclusion due to ethnicity or mental health problems is significantly correlated with pain expression, and exclusion due to ethnicity is associated with chronic pain, high blood pressure, and higher cortisol levels (527-529). The healthcare system can contribute to prolongation of chronic pain if the health professionals lack cross-cultural skills in understanding pain expressions from other cultures and if ethnic minorities are excluded or made invisible in pain research due to language problems or assumed compliance issues (530). Patients have noticed that they adapt their symptom presentation to the framework they encounter in the healthcare system; the sterile, white waiting rooms and consultation rooms cause patients to unconsciously prioritise somatic illness expressions because the physical framework clearly indicates that 'vague' mental health problems are not 'clinical' (531). Several large studies have since shown that there is no difference between a majority and minority populations with regard to pain presentation of mental health problems. A linear correlation has been shown where greater mental health problems lead to more somatic complaints and vice versa, regardless of ethnicity (532). What is interesting is that somatic doctors have very different attitudes towards unexplained pain, and they are not very likely to link a patient's pain to mental illness for fear of the patient's reaction. Thus, doctors, including psychiatrists, can contribute to keeping the pain unexplained, i.e. the doctor actively contributes to keeping the patient in a somatisation state due to the doctor's anxiety and/or lack of communication skills (533).

There are significant differences in somatisation across ethnic groups. Qualitative analyses of illness narratives collected from different ethnic groups have shown that somatic symptoms are classified into several different significance systems, each serving different psychological and social functions. Depending on the circumstances, these symptoms can be seen as an illness index or an indication of psychopathology, a symbolic expression of a mental conflict, a culturally coded expression of suffering, a tool for expressing social dissatisfaction/malaise, or a mechanism through which patients try to forge a new role or social position (534). The same symptom does not have the same significance across ethnic groups or across social strata (447). Strategies for avoiding the most common misunderstandings and useful approaches for unfamiliar symptoms and complex problems can be found in Figure 14.

Misunderstood symptoms	Think of the usual first: abnormal expression of a frequent illness.	Try to find the solution within the bio-medical mind-set, but look for and include socio-psychological information.	Culture, ethnicity, and xenophobia are not diagnoses, nor are they valid explanations.	Acquire cross-cultural communication tools to avoid unnecessary culturalisation of the patient's symptoms.	Ask the patient (and get help from the interpreter): <i>What would you call your illness in your home country?</i> <i>What would you do there?</i>
Neglected symptoms	Language barriers are barriers that require attention - and an interpreter.	Doctors know most of the symptoms and variants - but not all. Be humble in the face of new forms of expression.	Avoid labelling symptoms as 'strange' or 'foreign' - it affects the clinical judgment.	Always think of the usual, but expand the explained factors to include the patient's psycho-social environment and experiences.	Check with the patient whether the registered symptoms are correct and whether any symptoms are missing.
Diagnoses requiring special knowledge	They are rare, but search basic information on the most frequent tropical and hereditary illnesses and manifestations of e.g. late-stage infections (extra pulmonary TB, strongyloidiasis, Mediterranean fever, other worm diseases)	Know the basic principles of genetic counselling among ethnic minorities. Consult experts.	Understand the particular stigma associated with physical and mental disabilities (and how these may merge) in various communities.	Work with a standard set of questions asking about experiences, knowledge, and attitudes, particularly for sensitive subjects (trauma, reproduction, disability, heredity, infectiousness).	Methods of torture go beyond your imagination but involve stabs, blows, electricity, water, confinement, hanging, feigned executions - and they can affect the patient's attitude towards examinations.
Serious or complex issues	Never accept no for an answer. A no is the most uncertain way to 'play it safe'.	Assume that misunderstandings exist. Ask yourself: <i>What have I not understood?</i> <i>Is there something I am not allowed to know?</i> <i>What has the patient not understood?</i> <i>What have friends/ family not understood (or not been allowed to know)?</i>	The concept of risk is hard for patients who have not attended school. You have to speak more specifically about what it means to the life of that particular patient, and the message often needs to be simplified.	Too much information creates mistrust and can overwhelm patients and cause them to completely withdraw. Too much information can make the patient feel they are being persuaded to be a guinea pig or that the doctor wants to be in charge.	Guilt and shame are often the reason that patients will not talk about their symptoms and can be the reason why simple disorders become complicated over time.

Figure 14. Strategies for avoiding the most common misunderstandings and useful approaches for unfamiliar symptoms and complex issues.

Case 1

A 32-year-old woman from a country in the Far East, who had obtained family unification with her husband in Denmark, was referred due to suspected functional seizures (psychogenic non-epileptic seizures, PNES), tingling sensory disorders throughout her body, and a somatisation tendency primarily with headache. The patient is referred because insufficient seizure control has been achieved on habitual anti-epileptic treatment despite dosage increase. The doctors suspected that the patient does not have epilepsy but functional seizures and cognitive challenges. An interpreter who only spoke a dialect the patient understood very little of had previously been used in the healthcare system. The patient has not been able to explain this to the referring hospital department. At the interview in the MHC, an interpreter is used who speaks a dialect that the patient understands. The patient states that she has tried to have a conversation with the epilepsy doctors about medication side effects in the form of dizziness, headaches, and forgetfulness after dosage increase but did not succeed in explaining the problem to the department. The patient says that she has had epilepsy all her life, but that her mother would never accept her condition and therefore ignored her seizures, failed to give her medication, and hid her problem from the family. The mother attributed the condition to her being less gifted, and the patient had the feeling that the mother considered her to be possessed. However, the patient describes classic complex seizures with postictal symptoms. The patient is ashamed of her illness, and she dares not drop off her children at the day care centre for fear of having seizures in front of the staff. Moreover, she has stopped going to the Adult Education Centre because she was afraid of having seizures in class and thus disturbing the other students. She quit her cleaning job after having a seizure early one morning when she was alone at work. She never walks alone and does not dare to drive. She has taken her medication as prescribed and her husband confirms this. She has become afraid of referrals to hospitals because last time it took two years before she could get an appointment scheduled. The patient is sent back to the referring department, which, however, chooses to refer the patient to the psychiatric ward. Psychiatric assessment concludes that 'the patient has a stress reaction due to examination and diagnosis', but the psychiatrist also states that the patient 'has a different cultural understanding' of epilepsy. Consequently, the patient is referred by the MHC to a neurologist for a *second opinion* at another hospital for epilepsy and here they find a clear epileptic-shaped EEG with a bitemporal focus. Changing the epilepsy medication improved seizure control.

Comment: *Besides always making sure that the interpreter used speaks a language and a dialect the patient understands, the importance of a meticulous medical history cannot be overstated, especially in the presence of language barriers. The source of the patient's supposedly alternating seizure descriptions and variations in seizure frequency described in the medical record is the use of an unsuitable interpreter. It is also important to summarise and adjust the patient's medical history on a regular basis. Some illnesses may have special significances or be associated with stigma that the doctor should discuss with the patient (535).*

Case 2

A 41-year-old woman was referred with unexplained universal pain and headache with suspected simulation of functional disorder to avoid vocational training. After the information has been entered into the medical record and the video interpreter is turned off, the patient remains seated. The patient says she has something embarrassing to say about her pain, which stems from her marriage in her home country where at the age of 11 she was forcibly married to an older man who already had an age-appropriate spouse. The first wife hated the patient and treated her extremely maliciously. The woman forced the young girl to stand upright outside their bedroom, and she was not allowed to move or lie down to sleep. Her pain stems from the several years of spending long nights outside the bedroom. At the same time, she was severely malnourished because she was not allowed to eat. She had never talked

about her experiences before as she found them embarrassing. The patient explained that she would never speak about them again, but she would allow the nurse to tell the caseworker and the family doctor so that they could understand her pain.

Comment: *It can be beneficial to have conversations both with and without an interpreter, especially if there are unclear elements or conditions that have not been described in detail. It might be beneficial to try approaching sensitive topics with indirect questions that 'normalise' any experience, such as, 'Is there something important to you that you have difficulty talking about?' It is the patient who determines whether or not an experience is embarrassing.*

Case 3

A 56-year-old man from the Middle East was referred with universal sensory disorders and suspected somatisation. The patient underwent three surgeries for appendicitis. During the third surgery, the patient was discovered to have colorectal cancer. He had part of his intestine removed with sub-sequent chemotherapy during which the patient developed the said sensory disorders. Initially, the condition was interpreted as nerve inflammation after chemotherapy, but the symptoms were uncharacteristic and spread to such a degree that the doctors suspected the patient was exaggerating his symptoms. However, the life history and problem list clearly revealed that the patient had been briefly tortured in his home country.

The patient came from a poor home but was skilled at school and had been given the opportunity to study at a university in the United States. This required a visa, for which he needed to travel to Syria. In Syria, he was imprisoned and tortured in darkness with electricity applied to his hands, feet, and genitals. He never saw his executioners; he knew only the sounds they made. Birdsongs and pop music were played during the torture. The patient had neuropathy, but his pain experience was altered by his constant anxiety about meeting his torturers whom he had never seen. The idea that they knew him, but that he did not know them increased his alertness so that he had developed neurogenic pain on top of the neuropathy.

Comment: *The pain experience is often altered in the case of PTSD, and diagnosis should therefore always be considered before considering functional disorder or somatisation. The patient had also been sensitised by the many repeated surgeries before the diagnosis was made. The psychological consequences of diagnostics, surgeries, and treatments are often underestimated, particularly in bilingual patient contexts.*

Case 4

A 29-year-old woman from the Middle East is referred to the MHC with recurring pain in her body, primarily abdominal pain and headaches, over the last 10-12 years. The patient was examined extensively by infectious disease doctors, gastrointestinal surgeons, and gastrointestinal physicians, as well as gynaecologists, psychiatrists, and a pain specialist. The following examinations had been performed: gastroscopy, colonoscopy, barium enema, diagnostic laparoscopy, capsule endoscopy, CT scan of abdomen, vaginal ultrasound, MR scan of the cerebrum and the whole spine, MR scan of intestines, full-body PET scan, and examinations for porphyry and hereditary angioedema. All examination results up until this point were normal. A subsequent psychiatric assessment determined that the patient suffered overall from a psychologically conditioned somatoform functional condition with depression. Thus, a referral to the MHC for psycho-education was recommended. The abdominal pain comes in waves and is very severe, but non-steroidal anti-inflammatories offer some relief. The pain often goes away after 30 minutes to an hour. The patient has no psychological trauma, speaks Danish, and attends adult education without much trouble. She got a headache from going to a psychologist and psychiatrist.

Genetic testing detects mutations in the patient's DNA compatible with the hereditary disease Familial Mediterranean fever. Both of the patient's parents in the home country have the same symptoms but have never been examined. The patient is treated with colchicine, which greatly reduces the pain and frequency of her seizures. The patient had no depressive signs and scored normal on the Beck Depression Inventory and on Harvard's PTSD screening interview.

Comment: *The investigations are performed without relation to the patient's actual symptoms. Some patients who are found to have Familial Mediterranean fever end up getting a somatising characteristic before they are diagnosed correctly, which pursues them during the diagnostic process and is finally internalised by the patient. The incorrect diagnosis thus becomes a self-fulfilling diagnostic prophecy. After years of fruitless examinations, many patients think that any diagnosis is better than no diagnosis, and here 'psychologically conditioned somatoform condition' is an option that both doctor and patient can live with, but this does not make it more correct or acceptable.*

Case 5

A 43-year-old man from north-eastern Africa had been diagnosed with fibromyalgia nine years earlier by a private rheumatologist and was prescribed a massive number of painkillers. He was referred to the MHC for the purpose of adjusting his medication as there was no effect on the pain and the patient complained of increasingly poor sleep. The patient had significant psychological trauma from his home country and had clear symptoms of PTSD with neurogenic pain. After discontinuing the painkillers while also attending trauma and torture treatment, the patient slept better at night, had fewer nightmares, and needed no painkillers. The patient did not have fibromyalgia.

Comment: *Diagnoses such as fibromyalgia should not be made on such a vague basis as seen in this case. Moreover, because of the considerable language and illness perception barrier, the diagnosis must be deemed a specialist task that requires a better and more comprehensive examination than was done in this case.*

Case 6

A 46-year-old woman was referred with unexplained intermittent radiating pain in her arms, hands, and neck. She had been working actively in her own company for 15 years. She was examined in the rheumatology and neurology departments and was recently referred to the MHC for examination for functional disorder or fibromyalgia. According to her medical record, her pain had started after a fall from an examination bed during a consultation with a specialist. According to the patient, however, ever since she was a teenager, she had always had the feeling that something was bothering her in her back, from the back of her neck and down between her shoulder blades. The radiating pain started after her fall. A subsequent MR scan showed a congenital syrinx in the cervical medulla and high in the thoracic column. The patient has had symptoms most of her life but experienced a worsening after her fall. The patient did not want further examinations and was satisfied with the explanation that agreed with her notion that she was not mentally ill (which she had understood the referral to the MHC to be about) as there was no evidence of functional disorder or fibromyalgia.

Comment: *Causes and effects can become confused. If the starting point of a symptom is not carefully established, the doctor risks getting a false clinical picture.*

6. Health assessment of refugees: clinical points to be aware of and a checklist

The frequency and severity of illnesses vary with geographical lineage and general living conditions. Major global differences exist particularly in the incidence of infectious diseases and mental disorders, but also in congenital disorders, traumatising experiences, malnutrition, and complications from previous illnesses (176, 517, 536). The health reception of refugees is a complex task that requires input not only from clinicians, but also from several other disciplines (537). Thus, the Danish healthcare system will also encounter illnesses that they are not used to diagnosing or dealing with, and perhaps even more frequently, symptoms that are unfamiliar or not immediately unexplainable (302, 306, 492, 538).

Violent war experiences and possible language barriers, uncertainty about residency status, and limited options and ability to acquire and apply health knowledge can contribute to making communication difficult (51, 539). The initial interview with the doctor may be one of the refugee's first encounters with the Danish healthcare system, which tends to differ widely from the healthcare system they know from their home country. Refugees will also encounter a different medical role: usually someone who is less authoritarian and involves the patient more than they are used to. Because the refugee could interpret this as professional uncertainty or weakness, it is important to be very clear about why you as a doctor act as you do. There are wide ranges of guidelines for the health reception of refugees, but they bear the hallmarks of asylum/refugee policy and the organisation of the healthcare system, which varies widely across countries, just as the composition of migrants varies so much that it can be difficult to establish common guidelines (540-543). Several Danish studies have shown that the health assessment of newly arrived refugees is effective from a prevention perspective (544-546). In addition, there are various health risks associated with different stages of migration, for example regarding infections and chronic illnesses (547-549).

This chapter describes the special clinical points that doctors should pay attention to in their first conversations with a new patient with a refugee/immigrant background. In other words, the focus is on what doctors should think about *in addition to* the normal illnesses and symptoms that they usually have in mind.

6.1. Medical history and physical examination

Explain to the patient that not all information that may have been given to the staff of asylum centres has been sent on to the doctor and that it is important that the doctor receives all health information from the patient, even if it has been provided earlier. The following list of items should be enquired about:

- **Experiences during travel and the flight from home country, including stays in foreign and/or Danish asylum centres:**
 - All countries the patient has travelled through (often many countries). Please note that refugees who have stayed in camps may have been particularly exposed and traumatised after leaving their home country.
 - Particular experiences before and during their escape: Coerced to make the 'right' choices, humiliations, incarceration, violence, abuse, imprisonment, torture, experience of helplessness?
 - Long-term stay in (several) asylum centres, particularly unpleasant experiences in asylum centres (in Denmark or other European countries)

- Immediate family situation (is the family together? Scattered across many countries? Is the patient family-reunited or waiting for family reunification?)

- **Self-perceived health problems/symptoms**

- Problem list (see the section on ‘tools’)
- All health issues (now and previously)
- Previous illnesses and treatments
- Hospital stays in the home country, third country, during stopovers
- Do the health issues affect everyday life and function, including participation in possible language classes, jobs, and integration programmes?
- Vaccination status, if possible

These initial questions can be used to gauge how well the newly arrived refugee understands the questions asked and thus to get a first impression of the patient’s health knowledge. This enables the doctor to adapt their questioning technique to the patient’s language level, framework of understanding, and circumstances.

The systematic review of symptoms can be challenging and therefore deserves some comments. Basically, the vast majority of symptoms express quite common illnesses, but their presentation may have an unusual foreign or complex expression (e.g. due to anxiety, PTSD, insecurity, and low health competencies). This, combined with differences in dialects and the potential for imprecise conceptualisations and perhaps inappropriate interpretation assistance may complicate the recording of the medical history. Tropical diseases are not so frequent but can have symptoms that doctors are not used to. In some cases, the symptoms can resemble common diseases (e.g. strongyloidiasis may present like asthma), general symptoms can be downplayed (e.g. the fatigue of chronic hepatitis B or pituitary insufficiency), anaemia (in hereditary blood disorders), or recurring severe abdominal pain that seems excessive in relation to the objective examination (e.g. abdominal pain in Familial Mediterranean fever). A highly frequent phenomenon is hidden re-traumatisation with symptoms of PTSD that are difficult to identify in cases of accidents at work, car accidents, assaults, or major social events (e.g. firing, loss of family member).

Diffuse pain can be a difficult symptom to deal with. It can be advantageous to explore a more specific localisation, and to do this systematically together with the patient during the physical examination, i.e. by going through the different parts of the body and asking the patient to describe the pain in each area. Several independent pains or simultaneous symptoms may have gradually become one disorder such as diffuse pain. *Fatigue* is another symptom that can be triggered by many different illnesses. These include somewhat rare conditions such as tuberculosis, HIV, chronic hepatitis, rheumatic fever, and Sheehan’s syndrome, as well as PTSD, and e.g. severe vitamin D deficiency or hypercalcaemia. Fatigue can also be triggered by the known spectrum of disorders such as depression, cardiovascular and lung disease, anaemia, or myxoedema. *Headaches* can be due to past trauma and its complications e.g. chronic sinusitis, tooth abscess, impaired vision, and high blood pressure. *In other words, frequent and well-known diseases may be at play, as well as less frequent diseases that the doctor is not always familiar with.* The checklist below is a list of lesser-known yet frequent disorders refugees/immigrants may have. It is not a complete list and should primarily draw attention to the fact that there are diseases that are rare in individuals born and raised in Denmark, but frequent in individuals from other geographical areas.

Table 19. Checklist for use in the health assessment of adult refugees/immigrants

<p>Central nervous system/skull/face</p> <p>Neurology</p>	<ul style="list-style-type: none"> • Injuries to the skull (blunt/sharp force trauma) • Birth injuries • Visual problems (particularly in those who are illiterate and may not notice it themselves), hearing loss, defects of the eardrum, tinnitus (complications from, e.g. torture, explosions, etc.) • Particular problems in language school • Anxiety, internal restlessness, mood, chronic grief • Difficulties concentrating, memory difficulties, problems with anger management, sleep disturbance, hearing voices, increased alertness, avoidance behaviour (PTSD) • Dental status and toothache • Complications of meningitis including cognitive functions, birth injuries • Pseudo-dementia from PTSD (dissociation, depression, functional cognitive loss of function) • Cognitive loss of function (may be hidden by relatives) • Exposure to poisonous gas • Torture by electricity
<p>Skin</p>	<ul style="list-style-type: none"> • Chronic wounds +/- necrosis, signs of infection • Eczema - occupational exposure • Surgical scars • Complications from violence, burns • Fungal infection (HIV), uncharacteristic wounds (e.g. Trypanosomal chancre) • Necrotic wounds (eschar) • Dark elevated areas of skin (Kaposi sarcoma/HIV) • Seborrheic dermatitis (HIV) • Scabies • Case of jaundice? (congenital haemoglobin disorders) • Genital/anal fistulas, TB fistulas, previous surgery
<p>Lymph nodes</p>	<ul style="list-style-type: none"> • Enlarged lymph nodes without signs of bacterial infection: TB, HIV, syphilis, gonorrhoea, other sexually transmitted diseases?
<p>Cardiopulmonary</p>	<ul style="list-style-type: none"> • Cough, sputum (TB), TB exposure? Previous tuberculosis? • Shortness of breath, anxiety, complications from torture (water boarding, confinement) • Atypical asthma • Cardiac murmur (sequelae of rheumatic fever) • Heart valve disease • Workplace exposure • Poisonous gas

Gastrointestinal	<ul style="list-style-type: none"> • Helicobacter pylori is very prevalent, also among young people, compared to ethnic Danes • Diarrhoea, 'cow-pat stool', and food aversion (giardiasis), particular bacterial/parasitic illnesses in the home country/refugee camp (geography)? Worms seen in the stool? Blood in the stool • Chronic diarrhoea (HIV), malabsorption • Constipation (memory, PTSD, anxiety, diet) • Weight loss • Hepatosplenomegaly (hepatitis, sequelae of bilharzia infection, echinococcus cysts, etc.) • Recurring stomach aches and family medical history (Familiar Mediterranean fever) • Lactose intolerance • Coeliac disease, tropical sprue • Sexual torture (injury to anal area/muscles)
Urogenital	<ul style="list-style-type: none"> • Complications from circumcision, e.g. in women: fistulas, incontinence, both genders: sex life, frequent urinary tract infections • Infertility - rape is frequently used in torture of both genders and often results in severe mental and sexual problems • Sexual torture to the sex organs (electricity, violence) • Previous birth defects, ruptures, fistulas
Musculoskeletal system	<ul style="list-style-type: none"> • Congenital/less visible deformities (feet, hands, back, thoracic outlet syndrome) • Birth defects in shoulders, defective positions • Complications from polio • Grenade injuries (fractures, shrapnel) • Complications from torture (e.g. falanga with discomfort from the soles of the feet), back injuries, shoulder injuries from hanging • Signs of rickets
Medication	<ul style="list-style-type: none"> • Ask specifically what they borrow from friends/family, what has been purchased in their home country and possibly from other places than Denmark, actual intake and reason for taking them • Particular compliance issues (pills, injections, memory e.g. PTSD, anxiety)
Alcohol, tobacco, other recreational drugs	<ul style="list-style-type: none"> • Hashish? (ordinary as a daily 'recreational drug' in, for example North Africa and certain parts of the Middle East) • Khat? (same, e.g. in Somalia) • Borrowing morphine preparations

	<ul style="list-style-type: none"> • Alcohol (stigma) • Tobacco: ask specifically about waterpipe smoking (frequently used by women and children)
Psychosocial	<ul style="list-style-type: none"> • Special childhood conditions (separation, violations, abuse, war experiences, accidents, sexual abuse) - see the item on PTSD below • Early responsibility as an adult, early loss of parents • Upbringing in a family of strangers in virtually slavery • Psychological trauma history, remember traumas occurring during travel/escape route, stays in refugee camps (incl. in Europe) • Strong fear of illness, specific anxiety (blood tests, needles, cavities/spaces, invasive examinations) • Particular experiences in Denmark (racism, misunderstandings, assault) • Particular obligations in Denmark (care of parents-in-law, own parents, family members with disabilities) • Family in other countries, uncertainty concerning parts of the family (e.g. parents), worry about children/spouse • Schooling in the home country and Denmark, illiterate in own language or can actually read and write • Family unification without any network
Hereditary illnesses?	<ul style="list-style-type: none"> • Recurring stomach aches, chronic anaemia, e.g. haemoglobinopathies, Familial Mediterranean fever, others • Consanguinity • Known hereditary illnesses in the family

- **Ending the conversation**

- It is important to end the conversation with clear agreements about where and how further diagnosis and follow-up will be carried out for the identified health issues. Like-wise, it is crucial that patients are given the opportunity to explain what the plan is, who should do what, and so on.
- Finally, end the conversation by asking the patient if there is anything important that was not covered and whether the patient is satisfied with how the conversation has gone and its outcome - this is to rule out any communication difficulties with the doctor (and/or the interpreter).

A comprehensive transcultural questioning guide on mental health and psychological health issues (*Cultural Formulation Interview, CFI*) has been developed, but it has only proven valuable for use in patients with a cognitive surplus for existential reflection on identity, culture, and cultural background (550). Other patients find the question guide frustrating and confusing with regard to its structure and questions.

6.2. Potentially traumatising experiences and PTSD

Most refugees have experienced the direct or indirect consequences of brutal regimes, civil war, anarchy, environmental disasters, and famine. They have often been in danger due to their ethnicity, religion, or political convictions. They may have endured persecution, torture, rape, or abduction, or they may have witnessed a killing. Many arrive after dangerous travels and detention in refugee camps. They have lost their loved ones, social network, home, belongings, and work. Between 30 % and 70 % of refugees have faced severe traumatic experiences and have developed signs of chronic PTSD of various types and severity. Although it is important not to medicalise the effects war and other disasters may have upon individuals, it is also important not to underestimate their influence on the person's ability to adapt to life in a new society as a refugee in exile. PTSD affects people in highly individualised ways and also changes within the person over time, depending on internal and external factors. PTSD affects quality of life, sleep, language learning, self-care, and understanding of medical treatment. Some PTSD patients display changes in emotional expression and behaviour in the form of indistinct or ambiguous body language, lack of facial expressions, loud voice, and over-alertness, which gives an outward impression of disorganisation.

The presence of PTSD is central to an individual's capacity for self-care in physical and mental health problems, self-esteem, compliance, and so on. A refugee - by definition - will have been subjected to potentially traumatising experiences. One can begin an assessment of potentially traumatising experiences and PTSD symptoms by asking relatively harmless and indirect questions that can simultaneously convey the normalisation of the symptoms aimed at. The questions should create a safe framework for the conversation and help to identify possible trauma and any symptoms compatible with PTSD. Patients will often be very reserved in talking about their experiences and are often afraid of being labelled 'insane' by sharing their often-violent flashbacks or severe anxiety. There are several ways to ask, but here are some examples:

- Many people who have lived in war zones experience at some point in their lives something very frightening such as physical or psychological abuse, a serious accident, or war experiences:
 - *Have you ever experienced something that was scary, horrible, or disturbing?*
 - *Have you ever experienced something that is very difficult for you to think or talk about?*
 - *Has something violent happened in your life that you dare not think about?*
 - *Do you sleep at night or during the day?*
 - *Are you more scared than other people?*
- Follow-up questions can be:
 - *Is what you experienced something you have seen happen to others, or is it something you have experienced directly yourself?*
 - *Is what you have been through something you have told others?*
 - *Will you be able to talk about it (and if so, under what circumstances)?*
- If potentially traumatising experiences are suspected, the next step is to ask if the patient within the last month has:
 - *Had nightmares about their experiences or thought of them at a time when the patient did not want to think about them?*

- *Spent a lot of energy on (or tried hard) not to think about it, or gone to great lengths to avoid (or been very conscious of avoiding) situations that might cause the patient to recall these experience(s)?*
- *Been constantly alert, scared, or too easily frightened?*
- *Felt numb or empty inside and/or isolated from other people, from activities or their surroundings?*
- *Are there pronounced sleep problems/interrupted sleep? Nightmares about specific events?*
- *Absence seizures? 'Out of body' experiences? (dissociation-varying lengths of time feeling disconnected to one's own identity, one's memory, will, and sense)*

If the patient answers yes to at least two of the questions, there will be reason to either discuss the patient with a trauma and torture treatment centre or refer the patient to them for treatment. Note that many patients with PTSD have impacted memory and recollection as well as concentration and coordination difficulties. PTSD is often accompanied by other psychiatric disorders (OCD, anxiety, depression). Those with PTSD may have visual, hearing, and olfactory hallucinations, which in themselves are not psychotic symptoms.

The following conditions can affect the behaviour of the person examined and require gentle questioning techniques: parental neglect, experiences as a child soldier, medication abuse, physical disabilities, physical assault and congenital disabilities, circumcision, sexual assault, partner violence, concerns about the basis for residency status, finances, and debt. Note that relatives of refugees with PTSD may also have symptoms as part of a secondary traumatising.

6.3. Paraclinical examinations for suspected somatic illness

The following paraclinical examinations may be considered for suspected somatic illness:

- Haemoglobin, creatinine, C-reactive protein (CRP), leukocyte and differential counts, thrombocyte count, ALAT, hepatitis serology (HbsAg and anti-HCV), urinary test strip (dipstick), and faeces for worm eggs and cysts.
- Upon specific assessment, consider: HbA1C, ECG, thoracic X-ray.

In cases of doubt, confer with the relevant hospital department and with one of the Migrant Health Clinics.

- **Investigation of anaemia**

- MCV < 78 without signs of bleeding: **haemoglobinopathy (e.g. thalassemia): fractional haemoglobin (electrophoresis) - indicate country of origin**
- If haemoglobinopathy is detected, note the presence of competing or **contemporaneous causes, e.g. iron deficiency, infection**
- If signs of haemolytic anaemia and the patient's place of origin is Africa, the Mediterranean, the Middle East, India, or South-east Asia: **haemoglobinopathy or glucose -6-phosphate dehydrogenase deficiency**
- Thrombotic manifestations or bone pain and the patient's place of origin is Africa or the Middle East, sickle cell anaemia should be considered
- Iron deficiency, vitamin D deficiency, anaemia, and folic acid deficiency can be the expression of significant **malnutrition** and also certain **parasitic infections**

- **Infections**

- Leukocyte and differential counts, thrombocytes, eosinophilia, C-reactive protein (CRP)
- **Hepatitis B and C serology**
- **Tuberculosis:** if suspected (high prevalence area, stay in refugee camps, cough, weight loss, bloody sputum), refer patient to the infectious disease department; X-ray of thorax, culture and microscopy of expectorate/aspirate from abscesses.
- **Gastrointestinal infection/symptoms:** bacteria, worm eggs, virus. Indicate symptoms and country of origin/transit countries and conditions, Helicobacter pylori antigen. Consider ultrasound if hepatosplenomegaly (cirrhosis? cysts? portal hypertension?). Infections with Giardia lamblia parasite can sometimes only be identified through duodenal secretions.
- If specific suspicion e.g. hepatitis, HIV: do relevant serology; malaria: do microscopy (blood smear)
- If **thrombocytopenia:** consider malaria, HIV, chronic hepatitis, leishmania, schistosomiasis
- If **eosinophilia** – atopic, worm infection, medicine

6.4. Long-term aspects requiring attention (children and adults)

- **Prevention:** Refugees and family members who are reunited with refugees are less likely to be offered/receive preventive health interviews/examinations. Have a forward-looking active focus on cervical smears, mammograms, smoking, weight loss, hypertension, diet guidance, diabetes risk, cardiovascular risk, reproductive health, and paediatric examinations.
- **Cancer:** Cancer of the liver, oesophagus, and stomach is more frequent among the target group compared to the local population. Refugees have higher mortality from infections and cancers associated with infections (TB, HIV, chronic hepatitis B/C, HPV).
- **Language:** Be sure to request an interpreter in cases of language barriers, persistent compliance problems, or unexplained symptoms. It is important to explain and ensure understanding of common key concepts.
- **Medication:** Pay regular attention to medication review and remember to include information about medications from the home country or from friends/acquaintances.
- **PTSD:** Refugees with even severe trauma may experience a ‘honeymoon’ period at the beginning of their stay in Denmark. Even ‘minor’ events such as social, language, or work events can later expose PTSD symptoms or similar conditions. Sudden compliance failure, isolation tendency, and altered memory can be signs of PTSD.

7. PTSD and somatic symptoms

War is only exciting to those who have not experienced it. Most people who experience war do so as innocent victims or enlisted men, or as indirect victims of acts of war. Chronic conflicts, war, and crimes against humanity produce the most victims among the innocent, who in addition to poverty and ruined futures have to live with the psychological and physical long-term consequences of armed conflicts. It is easy to start a war but impossible to stop it. For many war survivors and refugees, the war lasts until they die; in the meantime, they have to live and fight with traumas that forever change their personality, memory, and social relationships. The hardest battles begin when the war ends (51). As a refugee, you fight to become yourself again, but you hardly ever win.

The effects of war cannot be solely judged by their psychological consequences however, despite the belief of Western psychiatrists that this approach is safe and comfortable. Not every act of war can be understood from an individual psychological angle in which the problem is the person's reaction, and where one violation leads to a specific reaction. You cannot ignore the context, relationships, or the reactions of the social network to the trauma. Most often, there are multiple traumas, and refugees often experience continuous traumas in the host country. There is no 'post' in post traumatic stress.

A Danish survey of torture survivors and war refugees revealed that 76 % of them suffered from chronic pain, and that somatic symptoms generally accompany patients with PTSD (551). Chronic illnesses such as chronic obstructive pulmonary disease (COPD), cardiovascular disease, and cancer occur more frequently among patients with PTSD (552, 553). A 2003 study among patients referred to a Danish centre for back problems found that almost 10 % had clinical or sub-clinical PTSD and that sub-clinical PTSD patients had less pain 1 year later than back patients with clinical PTSD (554). Multiple unexplained symptoms such as combinations of dizziness, fainting, chest pain, sensory disorders, and stomach discomfort are often some of the primary symptoms of patients with PTSD who contact the healthcare system (555). A 2014 Danish review article found that a link between PTSD and irritable bowel syndrome was detected in 11 out of 14 studies (556). It was suspected, however, that the medical treatment of patients with PTSD could have contributed to their symptoms. No longitudinal studies were available, but there was a strikingly high incidence of PTSD among patients referred with symptoms of irritable bowel syndrome. The theoretical mechanisms being considered are oxytocin dysregulation, hypothalamic-pituitary-adrenal axis dysfunction, vulnerability in the patient group, and post-infectious irritable bowel syndrome.

7.1. About PTSD

The incidence of mental illness among newly arrived refugees is high (557-560). Most refugees have potentially traumatic experiences in their home country or during their flight. Some ethnic minorities have suffered particularly severe and multiple traumas (561). Concurrent physical and mental illnesses, often also with disabilities or abuse, are frequent among refugees, and the clinical complexity challenges the often-unprepared doctors (562-564). Torture survivors are at high risk of being overlooked if their symptoms are primarily physical, and they often experience diagnostic delays (565). In a study at a US health centre, 1 out of 9 (11 %) foreign-born patients who presented to the centre met the criteria for being torture survivors - and they had lived in the US for an average of 14 years (566). In a study from the MHC, we found that over half of the patients referred with unexplained physical symptoms had symptoms compatible with PTSD - and they had lived in Denmark for an average of 12 years (31). A study at a Danish centre for trauma and torture treatment found that the referred patients with PTSD had experienced symptoms for an average of 14 years before being referred for treatment.

Many refugees have complex combinations of multiple traumas, and many of them are quickly suspected of having psychosomatic illness but in reality, they suffer from PTSD. A 2006 study of 145

former Yugoslav refugees referred to a clinic for psychosomatic illnesses found frequent occurrences of a wide range of potentially traumatic experiences - see Table 20 (567).

Table 20. Potentially traumatising experiences among 145 former Yugoslav refugees referred to a German clinic for psychosomatic illnesses.

Traumatic situation	Percent of N=145
Long-term food deficiency/hunger	75.9
No access to doctor/healthcare system	81.2
Long-term homelessness	86.8
Imprisonment	66.7
Injury with no help	77.8
Direct battle situation	54.9
Brainwashing	88.7
Rape	50.5
Unnatural death – close relative	79.3
Witnessed murder – unknown person	77.0
Experienced close relatives/close friend(s) disappearing	76.6
Torture	81.0
Forced long-term isolation	61.9
Near-death experience	87.9
Forced separation from close family	85.6
Murder of family member(s)	80.0

Due to differences in study methods and in war exposure, the incidence of PTSD among war refugees varies among existing studies, but most studies report incidences of between 20 % and 40 %, and some up to 76 % (568-570). The frequency of torture and other potentially traumatising violations varies depending on the country of origin and which wave of refugees the individual was a part of; the prevalence varies between 1 % and 76 %, with a median of 27 % (568). One review found a prevalence of torture of over 30 % in all the reviewed studies and that the combination of previous torture and long asylum phase was associated with a particularly high risk of depression added to the patient's PTSD (571, 572). A clear link exists between the development of PTSD and the experience of torture and other potentially traumatising abuses (66).

A higher risk of PTSD is associated with older age, lower educational level, more traumatic experiences during and after war, lack of combat experience, higher levels of migration-related stress, and having only a temporary residence permit (573). In a Swedish study, the combination of personal and potentially traumatising violations in the home country and post-migration stress with divorce, temporary residency, and work lay-off was frequently associated with PTSD (574). Post-migration factors and types/degrees of abuse affect long-term development (575). The common perception that war trauma alone is the cause of refugees' mental health problems is too simplistic and limits the chances of effective treatment and psychological interventions. Miller and Rasmussen have proposed an ecological model for describing the mental health of refugees that takes into account the stress factors associated with displacement, loss of identity, legislation, social network challenges, etc., which others call exile stress or post-migration stress (576). See Figure 15.

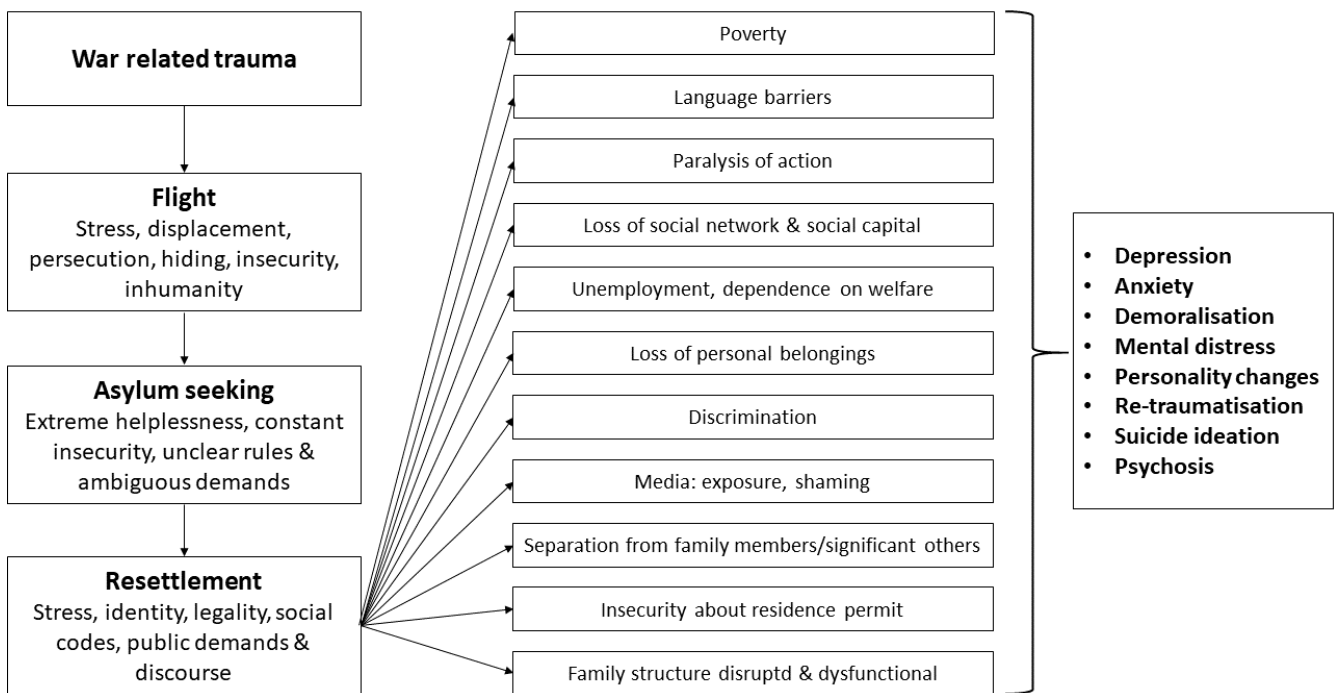


Figure 15. Armed conflicts, displacement, and mental health.

Among refugees arriving in Europe in recent years, 80 % had serious mental health problems and 30 % had experienced psychological trauma during the escape itself - half of the trauma was caused by border guards, police, or military in or at the European borders (557). Trauma during escape is often overlooked and is rarely mentioned spontaneously because it tends to be extremely meaningless and humiliating. Psychological symptoms do not change much over time, and severe mental health problems such as PTSD are still very frequent decades after the escape, with 20-30 % showing unchanged symptoms (570, 577, 578).

The feeling of extreme helplessness in the face of a violent experience makes it traumatic. The traumatic potential is amplified if the incident is meaningless in the patient's familiar mind-set and frame of understanding, and its sudden onset without any warning prevents the patient from changing or mitigating the experience (461, 579). The victim's encounter with the evilness of the executioner or abusers with their clear intentions to harm, injure, or kill is central to the course of treatment. Factors such as degree of loss of control, connection, locus of control, re-traumatisation, and subsequent social acceptance and psychological processing affect the course of the illness (580). This indicates that it is partly the person's interpretation of the experience of danger/loss of control - not the action itself - that is potentially traumatising and partly the reaction of the surroundings to the event (and reaction to the patient's reaction) that can be potentially traumatising. Lack of reaction from the environment can have the same effect (581).

The three core signs of traumatisation are physiological adaptation reactions: invasive thoughts, avoidance behaviours, and high alertness (arousal). The psychological consequences of traumatising events are repression of the experience, extremely vivid cinematic memories, dissociation, experiences of isolation/loneliness, meaninglessness, lack of control over one's own life, self-recrimination, guilt, and shame (581, 582).

Violent disaster-like experiences, extreme helplessness, and torture disrupt basic cognitive and relational functions. Victims of psychological trauma experience changes in normal basic mental processes, which causes disruption of identity and the ability to have intimacy. Experiencing a traumatic event can disturb or even destroy a person's self-perception and view of the external world. The mental numbness and confusion of normal symbolic thought processes resulting from traumatic events can interfere with the restoration of the original self-perception and relation to one's environment. If trauma victims lack a strong sense of self-confidence and feel guilty about what they have experienced, they may be unable to maintain close relationships. The result is isolation and withdrawal stemming from a fear of being close to others. Psychological deafness blocks emotions and prevents interpersonal relationships and intimacy. One's identity becomes marked by separation, disintegration, and stagnation (447, 583, 584). A number of requirements must be fulfilled before PTSD can be considered:

- A.** Previous exposure to exceptionally heavy stress (of a disaster nature). Exposure to extreme helplessness (torture, mass assault).
- B.**
 - 1.** Recurring re-experiences of the trauma by way of 'flashbacks', intrusive memories, uncontrolled re-experiences, or nightmares about specific events the patient has been subjected to; or
 - 2.** Severe discomfort when the person is exposed to circumstances similar to the trauma.
- C.** Avoidance of anything resembling the trauma.
- D.**
 - 1.** Partial (possibly full) amnesia of the traumatic experience; or
 - 2.** Persistent symptoms of physical hypersensitivity or alertness with at least two of the following symptoms:
 - a) Pronounced difficulty in falling asleep or sleeping through the night
 - b) Violent/conspicuous irritability or outbursts of anger
 - c) Socially debilitating difficulty concentrating, possibly a tendency towards dissociation
 - d) Unusual vigilance (hypervigilance)
 - e) Propensity for flinching, non-specific anxiety reaction to minor stimuli.

The most widely used screening tool for identifying symptoms compatible with PTSD is the *Harvard Trauma Scale*, which has also been validated in cross-cultural contexts (585, 586). Several simple screening tools for PTSD have been developed for general practice with virtually equal value and usability (587). The *Refugee Health Screener (RHS-15)* is a well-documented question-and-answer guide for conversations with refugees that is often used in asylum centres and has been translated into several languages. It was developed through participant research in collaboration with refugees and is considered to be particularly sensitive to cultural conditions and refugee experiences. In addition to screening for anxiety, depression, and PTSD symptoms, it includes questions about personal life story and coping strategies (588, 589). A multidisciplinary group of experts has developed a professional guide for family doctors with attention points and checklists for health interviews with newly arrived refugees (590).

It is important to understand PTSD as a normal human response to an extraordinarily abnormal situation. Many patients with PTSD have the perception of being broken, and they fear being 'insane' (psychotic). Patients with PTSD are on high alert and are constantly on watch, which drains their mental strength. The vigilance makes patients particularly sensitive to sounds, smells, physical surroundings, colours, music, or voices. They are easily disturbed by unexpected signals and quickly lose track of the conversation. Frequently, the patient may dissociate away from the situation or experience that body and head are being separated.

Table 21. Symptoms included in the screening tool HTQ-5 PTSD.
Patient should rate each question from 'not at all' to 'very much'.

<ol style="list-style-type: none"> 1. Repeated thoughts or memories of the most violent or frightening incidents 2. Feeling that the incident is happening again 3. Repeating nightmares 4. Feeling detached or withdrawn from people 5. Cannot feel emotions 6. Constantly feeling alarmed or easily startled 7. Concentration difficulties 8. Trouble sleeping 9. Feeling of vigilance, alertness 10. Feeling irritable or having outbursts of anger 11. Avoids activities reminiscent of the traumatic or hurtful incident 12. Inability to remember parts of the most hurtful or traumatic incidents 13. Little interest in daily activities 14. Feels like the patient has no future 15. Avoids thoughts or feelings associated with the traumatic or hurtful incidents 	<ol style="list-style-type: none"> 16. Sudden emotional or physical reaction when the patient is reminded of the most hurtful or traumatic incidents 17. Feels that the world is a very dangerous place 18. The patient feels like a bad person 19. Blames self for the traumatic incident 20. Strong sense of fear, horror, anger, guilt, or shame when the patient thinks of the traumatic incident 21. Difficulties feeling love or happiness 22. Taking risks that could harm self or others 23. Feels as if the patient has been damaged as a person by the traumatic incident 24. It feels like something reminds the patient of the trauma, but it feels like a dream that is not happening to the patient and/or that it is not a real experience 25. Feels people or objects around the patient are weird or not right
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Many clinical case studies have illustrated the central role of somatic complaints in PTSD symptom presentation among refugees (447, 592-595). The physical symptoms that can accompany PTSD include stress symptoms of anxiety such as palpitations, shortness of breath, cold sweats, hand tremor, dizziness, and feeling faint.

There is a complex reciprocal and synergistic relationship between post-migration factors, pain experiences, somatisation, anger/frustration control, and worsening PTSD symptoms (596-599). Negative self-esteem and low self-worth in patients with PTSD increase the risk of later developing somatic symptoms, but integration challenges and cultural traditions can also increase the somatisation trend (600-602).

PTSD affects emotional regulation whereby the patient loses control of emotions such as anxiety, anger, irritability, depression, guilt, and shame (603). The sleep pattern is destroyed by nightmares, and exhaustion is very prevalent. Pain is the most common physical expression in PTSD (604). Patients who have chronic pain also have a significantly higher frequency of PTSD (605). Patients with chronic pain have worse PTSD symptoms than patients with PTSD without pain, just as pain that occurred after a traumatic experience increases the risk of PTSD (606, 607). Patients with PTSD and concurrent pain experience significantly more somatic health problems, more acute hospitalisations, and more often multi-morbidity (608). Pain and PTSD are both characterised by fear and avoidance behaviour and when they occur simultaneously, they can mutually initiate and reinforce each other. Fear increases the pain intensity and prompts flight mechanisms and anxiety. Some believe this to be a reciprocally maintaining effect where an acquired hyper-attention to internal and external stimuli increases the awareness of pain stimuli (609, 610). In other words, a reciprocal vulnerability exists where the high alertness leads

to higher awareness of anxiety stimuli, which in turn increases the pain experience (604). For PTSD treatment to be effective, it must be accompanied by concurrent treatment for any pain symptoms (602).

PTSD and potentially traumatising assaults frequently lead to personality changes that persistently reduce the refugee's tendency to connect and may prevent the patient from being receptive to personal support and cognitive therapy (611). Many refugees experience new traumatic events in the host country, but we must distinguish between fluctuations in PTSD symptoms, re-traumatisation, and avoidance behaviour in connection with psychological/psychiatric processing (612). The complex adaptation process requires attention to both PTSD-related stress and integration/adaptation stress when assessing the patient's main difficulty and this is where one encounters large ethnic differences (613). See Figure 16.

Both forced and voluntary migration are associated with a higher risk of developing psychosis. In a large Swedish registry study, war refugees were three times more likely to develop schizophrenia than the local Swedish population, and for non-war migrants the likelihood was 1.7 times higher (559).

Somatic symptoms are frequent among refugees, but they also tend to be interpreted as somatisation with high risk of diagnostic delays, misdiagnosis, and treatment errors (31, 36, 51, 81, 180). Studies on the frequency of somatic symptoms without a known physical basis are sparse and have involved incomparable patient groups (psychiatric patients, surgical patients, medical patients), and no prospective population studies are available. Reviews often find a high degree of somatic symptoms in depressed migrants (over 80 %), while the degree of somatisation in surgical and medical patients is found to be around 35-48 % (614). The same uncertainties apply to patients with PTSD where most studies have been carried out on patients referred for treatment and there are no population studies. Somatisation among war refugees occurs in 18-30 % of the cases, but the incidence is almost as high among migrants with exile stress, unemployment, and integration challenges, and the same applies to adults who have experienced abuse as children (614).

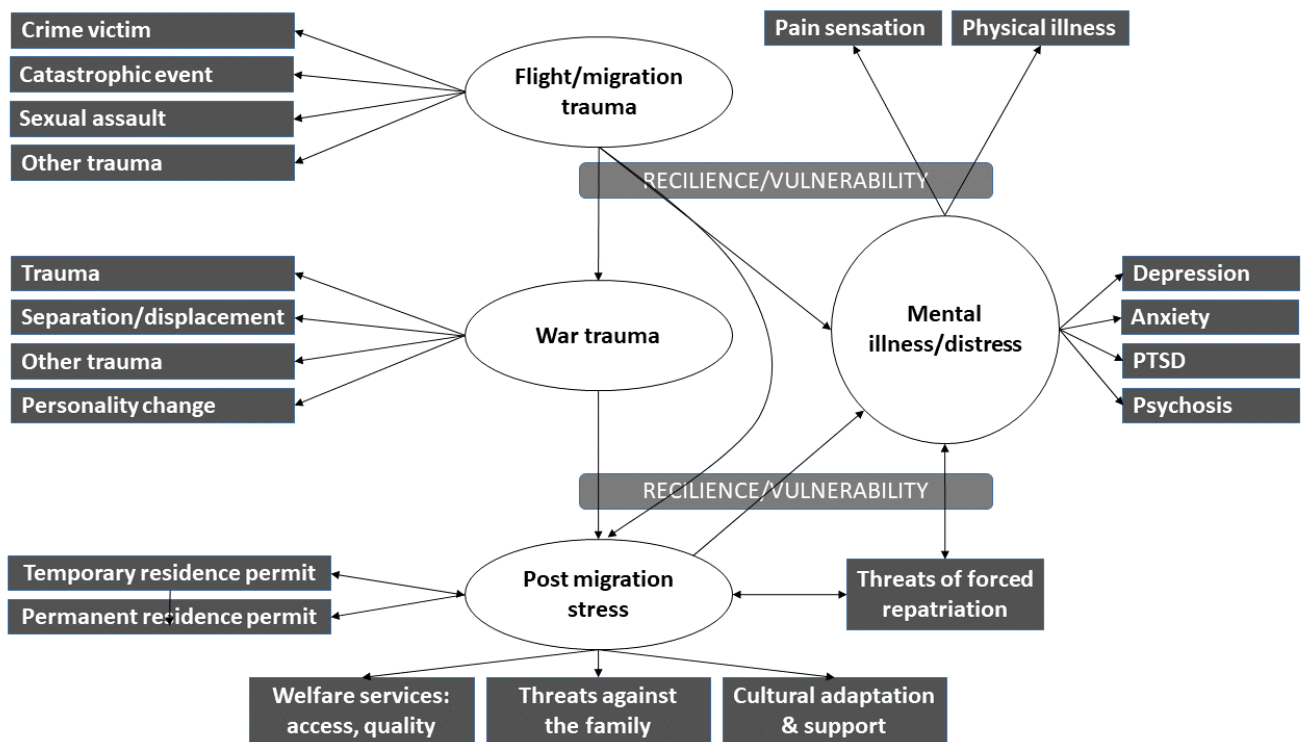
Torture is an extremely complex problem area (615, 616). Some types of torture are so bizarre that refugees dare not talk about them for fear that their explanation will be considered fallacious (and thus deny their credibility as informants). It often takes a long time before the torture survivor is examined, and it can be difficult to get all the details clarified, but obtaining a detailed verbal description helped by the doctor's knowledge and competencies can be crucial to detecting torture injuries (617). Some forms of torture cause nerve damage, permanent damage to connective tissue, or discrete fractures, the causes of which can later be downplayed if the doctor is unaware of potential links with physical abuse and torture (551, 618). Small scars after injections, sutures of wounds, anal and vaginal injuries, complications from torture with electricity, prolonged stay in ice water, or prolonged hanging can all be completely overlooked later or misconstrued as injuries and nuisances occurring after arrival in Denmark where refugees are often employed in physically demanding jobs involving heavy lifting, cleaning etc.

A Danish registry study found that PTSD with depression was associated with an increased concurrent incidence of a number of somatic illnesses such as infectious diseases, rheumatic and inflammatory diseases, neurological diseases, and lung diseases (619). Multi-morbidity is observed in about 40 % of newly arrived refugees, which often challenges the healthcare system in the recipient country (594). Acute calls most frequently concern infections, e.g. pneumonia and skin infections (620). Most refugees present with accompanying chronic symptoms such as dizziness, headaches, stomach-ache, difficulty sleeping, and reduced appetite. Refugees often present late with relatively acute medical problems together with severe mental illness, which challenges emergency rooms that lack adapted guidelines, medical skills, and time (621). Several studies have documented high incidence of epilepsy and of neuropsychiatric symptoms that may be caused by malnutrition, electrolyte disorders, previous head trauma, previous infections, and deficiency diseases such as vitamin B-12 deficiency (622-624).

Figure 16. Pre- and post-migration factors affecting psycho-social stress level.

Modified from Hollifield et al.: Mental Health Effects over the Lifespan of Refugees. *J Clin Med*, 7.2 (2018):25. (Licensee MDPI, Basel, Switzerland). This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution (CC BY) license (<http://creativecommons.org/licenses/by/4.0/>).

21. Cross-cultural conflicts and misunderstanding



One particular, but somewhat overlooked, problem with PTSD is that children who grow up with parents where one or both suffer from PTSD often develop signs of mental strain themselves. A large cohort study found that children of parents with PTSD more frequently developed behavioural difficulties (such as hyperactivity), mental health problems, emotional problems, and conflicts with others of the same age (625). The same study found that post-migration factors amplify and maintain PTSD symptoms that, along with the often multiple and unclear demands that society places on refugee parents, led to a tough parenting style combined with periods of emotional flatness depriving children of the all-important regulatory support that ensures healthy upbringing and ability to enter into normal relationships with others of the same age and adults. Other studies have shown how learning and negative educational culture can cause PTSD symptoms, stress symptoms, and reaction patterns to spread across generations (626,627). Torture trauma has even been found to transfer over three generations (628).

7.2. Migration, literacy, and patient communication

Migration involves loss of language (especially everyday language and dialect), attitudes, values, social structures, normal life strategies, management options, and support networks. The language, the mother tongue, will often be the only remaining item that gives the refugee identity, security, and peace of mind (196). For particularly fragile refugees with war trauma and no schooling, their mother tongue is the only sure means of communication, and attempts to change such a fundamental element of an otherwise chaotic and unsafe refugee life are associated with fear and high alertness. As a result, both

their own cultural identity and conformity to the new culture are being eroded simultaneously, leaving the refugee in an unconstructive linguistic no-man's land. Many of the patients referred to the MHC have ended up in a linguistic limbo and have given up on language, body, health, and social interaction. It is a humanly costly condition centred around lost language and consequently lost identity. The primary tool of patients and doctors is communication via language. Symptoms, causes, diagnoses, and treatment become meaningful through language. If the necessary understanding and respect for language is not present as the primary tool - and it must be as intact as possible - then mistakes, misunderstandings, and complications arise in patient care (178, 180).

Traumatised refugees who arrive in a new country are exhausted and disoriented. They face many concurrent and new challenges such as securing their stay, learning a new language, encountering a new culture, finding housing and employment, and adapting the parental role. Although it is important not to medicalise the effects that war and other disasters may have upon individuals, one should not underestimate their influence on the person's options to adapt to life in a new society as a refugee in exile. The challenges of resettlement in a new country cannot be separated from literacy and linguistic development. Literacy also includes numeracy, problem solving, and the ability to read in addition to being able to write and speak in Danish. Moreover, it involves emotional and social skills such as motivation, effective interaction with other people, critical thinking, and cultural awareness (629).

Most studies on learning processes for refugees document the importance of understanding the psychological trauma that many refugees have endured before arriving in their new countries. Trauma can include physical and psychological torture, living in primitive conditions in transit camps for long periods of time, long-term separation from family and friends, and cultural alienation in their new host communities (3). Refugees who are found to have learning difficulties are characterised by powerlessness, de-motivation, depression, anxiety, hopelessness, and lack of plans for the future. They often have unsuitable ways of resolving conflicts and have often only had sporadic, unscheduled schooling due to unrest, flight, and constant migration (630). A number of frequent learning challenges have been identified, which are rarely taken into account in the meeting with refugees/immigrants (631):

- Lack of education in the home country
- Inability to read/write in their native tongue
- Difficulty concentrating
- Self-perception - low self-esteem, low expectations
- Low motivation, no interest
- No trust in any result or purpose
- Distrust and fear of officials

No authoritative data exist on the educational qualifications among newly arrived refugees. New Zealand has investigated mandate refugees from Somalia, Zimbabwe, Congo, Iraq, Columbia, Indonesia, Ethiopia, Burma, Bosnia, Eritrea, Iran, Bhutan, and Afghanistan (i.e. countries from which Denmark also receives refugees). The New Zealand study found that since 1995, 80 % of adult mandate refugees in New Zealand had no primary education on arrival, and about half of this group were illiterate, with the remainder being functionally illiterate (i.e. able to read at a level corresponding to 5th grade level). Of the refugees, 40 % had no literacy skills in their own language (native language) (631). For adults with minimal or no schooling, the need is primarily centred on their lack of literacy (including in Danish), which is often complicated by the fact that many cannot read in their native language. Not being able to read in one's own native language has significant implications for learning a second language. If, for example, a person does not know that written words mean something (which one would learn in their own native tongue) then it will be difficult, if not impossible, to learn how to read in another language.

PTSD has similar cognitive consequences within a broad range of widely varying long-term consequences for quality of life, sleep, language learning, self-care, and understanding of disease treatment (31, 632-634). Often, a simultaneous development of mental and academic deficiencies takes place with elements of mental illness, affected learning, inadequate language acquisition, incomplete stress management, and anxiety of breaking routines (635). Some PTSD patients display changes in emotional expression and behaviour in the form of indistinct or ambiguous body language, lack of facial expression, loud voice, and over-vigilance, all of which can give an outward impression of disorganisation. Severe and long-term PTSD symptoms with memory problems are also associated with large 24-hour fluctuations in blood pressure (187). Some types of trauma even seem to reduce IQ (636). Moreover, refugees often have little or no schooling and are, by their very nature, typically older than the usual school age. While there may be a high motivation to acquire another language for biological and cultural reasons, it is significantly more difficult than expected (637). Culture-based incidents, experiences, and attitudes towards schooling and the acquisition of knowledge can also affect learning opportunities; just as the understanding that knowledge acquisition has meaning and opens up opportunities is strongly correlated with the development of language competencies (638). A British study on integration level and language acquisition among war refugees found that the strongest factor for high integration and usable language acquisition was the receipt of a permanent residence permit (639).

The link between trauma and impaired learning ability and memory is not new. Permanent and significant cognitive problems have been identified for adopted children, Holocaust survivors, elderly who were sexually abused as children, and Russian Mennonite refugees to Canada (1023,1323-1326). PTSD affects learning ability through several different cognitive mechanisms: impaired memory, poorer concentration, slower thought processes, poorer combining skills, inability to learn new knowledge, inability to perform actions, and reduced problem-solving abilities (1327-1330). Some forms of memory are particularly affected by PTSD, but verbal memory is consistently an early and persistent loss of function (1328, 1331-1333). The degree of memory impairment and misunderstanding is related to the frequency and degree of flashbacks (1334). Patients with PTSD have cognitive difficulties that are important in language learning; this can lead to difficulties in directing attention, uncertainty about relationships between cause and effect, planning, use of tools or materials, processing of new information, focusing on and completing tasks, and language development problems, e.g. in the form of a large discrepancy between impressive and expressive communication skills (1335-1336). Due to the impaired and distorted access to memory, patients with PTSD have a harder time 'reading' social contexts and are worse at solving social problems than others (640). Patients with PTSD more often misunderstand the meaning of negatively charged words and become more easily distracted in social contexts (641, 642).

7.3. PTSD-cases

Case 1

A 36-year-old man from a Middle Eastern country wishes to have a conversation without an interpreter. Four years earlier he had been referred acutely to the neurological department on suspicion of multiple sclerosis (MS). He was monitored in the neurological department for three years. However, in connection with a change in doctor, doubts arose about the diagnosis, and it is now believed that there is no illness of the central nervous system but that the peripheral system should be examined. The patient is frustrated by these new considerations, but it is uncertain whether the patient himself declined further examinations or whether it was the doctor in the neurological department who said he would be discharged from their care because he did not have MS. Interpreters were not always used in the process. The patient is now referred to the MHC with chronic unexplained pain.

The patient primarily suffers from sensory disorders of his fingers and face. He has a very high stress level, shows avoidance behaviour, is on high alert, and has to keep his anger in check (he was

subdued throughout the conversation despite its serious content; he was also subdued towards his wife and children). Furthermore, he has marked fatigue (often after five minutes of conversation) and constant headache in the crown of his head. He explains that he cannot tolerate breaks in his routines and has difficulty dealing with new situations (such as the diagnosis being called into question).

The patient had worked as a tailor since he was seven years old. However, he lost his right hand in a work accident when he helped a friend in a machine shop. He received only a small, symbolic disability pension. He recounts very violent experiences in his home country and especially during his escape, when he was forced to perform very unpleasant tasks under the threat of death, *‘Those soldiers were not people; they were like animals.’*

The patient has become forgetful: he opens his phone but immediately forgets what to do with it, and he can watch the same film several times without recognising the action. He often tries to go on a trip with his wife and children but turns around on the way out of town. His younger brother came to Denmark at the age of 16. Now 19 years old, the brother is living in a village 15 km from the patient. His younger brother often asks for money and help as an interpreter in meetings with the municipality. The patient feels stressed by this, and he cannot afford to send money to the family in his home country or to give his brother money. He has a large private debt of DKK 25,000 to shops, friends, and the bank, so he cannot see his friends or go shopping. Due to this overload, the patient has developed an erection problem that is about to break him - he is afraid of what his wife might think, *‘I have lost my life twice but will not lose it one more time.’* He feels his spouse is very understanding, but he blames himself, *‘I haven’t asked for these symptoms.’* He feels it requires too much energy to have to control himself, live with so much stress, and have so much undue responsibility. He feels helpless. He sometimes has thoughts that life would be easier if he was dead. He is now asking for help but only for the sake of his children, who mean everything to him and make him happy. Had he been single, he would not have asked for help because it requires him to recount and remember what he would rather forget. He is at a breaking point, he can no longer cope, and he is afraid of eventually not being able to control himself, *‘I don’t want the kids to experience that.’*

Comment: *The neurogenic pain that often accompanies PTSD is frequently misdiagnosed. Sexual dysfunction among refugees often has a complex background where sexually, explicit torture, and lack of options as head of the family, reinforce each other.*

Case 2

A 39-year-old woman from Northeast Africa. Persistent complaints of lower back pain. Acutely hospitalised many times with chest pain via the emergency department and the cardiology department. Sometimes via an ambulance. Nothing definitively abnormal has been found in blood tests or ECG, and the cardiology department recommended referral to the MCH. The referral also states: ‘Objectively: nothing definitively abnormal.’

The patient speaks Danish. She says that she comes from a rich royal family and that she has had 13 years of schooling. In addition to speaking Danish, she is fluent in English, which she learned in high school in her home country.

The patient presents with pain in her lower back, back and chest as well pain in her abdomen and during intercourse (although she is now divorced). A little hesitantly, the patient talks about her urinary and faecal incontinence. She has five children with the ex-husband (the one who demanded a divorce). One of the children has a mental illness, and the middle son is in prison. Due to her divorce and mentally ill child, she has been isolated from her ethnic group. She describes severe and specific nightmares, avoidance behaviour, and unspecific anxiety that overwhelms her several times a day. She cannot watch TV or tolerate loud noises. She dares not go outside, she feels persecuted, and her children have to do the shopping. The slightest sound makes her flinch. She is afraid of men. She was reported to the municipal control group after she was on her way out of Denmark with a large amount of money in cash

and without the permission of the caseworker. In connection with her life story, she says that when she and her sister were 10-12 years old respectively, they were subjected to an attempted rape by four men who dragged them onto the roof of an unfinished house. The patient saved her sister from rape but was herself pushed over the edge by the men and fell three floors down, landing on her back. The sisters' brother who came running to help was shot in the head by the assailants in revenge while the patient lay on the ground watching. She broke her back and after an operation, she lay in plaster in a hospital for three months. The parents were never told what happened, but the patient reacted so strongly psychologically to both being stuck in plaster and to the rape experience that she was considered insane, whereupon she was tied up and locked in the home for three years. Then a serious clan conflict arose that forced parts of the family to flee, first to Kenya and later to a refugee camp in Saudi Arabia, from where she and her father were granted refugee status in Denmark. The mother stayed with a relative in Saudi Arabia. Now, the mother has advanced metastasising breast cancer and is in a private hospital. So far, no one but her sister knows what happened in the home country. The patient has a complex mental and physical trauma that she cannot talk about, and there are obvious symptoms compatible with PTSD. It turns out that she has had urinary and faecal incontinence since the attempted rape, and this has been exacerbated by her five births. Due to her discomfort and pain during intercourse and the incontinence, the spouse demanded a divorce. Her back pain is well explained by her accident at the age of 12. Her chest pain turned out to be anxiety that she was suffering from breast cancer just like her mother. It was not heart pain, but pain triggered by anxiety and amplified by the elevated alertness due to PTSD. To help pay for her mother's cancer treatment, she had withdrawn her cash benefits, taken out a quick loan, and borrowed cash from her only remaining friend. She was stopped by police at the airport with this cash on her way to Saudi Arabia to pay her mother's hospital bill. The patient broke down at the airport when a customs officer berated her, saying she should go home if she was that rich because refugees did not have that kind of money. The patient was summoned for questioning at the municipality's control unit, but at that time, the patient was very anxious and unable to provide a coherent explanation. The money was confiscated, and the patient was sanctioned in her social benefits. Then came a series of emergency hospitalisations due to pain. Network meetings were held with the concerned municipal authorities, who were not aware of either the patient's own history or the mother's acute illness.

Comment: *Refugees with health problems or disabilities experience a stigmatisation within their own minority group: they feel physically and verbally imperfect, which reinforces the tendency not to talk about health issues, even to those who are closest to them. Strong family ties, social networks, and greater societal tolerance for deviations have a positive effect on living with mental illness in one's home country. When people migrate, protective factors disappear and are replaced by a very unfortunate and harmful exclusion. Together with the poor cultural competencies of the healthcare system and the social authorities that lack the necessary professional cultural skills, this puts particularly vulnerable refugees in an irreversible maladjustive situation with no possibility of fighting their way out. Refugees often struggle alone with their trauma, violent experiences, and abuses that are associated with guilt, shame, and social exclusion. As a starting point, neither the framework nor the approaches or competencies exist within the public authorities to deal with the refugees' full situation. This means that refugees end up in complex situations that can be difficult for professionals to understand or change.*

Case 3

A 55-year-old woman from the Middle East is referred with migraines over a 10-year period. She has pain in all joints, has no muscle strength, and is depressed. She could not handle her children and was in despair. Her own doctor writes that no physical abnormalities have been found and her blood tests are normal and that the patient has been seen by a private neurologist and gynaecologist.

In her home country, the patient worked as a judicial secretary. A militia soldier killed one of her nieces while she was forced to witness it. She came to Denmark as a refugee, learned Danish quickly, and got a job in a day care centre. The patient became ill on the day a bearded young male assistant started. The patient explained that the man was similar to the soldier who had killed her niece in her home country. The patient never returned to the labour market. She lost her Danish language and had attempted suicide several times, which she had not previously mentioned. The patient is referred to trauma and torture treatment. Routine blood tests showed very high calcium content in the blood, which could explain her fatigue and headaches. She also had impaired kidney function, which can also cause fatigue and muscle soreness. X-rays of her thorax showed large glands in the mediastinum, and the patient was subsequently diagnosed with sarcoidosis.

Comment: *The importance of a thorough medical history based on the life history is emphasised. Refugees who significantly change their behaviour or suddenly exhibit isolation tendencies should be suspected of re-traumatisation.*

Case 4

A 41-year-old woman from a Middle Eastern country. She was referred with headaches, shortness of breath, and unexplained sweating. At the time of the referral, she had been seeing a psychiatrist for anxiety treatment for two years and had participated in ten psychological interviews. The patient was referred to trauma and torture treatment by the family doctor, but she was rejected at the trauma centre due to no documented trauma history in the home country. The eldest, adult daughter always accompanies her mother to the doctor.

When interviewed at the MCH with an interpreter, the patient says that she was a strong person when she came to Denmark, but that *'something happened'* that made her weak. The patient is demonstrably evasive when requested to explain in more detail. Consequently, the interpreter and daughter are asked to leave the consultation room, and the patient describes a dramatic psychological change when she saw the neighbour's two-year-old son fall from the sixth floor and die. This reminded her both of incidents related to a bombing in her home country and that as a child she saw several mutilated children after a shelling in a playground. Later, a fire in the stairwell to her apartment in Denmark exacerbated her re-experiences, which became increasingly uncontrollable and invasive. The patient says she had previously blocked out that she had been in prison in a transit country on her way from her home country to a domestic job in Abu Dhabi. She had suffered physical and psychological humiliation in the prison and also had to witness physical abuse of fellow prisoners. She was never told why she was imprisoned. At night, they were all herded into a small, completely dark room where they could hear people screaming somewhere in the building, and several of them died along the way.

Case 5

Male refugee 29 years of age. Numerous emergency visits to the doctor and acute hospitalisations. According to his own doctor and the emergency department, he complains of many unclear symptoms. The cardiologists have investigated the patient for chest tightness and possible palpitations. Propranolol was tried with modest results. The psychiatric department does not believe the patient has PTSD and finds that he had experienced psychosomatic symptoms in his home country for years. They also find that he hyperventilates, uses a lot of painkillers, and is strongly somatising with anxiety symptoms in the form of chest tightness and palpitations. Anti-anxiety medications had scant effect. He appears upset, and this is attributed as a normal reaction for a relatively newly arrived refugee. On several occasions, he has left the psychiatric emergency department in anger, saying the medication does not help with his shortness of breath or palpitations. He has had five acute medical hospitalisations where he showed signs of hyperventilation and normal blood tests and ECG; it is noted that 'no signs of disease have ever been

found' and that there is 'hardly any evidence of serious somatic disorder'. He leaves the emergency department in anger each time, and no interpreter has ever been used.

During the patient's first interview at the MHC, he initially appears distrustful, disillusioned, uncooperative, angry, and disappointed, and he responds only with monosyllabic words. With the help of the interpreter, the patient is persuaded to tell his life story. He was jailed at the age of 14, punched and kicked, and he witnessed other prisoners being sexually humiliated. He has constant nightmares about his experiences and only sleeps during the day. He has witnessed indiscriminate summary executions and was forced to carry the bodies of dead soldiers. Meanwhile, his family was in a refugee camp surrounded by violent rebel forces and were unable to visit him. He explains that his symptoms started in his home country before the most serious acts of war. His doctors said he had weak lungs. He describes his symptoms as sudden onset of pain in his chest, arms, and back with breathing difficulty and a tightness deep in the chest. He has clear signs of early PTSD effects with personality disorders as well as high stress levels, isolation tendency, difficulty controlling anger, nightmares, paranoid thoughts, difficulties with waiting and disruptions to his routine, uncontrolled re-experiences, distrust, and dissociation. He also has difficulty reading body language, and all sounds are misinterpreted as torture sounds (children making noise, radiators, etc.).

The patient undergoes lung X-rays that are initially interpreted as tuberculosis. The patient rejects bronchoscopy. A PET scan is requested, but the patient refuses when he is informed of the radioactive tracer. He is called in for treatment for tuberculosis, but he leaves the outpatient clinics as no interpreter has been ordered and is terminated from the tuberculosis clinic. The MHC assigns a single contact nurse and an interpreter to the patient, and when a PET scan and bronchoscopy are performed, they show that the patient has sarcoidosis in his lungs and lymph nodes.

Comment (case 4-5): *Patients subjected to extreme violence or assault as adolescents are often unable to link their behaviour as adults to these experiences. Patients with PTSD and high stress levels have difficulty tolerating errors and waiting times, and they cannot adapt to new situations without support. It is important to know the patient's background, especially in examinations involving tubes, hoses, biopsies, oscopies, measurement of nerve conduction rate, scans with rays and/or injection of radioactive tracers. Many forms of torture involve physical restraint, confinement, needles, electricity, and sexual assault with devices similar to hospital instruments, and torture involving water and cold.*

Case 6

A 40-year-old man from the Balkans, who came to Denmark with his parents. His father has suggested that the patient be referred to the MHC. The patient has complained of neck pain and headaches for many years. He has been in a treatment program at the former Rehabilitation Centre for Trauma and Torture Treatment (RCT), but no trauma was identified and he was unwilling to discuss his past. He speaks Danish and is in supported employment. He has been treated at several headache centres and been examined by neurologists and several pain clinics without success.

While the patient's problem list is being drawn up, the patient says that he is not actually interested in pain management, *'You mustn't take the pain away from me. It is the only thing that keeps me alive and tells me that I have actually experienced what I have experienced.'* When confronted with RCT's observation that he would not talk about the past, the patient explains that what he has experienced is so strange that he has found it best not to talk about it. He was a prisoner in a camp that looked like a concentration camp. Here, the prisoners were subjected to bizarre acts and embarrassing torture that the captors said were done deliberately so that no one would believe them if they ever got out. He gave an example. When he came to Denmark as a refugee and was seeking asylum with his parents, the police interrogated him and laughed when he told them about some of the abuses - and not even the worst ones. They did not believe him and thought he was making it up to help his family to get a residence

permit. The Danish police laughed the same way as the torturing soldiers had in the camp in their home country. *'I felt sorry for them because they couldn't understand,'* the patient said. *'Even when I'm in Bosnia and meet others who were in prison at the same time, we avoid each other because our torture was too embarrassing and everyone knew, but no one could talk about it.'* The patient went on to say that the interpreter at the asylum centre in Denmark had started crying and stopped him, saying, *'I can't, that's not what I thought it was.'* The patient then learned that it was best to keep quiet. Later, a psychologist at a pain clinic told the patient that he should forget the past and look to the future. As a result, he continues to have uncontrolled re-experiences where he hits his head and back against a wall to stop his thoughts. The pain serves as a confirmation of and testament to the abuses he was subjected to, and the self-inflicted pain helps to soothe the pain from the torture. He lost his job after seven years due to having taken too many sick days. According to the patient, it was because his boss was scornful - the same way the guards had been in the camp. He forgot one appointment with the social worker in the municipality and was subsequently threatened that his cash benefits would be penalised. The patient describes his reaction, *'I saw a soldier laughing at me humiliatingly.'*

Comment: *It is quite possible that certain forms of torture are intended to be so deviant that the patient cannot talk about them. Humiliation and extreme powerlessness are elements of torture that can be relived, and these elements can amplify invasive thoughts in other contexts.*

Case 7

A 37-year-old male refugee from the Balkans. The patient was referred with headaches, difficulty concentrating, difficulty sleeping, and a tendency towards isolation. The patient appears at the conversation heavily sweating, with restless motor functions, hand-wringing, and pressured speech. He talks sporadically and incoherently. For many years, he has worked in a metal factory alone at night. He was fired after accidentally destroying an expensive piece of equipment. He says that he felt good working at night because he did not have to sleep. However, he started having many 'films' running in his mind at night at work. It was during such a 'film' in his head that he forgot to turn off a machine that then fried. He has flashbacks of being subjected to particularly cruel torture involving child abuse. He lives only for his daughter but can only talk to her 5-10 minutes before he gets nervous, starts shaking, and has an anxiety attack, and then has to go into his room. His parents come to stay with him during the day while his wife is at work and his daughter is at school. The patient is referred for treatment of his psychological torture injuries and subsequently undergoes an extensive treatment program with a private psychiatrist specialising in the treatment of PTSD. At the same time, the patient has supportive conversations at the MHC as he dares not talk about his thoughts with anyone else. He meets his caseworker every three months, but this is a heavy burden because he fears what the municipality might impose on him. Therefore, he uses the MHC as a stress-reducing buffer in relation to the municipal office. After five years of treatment and support, as well as a traumatizing resource process, the patient is granted early retirement and he buys himself an allotment garden house. These two circumstances put the patient in a calmer state where he achieves better control. He can now describe how his rapid pulse and profuse sweating contribute to continuing his state of high alertness. Treatment with propranolol nifedipine (P-N) is started, whereupon the patient gains further control over his PTSD.

Comment: *Some forms of torture are so bizarre that they forever change one's personality and cause uncontrollable, violent autonomic symptoms. As in this case, municipal measures and treatment can sometimes have an unintended and prolonged effect. The patient has pronounced autonomic dysfunction contributed to maintaining a state of alertness. It was only when he became 'free' of the municipality and was able to create a free space for himself that, with simple medical treatment; he gained control over his body.*

Case 8

A 32-year-old man from Northeast Africa was referred to the MHC due to diagnostic and treatment compliance issues. For one year, unsuccessful attempts had been made to get the patient to accept that he had tuberculosis in his spine with the development of a large, tuberculous spinal epidural abscess and that he needed six months of medical treatment. The disease was now endangering his mobility. The patient refused to believe he suffered from tuberculosis. He insisted that it was an infection and therefore asked for penicillin, which the department rejected. The patient speaks Danish and does not want an interpreter.

During the first interview, the patient was clearly distrustful and dismissive of any renewed conversation about his illness. He agreed, however, to tell his life story. At the age of nine, he was forced by a militia to kill his parents and was trained as a child soldier. He remembers that they were forced to take pills and smoke marijuana before partaking in war activities. At the age of 14, he fled through the desert to a UN camp in Kenya, and from there he became a mandate refugee in Denmark. He learned Danish and took the 10th grade public school exam. He has worked as a cleaner, taxi driver, and warehouse worker. He says that he sometimes hears voices that speak ill to him and tell him to do things such as setting fire to his apartment because the voices said there were soldiers who were after him and had been hiding in the apartment. He subsequently tried with some luck to keep the voices away by chewing khat.

His current illness started when he went to his doctor because of pain on the right side of his stomach. The doctor interpreted it as myalgia in the abdominal muscles and gave him an analgesic injection that also contained steroids. After the injection, the patient developed a chronic infection at the insert site, from which pus constantly flowed. The doctor tried antibiotics without success and referred the patient for hospital treatment. It was found that the patient had re-activated tuberculosis with an abscess formation that was so large it had caused the abdominal pain for which he had been seeking medical attention. The doctor's injection had created a fistula to the tuberculosis abscess. Faced with this information, the patient became angry. He did not acknowledge the Danish doctors' diagnosis. *'Tuberculosis is a disease of the lungs from which you die - it cannot sit in the stomach.'* He wanted the doctor who had given him an infection with his dirty needle to apologise and give him penicillin. Because of the patient's experiences in his home country, he tended to distrust adults - even doctors. He was afraid of needles and blood tests and had repeatedly refused to have a biopsy of his stomach. As an experiment, it was suggested that they enter into a something-for-something agreement; the patient would first get five days of penicillin, and if that did not help then he would start six months of tuberculosis treatment, but on the condition that the entire agreement would be kept. Otherwise, the patient would not get any penicillin treatment. The patient accepted this and after five days of penicillin with no effect, he completed six months of tuberculosis treatment. The patient is now physically healthy and has permanent work. He refused treatment for his complex PTSD as he was afraid of having to talk about the acts in which he had participated. He was convinced that having handled the illness that had been bothering him, only good work would cure his mental health problems. He was right.

Comment: *This is a very complex physical and psychological issue characterised by the early injury of the patient by forcing him to perform atrocious acts towards his parents and later, under the influence of drugs, as a young teenager committing crimes also under death threats. He has developed a paranoid personality disorder that has, along with anxiety and high alertness due to PTSD, affected his ability to communicate and maintain self-care. Stress reduction through recognition and mutual decision making was the solution. Some PTSD patients are best helped by engaging in good, calm work of their own choice. This case confirms what many refugees say: many dirty choices must be made during a war and while you are on the run. These are situations where you cannot be a hero and where the choice is between you or someone else dying. It is a trauma that you have to carry alone, but that does not make it any easier. Sharing these situations can make them easier, but it requires that the*

therapist recognise that most often they are human reactions to extremely inhumane situations and bizarre options. Many patients with PTSD self-medicate with alcohol, painkillers, extreme chain-smoking, nightly overeating, khat chewing, or drugs.

Case 9

A 47-year-old woman from a war-torn country in East Africa. She is a divorced mother with seven children who came to Denmark as a refugee in 1998. She was referred to the MHC due to: 'Many doctor visits with unspecific complaints. Blood tests normal. Symptoms cannot be explained by objective examinations.' Her own doctor has used an interpreter for the conversations.

The patient asks for an interpreter to be present and explains that all she wants is to have a full body scan that can '*see what is in there that has gotten stuck and hurts.*' When the patient is initially asked to tell her life story, she will only agree to do so if the male interpreter leaves the room. She says that she has experienced many atrocities in the village where she lived with her mother. The mother and patient were alternately raped, stabbed with sabres, and beaten with sticks. '*It's one of the only things Mum and I have in common, even if it's not nice.*' She saw her mother get buried alive, and she managed to flee in under a bush with many thorns. All of the village's remaining dead residents were thrown onto the thorny bush on top of the patient, and many thorns were pushed into her body. She was the sole survivor, which she feels guilty about. She now feels that there are thorns migrating around her body and brain, which gives her pain and ugly thoughts. She has continuous nightmares about soldiers coming and strangling her, so she barricades her front door and windows every night, even though the kids try to get her not to do it as it scares them. She gets up several times a night to check that there are no soldiers, and she wakes the children up to make sure they are not dead. She forgets her thoughts when the children are around, so she often keeps several children at home from school if she feels that she is going to have a day with many re-experiences. Two of her children are blind and mentally disabled, and they cannot eat by themselves. They are in special day care and school. The patient's biggest wish is to get a car for people with disabilities so that she can take her children out on trips, but the municipality has refused. The patient also stated that she had not been able to tell her doctor about her long-standing and socially debilitating urinary incontinence because it was always the same male interpreter who was used - an interpreter who, to make matters worse, lived in the same residential area as the patient. This was also the reason that she had never told the doctor about her past. She was aware that pain and thoughts could be linked to her past experiences.

A physical examination shows that the patient has several scars from stab wounds and multiple smaller scars that, according to the patient's recollection, stem from years of infections after she had been trapped in the thorn bush. A slightly larger scar on one of her thighs stems from a shelling that happened later in a refugee camp in the homeland - the patient had repressed this. She has suffered a fractured femur that grew crooked because she could not get transported to a hospital due to sustained grenade attacks. The patient was referred for trauma and torture treatment where she gained a more constructive understanding of her pain and thoughts.

The patient was found to have such large responsibilities of caring for her two disabled children that she had no energy left for her other children. Her obsessive barricading had become a major mental health problem for the children, who had difficulty concentrating at school. In collaboration with the patient, a note of concern was issued to the Department of Children and Youth in the municipality. A network meeting was then held with the school, her personal doctor, and the concerned caseworkers. During the meeting, a support person was assigned to the mother and to the children who needed it most.

Comment: *Survivor guilt and shame are frequent but devastating emotions among war refugees. Primarily physical injuries merge with psychological damage and give the pain a varying and incomprehensible expression. This easily leads the doctor to believe that it is unfounded 'ethnic pain'. In this*

case, the cause of the wounds (the thorns) had turned into sharp thoughts wandering around her body - at other times it was the thorns themselves, depending, she said, on how her thoughts were. It is not enough to use interpreter services. One must also ensure that no other factors are at play that could prevent the patient from talking about certain health problems (in this case it was sexual assault and incontinence that could not be mentioned to a male interpreter who lived near the patient). Video interpreting can reduce or eliminate the problem of the interpreter's gender because it is less intimidating than when the interpreter is on a screen. Moreover, with this system the interpreter often lives far from the patient's own area.

Case 10

A 47-year-old woman from the Middle East who has lived in Denmark since 1998. Many hospitalisations with diffuse pain in her head and back. She is referred to the MHC with this description: 'Tired and lacklustre with many hospitalisations and multiple symptoms without explanation.' She speaks a little Danish having worked as a cleaner for 11 years. She had a very strict upbringing with her in-laws where she worked as a slave from the age of 15. She had been married to a considerably older and violent husband who beat and starved the family. The patient was locked up in a dark room and has subsequently developed chronic anxiety, isolation tendency, nightmares, and self-recrimination thoughts. She lives alone with her 11-year-old son, who is left alone, it turns out, when his mother is hospitalised. The son is also the person who manages her medication and hospital appointments, and he is often used as an interpreter in the municipality and during medical interviews.

On closer examination, the patient had the following illnesses: myxoedema, low oestrogen (due to menopause), secondary adrenal insufficiency, ventricular ulcer, lumbar spinal stenosis, tinnitus, hearing loss (shelling injury), and osteoarthritis of the right jaw joint. Her headache was found to stem from pseudotumor cerebri (intra-cranial hypertension), and occlusion of the right transversus sinus in the brain was also detected. The patient had several symptoms compatible with PTSD. She had previously been assessed with regard to treatment but was rejected, as it was not possible to identify a trauma in the home country apart from a violent marriage. The patient herself connected her headaches and PTSD symptoms to the blows to the head from her spouse. The tinnitus and accompanying hearing loss stemmed from a shelling at their home in the home country where several family members died from severe injuries while the patient watched. The patient was accepted for treatment for PTSD and was treated for her intra-cranial hypertension. A support person was assigned to the son, who was also relieved of his adult responsibilities. The patient was given a hearing aid so she could communicate better with her son.

Comment: *The sequence of events is not unusual. The many hospitalisations and diffuse symptoms (compounded by her hearing loss) prevent the patient from undergoing a calm, overall clinical assessment. The criteria for referral to treatment for trauma and torture may seem too rigid in relation to the often-complex conditions of reality where war grenades, marital violence, slave-like conditions, and exile stress turn into a chronic mental-physical condition that the patient has no chance of explaining because no interpreter was ever used. The patient's proficiency in speaking Danish was associated with working as a cleaner and, despite the absence of a foreign accent, it was inadequate to explain the more sensitive and multiple trauma she had suffered.*

Case 11

A 33-year-old male refugee from the Balkans. He was referred with universal pain, fatigue, and headaches. He was fired from his work because he repeatedly damaged cars in the workshop while grinding and polishing. The patient turned out to be a torture survivor with very long-lasting flashbacks about his

torture experiences, which resulted in him grinding holes in the cars he was working on. The detailing shop where he worked resembled one of the places where some of the torture had occurred.

Case 12

A 38-year-old male refugee from the Balkans. He was referred with depression and memory problems. He had previously worked as a forklift driver but was fired from his job because he repeatedly broke pallets in the warehouse. The patient turned out to be a torture survivor with flashbacks. He was happy to work alone at night, but the storage hall reminded him of the hall where he had been confined.

Case 13

A 43-year-old woman from Iraq was referred with back pain and headaches. She no longer speaks Danish. The patient says that she had asked to work quiet night shifts, cleaning alone. Thus, the municipality sent the patient to the university for an apprenticeship where she was sent down to clean the preparation room in the basement. That experience re-traumatised the patient, and she began to have uncontrolled re-experiences of a shelling in her childhood home where body parts had been scattered everywhere.

Comment (cases 11-13): *Refugees who are repeatedly injured at work (flashback or dissociation), or refugees who ask to work alone at night because they have difficulty being with other people should be suspected of having PTSD.*

Case 14

A 57-year-old woman from Vietnam was referred due to unexplained headaches and suspected compliance issues with taking her hypertension medication. She was re-traumatised when her residential area in Denmark was flooded and the water rose up in her basement. The patient got flashbacks of a time as a child when bodies frequently floated in the river where they lived.

Comment: *Patients with PTSD can be re-traumatised without warning when they encounter new circumstances through smells, sounds, and spaces. New York witnessed many refugees with chronic illnesses who became non-compliant after the 9/11 attack (on 11th September 2001) (634). Patients with PTSD often look for work where there are few or no colleagues. Municipal caseworkers are seldom aware of this problem and the discrete signs of risk.*

7.4. Treatment options

Two systematic reviews on psychosocial treatment options for PTSD from 2017 and 2019 found medium to high evidence for the use of narrative exposure therapy (NET). The reviews found a significant lack of culturally adapted treatments, and there was less evidence to support standard cognitive behavioural therapy (CBT), Eye Movement Desensitisation and Reprocessing (EMDR), and interdisciplinary treatments (643, 644). Narrative exposure therapy has also been used successfully in low-income areas and with the use of laymen (645).

In studies combining cognitive therapy and treatment with antidepressants, no or only minimal effect was found - the latter could be primarily attributed to the antidepressant (646). Stress reducing efforts aimed at strengthening the family, their finances, and attachment to the labour market are often equal in importance to better pain and stress management. This is best done in a close cooperation between the family doctor, municipal caseworkers, and possibly hospital departments.

In Denmark, the treatment of PTSD and similar conditions occurs in specialised clinics for trans-cultural psychiatry or centres for trauma and torture treatment.

8. Other mental illnesses among refugees

8.1. Depressive disorders

The incidence of depression varies globally from 4-30 % (647, 648). Female migrants (both 1st and 2nd generation) have a higher risk of depression than men. A large pan-European study on ageing with almost 30,000 participants found that the risk of developing post-migration depression was much greater in northern European countries than in southern European countries (649). The differences were independent of known socio-economic and educational factors. Other factors found were familial disagreements over repatriation, divergent integration between family members, and loss of a close family member in the home country (650). In all studies, socio-economic challenges and only temporary residence permit contributed to increasing the risk of depression (651). Very few studies have been done on the link between language acquisition and depression. One study found that language acquisition did not increase the risk of depression in the first 10 years after arrival but did increase the risk in the subsequent decades, i.e. 20-30 years after the arrival of the migrant (652).

8.2. Psychotic disorders

As early as 1907, Thomas Salmon established a link between immigration to America from Italy, Ireland, and Scandinavia and the risk of developing insanity (653). Others demonstrated that migration is never a random phenomenon but rather a process in which, according to the economic outlook in Europe at the time, 'amoral women', criminals, and men with megalomaniac delusions seemed to dominate among migrants (654). In 1932, Odegaard found that Norwegians who migrated to Michigan had a much higher risk of schizophrenia than Norwegians in Norway did but that the increased risk did not appear until 10-12 years after their migration. This caused Odegaard to believe that post-migration factors must play a significant role (655). Historically, mental illness has always been politically linked to migration laws to legitimise the exclusion of certain ethnic groups (656-659). Although large differences between different ethnic groups exist regarding the risk of developing psychotic disorders, socio-economic conditions pervade the risk picture (559, 650, 660). A Danish cohort study found that second-generation migrants had a higher risk of schizophrenia compared to non-migrants, regardless of the place of residence, place of birth, or conditions of upbringing (661). Other factors associated with the development of psychosis include age at the time of migration, ethnic density, urbanisation, and negative social events (662, 663).

Concepts such as clarity of identity and identity values are closely linked to psychological wellbeing and can influence vulnerability or resilience to serious mental illness. At the same time, identity is considered to be closely linked to social and cultural affiliation (664). Feelings of insecurity in several existential areas (identity, social role, and cultural self-image) that can arise among migrants (especially if they are simultaneously experienced in a hierarchical and unequal power relationship with clear exclusion and alienation) can reduce the sense of meaning and coherence in the self and compromise the identity structure, thereby predisposing one to psychotic and near-psychotic experiences (665). The extensive legislative requirements surrounding refugees, with rules on settlement, family reunification, language, and education, increase the risk of their identity structures crumbling while calling into question the experience of being a meaningful and independent person. Demoralisation and failing personality structure increase the risk of psychosis-like conditions.

Torture is a particularly predisposing circumstance in that torture survivors have experienced such particular and boundless physical and psychological abuse that it has forever blurred the difference between self and others. What the torturer destroys is not only the ability of individuals to speak for themselves; when the torturer forces the victim to speak, not only does the 'I' who otherwise speaks disappear, but also the possibility of the tortured person ever being able to say 'we' - as described by Catherine Perret, who reports the devastating psychological consequences of torture in her book *The*

Doctrine of Torture (L'Enseignement de la torture) (666). Torture survivors have more psychiatric comorbidities, more often OCD and personality changes, and are more socio-economically disadvantaged than other PTSD sufferers (667). There is wide agreement that culture plays a central role in how individuals experience themselves and others and that maintaining a solid and coherent cultural identity can be a crucial aspect if the aim is to increase the resilience of refugees against serious mental illnesses.

8.3. Dementia

There are major cultural differences in how dementia is understood among ethnic groups in terms of causes, degree of acceptance, and stigma (668). A Danish study found a rate of dementia of 13.3 % in a population of older Turkish immigrants compared to 7 % in the background population (669). A Danish pan-European registry study found under-diagnosis among ethnic minorities over the age of 60 years but marked over-diagnosis among those under 60 in the same population (670). This may be partly due to atypical presentations of depression and PTSD with pseudo-dementia as well as less appropriate diagnostic tools for dementia (671-673). A large study of U.S. war veterans showed that their risk of developing dementia was twice as high as for the rest of the population, and the same was found among others (civilians) with PTSD (674-676). PTSD symptoms can worsen in connection with the development of dementia symptoms, which can complicate diagnostics (677). Inequalities exist concerning access to dementia diagnosis, treatment, and care in Denmark, and family doctors in particular face challenges in ensuring relevant examination and care (678-680). In families that have a person with dementia, a rotational plan whereby family members take turns to provide care is a widespread solution (681). A cross-cultural cognitive test battery has been developed and has shown promising results in multi-ethnic clinical studies (682, 683).

8.4. Suicide and suicide risk

Despite the increased incidence of mental illness among migrants, there is no clear evidence that this increases suicide rates (684). A Swedish registry study found that ethnic minorities in Sweden had a significantly lower risk of suicide than the general population but that the gap disappeared over time due to post-migration factors (685). A Danish registry study also found lower suicide risk among migrants (686), but findings vary across countries and ethnicities. A recent global review found that some ethnic groups had higher suicide rates than the background population, and in all the studies female migrants were at higher risk than male migrants. Young women of Turkish background had a particularly high suicide rate in Germany (687). Some studies found a higher risk among non-Western migrants relative to other migrants (688). None of the studies had systematic information on societal understanding of suicide, migration cause, residence status, or religion. Suicide is socially or religiously unacceptable in many societies, and in some countries, attempted suicide still carries a death penalty (689). By way of example, Muslims believe that the deceased are fixed in the exact physical situation they were in when they took their own lives. Neuner found that 40 % of refugees had or had had thoughts of suicide (690). Consequently, many refugees may have serious suicidal thoughts, which firstly, they do not talk to anyone about for fear of exclusion, and secondly, they cannot put into practice because of the shame it would bring to the family.

Case 1

A 57-year-old woman from the Far East. She was referred to the MHC with multiple pain and possible depression or personality problems, and a note stated that the patient was 'socio-culturally hard to understand'. She speaks Danish and came to Denmark at the age of 36, when she was family reunited with her Danish husband. Her husband died after a long illness with cancer, and the patient had taken family care leave for 1 ½ years at her husband's request. The patient was very fond of her late husband. She

says that since she lost him, she has had two partners, both of whom had disagreeable sides. She has worked in market gardening and cleaning for a total of 18 years. She originally started working in the rice fields in her home country at the age of seven and until she was 12. Then she worked in her family's restaurant. She says that her daughter was abducted in Denmark, but according to her doctor, the daughter was forcibly removed. For a while, the patient had a contact person who was a great support during a difficult time where there had been many suicide attempts. She has never told anybody else about these attempts. She tried to jump out a window, but her son stopped her. Another time later, the patient bought pills online, which she ingested, and she was found by one of her children. At the hospital she explained that she had taken diet pills to lose weight, so she was referred to the dietitian. The patient feels very lonely and does not think she has a good life. She is angry that her first, sweet husband left her with children that are so hard to care for in a country she still does not think she knows. She has daily thoughts about taking her own life. An MR scan of her knees shows treatment-requiring osteoarthritic changes, and a scanning of her sinuses shows pronounced chronic mucosal thickening.

Comment: *Efforts are made to use the patient's life story to create a sense of purpose and thereby move the patient's mind-set to the home country, this creating new connections and intervention options. The patient slowly gains an understanding of herself and that the solution might be in her home country and not in Denmark. The patient travels to her home country and seeks out, among others, a Buddhist monk who explains to her that suicide is a great responsibility to take on, since in Buddhism one suicide is believed to trigger 500 suicides due to the idea of reincarnation. The monk asks the patient to consider whether her problems are really worth 500 suicides. At the same time, the patient can see that her children in Denmark have a better future than the children who lived in her hometown. She also sees her sister, who had once sold her as a sex worker and now repented this act. The patient comes back from the journey with a new and more constructive view of her life. Now, the patient can see herself as an independent mother and woman, and she can think with joy instead of anger about the times she had with her first (deceased) husband. The patient had a very long work history, and her exposure to physically stressful work is significantly longer than immediately thought, which may explain her increasing physical weakness. Her headaches and knee pain are well explained and can be treated when the patient feels motivated for it.*

8.5. Other psychosocial challenges

Mental disorders among refugees are exacerbated by the typically lengthy asylum application process, unclear and changing asylum and integration rules, lack of system competencies, and language barriers (691). Access to the psychiatric care system is often made harder by a lack of interpreters, poorly trained interpreters, and a lack of cultural competence skills among staff (692). Treatment that is lacking, inadequate, or inappropriate can keep patients in debilitating mental health states. Actual or perceived racism and other discrimination can reinforce delusions, weaken anger management, and delay the patient in seeking medical attention (693). Stigma and fear of social exclusion due to mental illness that is associated with guilt and shame can also prevent timely treatment (694, 695). Patients' experiences with professional indifference, generalisations, stereotypes, and discrimination in their treatment create distrust of the healthcare system and of the quality of treatment choices (695). Housing in areas of a concentrated ethnic population protects against the development of mental illness, while housing in areas where the majority population is predominant increases the risk of developing psychosis (696). Challenged residential areas containing a high density of ethnic minorities can provide protection but also be pathogenic (166). Other factors such as social network, extreme poverty, and negative social events are linked to challenged residential areas, which can increase the risk of mental illness (697, 698). A persistent state of meaninglessness combined with the perpetual temporary condition associated with

the grounds for residence have psychological consequences that we can speculate on but do not know the extent of.

In a study conducted in a Norwegian psychiatric ward, all the hospitalised patients were systematically interviewed about psychological traumas, and 91 % of the patients had at least one potentially traumatising experience in their past, with 69 % having multiple traumas (699). There was a 78 % overlap between PTSD diagnosis and other mental disorders, and suicidal thoughts or suicide attempts were frequent. The study concluded that PTSD is underdiagnosed or misdiagnosed and that staff lack knowledge about PTSD. This problem seems to be even more pronounced in the case of refugees/immigrants (31, 700, 701). At the same time, it is well documented that there are insufficient cross-cultural competencies within psychiatric care and treatment (650, 702-704). Katrine Schepelern Johansen describes psychiatry's cross-cultural inadequacy in this way:

Psychiatry's perception of culture and of the relationship between culture and disease is rooted in a way of thinking that stretches back over 100 years to a time of colonialism, when the view of culturally different people was dominated by racial thinking and evolutionism. This has meant that attempts to introduce a more complex and dynamic cultural understanding into psychiatry have failed, despite the fact that various major research projects have pointed to the need for a more up-to-date and scientifically valid cultural perception (705).

Doctors and care staff lack knowledge about the links between PTSD, depression, personality disorders, and exile stress, and this can influence patients' behavioural patterns and lead to inappropriate or no use of the psychiatric care system.

All Danish studies have shown an increased risk of mental illness among migrants and their descendants compared to ethnic Danes, and this applies to schizophrenia as well as psychiatric hospitalisation (661, 706, 707).

Concepts of health and illness, and also expectations of treatment, depend on cultural background, traditional values, personal experiences, and ever-changing social relationships. Barriers in access to treatment can be removed or reduced when the living conditions of each migrant, their individual understanding of the disease, and their treatment expectations are taken into account (708). Training of linguistically competent interpreters is essential, but it is equally important to train doctors to conduct cross-cultural conversations in a professional and responsible manner, respecting the global diversity of languages and concepts (709). Factors that are often a burden on the health of immigrants and that are associated with a higher risk of developing mental illness include: social exclusion, low education, poverty, and housing in areas of low ethnic density. The impact of these factors can be minimised, but this requires a coordinated and robust multidisciplinary and cross-sectoral effort (710).

The essay 'Lost - and gained - in translation', which is about what is lost and won in cultural translations in a broad sense, describes how insensitive 'translations' of language, attitudes, and values can be experienced as an outright assault or as a complete disavowal of the patient's overall cultural values and background (102). The essay reviews a novel by Orhan Pamuk in which the sense of loss, a chronic sadness, can stem from the anger and anxiety linked to the experience of having been translated into something foreign that does not belong to the individual or their cultural/social group - a translation that does not add more sense, understanding, or recognition to the person or group (711). What is basically an attempt to understand a migrant's situation and needs solely in a Danish context through a 'translation' can end up acting as a fundamental abuse that may lead to treatment-intensive, chronic grief over what has been lost, which is re-interpreted as clinical anxiety or depression.

As an example, *illness* to an Arab patient is an alien element. There is no distinction between the body and the mind (the 'self'). There are good and bad feelings about one's deeds and thoughts, but they are woven together into a more holistic concept of a person than Western psychiatrists usually work with (712). Doctors are regarded as omnipotent and mysterious and are given ultimate power to heal the

patient. If the patient is not cured, the doctor is a bad doctor. The patient's role is to adapt themselves to the doctor's advice and treatment, and this can lead to difficulties in treatments such as cognitive therapy. Patients perceive themselves as passive objects for the doctor, and it is an expression of weakness in the doctor to ask for the patient's participation. The doctor should use their medical expertise on the patient (713). The patients see their symptoms in relation to their social circle and downplay problems by focusing on the values highlighted by the leader of the ethnic group. If one as an individual talks about having mental health problems, it can be perceived as a betrayal of the family and a sign of personal and familial weakness and defeat. Going to a psychiatrist is not only a sign of social weakness, but also a sign of religious insecurity and doubt, so the patient must be seriously ill before seeking help (714). If one does not follow the group's values and way of life, that person is considered to be a non-believer and shames the family. Social and psychological problems are not allowed to be expressed, and thus there is often a mixture of somatic, emotional, or behavioural expressions that can confuse Western doctors (715). Possession by a Jinn or evil eyes often requires more than standard psychiatric skills. Of particular interest is the observation that people with signs of mental illness can be forced into marriage because marriage is considered to be a form of treatment for mental health issues. Symptoms of mental illness are attributed to physical symptoms corresponding to the organ closest to it: thoughts turn into headaches and grief turns into chest pain. Symptoms of mental disorders are tolerated by the patient and reformulated into physical discomforts, and when the family simultaneously tolerates and neglects the patient's more or less deviant or outlandish behaviour, it may be difficult for the doctor to obtain the necessary observations. Illness is very much a family matter. The family decides what to disclose, how to disclose it, and when it is necessary to disclose it. The upbringing of children with a sense of shame rather than guilt and obedience through fear creates conformist children who fear only other peoples' criticism of their behaviour, which must therefore be suppressed - and this can further confuse Western doctors (715).

Professionals working with refugees tend to focus on the history of trauma and thereby fail to recognise the strengths, survival skills, and resilience of the individual refugee. This means that resilience is overshadowed by a dominant Western 'shortage' or 'error' model that defines refugees as traumatised victims - otherwise they cannot be described as refugees. The medicalisation of the refugees' traumatic history can further alienate refugees from full integration by demonstratively rejecting their inherent resilience, which has been developed in the face of extraordinary and/or violent life experiences. Factors that can inhibit resilience include language barriers, racism, discrimination, and categorisation/objectification of the trauma history. Studies suggest that the resilience of refugees should be understood outside the Western individualised concept as a more common social construct of resilience that encompasses the broader social context and living conditions of refugees in their home country, during flight, and in the host country (716-719).

The relatives of mentally ill minority patients may feel particularly challenged. The hidden burdens associated with caring for the family member can be quite large. Children in particular suffer from the stigma associated with mental illness, and often the whole family has to isolate itself because one family member has a mental illness (720).

The status of a residence permit affects motivation, mental well-being, PTSD symptoms, and language learning. Changing legislation with tightening requirements for residence permits is important in the analysis of the individual patient's mental state. A prospective Australian study of refugees reported two distinctly different mental reaction patterns between those granted temporary residency and those granted permanent residency. Refugees with temporary residency had significantly higher PTSD scores (Harvard trauma scale), were more isolated and lonelier, had more anxiety symptoms, and had significantly less English language skills than refugees with permanent residency (66).

Case 1

A 47-year-old woman of Asian background was admitted to a hospital with suspected anorexia. The staff have poor contact with the patient, who seems angry and distrustful. An employee from the MHC who speaks the patient's language saw the patient during her hospitalisation. The patient indicated that she was primarily annoyed at being served inedible rice dishes (which the staff assumed she wanted), and the patient found the quality of the rice and other ingredients distasteful. The patient would have preferred to have regular Danish food. The patient's nutritional state did not seem to fit well with the patient's considerable medical problems, and this led to a suspicion of mental illness. A home visit was subsequently arranged where the patient was found to have clear paranoid-schizophrenic traits and only allowed a few people (one particular home assistant) to enter her apartment, which was so filled with accumulated things that she only had a sitting space on her bed (hoarding behaviour).

Comment: *Diagnosis of mental illness in cross-cultural contexts requires patience, trust, and support from an interpreter. Home visits are important in diagnosing complex patient stories. Psychotic behaviour can be obscured by the perception of 'cultural differences'.*



9. Medication adherence

A review by the MHC has indicated that side effects and serious drug interactions due to absent, sparse, or misleading information about medicines (and especially about the rules for substitution of medicines) affect particularly patients with language barriers and low educational level (81). A Dutch study also showed that some ethnic groups were given prescriptions much more frequently than others when visiting their family doctors (721). Furthermore, variations in prescriptions show the difficulty with comparing areas of very different ethnic composition in terms of medication consumption, disease patterns, and access to healthcare. Many factors are at play, and research in this area is still mainly register-based or qualitative (722). Communication barriers with foreign language patients are frequent in pharmacies, and pharmacists report that patients are at increased risk of being exposed to adverse events, as documented in a Danish study from 2009 where over 50 % of the people interviewed took medication purchased abroad (723). This study had already pointed out the need for interpreter services (an interpreter hotline) to advise patients who collect medications from the pharmacy. Communication tools need to be developed and disseminated to support pharmacists in advising ethnic minority patients in pharmacies, and this includes providing these patients with access to interpreters and foreign language information leaflets (724, 725). A US study found that compliance problems were much more frequent among patients with language barriers (31 %) compared to other patients (12 %) but that an ethnically competent clinical pharmacist could increase compliance by 24 % (726). In Denmark, ethnic minorities have been found to start and then frequently interrupt pharmacological and non-pharmacological treatment after hospitalisation for myocardial infarction (727).

Little research has been done on the association between patient trust in the doctor and compliance, but studies suggest that patients with language barriers often express the need to build trust in the doctor before they can and will listen to a doctor's advice and guidance. Several studies, including a qualitative Dutch study, have shown that patients' distrust and lack of belief in their physicians lead to poorer compliance, lower perceived quality, inappropriate patient behaviour, and lower self-assessed health (204, 205). Especially with invasive procedures, distrust of the doctor can lead to patients perceiving the doctor's information to be inconsistent, vague, and imprecise (371). Uncertain patients who have language barriers want to be persuaded by the doctor before agreeing to invasive examinations, surgeries, or treatments with potential side effects. If the doctor does not pick up on this need and responds instead with arguments, the patient will refuse an examination that is other-wise justified and necessary.

Paul Farmer, professor of medical anthropology at Harvard University, describes in a 2006 article what he calls 'structural violence in clinical medicine'. His position is that while doctors at a general level are aware of how social inequalities, gender, ethnicity, and political conditions determine who gets sick and who has access to and benefits fully from the healthcare system, they do not use this insight in formal clinical settings when talking to the patient. The holy grail of medical science is still the molecular basis of disease, and this has contributed to an increasing 'de-socialisation' of health science research and physician-patient conversations. Biologically based questions are asked about phenomena that are essentially biosocial phenomena - patients who have diseases that have clear social roots and links such as HIV, diabetes, cancer, and asthma are less well understood by doctors and this adversely affects their treatment compliance. Farmer argues that structural interventions are needed. Doctors are not trained to do this, but they can learn to analyse the social forces at play. For example, the 'social' element of HIV infection is not promiscuity, but poverty, schooling, access to prevention and treatment, and certain poverty-related risk environments (728).

While it is readily understandable how bias can affect the doctor's judgement and motivation, there are more subtle and nuanced influences on clinical uncertainty and the less conscious stereotypes

that affect the doctor's clinical decision-making processes (and the patient's motivation). Moreover, neither the doctor nor the patient is fully aware of the many mechanisms at play during the conversation. Clinical uncertainty allows the choice of treatment and patient compliance to be influenced by the doctor's subjective views and preferences. Time pressures, problem complexity, and challenges to the doctor's cognitive abilities shape the doctor's perception of the patient's information and expectations of patient compliance. This can contribute to inequality in the choice of the amount of information given to the patient, and of diagnostics, treatment, and follow-up.

Studies of videotaped doctor-patient conversations have shown that the patient's ethno-cultural background affects the doctor-patient communication. Western doctors show less emotional involvement when talking to ethnic minority patients, and Western patients are more direct and needs-oriented than ethnic minority patients (729). Thus, it is harder to achieve good understanding and consistency between doctor and patient in cross-cultural medical interviews. Good medical care requires a common *understanding* of each other's perceptions and opinions although there does not necessarily have to be an agreement between doctor and patient as such (730). A Dutch study of physician-patient conversations found that ethnic Dutch patients had more varied conversations than patients of other ethnic origin, and that ethnic Dutch patients more often tried to slow down the conversation and manage it and were more often (25 %!) confrontational compared with immigrant patients (731). A Norwegian study found the same trend and also demonstrated that the concerns and fears of ethnic minority patients were often expressed indirectly in order to tone them down (732). In conversations with Arabic-speaking patients with diabetes, doctors and nurses subconsciously alternate between several roles: caregiver/carer, teacher/educator, and expert. Each role is associated with unconscious ideals, value dissemination, and framing of the patient - from being theoretically professional to pragmatically professional where the patient is seen as vulnerable, troublesome, or chronically ill (733).

9.1. Recognition and responsiveness

In an Arabic-speaking school for patients with diabetes in Denmark, a quantitative study found that many of the patients got more out of the setting and the approach than they did from the actual relayed knowledge. The patients experienced a respectful atmosphere and had plenty of time and an unstressed interpreter, and this allowed their individual stories to be witnessed and acknowledged. It was a feeling and experience that gave them strength and courage in their daily lives as patients with diabetes (734).

Evolution psychologist Jill Byrnit says that humans are mammals who through a socio-biological contract have been permitted to be born without competencies - in contrast to other mammals. Byrnit describes how humans are born in a social womb in which recognition is the sustenance (735). If we get recognition, our personal projects and relationships make sense and we can deal with adversity with the help of others - but it requires others to recognise our perceptions and behaviour. If we do not get recognition, we wither and cannot live with the illness. In a study from Copenhagen, the participants received a boost in their self-esteem and self-respect - factors that if absent can negatively affect compliance (736). It is probably the appreciative approach ('seen, heard and understood') that leads patients to listen and to believe that they can tackle their illness and treatment (737).

Medication review is time-consuming but instructive. By way of example, medication substitution had led to one patient being on two kinds of morphine, two kinds of Sertraline, and two kinds of Mirtazapine as well as Noritren (the patient was unsure what this was for) and Chlorzoxazone (the patient was unsure what this was for). None of the pills had any effect according to the patient.

In another case, the varying mental states (and compliance problems) of two parents meant that because of poor finances the medicine was shared between them: some weeks the mother was easier to talk to; other weeks the father was easier to talk to. Compliance problems need to be normalised - everyone can forget to take their medication or get angry about the pills. Make it a collaborative project to

get it sorted out, and create the necessary confidence so that information about missing doses is freely provided and can thus help in interpreting blood test results and to strengthen compliance efforts.

It is important to use the pauses in a discussion about compliance, as the following example illustrates.

Conversation between doctor, Chechen woman, and Russian interpreter

(Pauses are shown by the dotted lines)

Doctor: *How are you doing?*

Patient: *Bad ... really bad*

.....

Doctor: *Someone from ATT [Department for Treatment of Trauma and Torture survivors] is coming on a home visit. What do you think about that?*

.....

Patient: *They have not come yet...*

.....

Doctor: *Have you been to see the neurologist again about your headache?*

Patient: *No ..., yes ... I am not going there again.*

.....

Doctor: *Have you taken the Lyrica pills that the neurologist prescribed for your headache?*

Patient: *No...*

.....

Doctor: *Have you bought them?*

Patient: *Yes...*

.....

Doctor: *Can you tell me why you chose not to take Lyrica?*

Patient: *... In Russia, we say medicine is like street drugs...*

... And I'm a Muslim and we are not allowed to take drugs...

.....

Doctor: *Yes, but Lyrica is a medicine against pain and not a street drug. Did you know that?*

Patient: *Yes, I have looked on the internet...*

.....

Doctor: *So what is making you not take them?*

Patient: *... (low voice): I'm pregnant, and do not dare take them.*

Doctor: *Well, that is really sensible!*

Patient: *... Yes, but I am afraid...*

Doctor: *Of what?*

Patient: ... *That the scanning I got 2 months ago has harmed the baby because I did not tell the doctor or the people who scanned me that I was pregnant, and now I do not dare think about it.*

Doctor: *It was a scanning that doesn't hurt the baby.*

Patient: ... *Ok. Panodil also works well. Can I take those for my headache?*

Case 1

A patient referred to the clinic with poor medication compliance (for diabetes) turned out to be 'bankrupt on social benefits' because she had repeatedly received astronomical electricity bills. The social worker had not wondered why a single woman in a two-bedroom apartment could have such a high electricity bill. It turned out that the patient had severe PTSD and could not fall asleep when it was dark. Therefore, she tried to imitate daylight by buying and then turning on a considerable number of lamps with 100-watt bulbs so that she could get some sleep.

Case 2

The patient was referred to the MHC due to unusual fatigue and mental changes that had gone on for half a year. A simple interpreted conversation made it clear that the patient's fatigue was due to the patient taking three double doses of Mirtazapine because the patient was unaware that the three different packs were exactly the same medicine. In the absence of information from the psychiatrist and general practitioner who prescribed the medicine, the patient had been given the idea that one package was for her mood, the other for blood pressure, and the third was sleeping medicine. The pharmacy (always the same) had also failed to explain to the patient (61-year-old Iraqi woman without schooling) that it was the same medicine, but just with different packaging. The prescription renewal was managed by the secretaries of the two doctors the patient was in contact with and via the patient's 12-year-old grandson. The patient had not been to see the psychiatrist in person for half a year.

Case 3

This patient was referred with abdominal pain and headaches. An interpreted conversation revealed that the patient had been given the following: two kinds of morphine, three kinds of NSAID, two NSAID creams, Imodium, omeprazole, oxazepam, SSRI, and a variety of over-the-counter products. The patient was given simvastatin but thought it was for depression. The patient was severely constipated and nauseated and was not aware of the link between her medication and the symptoms she was referred with. A medicine review by the bilingual (Arabic-speaking) clinical pharmacist revealed that one of the NSAID creams worked the best and subsequently, an extensive medication reduction could be carried out. After the medication review with the bilingual clinical pharmacist, the patient said about the conversation, '*It was good that I could ask her anything. Some of the medications I took were all wrong, and there were medications I didn't dare take together. I do now. She made me feel comfortable about taking the medicine.*'

Case 4

A 34-year-old man was referred to the MHC with involuntary head and back movements, poor medication compliance, lethargy, and nausea and for an assessment of his mental health condition. The patient had previously been examined in the psychiatric department and during the same treatment course was assessed in the neurological department. However, the patient turned out to be a torture survivor who had been subjected to several head traumas. When questioned, the patient did not think he was taking

medication, but his memory was significantly affected and it was decided that the bilingual clinical pharmacist affiliated with the clinic, together with the patient, would review what medication had been prescribed by other hospital wards and what had actually been picked up at the pharmacy. It was found that due to substitution packs, the patient had been given a double dose of Truxal relative to what was prescribed, but the patient had also received both second- and third-generation neuroleptics. The patient received a high dose of Emperal (metoclopramide) to be taken both regularly each day and as needed (this preparation can lower the seizure threshold and increase the risk of convulsions). Finally, the patient had received several sedatives that affected cognitive abilities, as well as tramadol in a relatively high dose as an as-needed medication. After home visits where the patient presented his medicine stock and explained how he took the medicine, it turned out that due to his poor memory, he had been taking all his medication every day - including taking all the as-needed preparations all at once to be sure he took everything the doctors had prescribed.

It became clear from contacting the other treating departments that the neurologists and psychiatrists independently treated the patient for the same involuntary movements and on suspicion of a combination of a functional element and a poorly documented aggressive/impulsive element. The patient did not usually bring an interpreter to the interviews in these other departments and had no knowledge about what the various medications were for. In consultation with the other specialties, the patient's medication list was optimised.

Case 5

Blood tests showed that a patient with pituitary disease had difficulty achieving adequate levels of hormones in her blood. It turned out that the patient got up very early to pray, but she waited to take her medication until the time the nurse had determined at 8am.

Case 6

A patient had a very hard time remembering to take her evening medication. It emerged that the reason the patient consistently failed to take the medication was that she was afraid to take medication when it was dark. Both the patient's mother and the patient's sister had died at night after taking their evening medication.

Case 7

A man with a kidney transplant (kidney damage after torture) had many years of normal compliance with his immunosuppressive treatment. When he stopped taking the medication, he was referred to the MHC to increase compliance. The cause turned out to be that the patient had seen his torturer in the town where he lives and that this person had been given a Danish passport; in contrast, the patient had himself applied for Danish citizenship and had been refused.

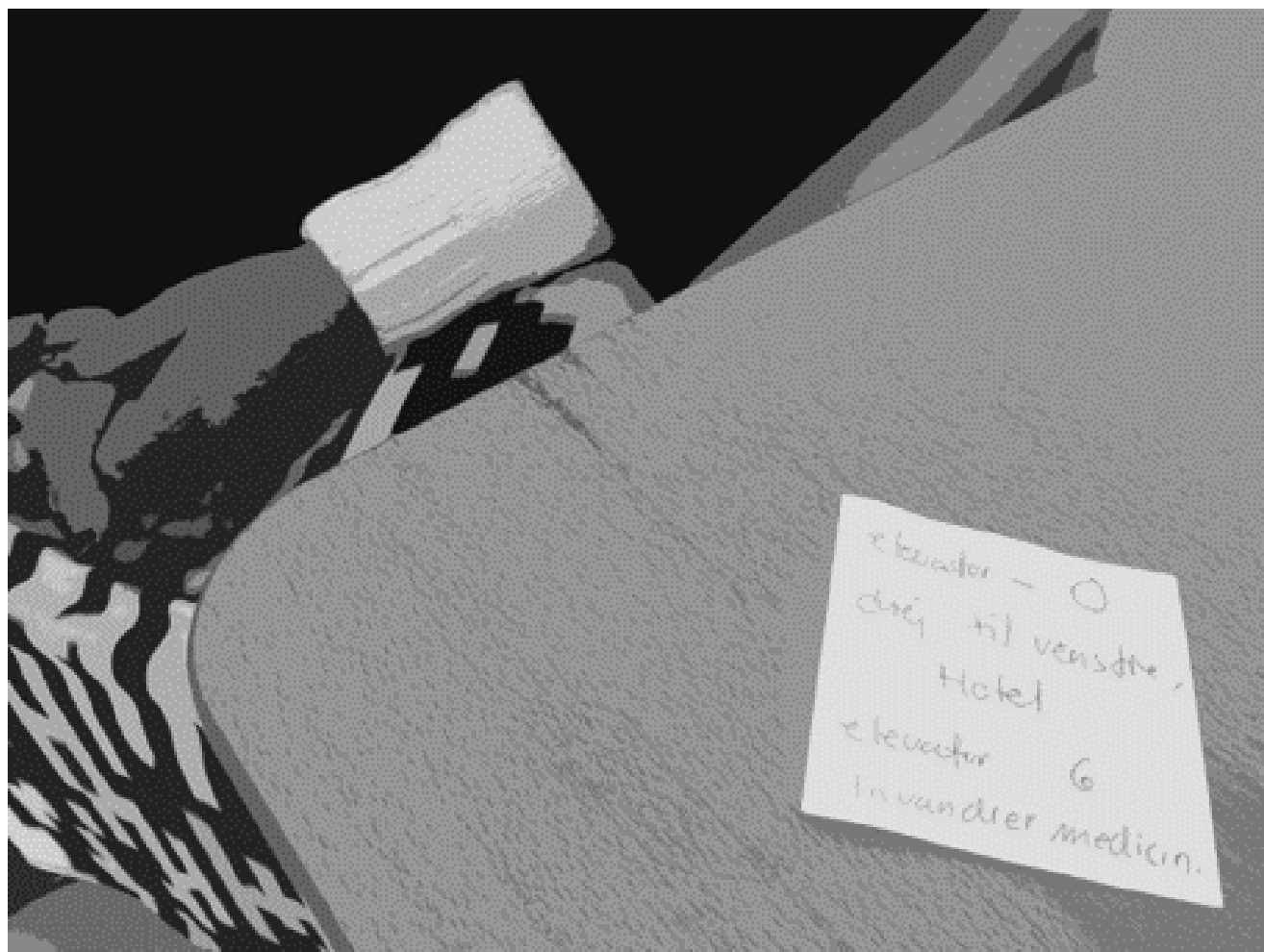
Case 8

A 49-year-old work migrant from the Far East who had worked since she was 17 years old as a nursing home assistant. At the age of 42, she broke down mentally, was ill for a long time, and got fired. She was referred to the MHC where she explained she had been traumatised when a male nursing home resident repeatedly behaved in a sexually unacceptable manner that involved physical coercion. The patient had been sexually abused as a young girl by an elderly family member in her home country. The working environment in the nursing home was also very bad, with bullying and verbal abuse. The patient was referred to a psychiatrist and put on medications. The patient was referred for occupational medicine assessment where it was found that she had been subjected to harmful bullying and traumatising abuse, which was reported. The patient also suffered from hypothyroidism and hypertension. The patient had

difficulty concentrating and tended to dissociate and could not handle taking her medication. A district nurse was assigned, but the municipality considered that the patient was self-reliant enough to be able to collect her own medicine from the nursing home - the very same nursing home where the patient had been re-traumatised. The patient did not dare collect her medication because she was already getting anxiety symptoms in the parking lot. The district nurses were not aware of the patient's history. Medication delivery to the home was then restored.

Comment (case 1-8): *As a doctor, you can rarely figure out why there are adherence problems - it should always be sorted out through a discussion.*

- *It is important to start by normalising forgetfulness and the problems of taking medication.*
- *Finances and adherence are closely linked, and solutions should be pragmatic.*
- *It is essential that the doctor regularly checks whether the patient has a correct understanding of their medication. Medication review is a difficult task that can be facilitated by using interpreters or bilingual clinical pharmacists.*
- *If a doctor knows the patient's daily rhythm, it is easier to find a suitable solution.*
- *Due to the impact of PTSD on memory, it is important to continually repeat and update the information; otherwise, it may disappear or become inaccessible to the patient.*



10. Somatic conditions requiring special attention

10.1. Skin diseases

Furunculosis and fungal infections that may resemble eczema are common and often require treatment. The same goes for ringworm of the scalp (tinea capitis). Head lice (pediculosis capitis) and scabies are seen in 15-25 %. Scabies in young children are often localised to the body rather than the hands and fingers and are frequently accompanied by impetigo. Signs of ritual scars (cutting, burning), itchy elements (larva migrans or strongyloides).

10.2. Anaemia

Microcytic anaemia can be nutritional iron deficiency or due to bleeding, caused by hookworms in the gastrointestinal tract. Microcytic anaemia may also be caused by lead poisoning seen in connection with the consumption of flakes of lead paint by young children (e.g. from old wooden houses), possibly in connection with pica brought on by iron deficiency anaemia. Finally, microcytic anaemia is seen in thalassaemia, which like sickle cell anaemia and a number of other haemoglobinopathies, occurs much more frequently in patients from the third world than in patients from Europe. A low mean corpuscular volume (MCV) can indicate suspicion of a carrier state of thalassaemia. Macrocytic anaemia due to folic acid deficiency (and in rare cases lack of vitamin B12) is seen, but mostly in children who have lived on vegetarian diets.

10.3. Disability

In many societies, descriptions can be found of how people with different bodily functions, builds, sizes, and shapes become subject to stigma, prejudice, and discrimination. A distinction is made between 'physically challenged' (weakened, impaired functional level) and 'disability'. The first refers to a loss of a body part or body function, while the latter refers more to the many social and psychological disadvantages and obstacles arising from their lost function (738). However, not all disabilities are associated with stigma and discrimination. Some with disabilities are considered to have special abilities (e.g. in many societies, blind people are attributed to have special abilities), but these are usually exceptions. In many societies, physical or mental abnormalities are considered to be a symptom that something is wrong with social relationships or that these abnormalities are a punishment or a reflection of a family weakness. Disabled people are 'imperfect' people who should be isolated from social relationships as they could reveal a family weakness. What the family does if they have a child with visible physical differences depends on the child's 'diagnosis'. In one society, new-borns that are unusual or abnormal in appearance are categorised into three groups: 'bad' (albino, Down syndrome, dwarfism, hydrocephalus), 'flawed' (deformed arms or legs, birth defects, polio), and 'ceremony' (twins, breech birth, club foot, malnutrition). The 'ceremony' group receives special attention and enjoys a certain social status, while the 'bad' are marginalised as 'non-humans' who are not expected to live a long life. The 'flawed' are considered to be a result of poor relationships either in the family or with the local community. In the home country, however, disabled people are not typically perceived as abnormal, deviant persons, but as persons with limited opportunities. They are very much involved in the work, routines, and relationships of the family.

Injuries from accidents, strokes, or meningitis in childhood can be difficult to discover during a short conversation, but it is important to consider possible neurological consequences after illnesses or accidents in the home country.

The protective factors that exist in refugees' home countries disappear in exile. Many social codes are tightened and distorted in the host country, and there may be social demands from the rest of the

minority group to be a 'strong' healthy family. Ideas about causes of disability and mental illness may also be reinforced in minority environments to such an extent that families with disabled children can become a minority within the minority. Among migrants and refugees, attempts will often be made to hide a disabled family member, but at the same time, there will be a great need to remove or repair the physical abnormalities.

10.4. Syphilis, hepatitis B

An examination for congenital syphilis may be relevant: anti-flagellum-IgM and fluorescent treponemal antibody absorption test for IgM up to three months of age, since Wassermann reaction (WR) and rapid plasma reagin test (RPR) will be falsely positive in a healthy child if the mother is positive; the corresponding IgG studies are used up to the age of 12 months. About 5 % of newborns and toddlers in low-income countries are positive for hepatitis B antigen, and the frequency increases to 15-20 % until adulthood. If the child is positive for both HBs antigen and HBe antigen, there is a risk of chronic active hepatitis, and the child should be referred to the relevant specialist department for treatment to reduce the long-term risk of developing liver cirrhosis or hepatocellular carcinoma. Since hepatitis B-positive children pose a risk of infection to the family and other close contacts, vaccination of close contacts is recommended.

10.5. HIV

Refugees and family who are reunited with refugees have a higher incidence of HIV infection than the background population in Denmark. There is also a higher risk of 'later presentation' than among others with HIV, but this is most pronounced among refugees from South-East Asia and sub-Saharan Africa (739). No studies have been carried out on what is behind the late diagnosis, but based on patterns from other illnesses, there is often an unfortunate combination of stigma and fear of the healthcare system; moreover, doctors may easily overlook the diagnostic possibility due to the common and vague symptoms or because they only at a later stage suspect heterosexually infected people (517). It is noteworthy that people infected with HIV are often identified in connection with other clinical contact: e.g. if they have another chronic disease, are pregnant, are suspected of malaria, chronic bowel disease, or anaemia, or attend for routine surgery (740). HIV testing should be part of the health assessment of all newly arrived refugees (544). HIV-infected migrants live difficult double lives with stigma, isolation, low self-esteem, and a high risk of depression (741, 742).

10.6. Malaria

Malaria can give rise to anaemia, but it most often presents as a febrile disease that may be accompanied by vomiting and diarrhoea. Falciparum malaria most often occurs within the first three months after arrival in Denmark; within this time period, it must always be suspected if a person develops a fever, and this necessitates an investigation for malaria.

10.7. Tuberculosis

Migrants have a higher risk of tuberculosis than the local population. In particular, UN mandate refugees, those who have been family-reunited with refugees and former asylum seekers are at high risk. A higher risk also exists among other groups of migrants and their reunited families (743, 744). Tuberculosis must be considered, therefore, in all migrant groups and their reunited families, regard-less of the reason for migration (745, 746). Extrapulmonary tuberculosis is frequent among migrants, and swollen lymph nodes should lead to further investigation (548). Screening for latent tuberculosis is also important (747). Tuberculosis can occur many years after arrival, and one should always be on the alert for

it (549). We are in imminent danger of relating tuberculosis control measures to ethnicity and exaggerating individual responsibility, and we need to have greater focus on the social conditions that produce TB infection (748).

Tuberculosis can be difficult to diagnose in children because the symptoms are uncharacteristic at first, but children have a high risk of developing serious illness (749). Children have little sputum, and the symptoms tend to be non-specific: failure to thrive, weight loss, fatigue, and sometimes persistent fever. An important clue is whether there are close contacts in the family who have chronic coughs or known tuberculosis. There should be a very low threshold for referring refugee children (particularly those newly arrived) at the slightest suspicion of tuberculosis. Children can be infected even during brief stays in refugee camps, so a precise history of their journey and where they stayed, including during their escape, is crucial. See chapter 6: 'Health assessment of refugees: clinical points to be aware of and a checklist'.

10.8. Ear, nose and throat

Eardrum intact? Hearing loss? Dental status, goitre, uvulectomy? Cervical lymph nodes? Ritual tooth changes?

10.9. Thorax

Murmurs (valve or anaemia), previous tuberculosis?

10.10. Gynaecology

Signs of sexually transmitted disease, genital changes/alterations.

10.11. Neurology

Loss of sensory and motor senses, polio, birth defects, congenital disorders.

10.12. Psychological and cognitive

Difficulty sleeping, nightmares, trauma, assaults, memory shifts, delusions, anxiety. Cognitive functions intact, literacy, vision and hearing. See also chapter 6: 'Health assessment of refugees: clinical points to be aware of and a checklist'.

10.13. Age

Be careful to check that the patient's actual age matches the date of birth. Errors often occur either in the registration (or lack thereof) of the birth in the home country, or not infrequently during registration in Denmark. Patients are often aware of the error themselves but do not mention it without being prompted. Self-perceived age can be a good parameter for self-assessed health in the absence of better cross-cultural tools.

11. Terminal illness and palliative care

Ilhan Ilkilic (750) refers to a case in which a 23-year-old Turkish man was diagnosed with metastatic cancer. Chemotherapy had no effect, and his condition deteriorated rapidly. He was transferred to a palliative care department (750). Neither the patient nor his parents spoke the second language (German), so an interpreter known to the family was used for a conversation about the serious situation. A Turkish-speaking nurse participated in the conversation and mentioned afterwards to the doctors that the interpreter had not translated the information that treatment was hopeless for the patient. A new conversation was arranged with an interpreter who did not know the family where the patient was told the 'truth'. Two days later, the young cancer patient died. The parents subsequently accused the doctors of killing their boy by telling him the 'truth', which was different from the family's 'truth'. The ethical problem is that doctors assume the truth is clear, and that there is 'only one right': the right to know. However, in many societies there is a right *not* to know, which nurses and doctors in Denmark and other countries have a very hard time accepting. As Ilkilic establishes, nothing is learned in the process. None of the involved parties finds out why the other person acted as they did. If we never reflect on these conflicts and clashes between rituals, we will never learn. Conflicts will continue to arise, and no one will be satisfied.

Ilkilic describes another case in Thailand involving a 39-year-old construction worker who fell from a scaffold and hit his head on the pavement. He is hospitalised and unconscious and put on life support, but he is brain dead. His brother is present and believes life support should be switched off to ease the suffering, but the doctors oppose this because they believe it is 'unethical.' It turns out that it is not so much a question of ethics, but rather a mosaic of arguments including the view that their professional training forbids them 'to kill patients', the fear of possible legal action, and a belief in the sanctity of life. The doctors are Buddhists, and Buddhism forbids killing. Also, according to their belief, breathing is the last thing that dies in a human being. Turning off the ventilator is thus equivalent to the doctor turning off the patient's soul, and the doctor will be perceived as a repulsive person with evil intentions. The doctor's karma is at stake although it is the patient who is at the centre. In Buddhism, action results in either merit or misdeed. If the doctor has a preponderance of misdeeds, it can affect them for the rest of their life. However, a female doctor has a solution: the reason the patient is still breathing is his mental bonds. The trick is that she uses the Thai term, 'a yarn ball of problems' as synonymous with mental bonds, suggesting it is the patient's worries and unresolved problems that are keeping him alive. She asks the brother what he thinks the patient is worried about. The brother says that the patient had often mentioned that he wanted to be ordained as a monk before his death. The female doctor then suggests that the brother go to his home region and become ordained as a monk as a 'stand-in' for his brother and then return to tell the patient and allow him to finally let go of his life. The brother does as recommended and comes back whereupon the doctors, without harming their own karma, can now turn off the ventilator. Again, the doctors prevent an acceptable solution by assuming the existence of a universal set of ethics that can be applied in every situation. In this case, the threat to the doctors' personal karma, their diffuse but noble ideas about medical education, and the Hippocratic oath are so closely intertwined with moral attitudes that they lose their decision-making power. The pragmatic solution that connects all needs to the needs of the patient (and the brother) is the winning solution, whereas doctors with their Western-coloured 'ethics' had difficulty establishing a compromise.

When it comes to telling patients the truth, opinions vary widely, and it is an important debate in bioethics. It seems that while the 'right to know' is central to bioethics, in some cultural contexts, health professionals are afraid to communicate bad news. Patients should not receive information directly because it is believed that the truth can make the patient feel hopeless and unable to cope with the illness. Yet, others believe that sharing information can strengthen a relationship of trust between patients and

doctors. In some cases, the principles of respect for the patient's autonomy require that the health professionals accept the patient's refusal to know the truth and stipulate that another person must receive the information so that medical decisions can be made on behalf of the patient. The health sector and individual employees should not work based on a common policy for all patients, but should examine what the real interest of each patient is in order to respect their personal autonomy (751). Often, the relatives are more worried than the patient is.

In many societies, you never talk about cancer. Cancer is cursed. It is an expression of weakness, punishment, and contagion. Illness in general is characterised by guilt, shame, evil eyes, and payback. Patients keep asking, *'Why was it me who became ill?'* The perceptions of the causes and effects of illness and death are conditioned by social and historical contexts, but schooling and a scientific approach can eradicate the differences between societies. It is, however, characteristic of patients who come from families and social networks with little or no schooling that breaches of routines, rituals, and traditions are violently anxiety-provoking. Thus, a culturally sensitive approach is often required to understand reaction patterns and patient needs in palliative care, life-threatening illnesses, and the process of dying. In Denmark, patients have an ethical, legislative, and culturally conditioned right to make informed decisions about their final time, but not all countries and cultures value this right/freedom - quite the opposite. In many societies, the *family* is the smallest unit, and individual members of the family cannot independently make decisions about illness, treatment, or death. In societies where the respect for doctors is considered inviolate, it can be difficult to involve the patient in decisions: *'You are the doctor, so you decide.'* Attempts by the doctor to involve the patient may seem out of place and appear to the family as medical uncertainty or weakness in an unpleasant situation precisely when the absolute decision-making power of the doctor is needed. For other patients, the course of the illness is predetermined although the doctor is allowed to help.

When more than 10 % of the population in Denmark comes from other societies, then serious illness such as cancer, sensitive processes such as the choice between active treatment and palliation, and rituals up to and following death will require new competencies from the health professionals. Just as death may vary for ethnic Danes, just as varied as it may be for Somalis and Chechen, and their variations are perhaps further from what ethnic Danes are used to. A German study of serious illness among migrants found the following crucial themes (752, 753):

1. Communication of unpleasant diagnoses in cross-cultural contexts is difficult. Requesting an interpreter is not a solution in itself if the information provided is (unintentionally) delivered in an insensitive, brusque, or offensive manner. Culturally borne perceptions, values, and rituals cannot be directly translated. Cross-culturally sensitive conversations require competencies, practice, and thought.
2. You cannot do a dress rehearsal for a difficult conversation. Thus, it is important to be trained in cultural transformation and adaptation during the conversation, i.e. continual consensus, partial conclusions, confirmation of agreements, and understanding of messages, as well as the opportunity to raise questions.
3. Treatment goals need to be reviewed several times with patients and relatives.
4. Pat remarks do not (always) make sense and are not necessarily a valid argument in all cultures, e.g. *'This treatment is in the best interests of the child'* may sound like a disavowal or brutal rejection of the interests of the parents or the whole family, thus creating a conflict. Health professionals must be trained to explain how they have come to their conclusions, and they must involve patients and relatives in the decision-making process even if their views differ widely.

5. Staff must be trained to deal with diagnostic and prognostic truth in cross-cultural contexts where the truth (cancer, incurable disease) can be relative or have a completely different meaning.
6. Cultural values are coded in the mother tongue, especially values concerning birth, illness, and death. Thus, a very liberal use of interpreters is particularly crucial in conversations where basic opinions, explanations, and perspectives need to be clarified - even if the patient or relatives are bilingual.
7. Interpreters need to be better trained for complex cross-cultural conversations where many opposing values and the interpreter's credibility, honour, and professionalism are simultaneously at play.

Contrasts between cultural/religious/traditional needs and medical needs can often create conflicts. In such cases, no single element will create a viable, acceptable, and ethically sound solution. The principle must be that the patient has informed autonomy. For instance, it is acceptable for Muslims to break fasting if they fall ill, but it can be personally very important for a Muslim, who is terminally ill with cancer and is undergoing chemotherapy, to do the fasting in what could be their last and most important Ramadan (753).

Using a professional interpreter is an important tool in achieving a common understanding and solution. However, it is not that simple for an interpreter to have a complete overview or control over the semantic problems and subtle signs and codes, in both languages, which can be critical to the patient and doctor understanding each other. Additionally, the presence of a third person in such a sensitive conversation may constitute a violation of intimacy, integrity, and confidentiality between patient and doctor. A family member or friend acting as an interpreter may manipulate or withhold information about a serious diagnosis due to the relationship with the patient without the doctor or patient noticing.

Deciding on treatment interruption or palliative care is a family decision in Islamic tradition. It is incorrect to speed up or cause death. Not giving the patient food or fluids can be problematic, just as it can be problematic to decide that there should be no resuscitation. As a Muslim, it is a duty to seek medical attention and protect/defend the body. Severe (terminal) illness is the Creator's test and a part of life's processes. Death means that the soul has come home to the Creator again. It is a natural part of life, and the Creator decides when and how this happens. In addition, there may be a perception of a certain consciousness after death, which can cause problems in relation to autopsy permission. Studies have found less knowledge and acceptance of a living will among ethnic minorities (754). African migrants (sub-Saharan Africa) were generally more prepared than many other minorities to give all treatment possible, while Asians and South Americans felt that family decisions about the final days were the safest. Migrants from some Asian and South American countries were very clearly opposed to notifying the patient, but the studies found large variations depending on integration and schooling, and that most migrants had hybrid perceptions and attitudes that needed to be discussed in each patient's case (754).

Particular challenges are associated with the death and funeral of migrants and refugees. A chronic state of grief can often arise if as a migrant (most often war refugees) one is prevented from seeing parents/grandparents before they die, or if one is unable to visit their grave afterwards. Similarly, it is almost unsolvable if a refugee family in which a member has delivered a stillborn child and buried it in Denmark is subsequently expelled from the country (e.g. if the temporary residence permit is not extended due to a political decision that repatriation has become justifiable).

Standardised guidelines on life-threatening or terminal illness often fall short with patients that belong to more collectivist cultures because the patients do not want to be informed and because deci-

sions often involve multiple family members who may reside in their home country (755). The significance, experience, and expression of pain are rooted in each patient's culture and past. Whether, how, and when pain is expressed depend on a number of cultural factors (507). For example, the pain associated with terminal illness can be perceived as a natural test in life of whether one is a good and strong person and whether one has a strong faith, or it can be a punishment. Thus, pain relief can go against the patient's basic attitudes in life (756). Pain is part of life and the path to a good afterlife (757). Hopelessness is considered in some religious contexts as a natural part of life, and it can only be handled as part of the path to salvation (758). Terminally ill Asian patients are aware of their psychosomatic symptoms and mental disorders but encounter a healthcare system that focuses on the physical symptoms and is annoyed by patients' attempts to discuss psychological disorders (759). The staff's lack of knowledge and understanding of different disease rituals and the often negative experiences that patients encounter within the healthcare system lead to unequal access to palliative care and suboptimal treatment of terminal illnesses that have institutional, and cultural as well as individual causes (758, 760, 761).

A study of physicians' verbal and non-verbal communication with African-American patients in palliative care found no difference in factual verbal communication between white or black physicians, but that there was significantly less empathy and relationship creation as well as less non-verbal sympathy from a white doctor relative to an African-American doctor (762).

The quality of palliative care is affected if a language barrier exists, and relatives of such patients receive significantly less information than relatives of other types of patients (763-765). Silva found in a review that in cases of dying patients with language barriers, relatives or ad hoc interpreters among hospital staff were often used, and these patients had significantly poorer pain control, more symptoms, and more anxiety than other patients where professional health interpreters were used (766). A survey of 142 certified professional health interpreters in the US with more than five years of full-time interpretation found that 85 % of them felt comfortable about acting as interpreter during palliative treatment and the final days, but 52 % felt that the conversations did not proceed satisfactorily. The crucial finding was that those interpreters who were aware of their role in the conversations were also those who felt that they progressed satisfactorily (767). A large study involving serial focus groups with experienced health interpreters came up with ideas to improve the quality of palliative conversations that had language barriers (768). The interpreters recommended: 1) that interpreters and doctors increase their communicative and empathetic skills, 2) that doctors have a clearer and more open understanding of cultural sensitivity and that they became better at speaking through an interpreter, and 3) that interpreters be given more conflict management tools, as they often experienced only being called in when the situation was acute and had a high potential for conflict. The interpreter role could alternate between being a pure language interpreter and being a mixed cultural negotiator and bilateral ambassador. The interpreters recommended that the doctor, nurse, and interpreter meet before the interview to agree on goals, structure, and roles - especially before conversations where the level of conflict was high (768).

A Swedish literature study on palliative care and care of ethnic minority patients found two main themes. The first main theme related to barriers to transcultural palliative care, such as ineffective communication between nurses, patients, and relatives. Communication problems between all concerned can be more complicated, when using interpreters and can create ethical dilemmas in information management. The second main theme related to strategies for improving the effectiveness of transcultural palliative treatment and care (through the education, training, and recruitment of health professionals), the desire to provide the patient with the best possible care, and better cooperation between actors (769). Ekblad et al. showed that communication between the patient, relatives, and health professionals is rarely without friction (770). Speaking the same language did not guarantee mutual understanding between people. The health professionals pointed out that communication between them and the patient deteriorated when they could not use a common language. Huang et al. showed that communication

took place on many different levels, of which verbal communication was only one (771). At the same time, it turned out that patterns of non-verbal communication could vary widely between different ethnic groups. This included the importance of silence for different groups, eye contact, touch, distance, personal space, and facial expressions during interaction and communication with the patient. Richardson et al. found that concerns among both health professionals and patients were always rooted in a lack of attempts to understand and reduce communication difficulties (772). Nurses, for example, were concerned that the patient did not understand the importance of the illness and the available treatment methods, as well as any side effects that could occur during treatments. Interpreters contribute to doubt and uncertainty because they often lack the necessary skills to translate difficult information in a value-creating way. Lack of knowledge prevented patients from being able to make informed decisions, and the palliative treatment course was characterised by fear of misunderstandings and treatment errors. Limitations in communication and perceived cultural differences directly affected the quality of the health professionals' work in measuring, interpreting, and treating the patient's pain and other symptoms (773). Health professionals often feel a dilemma between providing the best quality of treatment and care while also wanting to accommodate the individual patient's cultural values and routines. For example, decision-making about death and the dying person may be delegated in a way that is contrary to Nordic routines in the healthcare system, making the cross-cultural palliative processes seem like a difficult ethical balancing act between incompatible requirements (774). Others have identified challenges in cultural bridge-building with patients when relatives shield the cancer patient from being told the diagnosis, or when the relatives are highly selective about which information the sick person may receive. In other cases, it is perceived as taboo to talk about cancer, as it can mean that not only the patient but the whole family is weak or has failed socially. For example, a dying person may be referred to a hospice without even knowing that they are dying and without knowing that it is palliative care in a nursing home for the dying (775).

We have experienced that the staff's fear of contact, lack of willingness to negotiate, and limited cultural sensitivity to unfamiliar rituals around death and the dying can contribute to confusion and miscommunication. Having to deal with such a sensitive treatment course through an interpreter can be seen as an additional professional loss of control, but most conflicts around terminal care and treatment arise due to interpreters not being used and too much faith in the relatives' language skills and objectivity (776). Although having family members serve as interpreters may seem like an easy and convenient solution, it often results in misunderstandings, conflicts, and poorer quality of treatment (777). A notion also exists among health professionals that immigrant families 'look after their own' and therefore do not need special services. A number of other explanations have been presented, including the idea that certain religious traditions may be against the use of pain relief or that one should accept the inevitability of death. This has also been reported with regard to Judaism, although closer examination shows that a conflict exists between the 'ideal' views of certain opinion leaders and the practice of most followers (778). The problem remains that some misleading perceptions can be maintained by clinicians who have read fact-sheet-type summaries of cultural and religious preferences, yet apply this knowledge without adjusting it according to the needs and values of the individual patient or the attitudes of the relatives (779-781). Excessive focus on religion and culture reinforces the notion among health professionals that these factors are more important than the individual patient's needs, which is often incorrect (albeit professionally convenient because it relieves the employee of responsibility for the individual patient's needs) (782).

Decisions to stop certain treatments in, for example, intensive care units are a professionally and communicatively difficult task that is made no less difficult by cross-cultural and linguistic barriers. A major review explored the attitudes of different religions to decisions regarding dying patients and found that religious leaders have found it hard to keep up with opinions and developments in the area, and that there are, of course, disagreements within individual religions (779).

Table 22. The attitudes of selected religions to different decisions about the end of life.

	Withhold/decline treatment	Stop treatment	Stop artificial nutrition	Organ donation	Assisted death
Catholics	Yes	Yes	No	Yes	No
Protestants	Yes	Yes	Yes	Yes	Some
Muslims	Yes	Yes	No	Majority	No
Orthodox Jews	Yes	No	No	(Yes) - disagreement	No
Buddhists	Yes	Yes	Yes	(No) - disagreement	No
Hindu/Sikh	Yes	?	?	Yes	Some

However, doctors' decisions have also been found to differ depending on their own beliefs. Geographically large differences also exist in how each religion handles decisions towards the end of life (783). Thus, in addition to having routines for clarifying the patient's values and needs, the individual doctor and nurse must also clarify their own values and attitudes. Table 23 proposes questions that should be considered early in a palliative/terminal treatment course:

Table 23. Questions relating to the treatment of palliative and terminally ill patients.

<ul style="list-style-type: none"> • What are the patient's and the relatives' attitudes to the sanctity of life? • What are the patient's and relatives' definitions of death? • What are the religious affiliations of the patient and the relatives, and to what extent are they practised? • How do the patient and the relatives perceive the pathological picture and the causes of the condition? • Who constitutes the patient's social network, and who is part of the decision-making: <ul style="list-style-type: none"> ○ Who is there by duty, and who is there by personally? ○ Who is family, and who is friends? ○ Who can 'decide', and who really decides? ○ Who decides on which aspects of treatment, care, nursing, food/fluids? ○ Who is the voice with the most authority? ○ Do decision-makers change during the course of treatment if there is a change in the development of the illness? ○ Is this a first-time situation, or does the family have experience from other treatment courses or illnesses?

11.1. Patient narrative

Author Nicole Krauss writes in her novel *Great House*, ‘Perhaps all refugees try to recreate the place they have lost for fear of dying in a foreign place’ (784). A Danish PhD thesis on palliative professionals’ experiences of the impact of migration stories (life experience with migration) on care, and how migration stories affect the patient’s handling of a terminal illness, found that health professionals engaged in palliative care experience unfamiliar forms of communication, unfamiliar routines, and unfamiliar psychological trauma that play a key role in treatment. Patients expressed their migration stories in terms of requests for authentic food from their homeland, special requests for the presence and interaction of staff, as well as rituals around death and the funeral (785). The course of the illness and the end of life involve reflection on all things near and far. Here, the life story takes on a central role as the narrative that can form the basis for the co-creation of terminal care and treatment across cultures. The life story - the migrant narrative - motivates staff to adapt and change routines, while the staff’s interest in and responsiveness to the biography gives the patient the recognition that motivates them to use their life story as a tool to create recognition, security, and trust. As one patient at the MHC put it, ‘*I don’t want to die in a language I don’t speak.*’ If you are allowed to recreate your life through the life story in the language that best enables you to talk about your childhood and migrant life, then the palliative process can become a safe and trusting process.

The patient’s and family’s cancer experience cannot be understood as an objective event that develops independently of its cultural context. It would be prejudiced and unconstructive to consider cancer developed in an Iraqi woman living in Denmark as a ‘Danish’ cancer. Understanding requires an expansion of the mind-set of the health professional. Understanding arises by eliciting the cause and meaning of the cancer and how the patient and relatives are seeking to bring order into the chaos that a cancer diagnosis creates and the changes they introduce into their lifestyle. Cultural norms and expectations affect many aspects of a cancer diagnosis, including attitudes to treatments, their side effects, and pain; body image and sexuality; expectations of suffering and pain; public and private behaviour; interactions with the authorities; determination of who controls the family dynamics in the given situation and the family’s response to the life-threatening disease; and how dying and death are conceptualised, approached, and commemorated. One way to strengthen patient involvement is for the health professionals to attach clinical value to cultural diversity and insight because it can strengthen treatment quality and increase patient involvement in common solutions. Thus, start by getting familiar with the central cultural domains (see Table 24) that can form a thematic basis for engaging in an equal dialogue about similarities and differences in cultural values related to the body, soul, and serious illness.

Table 24. The cultural domains and their clinical meanings (in part based on reference 721).

Domain	Description
Ethnic identity	Country of origin, ethnic identity, reasons for migration, degree of cultural adaptation/assimilation, cultural division, and levels of cultural pride.
Taboo, stigma	What can be talked about? How it can be talked about? What is forbidden? Illness as a sign of human weakness.

Communication	Mother tongue and dominant language, dialect, vocabulary, willingness to share thoughts, opinions, or touch, use of eye contact, language division (e.g. simple everyday language in Danish, feelings and decisions in the mother tongue).
Time and space	Past, present, or future orientation, personal space, temporal understanding, concept of causality.
Social organisation	Family structure, gender roles, status/role of the elderly, extended family, decision-making, networking.
Labour force problems	Effect of illness and work, importance of work.
Health concepts	Cause of cancer, living with life-threatening illness, expectations from Western medicine and systems, religious/spiritual beliefs and practices, loss of body part/body image, blood transfusion/organ donation, patient role and health-seeking behaviour.
Nutrition	Significance of food, preference and preparation of food, taboos/rituals, religious influences.
Biological variations	Skin/colour of mucous membranes, genetic variations, specific risk factors and differences in incidence/survival/ mortality of specific types of cancer.
Sexuality and reproductive fear	Perceptions around sexuality and reproduction, taboos, privacy issues, interaction between cancer diagnosis/treatment and sexual beliefs.
Religion and spirituality	Dominant religion, faith, rituals, prayers, meditation, meaning of life, source of strength.
Death and dying	Significance of death and the afterlife, fatalism, rituals, expectations, sorrow and grief.

Decisions towards the end of life are rarely made by the patient alone, and the individual patient has their own model of decision-making that is also based on, whether they are introverted or extroverted decision-makers. However, death is not a process that includes a dress rehearsal. For many patients and relatives, it will be a first-time experience. It can be difficult for the patient and family to find the strength necessary to make such big decisions as avoiding or stopping active treatment. In many societies, large decisions are left to the family member who enjoys the highest respect, often the oldest member - whether or not this person can or will make the decision. This person is sometimes living in a different country and is unaware of the context and options in the country where the patient is located. Five challenges to the end of life have been identified (786, 787):

1. **Reactions to experiences of health inequality:** If the relatives have experienced discrimination in the past, it can either lead to questionable demands for the extension of futile treatment or the family may reject any treatment on the grounds that it is of poor quality. The fear that hospice care will be culturally incompatible can lead to rejection of the offer. Death can be an exile event where strong cultural values can be acted out and displayed.
2. **Communication and language barriers:** Without an interpreter, polite inquiries may sound like orders, and decisions or agreements that are clear to one party may be misunderstood by the other party.
3. **Religion and beliefs:** These must always be considered, but such topics are often associated with fear of coming too close, and a very skilled and knowledgeable interpreter may be needed. Who decides on death, and is it a necessary condition as a human being? The point in time when death is considered to have occurred varies greatly. The Western biomedical definition is the cessation of brain activity, while in most societies it occurs when the heart stops beating. There may be special rules about who should sit by the deceased and what rituals should be performed around the person's soul, etc.
4. **Truth, and the art of telling it:** In many communities, the transmission of bad news to the patient is considered an act that can accelerate death. Thus, it is important to ask questions such as, *'How much do you want to know about your illness?'* and *'do you want to discuss treatment options yourself, or would you prefer that we discuss it with your family?'*
5. **Expressions of grief may vary:** In some societies, it is socially unacceptable not to mourn the deceased loudly, while in other societies and institutions it is considered to be inappropriately noisy behaviour - especially in hospitals.

Anthropologist Grete Brorholt has defined a number of basic cognitive competencies that should be taken seriously in cross-cultural patient meetings (788). See Table 25.

Table 25. Useful questions and considerations for cross-cultural conversations that involve difficult, value-laden, or potentially traditional health contexts (modified per 788).

1. No automatic cultural links exist (manuals on ethnic attributes are meaningless in regard to the individual patient).
2. Step into character as a professional (your professionalism also helps with language barriers).
3. Consider your own preconceptions and the culture of the department (discuss it with your colleagues so that you know both points of consensus and differences).
4. Be explicit and direct in your formulations in a polite and welcoming way (caution and fear of personal contact are catching and can be confusing - be honest).
5. Listen to, what is *actually* being said, not what you *think* is being said.
6. Start from the specific situation, and speak from that point.
7. Discuss and explain the problem as you see it and seek consensus on the core problem.
8. Be aware of your own values and common rules.
9. Use an interpreter - and always in discussions about personal values and explanations so as to achieve a common language.
10. Your taboo topic is not necessarily the patient's taboo topic.
11. Give yourself and the patient extra time. It saves time to spend time.

11.2. Death and the dying person

Good care at the end of life can be complicated by disagreements between doctors and patients, difficult interactions, or decisions by relatives that the doctor does not understand. Conflicts in palliative care primarily concern the following themes: autonomy between the patient and the health professional; values at the end of life and preferences; the cultural meanings of pain and pain management; and the problem of stereotypical and non-emphatic behaviour towards patients and relatives, who are different from ourselves. Because expected deaths have increasingly been a result of an explicit negotiation on limiting or discontinuing treatment, the likelihood of serious moral disputes and obvious conflicts increases (789). Attempts to use ethnic background as a simplified, straightforward indicator of faith or behaviour inevitably lead to harmful stereotyping of patients and culturally insensitive palliative care for the dying. Culture is meaningful only when interpreted in the context of a patient's unique history, family composition, decision-making patterns, and socio-economic status. We cannot predict a patient's preferences and values by categorising the person into an ethnic group. What begins as a genuine desire to respect patients can very easily deteriorate into an attempt to simplify 'culture' into something that can be diagnosed and treated (removed). True cultural competencies require humility and curiosity and the willingness and flexibility to understand and respond to the patient's beliefs and how they want to be treated. For some patients, it may be inappropriate to be informed in detail about the truth about their condition, or to be questioned explicitly about the planning of treatment in their final days. However, rarely do people from any culture refuse to explain their own cultural beliefs and behaviours so the doctor need not fear having this conversation. Avoiding cultural dissonance does not require that doctors learn about a wide range of cultural beliefs and practices. Rather, doctors involved in palliative treatments should be sensitive to the arbitrariness of their own cultural beliefs about the value of telling the truth to patients and allow them to participate in decision-making.

All transitions of life are associated with rituals and traditions that are important in ensuring that the transition takes place safely. This also applies to death, but it can be difficult to establish a safe framework for the final days if you live in a society with rituals that differ from your own. One patient very clearly expressed the dilemma of bilingual death, *'I don't want to die in a language I don't speak.'* All societies have rituals around death and the dying person. It is not a process you, as a relative or patient, can practise, but you can clarify your needs and thoughts through dialogue. It is not a process you can repeat or reverse. It is a definitive problem that can only be solved once, and it has to be done right. Thus, both the stress level and potential for conflict are very high. Naveed Baiq and Hanne Bess Boelsbjerg address cross-cultural palliative care in their article: 'To die in the arms of a stranger' (790). They write:

... a different language is spoken where the illness is described practically in codes; one's everyday routines have changed and are subject to a recognition that the hospital is a workplace where many patients' needs have to be addressed. When you also have a different ethnic background than Danish, you will often experience a double alienation because you yourself can be considered foreign, and all the things that you associate with homeliness and security will be considered 'different'. There is a vulnerability to being in a foreign situation, which is exacerbated when you have a life-threatening illness. On the one hand, you cannot behave as usual, and on the other hand, you are faced with an event that you have never lived through before. The unknown that you are confronted with makes you vulnerable because you depend on others to help you. And it can be harder to accept if you are treated as 'a stranger'.

Death is not taboo for Muslims, but life is sacred and the protection of life is key. This may occasion relatives to ask for treatment that is medically unrealistic. In this situation, it is important to explain that it is nature and that you cannot medically change nature. It is also important to point out what may be obvious to the doctor: that the hesitance in treating a dying person is not caused by the patient being a 'foreigner'. Prejudice thrives in all contexts but is sometimes based on experience. Patients' and relatives' previous experiences can be integrated into the framework for understanding the current palliative process, but if the staff do not actively seek out information about past experiences, the doctor or nurse will be unaware of prior understandings when speaking with the patient and family (790).

Case 1

An elderly man of ethnic origin other than Danish was dying at a hospital. A representative for the family tries to make an agreement with the evening staff to allow more relatives to come the next day to visit the dying man. The agreement seems clear to the representative for the relatives, but it is not passed on clearly to the evening shift, who in turn fails to pass it on clearly to the day shift the next morning. Suddenly, a fairly large number of relatives show up at the ward and several are on their way in and out of the room. The staff are frustrated and appeal to the relatives, who in turn become frustrated that their need to see the dying is being rejected by the staff despite the agreement that had been made the previous night, according to the relatives.

To health professionals, death is part of the normal state of things, and for some it may be a daily routine. For patients and relatives, however, it is often the first time. The cocktail of language barriers, anxiety, stress, and the feeling of lack of knowledge and options is explosive if not tackled early by the health professionals. Use an interpreter as much as possible so that all relatives and the patient have the same dialogue and information. Try to come to an agreement on what is needed and feasible - flexibility and clear agreements that everyone can live with go a long way. Unilateral and overly categorical statements may provoke and hurt those involved.

Case 2

A child of parents of ethnic origin other than Danish died in a traffic accident. A bilingual doctor negotiated with a representative for the family about how to arrange for all relatives to see the child in the chapel. The doctor discovered that a conflict had arisen in the family between two groupings. Therefore, it was agreed that the two groups would arrive separately and they would each get one hour after which they would all leave the chapel to allow the next group to enter. Representatives of the family subsequently expressed great satisfaction with the way the hospital had fulfilled their wishes and needs.

Case 3

About 30 relatives are in a hospital ward and about 20 are in the hospital lobby after their countryman from an African country, who lived in Jutland, suddenly died in Copenhagen during a visit. They have a Muslim background, and several people have questions about transportation and burial. The mood is a little unsettled due to uncertainty about the rules. The doctor in charge of the department calls an imam, gathers all the relatives in one room with the imam present, and explains what has happened to their loved one and what the department will do. Subsequently, the imam provides information about transport to Jutland and about the burial options. With this information, the relatives are satisfied and leave the hospital.

Case 4

An 80-year-old man from the Middle East with terminal cancer. The patient wants active treatment but only talks about blood clots in his legs because he has heard that you can get them surgically removed in his home country. His adult daughters have interpreted for him throughout his hospitalisation. Despite several attempts, nobody has succeeded in explaining to him that he is terminally ill and dying. The patient wants to go back to his home country so that he can have surgery there. The MHC is asked to assist and since a professional health interpreter is used at the new interview, it becomes clear that the patient is unwilling to talk about his illness and is unaware of his actual diagnosis. The patient's desire to go home is fulfilled, and the patient dies shortly thereafter.

Case 5

A 76-year-old man from the Middle East with terminal cancer and dying. The patient only wants to go home, but his wife has rejected this due to his care needs. During his hospitalisation, the patient tries to kill himself several times by jumping out a window and lying down at a crossroads in frustration at not being allowed to go home. The patient only wants his (adult) children as interpreters and has so far rejected any professional interpreter. The MHC gets involved and explains to the patient that they are unsure, whether the patient understands his situation, and in such a situation it is a legal requirement that a professional interpreter is used to ensure that no patient errors occur. The patient accepts an interpreter. It turns out that the patient did not want to involve his children in the diagnosis and that he had experienced difficulty forming a clear concept of his options. The patient had been confused by the many doctors and nurses with whom he had been in contact and no longer felt a connection with the staff. The possibility of hospice where both his wife and children could be present around the clock is explained to the patient, and he accepts the proposal. The agreement is physically concluded by being acknowledged as a formal agreement with handshakes and eye contact between an MHC nurse and the patient. The patient and relatives welcome the decision.

Comment:

- *Remain in the room until a decision has been made.*
- *Be present and control the process.*
- *Stay seated - create physical calm.*
- *Make eye contact with the patient or key representative and maintain it.*
- *Remain in the room and prevent people coming in and out all the time.*
- *Summarise and seek agreement.*
- *Use old-fashioned protocol: 'We have a deal.'*
- *Be 'tough' when it comes to language and interpreter services: having an interpreter is as necessary for the doctor as it is for the patient. Use an interpreter - and make this decision for the patient and family. Most often, it is a relief that a professional decision is made.*

The book: *Faith, Care, and Cross-culture* offers many suggestions on how to clarify and conduct a dialogue with patients and relatives about basic needs and perceptions in the healthcare system (216).

12. Cross-cultural patient safety

Language barriers in particular appear to reduce the quality of treatment and lead to an increased frequency of medication side effects, medical errors, adverse events, and serious complications (791). Patients with language barriers experienced medical negligence and serious/fatal events twice as frequently as other patients (792). Patients with language barriers experienced twice as many medication errors and side effects as other patients, and the effect was amplified if the patients could not recognise potential side effects due to having received inadequate information from the doctor (793). Patients with language barriers find it harder to understand a disease episode and the hospital stay, they find it harder to understand patient information and medication labels, and they report more problems with side effects (794). A specific example of the direct effect of language issues in treatment quality was found in a clinical trial in a large anticoagulation clinic where patients on anticoagulation therapy (warfarin) who had language barriers had significantly less time in therapeutic care than other patients (795). Several other studies have made the same observation (796). Patients with language barriers had significantly less knowledge of the effects and goals of their anticoagulation therapy after a cerebral thrombosis, and they knew significantly less about their disease than did other patients (797). Pharmacies could play a significant and untapped role in this context (724). A Dutch analysis of ethnic differences in patient safety found that all reported patient safety breaches among patients with language barriers were due to administrative or professional failures: 1) inappropriate response to obvious (language) barriers and clear risk factors (country of origin, trauma, genetics), 2) misunderstandings between patient and therapist due to obvious differences in disease experience, information level, and treatment expectations, and 3) inappropriate treatment due to the therapist's bias concerning the patient's needs and possible behaviour and ideas about the patients' reaction patterns based on stereotypes (798). A US hospital study of 102,000 hospital records found, in addition to higher incidences of medication errors, that hospitalised ethnic minority patients had a 34 % higher incidence of hospital infections (nosocomial infections) than other patients, more bedsores, and less control of blood sugar and blood thinner treatment (799).

In Denmark, few studies have been done on patient errors in connection with language barriers. In 2007, the Danish Health Authority compiled a very brief thematic report entitled 'Language problems between health professionals and foreign language patients' based on 29 adverse events in 2006 in which language problems or ethnic elements contributed to the event.

A study of patients referred to the MHC investigated misunderstood symptoms, serious misconceptions, and adverse events, focusing on what type of errors occurred, when they occurred, how they played out, and what consequences they had for the patients (36). The study analysed 147 patients referred to the MHC in 2015–2016 and found that 95 of the patients had experienced a problem in diagnosis or treatment attributable to a language barrier. On average, there were two events per patient, but one in four patients had been exposed to three or more problematic events. Every third event was designated as serious or significant. More than one in four problematic incidents occurred because the staff overlooked a diagnosis of PTSD that was the direct cause of symptoms or health problems. Occupational injuries accounted for a relatively large proportion of the adverse events. The causes of errors included complex patient conditions, doctors' failure to get a complete medical history, and doctors' lack of clinical competencies in refugee/immigrant diseases and backgrounds. Moreover, a significant proportion of problems were due to a lack of coordination or cooperation between departments or between the municipality and hospital. Finally, some patients' symptoms were prolonged by inappropriate perceptions in the municipal sector. It is a fundamental problem that interpreters are still not generally being used for important conversations in the healthcare system and the municipal sector. Additionally, doctors tended to overestimate their patients' literacy level, thereby creating inequality in patient information, which other studies have also demonstrated (800).

MHC has indicated that side effects and serious drug interactions result from a lack of interpreter services, minimal or misleading medication information, and especially the rules on medicine substitution, all of which particularly affect patients with language barriers and low education (81). Dutch study also showed that certain ethnic groups were issued a prescription much more frequently than others when visiting their family doctor (721). Variations in prescriptions show the difficulty in comparing areas of widely different ethnic composition in terms of medication consumption, disease patterns, and access to healthcare. Many factors are at play, and research in this area is still mainly register-based or qualitative (722). Communication barriers with foreign language patients are frequent in pharmacies, and pharmacists find that patients are at increased risk of being exposed to adverse events, as documented in a Danish study from 2009 where over 50 % of the people interviewed took medication purchased abroad (723). Already then, this study pointed out the need for access to interpreter services (interpreter hotline) to advise patients who pick up medicines at the pharmacy. Communication tools need to be developed and disseminated to support pharmacists in providing guidance to ethnic minority patients in pharmacies and this includes interpreter access and foreign language patient information leaflets (724, 725). A US study found that compliance problems occurred much more frequently among patients with language barriers (31 %) compared to other patients (12 %) but that an ethnically minority-competent clinical pharmacist could increase compliance by 24 % (726).

A legal aspect of clinical and patient safety consequences concerns informed consent. Although no Danish studies exist, a US study showed that documentation is frequently lacking on whether ethnic minority patients have actually accepted the interventions or treatments given (801). In a US study, patients with language barriers had less knowledge of their diagnosis, the medication they received, the treatment plan, and whether follow-ups were needed at the hospital (323). During hospitalisation, language barriers resulted in significantly more blood tests and examinations being ordered than for other patients, as well as it taking longer to complete examination programmes. The differences were diagnosis-dependent where abdominal pain in patients with language barriers triggered a CT scan of the stomach three times as often as it did for other patients, while there was no difference in the frequency of examinations for chest pain (312). It is likely that doctors are better at assessing and performing differential diagnosis for chest pain than for abdominal pain.

Ethnic inequality has been demonstrated in standard treatment of acute myocardial infarction (blood clot in the heart) with beta-blockers and cholesterol-lowering drugs (802). There are no Danish studies on referral to cardiac catheterisation for patients suspected of cardiac infarction or after heart attack, but numerous US studies have shown that patients with language barriers or patients belonging to ethnic minorities are less often referred for cardiac catheterisation. Diabetes patients residing in Denmark who originate from Turkey, Pakistan, and former Yugoslavia start significantly later with cholesterol-lowering drugs (statins) than ethnic Danish diabetes patients (803). Inequality in access to (referral to) cardiac rehabilitation has also been identified (804). A US study showed that because doctors already considered it more likely that ethnic minority patients would stop cardiac rehabilitation prematurely, they were less likely to refer this group of patients to cardiac rehabilitation at all (805). This could be a significant healthcare mechanism that leads to general inequality in healthcare. Turkish and Lebanese diabetes patients have significantly poorer management of their diabetes. Whereas 72 % of ethnic Danes have normal blood sugar levels, this only applied to 50 % of ethnic minority patients (255). The existence of serious treatment failures is reflected in the fact that some ethnic groups in Denmark have a mortality rate from diabetes that is two to three times higher than that of ethnic Danish diabetes patients (806).

Cross-European studies suggest that diabetes, obesity, and cardiovascular disease are more frequent among Turkish, Lebanese, and Moroccan immigrants residing in Europe (i.e. outside their home country) than Turks, Lebanese, and Moroccans residing in their home country (807). Hypertension patients are subject to a clear treatment failure in the Netherlands relative to the local population, but

unfortunately no similar studies of hypertension treatment among refugees or immigrants in Denmark have been conducted (808).

Some ethnic groups in Denmark have significantly higher mortality from cardiovascular disease compared to ethnic Danes (161). A complication of heart attack is cardiac insufficiency and differences in treatment quality are evident here, with significantly higher rates of cardiac insufficiency among ethnic minority patients in the Netherlands, England, Scotland, and California (809). A Dutch study found that after the first hospitalisation with acute heart disease, mortality rates were higher among ethnic minorities than ethnic Dutch people and that the difference could not be attributed to socio-economic differences, but to differences in treatment quality and rehabilitation (810). Other studies even suggest vast inequality in the treatment of ethnic minority patients admitted with heart attack, which indicates that a treatment bias is expressed differently in different administrative environments and hospitals (811). Finally, some studies suggest that formal equality in treatment options in the hospital system does not in itself ensure equality in the treatment *actually* performed as is especially evident in subacute hospitalisations, e.g. for angina pectoris (812). A 2011 US study of 321,000 hospital records found that ethnic minority patients in hospitals less frequently received standard treatment after AMI (acute myocardial infarction, heart attack) with ACE inhibitors and aspirin. The same was true for uncompensated heart failure, and for pneumonia, they were less often offered smoking cessation guidance. Finally, the study found that general patient counselling and information were less detailed for ethnic minority patients (813). Also in the US context, basic medical discrimination has been demonstrated regarding transplantation, lung cancer chemotherapy, osteoporosis treatment, and pain management (343).

The consequence of the lower level of information is that patients understand neither what is being communicated nor their own role. In a study of patients' knowledge after a medical interview at a hospital emergency medicine department, 41 % could not account for their diagnosis, their treatment, or what the follow-up plan was, which they had been given immediately prior to the interview. Patients with language barriers performed significantly worse than other patients on all parameters: knowledge of diagnosis (61 % vs 83 %), what medication to take (12 % vs 39 %), and follow-up plan (57 % vs 74 %) (323).

Language remains the primary tool for both doctors and patients. Language barriers affect the tool's precision, and disrespect for this obstacle comes at a cost. Failing to try to mitigate this language barrier has well-documented, serious consequences for patient safety, complications, and survival (814). Use of professional health interpreters improves treatment quality and outcome, and reduces the number of patient errors, for a modest additional cost (815). Experienced professional health interpreters themselves cite patient safety as one of their most important tasks (816). Evidence shows that 1) increased health competencies, 2) use of interpreters, and 3) co-decision increase patient safety in conversations with immigrant patients (817). Well-trained interpreters can become an integral part of the clinical team where they know the doctor's goals for the interview, ensure relevant clinical information, help the doctor obtain the right information, participate with support in diagnostic tasks, and relay medical information tailored to the patient's needs and abilities (818). Finally, interpreter assistance helps to ensure that more patients feel involved and that more people understand informed consent (819). Particular attention should be paid to safe patient communication in new or sensitive specialist areas, such as genetic counselling, where interpreters are absolutely necessary, but where they also need continuous professional updates (767, 820, 821).

Doctors often have many excuses for not using interpreters: *'the interpreters are too poor at Danish'*, *'the interpreter gossips'*, *'the interpreter interferes and over-interprets'*, *'I am a skilled doctor so I don't need an interpreter'*, *'the information I have to give is very simple'*, *'the patient speaks a little Danish'*, *'the patient speaks a little English'*, *'the patient probably brings a relative'*, *'the interpreters are never on time or they fail to show'*, or *'the patients do not want an interpreter'* (822). None of these

arguments warrants further investigation, and they should be considered as convenient, opportune excuses to avoid extra work or longer conversations.

Interview studies with professional health interpreters have shown that doctors lack cultural skills and are challenged when participating in interviews with interpreter assistance (823). According to the interpreters, errors occur even with interpretation when the doctor has an imprecise view of the patient's disease perception, when no matching of expectations has taken place regarding the patient's needs, and when the doctor ignores or misinterprets non-verbal patterns. Various learning programmes for interpreted conversations have been developed for medical students (824, 825). In a comprehensive review of 106 studies of physician-patient communication from 2009, DiMatteo showed that when patients do not understand the doctor, it leads to improper medication breaks and unnecessary hospitalisations. If the patient does not understand the doctor, the risk of the medicine not being taken properly is 20 % greater (826). The review also showed that educating doctors in communication can improve the communication between doctor and patient to such an extent that the patient is 62 % more likely to follow the prescribed treatment (826, 827).

Several studies suggest that doctors frequently use generalisations and stereotypes when it comes to language barriers, and this leads to shorter doctor-patient conversations with less patient involvement (80, 828). A Dutch study of diagnostic medical errors demonstrated, how doctors, who make mistakes, are often: 1) too selective in their range of information, 2) too selective in the cognitive processing of the selected clinical information, 3) too inaccurate and superficial in their exclusion of other diagnoses, and 4) ignore the importance of co-morbidity (829).

Often, doctors fail to realise how their own (medical) culture affects their clinical decision-making skills, but gender, age, social status, educational level, and ethnic discordance/concordance between doctor and patient directly affect the doctor's clinical decision-making with regard to examination, treatment, and information level (and whether the patient understands and trusts the doctor) (246, 338, 367, 368). Although doctors do not believe they are doing social and linguistic categorisation in the clinical patient situation, it does occur as part of an unconsciously sophisticated individualisation strategy. In addition to considering the individual patient, they are sitting across from, doctors also 'read' their patients using a social radar that records the patient's physical and mental appearance, interaction, and language (369).

Doctors also tend to overestimate the patient's literacy skills, thereby risking that the doctor's information becomes too complicated for the patient. Often patients benefit so little from the doctor's information that they cannot ask questions because they do not have a sense of context or significance and therefore choose silence (800). Patients who are unsure of the doctor's clinical decision-making process more often regret later decisions about examination and treatment, which delays diagnosis and treatment.

A US study based on clinical databases found that patients with language barriers were more frequently exposed to patient errors and adverse events (medication errors, falls, incorrect identification, pressure sores, lack of consent or consent without interpreter, and incomplete hospital discharge information) and that they were more frequently exposed to near misses (814). The study also found that patients who used interpreter services reported more errors than patients who were not offered interpreters. The same study created a special database of errors due to language and interpretation. Most of the errors in the study resulted from non-use of interpreters, the use of family members for technically complex conversations, or the use of (poor) language skills by employees in the second language. The rest of the errors were due to improper use of interpreter services or of interpreters, unresolved cultural barriers, rude behaviour by health professionals towards interpreters, and patient consent obtained without interpreter assistance (814). A Dutch hospital study found that patients with language barriers were repeatedly exposed to threats to patient safety in nursing (medication, pain assessment, fluid bal-

ance) and in interaction with doctors (medical history, diagnosis, risk communication, and in acute situations). The same study found that the language barrier was undocumented in 30 % of patients who actually needed interpreters (830).

The main areas where patient safety is threatened for patients with language barriers include (831):

- **Informed consent:** Patients with language barriers more often experience that no informed consent is sought, that it is not documented, or that it is uncertain whether informed consent is understood. The use of ad hoc interpreters (staff, family) is often the cause of misunderstandings (801, 831).
- **Adverse events:** Adverse events are twice as frequent among patients with language barriers as other patients. Physical injury is more frequent (49 %) compared to 29.5 % in other patients. Twice as many incidents (46.8 %) were judged to be moderately serious to fatal, compared to 24 % among other patients (792, 795, 832).
- **Failure to treat or over-treatment:** This is inherently difficult to study. Significant differences in appendectomy and imaging diagnostics have been found, and one study found that minority patients were intubated more frequently than other patients 'as a precaution' (defined as intubated for under 48 hours) (833, 834). Conversely, asthma patients with language barriers were 17 times more frequent than others to be intubated during hospitalisation (835). Language barriers led twice as frequently to readmission and to prolonged hospitalisation (836).
- **Medication errors:** Side effects and drug complications are more frequent among patients with language barriers. However, patients who get interpreter services are more likely to report medication errors, and they understand significantly more of the medication information (98 %) than patients who need an interpreter but are not offered one (27 %). Patients with language barriers are less often informed about medication side effects and actions in this regard. When it comes to treatment with blood thinners, patients with language barriers are less likely to be in the therapeutic range than others and levels are frequently too low. Poorer asthma control in this group has also been documented (837-840).

Sector transitions and hospital discharges are some of the areas where patient errors frequently occur. An Israeli study found that at hospital discharge, patients who spoke the same language as the prescribing doctor (Russian or Arabic) were given significantly more and better information about danger signs, follow-up, and other advice regarding complications and where to get help (841).

The MHC has previously pointed out the overall problems of patient safety, compliance, and quality of treatment in ethnic minority patients (78, 81, 82, 178, 179, 842). Still, no records of adverse events or patient errors involving patients with language barriers are being kept. The only earlier account available is an old statement from the Danish Health Authority that is based on just a few individuals and randomly selected, general patient errors that were solely due to interpreter errors - none of the cases concerned errors on the part of the health professional. It is very significant for the area that the only adverse events that MHC is aware of relate to interpreter errors, which are not even recorded in the database for adverse events (because it is usually an 'external' provider and therefore omitted). We are not yet aware of adverse events reported to the Danish Patient Safety Authority, where mistakes have been made by health professionals in a patient with a language barrier.

Traditionally, errors due to language problems are not reported because they are considered to be a normal condition that patients have to accept and it is not the responsibility of the healthcare system. Errors due to low health competencies, functional illiteracy, or language barriers are considered to be predictable problems that must be addressed on an ad hoc basis without special guidelines or routines (843). The internal culture of each department is what tends to determine whether an error is perceived as a mistake in their area, or whether the errors are viewed as expected and inevitable events that cannot be changed by the hospital anyway. For example, a patient needing an interpreter was referred to a large university hospital with a highly specialised function but was sent back to the referring hospital department with the following message, *'Can't you teach patients Danish before referring them here?'*, implying that dealing with patients' language barriers was outside the university hospital's core tasks. This is not an uncommon attitude in Danish hospital departments.

12.1. Analysis of Danish data: Adverse incidents involving language barriers

The MHC investigated the concrete mechanisms through which language and cultural barriers affect clinical decision-making and challenge patient safety by reviewing data for patients referred to the MHC in 2015–2016. A further aim was to examine how factors in sectors other than the healthcare system can have an indirect adverse effect on patient safety and health.

The MHC reviewed all the incidents that were documented as part of the clinical routine at the clinic. An incident in this review was defined as a clinically unresolved, misinterpreted, or overlooked problem that fell into one or more of the following categories: 1) overlooked or misinterpreted disorders, 2) serious misunderstandings (patient or doctor), 3) lack of critical information, 4) adverse events, and 5) instances where cross-cultural and/or linguistic, but clinically unfounded, factors were assumed to have played a prominent/decisive role in the emergence or lack of resolution of a problem. Incidents were only included if they appeared in direct conversations with the MHC team or occurred during clinical treatment being provided elsewhere in the healthcare system.

The study included 147 patients who had at least two visits to the clinic during the period. Of these, we found that 95 patients (64.6 %) had one or more incidents and 35 (23.8 %) had no documented incidents. It was not possible to determine with certainty whether an incident had occurred for 17 patients (11.5 %). A total of 198 incidents were identified, with a median of two incidents per patient; 32 % of patients had one incident, 43 % had two incidents, 14.7 % had three incidents, and 10.5 % had four or more incidents.

Of the 95 patients with at least one incident, 26 patients (27.3 %) had an overlooked PTSD condition and 19 patients had known PTSD at the time of referral to the MHC. In total, 43.5 % of patients referred to the MHC had symptoms of PTSD.

It is estimated that 31 patients had two or more incidents, which overall must be seen as particularly serious with a clear clinical learning potential.

The 198 adverse patient incidents could be categorised into four areas of errors: 1) primarily patient-based, 2) primarily doctor-based, 3) primarily due to language barriers, and 4) primarily due to the municipality (Table 26).

Case 1

A woman from North Eastern Africa who had never gone to school. The rheumatology department had found she had spinal stenosis and a median herniation corresponding to L4/L5 with nerve impact. The patient is afraid of surgery (but the reason was not clarified by the doctor during the consultation), so the patient was offered a short training course under the municipality. It is noted in her medical record that the patient should contact the department herself if the training does not have the expected effect. The patient informs us that the department said they would send her a letter with a new plan. The patient

is terminated from municipal rehabilitation by a letter to the referring doctor in the rheumatology department. Two years later after a change of doctor, the patient is referred to the MHC where permanent nerve damage is now found in both legs. The patient maintains that she was promised a letter from the rheumatology department about surgery but has been waiting for it for 2 years. It turns out the patient also has PTSD, having been gang-raped and punched in the back with rifle butts in her home country. The patient was afraid of being re-traumatised by the surgery and was afraid of dying on the operating table (she had three children under seven years of age). After treatment for PTSD and support from a contact nurse, the patient agrees to surgery.

Comment: *The safe answer for insecure patients is 'no'. However, it is the therapist's job to investigate the patient's circumstances and understand why the patient has declined treatment. Correctable factors may exist.*

Table 26. Examples of incidents identified under four categories of error, based on a study of 198 adverse incidents occurring among 147 patients referred to the MHC.

Problem area/sector	Examples of incidents
Primarily patient	<ul style="list-style-type: none"> • Lacks knowledge about the illness and/or treatment. • Multi-morbidity where the patient has daily doubts about the focus, severity, or prioritisation between the illnesses. • Complex, compound symptoms that the patient has difficulty distinguishing. • Rejects examination or treatment due to lacking or erroneous understanding or information (e.g. scanning, surgery, or psychiatrist). • The patient fails to show up to avoid being scolded by the staff (forgotten medication, blood tests, or earlier appointment). • Misunderstanding or ignorance of the hospital treatment plan leads to breaks in routine, diagnostic delay, or termination of treatment. • Inadequate knowledge of past illnesses, injuries, and treatments in the home country. • Serious financial problems (high-interest loans for housing deposit, private loans for funerals, etc.).
Primarily doctor	<p>Psycho-social factors in compliance</p> <ul style="list-style-type: none"> • Overlooked familial/marital causes of compliance failure or symptoms (divorce, child's disability, spouse's illness, partner violence, loss of close family member, uncertainty about family member's fate). • Overlooked psychologically stressful incident (accident, racist assault, extreme decision and action paralysis, accident at work, lost family member in home country). • Incomplete medical history, coherence-based clinical bias, cross-cultural bias.

	<ul style="list-style-type: none"> • Omission of examination/treatment for a non-health/non-clinical reason (ideas that the patient is not really that ill, that the patient cannot handle the treatment, that the patient does not belong in the risk group, that the patient exaggerates symptoms, ethnic pain, symptoms are perceived as 'cultural' expression, etc.). Failure to register or describe accidents at work or injuries in Den-mark or the home country (including no reporting). • Poor/suboptimal quality of treatment relative to current best practices or usual standards because the doctor does not wish to spend the time needed for the necessary measures. • Pain is interpreted as ethnic pain (multiple myelomatosis, spinal stenosis, tooth abscess, osteoarthritis of the jaw joint, rheumatoid arthritis), depression (PTSD, loss), and headache called migraines (racing thoughts in PTSD or anxiety).
	<p>Inadequate clinical knowledge of illnesses among ethnic minorities</p> <ul style="list-style-type: none"> • Omission of examination/treatment on an uncertain or incorrect clinical basis (lack of relevant clinical knowledge, illnesses that occur frequently in particular ethnic groups, special hereditary illnesses, etc.). • Overlooked or misinterpreted physical and psychological torture injuries (electricity, falanga, water boarding, blows, muscle/bone injuries, soft tissue injuries, nerve damage, re-traumatisation, triggering sounds/smells or situations). • PTSD symptoms (alarm, stress, impulse control, isolation, evasive behaviour, dissociation, etc.). • Consequences of particularly violent sexual assault, gang rape. • Incontinence due to multiple births, rape, torture. • Somatisation in PTSD misleading the doctor in clinical decision-making. • Illnesses requiring observation over several years and 'accumulation' of symptoms with an element of negotiation, patient observationally heavy, and high patient involvement (special rheumatic diseases, certain neurological diseases, asthma, allergies, muscle disorders, side effects, occupational diseases).
	<p>Events due to language barriers</p> <ul style="list-style-type: none"> • Substitution errors due to lack of interpreter at the pharmacy or lack of information from the doctor. Examination not performed because the doctor had forgotten to order the examination, and a) the patient did not know what examination was involved, and/or b) the patient does not speak Danish and cannot himself or herself call and sort it out, or c) the patient is waiting for the appointment letter that never arrives.

	<ul style="list-style-type: none"> • Rehabilitation is not started, as the patient has not been informed via interpreter with specifics about location and purpose. The patient's trusted relatives are rejected as interpreters despite the patient's clear wishes (particularly sensitive crucial circumstances/traumas/assaults that the patient does not want the interpreter to know about, special cognitive deficiencies/disabilities where only the family can interpret, less common languages or special dialects where there are no interpreters). • Bilingual health professionals are used as ad hoc interpreters but do not have sufficient language skills in the 'mother tongue' and translate incorrectly. The patient does not dare reprimand or criticise due to the person's dual role and the patient's dependence on the goodwill of the staff. • Sick children: Only the parent who speaks Danish is informed, while the other parent does not receive the same information because the spouse is allowed to act as an interpreter without having sufficient Danish skills and without the staff making sure that the first spouse informs the other spouse. • Informed consent is obtained <i>after</i> the examination has been carried out, the treatment has commenced, or the operation has been completed and where it is documented that the patient did not understand the goals, significance, or consequences. • Written material on surgery, chemotherapy, and biological treatment has been provided to a patient who is illiterate. • Patients are informed by telephone about procedures or patient tasks without an interpreter. • Examination or treatment is carried out even when the patient has tried to resist (without interpreter), but this is not understood by the therapists. • The patient has lost their Danish language skills due to a work accident, social event, or illness without this being noticed
Organisational	<ul style="list-style-type: none"> • Patients are terminated at the first no-show. • The patient is a pawn between two or more departments that disagree on who is primarily/currently responsible for the patient. • The patient is used as an information carrier between departments but without the patient speaking enough Danish - verbal information is lost. • Incorrect referral resulting in significant delay and the patient does not know where they are being referred to or why and cannot explain themselves. • Patient fails to show at appointments: The patient does not use e-Box [the Danish electronic message system for information from the authorities], does not have a computer, lost their NemID [standard log-in solution for Danish Internet banks, government websites, etc.], computer broken, patient is denied help with e-Box by health professionals.

	<ul style="list-style-type: none"> • Some hospital wards consistently do not use interpreters. • Poor cooperation in the treatment chain creates delays that necessitate repeat scans, referrals or medical certificates as some departments have strict rules about the timeliness of medical information at the time of referral. As there are often several such 'blocks' in treatment chains, a single no-show can start an endless process of rejections that especially affects patients who lack a strong network and good system skills (spinal disc herniation, dementia, neuro-psychologist, trauma and torture treatment, MRI, etc.).
Municipalities	<ul style="list-style-type: none"> • Rehabilitation without using interpreters. • Illness-maintaining factors, e.g. incorrect and persistent perception of the patient as being 'poorly integrated' or a 'pension-seeker'. • Unresolved municipal tasks that become hospital tasks (notifications, disability aids, support contact person, homework help, glasses, rehabilitation, budgeting, etc.). • Lack of response to notifications about children's well-being, abuse, etc., ending up as hospital tasks. • Significant but overlooked or unacknowledged disability. • Rejection of relevant neuropsychological assessment delays or invalidates rehabilitation and traps the patient in an unclear illness role.

12.2. How important is the health assessment of newly arrived refugees for patient safety?

During the abovementioned review of patients referred to the MHC in 2015-2016, we found that 26 patients who were referred to the MHC had overlooked PTSD due to war or torture trauma from the homeland, and a further 12 patients had disorders that could have been diagnosed had these patients undergone a health assessment when they arrived in Denmark. Thus, we found that 38 (26 %) of the overlooked health problems would have been identified by a health assessment of newly arrived refugees. The 12 patients had disorders such as disability, work injuries in the home country, physical torture injuries, consequences of poison gas, consequences of infections, previous mental illness, rape, and significant failure/abuse during childhood.

Errors and events caused by language barriers need to be systematically recorded because they appear to be widespread and there is no sign of a positive development since the last patient safety study. The Danish Patient Safety Authority has an obvious task here. The use of interpreter services is an unclear issue that needs to be re-evaluated because interpreters are currently perceived as an external service that falls outside of the patient safety system. The use of interpreters improves treatment quality and safety: a comprehensive review of the scientific literature showed that the use of interpreters had positive effects on communication (errors and understanding), use of healthcare services, clinical outcomes, and patient satisfaction (33). A Danish study found that 15-20 % of refugees/immigrants needed an interpreter even after residing in Denmark for 7 years, and 30 % had experienced doctor consultations where an interpreter was needed but none were used (844). The Danish Institute for Human Rights found in their study on the health of ethnic minorities that poor access to interpreter services and lack

of cultural skills were prominent among doctors (845). Diagnostic delays in Denmark are particularly frequent among vulnerable patient groups such as refugees and immigrants (846). Doctors and nurses generally lack both clinical and cross-cultural competencies in this area. An understanding of the importance of language and illness perception is still too scarce among health professionals and social workers, and it continues to give rise to serious patient errors, diagnostic delays, and prolonged illness to a degree that should cause concern in hospitals, regional centres, and in all training institutions for doctors, nurses, physiotherapists, midwives, and social workers. Universities and colleges who lack adequate courses for their students on the health of ethnic minorities should take the current report as an opportunity to do a review of education. Hospitals must develop guidelines that unambiguously describe the requirements for doctor-patient consultations and patient information in cases of language barriers, including facilitating an organisation where all patients receive the same offers and benefits regardless of language and health knowledge. At the same time, this should be the moment that hospital owners ensure the establishment of a team of interpreters who have the necessary linguistic and health skills. The health and social care efforts toward vulnerable patient groups must contribute to improving patient safety and not, as presently, directly threaten it.

One in four of the health problems identified could have been found in an early refugee health assessment, and thus one in four patients could have been better treated with earlier rehabilitation. The recent refusal by municipalities to systematically assess the health of refugees is short-sighted and lacks scientific or practical evidence; it is an expensive decision with serious long-term consequences for refugee families.

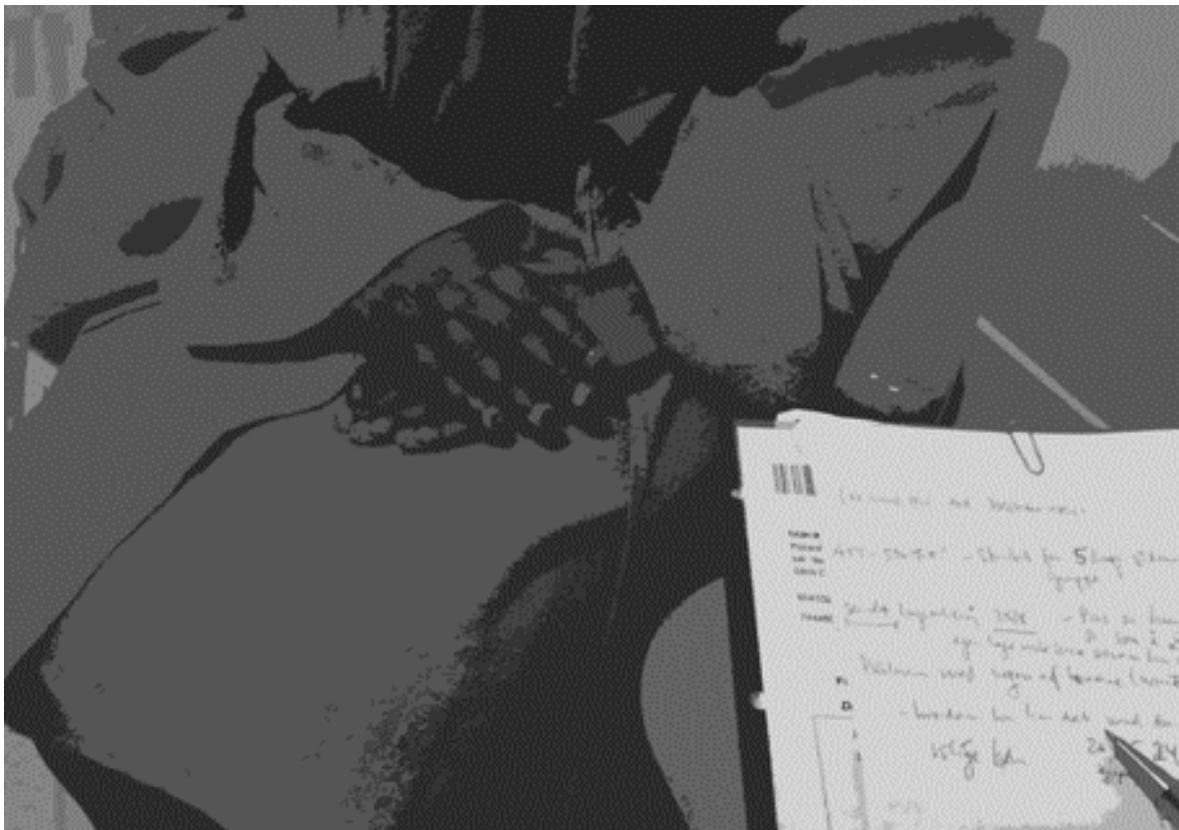
12.3. How can patient safety be strengthened?

Patient safety is easily compromised in the busy everyday life when one meets a patient with special needs, such as a language barrier. Here are some simple routines that can always reduce errors:

1. Be aware of your own conscious and unconscious prejudices/biases and work on them (attention, self-awareness, continuous reflection with colleagues, seek feedback from patients, humility, expand your concepts of normality, and seek knowledge of implicit bias types).
2. Always use 360-degree learning (ask the patient to explain to you what has been discussed, the patient's perception of the diagnosis, treatment, and future plan).
3. Give the patient the opportunity to seek further information themselves (sundhed.dk, patient association websites, websites with patient information in foreign languages). Patient groups?
4. Regard relatives as a source of a better medical history and a stronger treatment plan - not as a disturbing information or a barrier. Gain respect by inviting the family to take part in the conversation.
5. Always use an interpreter, even if you are in doubt. Illness is coded in the mother tongue, and technically difficult explanations must be understood in the mother tongue. Once the basics are in place, routine conversations can take place without an interpreter.
6. Be careful of assumptions that all patients know some English. They do not. Do not use the minimal language skills of colleagues or yourself when they are not verified. The evidence shows that 'false fluency' leads to patient errors.
7. It is not natural to talk through an interpreter - doctors and nurses have to train themselves in it. You should be aware of the interpreter's working conditions and linguistic challenges in cases of technical or untranslatable concepts. Changes in the structure of

the conversation and different interaction styles can negatively affect the communication.

8. Find realistic solutions for patients who cannot afford (all) medications or transport costs due to (slightly too) frequent medical checks. Be pragmatic and prioritise.
9. Encourage the patient to ask questions. Try to give examples of what other patients ask about, *'Have you read about the disease online? Have you heard about the treatment from friends? Is there anything you are particularly afraid of? Is there something important you have not yet asked?'*
10. Due to language and cultural barriers, minority patients are often (understandably) sceptical and unsure of new treatment (medical or surgical) or major shifts in treatment (experience of being a 'guinea pig'). Do not be dismissive of a second opinion. Patients often travel to a doctor with the same cultural background as their own in Dubai, Tehran, Germany, Turkey, or Kenya, but consider it a normal human reaction when you are in a foreign place and are forced to make a big decision.



13. Clinical cross-cultural competencies

One might wonder what makes migrant patients different from all other patients. The simple answer is that all the challenges that are consequences of ethnicity, language barriers, cultural blindness, brief or no schooling, and conflicting expectations only vary in intensity and frequency compared to the challenges that ethnic Danish patients may demonstrate. If you work with patients' feelings and involve the patient in creating valid explanations and solutions, then the biggest challenges will vanish in most patients. Thus, the needed skills are communicative and self-reflective rather than decidedly cultural. The cultural challenge is that ethnic minority patients force the doctor to spend time on the relationship, to listen, to get involved, and to empathise with the patient in a way that many doctors are not used to. The common biomedical algorithms and clinical guidelines can also be challenged when they have to be adapted to complex patient needs. However, the task is the same whether the barriers are cultural or linguistic.

13.1. Half medicine without the whole story

Just as one cannot be half-pregnant, one cannot be half a doctor who provides treatment that only works halfway. Every patient meeting is a cultural meeting and a clash of different illness routines. Doctors have their own routines just like patients do. When these do not mesh, then misunderstandings, conflict, and dissatisfaction arise. Through the life story, one gains insight into the background of patients' illness routines. All humans are rational according to their own terms. It is important not to get rattled or diverted by what is clearly irrational, alien, or unfamiliar. On the other hand, doctors must seek to understand, with professional curiosity, the patient's life, living conditions, and the mind-set behind their actions.

Doctor Rita Charon, who introduced narrative medicine to the medical field, does not believe that biomedicine works without the doctor paying attention to the human being behind the patient:

The price for a technologically sophisticated medicine seems to be impersonal, calculating treatment from revolving sets of specialists who, because they are consumed with the scientific elements in healthcare, seem divided from the ordinary human experiences that surround pain, suffering, and dying ... Patients long for doctors who comprehend what they go through and who, as a result, stay the course with them through their illnesses. A medicine practiced without a genuine and obligating awareness of what patients go through may fulfil its technical goals, but it is an empty medicine, or, at best, half a medicine (847).

Doctors tend to have a narrow view of illness as biological phenomena that require medical or behavioural intervention (perhaps 'disturbed' by the patient's mental appearance and interaction), while patients see illness in a much broader context of their entire lives. The patient's feelings such as shame, guilt, loneliness, helplessness, and fear permeate the expression of the illness and contribute significantly to exacerbating the existing disorders it causes. Unless the doctor explicitly acknowledges, actively investigates, and engages these feelings and the disorders they cause, in the treatment, the doctor and patient can become irretrievably separated from each other: The doctor sees the patient slipping away and interprets it as lack of compliance and poor motivation, whereas the patients see the doctor slipping away as, again, someone who would not take them seriously. Patients primarily want intimacy and presence on the part of the doctor, but are met by intimacy without intimacy – a short-lived, volatile, and uninvolved intimacy that offers only one chance and then it is gone forever without either party discovering it (848).

This chapter covers how one can lay the foundation for professional empathy with authenticity, self-awareness, a broad concept of normality, recognition of the patient's suffering, and acceptance of the fragility of any doctor-patient conversation, which can help maintain intimacy long enough for the patient and doctor to be honest without losing respect for each other.

13.2. The patient's voice: cross-cultural normality

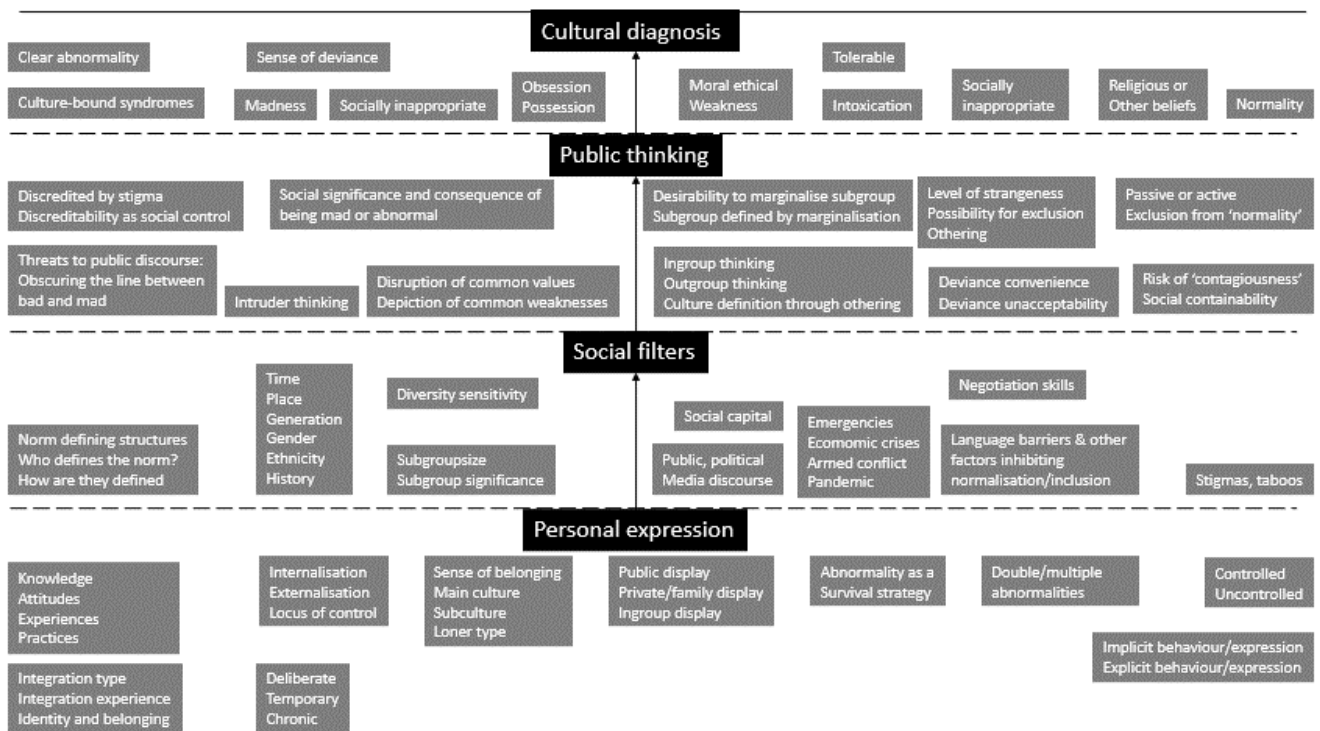
Patients mostly navigate their illness by themselves and in loneliness - isolated from the healthy, isolated from normal means of action, isolated from their own body (or in it), isolated from their loved ones, isolated from themselves. The same goes for their relatives, who see themselves isolated and paralysed in their roles as treatment coordinators, negotiators, organisers, logistics personnel, patient memory, and walking calendar. For ethnic minority patients, loneliness is reinforced by the fact that the family cannot be used to discuss illness. Language is a decisive ubiquitous loneliness enhancer and the ability to navigate is already disabled. Slowly, the sick internalise the perception that they are destroying the otherwise 'normal' and harmonious family landscape with their intrusive disease. Nor does the family try to change the patient's perception, and the healthcare system contributes to cementing the patient role because it clearly signals that it is easier to deal with patients who are (or behave as if they are) isolated and lonely. The patient's suffering and pain are signs of the patient's downfall and the doctor's inadequacy and thus, isolation is in everyone's interest (849).

When it comes to ideas and significance of normality, deviance from abnormality and mad-ness, we must realise that we enter a field where science has done little more than to confuse us at a higher level. Moral judgements and culturally coded stigmas keep interfering with professional assessments when it comes to the borderline between normality and deviance from social norms. Yet the longing for normality, acknowledgement and belonging are key fuels to human wellbeing. If we look at the dimensions of different 'cultural' mind-sets, they could include: 1) uncertainty avoidance, 2) power structures: distance, individualism/collectivism, masculinity/feminism, 3) orientation: past, present or future, 4) orientation: achievement or performance, and 5) locus of control: self, authorities, Gods, fate, group, indulgence versus restraint (1343). The factors that are frequently associated with social/behavioural judgements include: suffering, sorrow, maladaptiveness, irrationality, unpredictability, vividness and unconventionality, observer discomfort, violation of moral/ideal standards, inefficient self-esteem, unrealistic self-acceptance, involuntary control of behaviour, untrue perception of the world, inability to sustain relationships or give affection, lack of self-direction and low productivity, lack of self-awareness. However, if we dig even deeper into each of these dimensions an entire anthropology emerges (see figure 17).

What is deviant in one generation may be normal in the next generation, just as what is considered unacceptable may also vary. However, this model is applicable at any given time. The difficulty in cross-cultural clinical situations is the abnormal but controlled condition that could be several different conditions: behaviour that challenges common norms, breaks with cultural values, trance states, *susto*, evil eyes, *jinn*, demonic possession, or attempts to escape social ties. The controlled but abnormal condition can also occur as group behaviour (speaking in tongues, demonic possession, war, *Mardi gras*).

Franz Kafka said, '*A real doctor seeks the human being.*' Arthur Kleinman, Professor of Anthropology and Psychiatry at Harvard University, has years of experience advising doctors who cannot understand their patients. His advice to doctors is short and simple: if you only have time to do one thing for your patient, ask what matters most in the patient's understanding of illness and treatment. It is not a matter of technical competency but a human trait that doctors, who are doctors, do quite naturally to establish a good rapport contact with the patient. Focus should be on the patient as an individual, Kleinman says, not as a stereotype, but as a human being who feels insecure and in danger and is not just a patient case (92). The narrative approach is a vaccine against prejudice and bias in the doctor's understanding of the patient's medical history.

Figure 17. An anthropology of deviance, conformity, madness and stigma.



13.3. Inequality in the conversation: discordance and explanatory models

In 2003, the Institute of Medicine in USA published a 740-page ground-breaking report, entitled *Unequal treatment*, on racial and ethnic disparities in access to healthcare. The report describes several core factors that, knowingly or unknowingly, contribute to creating inequality in the interaction between doctor and patient: 1) prejudice and negative bias towards ethnic minorities, 2) increased clinical uncertainty on the part of doctors when interacting with ethnic minority patients, and 3) stereotypical ideas about ethnic minority groups. Patients, for their part, can amplify the effect of these factors by reacting inappropriately, thus contributing to increased health inequalities (80).

If ethnic minority patients do not trust the doctor's advice or treatment, they will tend to not follow the doctor's plans and as a consequence of a lack of clinical ethnic competence in the doctor, contribute to health inequalities. The ways in which bias can affect the doctor's judgement and motivation are readily understandable. However, it is more subtle and nuanced when it comes to the clinical uncertainty and the less conscious stereotypes that affect the doctor's clinical decision-making processes (and the patient's motivation) without the doctor or patient being fully aware of the many mechanisms that take effect during the conversation. The uncertainty opens up the possibility of treatment choices and patient compliance being influenced by the subjective view and preferences of the doctor. Time pressure, problem complexity, and pressure on the doctor's cognitive abilities shape the doctor's perception of the patient's information and expectations of compliance by the patient and contribute to the introduction of inequality in the choice of information level, diagnostics, treatment, and follow-up.

Studies of videotaped doctor-patient conversations have shown that the patients' ethnic-cultural background affects doctor-patient communication. Western doctors have less emotional involvement

when talking to ethnic minority patients, and Western patients are more direct and needs-oriented than ethnic minority patients (729). Thus, it is harder to achieve good understanding and consistency between doctor and patient in cross-cultural medical interviews. Good medical care requires a common *understanding* of each other's perception and opinion, while agreement between doctor and patient as such is not necessarily needed (730). A Dutch study of physician-patient conversations found that ethnic Dutch patients had more varied conversations than did patients of ethnic origin other than Dutch and that ethnic Dutch patients more often tried to slow down the conversation and manage it and were more often (25 %!) confrontational than in immigrant patients were (731). A similar Norwegian study found the same trend and also demonstrated that the concerns and fears of ethnic minority patients were often expressed indirectly in order to tone them down (732).

Concerning communication, five core areas have documented correlation with problems in doctors' conversations with ethnic minority patients: 1) differences in explanatory models for illness and health, 2) different values, 3) differences in perception of doctor-patient relationships, 4) stereotyping, prejudice, ethnic discrimination, and racism, and 5) language barriers. However, very few scientific studies try to involve these in their analyses and even less are included in education or practice (729).

In a Dutch study of video-recorded medical interviews with ethnic Dutch and ethnic minority patients, the analysis showed that doctors communicated less appropriately and less carefully with ethnic minority patients. Ethnic minority patients were less included in decision-making processes and were asked less often whether they understood the information (850). The worse the patients were at speaking Dutch, the less satisfied they were with the doctor-patient communication (851).

Cultural competencies involve more than having some knowledge about language, food, and religion. Patients from refugee-producing countries often have violent experiences that take on a somatic expression, but patients find it difficult to share these experiences with the doctor, and Danish doctors have difficulty understanding them in a somatic context (852). Ethnic minorities need more health support than they get. Several Danish studies have concluded the need for more training of health professionals on subjects such as communication and culture, as well as immigrants' health and morbidity circumstances and disease patterns in a global perspective (332, 336).

Controversy exists regarding the importance of 'ethnic concordance' (doctor and patient of the same ethnic origin) between doctor and patient in achieving equality in health for ethnic minority patients. The heart of the problem is likely that even if many patients would prefer to speak with a doctor or nurse of the same ethnic origin as himself or herself, it is a different situation when they have to comply with the doctor's advice and assess the doctor's professional competencies. Studies suggest that patients perceive bilingual doctors to be less professionally competent than other doctors (853).

However, the effect is unmistakable: ethnic concordance increases the ability of patients to navigate their safety, knowledge, and compliance, e.g. in cases of HIV, diabetes, and hypertension (854, 855). Doctors' ethnic competencies indeed influence patient satisfaction and confidence in the doctor, including the frequency of dissatisfaction and complaints (856). Doctors with high levels of patient involvement, judged according to the distribution between the doctor's speaking time and the patient's speaking time, have the most satisfied patients and receive far fewer complaints. Most studies seem to indicate that ethnic concordance between doctor and patient can positively affect the patient's experience of the doctor's empathy and patient involvement as well as actual compliance and illness control (857). However, female doctors have a higher level of patient involvement than male doctors do, and if the doctor and patient have a similar understanding of illness, and the doctor can discuss the patient's worries, then ethnic concordance is less important (858). In other words: regardless of gender and ethnicity, there are competencies that all doctors can acquire, and that offset much of the cultural differences in the doctor-patient conversation. If the result of acquiring these skills is that the doctor is perceived as being both empathetic and expert, then much has been achieved to mitigate language and culture barriers during the patient conversation. Still, doctors in general should have better ethnic skills (859, 860).

13.4. The cross-cultural *blind spot syndrome*

The role of the doctor entails several inherent contradictions. On the one hand, doctors try to create emotional distance to ensure a reliable diagnostic process that is independent of the doctor's personal feelings. On the other hand, patients want genuine empathy and insight from the doctor, and doctors want to reciprocate the patient's trusting desire in human terms. The clinical strength of empathy is being increasingly recognised, but it is based on the idea that there is professional empathy that preserves the doctor's independence. Outside the medical field, empathy means understanding each other's experiences. Inside medicine, however, the definition of empathy is maintained as 'the act in which the doctor correctly recognises the emotional state of a patient without personally experiencing the feeling or the problem.' (1339).

Doctors are given the key to diagnosis through the patient's description of their condition. However, as an unwelcome bonus, the doctor is also given a jumble of emotions and body sensations that threaten to weaken the doctor's cold clinical overview (in English aptly called '*Emotional vomiting*'). The doctors' ambivalent relationship with patients' feelings and experiences is not recent and is apparently an occupational hazard that was already problematic in 1923:

... too little do we teach that the patient is not made up alone of tissue structures but is a personality functioning in a given environment. Too often, hospital, outpatient, and even office practice becomes a mere routine, and the attending physician fails to remember that every case represents a human heart, crushed to the point of despair by sickness and resultant poverty (861).

With varying success, doctors with a humane mind-set have tried to make professional sympathy and emotional involvement part of the core medical services. You may have realised that some form of professional empathy is necessary and fruitful, but as a doctor, you have to work with a balance. A concept such as *compassionate detachment* has been used to describe a professional approach to the patient's suffering and feelings: medical recognition without getting immersed (862). Recognition of a patient's feelings and problems is different from participating in the patient's emotions, which in turn is different from ignoring the feelings of the patient. The empathetic, neutral doctor will do what needs to be done for the patient without grieving, regretting, or despairing. Some have described medical students as needing to learn to have *detached concern*; just as they must be able to dissect a corpse without feeling disgust, they must be able to 'dissect' a patient's feelings without becoming emotionally involved (863). Although sensitivity, empathy, and flexibility are relevant to all patients in a clinical context, many studies suggest that ethnic minority patients in particular are more aware of prejudice and lack of ethnic-cultural skills in doctors and other practitioners (864).

In a transatlantic comparative study, major cultural differences were found between the US and the Netherlands in doctor-patient conversations regarding how the conversations unfolded as well as the focus of their professional content. Conversations in the US were more biomedically focused, while those of the Dutch were bio-psychosocially oriented. US doctors asked more questions, while the Dutch doctors involved the patient more (865). This reflects differences in doctors' education and the philosophy behind the programmes, the focus in medical work as well as cultural values, and expectations of what the healthcare system should provide. Patients are likely to have the same basic needs, but they are met differently depending on how the doctors' and patients' roles are defined.

In the context of psychotherapy, one study found that the psychotherapist's multicultural clinical skills were strongly linked to how attractive, trustworthy, knowledgeable, and empathetic a therapist was perceived to be (866). However, there is also a tendency for the general clinical competence of the practitioner to be assessed through a filter of the patient's perception of the practitioner's multicultural knowledge and empathy (867).

The acquisition of cultural competencies enables doctors to provide better treatment and care of patients with socio-economic, ethnic, or other characteristics that differ from those of the doctor. However, cultural competencies can result in a cultural mastery of ethnic minority groups through ‘practical’ generalisations and ethnically specific illness perceptions. Cultural competence training often involves the distribution of lists of cultural characteristics: ‘*When a South American patient tells a story about ‘susto’, then the patient ‘actually means ...’.* ‘*When an Asian patient reveals mysterious round markings on his upper body, it means ‘that ...’* etc. This does not mean that familiarity with cultural beliefs and actions does not improve the doctor’s understanding of the patient’s symptoms and illness, but rather that the hidden premises and assumptions upon which the teaching is based (that doctors necessarily belong to a privileged cultural group, that all patients from the same ethnic background share the same attitudes and values, that the complex nuances of cultural differences can be taught as knowledge and ‘mastered’, and that cross-ethnic understanding between clinician and patient automatically leads to mutual understanding) punctures the otherwise well-intentioned purpose of increasing doctors’ cultural competencies. Like medical training, the traditional concept of cultural competencies primarily concerns the doctor having the proper clinical tools to ‘handle’ the patient rather than examining the internal cultures, prejudices, uncertainties, doubts, fears, and the doctor’s identity in relation to the patient as they play out in the conversation and non-verbal interaction with the patient. Cultural competencies get the same significance as blood tests and X-rays.

Understanding needs to be included in a far more proactive way in the doctor-patient conversation than we are used to with ethnic Danish patients. A teacher mentioned in an interview on the challenges faced by bilingual children that the very core of a Hans Christian Andersen fairy-tale of a princess is lost when the student does not know that a princess comes from a royal family. The student might know that the princess has a beautiful dress and a crown, but the core of the story remains unknown and incomprehensible. In a parallel experience, another teacher had to give a student a grade of 0 due to a ‘misunderstood’ interpretation of a picture of a message in a bottle. The student, whose parents came from a war-torn country in the Middle East, saw a petrol bomb instead of a message in a bottle and wrote a story about war and violence. In the clinical context, a doctor’s failure to clarify the patient’s understanding can have serious consequences: the core understanding of the illness and its treatment may be lost to the patient. If the patient’s experience with tuberculosis is that it is a disease that slowly eats up the body and that everyone dies from it, then time must be spent establishing where the patient’s perception originated and then adapting the patient’s concerns to the factually optimistic treatment options that exist. Saying it is not enough. Patients must acquire new meanings and internalise these into their own understanding. If the patient has the clear experience that everyone who undergoes surgery either dies from it or is harmed for life, then time must be spent changing this understanding so that a well-founded pelvic surgery is accepted by the patient. If the patient has no functional understanding of what viruses, lymph glands, or pituitary hormones are, then one should start by creating functional understanding because the treatment’s success and the patient’s joint responsibility increase with an individually adapted basic understanding.

13.5. Cultural humility and diversity sensitivity

Many suggestions have been made to replace the idea of having specific cultural ‘textbook’ competencies with more practical concepts such as cultural and narrative humility (868-870). ‘So much of an author’s life consists of assumed suffering, rhetorical disorders, ...’ writes Anatole Broyard in his book *Intoxicated by My Illness, and Other Writings on Life and Death*, a memoir published after his death from prostate cancer. Like the author, whose work depends on the ability to familiarise himself with the individual’s imagined disorders, the doctor is also caught in the ability to familiarise himself with the patient’s ‘experienced’ or ‘rhetorical’ disorder. This does not mean that pain, illness, or disability are not real for the patients and their doctor. Rather, it suggests that the doctor’s ability to empathise with and understand

the patient's condition, a disorder that resides outside the doctor's own physical and emotional being, depends on whether the doctor can find an entrance to the patient's suffering from his own interior - the ability to be able to meet in a shared vulnerability with the patient based on the doctor's own systems of understanding. Working toward gaining insight into another person's feelings and sufferings is similar to the novelist's attempt to get under the skin of his novel's characters, like getting to know new acquaintances and letting the central plot of the story unfold.

The life story ties the present to the past - this also applies to illness. With narrative skills, doctors are given a tool to meet the patient where the patient is right now, but viewed from a historical perspective (847). The art of listening professionally with a full understanding of the patient's situation is key and consists of many tricks: curiosity, empathy, respect for the patient's flow of thoughts, acceptance of ambiguity, structural competencies, hidden vulnerability, cultural humility, X-ray vision, etc. And at the end of the day, there may be basically only two possible starting points for a doctor-patient conversation: one, that the doctor has decided in advance that the patient understands what the doctor says, and if not, then that is the patient's problem; the other, that the doctor knows that the doctor does not understand the patient and that the patient does not understand the doctor. This is actually the purpose of the doctor-patient conversation - to make up for this little challenge.

A little cultural humility is needed instead of prejudice, stereotypes, and guesswork. However, cultural humility is, like the concept of culture itself, constantly changing. It is a plastic process. As doctors and students who meet people in crisis from all over the world, we need to be in dialogue with ourselves about the influence culture exerts on the option of a healthy life and the risk of illness. We need to be aware of our own attitudes toward cultural differences and improve our ability to objectively understand descriptions of cultural behaviour that are perceived as explanations for a health problem. That understanding should not lead to us into falling back on simple stereotypes of patient groups, however. What do patients themselves say about their relationship with the doctor? A Portuguese study showed that patients demanded three things of the doctor: attention/respect, broad knowledge, and specific skills.

A common problem in the European scientific approach to what professional barriers exist (and where they exist) is that most studies have concentrated either on the patient's angle or the doctors' own perceptions of barriers. The barriers patients experience are of course included in the overall analysis of barriers, but most often the patients focus on framework and communication, and they pay very little attention to medical quality. Based on interview surveys, the doctors' own perceptions of barriers tend to confirm ideas of lack of time, prejudices, stereotypes, convenient notions of poor interpretation quality, and 'cultural' symptoms; and studies of 'Best practices' end up mostly giving a picture of common prejudices and narratives about ethnic minorities in the healthcare system rather than professional barriers (871, 872).

Cultural competencies are more than just some knowledge about language, food, and religion. Patients from refugee-producing countries often have violent experiences that take on an intense somatic expression, but patients find it difficult to share these experiences with the doctor, and, similarly, doctors have difficulty understanding them in a somatic context (370, 873).

Edith Montgomery has demonstrated in her studies here in Denmark how patients with war/torture experiences and PTSD are often seen as unreliable informants because their memory and recalls can be very differently composed depending on external impressions, stress level, and general condition. Thus, patients with PTSD and somatic symptoms are at risk of either being rejected or misunderstood by health professionals.

There are unconscious psychological processes and factors in the doctor-patient conversation that can influence the medical clinical decision, such as age, gender, skin colour, and language. A study published in the *New England Journal of Medicine* showed how skin colour influenced the doctor's decision to perform coronary arteriography on suspicion of oxygen deprivation in the heart (86). Another study demonstrated how language barriers affect doctors' choice of pain management, dosage, and duration

(874) and affected the length of antibiotic treatments as well as the choice of thrombolytic therapy (875, 876). Nurses in hospitals find that patients with language barriers receive information and treatment of lower quality than that received by other patients and that the lack of clinical ethnic skills prevents equality in quality treatment (877).

13.6. Diagnostic discrimination

1. Too late or wrong diagnosis

Language barriers affect patients' ability to navigate and they change the routines of health professionals (798, 878). For example, the risk of being admitted to the wrong department is almost eight times greater in cases of emergency hospitalisation (879). In Denmark, patients with other ethnic background have a higher hospitalisation rate in the cardiology department on suspicion of heart attack, but as a group, they have the same frequency of heart attacks as ethnic Danish patients (365). This means that because of language barriers, ethnic minority patients are more frequently admitted 'as a precaution' to the cardiology department when they have complaints of somewhat diffuse pain in the chest. A Dutch study showed that ethnic minority patients were admitted five times more frequently with diffuse pain conditions (abdominal or joint pain) than the local population, but they were less often hospitalised with specific medical problems (366), which is confirmed by a study seven years later (880).

A literature study from KORA (National Institute for Analysis and Research of Municipalities and Regions in Denmark) entitled *Human Factors in Delayed Diagnostics* from March 2013 points out the scientific evidence of how ethnicity as an independent factor (along with other factors) contributes to delayed diagnoses. Twenty-three different types of diagnosis delays were identified. Unfortunately, the analysis is limited because some medical cognitive processes (described in this section) were not included in the literature study. One consequence is that the deeper mechanisms of patient delays and doctors' unconscious interactions with patients do not clearly come to light. However, the literature study is useful as a starting point. The analysis describes the following three groups of delays:

- Men, people with little education, and ethnic minorities waited longer before seeking medical advice, but the reasons for this are unknown.
- Medical delays are due to misdiagnosis, lack of clinical knowledge, and interaction style that is not conducive to highlighting all patients' symptoms.
- The medical methods in themselves can pave the way for reductive fallacies due to the doctor's lack of cultural or linguistic sensitivity as well as context-based decision-making, prejudice, bias, and theoretical preference.

The analysis demonstrates how the doctor's interaction style with the patient in can be either facilitating or directly stigmatising and thus affect the patient's motivation and self-care, which then leads to diagnosis delays. Interestingly, the study points to the need to develop communicative competence among medical students and doctors. The study suggests training in competencies with regard to narrative and rhetorical analyses to expand and sharpen doctors' interpretive ability and understanding of the individual patient. Structured communication tools for more complex health problems are also recommended so that diagnostics do not depend on individual doctors' competencies, interaction with the patient, or motivation to 'do a little extra' (881).

Some medical interviews may end up with a result that is the exact opposite of what was intended if the doctor is not aware of the needs that insecure patients with language barriers may have. The role of patients' trust in the doctor and how it relates to compliance is not well researched, but studies suggest that patients with language barriers often express the need to build *trust* in the doctor before they can and will listen to the doctor's advice and guidance. Especially with invasive procedures, distrust of the

doctor can lead to the doctor's information being perceived as inconsistent, vague, and imprecise by patients (371). Insecure patients with language barriers prefer to be persuaded by the doctor before agreeing to invasive examinations, surgeries, or treatments with potential side effects. If the doctor does not pick up on this need and responds to it with arguments, the patient will say no to an examination that is otherwise justified and necessary.

Language barriers in the healthcare system are not broken down simply by the use of interpreters. A Swedish study of patients' experiences with communication in the healthcare system showed that doctors lacked the transcultural skills needed to adapt their language, concepts, and choice of words. Doctors usually chose to use their standard vocabulary without any sense of whether patients understood the content of the conversation. Patients perceive the meaning of words and concepts differently and attribute different significances to them, but doctors did not have the skill set and understanding of how conceptual confusions affect the patient's understanding of the illness, examinations, and treatment. Confusion of concepts also led to patients feeling anxiety, uncertainty, and distrust. The study concluded that there was a great need to provide doctors with the clinical ethnic skills that they lack (882).

One crucial and often overlooked factor for the outcome of the clinical meeting is body language with its different significances in different parts of the world. Wittgenstein demonstrated that only 7 % of the words included in a conversation are part of the meaning of conversations, while the rest are interpreted through gestures, mimicry, intonation, eye movements, and body language. One frequent mistake is that shrugging is a globally understandable gesture, but a shrug by the doctor may, inadvertently, give the impression that there is uncertainty in the diagnosis or treatment; or the doctor may, incorrectly, interpret the patient's shrug as expressing doubt (883). A Norwegian study at a medical centre in Oslo from 1992 found significantly more immigrant patients in the diagnosis group 'Non-descript symptoms and indicators' and concluded that the difference was an expression of inadequate communication and interaction between doctor and patient (884).

Patients' and therapists' understanding of health and illness is linked to their cultural circumstances and educational background. Unequal understanding of illness affects communication during the doctor visit. An example of a lack of understanding of symptoms and illnesses in their social context is urine and faeces incontinence, which in some communities is associated with being severely disabled and so impure that you are not allowed to pray. If the problem is not addressed by the health professional, it does not get voiced voluntarily, and these patients are socially very isolated with far lower self-esteem than expected in ethnic Danish patients (885). Thus, health professionals need to have good cultural skills and understanding so that differences do not create unnecessary misunderstandings or stand in the way of examinations or treatment (827). In a comprehensive review of 106 studies of physician-patient communication from 2009, DiMatteo showed that when patients do not understand the doctor, it leads to improper medication stops and unnecessary hospitalisations. If the patient does not understand the doctor, the risk of the medicine not being taken, as it should is 20 % greater. The review also shows that educating doctors is effective and improves communication between doctor and patient so that the patient is 62 % more likely to follow the prescribed treatment as intended (826, 827). In a study of final-semester medical students in Oslo, three out of four found that they lacked the necessary clinical ethnic skills concerning migration and health (886). The critical, basic elements of cultural competencies for doctors are a broad communicative repertoire, situational awareness, ability to adapt, and knowledge of core cultural topics and problems (887).

2. Discrimination in clinical co-creation and patient inclusion

Several studies, including a qualitative Dutch study, have shown how patients' distrust of and lack of belief in the doctor leads to poorer compliance, lower perceived quality, inappropriate patient behaviour, and lower self-assessed health (204, 205). The digitalisation and scientification of health information is

a professional challenge that is becoming more obvious, but it has probably presented significant barriers for linguistically challenged patients. The consequences of digitalisation are called digital discrimination, but should be seen as digitising existing barriers wherein the digitalisation only becomes an additional barrier. A survey of the consequences of doctors being increasingly forced to communicate information based on scientific studies, probabilities, and hard-to-understand multi-factorial score systems found that 37 % of respondents felt unable to understand what the doctor said, and 67 % of those who failed to understand the figures from the doctor felt there had been 'poor or very poor doctor-patient contact' (888).

The pattern of illness and its association with clinical bias and prevention is supported by figures from Statistics Denmark. According to their 2010 study 'Immigrants in Denmark' refugees/immigrants have a lower mortality rate than ethnic Danes in all age groups (index 80 for women and index 76 for men where ethnic Danes have index 100). If you look at causes of death, however, a more nuanced picture emerges. The lower mortality rate is explained only by the fact that ethnic minorities have a significantly lower mortality rate of cardiovascular illnesses, COPD, lung cancer, stomach cancer, and liver illnesses - precisely those illnesses caused by lifestyle behaviours that are relatively rare among ethnic minorities in Denmark: smoking and overconsumption of alcohol. In addition, there is a lower mortality rate for suicides and accidents, partly due to the fact that suicide in many ethnic minority environments is religiously or socially unacceptable, and partly due to fewer accidents at work and road accidents. On the other hand, the mortality rates for infectious diseases are higher (137). These are typically illnesses that can be prevented with targeted information, and they are treatable when one receives timely treatment.

The obvious inequality in health can come about from stereotypes, time pressure, and fatigue because doctors and nurses fail to use interpreters or fail to adapt examinations and treatments to patients with language barriers (91). Between 30-50 % of ethnic minority patients report that they are not proficient in their mother tongue, but in a Danish population-based study only six out of 10 such patients are offered interpreters. In hospital studies, one in 10 are offered interpreters, and a study of family doctors in London revealed that only one out of seven interviews had interpreters when interpreters were needed (333, 889, 890). Unfortunately, these figures are misleading because they are based on questionnaires that have been translated into a few select languages, and answering the forms requires literacy. Thus, these studies do not describe the needs of illiterate people. At MHC, about 75 % of the patients need an interpreter. Furthermore, in the healthcare system, men are less often offered interpreters and they less often have a social network to support them with interpretation. Access to interpretation services is economically viable and increases the use of preventive health services, and it leads to more relevant visits to the doctor and more prescriptions being filled (891).

A 2013 German study provides an insight into how extensive language barriers can be, even in ethnic groups that have lived in the country for a long time. Of the Turkish hospitalised patients who took part in the study, 75 % spoke only Turkish at home, not German. Seventy-five percent of those who spoke some German, only spoke German at their workplace. Of those hospitalised, 26 % rated their mastery of German language as 'poor' or 'very poor' and 43 % were sure that an interpreter would have been extremely helpful during hospitalisation. Twenty-five percent found that the information they received prior to examination and treatment at the hospital (including informed consent) was inadequate or not understood at all (87). Similarly, other studies have shown that language barriers derailed quality routines, e.g. only 28 % of patients with language barriers gave informed consent, whereas this was 56 % for other patients (801).

There are no routines in Danish hospitals to screen language and reading skills among patients, and ethnic minority patients who have achieved everyday Danish language proficiency are not typically asked whether they need an interpreter. A Danish study at a large children's ward found that parents with language barriers had communication problems in 33 % of admissions and pointed out the lack of

interpretation even when needed (892). Most studies show that 15-30 % of patients with language barriers were not offered interpreters at the time of hospitalisation. This suggests that for patient safety reasons it should be an indispensable routine to use interpretation services and that declarations of intent, as formulated in the Danish quality model, are not sufficient in terms of patient safety.

In some societies and religions that are less characterised by science and broad general basic education, it is not acceptable to know anything in detail about bodily functions, while in other contexts it is normal to consider bodily functions and symptoms in the context of external social and physical phenomena. In other contexts, doctors and nurses are authorities and power people who should not be worried with details of symptoms and body experiences. This way, important symptoms are either not presented to the doctor at all, or they are given an appearance that the doctor does not perceive them to be important, or the patient puts the symptoms in a context that does not make sense to the doctor and therefore they are ignored or downplayed. The doctor, in turn, is unaware of these differences, and the doctor's questions fail to bring about much insight. Instead of the patient being subjected to questions based on professional medical knowledge, patients are subjected to 'ethno-centricity' and generalisations based on the diagnostic stereotypes on which individual doctors work. This delays diagnoses or leads to misdiagnosis because the conversations tend to be long negotiations about words, opinions, and consequences, and they result in very diffuse content professionally (179, 828, 893-895).

An equally important, yet less visible, inherent inequality exists in that even if the doctor does his best, it can be difficult to understand the patient's medical history or symptoms. Thus, the patient gets less out of the doctor's visit and receives fewer healthcare services. This is called statistical discrimination (896). Unfortunately, very few studies have been done on the mechanism of statistical discrimination and how to prevent or minimise its consequences. The basic elements that lead to clinical uncertainty at the doctor in the presence of language barriers have, however, been described (80, 343, 896, 897). Moreover, many theoretical models of doctor discrimination against patients have been reported - see the following model of the primary elements of doctors' fluctuating treatment type and quality (Table 27):

Table 27. Types of medical discrimination of patients (832).

	At the same doctor	Between different doctors
In the same patient	Unreliability - arbitrariness: Inconsistency in how the same doctor treats the same patient over time.	Disagreement: Different clinical practices, disagreement between doctors on diagnostics and treatment of specific symptoms.
Between different patients	Bias: Different treatment of patients with the same disease based on prejudice and bias; treatment very dependent on the patient's assumed preferences.	Interaction/relation: Different doctors treat the same patient differently depending on the relationship, and patients choose doctors who better match their preferences.

The results of clinical bias are shown, among other things, in that ethnic minority patients benefit less from the treatment offered in the public healthcare system. Ethnic minority patients with diabetes have a worse regulation of their diabetes than do ethnic Danish patients (255).

A big part of the problem is that doctors often fail to realise how their own (medical) culture affects their clinical decision-making skills, but unfortunately it is a fact that gender, age, social status, educational level, and ethnic discordance/concordance between doctor and patient directly affect the doctor's clinical decision-making with regard to examination, treatment, and information level (and whether the patient understands and trusts the doctor) (246, 338, 367, 368). Although doctors do not believe they are doing social and linguistic categorisation in the clinical patient situation, it does happen as part of an unconsciously sophisticated individualisation strategy. In addition to starting from the individual patient, they are sitting across from, doctors also 'read' their patients using a social radar that records the patient's physical and mental appearance, interaction, and language (369).

The doctor's bias, whether knowingly or unknowingly, affects the patient's perception of quality in the treatment received. This is documented in a study by the National Institute of Public Health in Sweden in the report: 'Discrimination - A Threat to Public Health'. The report states that the link between experienced discrimination and poor health is very strong both somatically and psychologically, and with a greater effect on men than on women (898).

Doctors also tend to overestimate patients' literacy skills, thereby risking the doctor's information being too complicated. Often patients obtain so little benefit from the doctor's information that they cannot ask questions because they lack a sense of context or meaning and so they choose silence (800).

In more ethnically complex countries such as Canada, USA, Australia, and England, the development of language and ethnic competencies in healthcare has long been a focal point, particularly in clinical areas where ethnic inequality is most documented (899).

13.7. Cross-cultural co-production

A silent patient is not a patient who consents. Silent patients are silent because they cannot express themselves and interact in a safe way. Co-production of solutions with patients requires, firstly, that the healthcare system is prepared to change its interaction with patients. This requires great flexibility and more freedom in appointments and the length of the conversation. It requires resources and motivation to test new methods, and it requires new forms of cooperation between departments. The framework for co-production requires patience and that the patient perceives the situation to be safe. It takes time to find the patient's preferences regarding language, degree of detail, and preferred decision-making process. A number of communication strategies have been identified to facilitate co-production: a) slow, clear speech and the use of simple words without jargon, b) the use of simple tools such as written instructions and visual materials, as well as the use of movements, and metaphors, and c) attention to non-verbal communication by observing behaviours and reactions that may indicate whether more explanation or time is needed to digest the information. Skilled, experienced interpreters are instrumental in this process (900-903). Having the opportunity to speak in the native tongue increases mutual understanding and gives the patient a sense of security, which helps to strengthen the patient-doctor relationship (904, 905). Whether or not the patient is able to speak another language (e.g. Danish), feelings and experiences are best expressed in one's own language - one is best at being ill in one's own language (906).

Co-production requires a sincere curiosity about the patient's story, and the patient must feel that the information shared with the doctor is of great importance. Not all patients have the same need for involvement in the decision-making process, but everyone needs to be taken seriously and be listened to and feel that their efforts are not in vain. Doctors need to pay attention to the patient's other priorities and social challenges, which, if left untouched, could destroy co-production. These include integration, identity, personal finances, basis of residency, family structures, child rearing, and discrimination.

Several studies have demonstrated that it is fruitful when doctors take the time to prevent harmful stereotyped thoughts concerning their patients' perceptions, norms, and backgrounds from influencing their clinical judgement (907-909). The important point is that the doctor must practice asking questions every time they would prefer to guess or categorise. This includes questions that may be sensitive. Sincere curiosity provides sincere answers - often better than the flimsy stereotypes one has available as a doctor (902).

13.8. Reduce the number of languages in the space

Many languages are often at play in a doctor-patient conversation. All of them can create language barriers between doctor and patient: the doctor's medical language, the doctor's layman's language, the patient's poor Danish vocabulary, the interpreter's poor medical language, the interpreter's and patient's poor mutual language (city/country, dialects), and the patient's own language for body and illness. An especially hidden factor in the conversation is grey-area language, which are the words that professionals think do not require any explanation. These are simple terms that doctors feel most patients should know. These are terms that we think give the conversation a 'professional' touch and which, together with the coat, defines us as doctors. The following concepts are examples of grey-area words: empty stomach, BMI, control, acute, intensive, obesity, preventive, and therapy. Unfortunately, these terms very often require explanation in the clinic to the interpreter, relatives, and the patient, but it is not obvious to the doctor that no one understands the doctor's questions or the information given. The trick is to be professional while adapting the information and conversation level to the individual patient or interpreter. It is important that the patient has understood their symptoms, plans for examinations, treatment options, and what the doctor expects the patient to do personally.

Language barriers affect patients' ability to navigate and change the routines of health professionals (798, 878). Language barriers affect the doctor's way of recording medical history, making it difficult to get a coherent story that makes sense medically. Language barriers create gaps in information that can lead to misdiagnosis, delays, and fruitless examinations (347). Illnesses that involve multiple organs and develop over many years, such as the connective tissue disorder lupus, are diagnosed much less often among ethnic minorities (348).

Language barriers in the healthcare system are not broken down simply by using interpreters. A Swedish study of patients' experiences with communication in the healthcare system showed that doctors lacked the transcultural skills needed to adapt their language, concepts, and choice of words. Doctors often chose to use their standard vocabulary without a sense of whether patients understood the content of the conversation. Patients perceive the meaning of words and concepts differently and attribute different significances to them, but doctors did not have the skill set or understanding of how conceptual confusions affect the patient's understanding of the illness, examinations, and treatment. Confusion of concepts led to patients having anxiety, uncertainty, and distrust. The study concluded that there was a great need for providing doctors with the clinical ethnic skills that they lack (882). In addition to language, miscommunication with patients and patient dissatisfaction (which may stem from ethnic differences in expectations) can also contribute to suboptimal treatment quality and malpractice (910-914).

13.9. Grey-area words

Grey-area words and concepts denote those words that are not perceived as requiring explanation by the doctor (or patient) (915). These are words, which lie between jargon and everyday language, but which in reality differ greatly from doctor to doctor and patient to patient. Unfortunately, many studies indicate that these words often still require explanation. Grey-area words become particularly challenging in the presence of language barriers, or when interpretation services are involved. Grey-area words

can be words that are perceived as everyday words with significant complex metaphorical elements such as ‘Heartbreak’, ‘Spoiled child’, ‘Wolf in sheep’s clothing’, ‘Skirting the hardest objects’, ‘Pig out’, ‘Honey’, ‘White’, ‘Dark’, ‘Toy’ etc. At the more serious end of the spectrum, an analysis of what are perceived as grey-area words among bilingual social health students has revealed that the following concepts are not immediately understood: performs, selected, consequence, circulation, impaired fitness, oxygen uptake, tissue, prevent, dehydration, fluid register, fluid intake, on suspicion of, increasing the risk of development of, preventive element, prescribe, treatment.

13.10. Illness interpretation

A subtle point that frequently affects the clinical conversation without either the doctor or patient thinking about it concerns the patients, who do not have interpreted conversations. This can occur because the doctor does not think it is necessary, *‘It usually works pretty well, and sometimes the patient brings her daughter along.’* It can also occur with patients who have the self-image that they speak Danish well enough for a medical interview, or it that would violate their sense of honour were they to have help with a conversation. It is our experience at the MHC that this group of patients often needs an interpreter because their vocabulary is too poor, especially concerning their emotions or getting more accurate descriptions of chronology or causation. The consequence of the lack of recognition of the need for interpretation, on both sides of the doctor’s table, is that patients only discuss minor and uncomplicated relationships with the doctor, while key and important experiences, symptoms, and connections are left untouched and ‘disappear under the doctor’s radar’. Even second-generation immigrants or immigrants with long working careers may need an interpreter when they suddenly fall ill, or need to explain a treatment with options and side effects.

The consequence of providing a low level of information is that patients will fail to understand what is communicated and what their own role is. In a study of patients’ knowledge after a medical interview at the emergency medicine department of a hospital, 41 % could not account for their diagnosis, their treatment, or what the follow-up plan was, which they had been presented with immediately prior to the interview. Patients with language barriers performed significantly worse in this study than other patients on all parameters: knowledge of diagnosis (61 % vs 83 %), what medication to take (12 % vs 39 %), or follow-up plan (57 % vs 74 %) (323).

13.11. Body language and hidden values

Evidence suggests that doctors, often unknowingly, convey non-medical social values into the doctor-patient conversation that can have a decisive impact on the patient’s compliance, quality of treatment, and effect of treatment. These may be moral values such as the need to ‘provide before you can enjoy,’ self-support, self-care, education, and the acquisition of information, or it may be that the doctor clearly signals lower expectations of the success of examinations, treatment, or ability to follow check-ups due to education, ethnicity, lack of networks, or other stigma (342, 343). The doctor should be aware of how irrelevant factors can affect clinical judgement and try to counter them.

13.12. Significance of stereotypes in clinical practice

Much indicates that barriers and delays that hospital staff and researchers perceive as *patient delays* can often be the exact opposite: a direct result of the patients’ past experiences with the hospital system. In a New York study, delays in seeking medical care, picking up prescriptions, and starting medical treatment were strongly linked to whether the patient had previously experienced unfair or direct discrimination at the doctor, hospital, or pharmacy (916). Very rarely do studies of patient behaviour and

access to healthcare take this into account. Recent theories about how the stereotypes of health professionals ('stereotype threat') negatively affect patients' behaviour, self-care, and acquisition of information are now gaining ground and being used in medical education (917).

It is an inherent understanding among doctors (and an expectation from patients) that we look at and assess patients objectively and without prejudice, in that we use biomedical observations from the objective examination combined with blood tests and other para-clinical examinations to make a diagnosis and treatment plan. Unfortunately, much research suggests that this is a completely unrealistic and wrong way to view the doctor-patient meeting, and this is definitely not new knowledge (241, 242). Mental or cognitive short-cuts lead to faster and 'easier' decision-making pathways, often without the doctor personally being aware of the mechanisms. Over 200 different cognitive or implicit bias mechanisms have been described. One study found that African-American pain patients were given fewer pain-killers than other patients were (918). Other studies have found that doctors unknowingly change decision patterns based on their latest patient who had the same treatment or disease: e.g., a higher tendency to perform caesarean section if the last patient received caesarean section, the doctor avoids treatments that caused side effects in a previous patient, or the doctor is looking for the same (unlikely) illness as the last 'exciting' patient had (919). In a review article, Van Ryn described areas with evidence of discrimination that lack medical basis: osteoporosis treatment and prevention, smoking cessation, reduction of overly high alcohol consumption, referral for mammograms, advice on breastfeeding, handling of pain management, referral for dialysis, referral for coronary angioplasty, recommendation for kidney transplantation, and psychiatric treatment (79).

The many non-medical factors that are involved when the doctor makes a clinical decision are documented in a number of lab studies, e.g. in a study where the test patient had chronic cough and was a smoker but was presented as having various social characteristics: 192 doctors were tested and a clear tendency was evident for younger patients to be told that the coughing was psychosomatic, and referral to X-ray examination or smoking cessation depended largely only on social (non-medical) factors (243). Others have confirmed that medical uncertainty in diagnostic deliberations, examination choices, and treatment occurred more frequently for ethnic minority patients (884,920). Apparently, more basic non-medical mechanisms need to be addressed in the clinical decision-making process, for even attempts to support the doctor cognitively in terms of increasing equality through the use of software programs had no effect on ethnic discrimination (921).

Van Ryn has formulated a model for how social notions and medical behaviour can contribute to creating, more or less unintentional, discrimination (79).

In trying to make sense when meeting others, people create and use categorical appearances such as stereotypes. There are limits to what we can find out in a short conversation with another human being, and social relationships can be very complex. Therefore, we simplify and 'rationalise' by applying categorical thought and assessment of other people. By looking at people based on the social category to which we feel another person belongs (age, gender, ethnicity, education, etc.), we can make use of the wealth of related (stereotypical) information we have available - even though we may know that most of this 'bonus' information is inaccurate or downright wrong. Rather than seeing individuals based on their unique composition of characteristics and inclinations, we prefer to form a categorical (i.e. stereotype-based) perception of others. Rather than reacting to the world as it really is, our conclusions and memories are adorned with schematic thought mechanisms that govern the way we end up perceiving a person, a situation, or a sequence of events with a result that is driven by what we *expect* did happen or will happen (922, 923). Table 28 below is modified from Van Ryn's original model. The arrows do not represent absolute established contexts but rather contexts that should be studied further.

Table 28. Factors involved in cross-cultural co-production of care (339, 340, 924-926).

<p>The doctor's ideas about the patient</p> <p>(social behavioural factors and resources. Known and unknown ideas)</p>	<p>Ethnicity and cross-cultural experiences and biases of the doctor</p> <p>(Prejudice, stereotyping, bias)</p>	<p>The doctor's interpretations of symptoms</p> <p>(Bias, experience, communicative skills)</p>	<p>The doctor's clinical decision-making process</p> <p>(Diagnosis, treatment, information, control)</p>
<p>The doctor's interaction with the patient</p> <p>(an involving style, respect, empathy, warmth, content, form, way of delivering information, way of asking questions)</p>	<p>Co-production of healthcare</p>		<p>The patient's behaviour and interaction with the doctor</p> <p>(asks questions, honesty, clarity, makes demands, way of expressing needs, appeal)</p>
<p>Ethnicity and cross-cultural (health) experiences of the patient</p> <p>(Previous encounters with healthcare in home and/or recipient country, previous illnesses)</p>	<p>The patient's cognitive and emotional factors</p> <p>(acceptance of the doctor's advice, attitude, self-care, intentions, health literacy, reading skills, previous experiences, stereotypes)</p>		<p>Patient behaviour over a longer period of time</p> <p>(compliance/adherence, self-care, use of knowledge and sticking to the plan)</p>

Stereotypes refer to mental concepts (*pictures in our heads* as they were referred to by Lippmann in 1946 in his book *Public Opinion* (927)) that help individuals to categorise the world and thus orient themselves in it. This also applies to professionals, and perhaps especially so. It is a way of economising on your energy and time because we would not be able to process the overwhelming number of impressions we are exposed to if we were not able to typify and generalise. For clinicians, it is part of the clinical tools you partly learn, while you study and partly acquire in conversations with patients. Stereotyping is a necessary evil in a specialised everyday life of time management and strict guidelines. Stereotypes help orient us, and they influence our perception of the world for better or for worse. Stereotypes are a professional survival tool that create much needed meaning in the many patients' very different expressions, conditions, resources, understanding, and self-care. See a more in-depth discussion of stereotypes in the article by Pia List 'About stereotypes, especially national' (928).

Most of the time, we do not look first and define afterwards. We do it the other way around: define first and then look. This also applies to doctors and nurses. In the vast flourishing, buzzing confusion of the outside world, we embrace what our (health) culture has already defined for us. We tend to perceive what we have chosen in a form that is shaped (stereotypically) for us by our private and our work culture without always realising which one is at stake. The systems of stereotypes can be at the heart of our personal circumstances, defended by our position as doctors, nurses, or caseworkers in society. They

represent an orderly and more or less consistent picture of the world that our habits, tastes, abilities, comforts, and abilities have adapted to. It is the collection of stereotypes that makes us feel safe and defines us as (professional) people. Thus, it is not surprising that any disturbance of stereotypes may be perceived as an attack on the foundation of our world (927). Stereotypes are unavoidable, but professionals who have to assess other people's needs and resources must be aware of how and when these stereotypes influence a diagnostic or treatment process, and that requires training. Diagnoses such as *ethnic pain* are an expression of a stereotype based on a linkage of the doctor's ethnic Danish stereotypes with another ethnic context and therefore are not productive, nor do they make sense diagnostically.

Patients, for their part, experience stereotyping as a 'generalisation' or disqualification. In a study of immigrant women with chronic illnesses, Sonne Nielsen found in her PhD thesis that patients' experiences of lack of recognition and understanding from the doctors, along with the lack of what she calls cultural capital, created fertile ground for feelings of discrimination, even when based on vague assumptions. The generalisations that these women were exposed to were perceived as an attack on their 'humanity', and they felt overlooked and neglected in the healthcare system (929).

There is no doubt that prejudices exist on both sides of the doctor's table, and this is certainly not new knowledge. In a 1978 interview, three Pakistani doctors working in Sweden pointed out the following prejudices at play in the conversation with an immigrant patient (1340):

Figure 18. Prejudice in doctor-patient interviews according to three Swedish doctors of Pakistani background.

1. Traditions: The doctor has many prejudices against patients with dark hair and brown eyes; patients are afraid of the white man.
2. Trust: The special rules that apply to immigrants are seen as signs that the host country does not trust immigrants.
3. Fear of contact: Doctors are afraid to touch patients and to ask about the patient's perception of symptoms.
4. Attributed illness: The many preventive examinations make immigrants feel sick and diagnosed with illnesses they do not know. In their eagerness to obtain a residence permit etc., they assume the idea of illness as a means of integration.
5. New illnesses, new explanations: Iron deficiency and constipation are rare illnesses in Pakistan but are frequent among immigrants in Sweden. It must be the climate, and they try to change their diet from 'hot' to 'cold' foods without understanding the link or the illnesses, because doctors are not recognising the problem.
6. Isolation: Women are isolated without any social network. The men are overprotective of them. The women get homesick, lose motivation, and neglect self-care. They dare not ask the doctor and have no female friends/family they can ask about women's health.
7. No understanding of the system: They like the comprehensive healthcare system, but they cannot figure out how to use it: they cannot make an appointment with the doctor, they do not know who to ask, and they can't find their way around.

The idea that ethnic minority patients are perceived as ‘taking up a lot of time and space’ and that they are resource-intensive in their encounters with the healthcare system is shown in both qualitative and quantitative studies (931, 332, 932, 933). A survey from the Central Region of Denmark in 2008 showed that 42 % of family doctors, 21 % of hospital doctors, and 18 % of hospital nurses often found contact with ethnic minority patients to be difficult. In Stina Lou’s survey of 335 hospital doctors, nurses, and midwives and 276 family doctors, medical receptionists, and nurses, 74 % of family doctors and 39 % of hospital doctors answered that ‘difficulty in distinguishing between the patient’s somatic complaints and social needs’ was the reason they experienced difficulty in their contact with a patient. In support of the notion that several dimensions are in play concurrently during a difficult contact is that 72 % of family doctors and 42 % of hospital doctors indicated that the reason could be that ‘the patient’s understanding of illness makes communication difficult’. Fifty-seven percent of family doctors and 38 % of the hospital doctors found that patients with contact difficulties presented their symptoms in an excessive way. Regarding the actual meeting with patients, 59 % of family doctors and 42 % of hospital doctors found that patients with contact difficulties were also time-consuming (934). Poor cultural competencies in the healthcare system have been found in virtually all European studies (935). In Germany, the use of the healthcare system by Turkish patients is directly related to their knowledge of the healthcare system (936). Turkish women are also more likely than German women to feel that they are not getting enough information and that the quality of information they receive from the doctor is unsatisfactory, and they change doctors more frequently (936).

In a 2009 survey of patients referred to several large Danish hospitals, the experiences of ethnic minority patients with the treatment from the family doctor and referral to the hospital were compared to the experiences of ethnic Danish patients (333). The survey found that 45 % of the ethnic minority patients felt that their doctor was not listening compared to 25 % of the ethnic Danish patients who felt this way. Nineteen percent of ethnic minority patients experienced one or more errors at their family doctor compared to only 9 % of ethnic Danish patients who experienced this. Lack of confidence in the family doctor was twice as frequent among ethnic minority patients compared to ethnic Danish patients, and it was twice as common among ethnic minority patients to find that the doctors’ examinations prior to the hospitalisation were irrelevant. As for the waiting time at admission, 7 % of ethnic minority patients found that it was too long, compared to 1 % of ethnic Danish patients. It should be noted, that 31 % of ethnic minority patients did not know where to enquire if their condition changed before admission, compared with 17 % of ethnic Danish patients. Forty-two of ethnic minority patients felt they received inadequate treatment while waiting for the planned hospitalisation compared to 66 % of ethnic Danish patients. Little or no confidence in hospital doctors was more frequent in ethnic minority patients (12 %) compared to 4 % in ethnic Danish patients. Overall, 13 % of ethnic minority patients had experienced discrimination during their management by the family doctor, including related to the planned hospitalisation (333). It is well-established that patients who have experienced discrimination based on their ethnic background, or who distrust the healthcare system, more often fail to show up for hospital appointments, choose to stop a treatment or examination program, and wait longer to pick up prescription medication (917, 937).

Besides the language issues, both miscommunication and dissatisfaction (due to ethnic differences in expectations) can contribute to suboptimal treatment quality and rehabilitation. This even applies in cases where illnesses are tightly controlled by national guidelines and where the effects of rehabilitation are well documented, e.g. cardiac infarction (910-914, 938, 939, 1341) Language barriers and low educational level reinforce the sense of isolation and loneliness of ethnic minorities with cancer, and this affects the quality and understanding of the information provided to them by doctors and nursing staff (940).

In her PhD thesis 'The ordinary in the different' Lise Dyhr, a family doctor in Copenhagen, highlighted problems occurring in the meetings between Turkish immigrant women and family doctors (335). The doctors identified three main problem areas: patient expectations, language barriers, and lack of time. Lise Dyhr found large differences in doctors' interactions with patients and use of interpreter services even for patients with poor Danish language skills. The medical quality of some of these doctor-patient encounters was questioned, and the encounters appeared to follow two main approaches: doctors who handled the given framework with flexibility achieved better results than doctors who did not try to adapt to reality. Some of the problems doctors experience are also seen among ethnic Danish patients; the problems are just more massive when language barriers cause doctors to give up faster than they would with ethnic Danish patients. In addition to minimising the language barrier, Lise Dyhr recommends that doctors arm themselves with patience in relation to expectations and that it is essential to listen to and express an opinion on all of the patient's information and messages to the doctor. Finally, she recommends that doctors should dare to set their own limits and to assign any sense of powerlessness to the current, concrete incident and not to a self-fulfilling, generalised perception that all immigrant patients are problematic. In clinical encounters, language and literacy are by far the most obvious obstacle to achieving quality in hospital care (236, 794).

The doctor needs to be aware of whether a patient has any counter-productive health information or other information that can negatively affect compliance and treatment outcomes (e.g. the culturally fixed idea that you should eat 'good' food when you are sick, meaning very sweet and oily food - even if you have diabetes). Life as a migrant can be characterised by many heavy or impossible decisions (finances, residence, education, future), all of which contribute to a certain decision-making fatigue that can affect the motivation and compliance of patients whom you try to involve in making decisions, e.g. about treatment. Moreover, limited or no schooling undoubtedly affects communication beyond what lies in the bilingual conversation. Doctors should be aware that logic, history, cause-and-effect, and basic scientific knowledge can be significantly different from what they are used to. Thus, it pays to try to understand the patient's mind-set. Refugees and immigrants are more often than other patients scolded for being late, turning to the wrong place, or seeking help in a 'non-Danish' way. The fear of getting scolded gets internalised and can negatively affect health behaviour; this fear can be reduced if you have a conversation about past experiences. Patients in this category often lack understanding of the course of action (which otherwise seems clear), and they easily diverge from self-evident treatment plans. A patient may have poor skills in navigating the health system, but this is mainly because no one ever tries to correct them. The importance of previous illnesses in connection with current clinical issues may also need to be explained more than is usual. Counter-productive ideas of organs may exist that need to be addressed (e.g. that the human body is a large 'plasma body' without distinct organs and that knowledge of the organs is not something humans should deal with). A feeling of being a guinea pig may arise if the doctor changes medication (as in diabetes treatment). Patients may have notions of becoming addicted or sterilised in connection with painkillers or contraceptives. Patients may refuse relevant examinations or treatments due to incorrect or inadequate knowledge from previous experiences in or outside the hospital (e.g. confinement or torture), which then needs to be addressed. Refugees, in particular, get the idea that all of the information about them flows freely from system to system - which is the case during the integration programme, but then a lot of the information disappears and can be difficult to find. Patients may thus believe that the doctor knows their history, so they do not themselves talk about their trauma or illnesses. In such cases, the doctor needs to actively ask.

In relation to their own behaviour, doctors should be aware that they may easily downplay or overlook the role of psychosocial factors in compliance failure. We often see patients being referred with an incomplete medical history. Contextual clinical decisions, bias, prejudices, guesswork, and clinical 'misfires' frequently occur. Both doctor and patient have affinity for the 'easy way out' in difficult conversations. One tends to choose the first option that appears, which could be a (highly theoretical) solution.

This can prevent doctors from getting a better medical history, and the patients get away with not having to speak about anything else. Also, a referral to a second speciality may stop current investigations due to an erroneous assumption that the patient's issue is resolved. There may be inadequate basic clinical knowledge of illnesses among ethnic minorities (infections, hereditary illnesses, particular types of cancers, ulcers at an early age). Finally, most errors occur when interpreters are not used for key conversations. Core symptoms are described inaccurately and are perceived as 'multiple unexplained symptoms' or 'ethnic pain' (see the chapter 5: Pain, symptoms and somatisation in a cross-cultural perspective).

At the MHC, we have found the following basic recommendations to be useful in conversations with language barriers:

1. **Brief the interpreter** (if an interpreter is used) about the goal and purpose of the conversation so that the interpreter can become a clinical co-player.
2. **Speak the same language** - not just language, but also dialect, linguistic level, professional expressions.
3. **You should want to help the patient** - the patient should be able to hear and see that you sincerely want to understand and help.
4. Polish the **cultural radar** - do not be disturbed by unfamiliar signals or different perceptions of illness but try instead to get to the reason for the patient's perceptions.
5. Address and respect **the patient's** anxiety, concerns - refugees and immigrants are used to feeling misunderstood, rejected, or being in the way; normalise and talk openly about what scares the patient.
6. **Create safety** - create a 'safe zone' where everything can be talked about, and nothing is considered to be wrong.
7. **Slow down** - build confidence slowly and use the time to repeat and summarise more frequently than usual.
8. **No guesswork** - you cannot guess what the patient thinks and feels – ask!
9. Focus on **clarity** - clear up doubts and misunderstandings.
10. Discuss the patient's **worries and expectations** - what you can and cannot do.
11. Confirm the patient's **understanding of each sentence** - seek frequent consensus, work to reduce uncertainty and complexity.
12. Something **important you haven't told me?** - even if you are busy, always remember this good question.
13. Think **ordinary first** - most people have ordinary human problems and symptoms of frequent illnesses that require ordinary examination and treatment. Be careful of *tropicalisation* or *alienation* of symptoms expressed in an unfamiliar way.

Refugees and immigrants are a challenge for the Danish healthcare system, just as it is in other countries. The reasons are often stated to be that this group of patients has health problems that are fundamentally different from those of other Danes. Research suggests that this is partly correct in that the group of refugees/immigrants is probably a particularly well-defined challenge, but there are huge differences between the various ethnic groups in their needs and problems. The documented morbidity and mortality rates are also not uniform enough to see them as a single group. Some ethnic groups have a very high incidence of mental disorders, while other groups have a high incidence of joint and muscle pain. Finally, major differences exist in the level of integration, language acquisition, and health literacy (knowledge and use of health information), which are only partly explained by ethnic differences and are probably more indicative of socio-economic differences in the country of origin before their refugee life started. These could be due to neglect, poor or no schooling, low quality of education, or poverty.

Mental health complaints are strongly linked to vulnerable financial situations and lack of social networks - factors that are frequent among ethnic minorities (941).

13.13. The pitfalls of cultural competencies

Multicultural competencies mean that you as a doctor are able to understand and constructively relate to the individual patient's unique composition of cultures that make up their basis and perspective (on health and illness). However, cultural competencies must be applied with caution and creativity to avoid unintended effects. Many research projects and intervention studies are shrouded in well-intended mists of stereotypes and prejudices that do not help reduce health inequality. Doctors often think of culture as a unique phenomenon that can be reduced to a few tables and a short manual.

The complexity of multicultural competencies is often overlooked by teachers, and this simplified presentation often inadvertently reinforces commonly held stereotypes. To combat this, Stuart has proposed 12 practical guidelines for guarding against stereotypical multicultural competencies (942):

1. Train your skills in exploring the patient's unique cultural perspective and outlook.
2. Recognise and control your own prejudices by expressing your worldview, critically evaluating its roots and validity.
3. Develop a sensitivity to cultural differences, but without reinforcing them.
4. Disconnect theory from culture.
5. Build a sufficiently complex set of cultural categories.
6. Be critical in the collection and use of cultural information.
7. Acquire tools with which to assess whether and how a person accepts relevant cultural themes.
8. Acquire tools for assessing how prominent and important ethnic belonging is to the individual patient.
9. Be aware when using standardised tests – always compare the answer to the patient's characteristics and an immediate assessment. Not all tests are cross-culturally validated.
10. Put all findings into their actual context.
11. Beware of standard solutions – always include cultural and ethnic circumstances in the choice of intervention.
12. Respect the patient's ideas, but try through critical dialogue to change attitudes that are in the way of an appropriate solution.

Figure 19. Twelve proposals to facilitate multi-cultural competencies (942).

Item four in the above table is particularly interesting. Stuart cites as an example that even if you have not attended school, you can easily have an academic approach to an illness and even if you are a drug addict, you can have more complex intellectual needs. He suggests acquiring a routine of 'unpacking' the importance of culture to the individual and allowing the individual person to come first and then involve 'culture' if and when appropriate, as just one of several different positioning factors in relation to life with an illness (943). You could also call it a cultural X-ray where, instead of applying simple demographics and a few prejudices, it is the patients, who sketch out their life and describe where their

perspectives, assumptions, and concerns are rooted. Religion, culture, and ethnicity are not always what explain vague symptoms. The patient may just be afraid of the doctor, have a great deal of sadness, or have difficulty articulating the most important thing. Item 10 is about avoiding the assignment of apparently common characteristics and ethnicity. Here, Stuart mentions that African Americans were previously described as 'paranoid', while in reality there was cultural distrust: widespread bad experiences with authorities gave rise to a natural and well-founded distrust of much of the African-American environment. The common environmental 'stress factors' were misinterpreted as ethnically cultural. This is also a frequent error in research.

The following 10 rules about patients may be useful in strengthening the relationship with the patient:

1. All humans are rational according to their own terms - go for the terms and do not be led astray by what seems (off hand) to be irrational.
2. Patients do not listen until they trust you - build trust before you get to what is professionally significant.
3. Patients are most motivated if they like you - be *likeable* in your own way.
4. Patients are smartest at home on their sofa - give patients the opportunity to send emails or text messages with questions when they get home; the good questions originate at home.
5. Patients ask more if you ask more - ask and get answers, ask and gain respect for your interest, and invite the difficult questions to be asked.
6. Patients only do as you say if you want to help them for better or for worse, through thick and thin, 'until death do you part' - show you want to help the patient and that you don't just give up halfway.
7. Patients will return if you do not scold them - even a discreetly reproachful tone can keep the patient away.
8. Patients will return if you ask good questions - build a battery of good open questions (like '*How old do you feel?*', '*Describe the family you grew up with?*', and '*Do you have many thoughts?*').
9. Patients are much more optimistic than you are - be precise and honest in an empathetically adapted way; patients like doctors who are honest (also concerning uncertainty).
10. Patients happily take medication if it makes you happy - talk to the patient about why they are taking the medication and who is benefiting the most.

A holistic clinical assessment of patients requires far more than a social history, clinical diagnosis, treatment plan, and prognosis. A culturally sensitive assessment requires that the doctor responds appropriately to the unique perspectives of each patient. Doctors have to be receptive to the patients' hidden messages and circumstances and should be aware of cognitive shortcuts. Doctors must recognise and control how their own prejudices affect the perception and interpretation of a medical history. Recognition of ethnicity is important. However, the simple fact that patients are part of one or more ethnic groups does not mean that the doctor can immediately accept any of the ideas that are considered typical of these groups. The cross-cultural literature in the medical field is useful in establishing a list of hypotheses, each of which should take the form of an issue rather than a set of assumptions that are routinely accepted as applicable to everyone in that ethnic group. Culturally competent medical work requires self-reflection, a critically evaluative use of literature, thoughtful collection and evaluation of personal experiences, and considerable professional sensitivity and curiosity about each patient's uniqueness.

13.14. Structural competencies

Virtually all medical research into health inequality is about changing patients to suit the healthcare system, and a smaller part is about creating equality in the meeting with the doctor or nurse by means of teaching patients to ask better questions of the doctor. Stigma is often mentioned in this context, but stigma occurs not only in the individual meeting between doctor and patient. It is typically shaped by structural organisational reasons (time, resources, physical framework, information, minority mechanisms). Structural frailty designates the forces that prevent a person from making appropriate decisions and limits choice and thereby the health of the socially marginalised and vulnerable (944). Others talk of *community resilience* as a hidden factor that can affect the frailty of the individual - a factor that, like social capital, can arise when help is seriously needed. Clinical education in ethnic competencies needs to shift its view from a narrow focus on the individual doctor-patient meeting to include the composition of institutions and the design of policies, as well as how the local environment affects the ill immigrant patient whose doctors will affect stigma-related health inequalities (945). In the medical context, the doctors' structural understanding is currently reduced to a simplistic discussion on the social determinants of health, which appear unalterable and inevitable in that they function independently of the work of doctors, and doctors cannot change them anyway. Medical education needs to be supplemented with knowledge of how social structures, hierarchies, finances, and social networks create and affect health and the course of illness. This approach, referred to as 'Structural competence,' consists of training in five core competencies: 1) recognition of the structures that shape clinical interactions; 2) the development of a conceptual apparatus that links structural causes of illness to social determinants and biological mechanisms; 3) reinterpretation of the significance of what is 'cultural' in a structural context; 4) observing and imagining structural interventions to reduce inequality; and 5) the development of structural humility. Structural competencies enable doctors to distinguish ethnic-cultural causal relationships from structural contexts. For example, if an Iraqi woman with a bleeding disorder seeks medical attention only after two months of symptoms, is it then a 'cultural' delay, or is it due to socio-economic/structural conditions such as having a sick husband, lack of a driver's license, tight finances, hard work at home, or working a night shift? Focusing solely on cultural competencies can exaggerate the (supposed) ethnic or religious barriers that the doctor sees at the expense of actual purely structural barriers. Through their training, doctors learn a helplessness in relation to structural knowledge and understanding of illness and fall into stereotypical interpretations of medical histories based on biomedicine, blind assumptions, and simplistic ideas about social determinants of illness.

13.15. Structural violations

As a result of their contacts with patients, doctors find it easy to understand that strong social forces, racism, gender inequality, poverty, political violence and war, and sometimes the policy decisions that target these factors will determine who gets sick, who has access to healthcare, and what the outcome will be of the treatment. The social determinants of illness are difficult for doctors and public health professionals to ignore. However, doctors are not trained to change structures and organisations, so their structural and social insights are rarely included in structural discussions. In addition, the doctor's social insight is rarely translated into a formal framework that links the doctor's social analysis with solutions in daily clinical practice. This is because modern medicine still focuses only on the molecular basis of illnesses. This has led to an increasing 'de-socialisation' by doctors only asking biological questions for clinical contexts that are, in fact, bio-social phenomena.

Medical anthropologists study how social conditions model disease and health. For example, they find that epidemics such as HIV and tuberculosis are the result of structural abuse or *structural violence* (946). The epidemics are not the result of a different 'culture' or individual character flaws, but of historical and economic processes that combine to limit individual options for action. Structural violations take place in all social structures and are normalised by stable social institutions (municipalities, social

services, hospitals) and cemented by ordinary, everyday experiences (728). Because structural violations are so common and well-integrated into our ways of understanding the world, they become invisible to us. Unequal access to public resources, political power, education, healthcare, and legal action are just a few examples of areas where structural violations of socially disadvantaged and vulnerable people play out, but they are commonly perceived as a 'necessary evil'.

Several anthropologists have examined the encounter between African patients with HIV and the Danish healthcare system. In the early 1990s, Seeberg found that cultural factors were given great explanatory value but that the health professionals' existing cultural understanding of the patients' illness were marked by attitudes from the media, and the picture in the media was characterised by Africans being a particular risk group for HIV/AIDS (947). In other words, there was no gain in experience and reflection based on a dialogue with the patients, but the patients' statements were analysed through the prior biases of doctors and nurses. Jöhncke found that medication problems, doubt, and difficulties with blood tests were falsely attributed to the patients' cultural background and not by their actual circumstances and psychosocial challenges (948). Mogensen found that Africans with HIV were very vulnerable in their conversations with doctors and nurses because they were 'twice as lonely or more,' and with a stigmatising disease they had a hard time balancing the simultaneous needs of proximity and distance in relation to the staff. Mogensen found that in the encounter between the African patients and the Danish hospital staff, a new 'culture' emerged, which arose along the way and was shaped by negotiations, problems, and solutions (949).

14. Clinical decision processes with ethnic minority patients

Doctors discriminate through several mechanisms simultaneously. Biases, stereotypes, prejudices, and negative biases against ethnic minorities are the obvious barriers. Prejudices and fixed ideas about other people have a powerful effect on thinking and actions on an unconscious level, even among well-educated and well-meaning doctors who do not feel that they are particularly prejudiced. Doctors show greater clinical uncertainty in conversations with ethnic minority patients and use 'cognitive short-cuts' more often in the diagnostic process. At the same time, there is an element of statistical discrimination and inequality because language barriers will always be an obstacle that cannot be completely erased - these can be minimised, but they never completely disappear. It is up to the individual doctor to determine how much they will do to reduce language barriers (and the barriers that result from language difficulties, illiteracy, lack of knowledge about diseases and healthcare, other perceptions of body and disease, etc.)

Unfortunately, clinical uncertainty opens up the possibility that the choice of examination, diagnosis, and treatment will be marked by the doctor's subjective opinions and preferences rather than medical knowledge and experience. Time pressure, the complexity of health problems, and pressure on the doctor's cognitive abilities shape the doctor's perception of the patient's information and the doctor's (hasty, incorrect) expectations of patient compliance. This can give rise to arbitrariness in the clinical process and, consequently, unsatisfactory and unproductive patient treatments influenced by social discrimination.

Immigrant patients and other vulnerable people often end up in a clinical grey area where decisions have to be negotiated and made outside the department's familiar framework and guidelines. This may be due to interruptions in examination plans and treatment programmes, incomprehensible delays, misunderstood information about the necessary preparation for an investigation, the patient's recurring doubts about the need for a procedure or treatment, and ordinary navigational problems in hospitals and between wards. There is no one person who is responsible for sorting things out when a complicated investigation or treatment programme fails. The problem often ends up with the family doctor, who has to start over without having the authority to resume a treatment course at the point where it 'failed'. A typical example would be the instructions for patients before they undergo a colonoscopy that may be perceived as being embarrassing or humiliating. If a patient does not understand the complicated text in the information sheet about where a suppository should be inserted, then the team of doctors and nurses will consider that the patient has wasted their precious time and a new appointment will have to be scheduled, maybe even with an interpreter - but still without attempting to explain to the patient that the suppository should not be taken orally three times daily.

14.1. A simple strategy

A simple strategy is for the doctor to ask, *'What have I not understood, and what has the patient not understood?'* The goal is to find an answer to both questions together with the patient. However, as the doctor is in a professional role, it must be the doctor's job to guide this process using the right tools. You need to keep the ball in the patient's court by being curious, *'When you say you feel that way, what do you mean (which I don't readily understand)?'* The goal is to achieve and maintain contact and presence, so the patient does not 'slip away', lose the thread, become unfocused, or lose motivation. Be persistent and honest without fearing contact: say, what your doctor's ears hear, and ask for the patient's comment or correction.

Both parties are vulnerable and insecure. The doctor is unsure of the integrity and reliability of the medical history and this rubs off on the diagnostic process, causing it to become a little hesitant. The patient feels that the doctor's questions are not helping, or are not relevant, but at the same time is not

aware of what the doctor needs to know. You and the patient need to meet somewhere within this vulnerability. Abraham Verghese, Ethiopian-Indian physician and author, describes in his book *Cutting for Stone* how his practice of medicine is challenged by the patients’ low level of body awareness and high expectation of his abilities (950):

The most common complaint among patients was: Rasehn ... libehn ... hodehn. (My head ... my heart ... my stomach). The complaint was accompanied by the patient putting his hand in the three places. When you pressed them to be more specific, they said they were dizzy or hot in the head or had stomach cramps - but these specific symptoms were only reported with reluctant grunting because Rasehn ... libehn ... hodehn really should have been enough for any proper doctor.

14.1. The likeable-competent patient

We cater to the strong, agreeable patients who are good at talking to doctors and nurses, and who slip effortlessly into the ‘system’ without causing anxiety or disrupting routines. They are the patients who willingly listen to what we say, go through examinations without protest, receive the treatment, and then immediately return home. The resource-weak patients get attention if they are nice and show gratitude. However, some patients cause frustration because they behave differently than expected. They do not know the rules or codes. They challenge the routines and do not readily accept standard information. They expose the weaknesses of the system and create uncertainty because we find it hard to change the way we usually work. There is no time - and even if we had more time, we do not quite know, how to deal with the heartsink patient. The challenge with this type of patient has been called *the broken shoelace* - a routine that should work without any hassle, but when it breaks, you have no plan B, and the rest of the day has been ruined by a small break in the routine. In a simulated study of 94 doctors’ interactions with *likeable-competent* patients, *unlikeable-competent* patients, *likeable-incompetent* patients, and *unlikeable-incompetent* patients, the *likeable-competent* patients were offered more follow-up visits, were more often encouraged to call in case of any questions, and were more frequently given more specialised and individualised treatment than the ‘less sympathetic’ patient groups (396).

<ul style="list-style-type: none"> • Likeable-competent • Likeable-incompetent 	<p>Gets more attention, spontaneous bonus information, gets more forgiveness, longer patient conversation time, is invited to participate in the conversation, gets extra follow-up, is offered more treatment options.</p>
<ul style="list-style-type: none"> • Unlikeable-competent • Unlikeable-incompetent 	<p>Gets less information, shorter conversations, is told off more, has longer waiting times, is not so frequently invited into a dialogue, gets fewer follow-ups and fewer treatment options</p>

Figure 20. The doctor’s perception of the patient’s personality and competencies.

A qualitative study of doctor-patient interactions found that doctors were more patient-centred in their communication if they deemed that the patient was good at communicating and appeared to be a satisfied patient, and if they expected patient compliance would be high. There was a clear bias of doctors generally considering that ethnic minority patients were worse at communicating, more dissatisfied, and less compliant than other patients (951). The hidden curriculum often comes into play with challenging

patients (240). These patients are not necessarily referred to as ‘annoying’ or ‘frustrating’ by senior doctors, but proxy terms derived from the hidden curriculum are used instead: the patient is ‘demanding,’ ‘distrustful,’ or ‘non-compliant.’ The patient is ‘a bad informant,’ ‘incoherent,’ or ‘opposed to medical advice.’ Junior doctors learn through the language of senior doctors what characteristics are attributed to troublesome patients. At the same time, they learn not to expect much from this type of patient, that one should refrain from having ambitions on their behalf and implicitly, that one should refrain from showing empathy. However, this is emotionally hard on young, unprepared doctors as they experience an internal conflict, between their own human ideals and the hidden curriculum pushed by the senior doctors (952). The result is burnout and cynicism.

Something else that must be kept in mind is that patients are rarely static in their characteristics. In particular, chronically ill and young patients may have periods when they become worn out by their illness(es) and more or less deliberately skip medical check-ups or medication dosages. One may have to neglect one’s illness for social (or mental) reasons. Some patients do it in a rationally structured way, while others are more unpredictable in their patterns of action and attitudes (see Figure 21). The key is to understand it as a dynamic picture and be supportive of the patient during the periods when they may have other priorities in their lives than their illness. If the pattern is more constantly irrational, the patient may need more focussed information, more explicit agreements, and clearer expectations from the doctor.

Patient characteristics	Rational	Irrational
Knowing	Expert, all-knowing, challenges professionalism, changes patient role	Unpredictable, incorrigible, ambiguous, dividing
Not caring	Ostrich syndrome, if uncertain it is best not to act, cheats about own care	Illusory, minimising, overconfident

Figure 21. Dynamic patient characteristics and their influence on self-care.

The basic perception of one’s options as a patient is another hidden element of patient characteristics. It is called a *stable internal locus of control*: it was because my abilities were insufficient that I became ill - if I had been able to, I would have avoided the illness. *Unstable external locus of control*: it was just, because I was unlucky - fate made me ill and I could not do anything about it.

Locus of control can also determine, whether a challenge is something you can handle or whether it will require a huge personal effort to overcome it. The task you face can be difficult but manageable, or the patient may have the opinion that the task requires considerable luck, which you just have to wait for (953).

14.3. The informed decision

It is ethically, legislatively, and culturally conditioned that patients have the right to, and generally ask for, informed decision-making about their health and treatment. However, far from all countries and cultures value this right/freedom - quite the opposite. For some, it is inconceivable to know anything about the functions of the body, especially those associated with urine, faeces, and secretions. To others, the body is a collective organism without individual parts, but separated from the family and the outside world by its skin. Finally, certain parts of the body are often not considered to be one’s own, e.g. the

heart or, in women, the abdomen. A woman's abdomen belongs to the family (and the in-laws), and one cannot make individual decisions about treatment or surgery. The simple and easy solution is to ask the patient about these conditions and to clarify, how they see their body, and whether there is anyone other than themselves who should be involved in deciding on the specific examination or treatment proposed by the doctor.

The challenge is that if you do not know enough about the patient, either because you have not spent time finding out, or because it may require more time than has been allotted, then this lack of knowledge gets filled with substitute knowledge in the form of prejudice and bias and whatever patients in the (supposed) culture-sociological group usually do or think. In the quest to understand, but with a lack of insight or explanation, the doctor exaggerates the importance of cultural, ethnic, and religious explanations for the patient's unexplained symptoms, poor illness control, or lack of compliance. If you are selective, when gathering and processing knowledge, and at the same time substitute the lack of knowledge with non-professional prejudices, then you have a recipe for diagnostic cowardice and delays as well as patient injuries.

Hidden moral values represent another type of non-medical factor that influences the diagnostic process. Attitudes like, *'You need to make an effort to get a reward'*, and *'You do not yet deserve that we start this or that treatment'*, or ideas about expected self-care or motivation are values that are transmitted to the patient without the doctor even thinking about it. However, many patients can sense it, or they over interpret it, which thereby indirectly affects their role as a player in the clinical process (91). The doctor's style of interaction may signal that extraneous moral values are underlying the doctor's plan or explanations: *'Menstrual pain is something you have to live with'*, *'You must lose weight before I will talk to you about your knee pain'*, or *'If you just pulled yourself together and learned Danish, I could understand what you were saying.'* Hidden moral values affect doctors' clinical judgement and should be dealt with in medical school (954). Solid evidence shows that male patients are overrepresented in delayed diagnoses because their interaction style is less overt when it comes to vulnerability and expressing the need for help (846). However, male doctors also have a different clinical decision pattern than female doctors, e.g. in prescribing painkillers and antibiotics (regarding strength and duration) (955). This is particularly true for ethnic minority patients, and the doctor has the specific professional task of avoiding clientising or intimidating immigrant patients. When we encounter a patient who speaks very little Danish, we change our tone of voice to a mixture of speaking to a child and a deaf or demented person. Patients pick up on this, and then resist, get angry or sad, and lose confidence. It is mature and professionally empathetic to use interpreter services because it enables you to have an adult conversation on an equal footing.

Other aspects can also be communicated more indirectly: the doctor's expectations of the success of the examination, the doctor's belief in whether 'the patient can figure it out', investigation or treatment choices dependent on the patient's (presumed) education level, ethnicity, expectations of network support, or the doctor's own unrecognised use of stigma (243).

Finally, many doctors are so overloaded these days with research results from large national or international double-blind studies and public health studies that they fill their lack of knowledge about the individual patient with arbitrary research results - also called *over-application of epidemiological findings to individual patients in the clinical space*: all Somalis have TB, so they are collectively and exclusively studied for TB, but the doctor does not include the more likely diagnoses until late in the course: hypertension, diabetes, cancer, rheumatoid arthritis, PTSD, and lactose intolerance (90, 243).

14.4. Starting point of the diagnostic conversation

Two mind-sets (and goals) have to meet in a cross-cultural doctor-patient conversation. Conditions and starting points are important, but they inherently vary. On one side is the doctor who has a given set of skills, knowledge, and experience that have to come into play within a narrow time frame. In a recent

interview study of family doctors, 68 % answered that consultations with immigrant patients were time-consuming, 54 % said it could be difficult to assess symptoms, and 46 % answered that they lacked a place to refer immigrant patients with complex issues (845). On the other side are the immigrant patients - who in 37 % of the cases had no access to interpreter services, even when they feel the need for them. Half of the patients did not feel that the doctor was sufficiently responsive (one-third as many as ethnic Danish patients), and one in five patients (twice as many as ethnic Danish patients) had experienced errors on the part of the doctor.

We need to work determinedly and tenaciously from both sides to make those platforms work together. If one neglects to clarify the agendas, basis, and starting point of the conversation, the diagnostic process is at a high risk of getting derailed or delayed. It may be an advantage to familiarise yourself with the most common disruptive and delaying factors of the process: expectations, the actual needs, anxiety, reading and language difficulties, memory and concentration abilities, trust in the doctor, suspected cancer, fear of death, fundamentally different perceptions of symptom causes, different chronological understandings, etc.

Poor or no schooling can reinforce existing misconceptions and complicate already difficult topics in a conversation because many concepts need to be explained and not just translated. You may have to describe the difference between being a carrier of a disease and being ill with the disease. This could relate to infections such as hepatitis, tuberculosis, or HPV, it could be complicated genetic defects where risk and the carrier condition must be linked together, or it could be the compound risk of diabetes or heart disease where living conditions, diet, exercise, and genetics all play a role. Another challenge is to balance the expected benefits of a painkiller or an antidepressant against the long list of possible side effects on a patient information leaflet.

It is important that the doctor separates assumptions based on own 'clinical knowledge' from the patient's emotions and needs. Listen to what the patient says - not what you think you know. Patients very often misinterpret everyday situations, particularly when they are sick or afraid and have language problems. Stressed patients can be hypersensitive to signals and downplay the verbal content in favour of the doctor's conscious or unconscious signals. Patients may sense that they do not understand the doctor anyway or do not get 'the whole truth', and then they struggle to scan the doctor's body language and eye movements for hidden messages and a little common humanity - all while the doctor explains in detail what lymphoma is, the side effects of the treatment, and the chances of survival. When the conversation is over, the patient asks the interpreter, '*What was the lymph doctor saying?*' Patients are extremely aware of and sensitive to doctors' and nurses' assumptions, prejudices, and evaluations of them. This may colour the patients' perceptions of the entire conversation, and this is where body language can be the determining factor for whether they can achieve trust and be listened to or not.

Misdiagnosis and delayed diagnosis occur when the doctor is insufficiently self-critical, cautious, and tolerant when diagnosing. The lack of a diagnosis can be a challenge in a doctor-patient relationship, particularly in maintaining trust. If there is no diagnosis, the doctor may think that it is '*all in the patient's head*', and the patient may think that it is '*probably cancer because the doctor is constantly ordering new investigations without saying anything clearly*' or '*the doctor is not skilled, because she is constantly looking at the computer screen, ordering investigations that show nothing.*' The doctor must always have two ways out: either a clear and effective diagnosis or an explanation that the patient can live with, thereby helping the patient to become stronger and better informed. One cannot sit on the fence in this context without sending the patient away with doubts, anxiety, and distrust of the doctor and the nebulous diagnosis. Sending patients away stronger after a series of investigations is a task that requires attention, empathy, and professionalism so that patients do not feel neglected or trivialised. Before the next step is taken, each step of the diagnostic process must be firmly grounded, both in terms of knowledge sharing and what the patient's understanding and self-perception are at that time.

14.5. Dehumanisation

Empathy is good for the soul, but that it is also good medicine may be less obvious. In a study exploring links between diabetes control and the doctor's empathy for the patient, patients had significantly lower HbA1c and LDL cholesterol levels in the blood if doctors had a high empathy score, and apparently, some dosage-response effect could be seen (955). The same effect is shown in a wide range of other clinical contexts (956). Empathy is evidently a non-permanent ability because studies suggest that medical students lose empathy during their education at about the time when they begin seeing patients three years into their studies (957). Male students lose more empathy than female students do during medical school, and students who consider a future in more technologically based specialities lose more empathy than those who consider a more human/person-oriented specialities. While those with the most empathy from the start of their studies lose the least empathy during their studies, students with the least empathy have a high risk of losing the little bit of empathy they might have on day one of medical school (958). The escalating cynicism and 'atrophy of ideals' are described as being part of the socialisation of medical students that happens as part of preparing them for their professional medical life (959). The process continues as the *ethical corrosion* that occurs during their clinical training (960). Among medical students, 80 % had done something they considered directly unethical or had deliberately provided false information, and 98 % of students had witnessed an older colleague speak disparagingly about patients (961). Some students develop a collective 'social amnesia' in which empathy gradually disappears 'like an endangered species' (962, 963). Mary-Jo Good demonstrated in qualitative studies of medical students how the *medical gaze* gradually becomes the only dominant framework of understanding in medical school, and students are taught to appreciate and prioritise time consumption, management, and efficiency. Medical students learn from their older colleagues to be most interested in, and to do the most for, those patients who want to be part of our 'medical narrative' and the investigations and treatments that we want to carry out (964).

Much evidence suggests that medical students and newly qualified doctors find it difficult to navigate between the formal, informal, and hidden learning goals. Frameworks and values for their contacts with patients, colleagues, and the healthcare system are perceived as hidden codes, and the survival strategy is to copy older colleagues without any theoretical framework of understanding (957). Doctors become shy when confronted with patients' emotions, and even if they want to appear empathetic towards patients, most doctors indicate that they are afraid of being overwhelmed by the patient's or their own emotions (965). The hidden learning goals give doctors the impression that a patient's obvious display of emotions is a clear barrier to patient involvement in treatment (966). Demands, morals, and goals at the university and hospital are often uncoordinated and contradictory. In the article 'Vanishing virtues' Coulehan describes the contradiction in explicitly teaching classical medical virtues such as empathy, compassion, relief, altruism, while at the same time tacitly teaching objectivity, self-centring, and ethical emancipation from the patient (967). It is not clear where medical students can obtain support in forming their own opinions and identities. In a large qualitative interview study of British and Australian medical students, it was even described by the students as a cultural clash - a meeting they were not prepared for and which left them perplexed and paralysed. The students considered their learning situations to be inconsistent and with no goal or direction, and they found that their medical identities developed randomly as a series of cultural clashes (968). The link between hidden learning goals and dehumanisation was particularly evident in a Canadian study among medical students. The students described how they gradually adopted the value perception of the clinical lecturers by copying language and the perceptions that obesity, drug addiction, poverty, and mental illness reflected individual failure or moral decay, and ethnic minority patients were reduced to one group with congruent stereotypical characteristics (968).

It is worrying that even after students obtain their medical degree, there is a slow *dehumanisation* that occurs in the clinical environment (969). A number of factors have been described, each of which

contributes to an insidious reduction of the human factor into an annoying and disruptive element: first is the de-individualisation of the person by perceiving some patients as belonging to a group/type of patients. Dehumanisation means rejecting the patient's right to a particular identity and ignoring their need to be an independent person with traits that clearly distinguish them from other patients. The doctor dismisses the patient's right to make decisions and make their own choices. Dehumanisation is amplified particularly among ethnic minority patients because they are seen as marginal groups with low heterogeneity through a battery of prejudices and stereotypes. Dehumanisation is reflected in not spending as much time trying to understand the patient's health problems, and this results in the investigation and treatment plan being decided on the basis of a group-based picture of the patient rather than on the individual patient's symptoms, resources, and needs (970). This inhumanity is reinforced by the patients being unwell and less able to act normally and to express themselves clearly, and they lack the strength to defend themselves. Several studies show how professionals dehumanise patients into a diagnosis instead of treating them as a person with a name, and this is amplified the sicker and more deviant the patient becomes compared to a normal healthy adult (971). When people become patients, they change behaviour and reaction patterns, basic human functions are affected, and in the doctor's view, they get a less human face (972). Perhaps the doctor needs to de-compose patients into physiological or organ systems out of necessity for the diagnostic process, but the risk is that the doctor does not get to re-compose the patient, and that contributes to dehumanisation.

Clinical strategy is a constant balance between, on the one side, the dissolution of the patient's social being and cohesiveness as a human being and, on the other side, the decomposition into biomedical elements as a prerequisite for specialised medical thinking and decision-making. If emotions threaten to affect the doctor's 'objectivity', the doctor can simply tone down the empathy felt for the patient. Dehumanisation is an internalised 'professional' down-regulation mechanism that has been acquired through copying clinical role models and experiences from doctor-patient contexts. If doctors want to win their patients' trust (back), they must know the emotional, physiological, and practical consequences of disqualifying the patients' feelings and needs for respect as complete human beings. Research indicates that patient trust in the doctor is related to whether the patient unknowingly registers that the doctor has empathy and honestly feels for the patient. This is called 'physiological concordance' and can be observed and measured by neurobiological radiological examinations (973). A key aspect of doctors' competencies is the ability to live with and deal with doubt, ambiguity, and uncertainty (concerning symptoms, medical history, or patients' needs and resources) (18). Indeed, this is so important that an *ambiguity tolerance index* has been developed (974, 975). A number of studies have been carried out among medical students and doctors over the past 25 years. As a starting point, *the tolerance of ambiguity* decreases for 70 % of students during the course of their medical studies: the tolerance of ambiguity they possess when getting their master's degrees is lower than, or the same as, the level they started with in their studies. Those who are able to preserve it are the ones with high ambiguity tolerance and who have the highest tolerance to begin with, and they are mostly female students (976).

14.6. The doctor's tasks prior to a conversation

Doctors typically have inadequate time to prepare properly before a consultation with a patient, but there are reasons to spend some extra time in considering the strategy for a conversation that involves language barriers. We usually say that if you as a doctor do not take your time with the patient, then the patient takes your time. For example, it is a good idea to consider whether the interpreter (if it is an interpreted conversation) should be briefed before the interview when it involves a difficult conversation, e.g. a cancer diagnosis or a serious chronic illness. You could have cases needing special examinations or treatments with side effects. If the interpreter is prepared, the conversation gets off to a better start and can be tailored to the upcoming topic. Interpreters have described embarrassing situations in which they started with joyful greetings only to find out that the conversation involved a cancer diagnosis

or a death. It is advantageous to review the conversation’s structure and objectives with the interpreter so that the interpreter can be a co-actor in the doctor’s plan.

14.7. A strategy for the conversation

At the MHC, the initial conversations are structured around five tools that together form the basis for a holistic understanding of the patient - the person with illnesses:

1. **Life story** – in which upbringing, positive and negative social events, life transitions, illnesses, and trauma are explored and placed in a time sequence that can be used for possible explanations of current symptoms. Mental health problems can often be explained by the patients themselves, based on events in their life story.
2. **The genogram/family tree** – provides structural insight into the patient’s life and can be a good conversation tool if patients have difficulty explaining their situation in their own words. Family members who have made a positive or negative impact can be mentioned and this may shed light on current medical conditions. This approach allows the patient to be the one who speaks with expertise.

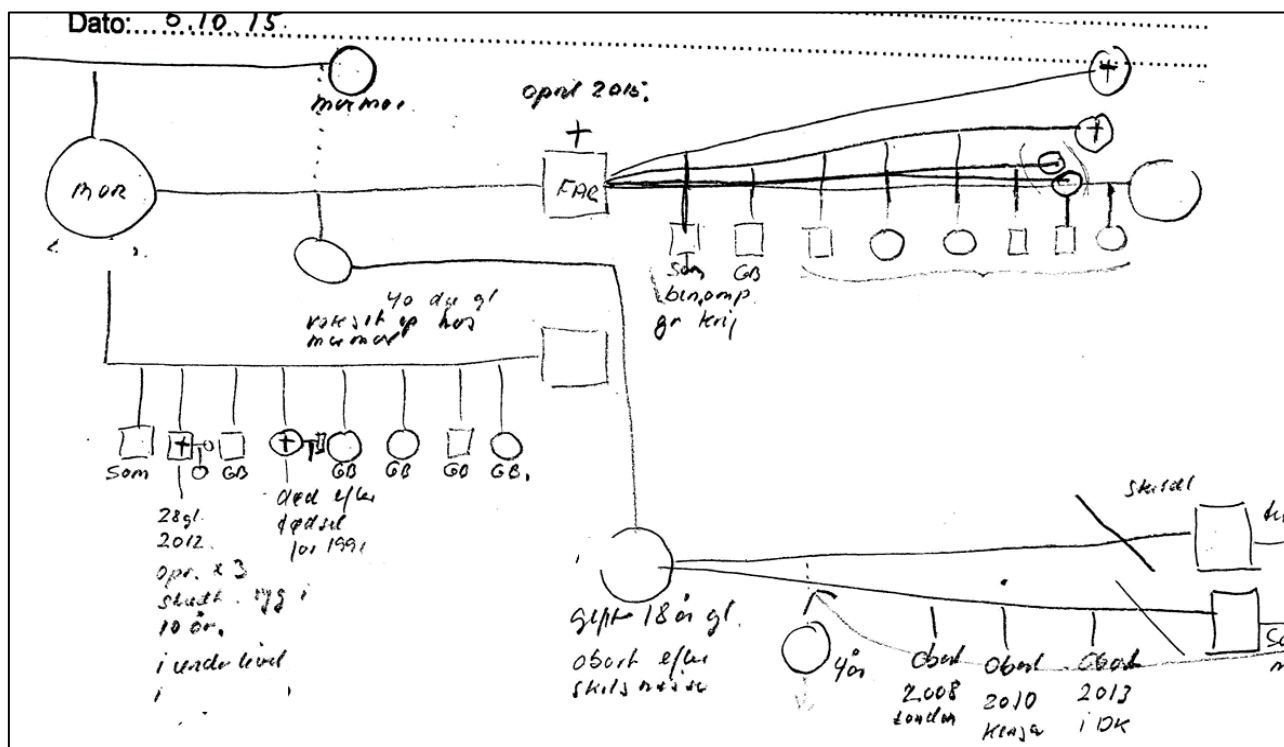


Figure 22. Genogram example (names and some place names deleted).

3. **The problem list** – a complete list of all the patient’s problems: mental, physical, financial, social, marital, relating to the authorities, basis of residency, family disputes, etc. This list serves several purposes: it helps patients to structure their problems and is a tool that actively involves the patient; it is also an exercise that in itself is stress-reducing; and, finally, it ensures that all problems that can affect symptom perceptions, investigations, diagnostics, and treatment are documented and can be used for therapeutic and educational purposes. When the problem list is complete, you systematically go through it with the patient, item by item, and for each problem an action must be agreed upon:

who does what? Note that an action could be that the problem is put on hold because it is too big right now, or that the problem is unsolvable - provided the doctor and patient agree. Figures 23 and 24 show examples of problem lists and how widely they may differ.

Hej Sygeplejerske og Kommune!
 Vil De være så elskværdig, at hjælpe mig - Jeg vil snakke med
 Dem Sundhedsplejerske og Sundhedsstyrelse læge hvis jeg skriver
 på papir ord bog dansk - Jeg prøver udtaler ikke godt og
 Fortæller dansk ikke godt - vil Dem ser laser på papir - Jeg
 har Syg meget er dårlig min's krop ikke rask, Kold og
 Fingre, ~~Kno~~, Knogler, Knæ, Ben Svæppe trætte, taen,
 Sene, Ribben Knogler, muskel Krampe Spasme, Hikke, Indvo
 lde, Diarree, Influenza, Infektion, Jeg svimmel, opkastet
 tørste, smerteful, Røvhul forstoppet - Betændelse balde
 pukkel, Forkølet - forfrossen vammel, Knurre pukkel, snøt
 snue, skodde - skoldkopper min krop Foyse og Jkøp Jeg er
 min Svækling Svække, tarm Svullen, Balde har pukkel
 Svulme, Svulst, hjerte åndenød, ånden, ånder forpustet
 og forfrossen - Utilpas, Jeg hoste slim floppet i næsen
 ondt i halsen, Forkølelse hals - Jeg er forkølet - Jeg
 vil gerne har medicinske tabletter pille hedder - Influe
 enza, Forkølelsen, Svimmelhed, Snøt snue, hoste
 slim, Sene Ribben Knogler Knæ Spasme Krampe, tarm
 Balde pukkel Snøt snue Jkøp pollenallergi, Benaliv
 Øjendråber, halsbrand hedde gavison Jeg tigge håb
 Dem hjælpe og villig glad Fordi Jeg er ensom Jeg bor enlig
 Hvis Dem hjælpe mig med medicin Jeg er Spasme og dejlig og
 trykkelig og Jeg Dem villig hjælpe enig Jeg ønske meget
 gerne vil godt lide vil venstabelig Jeg vente det svar og
 håbe herne fra Dem til mig Jeg er Totak
 Marcophysin letter hosten, og Zyx mod halspine } Tusind tak
 Zyx • eukalyptus Benzylaminhydrochlorid } Med venlighilsen

Figure 23. A patient's handwritten problem list.

The patient did not speak Danish and used Google Translate to translate from his native language into Danish.

Figure 24. Example of a problem list (59-year-old male refugee).

Health problems	Other problems
<ul style="list-style-type: none"> • Consequences from stomach cancer • Hypertension • Diabetes • Cerebellar infarct • Cervical spinal stenosis • Lumbar spinal stenosis • Ulnar neuropathy • Recurring deep venous thrombosis • Erection problem • Unexplained weight loss • Anaemia 	<ul style="list-style-type: none"> • Has always been the boss – now dependent on social services • Lost zest for life after son’s death at 27 years old from cancer • Uses a wheelchair to get around • Huge medicine costs (debt), frequent medication pauses • Accused (wrongfully) of social fraud • Can’t help his children financially, worries about them • Lonely (daughters only come to visit when there are problems) • Lost Danish language after cancer – humiliating to be dependent on an interpreter • Humiliating having to ask the caseworker for permission to go on a holiday • Nightmares and poor sleep • Afraid of being alone • Afraid of becoming more disabled • Feeling of guilt for causing the family to flee

4. Background information - schooling, education, language skills, literacy, dialect, family relationships, social conditions, functional level, sleep, trauma and PTSD screening, depression screening, contact preferences, interpreting preferences.

5. Clinical checklist - a specially developed list of cross-cultural clinical attention points (see chapter on the medical examination of newly arrived refugees/immigrants).

14.8. When everything fails

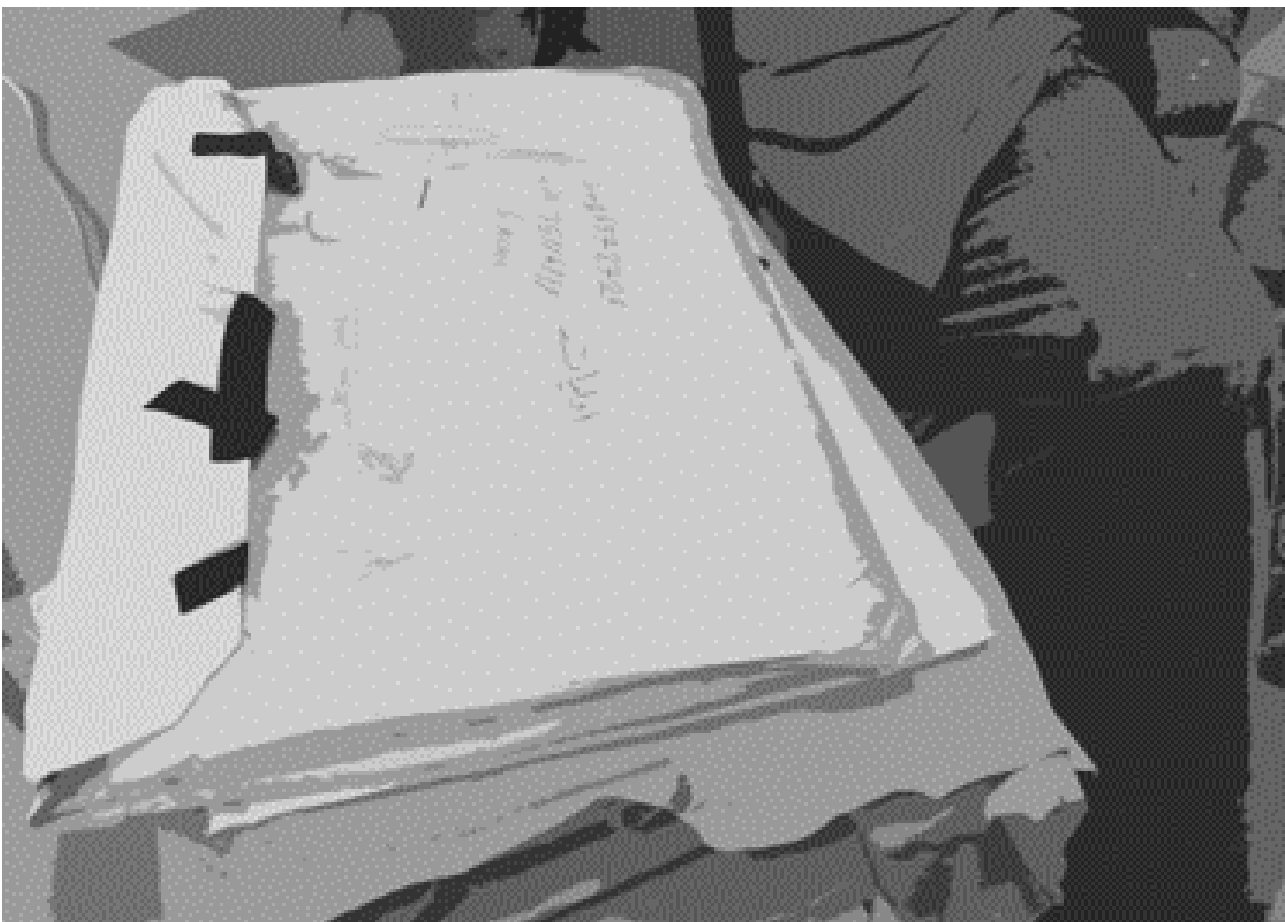
If there is little time for the conversation and perhaps only time to do one thing for the patient, then ask what matters most to the patient in their understanding of the illness and treatment. It is not a particular

competency but rather a human trait that all doctors should do quite naturally to establish proper contact with the patient. The focus should be on the patient as an individual - not as a stereo-type, but as a human being who feels insecure and in danger and not just a patient case (92). Kick the ball back and try to meet the patient in the 'common vulnerability' of being insecure, disagreeing, and not understanding each other, and take note of whether there is an abyss between your perception of the symptoms and the patient's perception of what is happening to their body. Say what you are unsure of, explain where you experience disagreement, point out the unclear points in the patient's story or explanations of causes, and present your responses to the patient's demands and ask for their comment. We often find that the conversation 'is going nowhere' because there are topics, problems, worries, or anxieties that have not been included in the conversation. Here it is to your benefit to get straight to the point:

- *'Is there something important that you have not told me?'*
- *'Is there something important that you cannot talk about?'*
- *'Can you explain to me if there is something you are particularly afraid of?'*
- *'What would it take for us to talk about it?'*
- *'All people have secrets, and some can be important but hard to talk about', etc.*

You can also take another direct route:

- *'Are you afraid it's cancer?'*
- *'Are you afraid it's something you will die from?'*
- *'Is it because you're not taking your medicine at all?'*



15. The patient's narrative as a clinical tool

15.1. Stories and interpretations

The traditional medical interpretation of a patient's medical history is summarised as an anamnesis in the journal - or as a brief clinical case report that follows strict rules. The patient's medical history may be an expression of a natural history, but it says nothing about the individual or the person in a historical or social context. The life story, experiences, burdens, and living conditions in which the illness exists are clinically removed, so that the selected symptoms lead directly to a diagnosis. There is no subject in a tight anamnesis; rather it indirectly refers to the subject of professional attention such as '21-year-old primipara with hyperventilation'. In order to put the human being back into the centre, doctors need to deepen the case history into a narrative - a story. In this way, a 'who', a 'what' (a real person, a human being with an illness, a patient) can be placed in relation to the physical natural history observations and perhaps give them a new and much-needed spark of life. Neurologist Oliver Sacks describes clinical examples of this in his 1985 book *The Man Who Mistook His Wife for a Hat and Other Clinical Tales* (1977). The use of narrative medicine as a conversational tool is slowly gaining ground as a topic in medical schools (1978). From the beginning, empathy has been the cornerstone of narrative medicine. This is probably due to a general awareness that today's medical education and health system seem to create a 'deficit' of empathy. Through close reading and creative writing, the professional empathy and ability of medical students to make clinical decisions are enhanced in complex ambivalent patient narratives. Doctors often meet patients in crisis where patients are unable to express themselves and are overwhelmed by unknown emotions and reactions. Literature can help to put into words all of these worries - the hidden burdens of illness and treatment, the fear of losing one's power over life or losing mobility, or the fear of dying - when the patient cannot manage it.

Narratives and versions of narratives are fundamental ways to make sense out of experience and incidents. The narrative can be a facilitator between inner thoughts and emotions and the interactions and state of the outer world when one is telling about and interpreting experiences. The narrative is an active, productive process that draws on both personal and cultural resources. Stories can be an effective tool for communicating incidents to a person, such as a doctor, who has not had the same experiences (1979). The narrative is a hybrid between what is remembered and the way it is interpreted through the current filter of experience and in the specific context in which the narrative is presented. Perhaps Freud - who was called the master of the narrative tradition - was the first to show how to link random events and memories with associations and dreams into a coherent, meaningful narrative that can form the basis of self-awareness and treatment. The goal in treating PTSD patients has always been to re-establish a connection in the narrative in order to make sense of a meaningless experience that has disrupted one's whole life story. By allowing others to witness the experiences and acknowledge the narrative, the patient can potentially regain control and self-respect, despite the often horrible traumas and invasive thoughts. Through decoding and retelling of the past - together with the therapist - the chaotic surface takes on a deeper meaning. Eisenberg believes that a fundamental common goal of the doctor and the patient must be the co-creation of a valid and credible patient report (1980). When the patient goes to see the doctor, it is a request for an interpretation. The doctor is the patient's interpreter, and together they navigate through experiences, memories, feelings, and explanations of a medical history. Through recognition of the whole story, the patient ceases to feel like the victim of what is unexplained and uncontrollable, and the symptoms lose their anxiety-provoking potential, become bearable, and may eventually disappear. If the doctor is a skilled and trust-inspiring interpreter, multiple alternative or parallel versions of the life story may arise in the co-creation where new possibilities for explanation (and treatment) emerge. Many refugees have multiple versions of their lives because they are often forced to justify

or explain themselves and adapt to new legal, cultural, social, and health contexts. There are 'hero' stories and 'victim' stories, and there are 'anti-hero' stories in which necessary, but highly unpleasant, decisions were made - experiences that one must live with alone until a therapist can help address them.

The basic elements of life stories are plots and metaphors. It is in the interest of the healthcare system that the patients' multi-faceted, complex, and incomplete medical histories are reduced to a single, short-structured medical history or life abstract containing only the clinically interesting *high-lights* and plots necessary to support the diagnosis and treatment that have been selected. Preferably, there would be one story with one plot and therefore, only one diagnosis with its treatment. Different types of plots, such as comedy, tragedy, or melodrama, are widely known. Within each plot type, it is important to notice what happens when the direction of the story changes (i.e. the situation gets better or worse over time). In fact, the classic plot can be characterised as a series of narrative tendencies, e.g. things get better in a melodrama, then worse, then better, then worse. Another approach to plot analysis is to find a route to the core narrative itself, which is a picture of the structural essence or plot of each story. This patient's story is an example that also says something about self-perception and options, '*When I was young, I had a bright future, but bipolar disorder has ruined my life and will likely undermine any attempt by me to improve my life in the future.*' Another patient summed up his life as follows, '*I've never had a good day in my life.*'

Metaphors are essential components of any patient narrative or story where the metaphor supports the common thread of the story and provides meaning to the complex experiences that the patient would otherwise find hard to describe. Patients use metaphors to say *what is wrong* and what they need *help* with. Metaphors represent the current version of their lives, and they are tools for explaining something new using a familiar object or phenomenon that replaces the description of an otherwise unclear event or situation. Unlike parables and analogies where an object or event is considered to be like someone else in one respect or another, the metaphor completely replaces the experience or feeling. Metaphors are valuable because they enable both the narrator and the listener to understand complex and detailed experiences in a concise way. In fact, metaphors allow both listener and narrator to be actively involved in an interpretation process and a description of a symptom, as an example. The use of metaphors facilitates and encourages an interpretation process by creating links between the known and the unknown.

Metaphors often create clear images of the emotional universe the patient is talking about and of the elements contained in the symptoms. Metaphors provide a way of seeing a phenomenon that would not otherwise be clear. A brief description like, '*I am fighting my illness*', can elicit insight and compassion. The metaphor effectively personifies the illness as an opponent, and the victim of the illness as a protagonist, with the two locked in a fight that ripples back and forth. Doctors, nurses, and therapists become allies or co-fighters who are involved in the war against the illness. Medicine, surgery, and conversation are weapons aimed at destroying or defeating the illness. The patient's metaphors give a name to the problems and narrow them down and indicate to the doctor, how the patient sees their own world. Metaphors can also give the doctor an idea of, how a patient will react to attempts to help solve their problems (981). Researchers have found that patients use two main groups of metaphors to describe and organise their patient narratives (982, 983):

1. **Metaphors that describe a changed momentum in life:** speed, inertia, drive, acceleration, and deceleration, i.e. images of processes that are about getting one's life going again, life slowing down, life going by, life pausing, or life stalling and getting nowhere.

2. **Metaphors that describe a feeling of captivity:** These illustrate a way in which patients can organise and interpret their life stories that differ significantly from momentum metaphors. These metaphors refer to being severely limited or restricted by circumstances in life and to a great desire to escape or find a way out of the deadlocked situation. Patients describe themselves as being both unable to tolerate and unable to escape their life situation. Common to these life stories is a conflict between the patient's wishes and reality. There is a conflict between the story they want to tell and the events in their lives as they are currently unfolding, which keeps the person in a paralysed and hopeless situation. Concepts such as fixedness, loss of control, victim, imprisonment, abandonment, and inadequacy characterise the images the patient wants to create with the recipient.

Examples of patient metaphors from different areas of life and living with an illness are listed in Table 29. The examples are taken from conversations with patients at the MHC.

Table 29. Examples of patient metaphors from different areas of life and life of illness, MHC.

Subject	Patient metaphor
Children and adolescents	<ul style="list-style-type: none"> • Have you ever had the experience where not even your own mother could protect you? - Then nothing is safe in this world. • Do you know the feeling that nobody can help you except the ceiling above you, which - possibly, possibly not - can keep out the bombs?
Becoming an adult	<ul style="list-style-type: none"> • I feel like a newborn baby that the parents have to take care of.
Parents	<ul style="list-style-type: none"> • Small children eat bread - big children eat hearts.
Medication	<ul style="list-style-type: none"> • My children are like medication; they take away my pain.
Memories	<ul style="list-style-type: none"> • I feel like a newborn with no memories.
Identity	<ul style="list-style-type: none"> • I feel like an unwelcome guest at a party that don't have enough food for everybody.
Sounds	<ul style="list-style-type: none"> • The sound of a stamp is the sound of a death sentence.
Language	<ul style="list-style-type: none"> • I am poor in Danish but rich in my own language.
Life choices	<ul style="list-style-type: none"> • My life is like a round-about with 1000 exits. I don't know which one to take and it goes way too fast.
New circumstances and values	<ul style="list-style-type: none"> • I don't have a driver's licence for this life.
Energy	<ul style="list-style-type: none"> • You have good hormones in your home country.

Help	<ul style="list-style-type: none"> • Can you teach me to walk again?
Traumas	<ul style="list-style-type: none"> • Bad experiences are cut into the heart with a dull knife.
Materiality	<ul style="list-style-type: none"> • A broken hand heals – a broken heart does not. • My heart is like a piece of paper with burnt edges. • I feel like a flat and boring soft drink. • There is no more water in my brain for crying. • My life is like shards of glass in my pocket - every time I stick my hand in my pocket, I cut myself.
Inflections of darkness	<ul style="list-style-type: none"> • I know how darkness looks, but this is really black.
Weakness	<ul style="list-style-type: none"> • I was so weak that the wind blew me over and even the darkness of the night was too bright for me. • I no longer trust my bones.
Hopelessness	<ul style="list-style-type: none"> • I am afraid that I might be a dead man ... but I'm not sure. • I have lived an unliveable life so far.
Healing	<ul style="list-style-type: none"> • The scar you get in your heart never fully heals. You just get a zip in your scar.
Understand your body with your head	<ul style="list-style-type: none"> • My body is taking notes in a language that my head does not understand.
Living without living	<ul style="list-style-type: none"> • I have experienced so much and yet I have never lived.

A completely different and diverse narrative reality opens up when one delves a little more deeply into the medical history of the exposed, vulnerable, or complex patient. Their story often comprises a primeval forest of continuously changing, parallel, and circular medical histories - some rudimentary, others more complete. Each of them represents a narrative created at a given time in the patient's life in the circumstances at the time. At a high level, patients often have very different versions of their medical history for the contexts in which they may be relevant: for themselves, at home, for the spouse, for the children, for the family, for friends, for the area they live in, for their own doctor, and for a specialist, the hospital, the municipality office, and their workplace. Some narratives have had a certain meaning or function at a specific time, but circumstances may have changed so that version has been abandoned in favour of a newer version (*'For many years, I thought that I had cancer, but it was anxiety'*, or *'I'm sure I had allergies, but they disappeared. Now I have ulcers'*). Other narratives go in circles and never really arrive at a clear meaning or significance (*'Maybe I had cancer back then, maybe I was going crazy, maybe the doctor missed something, but I've learned to live with it'*). There are some narratives that the patients cannot even tell themselves, yet they happened (sexual abuse, slowly escalating abuse, observed weight loss and repression due to anxiety about cancer, or psychological trauma with somatic symptoms). Some stories have been developed in close cooperation with family or relatives, while others are tailor made for the meeting with the healthcare system. And then somewhere in there is the least complicated version of the overall complex story that patients rarely manage to put together themselves without professional, structured help. Patients do not go to the doctor to be encouraged to tell one simple

medical history; they go there to get the doctor to witness their experiences, to listen to them together with the patient, and to help the patient obtain a mainly verbal relief through meaning and to achieve a different, less bleak future than the one the patient has presented to the doctor. The patient ought to be more satisfied and less afraid when leaving the doctor than when arriving. This requires the doctor to be motivated to listen, co-create, and interpret the patient's fragmented experiences into a coherent meaningful narrative.

15.2. The life story that is not coherent

Life is linked by social events, each of which brightens or fades depending on context and goals. We have all developed many different life stories to be used in various contexts. In most versions, we are heroes or, at worst, victims. It is rare for our life story to be based on all the less fortunate decisions we have made or to include the situations where we acted as anti-heroes. One refugee said, *'Believe me, you don't make very honourable decisions during a war or on the run.'*

Life in the host country is not always a successful process. Lack of recognition and failures in the field of education and the labour market are replaced by family conflicts and uncertainty about the continued basis of residency. The refugees' self-perception is shaken, and it can be difficult to create a coherent life story that you can live with and that can endure being shared with other people. Thus, many refugees have only fleeting fragments that resist being pieced together into something meaningful. The doctor or nurse must realise that many parallel and fragmented life stories may exist, and the patient may never have tried to present them in a more coherent form. Refugees say that in their attempts to be understood in the host country, they have tried to present sensitive parts of their life story to authorities and practitioners. In such attempts, they have often experienced that they were ignored or that their narrative was disqualified as uninteresting, untrue, or incoherent. The life story stops at the points the patient underwent unpleasant experiences, and the narrative tends to get bogged down in the midst of the desperate struggle with language, social legislation, the authorities, and a family falling apart after arriving in the host country. You move around with no language in a society you do not understand, and you internalise a sense of being useless, an uninvited guest, or 'lost baggage'. The constant temporariness in the lives of refugees or immigrants is an exclusionary inclusion without access to the social connections that usually make people human - where, as one refugee put it, *'You are allowed to graze like cows, but no one does any milking.'*

In cross-cultural contexts, cultural knowledge of illness is important, but it is not always the case that knowledge of illness from other societies is straightforward with a deterministic pattern of cause-and-effect. There may be many contemporaneous, but mutually contradictory, explanations. As an example, Farmer described how two different explanations for HIV disease emerged in Haiti (1342).

It is the health professional's job to help the patient put the pieces in a large pile and start assembling the puzzle. The missing pieces will show up, and with them come the therapeutic hooks that can serve as clinical tools. Sometimes, however, the patient goes to the doctor as a kind of self-medication where the consultation room is just the frame of a narrative and the doctor is a facilitating extra. The following is an example of how narratives can occur if the doctor does nothing - perhaps the most difficult clinical exercise.

15.3. A narrative example: The man with the red eyes

1. Debt and red eyes

Salomon comes from a violent country on the African continent. Today he is 44 years old, and he has a serious chronic illness that requires daily medication and frequent contacts with the hospital. He takes

care of himself, takes his medication, and shows up for every hospital appointment. Salomon has a physically hard full-time job and a boss who is not very friendly in Salomon's opinion, but Salomon is proud of his work and his ability to feed a rather large family. The most important thing for him is to ensure the safety and stability of his family, i.e. to earn enough money, to behave normally, and to get a passport for himself, his wife, and his nine children. He has an outstanding debt with the public sector because of small arrears in child support for a child he has with his former wife. He works to make the whole family feel safe with him as head of the family, but he struggles with work. One day Salomon tells the doctor at the hospital that he was suddenly fired the day before. The boss had told him that he always had red eyes when he showed up at work and the boss also thinks that Salomon talks back too often and interferes with the boss's management. The boss thought Salomon was on drugs due to his red eyes and mood swings. Salomon got so furious that he just threw the broom at the boss and left the company. The truth was that for years, he had had hour-long nightmares about some specific experiences he had in prison in his home country, but he did not want to talk about it. He just went to the doctor, with his wife, to get a pill that would enable him to commit suicide painlessly. The wife was distraught, but Salomon was determined: no work, no passport, no head of family, no family, and therefore no reason for him to stay on this earth, which would probably be better off without such a hopeless man who could not even make money. The doctor wanted to hear a little more about Salomon's life and background before discussing his lack of zest for life. Therefore, Salomon told his life story (anticipating that afterwards he would finally get peace with a pill). Alice, his wife, was present during this conversation in the doctor's office.

2. Wrong name with the wrong nose

Salomon's hands are alive and fly around - the old Salomon is in there somewhere, and he would like to return to what he once was: a respected, highly educated, and proud man. In his home country, Salomon was the family's breadwinner and was politically active in helping to topple his country's long-time dictator. After this, he was hired as head of a branch of the country's intelligence service under the new president. Salomon now lives in a neighbourhood of public housing in a large Danish town with his wife, Alice, and four of the nine children they have between them. In the four-bedroom apartment, Salomon's trauma and powerlessness are constant factors that frustrate him as much as they frustrate the rest of the family - like today, when life is no longer worth living. Salomon can no longer recognise himself. He wants to be a good father to his children and take care of his family, but he lacks the strength to work and be accountable to them. Salomon feels that his heart is tired and his head is tired, and he drifts into his own thoughts. Alice pokes him - then he lifts his head again and returns to his story. In his home country, his position as intelligence chief quickly faltered. The new president would not share his power and to avoid a coup, everyone from Salomon's ethnic group had to be killed. Suspicion was thrown on Salomon. His mother was from the persecuted ethnic group, which meant that Salomon had a last name that revealed their connection. He has a characteristic nose that is 'too pointed' and by which his ethnic group is characterised. Anyone with a pointy nose had to be killed.

3. The hole in the floor

One day, some military men showed up at the Department of Intelligence and told Salomon to appear at the President's office. *'That was the day I was caught,'* says Salomon. They had electrical wires that they attached to his body and powered up if he refused to talk. Salomon also had a black hood pulled over his head before they dunked his head into water. At one point, they put Salomon into an empty black room where he was supposed to be for a week with no contact with anyone, *'They just pointed to a corner and said it was my toilet and that I was going to sleep on the floor.'* *'The torture,'* he says, *'was part of daily life, and the psychological punishment was at least as bad as the physical. There was a lake under the prison, and if they wanted to kill you, they just opened a door in the floor and threw*

you in. I woke up every day, sure that this would be my last one - and it went on like this. I got to the point where I was prepared to die every single day. It was hard. I didn't know if I would ever see my children, wife, or family again. Salomon had several friends who lost their lives in prison, and by then, he and Alice had been together for four years. She worked in a restaurant for senior officials and military personnel, who helped her get Salomon released. In early 2001, Salomon fled to a UNHCR refugee camp in the neighbouring country. Alice was supposed to join him as soon as possible, but before that, something happened that changed the family's life forever. The military entered the couple's home to look for Salomon, who had already fled the country. Instead, the soldiers raped the pregnant Alice and infected her (and subsequently the infant) with HIV. The family only found out they were ill after arriving in Denmark in November 2002. At this point, Salomon was also infected.

4. The pursuit of a normal life

Salomon and Alice have not only brought cultural traditions with them to Denmark. Their traumatic experiences in their home country are part of life in Denmark, and both have been diagnosed with PTSD. *'When I hear sirens from an ambulance or a police car, I get really scared that they will they come here and catch me. I am constantly uncertain; it is daily life for me,'* says Salomon, who together with Alice and the couple's two joint children came to Denmark as UN mandate refugees. Salomon tries to live a normal life in Denmark and forget about the torture, but it is not easy. *'When I sit there alone, it all comes back to me, and I see it again like a movie,'* he says, pointing to his fixed place in one of the couple's two black sofas. *'The last few days have been extra tough because I have seen on TV how they killed Gaddafi and Saddam Hussein and how they caught them. It scares me when I go to sleep.'*

Like many traumatised people, Salomon sleeps poorly at night. About four out of seven days of the week, he wakes up many times due to violent nightmares. During the day, his mind can replay the torture he was subjected to and he remembers the hole in the floor down to the lake under the torture room in the prison. *'My heart starts beating very hard. I have to wake Alice up when it happens because I can't sleep and I'm scared.'* The many nightmares often make Salomon feel exhausted. He gets headaches and has unexplained pains in his body, and it is hard for him to hold down a normal job. That is why he has red eyes in the morning; Salomon does not touch alcohol or drugs and has never done so. The former intelligence chief has been on sick leave for the past two years: *'Three weeks after we arrived, we had to go to language school three days a week and work training two days a week. Nobody asked about our mental state, but I could feel how my experiences had changed me.'*

5. The brain says stop

Salomon's brain says stop on New Year's Eve 2002 where he suffered a brain haemorrhage. His right side was completely paralysed, and he had to spend the next six months in hospital: *'The doctors said it was due to stress. I had a lot of thoughts during the period when we had just arrived, 'What am I going to do here?', 'What is my future?' I had to start all over again. I'm a trained psychologist, but I couldn't do that job here. I had to start language school and only then begin a new education,'* says Salomon, who got his feeling back in his body after 6 months.

After completing language school, Salomon trained as a service assistant, and he receives a student allowance instead of start-up help. *'At the same time, I had to have a job in order to support my wife and children,'* says Salomon, whose family went from two to three 3 children after Alice's daughter from a previous relationship also came to Denmark. *'It was at night, and I had to empty containers in a row of shops. I finished work at 5 a.m. and was supposed to be at school by 8 a.m. I managed to sleep for two hours and sometimes also four hours in the afternoon, so I was tired all the time. The work destroyed me, my arm, and my back because it was physically very hard. Do you choose to stop school or work? I stopped school and continued to work.'*

6. Nervousness is in control

After just 3 months, the job became too much for Salomon. His body was weak due to HIV and medication, and at the same time his mental health problems increased again. *'I was forced to drop out of my education, and I couldn't plan my life. I felt nervous all the time but did not know where the nervousness came from. I couldn't control it.'* Since then, Salomon has had various jobs, but he has not been able to keep any of them for very long because of his health problems. His last job was at a cleaning company where he worked for 2 years, *'I was happy to work there. It was tough, but it was good to get out and meet new people.'*

In addition to HIV medication, Salomon also takes medication for depression and anxiety, and he goes for check-ups at the hospital every three months. Salomon says he would love to work and that the municipality has been saying for the last two years that they are trying to find him a flex job, *'I'm still waiting. Even though my body doesn't work well, I want to work. You don't gain any respect just sitting there looking at your kids. It makes me frustrated,'* Salomon says.

7. Did not come here to be sick

'I didn't come to Denmark to be sick and get social assistance. I'm sick, but I'm not stupid. I want to contribute. I want to use my hands to make money because I don't want to be like the people that they talk about on television who are just here to get social assistance and steal society's money. I don't want to be one of those people.' The children's situation in particular often makes Salomon feel guilty, *'One day, when I was sad that I could not get permanent residence, my son came up to me and said, 'Dad, don't be sad. When I grow up and start working, we'll save 10,000 kroner each and pay your debts. Then you'll get permanent'. It's not nice when your child tells you something like that,'* Salomon says.

Salomon cannot be granted permanent residence because he owes the municipality money for child support to his ex-wife. She was also politically active in her home country and had to flee with her and Salomon's three children. They have now lived in Denmark with their mother for 5½ years, and Salomon has calculated that when all three children are 18 years old, he will owe the municipality DKK 136,000. He cannot get permanent residence status until he has paid this debt off, *'I want to pay, but I don't understand why I should be punished and refused a permanent residence permit. I have not done anything illegal. I've been waiting for this day for seven years, and then I get a rejection. I have to renew my residence permit every other year, and this stresses me out. I do not feel welcome or really integrated,'* Salomon says.

8. You cannot watch the news

'It affects my children to see their father powerless, and they get heavy thoughts, even if they are only children. It is not normal. I'm the one who has to take care of them, but they're the ones who wonder how to take care of me. It makes me sad' ... 'I get upset about small things but because I am a trained psychologist, I try to control my temper so that I do not get worked up every time. I've made a rule for myself. If I get very upset, I take my jacket and walk out,' Salomon says. *'It's not good for the kids that one minute, Dad's happy and a minute later, Dad's upset. The children don't understand why mum and dad react like that because they have trauma. Children learn quickly though. They know exactly what situations make me nervous. For example, they tell me not to watch the news.'*

In addition to the six children at home (Salomon had adopted two of his killed brothers children), he has three more children, whom he supports and has struggled to get to Denmark - an 18-year-old girl, who is his eldest child and from a previous relationship, as well as his nephew and niece who came to the country six months ago, and briefly eased the guilt that Salomon had been carrying for a long time. Salomon's younger sister, the mother of his nephew and niece, was raped and killed in the church where

she worked as a priest, because the soldiers were looking for Salomon. His guilt has made him take this on as a family project - even more urgently - so that he can live with his feelings of guilt.

9. The past is knocking on the door

Salomon tells the doctor about a day when he got extra scared. A man from his home country (now living in another country in Europe) had contacted his 18-year-old daughter and a couple of the other children and asked strange questions. When the same man also contacted Alice, Salomon got seriously frightened because Salomon had found out that it was a man who was employed by the new intelligence agency in his home country. Salomon explains that the new government in his home country has people in all European countries and that you can never feel safe. Salomon reported it to the police, and the man disappeared from the city.

There have been times when life in Denmark went well. After his brain haemorrhage, he received treatment at a rehabilitation centre for torture survivors, *'that's when I got my strength back and went to see a psychologist. We went on group outings to the amusement park and the Zoo, and I was able to get all my questions answered. They helped me get all my children to Denmark, and it was great to have someone to share my burdens with,'* Salomon explains. *'After that, I felt good, and I worked for almost two years without any problems, but all of a sudden I went down again.'*

10. Caged parrot

'If I were offered treatment again, I'd say 'yes', because it helps. You can get a handle on your situation and get help to start over. Right now, I feel like a parrot in a cage.'

It is not easy to get treatment, however. At least not at the very moment, you feel you need it. The wait is long and, according to Salomon, he asked his caseworker to get into treatment again two years ago when he had to stop at the cleaning company and start getting sick pay. He is still waiting. Salomon wishes he had received treatment earlier - before the symptoms of the trauma developed into a brain haemorrhage, *'Also, because as a new arrival you are looking forward to a new start and feel you can make a contribution. I was looking forward to forgetting the past and starting a better future, but I didn't get any help. The Danish system is very rigid, and I only got help when I hit rock bottom. Why only then?'* Salomon asks his doctor.

11. Maybe life is worth living after all

Salomon explains that his life is a struggle - for himself, as head of the family, to keep the family together, and to repair the damage he has indirectly caused his family. The trauma of the past and today's frustrations have piled up inside of him and has created a wall that is hard to scale, *'I feel Danish. I have nowhere else I can go. I will fight until one day I get an identity - my permanent residence permit. My life is a struggle towards this and towards getting the strength to take care of my children.'*

Finally, Salomon says that he will never be able to travel back to his home country - he would be killed immediately. This is a great sorrow to him, which he tries to process by being in charge of collecting hospital equipment to be sent to the hospital in the area he came from. He has a large shipping company to provide a free container. He asks if the doctor can help him get used equipment from the hospital. *'Maybe life is worth living anyway,'* Salomon says in the end. Alice looks happy. Salomon has forgotten all about the pill that he went to see the doctor to get. It was never mentioned again.

At the next interview, the topic of conversation is the future. Salomon feels like a respected man and head of the family. One of his eldest daughters has started writing a book, in French, about his life story. Salomon is proud of this - now his project is beginning to succeed.

Comment: *The doctor lets the patient's request for assisted suicide hang in the air as the obvious trial balloon that it is. Instead, the doctor creates an alternative framework for the conversation by shifting the focus from suicidal thoughts towards the background, the circumstances, and the sequence leading up to the patient's decision. The doctor asks the patient to tell her about his life. By not responding to the patient's direct request for a pill, the patient's trial balloon is recognised - it is allowed to float in the room and is not actively rejected. The doctor could have chosen to shoot it down immediately and refer the patient to the psychiatric emergency room, but then no narrative would have been created, and the patient would not have healed himself. The patient shoots the balloon down himself.*

(Thanks to Kristine Bugbee and Tina Tjørner for permission to use selected quotes from their inter-view assignment titled "The Eternal Struggle").

15.4. A narrative example: I would like to move in with my own people

Halima is a 49-year-old woman from Northeast Africa who was family-reunited with her husband in 2003. Halima has never gone to school and can neither read nor write. She is referred to the MHC with fatigue and unexplained pain and because the municipality wonders why she can no longer work. No interpreter has been used previously as Halima was expected to be able to speak Danish after having lived in Denmark for so many years. She has been pregnant 12 times and has nine living children. Halima has temporary residency in Denmark, while her husband (now ex-husband, who has moved away from Halima) has a Danish passport just as three of their children have. This has caused many conflicts in the family: who can stay and why can't others? The youngest children are most afraid that their mum may be sent back to their home country. The husband self-medicated due to nightly nightmares and was mentally unstable due to his drug abuse, which is why Halima eventually had to evict him. For some years, Halima worked in a kindergarten. She was very fond of the work, but suddenly she began to have many sick days without being able to explain why or how she was sick and eventually she was fired. Halima is well-dressed, she always wears many colours, and she likes to wear make-up. She belongs to a very small ethnic group and was seen as a threat to the other married people from the same country, but at the same time she was an easy victim without a network in Denmark to protect her.

Halima's immediate family and friends live in London, but without a permanent residence permit in Denmark, she cannot get a visa to England to visit her family - just as they cannot be admitted to Denmark. As a result, Halima is constantly persecuted with heckling and insults in her immediate environment: a crime-ridden apartment block in a small town. Her children are harassed by a group of youths driving around on mopeds. One of her children is run over, another is hit by a bottle in the head, and several of her children dare not walk to school or play outside. Halima breaks down after they repeatedly get paving stones thrown in through their windows at night. She isolates herself, gets headaches, cannot tolerate noise and stress, and lies awake all night or has extensive nightmares. Halima frequently goes to the doctor with aches in her back, head, and stomach. She has pelvic problems, migraines, and sweating, and she complains, *'my heart is busy.'* She is sent to a lot of examinations and specialist doctors, yet all the examinations show 'perfectly normal', and the doctors say that nothing is wrong with her. This confuses her and makes her feel insecure that the doctors cannot see she is in a bad way, so Halima starts thinking about where else she might get help or whether she is going crazy. *'Maybe it's boofis,'* she thinks - a condition that in Somali means you are very upset, isolate yourself, and become erratic in mood. An acquaintance tells Halima that there is a clinic for *'someone like us'* at the hospital, and she asks her doctor to be examined at this clinic. She is referred to the MHC. Here, Halima says that she has headaches and pain throughout her body, has difficulty remembering, and cannot concentrate but that she is better off during the day when she is home alone. Halima has been examined several times by specialist doctors and has had her head and neck scanned, but they said there was nothing and that her headaches are caused by knotted muscles because she does not exercise. She was also examined

by a spinal specialist, who found a spinal disc herniation. Halima was offered surgery, but she did not dare do it for fear of dying while sedated. Halima tells about her life in her home country where she saw her father get killed and her mother raped on top of the body of her father. She describes a later incident as a really bad film in which soldiers killed Halima's pregnant sister and her uncle, *'They weren't normal people, so I chose to forget them by not talking to anyone for three months after that, but they're still in my head.'* She relives those scenes day and night in a film that will not stop, *'I don't have a remote control.'* A third situation scares her in another way, *'I became afraid of myself when, during the escape, I stood 10 meters from two militiamen who were buying cigarettes at a vendor and holding a bazooka between them. One of them hit the bazooka, and the next thing I saw was the head of one and the body of the other landing right in front of me. I just looked at them and didn't feel anything. It was strange, but I had chosen to forget everything, so I also chose to not care about half people.'*

When Halima came to Denmark, she got a job. However, *'After two years working in the kindergarten, I suddenly started crying... Those years the only thing I could do was cry-work-cry-work-cry.'* Halima says there was a male kindergarten teacher with a beard that looked like the beard of one of the soldiers who killed her sister, but she did not dare say anything and she was happy with her job. Halima asked for help, initially when she wanted assistance to escape from the town she lived in, *'In my home country I knew who could help me and which way to escape, but I do not know who can help me in Denmark.'* Thus, she asked that the family be allowed to move to Vollsmose, a suburban area housing many immigrants, *'To my people, so it is easier to get help to protect my family.'* Halima also says that her husband spent too much money, including misusing her name, and that they owe money to the bank, the supermarket, and private individuals. Furthermore, her now ex-husband also turned out to have another wife with six children. Two of Halima's own children are bed-wetting, which has caused problems in school during outings, and Halima knows that everyone talks about her having disabled children. Halima is in despair, yet she is hoping for a miracle, *'I would prefer not to be here. I don't like my life, and I don't want my life ... Still, I won't do anything bad because I might get well ... and you can't kill yourself ... not while the kids are little.'* Halima also has severe asthma (like several of her children), blood in the urine, tooth decay with dental abscesses, sinusitis, and incontinence as well as severe dust mite allergies - many people live in the small apartment, and she has never been taught to air it out.

Halima and her family move out to Vollsmose into a bigger and better apartment, but her health does not improve. She is refused permanent residency several times, and she is demotivated and prepares to leave the children with passports in Denmark while the rest can go back to their home country. The harassment from her compatriots does not stop. There are daily domestic disturbances, public quarrels, and shootings in Vollsmose and many emergency responses. The children feel unsafe and their bed-wetting problem flares up again. As Halima said, *'It's as bad as where we moved from, just a lot more and worse, and I can't get out of here. It's too expensive.'* After obtaining a new medical statement, Halima files a complaint about the denial of her permanent residence permit. The Danish Immigration Service then requests an even more detailed medical certificate, after which she obtains permanent residency after 12 years of applications and 12 years of uncertainty. As Halima sees it, *'It's not 12 years; it's every day for 12 years.'* Two years later, Halima and her children have the same symptoms and unresolved problems, and their financial situation is even worse due to cuts in their social benefit. Some of her children have moved away from home, and one of her boys has joined a *hang-around* group for one of the area's criminal groups. Halima feels unsafe and uncomfortable, and she does not know who she can get help from. Halima has heard that the Danish government is now sending Somali refugees back home. She cannot get any information as no one knows anything, but everyone says the first ones are already on a plane. The older kids are worried about their mum, *'She's like a ghost at home. She keeps to herself and doesn't want to go out any more.'*

Halima recovered slowly by going to supportive conversations about her big and small challenges, getting help with her decisions, and strengthening her self-esteem - all based on her own life story.

Comment: *Halima sought peace in a small town in Denmark, but did not find it - quite the contrary. This 'peace' led to new conflicts, some of which were carried along from her home country, and so Halima had to flee to a larger city. However, she found no peace there either. There came a new and unfamiliar unrest, and the social structures did not work as they had in her home country. Halima also gets pushed into a state of emergency as the flight to Vollsmose did not get the expected peaceful result. She is often by herself and 'sits and stares' and acts like a ghost, as her children say. Halima had to contend with her exclusion from her ethnic group and a coinciding difficult inclusion into the Danish society. She lives in a chronic state of fleeing and will not find peace until she gets into a process where emotions, experiences, and decisions are anchored in the patient's own life story. Halima's life story was filled with adversity, bad luck, and difficult choices, but it was also an expression of resilience, will power, and action. Seen in this light, Halima could maintain courage. Halima lives as closed off in Vollsmose as in a deserted village in her home country. She lives in Vollsmose out of necessity but cannot stand it, and she is locked in place because it costs money to get away. If you compare yourself to others with equally bad health, the illness becomes a normal condition. She asks to move in with her 'own people' in her dream of safety but finds the same illnesses and inequalities from which she fled. Halima tries to lift herself, her appearance, and her family up the social ladder, but she finds that being ambitious in Vollsmose is frowned upon. She ends up in what is sociologically described as the de-compensation of refugees: the total collapse of self-care, overview, coping strategies, morale, motivation, and life energy. She is overwhelmed by even the smallest of life's challenges, changes in the routine are experienced as anxiety-triggering frontal attacks, her ordinary memory processes are at a standstill, and the void is filled without restraint by old problems, traumas, and unresolved conflicts. The broken family relationships lead to uncertainty and arbitrariness, and an unsustainable decision-making structure in family matters leads to unfamiliar conflicts between generations, which are attempted to be solved by adult sons who lack the necessary decision-making certainty in older role models. Halima's lifelong dream of a normal and invisible 'civil' life is burdened by an intense performance pressure because you have to be '1000 times better' than everybody else. Her dream is further disrupted by the authorities and institutions on which the dream depends - the police, social services, and healthcare system - not always helping in a predictable way. However, for better or worse, her own life story becomes her lifeline. By understanding herself as a story, the future makes sense to her.*

16. Language in identity, health, and integration

Language is the doctor's primary tool and the patient's only tool. However, language barriers can make conversations with ethnic minority patients difficult. Almost no research has been done on the cross-cultural language of illness, but doctors can learn a lot from general language research and in particular from research about how exile stress, PTSD, and socioeconomic conditions can affect learning, memory, and language acquisition.

Language should not be taken lightly. In any language, including our native language, we fight to express exactly what we mean. But what is language really, other than rough translations of thoughts? We have to be mindful of language - it is our only connection. You learn to vomit, have a stomach ache, break a leg, be sad, and have feelings in your native language. You are the wisest in your native language, and you are best at being ill in your own language. Concepts, values, and experiences are encoded, categorized, and remembered in the native language. As the Danish politician and former minister Birthe Rønn Hornbech said in a column in the newspaper *Kristeligt Dagblad* 19 March 2011, *'Your faith is in your native language.'* Our native language is a measure of life - we become individuals through language. We become members of a community through language that makes the world understandable and meaningful. Our lives become real through language. We become visible and meaningful through language (106). Memories that help us to understand the present and feel confident about the future are created in our native language. We can bring our stories to life and present ourselves as individuals. One gains respect and acceptance in one's native language.

Every medical interview starts with language as the only tool. Scans, blood tests, and treatments are secondary to language. A chief physician once told a patient who needed an interpreter, *'If you don't speak Danish, you'll have to see the veterinarian the next time.'* Based on comments in the media and from politicians, there are many prejudices and theories about language acquisition, linguistics, and cultural adaptation, such as: patients with refugee backgrounds who have lived in Denmark for three years should be able to speak Danish; it is their personal responsibility to learn Danish; only lazy refugees do not learn Danish; social benefits should be revoked for those who do not speak Danish. We find it hard to tolerate even the slightest French accent destroying our Danish language. We consider it to be brazen, disrespectful, and intellectually lazy to cling to this little linguistic business card - an expression of delusion, a provocation, and a clear resistance to assimilation. Yet the famous Nazi-hunter Wiesenthal was described in a speech at his 100 years birthday in Austria in 2009 by the Israeli journalist Tom Segevas as, *'A refugee who has lost everything except his accent.'* Paradoxically, Danes think they are good at English - really good even. A study that compared the same university lecture being given in Danish and English by a Danish lecturer found that in English, the language became rigid, boring and impersonal, the nuances disappeared, the good stories were omitted, key points disappeared, associations were omitted, things were explained in long unfinished sentences, and the academic content became unacceptably poor. British people are used to having their language abused by other language traditions, so they refrain from commenting on our language skills, but that does not mean that Danes are good at English - the British are just politer and gentler than Danes on this point. The author has met Danes in Africa who could not speak understandable English even after 25 years abroad. They still spoke some dialectical Danish-English gibberish. I have an ear for languages, but never managed to achieve anything but a tolerable working language after working almost four years in Guinea-Bissau in West Africa. Irony, jokes, and metaphors were never part of my language; and the times I tried, it ended up as a disaster.

It is important to understand that the second language is a secondary language and that many basic concepts and their cultural values are coded very early in childhood in the native language. Furthermore, bilinguals often have an everyday language in the second language and a complex language linked to the native language in which emotions, values, life positions, and technical concepts, e.g.

health-related, are also encoded. This means that even relatively common health-professional concepts are difficult to understand in Danish for bilinguals (985).

The largest international surveys on language acquisition among refugees and migrants show that 50–60 % of refugees acquire moderate language skills within 10 years, while around 70 % of (working) migrants acquire moderate language skills over the same time period (986). Almost 10 % of refugees have no language skills in their second language after 10 years. It is also logical, but rarely respected by the health care system, that older people have significant language barriers more frequently than others (987). The difference in the literacy level between refugees and the local population is greatest in the Nordic countries, and this large difference contributes to demotivating refugees from learning the second language. According to international studies, 6 out of 10 refugees speak the second language well enough to cope at their workplace and when shopping, but it is totally inadequate in unfamiliar social contexts or when dealing with illness (986). Migrants coming from countries with a globalised economy find it easier to learn a second language (like Danish), but the same ethnic group can have very different language acquisitions in other countries (Somalis, for example, are better linguistically integrated in some countries than in other countries; the same applies to people from Iraq and Burma/Myanmar). In countries with a relatively anti-immigrant environment, fewer migrants acquire sufficient language skills in the second language. The same applies to countries where active linguistic integration efforts are lacking (988). Studies have found that when ethnic identity, in general, is threatened in the public sphere, it can negatively affect language acquisition (989). Stigma, isolation, and functional expression can demotivate language formation (990). The constant push of the idea of parallel societies is counter-productive because it cements exclusion and locks in monolingualism.

A resident in a housing project near a major city in Denmark noted that fewer people in her circle of acquaintances spoke Danish now compared to previously. Language acquisition is not the particular Danish integration problem that the governing parties, and most recently also the opposition party, have tried to make it into. It is a migration condition that has never been understood or taken seriously enough. Several studies suggest that systematic language teaching can correct this, but not all refugee immigrants have been offered this teaching, and the lack of enthusiasm from the authorities for keeping students in fertile learning environments has contributed to low success rates (295, 991). The more the language families differ, the harder it is to achieve a moderate mastery of the second language. That it takes more time or requires adapted language teaching for certain languages has not been taken into consideration politically in integration (992, 993).

Success in language teaching among refugees is clearly greatest among refugees who come from a background with a high level of education and from major cities. Language teaching is a generic product aimed at a level of education that is often too high and socially skewed for most refugees (994). The young and younger middle-aged migrants obtained the greatest language acquisition, but only if they had a clearly defined career ahead of them (995). The composition and the collective level of ambition of the language classes have a significant impact on motivation and degree of language acquisition (996). A wide range of motivational factors in language teaching need to be further explored in the context of integration. Motivation for language acquisition is a cultural construct; one can collectively form an opinion that one CAN (must?) acquire another language or the exact opposite. This can affect the individual's decision-making and commitment - but this link has not been referred to in language politics (990). Even personality types have been shown to have an impact on how and how much language one acquires (997).

When it comes to language and integration, there is a huge difference between being socio-culturally integrated and socioeconomically integrated in terms of language and integration to acquire the Danish language (295). Danes do not agree on what they mean when they say 'integration' because they think about work integration. However, it is sociocultural integration that contributes most to language acquisition. Unfortunately however, sociocultural integration requires Danes to make an active effort,

and they do not do that. Furthermore, it is a legal requirement that the language schools teach refugees 'vocational Danish', while in reality what they need are 'social, everyday Danish' and 'illness Danish'. In Denmark, an entire generation of young 'foreign workers' from Turkey was politically and socially neglected. They got off the plane from Turkey in the 1960s and 70s, started cleaning the next morning, and continued until they were fired at age 55 with no language, friends, or meaning in life (998). Back then, not a single politician rejected their labour, but now members of parliament queue up to blame them for not being able to speak Danish. In general, we have socio-politically failed migrant women: in families with children, immigrant women have significantly less chance of learning the second language (e.g. Danish), while this has no impact on men (999). It has not been understood that virtually all ethnic groups struggle with language acquisition. People's language skills, social support, financial stability, and expectations and satisfaction with life in the host country affect the stress of integration and consequently learning. Language problems and barriers to education, employment, and health care cause demotivation, low self-esteem, and learning difficulties in all ethnic groups (1000). Depression and unemployment prevent language acquisition (652). War trauma, PTSD, and similar conditions directly affect memory, concentration, and learning ability - especially language learning - which is a major challenge for social, health, and integration policies (36, 178, 1001).

16.1. PTSD, language acquisition, and learning difficulties

Between 30 % and 70 % of refugees have faced severe traumatic experiences and have developed signs of chronic PTSD of various types and severity.

Migration involves loss of language (especially everyday language and dialect), attitudes, values, social structures, normal life strategies, options for action, and support networks. The language, the native language, will often be the only item remaining that gives the refugee identity, security, and peace of mind (196). For particularly fragile refugees with war trauma and no school education, their native language is the only sure means of communication, and attempts to change such a fundamental element of an otherwise chaotic and unsafe refugee life is associated with fear and high alertness. As a result, both their own cultural identity and conformity with the new culture are being eroded simultaneously, leaving a refugee in a non-constructive linguistic no-man's land. Many of the patients referred to the MHC have ended up in a linguistic limbo and have given up on language learning, body care, health, and social interaction. It is a humanly costly condition centred on lost language and, consequently, lost identity. Traumatized refugees arrive in a new country exhausted and disoriented. At the same time, they face many concurrent and new challenges, such as securing their stay, learning a new language, facing a new culture, finding housing and employment, and adapting their parental role.

Although we must avoid medicalising the effects that war and other disasters may have on individuals, we should not underestimate their influence on the person's ability to adapt to life in a new society as a refugee in exile. The challenges of resettlement in a new country cannot be separated from literacy and linguistic development. Literacy also includes numeracy, problem solving, and the ability to read, in addition to being able to write and speak in Danish. Moreover, it involves emotional and social skills such as motivation, effective interaction with other people, critical thinking, and cultural awareness (629).

Most studies on learning processes for refugees document the importance of understanding the psychological trauma that many refugees have endured before arriving in their new countries. Trauma can include physical and psychological torture, living under primitive conditions in transit camps for long periods of time, continuous separation from family and friends, and cultural alienation in their new host communities (1002). The refugees who turn out to have learning difficulties are characterized by powerlessness, de-motivation, depression, anxiety, hopelessness, and lack of future plans. Often, they have unsuitable ways of resolving conflicts and have had only sporadic, unplanned schooling due to social unrest, flight, and constant migration (1002).

Patients on high alert access information in their brain (cortex) differently than calm patients. Even if new knowledge has been stored appropriately in the cortex, it can be difficult to retrieve it when one is anxious and on high alert. If the patient is very afraid, access to 'adult and rational' thought and analysis may be completely blocked, and the patient may suddenly appear to be immature in their thought processes - it is the primitive and less rational areas of the brain, below the cortex level, that are in control. Verbal and non-verbal signals are over-interpreted and distorted, so the patient appears to be untrustworthy, immature, and intellectually inferior. Patients in fear focus on a few impressions that seem relevant to the anxiety, and new knowledge or new tasks are ignored or they provoke more anxiety. Adults with PTSD may find it difficult to be 'present' in the language class. They have difficulty in dealing with linguistic ambiguities and discussions or doubts as being anything else than anxiety-inducing (181, 182, 1003). As a result, patients may have very negative school experiences that compromise their opportunities for continued learning (183).

The scientific basis for the generally reduced learning ability, including affected memory, in chronic PTSD is solid (1004-1013). PTSD affects concentration and both short- and long-term memory (181, 1003, 1013-1016). Learning difficulties and cognitive problems in patients with PTSD increase with the severity and duration of the PTSD symptoms (1017). The memory and concentration impact on patients with PTSD seems consistent, regardless of the type, circumstance, or geography of the trauma (1018-1024). However, fragmented and disorganised memory, especially around the trauma, can keep patients with PTSD in a situation where they cannot start a course of investigation and treatment for a somatic illness until a prior and targeted treatment aimed at an improved memory structure has been initiated (184, 185). Many refugees have symptoms that directly affect learning and attention. In one study, 69 % of the participants had headache, 58 % had difficulty concentrating, and 57 % complained of obvious memory problems (1014). There are a number of neuro-anatomical studies to support the cognitive findings connected to PTSD (1025, 1026). A series of studies has also provided an emerging biological basis for understanding the neuro-hormonal backgrounds for the learning challenges of chronic PTSD (1010, 1027).

Several studies show that the combination of PTSD and illiteracy due to interrupted or discontinued school education in the home country impedes the language learning process (1028, 1029). These factors influence the learning process of refugees because they lead to increased isolation, memory disorders, and changes in normal neurological processes (1030).

A ground-breaking Swedish follow-up study (longitudinal study) of PTSD-affected Iraqi refugees' language learning found that the more PTSD symptoms the refugee had, the longer it took to advance linguistically and the less language they learned (1017). It was the first study to directly demonstrate the effect of PTSD symptoms on language learning. The more extensive the patient's PTSD symptoms are, the more the person's way of thinking, talking, and writing is affected. The person's mind-set changes in that metaphors are changing, sentences are built differently, concepts are used with different meanings, and the whole thought and memory structure alters (1031).

Much evidence suggests that when an incident, accident, event, or a situation breaks a person's protective psychological shield, the person is thrown back into old reactions to unmanageable problems and into reaction patterns that have not previously seen the light of day. These patterns are behavioural and bodily, but also linguistic. Traumatic language is a verbal version of the visual language of dreams, words are metaphors, parables, and symbolic equations; they have the status of inner but not internal objects, and they become expressions of feelings rather than meanings. Sometimes language and conceptualisation become almost autistic or functionally aphasic in trauma victims (1032).

PTSD is equivalent to uncontrollable anxiety, constant alertness, and rapid activation of high stress levels. Anxiety and stress affect the way the patient thinks, feels, and acts. A patient on high alert has difficulty concentrating, shuts out many sensory impressions, and focuses attention on non-verbal

signs such as voice, pitch, intonation, facial expressions, and body language. Non-verbal signals are often misinterpreted due to the high alertness, which severely limits resources by which to acquire a new (second) language (1003). These mechanisms are important in understanding what happens to adult learners in language-learning situations (1033). The negative consequence is that language learners with PTSD find it difficult to get an overview and to assess risks; they are reluctant to start new tasks/challenges, answer questions, or merely consider an alternative argument in a discussion (1034). Students with PTSD can be in a state of alarm without the teacher noticing, and the teacher's well-intentioned orders can be misinterpreted and lead to a cascade of misunderstandings that build up and amplify the patient's discomfort with the teaching method; this can lead to cognitive absence and, ultimately, discontinuation of the language course (1033). A significant proportion of refugees also have unpleasant experiences from their childhood school in their home country that can be at play without the students themselves being aware of it or being able to separate PTSD stress from re-experiences from that time.

A specific problem for patients with PTSD is that the degree to which new words and concepts are understood and remembered depends on the type of emotions associated with them. Patients with PTSD cannot remember all words equally well or understand them correctly, and the concepts that are problematic depend on the individual (1035).

Basically, the acquisition of a second language is a real cultural clash with constant conceptual doubts, discussions about meaning and context, etc. - the very experiences that patients with PTSD fear most because they exacerbate insecurity and provoke anxiety (1036).

A recent Danish doctoral thesis showed that dissociation due to PTSD is much more frequent than previously thought (186). Dissociation is a basic mechanism of PTSD that greatly impairs learning ability (1037, 1011, 1035, 1038). Patients with PTSD find it difficult to distinguish between dangerous and harmless concepts. The result is that dangerous concepts with strong, associated emotions gain the upper hand, which is highly inconvenient in learning situations (1038, 1039). Students affected by PTSD can therefore appear to be age-appropriate and present one day and act confused and unschooled the next day in the language school.

For some refugees, resettlement in the host country can be a greater trauma than previous traumas from war and refugee camps. They may have been in refugee camps for most of their lives and not know about 'ordinary everyday life' at all or know very little of their own country. They may have fallen years behind in education or never had any formal education. These refugees know even less about the new society they live in and its construction, and they are unable to access and use knowledge that is only available in Danish. This may have the following consequences for learning:

- **Invisibility:** the skills (academic, social, and creative) they come with have little chance of getting used. They lack a connection with the new culture, and it is difficult to express and show cooperation skills until sufficient knowledge of Danish has been acquired. This could take years.
- **Poor skill set:** language teachers are unable to have detailed discussions with students due to excessive language differences.
- **Lack of cross-cultural understanding:** most teachers have a limited understanding of what has happened to the refugees, and they often know too little about the process of cultural learning.
- **Guilt and shame:** the refugees blame themselves, not their situation, for their dissatisfaction and failure.
- **Defeat:** language school becomes another defeat.

Besides the pronounced influence on memory, impaired language learning is the most studied effect of PTSD. A doctoral thesis demonstrates how language learning is affected independently of the

effects of memory through incorrect language coding, incorrect storage, and disconnected access to conceptualisation (1040). Several studies suggest that it is primarily learning ability that is affected, while memory is secondarily affected (1005, 1041). A less direct but more practical example of evidence of reduced language learning is that refugees with PTSD in the Netherlands were more likely to ask for interpreter assistance, and the need for interpreter assistance increased linearly with the number of traumas and severity of the PTSD symptoms (1042).

For some patients with PTSD, language learning is a safe haven where they have the opportunity to share their experiences, and for others, the classroom is a safe haven where they simply are free from having to tell their own story or hear the stories of others (1043). For the latter patients, language learning is severely compromised and many of them have their language lessons interrupted either by the teacher who discovers the problem or by the individual patient. No matter who stops the education, interrupted language courses will become another defeat in their lives, and it is rarely in the patient's interest to try again (1016). Due to the distorted access to memory, patients with PTSD have a harder time 'reading' social contexts and are worse than others at solving social problems (640). Patients with PTSD more often misunderstand the meaning of negatively charged words (1044), and they become more easily distracted in social contexts (642). This factor also influences learning in classroom contexts.

One of the big challenges in the encounter with ethnic minorities is that both sides have unknown, but very important, codes that need to be recognised and cracked. The MHC has described several examples of why it is important to clarify the cultural ethnic codes of the clinical meeting between doctor and patient (78, 179, 180). This problem also seems to be playing out in an invisible and non-constructive way in educational situations. Lack of understanding of the cultural knowledge and values that are fundamental to language and conceptualization prevents language learning and leads to what some perceive as *cultural trauma*, because it is humiliating and paralysing to a language learner (or patient) to sense that there are important codes, you have not cracked, and that you are helpless in finding a way out (1045, 1046). Languages and concepts are stored differently in the native language than in the second language. For many patients with PTSD, the native language may be associated with trauma while the second language is a 'safe language', but for patients with PTSD and language difficulties, the second language is also traumatized (also called 'second language anxiety') (1047).

Finally, there may be teaching of and knowledge about world history that create uncertainty and doubt because these contradict what the student has previously learned. This is directly undesirable for patients with PTSD, who risk experiencing an increased arousal and dissociation that prevent learning (1048).

In addition to obvious barriers that ethnic minority women often have to contend with, such as freedom of movement, access to education, and large domestic tasks, many studies also point out that women who have severe trauma are older than other refugee women, have more children, and more frequently have poor or no schooling. Women from war zones have also frequently experienced sexual assault, including during their escape and in the refugee camps. These are abuses that they must bear and suffer alone and which cement a fundamental insecurity, even towards teachers (1049). Gender-dependent linguistic effects of psychological trauma may also be present, as well as gender-diverse access to memory, which may have an impact on language learning and new knowledge (1050).

An overlooked aspect of life in exile is that imposing silence upon themselves and even towards family and friends can become a survival strategy for a number of reasons among patients with PTSD (1051). This means that one may not actively participate cognitively in conversations, either at home, in school, or at language learning. Silence can also be a combination of slow or 'wrong' access to memory, which can even be amplified by psychosocial pressure not to talk about the past (1052). Whatever the cause, these factors significantly affect learning ability in patients with PTSD.

Two specific conditions that can have learning consequences and deserve to be highlighted are sleep deprivation and pain. Lack of sleep and sleep disorders are basic symptoms in patients with PTSD.

These symptoms are caused by a combination of evasive behaviour, hyper-arousal, uncontrolled re-experiences, anxiety, nightmares, and racing thoughts (1038, 1053). Pain is also a key and frequent companion phenomenon to PTSD, partly as a direct physical injury due to bodily injury during torture, gunshots, or grenade impact, and partly with elements of neurogenic pain syndromes mixed with anxiety-driven pain experience (1054). Nightly pain in patients with PTSD affects sleep patterns and vice versa, which places many patients with PTSD in a vicious circle that prevents them from participating in learning environments and in other social contexts. PTSD and chronic pain syndromes are triggers and amplifiers that reinforce each other (610).

A Swedish survey of adult, relatively well-educated refugees (11 years of schooling in their home country) at language school showed that 44 % had clinically defined insomnia (the corresponding figure was 15 % for ethnic Swedes). Eighty per cent experienced significant concentration difficulties at school due to trauma and concerns about their future and the welfare of their family. The majority had moved between two and seven times during their education. Overall, the report concluded that insomnia due to trauma and worries was a significant and serious obstacle to language learning (1055, 1056).

Bilingual patients express intensity and characteristics of symptoms more strongly and more clearly in their native language than in their second language (even with interpreter assistance) (1057, 1058). Patients examined by psychiatrists were more psychotic and had more hallucinations in their native language than in their second language (1047). This means that by forcing patients to express themselves in their second language through, for example, language training, patients are prevented from expressing themselves accurately about symptoms and/or trauma intensity. Patients with PTSD will therefore experience anxiety when having to speak in the second language because of a clear sense of not being understood well enough and that one's needs are not being expressed clearly. Contrary to the objective, the language teaching itself can have a negative integration consequence for patients with PTSD because these patients do not experience a link between their native language and the second language.

Patients with PTSD develop dementia more frequently and at a younger age than other people do (674). Physical signs of premature ageing (hearing loss, cardiovascular disease, osteoarthritis) are more often present, and the underlying genetic factors are partially described (674, 1059, 1060). In a study on self-perceived age, patients with PTSD with an average age of 42 years rated themselves 20 % *older* than their biological age, versus ethnic Danes in the same age group, who rate themselves 20 % *younger* than their biological age (1061). In addition to biological age, functional dementia and premature ageing probably also play a role in delayed/no linguistic learning.

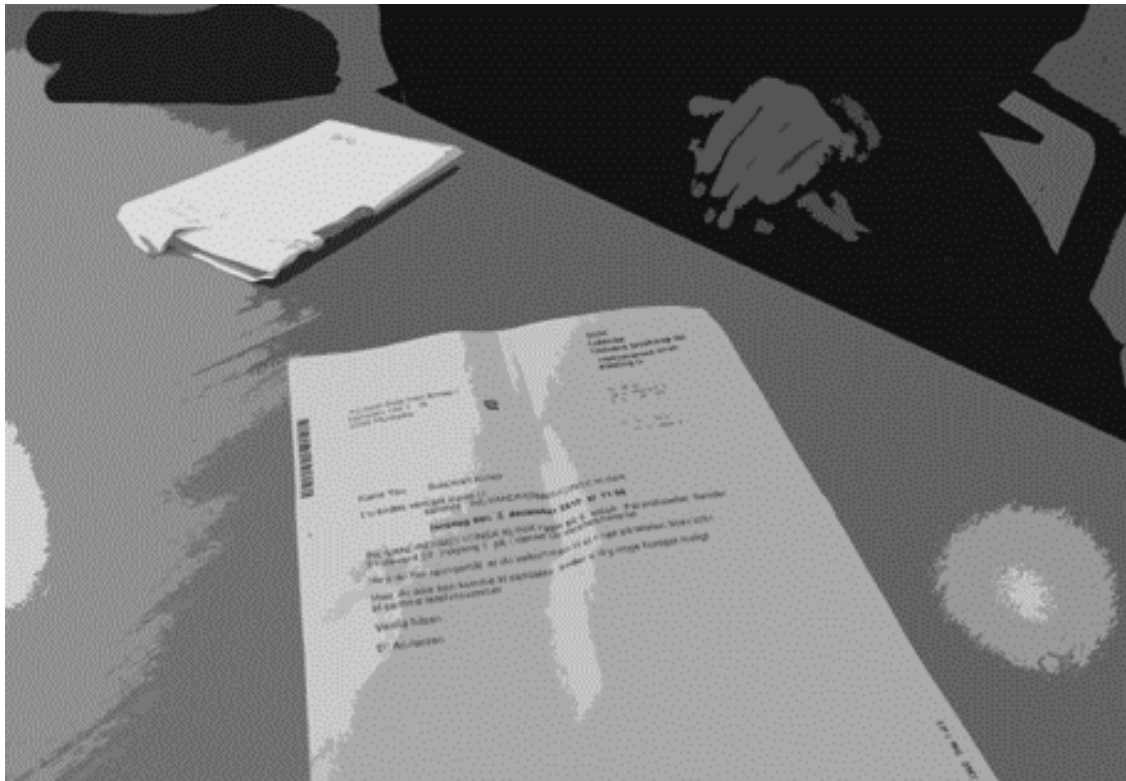
In addition to the psychological barriers to language learning already mentioned, life as a refugee involves a number of practical barriers that are reinforced by a lack of language control, weak system competences, and poor finances. These include living in outlying areas, expensive public transport, many family members, chronic diseases and disabilities, housing problems, gender issues, and difficulties navigating the systems.

An Australian study found that refugees who could read in their native language needed 900-1000 hours to obtain the English language skills necessary to be able to function minimally in social/work contexts. For functionally illiterate people, it took twice as long, i.e. 1800-2000 hours, to achieve the same skills. For completely illiterate people, the situation was quite different: The report concluded that '*... learning progress for pre-literate learners is extremely slow. Traditional assumptions about stair-casing to higher level programmes need to be challenged in the case of pre-literate learners ...*' (1062).

The MHC has previously reported on the specific clinical challenges associated with learning and language formation among patients with PTSD and physical illness who get referred to the clinic (51, 78, 179, 180). Patients with PTSD have difficulty coping with symptoms and treatments due to the same memory and concentration difficulties that impair their language-learning capabilities (1063). We should also note that many patients lose vocabulary in their native language because they live isolated

lives without contact to anyone other than close family members, and because they do not dare to watch TV as part of their PTSD condition. Their children speak a post-migration language that these parents cannot understand (1064). Patients with PTSD very easily lose their Danish language skills if they are subjected to breaks in their routine or to social, physical, or psychological events. At the MHC, we have seen examples of loss of Danish language after car accidents, work accidents, demands regarding employment or activation, surgery, loss of family members, divorce, and frequently after discontinued language school courses.

If patients with PTSD do not get treatment, there is a risk that their insomnia and memory loss will become chronic, whereby their ability to learn new things and maintain existing language skills - in the worst-case scenario - will be destroyed. Patients with PTSD need and will clinically benefit from two key interventions: treating their PTSD and calming their lives through a secure basis of residency.



17. Blind spots in the conversation with the immigrant patient

17.1 Circumstances of exile: absence of the narrative

One of the biggest barriers in the conversation with immigrant patients is that doctors often fail to consider the circumstances of the refugees or immigrants in their conversations with them, information given to them, and during investigations and treatment. The broader background and understanding of these circumstances are described in a new report from the MHC entitled 'What you don't know, will hurt the patient' (1001). Health professionals find it difficult to understand and take into account the lives of ethnic minority patients *before* they came to the host country. This often leads to failed examination programmes, low-quality treatment, medical errors, and ineffective health education measures (51, 173, 174). Current life conditions and concerns are rarely the focus during the planning of examinations; however, they may impact patient participation in clinical examinations whose purpose is not entirely clear (175).

It is not particularly difficult to consider the patient's background, but many doctors do not realise how large a role the patients' circumstances play in relation to self-care, health, and illness - especially for patients with language barriers and who grew up in a cultural context widely different from the Danish one. It is not clinically productive to pretend that the patient's life only began on the day they set foot on Danish soil. If the doctor also ignores or downplays the language barrier, patients will experience a feeling of being disqualified in their ancestry, upbringing, culture, and language. The doctor thus sets a condition for the conversation that the patient has no chance to change - and the patient's only way out is to protect themselves. Patients do this by: 1) teaching themselves the doctor's code language, i.e. presenting only one symptom and asking only one question, 2) saying 'no' if the doctor's information is not understood, 3) providing the doctor with information only on a 'need to know basis' - the doctor will have to ask, if they want to know something (conversations between immigrant patients and their doctors are fragile and break down easily), and 4) saying 'yes', but thinking 'no' because the doctor still does not understand what it is about. Unfortunately, neither the doctor nor the patient notices this until much later. The patient thinks, *'the doctor's question does not help me'*, and again the doctor feels powerless and confirmed in thinking that immigrant patients do not listen to what the doctor says. A Dutch study showed that family doctors spent less time in patient conversations involving language barriers and they were more domineering than they were with other patients. In contrast, patients with language barriers were less assertive than other patients (52). Figure 25 below illustrates examples of blind spots in the doctor-patient conversation.

Case 1

A 45-year-old woman with stomach aches is referred by the gastrointestinal medical department for an MRI scan of her abdomen. The patient fails to show up at the first appointment for a scan but is rescheduled. This appointment is, however, cancelled by the X-ray department, who informs the referring department that the patient has been rescheduled. The referring doctor, however, cancels this appointment that had already been sent to the patient. The doctor justified his request for cancellation on the grounds that the patient had failed to show up for the first appointment and would probably be absent again, and that perhaps the patient's symptoms had diminished as the patient had failed to show up once. It was later reported that the ward was in the habit of terminating patients when they failed to show up the first time.

The patient explained to the MHC that she suffered from PTSD, difficulty sleeping, memory problems, and orientation difficulties and that she was 100 % dependent on her eldest son when she went to hospital, otherwise she would lose her direction and get lost. She and her son had turned up for

her first appointment five minutes late (due to a one-hour train delay), and they were rejected by the secretary at the front desk. The note in the X-ray department only states that the patient was absent. The son could not go with the patient to the new appointment and had tried several times to call and cancel without success.

Figure 25. Examples of coupled bilateral blind spots in bilingual doctor-patient communications.

The doctor	Relation and interaction	The patient
Unusual person with a normal illness	Social concordance	Physical expression of a mental problem
Normal person with an unusual illness	Social discordance	Mental expression of a physical problem
Wrong translation of correct symptom	Do we like each other	The doctor is friendly, sympathetic
Correct translation of wrong symptom	Do we dislike each other	The doctor is unfriendly, unsympathetic
Ordinary illness with strange symptoms	Doctor bias, prejudice	Social problem that exacerbates the illness
Rare illness with normal symptoms	Patient bias, prejudice	Illness that exacerbates the social problem
The doctor's blind spots	Readiness to adapt	Patient: Body and psyche connected
The patient's blind spots	Tolerance of ambiguity	Patient: Body and psyche disconnected
The patient is likeable	Respect and trust	Learned symptoms
The patient is unlikeable	Disrespect and distrust	Actual symptoms
Applies cross-cultural knowledge	Motivation	Hidden burdens of illness
Has no cross-cultural competencies	Attitudes	Obvious burdens of illness

It is inherently understood among doctors (and is expected by patients) that we look at and assess patients objectively and without prejudice, in that we use biomedical observations from the objective examination combined with blood tests and other paraclinical examinations to make a diagnosis and a treatment plan. Research suggests that this is an unsuitable way of viewing the doctor-patient meeting (241, 242). Van Ryn has described the areas that show evidence of discrimination and that lack medical evidence: osteoporosis treatment/prevention, education on smoking cessation, reduction of excess alcohol consumption, referral for mammograms, advice on breastfeeding, handling of pain management, referral for dialysis, referral for coronary angioplasty, recommendation for kidney transplantation, and psychiatric treatment (79). The many non-medical factors at play when the doctor makes a clinical decision are documented in a number of test lab studies, e.g. in studies where the patient had a

long-term cough and was a smoker but was presented as having various social characteristics: 192 doctors were tested and a clear tendency was evident for younger patients to be told that the coughing was psychosomatic, and referral to X-ray examination or smoking cessation depended largely only on social (non-medical) factors (243).

A Swedish survey of 149 doctors and nurses in the field of diabetes examined perceived differences between ethnic Swedes and ethnic minority patients with regard to attitudes towards diabetes. Depending on whether attitudes or behaviour were asked about, 12-31 % of health professionals replied that they knew nothing about these differences (1065). They perceived migrants as being less knowledgeable, less interested, and more bound to their traditions and old habits than ethnic Swedes. Most (89 %) answered that communication and cultural differences were the main cause of compliance problems.

In their book on diversity in health care, Gardenswartz and Rowe describe six realities of cultural programming (1348):

1. Culture is not obvious. Culture is only discussed when rules are broken. You cannot 'see' a culture by looking at a person.
2. We are all ethnocentric ('from here my world extends'). We assume that the pain, emotions, and attitudes we are familiar with are more valid than those we are not used to being confronted with. Pain must be expressed 'my way', otherwise it is not believable. The patient role is the one, I know - other patient roles are strange (or even scary).
3. We observe non-verbally, and we interpret what we see without discussing it openly. We do not ask for any dialogue on prejudices and generalisations - they are, we believe, a certain DNA. But, we often misinterpret without realising that we ourselves are the cause.
4. We often fail to realise when we have insulted or offended others with our attitude or behaviour.
5. Attention, sensitivity, and knowledge increase our breadth of action and choice. By seeking to know and recognise differences and barriers related to other people's backgrounds, we can establish better interactions and thus safer solutions. The first step in a cross-cultural meeting is to know and acknowledge one's own cultural 'software'. Knowing your own values, boundaries, and barriers makes you more culturally sensitive because many reactions are personally rather than professionally motivated.

It does not require much for patients to be perceived as foreign, strange, deviant, or bizarre. In two hospital wards, Mari Holen examined how patients could be perceived based on how the staff categorised them (1066). She found four norms:

1. **Being an object** - patients who make themselves into an object for the medication/treatment and at the same time ensure that they fit in smoothly, i.e. effectively and productively.
2. **Being independent** - patients who activate themselves in ways that show that they want and are able to contribute as a patient.
3. **Being trustworthy** - patients who show sincerity in their desire for the treatment to succeed.
4. **Being special** - some patients are used as role models for the staff's approach to patients and the purpose of the work.

However, Mari Holen also concludes that the residual group - the patients who do not meet the four norms - are *odd*. Here the patient as an individual becomes the problem. She found that patients find it

difficult to make their own needs and desires known, especially when they do not fit in with the four norms. Breaking with the prevailing norms leads to a problematic patient position that often persists for the rest of their lives. Patients who do not adopt the norms threaten the order of the department and the professional work, the other patients, and the department's ability to achieve its goals. These 'odd' patients disrupt production. Holen observed that being odd relieves the professionals of their responsibility and it became the patient's own responsibility to earn the attention of the staff. They have been put on hold and now it is up to them. Only odd patients with a broad 'customer register', negotiating skills, and a strong social network can break the norm without becoming estranged. The latter is rarely the case for refugees or immigrants.

1. Cross-cultural tools

Cultural competency building can prevent some of the encounters that lead patients to being perceived as strange or odd. This is a five-step model:

1. Building the relationship
2. Assessing the patient's problem
3. Understanding the patient's social and health capital
4. Negotiation
5. Co-production of solution/treatment for the patient's issue

17.2. Building the relationship

In direct language communication, it is important to speak directly and at a normal pitch, without using slang, metaphors, or technical terms. Ask only one question at a time with the objective of achieving consensus for each piece of information. As for non-verbal communication, care must be taken and close attention paid to how messages are actually received.

Gesticulations and signals are not universal (beware of ethnocentricity). It is better to use linguistic emphasis. But show willingness to understand and smile so that information is received as 'friendly' information and not as 'telling off'. With or without an interpreter, the common language in bilingual conversations is greatly reduced, and friendly information or advice can sound accusatory or stigmatising because the tone is perceived as harsh, and the language seems rough because the eyes are not friendly. The less you understand a language, the more you have to depend on non-verbal language, and things can very easily go very wrong.

Ideas regarding personal space are socially determined. In Western societies, the personal space of the doctor has been calculated to be between 46 cm and 120 cm (1.5-4 feet), while in ordinary social contexts personal space is 120 cm to 3.6 m (4-118 feet). By contrast, personal space in many non-Western societies is significantly less, which can cause unaware doctors and nurses to misunderstand the patient's mental state to be heavily affected or behaviour to be professionally intimidating (1067). The same applies to eye contact, where a patient who does not keep eye contact is perceived as someone who is not telling the truth or is ashamed of what is being talked about, while in many societies it is disrespectful to look directly at another human being - especially a doctor - for too long.

17.3. Assessing the patient's problem

Here, the good questions are aimed at clarifying the patient's perception and framework of understanding. The expression of symptoms and their importance are culturally anchored, and the same applies to illnesses (1068). Stigma, acceptance, and past experience with illness form and reinterpret symptoms. Thus, it is important to move the patient's mind-set to the context in which the symptoms occurred:

- *What do you think caused the symptoms?*
- *What happened when you discovered the symptom?*
- *What is the illness doing to you?*
- *What about this illness are you most afraid of?*
- *What is important for you to say about the illness?*
- *How serious do you think it is?*
- *What do you hope will be the result of the treatment?*
- *What does the illness do to your relationship with your family? Friends? Work?*
- *What would you do if you had been in your home country? (if applicable)*
- *Have you already sought help or guidance elsewhere?*
- *Who decided you should see a doctor?*
- *What do your loved ones tell you about the symptoms?*

17.4. The patient's social and health capital

Once you have obtained an overview of the illness, how it is perceived by the patient, and what treatment options are available, the next step is to get an overview of the patient's social circumstances - an overview of systems in the patient's life:

- **Strategy:** Who is in charge in your family? Is anyone in charge of your health? Does anyone help you make decisions?
- **Finances:** How big of a problem is money in your everyday life? Is there a financial resilience? How much is available for medicine? Is a budget arrangement needed at the pharmacy? Medication support? Who decides?
- **Appointments:** How does the patient keep track of appointments? Need any help? (SMS, smart phone alarm)? Does the patient have a support person or mentor?
- **Basis of residency:** Type? How long is the patient's residence permit? How many people in the family have permanent residence? Is there a big problem, and for whom? Need for support?
- **Family overview/genogram:** Who is in the family, who is missing, and where are they?
- **Social network:** Close confidants? Loneliness? Conflicts? Religious affiliations? Does the patient have a support person or mentor?
- **Stress factors:** Something that is particularly stressful? (places, persons, situations, organisations, family)
- **Language.** Writing and reading maternal language? In Danish? Always an interpreter or only an interpreter for specific (which) problems? Particular language needs (dialect, language family, level of language)? Is there any guilt or shame in connection with language (mother tongue or Danish)? What is spoken at home? Who mostly interprets for the patient?

17.5. Negotiation

To avoid resistance to diagnosis and treatment or to avoid the occurrence of compliance problems later on, it is a good idea to look at the following:

- The patient's explanation model for the illness. Deepen it and show professional curiosity.

- At what points does the explanation model differ from the one used by the doctor?
- Explain the biomedical model in simple concepts and apply some of the patient's own concepts to it, if you can.
- Find out to what extent the patient understands and accepts the biomedical model.
- If any inconsistencies remain, then re-assess core cultural values and the social context: Are there any understandings that can be changed or reformulated? Are there any other people in the patient's network who could help increase understanding? Do use the interpreter for a more open dialogue about differences and similarities and valid arguments.
- Prioritise therapeutic information and keep it simple.
- Find out the patient's therapeutic preferences.
- Find out the extent to which the patient agrees with the mutual plan. (What can the patient live with, what should the patient learn to live with, and what is the patient sceptical about?)
- If any disagreements about the treatment choices and plan still remain, then focus the negotiation with the patient on the absolutely most necessary elements of the treatment. Can the usual criteria be reduced? Can agreements be made on mutual actions? In crucial or more serious cases: Is a family council with medical participation needed?

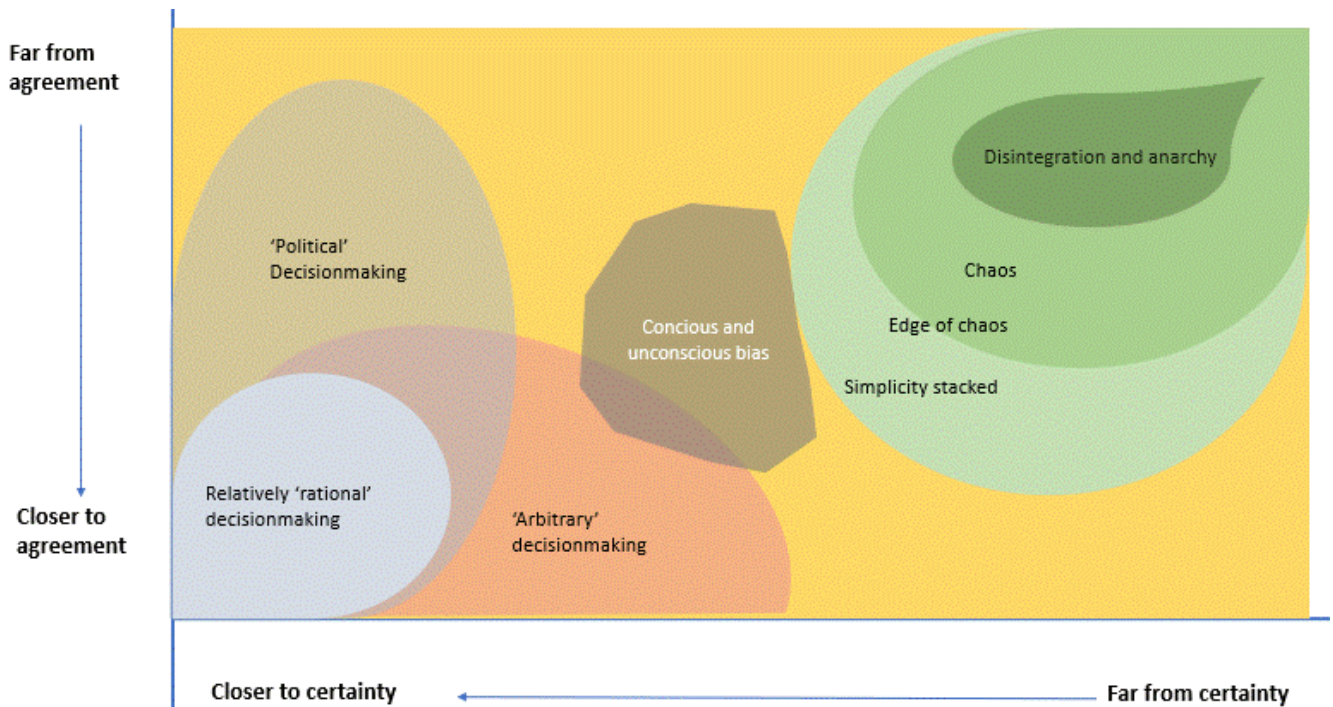
17.6. Co-production of solution/treatment for the patient's issue

Willingness to negotiate is key to cross-cultural decision-making processes, and it is important to quickly become aware of the role of the family in treatment decisions. Make sure that the information is necessary and sufficient for the specific patient, especially in relation to the patient's health skills and the patient's real needs. Some patients just want to hear what options exist but leave it to the doctor to suggest a solution, while other patients are more cautious and will think about each solution. Ad hoc drawings can be a useful joint tool, and continuous attempts at consensus actively involve the patient in a process towards a solution that they themselves are comfortable with. Brusque decisions often have the opposite effect and scare the patient away. Too much focus on risks on the part of either the doctor or the patient can distort a good solution. Continuously seek to get the patient to come up with part of the conclusion: *'What do you agree with?' 'What are you comfortable with?' 'What are you still afraid of?' 'How do you think you can get closer to a solution?'* Let the patient think about the information they have received and then work actively with any doubts they still have. Often it may be of benefit to clear the patient's 'elephant' out of the room, *'Will I become addicted to the treatment?' 'Will I become disabled or go crazy?' 'Am I going to die from it?' 'Is it cancer?'* In other words, the first step is to find out what the patient needs to know before telling the patient what the options are. If you fail to do so, the patient will only listen to their own inner voice that says: *'It is cancer!'*

There are many pitfalls, but here are some that are important to know: in the Western context, social status is materialistic and physical and is based on career achievements, while in other societies, social status is tied more closely to family strengths and gender. Illnesses may change one's status in some societies but not in others. Concepts such as moderation, restraint, and shame can mean a lot in some societies but not as much in other societies. Fatalism and the responsibility of external factors in illness and health also vary greatly and influence whether the patient adopts introverted or extroverted decision-making patterns. A medical interview often consists of good news and bad news, but in some societies, you do not pass on bad news. This is a form of communication that is unfamiliar to Western doctors and often causes trouble and leads to disagreements and conflicts if you are not used to negotiating or creating solutions in cross-cultural patient contexts.

In cross-cultural contexts where there is a great distance between the doctor's and the patient's frame of understanding and priorities, it may be beneficial to think of the conversation as a process of moving from chaos, disagreement, and uncertainty into a state with less uncertainty, less disagreement, and more complexity than chaos. See Figure 26.

Figure 26. Complex co-production and decision-making.



18. Cross-cultural health communication: the body in the language, the language in the body

The power relationship in cross-cultural meetings: ‘Who has the right to decide what an image shows and means?’ ‘Who has the right to decide which framework of understanding should be used?’ If you show a hand where you show four fingers while the thumb is hidden, someone who has never gone to school will say that it is a person who has a hand with a missing thumb (lost in an accident), while someone with a school education will see the number ‘4’. A drawing of three beer glasses - one filled, one half-filled, and one empty - was supposed to form the basis for a discussion about different viewpoints on reality. However, the discussion went in a completely different, unplanned, direction because the empty beer glass did not have a coaster under it, and this distracted from the planned goal of the drawing (the artist had overlooked the missing coaster). An image or metaphor that is used may have a unique meaning in the doctor’s own social environment, but this does not mean that it is generally valid in all environments.

It would be sensible to consider the power relationships at stake in a bilingual conversation. Is this an exciting cultural meeting, a clash of cultures, or a show of force carried out through an interpreter? It is usual to talk about the interpreter assisting in a cultural translation, but the term *cultural meeting* is most often used for situations where the power relationship is highly asymmetrical. For more equal power relationships, it is better to use concepts such as *interaction*, *interplay*, *exchange*, etc. The concept of *cultural meeting* thus contains certain preconceived power structures that are reproduced using an interpreter. Particularly in post-colonial studies, the concept *translation* has been introduced as a concept that is better at opening up minority issues in a doctor-patient interview and focuses on creativity, negotiation, and transformation rather than on integration and assimilation. This is not to say that the concept *cultural meeting* should be avoided; it is probably as impossible as eradicating the concept of *culture*, which is similarly controversial (102, 1069).

Emotions can be expressed through words and expressions (*‘I dare not’, ‘I have doubts’, ‘I am afraid’*); through the voice (voice quality, pitch, speech speed, hesitation, etc.); or through the body (gaze, gesticulation, trembling, sweat, evasive manoeuvres). Different languages describe the emotion in different ways, e.g. in Arabic: *‘My condition is tired’*, or in Somali: *‘I have boofis (my body aches, I am tired and sad)’*. If the patient’s intonation, facial expressions, tone of voice, or gestures are not conveyed by the interpreter, valuable nuances are easily lost in the patient’s description of the problem. Conversely, the doctor’s empathetic facial expressions or tone of voice may be lost in the translation. Without an interpreter, you can sometimes end up with an empty and emotionless conversation even though, in reality, each party has individually communicated in detail and with emotion.

Refugees in Denmark find it difficult to navigate the many new illnesses and illness concepts that would hardly have had a name or triggered a reaction from the health care system or society of their home country. When you go to a doctor, dentist, or physiotherapist in Denmark, you are expected to have a diagnosis. However, if illnesses such as periodontitis, flat foot, bunions, obesity, or hearing loss are not communicated in detail (via interpreter if necessary), they can be understood as illnesses that have the same significance and expected loss of function as coronary thrombosis or cancer. Osteoarthritis [in Danish called ‘wear-and-tear-arthritis’] gets associated with being *worn out* or *worn down*. For various professional and legal reasons, X-ray descriptions have become more and more detailed, and everything that has been observed must be documented; most adults have degenerative changes to varying degrees, but these can be difficult to explain or translate without the patient getting a picture of a body that is already in complete disrepair. Varicose veins and ‘Spider veins’ [in Danish called: blood-vessel-knots] can sound dangerous and highly unpleasant if one is not aware of the difference between arteries and veins. Hard of hearing [in Danish called: heavy-hearing] could be perceived as if it were the

whole brain that was sick, and that the patient is perceived as 'heavy' in understanding and less intelligent.

In her book, *The Spirit Catches You and You Fall Down*, Anne Fadiman describes a specific conflict - a prolonged slow-motion clash between the American health care system and a Hmong family with a child who, from the age of three months, developed seizures during which she collapsed with convulsions. Doctors at the hospital say it is epilepsy, but the family does not accept that (epilepsy equals mental illness in the Hmong community). On the contrary, the Hmong family believes that the girl has been specially chosen and that it is a blessing. However, no attempt has been made to exchange this information because the hospital rarely uses interpreters. The parents did not understand that doctors thought it was epilepsy, and the doctors did not know that the parents had already determined that the spirits had taken residence in the patient. The Hmong community was generally sceptical of the American healthcare system, where doctors took a lot of blood out of patients and cut them up when they had died to remove and sell the organs. The Hmong people believe that you are born with a certain amount of blood and that every time a blood test is taken, there is less blood left. When you are sedated, the soul is still awake, and therefore surgery can be dangerous to the soul. Thus, the Hmong family was dismissive of the use of anaesthetic when their daughter needed to be examined, and they argued with the doctors about the necessity of every blood test. The doctors considered them to be 'troublesome patients' without trying to understand the underlying reasons. The daughter was severely obese, and the doctors were very reproachful of the parents' neglect of any diet. The staff never got an insight into the social code: a child should look healthy so that others can see that the parents are taking good care of their child. Health equals obvious obesity, and it is particularly important to maintain the image of being good, strong parents when one's child is sick. The Hmong's social code on the value of obesity was stronger than the hospital staff's less understandable demand to starve the child, which would give the parents the reputation of being bad parents. When the girl was hospitalised, the relatives removed her surgical tubes and placed her on the floor so that they could sleep together - a child must not sleep alone. Attempts were made to send a community nurse and an interpreter home to the family, but they ended up sending continuous replacements because the nurses were busy and had no time to listen. The family experienced it as abuse and the replacements as uninvited guests. The nurses saw the family as 'non-compliant'. The interpreter never got a chance because he had married an American and thus had turned his back on his country and culture. Guests must behave in a certain way and are only slowly accepted into the family. A constant point of conflict was the epilepsy medication that the patient received only sporadically because of constant new questions about the purpose of continued treatment. To the Hmong parents, medication was a brief cure and then you are well. Long-term medical treatment is harmful and leads to addiction, infertility, and rumours about the patient being insane. The parents appeared proud and defensive, but no attempt was made to allow the parents to withdraw a little without losing face. Fadiman summarises the situation, '*What the doctors viewed as clinical efficiency, the Hmong viewed as frosty arrogance.*' In interviews about the challenges that the hospital doctors faced in dealing with the Hmong community, it became clear that doctors were triggered by the Hmong patients being passively submissive and obedient, thereby protecting their dignity by hiding their ignorance and protecting the doctor's virtue by pretending to listen reverently. The doctors invented a 'Hmong cocktail' for unexplained symptoms in patients from this ethnic group. The cocktail consisted of a painkiller, an antidepressant, and a B-12 injection. The doctors and midwives at the maternity ward were terrified of deliveries by Hmong mothers because they never said anything during the delivery. The staff did not realize that the mothers were terrified because they had been prohibited from performing the usual rituals around childbirth, or that you are considered a bad mother if you scream when you deliver.

The epileptic girl was forcibly removed from her family due to considerable neglect on the part of the parents. However, the result was that the girl stopped taking her medication altogether. She suffered

a severe, lasting seizure and subsequently went into a coma. After scans and other examinations, she was declared brain dead. The doctors only spoke to one of the daughters who spoke the best English. The doctors told the daughter that they would stop all treatment, and then a doctor removed the ventilator tube and her vein access. However, the daughter's understanding had been that the doctors were going to use the ventilator for another patient, and she did not understand that her sister was dying. When the family realized the girl was dying, they demanded to bring her home. This required the forced removal to be lifted, which happened when doctors explained that the patient was brain dead and did not have long to live. The girl did not die, however. She was fed a special Hmong diet for this condition and she was carried in a sling on the backs of her siblings in turn. The girl was dutifully brought to the hospital for annual check-ups.

The life story - and in some cases, the cultural life story as seen in this Hmong case - is important in order to understand the perception of illness and the needs and desires for treatment. The life story gives meaning to meaningless treatments; it creates opportunities for mutual solutions. Intercultural communication is not only about getting an interpreter. It is also about everything, you do not know that you do not know, and how to prepare for this circumstance.

In her book *Intercultural Communication* Ingrid Piller describes two studies of cross-cultural attitudes and behaviour. At an airline with British and Italian employees at transit desks, you could see that the employees exhibited much of the same behaviour towards passengers who experienced errors or cancellations during their journey. However, the Italian staff were prepared to go a little further to find pragmatic solutions, which they justified as 'compassion', while the British staff never went beyond the rules. Attitudes are mostly influenced by culture, whereas behaviour can be learned. The second study examined communication in Asian shoe stores in Los Angeles. The employees always followed the same approach to customers: greeting - transaction - ending, no matter whether the customer was Asian, African American, or white American. However, the African-American and white American customers felt ignored and badly serviced by the clerks, whom they perceived as racist. The video footage showed the customers trying to small-talk about weather and generalities, while the clerks either gave no response or were demonstratively brief. When the clerks were asked what they experienced, they said they found the customers' comments to be inappropriate and intimidating in a professional customer relationship - it was an expression of bad manners (1070). Cross-cultural communication is not only about reducing the language barrier, but also about understanding how people create a language of illness shaped by life experiences, living conditions, relationships, and different contexts. Attitudes and behaviours do not have the same origin, and all human beings have their own language coded in their body. To approach another person's language of illness requires the establishment of a good relationship and a conversation that does not just consist of two monologues, but a real dialogue.

Everyday words such as *stress* and *depression* have, to some extent, a similar meaning in Danish. However, when the interpreters have to translate them, they quickly get into trouble. In Russian, *stress* means that you are busy in a good way, while many languages have no term to match the concept of the Danish *depression*. To the contrary, it is often a completely different understanding of body-psyche connection and of mental discomfort that makes a translation almost impossible because in many societies the feeling is described as frustration, insecurity, helplessness, guilt, shame, lack of prospects, loneliness, paralysis, shock, anger, loss of control, or betrayal or as physical symptoms such as insomnia, headache, and stomach ache (1071). Since the Danish concept of *depression* is based on the notion that it is the patient who is ill and has a psychological problem, thus *depression* has a negative connotation. In other societies, on the other hand, psychological discomfort is understood as a relational and less individual issue. You may have negative feelings, but they have a different cause and consequence when experienced in a different society than where you grew up. As one patient from an African country explained, *'I feel like a bird without wings. The people who usually help me are not here in Denmark.'*

Somali refugees came to Denmark in the 1990s and experienced that many of them became sad, suffering from loss, chronic grief, and muscle pain. They attributed it to the foggy and cold Danish winter air and could only find one Somali expression for it, *boofis* which in their home country means a person who is sad and isolates themselves and is unable to achieve what they want. It is also a person who is tired of themselves and whom one should stay away from. In Afghanistan, one does not treat depression, but possibly *mualag*, which means, 'a very sad sensation of hovering stretched out in mid-air' (1070). It takes a dialogue, not a translation, to approach a mutual understanding of what the patient is actually struggling with. Depression itself does not make sense without an associated patient perspective.

Chronic grief due to loss can affect self-care and quality of life and prevent language acquisition (1072). Chronic grief can be complicated by concurrent PTSD (1073). However, grief is a cultural construct, and tears are considered to be a luxury in many societies (1074).

18.1. I am not listening to you

We are deaf in the languages we do not speak, and at the same time, refugees are afraid of dying in a language they do not speak. It may be effective to turn a deaf ear, but doing so has consequences.

Relatives of a mentally ill person reported that staff ignored the patient's complaint of headaches after having fallen off a roof. The staff interpreted the information as a psychotic experience, but the patient turned out to be right. An Australian intensive care doctor had to get help from a colleague at another hospital to explain to the surgeons that he had not had a heart attack but appendicitis. He tried to explain that his ECG looked strange because he had undergone heart surgery as a child, but they did not listen to him because he was no longer considered a doctor, but a patient (1075). Confirmation bias, convenient assumptions, and prejudices always plague medical clinical decision-making and are considered to be part of the informal and hidden curriculum that medical students go through (1076, 1077).

Similarly, younger colleagues are taught to 'getting rid of patients' (GROP-techniques) through a series of hidden tricks and skills such as objectification, intimidation, ignoring, and omitting otherwise relevant clinical details (456). Many of these hidden textbook competencies come into play in the meeting with ethnic minority patients, to which a failure to obtain interpreter assistance can be added. When a clinical problem is out of the doctor's control, it seems like a rational solution to ignore the patient by not allowing the patient the opportunity to speak. One can even facilitate *victim blaming* (that it is the patient's own fault) to colleagues by exploiting the language barrier. By rendering the patient silent and without any language, the doctor paves the way for stigmatising attitudes about the patient (and this may follow patients for the rest of their patient-life): '*the patient behaves like a child*', '*the patient is a poor informant*', '*the patient is not that bright*', '*the patient does as he/she pleases*', '*the patient is stubborn and non-compliant*', '*the patient leaves the ward against our advice*' etc.

The hidden social learning of medical students already begins in their third year. In a classic article entitled 'The devil is in the third year,' Hojat described through interviews with students, how the older colleagues modelled their medical role in the direction of a patient approach that was effective, and this gave the medical students a sense of teamwork with their senior graduated colleagues and role models (958). Through interviews with medical students, Kenison examined the way in which senior medical colleagues influenced the students' self-image, roles, and patient approach. As they were students, there were several mechanisms they did not 'discover', which are still part of the role modelling. Based on experience from teaching and from patient interviews in the MHC, Table 30 shows how senior colleagues convey role models to students and junior doctors in ways that are indirect, direct, indifferent, or ambiguous.

Table 30. Ways in which senior colleagues convey role models to junior colleagues regarding perception of patient conversations with a language barrier.

Based on experience from the MHC and (1000).

Theme	Typical attitude/behaviour
Indirect negative role modelling	<ul style="list-style-type: none"> • Poorly hidden ‘rolling of the eyes’. • Obvious dissatisfaction with having to call the interpreter. • Non-verbally expressing, <i>‘I’m already running behind, and now I am getting a patient who doesn’t speak Danish.’</i> • Clearly refrains from any conversation with the patient and goes directly to examining the patient. • The same amount of time for all patients regardless of the need for an interpreter. • Lack of information material in foreign languages. • Uses the cost of a treatment as an argument. • The patient must earn a specific treatment. • Patients are rejected simply because there is a language barrier (psychologist for cancer patients, patient school, pain team, weight loss, rehabilitation, sex therapy, adults who were sexually abused as children). • Mentioning some illnesses as being more interesting than others. • Mentioning some illnesses as being self-inflicted and thus not worthy of attention.
Direct negative role modelling	<ul style="list-style-type: none"> • We see that often, <i>‘It is ethnic pain’</i>. • Prior indication that <i>‘this type of conversation takes an annoyingly long time.’</i> • Irritation that the patient does not speak Danish after x number of years living in Denmark. • <i>‘They come with pain all the time, but their tests are always normal.’</i> • <i>‘They have a different pain threshold than we do.’</i> • Patients who do not speak Danish must go to the veterinarian. • <i>‘We do not use interpreters because it takes too long and the interpreters are not good enough at the language.’</i> • <i>‘Interpreters just interrupt - most patients know a little Danish or English.’</i> • The patient does whatever he/she wants. • <i>‘We do not need any follow-up here; the patient will not show up anyway.’</i>
Indifferent role modelling	<ul style="list-style-type: none"> • No clear instruction or articulation of what is the minimum reasonable standard for patients with language barriers. • It is up to the individual person how far they will go.

	<ul style="list-style-type: none"> • It is tacitly legitimised that in some departments interpreters are never used. • <i>Now, let us get this over with - we are busy.'</i> • Cumbersome procedure for ordering an interpreter (or approval is required before using an interpreter).
Ambiguous role modelling	<ul style="list-style-type: none"> • Half-hearted attempts that are stopped before they are completed.
Intimidating role modelling	<ul style="list-style-type: none"> • Extroverted older colleagues who do not tolerate contradictions. • Postulated zero-error culture: <i>'We do not make any mistakes here. If patients complain, it is their own fault that mistakes have been made.'</i>
Structural role modelling	<ul style="list-style-type: none"> • Patients are only accepted if they speak Danish, English, or German. • Lack of information sheets in foreign languages. • Patient errors due to language barriers, lack of interpreter, or lack of consent are not considered errors. • No emergency interpreter services. • Lack of treatment programme coordination for vulnerable patients. • Epidemic situations: lack of information in foreign languages. • No health assessment of newly arrived refugees or migrants at particular risk. • There is a fee for using interpreter services. • Patients pay a fee if they do not show up. • Not enough time is assigned to ward rounds, patient conversations. • Efficiency language prevails. • The patient is seen as an obstacle to production. • Relations with co-workers have a higher value than the relation to the patient and are more important than the patient's experience. • No way of pointing out structural inequalities.

Preventing patients from speaking is considered a lesser sin than their not being diagnosed or receiving treatment. Even the best medicine will not work on the wrong history. So far, the focus of migrant research has not been on the long-term importance that people are systematically deprived of the opportunity to speak, explain themselves, clarify, reflect, and respond. Over time, the muzzle is internalised and cognitive functions wither (68). The biographer Caroline Moorehead followed refugees in North-East England and witnessed several suicides among linguistically isolated people. Absence of any opportunity to communicate led to loneliness, fear, and slow demoralisation due to the senselessness. Their lives shrivelled to nothing, with death as a fine alternative (1078).

For the doctor, it is important to be aware that if you do not lift the language barrier, the relationship with the patient changes character. The patient experiences it as yet another rejection, and for some yet another hateful assault in a long line of abuse (1070). Thus, the balance of power in the already asymmetric doctor-patient conversation has been pushed so far that the patient either gives up or assumes a hostage role in which everything must be negotiated (1079).

Roberts analysed 232 videotaped medical consultations in four different areas of London that had a good share of ethnic minorities. He identified crucial misunderstandings in every fifth patient interview and found that language barriers were the key issue, while culture-related perceptions of disease - which are usually perceived by doctors as the main problem - played no role in the misunderstandings (1080). Roberts et al. identified a number of common themes in the reasons for these misunderstandings:

1. Misunderstandings due to unclear pronunciation of common words.
2. Imprecise grammar, especially about times and relationships.
3. Semantically problematic expressions and metaphors.
4. Technical terms that the doctor considers do not need explaining (grey area words).
5. Unusual expressions.
6. Unresolved differences in expectations for the conversation.
7. Not knowing the reason for the doctor's questions.
8. Differences in presentation and interaction style (how and when to present core information in the conversation).
9. Differences in verbal interaction style between patient and doctor.

All the misunderstandings revolve around language use, semantics, metaphors, pronunciation, and the lack of common contextual knowledge. Differences in presentation style were a more subtle cause of misunderstandings that, curiously, most often occurred on the medical side. Doctors were generally worse than patients at perceiving when misunderstandings arose. Perhaps being bilingual sharpens the sense of possible misunderstanding because refugees/migrants have had years of bitter experience with such misunderstandings and therefore know more of the most frequent reasons than the doctors do. Doctors rarely realise that there are many languages involved in bilingual conversations: medical language, the doctor's layman language, the interpreter's perception of the doctor's layman language, the interpreter's language, and the layman's language in the patient's language. The language is also peppered with metaphors, images, and often drawings with symbols and simplifications. Each of these communication languages and tools has culturally borne meanings that are not always negotiated unequivocally. Roberts's points out that medical students' communication lessons are based on a mono-linguistic, ethnocentric understanding of the relationship with the patient. Doctors should have the skills to assess subtle language challenges and learn from bilingual patients' solid experiences with the most frequent linguistic causes of misunderstanding.

It does not get any easier when people are not always motivated to understand each other. In cross-cultural conversations, very different needs may be at stake, and the differences are sometimes so large that they are unsolvable until they are directly addressed. It is not enough to have an interpreter and cross-cultural skills; you also need to be aware that the doctor and the patient can always have divergent goals with the conversation. Language barriers and perceived cultural barriers may block the real barrier: the lack of expectation or concern is attributed to language and cultural differences (or even racism), but it is actually only a question of the basic conditions of the conversation not being handled as one normally would.

In bilingual conversations, misunderstandings frequently occur due to:

1. Frequent interruptions on both sides. Great differences in topics and mind-sets.
2. Differences in reasoning level.
3. Participants speak with very different purposes without being aware of it.
4. Confusion if one party answers a question in an inaccurate or confusing manner.
5. Inadvertent use of hurtful expressions, insults.
6. Divergent view of the meaning of a pause (*'have I said anything wrong/hurtful?' 'Does the patient have a hard time understanding?' 'Conflict of authority?'*)

7. One party tacitly withdraws from the conversation and responds with, 'hmm', which is (erroneously) interpreted as consent.

Linguistic simplification typically takes place when several languages are involved. Language barriers lead to both parties becoming passive in their interaction style. Significantly, fewer questions get asked, and the conversation parties are less likely to discuss and clarify uncertainties. The language becomes rigid, formal, textbook-like, and one-sided, just as the person's particular linguistic nuances disappear. The professional content starts diminishing, and many more sentences are needed to explain the same thing. Often, explanations do not succeed because the exact word is missing, which is why several words have to be explained indirectly, and this makes the basic information disappear in partial explanations. Humour and its body language disappear, just as the apt metaphors, illustrative anecdotes or comparisons, or entertaining anecdotes are omitted.

A health professional experiences many concerns about conversations involving language barriers. Doubts occur whether the message has been understood, '*Why does the patient ask the same questions over and over?*' You lose the certainty of professionalism, and opportunities to vary and adapt the message disappear. The professional level becomes a mockery. A very basic everyday language is used, with only overarching themes and yes/no answer options. Dialogue is not an option. The non-verbal language can, in the desperation to be understood, be caricatured to an extent where it confuses and disturbs. It can be difficult to know when to 'dig' for the important information and when you have already received it without realising it. What is implied is not clear. Personal information does not spontaneously appear when there is a pause in the doctor's questioning. The dynamics and timing of the conversation are unfamiliar. One question does not automatically lead to the next, and the answer does not quite hit the mark. It is enough to make you wonder, '*Has the question been understood or is this the answer?*' It quickly becomes (too) complex, and the conversation becomes a series of attempts to restart an explanation that has been altered so many times that the patient loses track or gets the feeling of being part of an experiment. Ideally, the participants in the conversation would constantly relate to each other's contributions to the conversation. Through analysis of the structure of the conversation, you can see how participants show each other how they understand each other's actions. If one fails to reflect on the conversations and their course of events, one loses the ability to catch patients' allusions and cues in their indirect attempts to explain their experiences. One of the hardest aspects of the bilingual conversation is actually the end of the conversation. Here, there is often a clash between the needs of the institution (time, checklists, etc.) and the need for relationship care (the relational: the conversation ends in mutual respect when both parties are in on it). Moreover, 'goodbye' phrases and rituals in many languages are filled with sociocultural values and religious beliefs. If they do not come into play, it is not certain whether the health message of the conversation will be granted the necessary importance.

The second language is a strangely loose language that is strictly tied to the working contexts in which one has acquired the language: job activation, kindergarten, horticulture, family, or bus driver. Ahmad had been driving a bus for 12 years. He spoke Danish on the bus but spoke his own language at home with his wife. When Ahmad fell ill, he had no language. He did not know about illnesses and had no Danish words for illnesses or organs. Ahmad took it as a defeat because he thought he could speak Danish and yet he became completely dependent on an interpreter when he became ill. This became such a fundamental humiliation to him that it triggered a social downfall, where he also let go of his control of other areas of his everyday life, even though he still managed them. He spoke bus language, while other patients spoke a perfect plant language (garden centre) or car language (auto repair shop) with great vocabulary. These patients, however, did not have any vocabulary in other areas, such as body, illness, and health. Bilinguals can thus deceive both the doctor and themselves.

A Franco-Arab immigrant had three languages: one at work as a mechanic (Danish), one in the municipal offices (Arabic), and one in the hospital (French), depending on where he had the best vocabulary. He had worked in a repair shop for most of his life and had difficulties finding the language tone towards female nurses at the hospital when he fell ill: he spoke a (male) repair shop language to them and was met with reluctance and some uncertainty on the part of the nurses until it became clear that it was the only language he knew. He was of the clear opinion that this was how people spoke to each other in Denmark, while it was perceived by ethnic Danish professionals as a highly unacceptable language.

A patient from the Middle East had been working in Denmark for 12 years when he was fired and later accused of stealing from the cash register of the company, which had an electronic accounting system and receipts that the patient had stored in a folder. The patient was acquitted in the district court but convicted in the appeals court. This began a psychosocial downfall, and he had difficulty handling his illness. He understood nothing of what was going on in court, *'I understood less than 10 % of what they said. I lost my language when I was fired.'* He was never asked whether he needed an interpreter. His polite nature and taciturn answers were evidently considered modesty rather than a lack of language skills.

Language not only transmits meaning, it also forms and models meaning. Language is often emotionally processed and integrated into the main language, but this is not necessarily available in the second language. Cultural nuances can be encoded into the language, knowingly and unknowingly, in such a way that they are not immediately expressed in the second language without the intervention of a professional interpreter. A 35-year-old refugee from an African country told a nurse at the MHC, *'You have to understand how it feels to not be understood in order to understand it.'*

Language barriers play out directly in professional communication with the patient and reinforce existing misconceptions, e.g. a conversation that should be about informing and reassuring the patient could have the exact opposite effect if it is about a case of being a 'carrier' of a disease as opposed to actually having the disease or being sick from the disease. In such instances, a patient with little or no schooling quickly loses track and 'gets out of the conversation' before the full information is delivered or understood and leaves the conversation convinced that they have the disease. An example could be having a high risk of diabetes or cardiovascular disease as opposed to actually having these diseases; or having hereditary disease genes that are not expressed but can be passed on to any children and then appear as a disease. It can also be difficult to communicate about illnesses that are only infectious under very specific conditions (chronic hepatitis B and C) or HIV, which today is only evident and contagious if the patient does not take or pauses the medication.

Lack of information in foreign languages about the swine flu epidemic and vaccination opportunities occasioned many distrust-based rumours among ethnic minorities about the Danish healthcare system, the name of the epidemic, and ingredients in the vaccine (1081). In a qualitative study of the perception of the HPV vaccine among Arabic-speaking and Somali mothers and their teenage daughters, it emerged that in some ethnic environments there was a widespread suspicion that the vaccine made the girls infertile, and that the girls could only get the vaccine, if they were examined by a doctor who had to demonstrate that they had not yet had their sexual debut. Both were unacceptable to the mothers, but it is thought-provoking that there are elements of truth in the mothers' perceptions, which are then understood in a different cultural context and thereby misunderstood in a Danish context and become directly exclusionary in their message (1082).

Case 1

A woman referred to MHC was distraught after being in the emergency room with her daughter, who had fever and purulent ear discharge. No interpreter was used and the mother felt the nurse was scolding her. The mother understood that she and her daughter had infectious MRSA bacteria and that they had to stay away from other people. She dared not touch her children or her husband, and dared not stay at

home. She was also afraid that if her husband, who had sclerosis, became infected with MRSA, he might have another *attack*, in which case it would be her fault. It turned out that the mother and her daughter had been swabbed for MRSA in the emergency room for some unknown reason. They did not have MRSA.

One concept that few professionals are familiar with, but which nevertheless masks the core of misunderstandings, is **grey area language**. Grey area words are words that we assume are known and therefore do not need further explanation. Over 50 % of the words in this group are completely subject-specific, and we use them as the foundation in a doctor-patient conversation to explain even more professional expressions to patients.

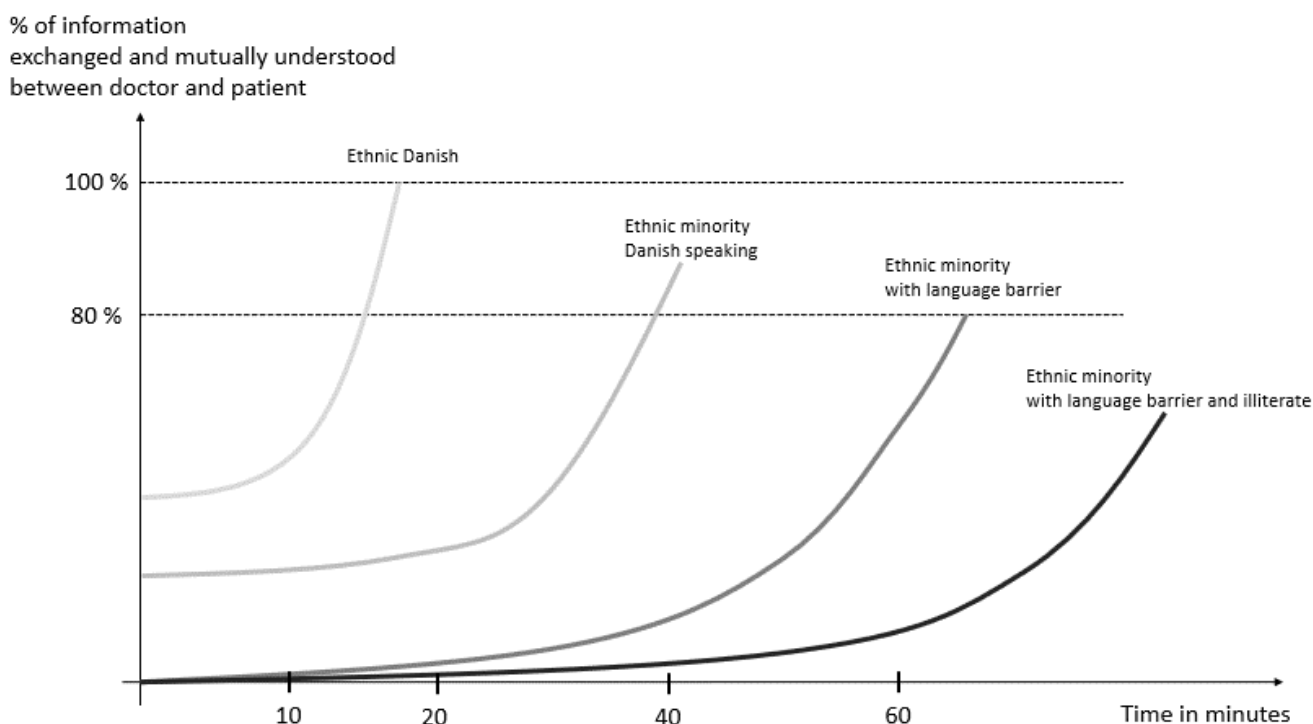
Examples of frequently used grey area words are: perform, selected, consequence, circuit, impaired fitness, oxygen uptake, tissue, prevent, dehydration, fluid register, fluid intake, upon suspicion, increases the risk of developing, preventive element, prescribe, and treatment. The majority of ethnic Danish patients have an idea of what they mean and would know when to ask for an explanation, but for bilinguals and patients who are 100 % dependent on interpreter services, almost all the words need to be explained. Unfortunately, interpreters by experience have a very difficult time mastering grey area language but feel that they should know these words; therefore, they may tend to invent their own explanations/translations.

A study of junior doctors in the US found that their own assessment of how understandable their language was, including body language, turned out to be far removed from reality as seen in subsequent video recordings of doctor-patient conversations. The doctors used an average of two medical jargon (grey area) terms per minute, and only one in five of the doctors used supportive body language. Four out of five did not try to involve the patient in the conversation by asking for feedback about understanding or patient perception (1083).

It can be challenging to communicate risk as a *concept* to patients with little schooling. This also applies to the *balancing of risks* against each other, e.g. between types of treatment or between a given symptom and a perhaps very minor risk of liver damage or an 8 % risk of headache. Just as literacy can be an obstacle, so too can a lack of *numeracy* - although it is less often recognized as an obstacle - in a conversation about the pros and cons of a treatment, as in the choice between many different surgeries and chemotherapy in breast cancer (1084). A proactive attitude in which the patient's concerns and need for information are met from the start can be sensible. The information leaflet for preparations like paracetamol is very extensive for good reason; however, although the preparation will be perceived by most as a harmless pill in normal doses, the contents of the information leaflet may be misunderstood if not discussed with the doctor in advance. The same applies to other common and effective but relatively harmless products, such as weak hormone creams for urinary incontinence. The alternative is likely that it will be discussed with the patient's 12-year-old son or daughter, who may read Danish but can hardly understand the significance of a microscopic risk of cancer compared to the mother's primary problem of incontinence.

The following Figure 27 shows how the time factor in a conversation plays a role in achieving one's goal, here set arbitrarily to 80 % mutually exchanged and understood information between doctor and patient. The necessary conversation time in minutes increases when there are words to be explained (many grey area words), which is the case even for genuine bilinguals. However, it dramatically increases in the case of functionally illiterate people and patients with very little or no schooling. It often takes many hours to obtain the same exchange of information compared to an ethnic Danish patient. Please note that ethnic Danes - and, to some extent, patients born in Denmark to foreign parents - have a certain level of knowledge (*health literacy*) to start with. For other patients, no such starting point exists. They may even have negative or counter-productive knowledge that needs to be processed before new information can be added.

Figure 27. The link between the amount of information and the time needed for the conversation, taking into account language barriers and schooling.



Patients with language/reading difficulties ask the doctor fewer questions about medical issues during a conversation than other patients (median = four for patients with language difficulties as opposed to six questions from patients without language difficulties). They also ask fewer questions about general (e.g. practical) topics. Patients with language barriers were also more likely to need more information repeated more than once, suggesting that basic information was not understood from the beginning. They were less likely to use medical terms, to refer to medications by their actual names, or to ask for additional help or information, and they rarely sought new information elsewhere about their illness. These findings were not related to gender, age, or education (1085).

18.2. Cultural sensitivity and adaptability of doctors and patients

Some of the factors that have attracted attention are the patients' degree of socialisation in the host country (primary cultural orientation, *acculturation orientation*) versus the doctors' cross-cultural sensitivity (and cultural orientation). Cultural orientation is assumed to have an impact on patients' thoughts, expectations, and behaviour and on the majority population's attitude toward the 'value' of different ethnic groups (1086, 1087). Doctor-patient relationships often become more complex and suboptimal in intercultural contexts. Cultural rapprochement or adaptation is a particularly important factor in this process, and doctor-patient relations are a key component of patient care. This is why it is important to be aware of the interrelationship between the cultural orientation of each immigrant patient and the quality of the doctor-patient relationship based on the patients' perceived quality of care, and how this relates to immigrant health behaviours and quality of life of the patients. In a PhD thesis on cultural orientation, Whittal found that the doctor's cultural orientation had the greatest effect on

medication compliance, while the effect was less for SNAP factors (smoking, nutrition, alcohol, and physical activity) - which were more influenced by the patient's cultural orientation (1088).

A Canadian study found significant correlations between cultural attachments based on various factors that describe the degree to which participants felt connected to the host country or the culture in their home country. The patients' expectations of their doctor were significantly related to the patients' perceived quality of treatment, which was also correlated with improved health behaviours (medication compliance, diet and exercise advice, as well as maintaining self-care). Cultural orientation can be an important factor in the relationship between the doctor and the migrant patient through a complex process involving the patient's perception of the doctor's expectations and the perceived quality of treatment (1088). In a comparison between Arabic-speaking patients with type 2 diabetes and English-speaking patients with diabetes, Arabic-speaking patients were found to visit the doctor later than the English-speaking patients, even when they had obvious symptoms. The barriers identified included: previous bad experiences in connection with doctors and nurses, no use of interpreters, poor network, and lack of knowledge of the health care system (1089).

Doctors who have been taught cultural competencies are better at communicating with ethnic minority patients due to: 1) a greater communication repertoire, 2) better and safer situational awareness, 3) greater adaptability, and 4) more knowledge about key cultural issues. Such training tends to increase the doctor's interest in other cultural approaches and motivates them to apply cross-cultural knowledge and curiosity in diagnosis and treatment, and in patient involvement (1090-1092).

18.3. Points to be aware of in cross-cultural communication tasks with patients

If one wishes to work on strengthening cross-cultural communication, here are a number of general and specific points to be aware of.

1. General tasks

1. Interpreter assistance: Identifying needs, type, and scope.
2. Communication skills for interviews with patients in need of an interpreter.
3. Competences in linguistic variation and level of complexity.
4. Interdisciplinary and intercollegiate communication during a patient interview.
5. Reflection over own strengths, weaknesses, and limitations as well as critical assessment of own skills.
6. Managing your own emotions and reactions in interactions with patients and relatives.
7. Awareness of own views and prejudices towards the patient.
8. Consciously active involvement of empathy, sympathy, and professional curiosity.
9. Downplaying dislikes, cynicism, and indifference.
10. Recognizing one's own ambiguity tolerance, concepts of normality, and sensitivity towards diversity.
11. Questioning techniques (e.g. appropriate use of open and closed questions).
12. Handling situations where the doctor/nurse does not feel sufficiently competent.

2. Frameworks and starting the conversation

1. Establishing an appropriate physical framework for the conversation.
2. Establishing partnership in relation to the patient.
3. Showing respect in the interaction with the patient.
4. Building trust.
5. Reducing disease-related stress.

6. Awareness of cultural and social factors (e.g. religion, sexual orientation, ethnic background) in relation to the patient.
7. Strategy to uncover hidden treatment burdens, social burdens, and significant psychosocial events of importance for symptom presentation, diagnosis, and treatment.

3. The conversation

1. Confidentiality is often an unknown phenomenon - name it and explain it.
2. Use language that the patient understands - methods of language customization.
3. Language clarification of the structure, agenda, and objectives of the conversation (explanation building, partial conclusions, consensus clarification, compilation, repetition).
4. Continuous summary and ensuring patient understanding (*'is it correctly understood that ...?'*).
5. Use alternatives to the normal very direct style of 'question and answer' when seeking information (try a more conversational and more indirect questioning technique).
6. Actively follow up if the patient provides information that appears to be unrelated; it may have an impact in a way that cannot be anticipated or guessed at.
7. Return to topics that give rise to very short answers or very nebulous answers. Make sure that the interpreter understands the question and that it is not a sensitive subject.
8. Repeat information: if there are several alternatives, review them in detail and make a clear distinction between them.
9. Signalling (use of phrases that clearly mark transitions in conversation).
10. 'Chunking' information (providing small chunks of information at a time).
11. Pay attention to and respond to the patient's indirect attempts to explain things and hidden allusions (clues).
12. Avoid abstractions, metaphors, idioms, etc. as they can never be translated unambiguously and there is a great risk of serious misunderstandings because metaphors often involve traditional values about objects and animals that are not uniform across societies (dogs, foxes, snakes).
13. Beware of vague hypothetical phrases that require deeper language skills, e.g. phrases starting with, *'What if ...?' 'Could you, for example, think ...?' 'Maybe, it would be a good idea...?'* (for people who have attended school only a short time, such wordings can be confused with definite statements).
14. Be clear about your limitations - listening to a problem does not necessarily mean you can solve a problem.
15. Thoroughly consider strategies for preferential diagnostics - identify the patient's expectations and needs and immediately preferred outcomes of the course of treatment.
16. Patient involvement in the decision-making process based on the patient's wishes (assessment of the patient's wishes regarding involvement in decision-making). Inclusion of patient perspectives (e.g. ideas, concerns, and feelings).
17. Inform about the 'pros and cons' of treatment and the expected results, as well as consequences of different choices and of opting out of treatment.
18. Adapt the treatment plan in line with the patient's perspectives, needs, resources and strengths.
19. Validate and respond to the patient's perspectives on their own illness.
20. Managing uncertainty in the conversation with the patient (in terms of diagnosis, treatment options, prognosis, etc.).
21. Clarifying the clinical basis for the decision-making.

22. Tackling multiple illnesses and prioritising among illnesses.
23. Communication of risks, balancing the pros and cons of procedure or treatment - and adapted to the patient's situation and level of understanding.
24. Managing situations where the patient asks for the doctor's own opinion; is a balance between the doctor's own contribution and support of the patient's decision-making.
25. Responsible strategic use of authority.
26. Managing situations that may be embarrassing or sensitive to patients.
27. Planning further treatments with the patient.
28. Obtaining informed consent.
29. Involvement of relatives.
30. Strategies to support behavioural changes in the patient's lifestyle as well as health promotion.
31. Prevention and management of conflict situations and strategies for conflict resolution.

4. Special situations

1. Handling emotional patients (e.g. pleading, crying, anxious, unexpressed feelings)
2. Managing dissatisfied and demanding patients.
3. Managing patients with strong emotions (e.g. anger, denial, stress).
4. Dealing with unusual patients - patients with abnormal forms of communication, deviant language usage, or ambiguity.
5. Managing patients with loss of impulse control, aggression, or particularly high stress levels.
6. Managing very talkative patients or patients under great pressure when talking about highly unpleasant experiences.
7. Dealing with silent patients.
8. Management of psychiatric patients (e.g. psychosis, suicidal thoughts, etc.).
9. Communication with children and their parents on difficult issues of importance to the whole family.
10. Communication on ethical considerations and dilemmas.
11. Handling errors and adverse events.
12. Communication about death and dying, delivery of a serious message.

19. Sexology from a cross-cultural perspective

When you cross national borders, you also cross linguistic, emotional, and behavioural borders. Opportunities and barriers change, social norms are modelled, and roles also change. Perhaps what was banned in the home country is now possible, or the opposite may be the case. Words and concepts that are taboo in the native language may be more easily expressed in the second language. If one comes from a culture where it is impossible to talk about sexual relations, the second language can serve as a tool for discussing issues that are too embarrassing to discuss using the 'forbidden' words in one's first language (1093, 1094). Almost half of the young people of Turkish descent in Germany preferred the German language when talking about sexual subjects. The same seems to be the case in Denmark (1095). Gender roles are always an area of tension that undergoes constant negotiation and transformation, but in a new country, with a new language and new (often dual) identity, gender roles become difficult. Many migrants are unprepared to have their emotional and behavioural boundaries moved. The 'right behaviour' for women and girls is usually equated with the fulfilment of traditional gender roles, which means women's adherence to family and traditional cultural values. Women's roles and sexuality become the 'bastion' of tradition against the confusing and disorienting cultural differences in the host country (1094). Some minority groups create the image of an ideal 'virtuous' woman and strongly support the contradiction between 'the purity of our women' versus the notion of 'promiscuous Danish women'. Young women from minority groups are being challenged by additional conflicts. They need to find a balance between the imposed hyper-sexualisation of a mainstream culture that sees them as 'exotic' and at the same time the 'hyper-purity' that is expected of them. For immigrant families and groups, the constant monitoring of women's bodies and behaviour becomes a means of asserting moral superiority and sticking to the old and familiar against the new and unknown. Women's gender roles can change because of migration to a country that has more equality and because they need to take jobs in environments that differ from those they are used to and that are away from family surveillance (1096). Sexuality is largely governed by culture. It is not considered abnormal if an Asian woman does not have a sexual drive (1097). Sexual notions are cultural beliefs such as the Latino American man's *machismo* and the woman's *marianismo* as well as the Iranian women who maintain, and are expected to maintain, family honour in a *khanum* image (1098, 1099). The concept of *marianismo*, rooted in Catholicism, places the Latina woman in a role model of sexual morality, honour, self-sacrifice, passivity, and care, while *machismo* defines a man's role as the outward masculinity, which is quite the opposite and challenges female honour and passivity (1100). The role of Spanish men as *machismo* can be performed by having intercourse, but in the end only pregnancy, either premarital or during marriage, is the authentic proof of his *machismo* or manliness (1101, 1102). In an interview with 50 Bangladeshi men, power over women was described as 'natural' and 'normal'. Sexual intercourse was described as a 'game', a match (*khela*) and was perceived as the only competition between the sexes and, therefore, the only game in which a man can lose to a woman (1103). Thus, sexual intercourse poses a threat to his natural power over the woman. The shame of 'losing' or ejaculating before the woman wants to stop the intercourse threatens his masculine sexuality. In many societies there is a distinctly negative attitude towards premature ejaculation as seen among Muslim men, who describe premature ejaculation as a punishment (1104).

Motives for sexual activity vary from culture to culture. In cultures where sexuality is considered an expression of love, affection, and intimacy, sexual dysfunction can be seen as a threat to the relationship and to the personal relations between two people. Where sexuality is considered a source of pleasure, interruption of sexual function leads to a loss of quality of life. However, when the motivation is reproduction and marital duty, sexual dysfunction has a completely different meaning, and here there will be quite different sexual problems that can mean divorce or social exclusion. French men and women associated sexual activity with pleasure (44 %) and love (42.1 %), but rarely with reproduction, children, or motherhood (7.8 %) (1105). In Mozambique, women see sexual encounters as pleasant and

successful when the direct purpose is to get pregnant and thus create stability in the family - until the next child (1106).

Sexual problems are a global issue, but symptoms and expectations of treatment vary widely. Western-defined dysfunction may come with a culturally adapted explanation and treatment, as is the case in rural areas of Iran, where patients with 'imperfect' marriages believed that women were 'locked' and therefore needed to be 'opened' by a traditional healer (1107). Newly-wed women suffering from vaginismus (the involuntary contraction of the pelvic floor muscle group that leads to painful and/or impossible vaginal penetration) have enormous social pressure on them to consummate the marriage on the first night of the marriage or soon thereafter (1108). An 'incomplete' marriage can expose these women to a loss of social status as well as further trauma.

Local perceptions are not always in line with those of health professionals. The practice of *dry sex* practised in sub-Saharan Africa as well as Asia and Latin America is described as a voluntary change of the vagina to create a virgin state that represents a woman's youthfulness and creates more friction and greater enjoyment during intercourse (1109, 1110). This view is also found in the Zulu population in Southern Africa, where tradition says that abundant humidity during intercourse is a result of illness or infidelity. Western doctors are more likely to consider vaginal dryness a dysfunction, such as a lack of sexual arousal (1111, 1112). In addition, religion is a sociocultural factor that is closely related to sexuality. Values and traditions concerning sexual significance and rituals are essential to religions. Factors such as sexual guilt and shame are closely related to religious influence (1113, 1114). Negative publicity and ambiguous values around sexuality affect sexual self-esteem, and unclear sexual norms create insecurity and guilt (1115-1117). Several studies have shown that a lack of sensitivity to diversity in sexual counseling and treatment leads to inequality in sexual health, especially among minority women (1094, 1118).

At various times, increased numbers of migrants arrive in Western Europe. Both the number of arrivals and new ethnic minority groups lead to specific challenges and dilemmas in sexual and reproductive health. Access to the health care system is often problematic and so is the nature and availability of information, which challenges the health of vulnerable migrant groups (1119-1122). The 'social' and cultural components that can contribute somewhat to sexual dysfunction often fail to get enough attention from health professionals. Sociocultural factors are significant because they constitute the uniqueness that each person brings to the clinical conversation. Culture affects not only how the individual talks about sexual problems, but also what sexual problems he/she is most likely to talk about and how they are perceived or explained by the patient. Political correctness, lack of cultural competencies, and a micro rather than a macro view of sexual dysfunction often prevent adequate involvement and analysis of the possible role that culture, religion, and social norms may have on sexual behaviour and function. That said, health professionals are challenged professionally and experientially when it comes to reproductive health and sexology issues (1123-1126). Female interpreters are exposed to a particular but not uncommon problem in which their ambiguous role as the patient's confidential and professional interpreter can put them in situations where male patients can misunderstand the 'intimacy' of the conversation and invite them to, and perhaps expect, a sexual relationship (1127, 1128). Internally displaced persons and people fleeing war and conflict can often witness or be subjected to torture, killing, atrocities, imprisonment, hunger/deprivation (e.g. food, shelter), individual or mass rape, sexual assault, and physical fights. Many refugees experience several traumatic events, yet their escape to refugee camps does not guarantee a safe haven because the camps are often overcrowded, unsanitary, and physically unsafe, especially for women (but also for men). Furthermore, violence and sexual assault can create a dangerous psychological environment in the camp, where pre-existing trauma and psychological problems such as sexual dysfunction can be aggravated and become chronic (1129, 1130). Pregnancy is an important condition, especially for a fragile refugee family, but many pregnant women have trauma from their home country that can have an impact (including re-traumatisation, heightened alertness, and depression) during pregnancy. In a Canadian study, over 50 % of pregnant migrant women said that they

had been exposed to partner violence that affected their marital relations (1131). Female circumcision is by its very nature a complex health problem requiring knowledge, experience, and intercultural competencies that are not covered by the general curriculum of health education (1132-1134).

Reproductive values and attitudes towards sexual life among migrants can be far removed from the knowledge and attitudes conveyed in health education in countries like Denmark (1135, 1136). For female migrants, sexual violence and sexual exploitation are among the main health issues for which they lack adapted health care services (1137, 1138). For male labour migrants, particular attention is paid to changes in sexual behaviour (called *situational inhibition*) that can expose them to sexual failures, rape charges, HIV, and other sexually transmitted diseases (1139). Collecting migrants' knowledge and attitudes about sexual and reproductive health requires customized and sometimes unconventional strategies and research methods (1140, 1141). Women in particular may need help balancing the often conflict-laden values of the home country and the host country in exile (1142-1144). Sexual minorities may end up being minorities within the minority as doubly excluded, and their quality of life is often considerably inferior to that of other minorities because they live multiple double lives. For this reason, they can be difficult to identify and get into communication with; at the same time, the available professional literature is of little help in this area (1145, 1146). Sexual abuse, rape, and child abuse are not unusual in chronic conflict zones, and this gives rise to major problems of understanding for health professionals because these events can be associated with early harm, psychological scars, guilt, shame, stigma, and language barriers that all must be included in the diagnosis and treatment of sexual dysfunction (717, 1147, 1148). Migration to more Western societies often leads to cross-cultural conflict areas between sexual and family (generational) cultures vis-a-vis the host country. These problems and dilemmas can be divided into four main categories: 1) frequency of illnesses and specific risk factors, 2) psychosocial, ethnic, and cultural aspects, 3) communication, and 4) moral and ethical dilemmas. Fundamental ethnic differences in 'what you need to know about' and how obvious the need for knowledge may be expressed are challenges that have never truly been addressed by the health authorities of countries receiving migrants (1123, 1136, 1149). The need for interpreters is an additional barrier that is rarely taken seriously in the host country (1123). Large ethnic differences have been found in the propensity to speak about or report sexual abuse of children, and it is important that doctors and other professionals working in this field acquire skills in detecting the often subtle signals that tend to appear in connection with social events (work, childbirth, family reunification) (1150).

In terms of epidemiology, an increased incidence of unwanted pregnancy and abortion, HIV/sexually transmitted infections, and sexual violence is seen among ethnic minorities. Effective contraception is limited by little and imprecise knowledge of bodily functions, poor finances, ambiguous attitudes towards the use of contraception, and barriers to accessing information on contraception. Psychosocial and cultural aspects affect the values, norms, and attitudes of individuals and ethnic groups with regard to family, social relations, sexuality, and gender. Norms and attitudes influence the sexual and reproductive choices people make as well as the opportunities and limitations they perceive in their choices. Problems in communication relate not only to language, but also to the style and framework of communication, the way patients present their problems, and the expectations they have of the health care system. Communication problems easily lead to discrimination and poorer quality of treatment. Moral and ethical dilemmas arise when cultures and ethnicity meet in areas where there are strong and deeply entrenched, but disparate, values and practices. This is evident, e.g. in relation to sex education, issues of virginity/chastity, the importance of reproduction, the right to one's own body (and womb), and access to reproductive guidance. In many multi-ethnic Western societies, differences exist across ethnic sexual cultures as abortions (and unintended pregnancies) are relatively more common among women of immigrant background compared to their Western counterparts (1151).

19.1. Hidden factors

Some topics are considerably more sensitive to talk about than others. Particularly in the cross-cultural field, there is a risk of communication failures, exclusions, and serious misunderstandings. Sexuality and sexual life are often considered particularly sensitive issues and, in the context of ethnic minorities, they can present particular challenges. However, it is more the context in which they are discussed and the situation being addressed that determines whether or how sensitively they are perceived. The framework of the conversation, the concepts used, and the way the topics are addressed are absolutely crucial, and this requires a basic understanding of the circumstances and differences of refugee immigrants. There are three hidden factors in the conversation with potentially sensitive content that need to be understood from the start:

1. Many people only rarely have conversations about sexual identity, concepts, or experiences and may therefore lack a safe language and conceptual apparatus in the conversation. The language used by the questioner (the professional) can therefore determine whether the patient/client experiences it as an unexpected and violent intrusion into private life or a safe and friendly conversation on the person's own terms with the patient/client's own concepts and conditions. Many ethnic minority patients express, '*the doctor's questions do not help me.*' As professionals, we can use words and concepts that disturb or confuse, and our questions may be far off from where the patient/client would like to go with the conversation. Although a person seems interested in talking about sensitive sexual relationships, it is not a given that the client and the therapist/doctor have the same ideas about the content and objective. Thus, it is the task of the professional to clarify objectives, the level of detail, and the concepts to speak about so that both parties can move in the same direction. For example, try to clarify the perception of sexuality: is it primarily a reproductively defined activity or are there also other, more sensitive elements in the sexual intercourse? Are there different sexual lifestyles or is there only one, or is there no notion at all of sexuality as something that can be subject to experiences, attitudes, or problems?
2. Patients/clients may perceive certain actions or circumstances to be deviant or repulsive. It could be actions they regret and that could lead to reprisals and immediate exclusion were they to come forward within their own ethnic group. In a small minority group, social contacts (even the weakest ones) are essential and there may be a fear, often completely out of proportion, of something deviant and abnormal, which inhibits the conversation if this fear is not addressed directly by the professional. Often, the feeling of 'normal' is disturbed and unclear in a foreign country and in the framework of a small and diverse ethnic minority that does not always have a clear concept of normality as a group. There are few and more often no opportunities to clarify personal fears and doubts about sexuality and practices. Thus, the individual is often left to make an assessment alone that typically ends with guilt, shame, and excessive self-control. For example, several wrongful acts are considered *haram*, i.e. sinful, illegal, and forbidden in Islamic practice. 'Unacceptable' behaviour can have many forms of which 'illegal' sexuality constitutes one of the most important categories. Because heterosexual marital sex is the only permitted form of sexual behaviour according to Islamic jurisprudence, men may engage in *zina* or 'illegal' sexuality. Although there are many 'sinners', Islam is not a religion that promotes individual confession (either confession in church or confession to others). Islamic imams do not usually assume a pastoral role as a witness, and thus individuals cannot confess a sin to obtain 'official' forgiveness. As a result, Muslims who have 'sinned' have no religiously sanctioned

or socially accepted ways to remove their *asrar* or 'secrets', including through support groups or psychotherapy. As a result, the patient may develop chronic feelings of shame that can affect sexual desire and cause erectile dysfunction (1152, 1153).

3. The importance of ethnicity in the specific conversation must be made clear. No one is 'ethnic' in isolation. Ethnicity is something that occurs in the meeting with someone who is not part of one's ethnic group. It is the clear difference one or both experience in the meeting/conversation between two ethnic groups. Most often, it is more of a perceived than a real ethnic difference. Schooling, social status, language control, level of integration (acculturation), and health competencies are often the factors that must be taken into account (1154). An unknown, but frequent, social factor is refugees' fear that manifestations of health problems of any kind may affect their residence permit, social benefits, and requirements from the municipality; thus, they are not likely to reveal anything beyond 'the most necessary' symptoms. Therefore, it can be a lot of work for the professional to create trust and motivation to talk about more sensitive and deeper topics. The issue of confidentiality, including the interpreters' confidentiality, is key. Active information on professional confidentiality is an important instrument in conversations of difficult content and surprisingly, many patients are unaware of this duty (1155).

19.2. Reproductive exile

In several studies, the anthropologist Inhorn interviewed Iraqi men who contacted a private fertility clinic in Detroit, USA, where they talked about their reasons for contacting the clinic and their own understanding of their sexual challenges as refugees in the United States. One case concerns a man, Shaykh Ali, who was born with testicles that had not descended. He underwent surgery in his home country, but there was no evidence of live sperm cells either in his semen or in a testicular biopsy. Nevertheless, he tried, unsuccessfully, to have children with several different women in his home country. The war came and like many other young men, he ended up as a refugee, first in Saudi Arabia and later in the United States. Here, he succeeded in finding and marrying an Iraqi woman, but after three years of strenuous efforts, the wife asked for a divorce due to infertility. She found herself a new man with whom she had two children. Out of respect, she named one of her children after Shaykh Ali and called him the children's 'uncle.' This made the patient proud, but at the same time it hamstrung him. Shaykh Ali found a new wife and applied to the fertility clinic for help. He had heard from some of his friends about an American footballer whose testicles had been injured in a football match but who had become fertile again by having one of his brother's testicles transplanted. The clinic rejected the option but recommended as a start that he provide semen (through masturbation) that the clinic could 'concentrate'. The patient rejected the option because masturbation is prohibited (*haram*). On the other hand, the result of involuntary 'nocturnal ejaculation' was allowed. That solution failed, however. The clinic then suggested the possibility of donor sperm, but that option had the immediate effect of giving the patient what he himself called 'bad psychology' and loss of self-esteem with regard to his new wife. Shaykh Ali had to acknowledge that there was no acceptable solution for him, and so his new wife also left him.

In another case, Inhorn describes 37-year-old Ibrahim, an English-speaking engineer who had taken part in the uprising against Saddam Hussein and who had been hit by gunfire in the pelvis, leading to a lengthy hospitalization with many operations. While he was hospitalized, his family was punished by Hussein in that the patient's brother was jailed and '*disappeared*'. Ibrahim escaped but ended up serving six years in a Saudi prison before he was finally granted refugee status and arrived in the United States. By the age of 30, Ibrahim had had two instances where he paid for sexual experiences with women, both in his home country. The free sexual morality of the United States facilitated Ibrahim's attempt to impregnate several women in the United States but without success. He blamed himself and

the fact that he had *'used all his sperm'* in his home country when buying sex, and now Allah was punishing him harshly by making it impossible for him to have children. Ibrahim's father in Iraq arranged a marriage to a woman from Iraq who obtained family unification in the United States. When the new wife got the impression of there being a fundamental reproductive problem, she arranged for an examination at the fertility clinic, which showed that Ibrahim was unable to deliver the sperm to have children. The wife was understanding and loving, but Ibrahim was devastated, *'I'm not a real man. It's a really unpleasant feeling.'* However, his wife persisted, and the clinic provided information about his condition, until Ibrahim eventually accepted his condition as a relatively normal condition that many men must accept, like the hair on their head, their height, and their appearance. Ibrahim had to learn that manliness is not necessarily expressed by how many children one has and that a marriage can be based on something other than children.

HIV infection in ethnic minority groups is a typical example of a sexually related issue surrounded more by perceptions than facts and where most people choose silence out of a fear of exclusion. It may also be that dominant leading figures in their ethnic group have a clear, but inappropriate, attitude towards sexuality. Normality in the minority context is central - one must not deviate; ill health causes concern and leads to accusations from the surroundings. In this context, it may be forbidden to discuss any health problem, sexual or otherwise, with others in the family or a social network. Thus, the professional can be faced with the huge responsibility of being the only person that the patient/client can talk to about these often ordinary but crucial problems and values. A respectful and professional curiosity in a framework that is initially built up by the client and on the client's terms is key: most people are rational on their own terms. Therefore, these are the terms that need to be brought forward.

A large study from the Danish Health Authority in 2005 on knowledge about sexually transmitted diseases among four large ethnic groups in Denmark found that the abortion rate was higher for ethnic minority women, while knowledge about sexually transmitted infections and reproductive health was very modest. Unsafe methods such as interrupted intercourse and 'safe periods' were frequently used. Among young people, there was a widespread perception that sexually transmitted infections only affected ethnic Danes, and many believed that you could not get sexually transmitted infections if you had sexual intercourse with someone from your own ethnic group. There were large ethnic differences in knowledge and behaviour, but some ethnic groups only came across information about reproductive health in connection with pregnancy (1156). The attitudes toward women's sexuality depend on ethnicity. In Somalia, Sudan, Egypt, and the Gulf region, female sexuality is highly taboo, and in narrower circles within those countries, it can even be directly regarded as shameful. On the other hand, it may seem easier for women from Palestine, Lebanon, Jordan, and Syria to talk about women's sexuality. There are no clear, applicable rules, and the only solution is to concentrate on the patient's own circumstances.

Existing offers concerning sexual health are often considered culturally insensitive in their language and content, and the way sexual topics are referred to can cause certain groups to directly reject these offers: *'These issues do not concern us. They are not problems we have.'* (1157) With their language choices, some campaigns have had a directly opposite effect from what was expected: The HPV vaccine was partly presented as a vaccine against sexually transmitted disease and worked best if given before sexual debut. In some ethnic groups, that message was understood to mean that the girls had to be examined for sexual activity by the doctor before they could be vaccinated. The vaccine was rejected by the mothers, who firmly denied that their daughters were sexually active, and they did not want their daughters being examined by a doctor who could risk breaking the hymen with consequential marital problems in the future (1158).

Cultural differences in the social significance of specific disorders are frequent but often hidden. In some ethnic groups, urinary incontinence is a totally unacceptable disorder - socially and humanly. As an 'unclean' person, one may not pray, and incontinence is an expression of the body being abnormal

and imperfect, and it is considered a childish and immature problem. Unfortunately, it is a highly frequent issue for women but a subject that should not be talked about, even with the doctor. The problem is internalized, and it affects the patient's sex life and religious life and reduces self-esteem, and there is a high risk of stigma (1159).

Culturally sensitive and validated methods have been developed, however, to obtain sensitive information on sexual behaviour and reproductive health that combine computer-assisted questionnaires with direct interviews (1160).

19.3. Age and generation

Young refugees/immigrants can pose a particular problem due to having very little knowledge as well as having language barriers to acquiring knowledge. The social framework changes after migration, and opportunities may open up for contact with sexual partners in other ways and contexts than in the home country, which may give rise to sexually risky behaviour (1161) (1162). Many young people experience emotional conflicts between morality and norms at home and the new opportunities. Complicated double lives are common, but are not without cost and conflicts, which can affect sexual pleasure in the interface between two cultures (1163). Also, among young people, questions of confidentiality, guilt, and shame can act as barriers to acquiring knowledge (1164). Gender differences in sexual values can give rise to frustrations between the sexes: most often, young women are subject to clearer and tighter sexual frameworks (abstaining) than are boys who, in contrast, are allowed to have several sexual partners before marriage (1165). Similarly, areas of conflict in behaviour and language can occur between the knowledge girls acquire in school versus the knowledge boys acquire outside school, e.g. through the Internet (1166). Teenagers belonging to ethnic minorities are also vulnerable to sexual activity being used to replace care, love, and acceptance because they need to fit in and may have limited social support in the new country. For young immigrants, becoming sexually active means that they are adults (1167). There is often greater sexual freedom for boys than for girls in ethnic minority groups and a greater acceptance of occasional sex. Premarital sex is openly accepted for boys, and a 'double standard' may even be sanctioned and be considered masculine in some ethnic groups (1168).

At the other end of the age spectrum, menopause is a turning point for many women with regard to the sexual context. In some ethnic groups, menopause means that you stop being a woman because the reproductive capacity ceases. One woman described it this way, *'In my country, you are almost dead when you are 60 years old. Everyone is waiting for you to die. In Denmark, the good life starts when you are 60. I see 70-year-old (ethnic) Danish men kissing their wives and holding hands as if they were 20 years old. When men turn 50 in my country, they turn their heads away when they see their wife, and you have to be grateful for a 'good evening'. It's a good day if you get it.'*

There are large ethnic differences in sexual desire and activity leading up to the menopause, but these are primarily due to differences in expectations and relationships between the sexes (1169).

19.4. The healthcare professional and religion

Few studies have explored the professional challenges of sexual counselling aimed at ethnic minorities with very mixed religious affiliations. One study conducted among staff at a sexual health counselling clinic in London found that the following topics often required more time and cultural/religious adjustment: homosexuality, termination of pregnancy, treatment of sexual dysfunction, knowledge of sexual relationships and anatomy, and the perception of high-risk behaviour. The study noted that there could be large differences in how much knowledge and how much detail it was considered necessary to have about bodily functions (1170). It is important to emphasize that culture and traditions are one thing, and religion is another. Many of the myths and 'rules' that ethnic minorities follow are ancient traditions, but they are given a religious basis in exiled ethnic minority contexts. Generally, religion and ethnicity

are not in themselves associated with more frequent sexual dysfunction among ethnic minority women relative to the local population, but ethnic minority men have more frequent medical conversations about sexual dysfunction than other men in England (1171, 1172). The best indicator of an underlying sexual dysfunction in men were frequent appointments with the doctor about 'trifles'. Culture and religion also affect sexual function/dysfunction, as well as the understanding and treatment of cohabitation issues. Cultural learning and cultural and religious restrictions can often lead to sexual dysfunction, especially when they have to be lived out in a cross-cultural field between the sexual attitudes of the majority and those of the minority. Young people belonging to ethnic minorities, in particular, are burdened by a double life in relation to sexual norms and religiosity (1173, 1174).

19.5. Special vaginal practices

A wide range of ethnically specific procedures around vaginal hygiene has been described, which in some cases can be harmful to health and are therefore important to know, see (1175, 1176). For a more detailed review, see the chapter on cross-cultural sexology in the book *Sexology – Professional Perspectives on Sexology* (1133).

19.6. Sexual violence

Sexually explicit violence has become a weapon of war that is most often directed at women and children, but men can also be subjected to sexual humiliation in prisons (1177, 1178). Sexual violence has long-term consequences and puts a lasting stamp on adult sex life (1179, 1180). It should be particularly pointed out that many patients with PTSD lack the desire to feel desire. Having vaginal intercourse can be re-traumatizing because it can lead to flashbacks (uncontrollable re-experiences of torture or rape). For fear of affecting the partnership or marriage, patients with PTSD may choose not to tell their partner about past experiences, but past sexual assault or torture often becomes an ongoing point of conflict between spouses and frequently leads to sexual dysfunction. In particular, torture with sexual content can lead to both specific and non-specific sexual dysfunctions, but it can also lead to anxiety about modern endoscopy in hospitals, rehabilitation machines, or training in swimming pools.

Sexual violence has had an almost epidemic proportion during wars in central Africa, but there were also war-related rapes at the end of World War II, as in Germany. Very few war refugees spontaneously share these experiences, although for most people they come into play daily and are the cause of sexual dysfunction (1181).

19.7. Specific challenges faced by migrant women and young people

A woman's status is usually linked to her role and status in the family and is defined in relation to her male partner. Migration can therefore place women in situations where they experience stress and anxiety due to the loss of their relative safety in their traditional social settings and environment. Migrant women are more vulnerable and prone to sexual abuse and violence, which also exposes them to higher risk of sexually transmitted infections, including HIV, and a range of PTSD associated with sexual violence. Their social integration into a new society and the knowledge that comes with it may be limited by a short education and lack of work experience. Their need for knowledge about reproductive health often goes unnoticed, and they are often quite unprotected, even in well-organized and safe refugee and immigrant situations. Health professionals are often unaware of the immigrant women's need for special services and targeted information (1182).

A Swedish sociological study of the sexual difficulties of Somali women and young people in exile showed that the Somali culture does not support children having sex education in schools or referring to the names of genitalia except as metaphors (1183). Girls, unlike boys of the same age, experience a very frightening process in childhood, where their self-esteem is reduced through social management

and active control of 'virginity' and sexuality. Their integrity as women is disregarded. When Somali refugees came to Sweden, the young ones in particular adapted to Swedish lifestyles and cultural norms. The relationship with a new culture with its new expectations of obedience to norms created new opportunities to strengthen self-esteem. The situation of being in exile tends to generate horizontal conflicts between spouses and between groups of people with different and conflicting views on the balance between traditional Somali values and Swedish values of gender and sexuality. Being in exile also tends to generate vertical conflicts because the values of the generations collide - especially when it comes to sexuality and sexual relations. The younger generations question the authority and insights of adults as parents because young people are given information through channels other than those normally controlled by parents. However, the young people's new dreams and choices do not match their parents' expectations, which sometimes leads to major problems and impossible choices between family life and social life. Political turmoil and domestic poverty have forced many Somalis to emigrate. They have left not only their house, families, relatives, and friends but also their culture, customs, and routines, and they often end up in a no man's land in terms of values, while the young people challenge their authority, knowledge, and routines. From a traditional perspective, young people lack respect for traditions and indigenous culture. From a male perspective, this means more specifically a lack of respect for male dominance and superiority in sexual contexts. In Asian migrant environments, many develop a hybrid 'migrant identity' that entails sexual behaviours and values that can be difficult to understand and are therefore inaccessible to influence (without qualitative studies) (1184). Values related to sexual and reproductive health are formed primarily in the cultural context where one feels most secure, but they are constantly remodelled by new cultural and societal contexts. Second- or third-generation immigrants in the West often have a more fluid and mosaic sexual morality with elements from multiple cultural contexts (1185). For example, notions and ideals of 'virginity' can be mixed and updated in the encounter with new cultural contexts (1186-1188). The young female migrants are very clear about their dilemmas in this double life: their parents' routine distrust and constant social control are mentally fatiguing, and eventually the easy solution is to find a young man 'who understands' and thereby regain a small corner of power over your own (sex) life (1189, 1190).

There is an increased incidence of unwanted pregnancies, abortions, sexually transmitted infections, and sexualised violence among immigrants relative to the host country's local population. Being an immigrant or refugee can pose an obstacle to accessing sexual and reproductive health services, and the use of contraception may be deficient, just as the abortion rate is higher (1191). Several studies suggest that the level of knowledge about reproductive and sexual health among refugees and immigrants is lower than in the general population. Possible barriers could be language or social barriers, shame, misunderstandings, poor communication in the family, and lack of cultural sensitivity in the health care system (1164).

Health depends largely on past experiences, where negative sexual and reproductive experiences are closely linked to violence and mental health problems. Many refugees come from areas where they were barred from counselling and available reproductive health and where sexual assault and partner violence were rife. The result is internalised guilt, shame, and stigma, where silence seems to be the only way out. In a qualitative study among female Somali refugees in Sweden, silence, isolation, steadfastness, and religion became the only ways to live with the negative sexual experiences (1192). The study concludes that violent sexual experiences are often not mentioned spontaneously and are frequently overlooked in health care, even though they can contribute heavily to isolation and negative integration. Many women, particularly those who have been family united, fear that a possible disclosure of past sexual assaults could dissolve their marriage and send them back to their home country. Family-reunited women who have since divorced are not infrequently pressed into sexual compensation by the ex-husband in return for him taking and collecting the children from school or driving the woman to the doctor or a meeting in the municipality. Though perceived as sexual assault, it is not reported for fear of losing

children, transport support, or residency. To talk about sexual assault and its consequences takes more than an interpreter: one must concentrate on the individual's conditions in addition to what is usually perceived as 'the ethnic' and 'the cultural'. You need time to build trust and calmness in the conversation. The whole truth does not always come out when using an interpreter - so you have to try without an interpreter.

Men and women belonging to ethnic minorities change sexual behaviour in the host country depending on how and the degree to which they are integrated into their new society. For different reasons, some adapt completely over time, while others retain some attachment to their original ethnic attitudes (1193). Now there is talk of intimate citizenship: in addition to the known rights and duties of citizenship, the right to have control over one's sexuality and body should also be included (1194).

19.8. Exile and Integration

Northern European countries are characterized by relatively individualistic behaviour and orientation towards independence, autonomy, and personal goals, which may even increase sexual exploration and risky sex. On the other side, family-oriented cultures and disciplinary rules can protect one against sexually risky behaviour. Some studies suggest that immigrants retain their own sexual behaviour in the host country (1195, 1196).

Immigrants cannot be considered a homogeneous group, and some minority groups change attitudes towards sexuality faster than others. For example, Iranian immigrants in Sweden have changed their views on sexuality in the direction of more openness. Issues related to sex and sexuality are no longer taboo, and the immigrants' knowledge of sexuality has increased. However, the dialogues on sexuality are often aimed at young people, while older generations are more limited in this communication. The process of integration has also brought the two sexes together on a more equal footing, and Iranian male immigrants have lost some of their dominance in sexual relations. These changes are not permanent, and they are context-dependent. Iranian immigrants follow Swedish sexual norms while living in Sweden, but when they are closer to their Iranian roots, they follow their traditional domestic sexual norms (1197, 1198). Iranian immigrants living in Canada have developed their sexual views partly towards more openness, but at the same time this process has had negative consequences for women. Iranian women are pressured by their group to act in accordance with traditional norms from their homeland while still having to tackle Iranian male dominance and with the men's increased and more open interaction with the opposite sex in Canada. These negative consequences have mainly affected the second generation of Iranians in Canada (1199). Integration can play an important role in immigrant groups for changes in sexual behaviour including sexually risky behaviour. However, the integration process is not the only factor that increases risky sexual behaviour (1151, 1196).

A comparative study between Muslim immigrants and young people from the local population in France shows that immigrant youth more frequently misjudged the number of sexual relationships, their ability to communicate about sex and sexuality, and their experiences about sex. Even when Muslim youth have lived in the host country since early childhood, their cultural background is so strong that it dominates their attitudes toward sexuality. For them, sexuality and intimacy remain taboo (1200). The same conclusions were reached in a later study comparing young people of Muslim and Christian affiliations. The sexual behaviour of Muslim immigrants is strongly governed by tradition and fear. Young people fear their parents' reactions, and they fear damaging their reputation (1201).

Being a refugee, a teenager, or belonging to an ethnic minority can pose an obstacle to accessing sexual and reproductive health services (19, 1191, 1202). Studies show an increased incidence of unwanted pregnancies, abortions, sexually transmitted infections, and sexual violence among immigrants compared to the host country's local population. The use of contraceptives is also lacking (1203). As a result, sexual health among immigrants is lower than in the majority population. A 2011 investigation on the health and quality of life of Russian, Somali, and Kurdish immigrants in Finland found that the

use of contraceptive methods among immigrant women was lower than in the general population. The number of abortions was higher among immigrant women, the highest incidence occurring among Russian immigrants with more than 50 % having had at least one abortion (1151, 1204, 1205).

19.9. Cultural conditions: Koro and dhat

Koro is a Malaysian word for the head of the turtle, which can be pulled completely in under its shell. The condition is characterized by an anxious experience of the penis gradually ‘disappearing’ into the body, without the man being able to control the slow shrinkage. In women, similar metaphors have been described with regard to breasts and labia. *Koro* (sometimes referred to as *jinjin bemar* or *suk yeong*) has been described in a wide variety of cultures, but it has many different expressions (1206). *Koro* epidemics have occurred in several Asian countries, while the phenomenon is largely unknown in Europe and the US. *Koro* diagnostically belongs to a group of culture-specific diagnoses that are treated psychiatrically. *Koro*-like symptoms can be signs of an underlying psychotic condition. *Koro* is akin to the cultural diagnosis *dhat* (also called *dhatu*, *jiryān* or *shen-k’uci*), where the patient experiences fatigue and muscle pain in connection with the fear of having lost vital seminal fluid. *Koro* is mentioned in the DSM-IV, while *dhat* is mentioned in the ICD-10.

19.10. Media, ethnicity, and stigma

Stereotypes and prejudices are frequently used tools when we have to understand people we do not know. A PhD thesis about the Danish media’s mention of ethnic minorities demonstrated that the news media plays a major role in the way refugees or immigrants are perceived, and sexuality is a central part of the image the media gives readers. It is often an ‘us’ and ‘them’ dilemma, where Danish sexual morality is the golden yardstick. The ‘criminal immigrant’ is often mentioned in the press in connection with the ‘sexually aggressive Muslim man’ and the ‘oppressed woman with a headscarf’ - while the ethnic Danish population implicitly becomes a law-abiding, both chaste and liberated population. Sexuality is used as a platform for a binary, race-based discussion about sexual rights and behaviour, where ethnic Danish behaviour is assumed to be ‘good’, and sexual immigrant behaviour ‘bad’ (1207). Sexuality and sexual behaviour vary widely between different sociocultural spheres, which requires the healthcare professionals to have a culturally informed approach to diagnosis and treatment within ethical frameworks that have respect, understanding, and tolerance as fundamental elements. Stereotypes and prejudices about sexuality from a cross-cultural perspective should be replaced with curiosity, knowledge, and insight (1208, 1209).

19.11. Recommendations

Because most methods of sexual counselling lack diversity sensitivity, doctors and psychologists must adapt to gain insight into the patient’s and partner’s culture, values, and experiences through conversation (1210). Here are four good pointers or themes that can be used in the approach: (1) awareness of cultural differences, (2) knowledge of the client’s culture, (3) distinction between pathology and culture, and (4) the use of a culturally appropriate therapy. Our own cultural standing, as practitioners, can act as a yardstick, but it expresses a cultural blindness that can only be changed through professional curiosity and knowledge (1211, 1212).

In conversations about sexual health, the health professional must create an environment where the sociocultural and religious values of the client can be properly examined with respect, sensitivity, and good conscience. The fear of being uninformed or ignorant of other people’s cultural norms easily leads to the doctor hesitating to touch on sensitive topics. Political correctness or direct fear of contact, especially with regard to immigrant and minority populations in Western countries, is a frequent reason for reluctance to mention aspects of patients’ sexuality that may be important for treatment and quality

of life. Making assumptions about a patient's cultural values based on behaviour can prevent proper medical assessment of the patient's goals and expectations. Sensitivity to a culture does not indicate, as many believe, agreement with the patient's beliefs about a sexual problem, but is rather a method of accepting that there are differences in values and that one can therefore create solutions within the patient's own mind-set. Introspection of one's own feelings and beliefs is especially necessary in this area to avoid prejudiced and wrong decisions. The need for co-production with the patient in perception and solutions cannot be overstated in the cross-cultural sexual field (1213). While social factors and culture contribute to sexuality, their impact in relation to integration is still unknown, which is why the conversation becomes an important part of learning about the client's cross-cultural influences and their relevance to sexual health.

In summary, sexual health assessment should include curiosity and cross-cultural competencies, and it should follow guidelines such as those recommended at the Fourth International Congress on Sexual Health – see Figure 28.

Figure 28. Recommendations for conversations about sexual health (per (1190)).

- Evaluate patients and their partners in the context of their cultural background, values, and preferences.
- Evaluate disturbing sexual symptoms, whether or not they are a recognized dysfunction.
- Carry out the conversation in a culturally sensitive and diversity-sensitive way that recognises cultural factors and language barriers and includes agreement on which concepts, style, and degree of detail are most comfortable for the client or couple.
- Evaluate heterosexual couples who show up with 'unconsummated' marriage for the presence of female (e.g. vaginismus) or male sexual difficulties (e.g. premature ejaculation) and how they affect each other.
- Culturally and religiously adapted conversations and assessment tools should be developed to protect against prejudices, misunderstandings, and omissions.
- Know and recognize your own prejudices and preconceptions about clients' ethnicity, gender, sexuality, and their family members. Reduce influence of prejudice by seeking information and through knowledge of the individual client's experiences, attitudes, and preferences.

19.12. Cases

Case 1

A 34-year-old well-integrated man who has held several jobs and is highly educated. Social downfall, business goes bankrupt, fired from cleaning jobs. Hospitalized with chest pain but is discharged again. Consults the doctor weekly with insignificant issues. Imprisoned in his home country, sexually tortured with electricity to his genitals, resulting in faecal incontinence and intermittent impotence. Impotence worsened when his business went bankrupt. He no longer feels like a proper man.

Comment: *Injuries from the torture take on new significance as the patient is hit by bankruptcy with subsequent loss of manliness and a sense of general inadequacy.*

Case 2

A 32-year-old man from a West African country was referred with 'many African symptoms'. The patient had been complaining for a long time that his penis was very small. The patient had been examined by a number of specialists (a neurologist, urologist, psychiatrist, and psychologist) to no avail. The patient insisted on this description of his problems: small penis, being tired, and feeling that he had become lower in height. When asked how he would perceive the same problem in his home country, he explained that it meant he was unable to be with women, i.e. an erection problem. Where he came from, they said 'little penis' when they meant 'erection problem'. He thought this was a term men used all over the world and did not understand why Danish doctors did not know it. The patient had become impotent after his ex-wife allegedly cheated him out of all his money, his car, and a condominium, and now he was relegated to living in a shelter for men. He felt like a little man, and he had become shorter. He was referred for sexology counselling.

Comment: *It is important to create an environment where the patient's framework of understanding comes into play and the therapist enters into the patient's mindset in order to co-produce a solution with the patient. It is often a good idea to ask patients to explain how the problem would be perceived and understood in their home country.*

Case 3

A 26-year-old woman complaining of bleeding disorders. Many doctor visits; a (male) gynaecologist finds nothing abnormal; the patient tells a female (elderly) gynaecologist that she has an infertility problem and pain during intercourse. The patient tells a female doctor (of her own age) that she lost the desire for sexual intercourse with her spouse after her first pregnancy seven years ago. She does not recall how she became pregnant and wants to get pregnant without sexual intercourse. She does not like physical contact and is sure her husband has another wife. There is a lot of pressure from her in-laws about having more children, and the patient would like advice on how she can get pregnant without physical contact.

Comment: *It is important to work with relationships in order to ensure the necessary trust and intimacy. Do not underestimate the importance of identification (age and gender). Sexual counselling is also about having a sense of the patient's knowledge of the body and about reproduction - not everything is obvious.*

Case 4

A 36-year-old woman bleeding to death during childbirth. The surgeon cannot stop the bleeding and must remove the uterus. The child and mother barely survive. The surgeon is clearly relieved and a little proud to have saved both as he announces the result to the family in the waiting room. The surgeon emphasises that they are both alive and well and mentions as an aside that they had to remove her uterus. The husband suddenly and brusquely leaves the waiting room. Years later, the woman is referred due to universal pain and depression. The woman explains that her husband did not want to have any sexual relations with her and that he now wants a divorce. The woman believes her husband is angry that the surgeon removed her uterus without first asking the family. A *debriefing* meeting with the surgeon is called during which it becomes clear that a uterus does not just belong to the woman but to the whole family. It is the family's organ that ensures that the whole family can survive, and it must not just be removed without their permission. The case is resolved with an explanation and apology from the doctor and a request that the woman not be blamed for the surgeon's decision to save the life of the mother and child. The husband accepts the explanation.

Comment: *It is important to start out with the patient's perception and situation - no matter what one may think of it. The body is a gift, and it belongs not only to the person but to the whole family. The uterus belongs to the family because it is perceived as ensuring the continued existence of the family.*

Case 5

A 32-year-old man from the Middle East is referred from the sexology clinic with erectile dysfunction that had not been successfully treated. A male interpreter is used for the first interview, and the patient's wife, who is 11 years younger, is part of the conversation. They had been married for just 1½ years before the interview at the MHC. It turns out that the patient would rather speak Arabic than Kurdish on this subject. Therefore, another (older) male Arabic interpreter is used. The wife is remote throughout the conversation and seems disinterested, but she sometimes interrupts with a laugh that seems 'goofy' and a little inappropriate. The patient states that he just wants to 'fix' his problem and he sees no need to talk about it anymore. We know what it is about - he has tried everything to no avail, and now he wants surgery so that it can be 'fixed', as the patient puts it. Attempts to involve the wife in the conversation are unsuccessful. It is agreed to contact the sexology clinic to find out what treatment options have been tried. For the next interview, the patient comes alone, and a female interpreter of the patient's own age is chosen. They speak Kurdish. The patient is confused by the conversation, and he asks the interpreter to explain that there must be a misunderstanding. He does not have erectile dysfunction, but his new young wife says he has serious problems with premature ejaculation, and she scolds him about it. He wonders how his wife knows about that sort of information and whether she has had sexual experiences with other men. He says that he had been unable to speak to the interpreter used in the sexology clinic because that interpreter was 'insensitive' and seemed judgemental. The patient had not been interested in the spouse attending the previous interview at the MHC, but she had insisted. Therefore, the patient had asked for an Arabic interpreter because his wife does not speak Arabic. The wife had laughed because she knew why he had chosen a different language and teased him a little about it. The patient said he had not had sexual intercourse before his current marriage at the age of 32. The patient was given information that premature ejaculation was a frequent problem for men, but that it could be prevented. He was then instructed in exercises to prevent premature ejaculation and was shown a website with the exercises that he could show to his wife.

Comment: *The linguistic distinction between an erection problem and premature ejaculation is difficult and requires active questioning and an interpreter who takes a professional approach to sensitive topics. Lack of knowledge on both sides can complicate understanding and treatment if it is not corrected by the healthcare professional. It is important that the interpreter avoids inadvertently becoming a barrier.*

Case 6

A 42-year-old female refugee from Afghanistan was referred with chronic lower back pain and tingling paraesthesia in her lower limbs. She sees a privately practising psychiatrist due to anxiety. She explains that she has improved after beginning municipal rehabilitation, and the conversations with the psychiatrist have helped so that she can now feel happy about little things. She describes having developed thoughts of catastrophes and constant unspecific anxiety that has taken over her life. Her lower back pain started when she lifted something very heavy in her home country. A recent epidural block has helped somewhat. The patient is restless while at the same time she is demonstratively expressing that she is doing better. When directly questioned about any important problems in her life that she has not talked about or has difficulty talking about, the patient breaks down. She says that she cannot tolerate her parents, even though she should be able to. The patient asks if she may tell her story, and when this

is confirmed, she says that her father was a compulsive gambler and an alcoholic and that her mother was temperamental and depressed, never happy. Her childhood was full of physical and psychological violence from both her parents, and the patient was very angry with both of them. She wishes she could love them, but she cannot. In particular, she talks about repeated unpleasant incidents from when she was eight years old when her mother would send her shopping every day to a place where there were many men who groped her in a very abusive way. Her mother said it was her own fault for being condescending, and she was told she had to learn to be chaste and not tell anyone. Since then, sexual activity has been shrouded in guilt and impurity for the patient. Her current husband and father of her children has been unfaithful to her in Denmark - with his previous fiancée. The patient always thought she had a dirty and ugly body, and the acquired guilt has been further reinforced by her husband's infidelity. The patient did not want her psychiatrist to know anything about these aspects of her life, but she was willing to talk about it at the MHC. The patient explained that she had a clear sense that her pain and sensory disturbances were related to her childhood, but in her view, there was no way she could talk about it. After more conversations at the MHC, the patient chose to tell her psychiatrist about her childhood experiences.

Comment: *It is not uncommon for patients to limit (and distribute) the topics discussed in the individual meetings with doctors. This may be due to a need for control over the narrative and an experience that if one person has the full patient narrative, it is too 'dangerous' or it makes the patient particularly vulnerable. The telling of a life story is important. This includes talking about unpleasant or sensitive topics such as in this case, where there is sexual assault in childhood and where the patient hated her parents for her traumatic childhood. The patient had seen the connection herself, but as a starting point, it was taboo to think about it. The life story gave the patient a natural reason to talk about it anyway. It is essential to establish a context that facilitates trust through the normalization of human experiences of abuse.*

Case 7

A 51-year-old man from the Middle East is referred with worsening back trouble after losing his job as a garbage man. Getting fired took a toll on his dignity. He also suffers from extreme fatigue and problems with a hiatal hernia. It turns out the patient graduated from high school in his home country and worked as a mathematics teacher in a high school while also being a business owner. He was imprisoned and tortured with sexual humiliation at night. He has faecal and urinary incontinence. He has nightmares of being strangled by a big muscular man every night. Upon his arrival in Denmark, he was registered with the wrong date of birth, but after several attempts he has given up getting it changed. He is actually eight years older than what is stated in his papers. Liver biopsy shows pronounced cirrhosis of unknown origin, which is being monitored by the gastroenterologists. Additionally, the patient has signs of sleep apnoea, but the BIPAP treatment exacerbated his nightmares. However, the patient himself finds that his erection problem that occurred after his being laid off is his biggest problem, which is why he is referred to the sexology clinic.

Comment: *Even when the somatic problems seem manageable, you should pay attention when a relatively well-functioning patient develops increasing general symptoms and loss of function after, for example, a social event. Something like being fired from work can often re-traumatize patients, and loss of work can start a social downfall due to loss of dignity. There is often an increased awareness of the body's signals during a social downfall. Clinical focus must always be reassessed and evaluated.*

For a more detailed review of cross-cultural sexology, the chapter 'Sexuality from a cross-cultural perspective' in the textbook *Sexology* is recommended (1133).

20. The interpreted conversation

20.1. What is important?

1. Use an interpreter for the most important conversations and for reconciling concepts and expectations. Most errors occur because no interpreter has been used.
2. Set aside extra time for interpreted conversations - everything has to be said twice.
3. Brief the interpreter on the overall content of the conversation and expected goals - then the interpreter becomes an involved partner. Ask the interpreter to let you know if there are any difficult or unknown words or concepts.
4. If the conversation does not proceed as it should, ask if there are problems regarding: dialect, sensitive topics, the interpreter's gender/age, fear of the interpreter gossiping.
5. Many specialised terms cannot easily be translated; they must be explained (often several times). Allow the interpreter time to explain.
6. Relatives are relatives and should not also be interpreters. Under no circumstances should children be allowed to interpret.
7. Incorrect questioning techniques and a lack of intercultural sensitivity can make it impossible even for skilled interpreters to do a good job. Get training and practice in communication and cultural sensitivity to get maximum benefit from interpreters.

20.2. Language and interpretation

Even the best medicine will not work on an incorrect medical history, and failure to use interpreter assistance leads to erroneous medical histories (1214, 1215). A major Canadian review from 2008 identified 82 studies on the importance of language barriers for patient safety and found that 85 % of the studies demonstrated a significant negative effect on prevention, treatment, and patient safety (1216). The most frequent reasons for not utilising interpreters are that their need is not documented, that it is 'better' (easier) to use the relatives as interpreters, and that the doctor downplays the importance of the language barrier (1217). Several European studies suggest that approximately 30 % of bilingual patients need interpreters (50, 830). As early as 1970, Tumulty concluded in the *New England Journal of Medicine*, 'We clinicians are better educated and more scientific than ever before, but we have a great failing: we sometimes do not communicate effectively with our patients.' (1218). Language barriers pose challenges to health policy development and equal access to healthcare (1219). Inability to communicate in doctor-patient conversations has major implications and involves more than a simple translation of words as the *Lancet Commission on Culture and Health* concluded (1220). Patients go to the doctor less often, consultations take longer, and there is less mutual understanding, which in turn leads to poor medication compliance and fewer referrals to other specialities and psychologists (1221-1223). Other consequences include the increased risk of misunderstandings, delayed diagnostics, and misdiagnosis (33, 34). Extensive paraclinical examinations are often required to compensate for poor communication. You try to avoid being wrong by ordering more samples and examinations (871).

Intercultural communication and understanding, however, extend far beyond language. Skills in intercultural communication include the ability to ensure a common understanding of people with different social identities and migrant backgrounds. Intercultural health communication involves more than the simple translation of languages. It is also about health attitudes, quality of life, and illness behaviour. Attributing this to being solely a language problem hides the many other elements of cross-cultural communication. Flores found that the use of uneducated ad hoc interpreters (family, friends,

and children) led to poorer quality of treatment, more errors in interpretation, and lower patient satisfaction (34). Conversely, the use of professional interpreters resulted in fewer misunderstandings, increased patient compliance, reduced inequality in access to health care, improved clinical outcomes, and higher patient satisfaction. Hsieh has tried to analyse the different roles played out in an interpreted conversation. She observed interpreted conversations at hospitals in Mandarin Chinese (in which she was fluent) and also interviewed the professional interpreters (818). The study showed that interpreters could take on four possible roles, often within one and the same medical consultation. The predominant role was the invisible, professional 'robot' role. The second role was the patient advocate, although not all interpreters were equally familiar with this role. The other roles were the cultural mediator or negotiator and, finally, the trained professional role, where the interpreter felt on an equal footing with the clinician as opposed to someone who was 'merely' bilingual and only provided an instrumental 'interpreting service' (1224). A Canadian study found that immigrant groups have different language capacities, especially in discussing health, illness, and disability. Therefore, establishing a meaningful physician-patient conversation requires professional interpretation as well as cross-cultural skills on the part of the doctor (1225). When understandings of the differences between ethnicities are overly simplified and too narrow a focus is placed on language barriers, it limits the possibilities of developing relevant health services for refugees/immigrants that take intercultural complexities in illness and health into account. Social labels and codes can affect the interpreter's ability to translate correctly. Japanese interpreters found it difficult to translate former President Trump's incoherent, fast-associating speeches in a language that is socially unacceptable in Japanese (1226).

Several studies have shown that the use of interpreter assistance is not based on objective criteria or clinical guidelines but is merely an institutional construct based on the practice of the hospital or typically the department (1227). There are large differences in the frequency with which interpreters are used among different departments in the same hospital, indicating arbitrariness and lack of managerial interest (1228). In a study of language barriers at a Danish children's ward, language barriers were frequently encountered, yet no interpreter was used for a single one of the studied conversations (1229). A Finnish study found that in 30 % of cases where the patients themselves indicated having a language barrier, the need for interpretation was not noted in the medical journal (830).

A frequent solution in the public sector is to use ad hoc interpreters such as children, relatives, or a bilingual colleague in the health care system. Most people have the incorrect assumption that a bilingual person can interpret effectively simply by being bilingual. In reality, bilingual individuals who have not received interpreter-specific training are more likely to add or omit information in the conversation between doctor and patient. They also tend to mix their own opinions and assumptions into the discussion, resulting in incomplete and/or inaccurate information. This introduces a bias into the conversation and can potentially threaten the patient's safety and well-being. In addition, uneducated interpreters are more likely to engage in conversations with the patient or doctor that are not related to the actual topic. These 'side conversations' are counter-productive to the conversation, both doctor and patient are distracted from the actual agenda, and the patient may feel ignored. In a survey of all Arabic health interpreters in Denmark, barely one in five interpreters was fluent in both Arabic and Danish. In the same study, Danish-born Arabic interpreters were the group with the worst command of the Arabic language - partly because they had learned it as a simple everyday Arabic from their parents (709). The same tendency was found in a US study, which showed that ad hoc interpretation by health professionals without interpreter training led to more errors than with professional interpreters (1230). Evidence suggests that systematic training in cross-cultural sensitivity and communication significantly increases the use of professional interpreters (1231, 1232).

20.3. Is it beneficial to use interpreters?

Over the years, several studies and literature reviews have tried to answer the obvious question of whether the use of interpreter results in better treatment outcomes and fewer patient safety breaches (see also the chapter 18). If you ask experienced interpreters, there is no doubt: they often feel they make a difference between life and death, they often prevent patient errors from occurring, and they stop violations of patient safety (816). However, we still do not know how to measure the effect as it is a very complex problem area. Moreover, most studies are conducted in the US and involve relatively few languages (typically Spanish and Chinese) and are usually among labour migrants. In a 2005 review, Flores et al. found that interpreters increase the quality of treatment among patients who would otherwise receive relatively low-quality treatment (34). In another review, Karliner found that professional interpreters compared to ad hoc or informal interpreters (e.g. bilingual hospital employees) increased the patients' access to and use of the health care system, increased patient understanding of information, and improved individual clinical outcomes (33).

Patients with language barriers undertake fewer disease prevention measures, are less often offered mammograms, vaccination, and instructions for smoking cessation, and have poorer medication compliance. Interpreter assistance is obviously an additional expense, but the economic and human consequences of errors arising from a lack of interpreter assistance are much greater (36, 178, 792, 1013, 1233, 1234). Lack of interpreter assistance leads to a higher number of unnecessary hospitalizations, dangerous invasive procedures, blood tests, radiological examinations, medication errors, and complications as well as significantly longer hospitalisation and less use of psychiatric assistance (312, 313, 834, 1235). Interpreter assistance has a positive effect on compliance, understanding of information, use of the health care system, clinical end goals, and patient satisfaction (33, 1236, 1237). Interpreter assistance increases the patients' understanding of information, especially when they are being discharged (1238). Interpreter assistance results in patients with language barriers having fewer, but more focused, medical visits, and these patients use acute health services less often than do others (1239). Trained interpreters lead to fewer patient errors compared to untrained interpreters (34, 1240, 1241). A study in an acute medical department found that patients with language barriers who received interpreter assistance were hospitalised for longer periods and had more examinations, more intravenous fluids, more medical treatment than patients with language barriers who were not offered interpreters (1242). Several studies suggest that interpreters or bilingual physicians may encourage patients to discuss psychosocial problems with the doctor, and there is a greater degree of patient involvement (1243, 1244). In one of the few major prospective randomised studies undertaken, the interpreter assistance provided in the intervention group significantly increased the appropriate use of family physicians and emergency health services, the number of prescriptions written and redeemed, and the use of preventive services such as flu vaccination and screening for blood in the stool (1245).

A study of doctors in training showed that doctors are reluctant to use interpreters and prefer to try using their own often completely inadequate language skills or avoid talking to patients with language barriers altogether (1265). Doctors seem to think that they are doing very well without interpreter assistance, but this misconception is allowed to persist precisely because patients do not have a say without an interpreter (204, 1266-1268). Even though interpreters were available in an emergency reception department, they were not used by doctors (1269). When doctors exhibit linguistic and cultural sensitivity, patients have better self-care, interact more, and achieve better health skills (1270).

Having interpreter assistance, however, does not necessarily ensure that patients understand all the information. One study found that 67 % of patients who had the main language as their native tongue understood the doctor's information, while only 57 % of patients needing interpreter assistance understood the doctor's information (1271). One should be aware that these patients often have few health

skills and that this cannot be compensated for by an interpreter (1269). Thus, not only is the interpretation itself important, but also how the information is delivered to the patient, how the doctor adapts his/her interaction, and how the doctor ensures that the patient understands the information. Untrained doctors may create confusing disruptions by interrupting or being set on one diagnosis (see *coherence-based decision making chapter 13 and (240)* without respectfully involving the patient (1272). Another example is communicating the risks of a surgical procedure or medical treatment, where the information typically involves lots of numbers. Studies have shown that ethnic minority patients need verbal explanations of risk estimates in understandable concepts. It is the doctor's task to acquire the appropriate vocabulary and rehearse appropriate formulations – this is not the interpreter's job (1273). A large and ambitious study of international differences in somatic symptoms of depression found significant differences. These differences were just as much the result of variations in medical definitions and traditions and the patient's encounter with the health care system as they were the result of cultural differences.

Table 31. Examples of studies showing negative effects of lack of access to interpreter assistance for patients with language barriers in the health care system.

Observation	Source
Less use of contraception	1246
Greater use of emergency room and on-call doctors, inappropriate use of family doctor	1247
Understand less information when discharged	323
Lower medication compliance	1248, 1249
Less use of painkillers as emergency treatment	1250
More frequent hospitalisation of children	1251
Medication errors, fluid balance errors, less pain management	830
Lack of informed consent	819
Less patient involvement in medical conversations	328
Risk of serious patient errors	792, 1252, 1253
Less use of the psychiatric health care system	1254
Less frequent outpatient clinical follow-up and fewer blood tests	1255
Poorer blood sugar control of diabetes	321
Do not understand medication information leaflets, more medication errors, more side effects, do not understand their own disease	794
Incorrect or inadequate visitation for social services and aids	1256
Patient does not return	329
Lower quality of palliative treatment and care	765
Contacts the doctor later than others	1257
Pregnant women receive anaesthesia less frequently during childbirth	1258
Discharged more often 'against medical advice'	1259
Patients are more frequently diagnosed with 'psychosomatic' symptoms	1227
More frequent use of ventilators in children and teens with asthma	1260
Less use of cancer screening	1261, 1262
Later diagnosis of dementia	1263
Increases the work-related stress of junior doctors	1264

The current medical curriculum conveys stereotypes and an ‘us versus them’ mind-set, which can be difficult for an interpreter to smooth out (367). How the doctor creates, or breaks down, the relationship with the patient (and the interpreter) affects the interpreter’s ability to provide meaningful interpretation. Doctors may be afraid of losing the direct doctor-patient relationship by using interpreter assistance (1274). Interpreter assistance is perceived by young doctors as stressful and time-consuming, and doctors do not feel it is possible to achieve the same degree of contact with the patient when an interpreter is involved (1264) - but in reality, studies show the exact opposite: interpreters contribute to many more topics being addressed; the dialogue is more natural; less time has to be spent on the patient; and patients are more satisfied. It seems that the doctors’ anxiety and prejudice are the problem rather than the interpreter’s presence or the patient’s experience (914, 1267, 1275-1277). Interpreters can improve treatment quality and other clinical and non-clinical parameters almost to the level of that rendered to patients who require no interpretation (1251).

Patients’ perceptions of interpreters are naturally diverse. An interpreted interview is a sensitive and complex task in which the interpreter must satisfy both the doctor’s (often unclear and unrealistic) requirements for the interpreter’s health knowledge, vocabulary, and loyalty, while also meeting the patient’s requirements for the interpreter’s age, gender, dialect, political attitude, ancestry, social status, and unconditional support for the patient. Patients want an interpreter who is both a professional interpreter and an empathetic relative (1278). Studies of patients’ requirements for interpreters show that patients often have opposing and relatively personal requirements for interpreters while also needing them to be spokespersons and to be objective, neutral, and respectful of the private sphere (1279-1281). At the same time, interpreters must grapple with the balance between their desire to be an integral part of the clinical team, keeping some distance from the patient, and the need to build trust in the relationship (1282, 1283). There is evidence that patients and doctors do not agree on the qualities of interpreters, the most appropriate interpretation approaches, or interpretation technologies, which complicates studies and analyses (1284). It can be difficult for outsiders to fully understand the complexity of interpreters’ work, but from video-recordings of conversations using an interpreter, it is clear that the interpreters constantly negotiate, communicate, and interpret both concepts that are not immediately translatable and clinical decisions based on medical premises (1285). Interpreting conversations involving war crimes, torture, violence, or abuse is particularly complex for interpreters, who have often had similar experiences themselves (1286). There is much discussion about differences and similarities between the role as an interpreter and the role as a cultural mediator (1287). The problem is that although they are theoretically two different tasks, in practice they are always mixed up because the doctor, patient, and interpreter themselves may need each of the roles at different times during the interview or over the course of the patient’s treatment (1288). Thus, a slight dissonance arises regarding when the interpreter should act as an interpreter and when the interpreter is required to be a cultural interpreter, health professional, conflict mediator, or social worker (818, 1289). Several studies have clearly shown that linguistic and cultural agreement (concordance) between doctor and patient increases patient safety and treatment outcomes (794, 1290).

In recent years, the focus has been on interpreting apps and mobile solutions with iPads (1291-1293). However, most apps are either tightly locked into a target group and content, while the more open apps, such as *Google Translate*, are not yet reliable. Challenges such as dialects, diaspora languages, international differences within clinical standards/guidelines, and constantly changing professional expressions make apps unreliable and unusable in clinical everyday life. However, they undoubtedly get used anyway and often completely uncritically.

Finally, it is important to point out that access to interpreter assistance is not enough to reduce language barriers. The information the interpreter must pass on, the questions asked, and the way the patient is involved are cultural competencies that many doctors lack (233, 1242, 1294). A study from

London in a gynaecology department showed that accessibility, interpreter quality, and the doctor's cultural sensitivity and communicative abilities were just as important as the interpreter (1295, 1296). Another study found that some illnesses cannot be directly 'translated' into meaningful concepts of illness in the second language, such as contagious hepatitis B among Khmer people (1297). Many interpreted conversations develop into mere monologues because doctors lack the skills to create dialogue through an interpreter (1298). Sociolinguistic studies have demonstrated that untrained physicians in interpreted conversations miss or overlook important signals, clues, patient cues and information, forget to small-talk, and fail to develop relationships with the result that the patient's values, feelings, and preferences are absent from the patient history (1299). Interpreters have proven to be capable of dealing with even complex issues, but doctors often neglect to effectively use interpreters when they are present in discussing sensitive and/or psychologically complex topics (1243). A culturally and communicatively sensitive doctor can make the most of a mediocre interpreter, while a culturally ignorant doctor can turn even the best interpreter into a 'poor interpreter'. Doctors who have access to professional and ad hoc interpreters choose professional interpreters, who are more cost-effective than bilingual health professionals (1300, 1301). Doctors who have many interpreted conversations should regularly practise their cross-cultural and communicative skills. Evidence suggests that this strengthens their communicative competencies in interpreted conversations (1232, 1302, 1303).

20.4. Hidden mechanisms in interpreted conversations

There are at least eight important causes of cultural communication problems in doctor-patient conversations (31, 240, 729):

1. Cultural differences in ways of explaining health and illness
2. Differences in cultural values around illness and health
3. Cultural differences in patient preferences in doctor-patient relationships and in treatment
4. Prejudices, biases, and generalizations
5. Language barriers
6. Conscious/unconscious blind spots
7. Unrecognised misunderstandings
8. Significant cultural differences in the power balance, framework, structure, and turn-taking in the communication

Problems in communication between the patient and doctor may occur when:

- The parties do not speak the same language
- The parties speak the same language, but do not use symbols in the same way and do not share the same value system and goals
- The patient masters the language of the doctor to some extent but does not know all the nuances

A Norwegian qualitative study of interpreted conversations identified five themes of problems in interpretation and the use of interpreters that were difficult to translate (and which the doctor often failed to get clarified) (1304):

1. Indirect expressions. While the ethnic Norwegian patients were clear, nuanced, and 'extroverted', patients who needed interpreters were the exact opposite. They expressed the same feelings and nuances but did so indirectly.

2. Patients adapted their language and rephrased their observations with the goal of being perceived as 'good patients'.
3. Laughter was part of all observed conversations and had the medical function of reducing the severity of the patient's condition, but it was often perceived as a ridicule because it was not accompanied by a verbal explanation through which the interpreter could legitimise the laughter.
4. When problems in understanding existed, despite the interpreter, both the patient and the doctor were looking for more neutral, semi-accepting, or downplaying language such as 'OK', 'Hmm', or 'It is no problem', even if the information was ambiguous or incomprehensible.
5. The many hidden agendas and miscommunications led to a 'soft' and imprecise language communality, where the real problems and genuine feelings were expressed low key or as insignificant. When basic emotions are wrapped in untranslatable discrete, but complex, innuendo, the interpreter cannot translate them and the doctor risks getting an incorrect medical history, or none at all.

The same study found that what was missing was real patient focus, an insistent close dialogue, follow-up questions, ongoing clarification, and consensus.

For refugees, language has very special roles that are often overlooked. From a refugee's point of view, language has uncertain, perilous, and to some extent contradictory roles as either a tool for making sense (representing the refugee's report of events), for categorising (legally classifying the refugee's rights, status, and grounds for residence), or verifying (assessing how correct the refugee's report is and how credible the refugee appears) (1305). It can be hard for a refugee to decode what function the conversations, and thus the language, have in a given situation. Most conversations are conversations with authorities that leave little room for cultural sensitivity. The language used is a rather direct and brusque bureaucratic language reminiscent of police interrogations, conversations with border guards, or asylum conversations with Danish authorities. When you complete a questionnaire with the patient, fill out a template in an electronic health record, or prepare the patient for an operation, the language may sound like a categorization conversation with some public authority. When the doctor persistently questions the patient's experiences or symptoms, it can feel like a verification conversation. From the patient's point of view, both conversations can come across as an aggressive and negative form of interrogation and the answers become that way too and on a 'need-to-know' basis. If the interpreter is asked to interpret directly, without culturally adapted formulations, then the interpreter will be bound to convey an interrogation-like conversation and thus also be associated with an authority (1306).

How to work with an interpreter is often taken for granted, but using an interpreter to communicate is not as straightforward as commonly assumed. Doctors who have little experience of working through interpreters are more likely to avoid talking to the patient. This alienates the patient by turning the conversation into a dialogue exclusively between the doctor and the interpreter ('tell the patient I am going to examine his stomach'). Side conversations also become more tempting when the doctor and interpreter exclude the patient from the interaction. It somehow feels 'easier' to talk to the interpreter than the more artificial method of talking to the patient through the interpreter. In addition, when doctors address the interpreter instead of the patient, they are ignoring the fact that many patients can understand some Danish, despite their limited knowledge of Danish. The doctor may feel strange approaching the patient directly, for fear of being rude. In fact, it is the other way around: it is disrespectful to avoid talking to the patient on the assumption that she or he cannot understand. Doctors who are not familiar with language interpretation tend to speak in long sentences, or they speak too quickly for the interpreter, who then translates the information incompletely and imprecisely. Doctors often unknowingly make the mistake of talking down to or infantilising adults with limited skills in Danish. Another

common feature is that doctors raise their voices, although the problem is more of a language barrier than a hearing problem. Patients hear, see, and understand the verbal and non-verbal signs as an exclusion from the conversation.

Most interpreters experience daily conflicts between their many potential roles and their relation to, e.g. the communicative style of doctors. Five main groups of conflicts that create credibility or trust issues have been identified for interpreters:

1. **The communication style of the practitioner:** The doctor can concurrently make 'reference' remarks to the interpreter, glance at and use other facial expressions, or conduct parallel conversations with the interpreter in the belief that the patient does not understand what is being said or signalled. It may be that the interpreter must convey a 'standard Danish' value or a simplified message on side effects from an examination or it may be about the interpreter having to inform the patient that no special consideration (gender, food, level of information) will be afforded. According to the interpreters, doctors often argue that *'this is how it is - that's how we do it here in Denmark'*, but this becomes an empty and meaningless argument when translated for a deeply traditional patient who has never gone to school. Some interpreters recount that they were called by a doctor and asked to call the patient to say that cancer had been found in a tissue sample, at which point the patient understandably had a lot of questions that the interpreter obviously could not answer.

2. **The interpreter's humanity:** The interpreter may sense that the doctor does not explain himself well enough and that the patient is clearly frustrated, but the doctor refuses to listen to the interpreter's attempts to get a clarification from the doctor. Like doctors, interpreters often encounter patients at very sensitive moments, but the roles of the doctor and the interpreter differ widely. One interpreter said she was reproached for letting the patient give the interpreter a very heartfelt hug. The interpreter was ashamed of getting reprimanded and therefore had not explained that she had been present when this patient had lost a child a few years earlier and that it was a spontaneous reaction on the part of the patient to someone (the interpreter) with whom the patient had gone through a terrible experience. In many societies, especially on the African continent, any symptom of illness (sign of weakness) can be used in a personal attack - that the patient is cursed and spreading illness and suffering to others. The interpreter knows this and senses that the patient behaves less competently or imprecisely as an informant - to the detriment of the patient's own medical history. Should the interpreter push the patient or just translate verbatim? Interpreters find it particularly problematic if the doctor lacks basic communicative skills. One interpreter cited as an example a doctor who asked the patient, *'Do you want to have amniocentesis?'* The patient first asked the interpreter and then the doctor, *'What do you think I should do?'* The doctor answered, *'This is not how it goes. It is your decision, not mine.'* The interpreter had previously interpreted a conversation in the same department in which another doctor had related three different women's choices and the underlying reason for each choice. This doctor had even explained that he and his wife had been in a similar situation and had chosen not to have the amniocentesis because they had decided they wanted their child no matter what. The first doctor did not ask the right question, while the second doctor gave the patient several options to compare for herself and allowed her to hear about how other people had processed this difficult choice. Cancer diagnoses and death in general are highly culture-

bound areas that require more than just interpretation. Here, the interpreter has multiple roles and may find it difficult to separate emotions from work. There is no dress rehearsal for a course of cancer or palliative treatment. Thus, it is important that it happens on the terms of the patient and relatives as much as possible. However, is the interpreter supposed to be an ambassador or conflict mediator (1307)?

3. **Changes in the dynamics of the conversation or the participants:** This may happen if a nurse enters the conversation, thereby changing the structure and turn-taking of the conversation in a way that can be difficult to translate. Although the doctor and nurse may have a professional interaction that they do not expect the interpreter to translate, the patient may feel uneasy or curious and prompt the interpreter for a translation. The doctor may talk directly to the patient, bypass the interpreter, and 'overrule' the interpreter's work. Similarly, a relative may have a 'confidential' conversation with the patient without expecting it to be translated, and the relative may address the doctor directly and bypass the interpreter.
4. **Structural barriers:** In theory, the interpreter must not be left alone with the patient. In practice, however, doctors and nurses often leave the conversation. If the interpreter tries to leave the room, they are blamed by the staff, who do not know the rules. The health care system frames patient interviews on the basis that the doctor's time is precious and scarce. The interpreter has to try to be a link between a patient who would like to spend time with the doctor and a doctor who does not have the time. Interpreters may find that they are considered to be a kind of caregiver who is required to go over guidelines and leaflets with the patient and accompany the patient for examinations and blood sampling as part of their work (often supported by the patient's needs). However, interpreters are employed by an external provider that operates a purely interpreting business that does not include these types of services.
5. **Problematic expectations for the interpretation role:** Trained interpreters learn to try to avoid eye contact with the doctor and patient to create the illusion that it is the doctor and the patient who talk directly to each other. Inexperienced doctors and patients may perceive this as culturally alien, impersonal, or insulting. Patients can provide the interpreter with information that the interpreter is not allowed to pass on, as can the doctor. The interpreter can rephrase the doctor's information into a more adapted information, in the interpreter's opinion, e.g. the interpreter can rephrase '*you need to be examined for glaucoma*' to '*you need to get the pressure in your eye examined*'. This could, however, be perceived by the doctor as an inappropriate and imprecise rewording when the doctor has not been informed of the patient's framework of understanding. Conversely, interpreters can face major challenges if the patient is agitated and uses offensive language, or if the doctor speaks very derogatorily to the patient. In such cases, the interpreters must step out of their role at great personal risk and confront the patient or doctor with the consequences of translating what has been said.

Interpreted conversations impose great demands on the doctor's skills in communicating and listening. Interpreted and uninterpreted conversations differ in structure, content, and objectives. Patients are much less included by the doctor when interpretation is needed, and the patients are more passive. In videotaped doctor-patient interviews with and without interpretation, it was found that patients in

interpreted conversations made far fewer spontaneous ‘proposals’ to the doctor concerning further explanations of symptoms, expectations of illness/treatment, thoughts, and feelings concerning the illness and non-specific clues/patient cues (328). Patients in interpreted conversations were less likely to comment on psychosocial circumstances with the illness and most often they describe only physical symptoms to the doctor. Patients in uninterpreted conversations provided three times as much spontaneous information to the doctor as patients who needed an interpreter. Patients who provided spontaneous information in interpreted conversations received responses to their information less often than patients who did not need interpreters. Patients who did not need an interpreter were generally more involved in the conversation and decision-making process.

20.5. Problematic reinterpretations and omissions

Interpreters are busy and have to condense the doctor’s numerous and sometimes disjointed information into a meaningful conversation. This is no easy task when doctors often use sequential, professionally acquired, automatic phrases that compress together important pieces of information about treatments or side effects. It is especially difficult because doctors do not allow interpreters time for reflection or clarifying questions and because the medical language is not always translatable. However, it is still important that the doctor is aware of whether what the interpreter translates is exactly what the patient actually said:

- Patient 1 : *This cough just goes on and on, sometimes it’s gone, but then it comes back, and I can’t sleep at night. It’s worst in summer.*
 Interpreter 1 : *The patient coughs a lot*
- Patient 2 : *It’s my ear ... it’s completely blocked and closed. My head is like a glass bell. There’s a howling tone. I can’t hear anything. I have a headache, and my neck is completely stiff.*
 Interpreter 2 : *She says she has an earache and a headache.*
- Patient 3 : *This leg. It hurts inside at night. In the morning I can massage it to get going, but in the afternoon, I can’t walk around like I usually do. If I bend it, I can’t stretch it out again due to the*
 Interpreter 3 : *He has a sore right leg - inside the bone.*

In all three cases, the doctor misses out on information, which increases the number of differential diagnoses. The interpreter, who does not think the doctor needs details, painstakingly removes information from the translation. The patient ends up being considered a ‘poor informant’. The most frequent interpretation errors concern reinterpretations and gaps in the translation of the patient’s statements. Most errors involve names, omissions, ‘additional’ information, replacement of patient concepts, incorrect figures (date, quantities, time), and distortion of the patient’s or doctor’s message/response (1308). Reinterpretations can occur when the interpreter combines two separate messages into one (disjointed) message. Patients may casually or briefly mention information that is essential and decisive to the doctor, but the interpreter perceives it to be insignificant and omits it from the translation. The interpreter has the best intentions but does not wish to bother the doctor with inconsequential information; this may prevent the doctor from getting important information. Interpreters may, on behalf of the doctor, send negative signals about the patient’s cooperation or ability to relay information:

- Interpreter : *Are you constipated?*
 Patient : *Yes*
 Interpreter : *The doctor asks if you have diarrhoea.*

- Patient : *Yes, like a water tap.*
 Interpreter : *You say yes to being constipated, and you say yes to having diarrhoea. Do you think we're playing a game? What's the doctor supposed to believe?*

The above conversation is problematic on several levels. In addition to the interpreter scolding the patient's misunderstanding and ambiguous answers on behalf of the doctor, it turned out that the patient had understood 'constipated' (in Danish called 'hard stomach') as a 'stubborn' or 'annoying' stomach, which is not incompatible with diarrhoea.

Concepts cannot always be translated word-for-word and in some cases, there is no translation.

- Doctor : *Have you had any allergic reactions to the medication you were prescribed last time?*
 Interpreter : *Does the new medicine make you throw up?*

The interpreter knows that the patient does not understand '*allergic reaction*', which is a biomedical concept, so the interpreter is more specific - a little too specific, but it illustrates that the use of grey-area concepts gives interpreters unsolvable tasks. Instead, be specific: ask for 'rashes', 'headaches', and 'vomiting'. The same applies to words like bacteria, depression, anxiety, or diabetes. Avoid using culturally defined metaphors, idiomatic expressions, ironic expressions, and sayings no matter how common they are, such as: 'That's the root of the problem', 'You cannot make an omelette without breaking some eggs', 'She wears the pants in the family', 'He kicked the bucket', 'Do you have butterflies in your stomach?' or 'Burnt child shuns the fire' since *root*, *omelette*, *pants*, and *fire* have very different, often unpredictable, cultural meanings.

Through education, interpreters can be trained to help doctors ask appropriate questions that give the doctors the answers they need. Doctors should practise asking good questions in plain Danish and should continually ask the interpreter to interpret the meaning of the patient's concepts and feelings so that everyone speaks the same language and achieves the same understanding in the conversation.

Curiously, ethnocentric expectations can be counterproductive. The following is a conversation between a psychiatrist and a Vietnamese woman through an interpreter.

- Psychiatrist : *Ask the patient how long she thinks she should take her antidepressant medication.*
 Interpreter for patient : *The doctor says you should take the medication for two weeks and then come back for a new conversation with the doctor.*
 Interpreter to doctor : *The patient says she will take the medication for two weeks and then she would like a new appointment.*

The psychiatrist is trying to involve the patient in the decision in a contemporary fashion and at the same time trying to uncover how motivated the patient is to have the treatment. The interpreter, on the other hand, believes it is the doctor's job to be precise in his orders if the patient is to comply with the doctor's decision. Making it the patient's choice is, in a Vietnamese context, tantamount to revealing the psychiatrist's insecurity and incompetence, thereby reducing the patient's motivation to take the medicine.

Some doctors are very dismissive of interpreters openly reinterpreting words that cannot be translated directly, but still demand that interpreters do it. Other doctors scold interpreters for what the patient has said, implying that the interpreter did not need to translate it. These can be disparaging, stigmatizing statements, or it may be about non-biomedical illness models, or that the patient has sought alternative treatment. Over time, this may cause interpreters to completely omit certain topics or utterances from their translation. Interpreter training and the education of doctors in cultural sensitivity can eliminate fear of contact in conversations.

Because interpreters have limited knowledge about health conditions and psychiatric illness, they may normalise conditions that actually require treatment (1309). Knowingly or unknowingly, patients often send out verbal ‘cues’ in conversations - a kind of vague attempt to mention emotions or experiences whose importance they themselves are unsure about. If the interpreter does not catch the language ‘bait’, or if the interpreter has a need to normalise the patient’s thoughts, then the doctor may miss danger signs (1310), like in this conversation:

- Doctor : *Do you have thoughts that scare you or confuse you?*
 Interpreter to patient : *Is something bothering you?*
- Patient : *I know ... I know God is with me in this. I'm not sure ... but I'm not afraid ... they can't hit me ... I'm wearing these new pants and a strong shirt, so I'm well protected from them. I'm fine ... no headaches, and they're not taking me.*
- Interpreter to doctor : *He says he is no longer afraid. He is doing really well and no longer has a headache.*

The patient clearly has invasive thoughts and paranoid notions that should have been further investigated by the doctor, but the small, distinct signs disappear in the translation.

Doctors who ask a lot of questions can frustrate the interpreter and the patient, making the interpreter feel called upon to limit the number of questions or to rephrase a repeated question that the interpreter, and probably the patient as well, does not understand. It may be a good idea to explain the reason for certain questions and why exactly that information is key (e.g. seasonal variation, symptoms during holidays, or stress-related illness). Questions regarding numbers or frequency can be problematic to translate if the interpreter knows the patient has had no schooling. The same applies to questions of temporal correlations between cause and effect, or questions where the patient is asked to judge the intensity, importance, or relation of the symptom to certain actions. Questions where the patient should rate on a scale (0-10 or smileys) are difficult to translate for patients who are not used to looking at drawings, numbers, or sequences from left to right etc.

Very routine conversations with highly compressed information levels are especially challenging for interpreters. The time frame is clear, the pace is fast, and the interpreter must find a diplomatic middle ground, but since there is no time from the medical side to reflect or ask, the interpreter must make quick decisions. Here’s a conversation between a patient, a gynaecologist, and an interpreter:

- Doctor : *I'm going to examine your abdomen. I'm taking a tissue sample from your uterus– it's just a muscle, so it will grow back again.*
- Interpreter to patient : *The doctor will take a piece of meat from your life... from the stomach, but it will come back*

The interpreter misunderstands the doctor, and the patient is terrified, but dares not ask and concentrates on the fact that a large part of her stomach is now going to be removed.

The misunderstanding was later corrected because in a subsequent conversation with another doctor. The patient tearfully asked to be told *'how much meat was left in her stomach.'*

The doctor’s interview with the patient is structured according to specific goals, but its focus alternates between data collection, problem solving, treatment options, and patient information/health education. This means that the interpreter must constantly change roles and tone. If the interpreter does not know the doctor’s goal or conversation structure and is not used to the doctor’s specific style of interaction, the interpreter may be left behind or seem to be untrustworthy in the patient’s eyes.

The interpreter has two clients with very different interests. However, the interpreter is paid by the medical/health care system, and interpreters may need to be on the professional side of the triad, which is why interpreters subconsciously tend to prioritise the health care system's need for speed and precision.

Interpreters live in an environment where relationships are made with people from the same ethnic group. The interpreter may be burdened by general inside knowledge about the environment, conflicts, and patterns of action, which can influence the way the patient's information is perceived - even when the interpreter and patient do not know each other.

20.6. General

Most patient errors involving ethnic minority patients occur due to a failure to use interpreters for the most important conversations in the health care system. Many interpreters are either good at Danish or their native tongue, while few are fully proficient in both languages. This requires interpreted conversations to take place at a relaxed pace and in a trusted environment with a clear framework.

The interpreters, we use, come from interpreter agencies approved by the various administrative regions. Although efforts are currently under way to achieve proper certification of interpreters in the healthcare system, neither training nor assessment criteria have been established as of January 2018.

- Assign the necessary time for an interpreted conversation: it will take at least twice as long as an uninterpreted conversation simply because everything has to be said twice.
- Do not blame the interpreter if there are problems - it is rarely their fault or something they can handle (immediately).

Simultaneous interpretation (concurrent direct) is not possible or desirable in the healthcare system. These are conversations about highly charged, culturally anchored concepts of illness and specialised terms that require sensitive translation. Interpreters in the health care system are not, and never will be, doctors, and they cannot be expected to have a specialist vocabulary within each of the 127 medical specialities.

20.7. Technical and practical comments

1. Phone interpretation

This is quick to set up and good for brief messages (reminders, planned follow-ups, i.e. where the context is clear), but it is associated with several problems: no impressions from facial expressions; dialect problems in particular are amplified; many patients cannot understand the interpreter due to poor sound quality; and many refugees have damaged hearing and tinnitus. Make sure that the interpreter has a proper interpretation setting, i.e. that the interpreter is not sitting with others and is not driving or sitting in public transportation where unauthorised persons can listen in on the conversation.

2. Video interpretation

This requires a screen, but most video programs can now be run on laptop or tablets over WIFI or 4G mobile networks. The screen can be turned off so that only the sound is heard (e.g. during direct examinations), and the screen can be packed in a sterile plastic bag (in operating theatres). Sound and image are digital and HD quality (i.e. facial expressions can be observed, and the sound corresponds to normal voices). There is evidence that video conversations with interpreters are more focused and take less time than conversations where interpreters are physically present. Video interpretation offers a number of benefits to the interpreter and the patient - see the next section on attending interpreters.

3. Interpreters present in person

This is logistically more complicated. More people are in the room. Having interpreters physically present is traditionally perceived as ‘the best’, but evidence shows that video interpretation is at least as good. Physically present interpretation entails that there are many people in the room, which patients may find intimidating. Interpreters do not like to have contact with patients in the waiting room, where patients may try to influence the interpreter prior to the interview.

4. Bilingual colleagues

Bilingual colleagues are often used in emergency situations, but some departments consistently use them. There is no evidence that a colleague is necessarily the best interpreter. There may be a conflict between the colleague’s role as a health professional and that as an interpreter, which causes the patient to speak out in a different way or to omit information. Mixing care and interpretation or treatment and interpretation is not optimal in the long run.

5. Family or friends as interpreters

Most relatives who are considered to be interpreting for the patient are in fact just ordinary relatives. They are there so that more people can listen to the doctor and ask questions. They interact with the patient exactly as ethnic Danish relatives do, i.e. they correct, elaborate, follow up, and handle practical matters. Unfortunately, however, many patients find that professional interpreters are typically not requested for interviews in the healthcare system. Therefore, family and friends are often used by patients as interpreters with the blessing of healthcare professionals because it is convenient and easy. Firstly, under no circumstances may children be used as interpreters for a wide range of reasons. Secondly, it can be problematic for close family members to interpret sensitive or serious matters, including intimate, psychological, and relational issues. Topics and information may emerge that the patient is not prepared for and that relatives may not need to know about. Relatives can be used initially in very acute cases and for short practical interpretations of a neutral nature concerning appointments or transport if professional interpretation is not considered practical. In rare cases, the patient may demand that a specific relative acts as the interpreter when talking about certain topics. In this case, the health professional must take a stand in the situation and consider, for example, whether potentially valuable information should only be shared with that particular person as an interpreter.

6. Google translate, apps, and software

For practical purposes, there is no evidence that Google translate has any place in interpreted conversations (dialect, language group, incorrect professional concepts, incorrect word positions, problems with negation, and endings that can confuse). A variety of apps are being developed that are primarily aimed at anamnesis recording and simple information about surveys, but they are typically country-specific and are not directly appropriate for a Danish context. Some apps can be better adapted to Danish conditions than others, but as of October 2020, no app is widely available for use in Denmark.

7. Preparing for the interpreted conversation

It is crucial to prepare for an interpreted conversation because the structure and objective of the conversation can easily be disrupted or delayed if there is no clear plan. Prioritise topics and consider how the information should be provided and what the conclusion (preferably) should be. Are there concepts that will require a simpler or more detailed explanation? (Examples of concepts that often require further explanation: body mass index, spleen, pituitary gland, liver count, hepatitis carrier, heredity, chemotherapy, white blood cells, PET scanning, metabolism, epilepsy, stress, etc.).

- Do the patient and the interpreter speak the same language and dialect? Ensure consensus on language and permission to continue the conversation.

- Brief the interpreter on the objectives of the conversation (especially in the case of a very serious or particularly sensitive subject).
- Briefly explain which department the patient is in and what the doctor's role is as well as what the plan is for the conversation.
- Explain or emphasise confidentiality (if deemed necessary in relation to the subject of the interview). In practice, it is extremely rare for interpreters to gossip, but the fear of this happening is substantial, and there has to be some leeway on the part of the health professionals if the patient insists on declining specific interpreters on this basis.
- When half an hour has been ordered on the interpretation voucher, it means 30 minutes and not 50 minutes. Interpreters experience that departments are late in calling because they think they have plenty of time. This affects the interpreter's next conversations, and it is not the interpreter's responsibility or job to manage hospital appointments.
- Call the interpreter a few minutes before the patient is called in. If the interpreter is a male, then advise the patient (if female) of this to prevent any surprise when they come in or the screen is turned on. The element of surprise can give the conversation a skewed or completely wrong start. The same goes for male patients.
- Prepare the interpreter on what the conversation is about shortly before the patient is called. It provides for smoother and more natural sequences if the interpreter knows the key points and (expected) goals of the conversation.
- Pay attention to the time used with the interpreter. Many interpreters find that patients get annoyed at them if it is only the interpreter who mentions that there is little time left. Agree on the time remaining and inform the patient so that the patient does not think it is the interpreter who is ending the conversation (but the doctor).
- The best interpretation is achieved when everyone can see each other. Thus, only turn off the screen when absolutely necessary. This may be necessary if the patient wishes to remain anonymous or if the patient needs to be examined and possibly needs to remove some clothing.
- Pause or look at the interpreter when you want to ask him or her to interpret. Do not assume that the interpreter automatically knows when to interpret. While talking to the patient, the interpreter is entirely focused on remembering your information in order to be able to repeat it to the patient in the second language. The interpreter is constantly monitoring your communication to make sure that you don't say too much to reproduce it accurately in the second language. You should pause purposefully after speaking a few sentences to let the interpreter know when to start. A quick glance or nod towards the interpreter can also serve as a clear and useful sign in the turn around. Do not use long sentences or many sentences, and only ask one question in the same sentence. Build up your argument clearly and explain, if necessary, the structure of your reasoning to allow the interpreter to support your argument structure in the translation.
- The conversation can benefit from the interpreter being able to also act as a cultural bridge between the patient and the doctor, while at the same time staying within the framework of interpretation. In addition to repeating what the patient says to the doctor, the interpreter may sometimes need to explain the cultural context of a particular consideration or expression. However, great care must be taken to make the interpreter provide only the most important cultural background information. Guesswork, conjecture, and prejudice are unacceptable. If the interpreter does not understand what was said, he or she must ask for clarification in order to give a complete and precise interpretation.
- Interpreters CAN, like doctors, get distracted and lose the thread. Be patient if the interpreter asks you to repeat a sentence or explain a complex problem once more. Ask the interpreter to

let you know if there are any concepts they do not know or if it is difficult to translate the doctor's information (not all concepts can be translated directly). If the conversation contains particularly sensitive topics, it may be beneficial to be very direct and open about it and to ensure that the interpreter and patient each agree with the content and concepts of interpretation (rape, deformities, psychological trauma, assault, violence, sexual problems, contagious disease). Be aware that some interpreters are refugees themselves and may have experiences similar to those of the patient. Debrief the interpreter if there is any suspicion, but pay attention and if in doubt, say so.

- Speak slowly in short sentences with one piece of information per sentence. Pause and observe the reactions of the interpreter and the patient. Doubts are often visible in facial expressions. If you suspect doubt, say so. This will invite the patient and interpreter into a dialogue and to participate in the decision-making processes. Ensure consensus on important information: Are the basic concepts and reasons for key actions understood? Does the patient know the organ, the illness, the procedure? Draw and show more than usual. Ask the patient to tell you what the plan is and who's going to do what.
- Watch the eye contact between the patient and interpreter; indecision and ambiguity are often indicated through facial expressions.
- If the conversation doesn't go as expected, say so. If the conversation is uneven or choppy or if it skips more than is reasonable, say so. If the patient answers superficially and imprecisely, then say so and find out what the reason is (Dialect? Gender of the interpreter/doctor? A particularly sensitive subject? Does the patient doubt the quality of the interpreter? The patient is manic/psychotic/has a personality disorder? Is the interpreter an experienced interpreter? Is the patient afraid of the interpreter gossiping? Ethnic clashes (tribal relations?))
- Ask what the problem is if the interpreter has to explain the same thing several times.
- Be sure that key concepts and explanations are understood by the patient.
- If the patient and the interpreter are arguing, ask what the argument is about (most often it concerns clarification of concepts or comparisons if the information cannot be translated directly).
- Do not guess - ask if you are in doubt.
- Continuously confirm the patient's understanding through partial conclusions, especially with regard to key explanations, studies, treatments, rehabilitation, side effects, and complications (not from the interpreter, but from the patient).
- Confirm the plan here and now and going forward (not from the interpreter, but from the patient).
- Finish by asking if there is anything in the plan that the patient is unsure of, afraid of, or unsure about. Ask the patient directly if there are any examinations that the patient is particularly afraid of.
- Ask if the patient has any important questions that have not been discussed and observe the interpreter's and the patient's reactions.
- If it is important, ask the patient whether the interpreter was acceptable?
- Everyone needs praise once in a while, so if you experience a good interpretation and a good interpreter, remember to praise them.

8. If the conversation does not proceed normally or as expected

- Do the interpreter and the patient speak the same language?

- Is it the interpreter's primary or secondary language that is interpreted?
E.g. a Somali interpreter interpreting Arabic
 - Serbian interpreter for Bosnian patient
 - City language versus country language (complexity, jargon)
 - Language level: for example, the Arabic language has five different levels of complexity, and few patients master the highest levels.
 - Level of education (in some languages, highly educated people perceive everyday language as vulgar and offensive, etc.)
- Is it the same dialect?
 - Kurdish dialects
 - Arabic dialects (e.g. Moroccan Arabic)
- Does the interpreter (i.e. the doctor) use language that is too advanced? (Interpreter highly educated, patient little educated)?
 - Gender: are there certain topics that may be difficult for the interpreter to talk about, or topics the patient cannot talk about with someone of the opposite sex?
 - Is the topic something the patient and interpreter find hard to talk about due to gender, age difference? – i.e. they use evasive indirect answers/questions
 - Is the interpreter experienced?
 - Is the interpreter inexperienced in the specific subject area?

Stop the conversation if you have a lot of doubt about what is going on and tell the interpreter about your doubts. Have a dialogue about it. If the interpreter cannot establish a normal conversation and there are no explanations as stated above (i.e. the interpreter is not able to interpret properly), then the interview should be stopped and the interpreter agency should be informed of the inappropriate interpretation.

9. Other advice

- The interpreter is the 'smartest' person in the room in the sense that the interpreter is the only one who verbally connects the patient and the doctor and can create a meaningful communication.
 - Make the interpreter part of the clinical conversation and avoid placing the interpreter in the role of an 'interpreting machine', which is inappropriate and leads to disjointed translations.
 - Speak the same language - find a language tone and a language level that match the patient's own. It is easy to be deceived by the fact that the interpreter is highly trained, leading to the doctor and the interpreter having an academic interview while the patient is not actually part of the conversation. Because the interpreter speaks 'good Danish', one can be fooled into thinking that the interpreter is also skilled in his or her mother tongue. There is no reason to believe that. It is the flow and content of the conversation that should be assessed - not the interpreter's ability to speak Danish. The same can happen to the patient and the interpreter: good Somali language does not necessarily equal good Danish language.
- Patients are often used to interpreted conversations being short with no extra time set aside for the conversation. This means that patients are used to saying little and not addressing difficult issues.

- You need to make sure that patients have the time and space to ask and clarify.
 - Non-verbal content is especially important in an interpreted conversation: you should ‘want’ the patient in your body language, so the patient makes the extra effort to explain themselves.
- Polish the cultural radar: Think of the ordinary first: although the patient’s explanation sounds exotic and foreign, most clinical problems are common in nature.
 - Actively address and respect the patient’s anxieties and concerns. Patients are not used to talking about these matters, so do not mention them spontaneously, especially with an interpreter present.
 - Create security, build trust, and spend some time on it. Both patient and interpreter are nervous.

It is always beneficial to discuss concerns and align expectations, especially in bilingual contexts and in relation to the role of the interpreter. An experiment with a regional educational programme for interpreters has recently been initiated in the Region of Southern Denmark, and national interpretation certification is being discussed.

10. Examples of situations that interpreters find particularly difficult

- Grumpy doctor and/or nurse - because it is contagious, and the interpreter loses motivation and feels worthless and loses concentration.
- That the secretary thinks the interpreter knows the patient - the interpreter has to go around the waiting room and ask, *‘is it you who needs an interpreter?’*
- Disrespect from professional staff - affects mood/behaviour of the interpreter, *‘I get angry if it goes beyond my limit.’*
- Too little time between interpreting assignments (paperwork takes a lot of time because the hospital department has not prepared it).
- The doctors are always late - this takes up the interpreter’s time from their next appointment. The interpreter gets criticised.
- Too much detail/too difficult information - too much demand is placed on the patient.
- The sound quality in phones is poor - phone interpretation is not the best.
- Relatives who keep interfering - too many people to interpret for at the same time.
- Patronising speech from doctors and nurses or disrespect toward the patient is difficult to deal with for the interpreter: Doctors who talk down to Danish residents who do not speak Danish - *‘Why don’t you speak Danish if you have been here for 20 years?’*
- Offensive language that can be difficult to deal with when translating.
- When the doctor wants the interpreter to select information from the patient to be interpreted (especially in municipalities/psychiatry) – they actually ask the interpreter to be the one who selects the medically relevant information.
- It is uncomfortable for the interpreter if he or she loses track of the doctor’s information or if the doctor’s information is ambiguous and the doctor does not allow time for questions or clarification.
- All patients have difficulty answering the doctor’s first question: *‘How are you doing?’* - The patients think they should start explaining about all symptoms, whereas the doctor only sees it as a short introductory greeting.

- Patients expecting too much help from the interpreter - *'The patient wanted me to drive her to Copenhagen. When I said no, she didn't want me anymore.'* Many interpreters experience getting disqualified in their interpretation service because they do not want to help the patient with other practical problems.
- The hospital staff ask the interpreter to call the patient to deliver a message/answer - but the patient has questions about the answer that the interpreter may not/cannot answer. This can cause the interpreter to appear untrustworthy.
- When the interpreter does not know what the conversation is about before the conversation gets started. Or, does not know the context or goals of the conversation and cannot assist in facilitating the conversation. No conversation 'contract' is made, and it weakens the interpreter's work in explaining the doctor's information.
- When the interpreter finds out that the patient has been 'acting' and, for example, suddenly recovers when granted early retirement. It is difficult for interpreters to handle information that the patient will not allow them to pass on to the doctor.

21. Cross-cultural conflicts and misunderstandings*

Due to increasing globalisation, more and more people are living close to other people from completely different religions and societies. This creates the potential for conflict in many areas of society, including health care. However, cross-cultural conflicts occur primarily because many people are not aware of their own values or those of their own social network and their own culture, nor the values of other cultures.

Cultural codes and values are a central part of any conflict because conflict is about relationships - how they are created, maintained, and broken down. Conflicts contain three elements: the material (what is wrong), the symbolism (the significance of the ingredients of the conflict), and the relations between the parties. Each of these elements is culturally anchored, and not knowing this makes it difficult to prevent or resolve conflicts (1311). Internationally, there are major differences in how to perceive and resolve conflicts, e.g. in relation to preferences about mediation, compromise-seeking, consensus, and negotiation, as well as involvement of religious or ritual methods ('quid pro quo') (1312-1316). A meta-analysis of cross-cultural conflict resolution models (1317) found that:

1. Individualistic cultures choose coercion as a style of conflict more than collectivist cultures do.
2. Collectivist cultures prefer a style where you retreat a little, compromise, and solve problems more than in individualistic cultures.
3. In individualistic cultures, a compromise is approved more often by women than by men.
4. Women are more likely to approve of the use of compromises than men are, regardless of culture.
5. Men involved in conflicts report more often that the opposing party uses coercion than women do.
6. In terms of the organisational role, men are more likely than women to choose a style of resolution involving coercion.

Most clinicians lack the knowledge to understand how culture affects the clinical meeting, and they lack the skills to effectively bridge potential differences between the patient's and the doctor's perceptions. The function of any culture is to ensure that its members survive and thrive within a certain ecological niche. A comprehensive social science literature study clearly shows that health and the means of maintaining, regaining, or achieving well-being are culturally defined (1318). Each culture defines what good health is for its members, determines what causes illness, determines the parameters within which discomfort is defined and signalled, and prescribes the appropriate means to treat the disorder, both medically and socially (1319). An understanding of the importance of culture to the patient is therefore absolutely fundamental for medical examination, treatment, and rehabilitation (535). By necessity, cultures are dynamic, responsive, coherent systems of attitudes, values, and lifestyles that have evolved within a specific geographical location using the available technology and economic resources. The culture develops as needed to adapt to changing environmental conditions and circumstances - including during exile (166).

Conflicts and challenges associated with conversations with ethnic minority patients and relatives are almost always based on language barriers, which are played out through unprepared conversations in ad hoc contexts with uncertain frameworks and unclear role-sharing. Moreover, these conflicts and challenges are exacerbated by different ways of using language, different ways of entering into agreements, and different patterns of taking turns in a conversation.

Case 1

Staff at a kindergarten scolded a child's parents because they continued to give their child a small bag of sugar to give to the nursery, even though staff had several times said they should not do this. The staff saw it as a direct provocation. It turned out that the parents had misunderstood a note they had brought home, requesting that the children bring extra *socks* for indoor use. The parents thought it was a 'contribution' for kindergarten cooking and did not understand why they were scolded for doing what was asked. (The words for *socks* and *sugar* sound almost the same in Danish.)

Often, one party feels that a clear message has been delivered to the other about a unilateral decision that has already been made, while the other party perceives that a (different) clear mutual agreement has been reached - yet neither party tries to confirm this understanding. Moreover, two monologues do not make a conversation, and two unilateral agreements are not a common agreement.

Case 2

A male patient with only a few years of schooling has an interpreted conversation with a psychologist. The patient says, *'It's like there's an elephant stomping around on me at night.'* The interpreter tells the psychologist that the interpreter would like to explain what the patient means by it. However, the interpreter is cut off by the psychologist with the message that the interpreter should only translate exactly what is said and not start rephrasing or explaining what the patient says in a different way. Instead, the patient is questioned about the appearance of the elephant, its colour, when at night it comes, whether he experiences it actually being present, etc. The patient becomes clearly confused, stressed, and eventually angry about the direction of the conversation. When the psychologist asks the patient if he knows why he is ill, he answers, *'It is fate,'* and to the psychologist's question, *'Do you think you will recover?'* the patient answers that it is up to God. This clearly irritates the psychologist, who says to the patient, *'Can we just park God over there in the corner?'* The patient becomes even angrier and says, *'People who need to park God need God themselves,'* and the conversation is ended by the patient due to the high level of stress/conflict he felt in the conversation. What the psychologist never discovered was that the phrase *'an elephant stomping around on me'* is a common expression for back pain in the patient's own language.

Ethnic minority patients easily break or challenge customary rules, frameworks, and routines - usually because these are unknown or considered meaningless. Negotiating pragmatic solutions can often be the way forward.

Case 3

Some Muslim parents whose newborn baby is in an incubator in the neonatal ward have a strong desire for the child to have a copy of the Koran inside the incubator. Several routines collide in this case. As conditions are cramped in the incubator, the hygienist resists placing 'unclean' items in it. Some neonatal departments have solved this by either placing the Koran in a sterile plastic bag or negotiating a solution where the Koran is close to the child but outside the incubator.

21.1. Illness or disorder, cause and effect

Korbin and Johnston (an anthropologist and a paediatrician, respectively) describe in an article a case where a medically successful treatment results in the mother of the sick child never again wanting to have her child treated at the hospital (1320). When the child was hospitalized, it was severely affected by a high fever and extreme fluid deficiency caused by typhoid. The child received treatment and was later discharged when healthy. The problem is that the doctors did not realise that the mother had a fundamentally different view of the problem on two key points. The mother believed that her son's illness was due to him having fallen down a flight of stairs the day before he got sick. He hit his back and

had had a sore back since then. She was angry that the doctors neither examined the boy's back nor treated his back pain. The mother came from Jamaica and was used to the local traditional healer taking a small drop of blood, which he used to make a diagnosis, then starting treatment and predicting the prognosis. The mother felt it was unsafe for the doctors to continue drawing large amounts of blood for blood tests. Furthermore, the mother believed that people are born with a certain amount of blood and that the paediatricians' excessive consumption of the child's blood would leave her son with very little blood reserves for the rest of his life. From the hospital's point of view, the diagnosis was clear and the mother opposed the doctors' treatment; she was consequently threatened with a legal injunction or a forced removal of her child if she prevented the doctors from continuing the treatment. On this basis, the mother accepted the treatment. The doctors were thrilled that they had diagnosed a relatively rare (for the US) and fatal typhoid infection and that they had saved the child's life. However, for too long they ignored the mother's obvious displeasure with the doctors' diagnosis, blood consumption, and improper treatment of the boy's back. As a result, when the boy was healthy, the mother left the hospital and commented that she would never go to an American hospital again, *'They do not listen, they do not understand, and they tap the patients' blood.'*

21.2. From culture clashes to routine clashes

These are not clashes between cultures, as many would otherwise see it, but rather clashes between different routines (the patient's and the staff's), different frameworks of understanding, and different social codes (family and hospital/department culture). All humans are rational according to their own terms. Thus, it is the terms that are the solution, whereas the clash between rational arguments perpetuates and escalates the conflict. You should not eliminate differences in terms: perceptions/values/needs, but use the dynamic that arises from professional and curious interaction.

The healthcare professional should encourage openness, exchange ideas, compare points of view, and deliver a professional summary in cooperation with the patient; otherwise disagreements, misunderstandings, and conflicts will occur.

The terms for action patterns are important, but they put the following demands on employees - especially in cross-cultural patient conversations:

- You have to understand more about the patient
- You have to learn about what is important to the individual patient
- You have to be more aware of the patients' vulnerabilities, which are often unfamiliar to you
- You are forced to work outside the usual guidelines, time frames, and competencies.

These points are often demands that make employees vulnerable and put them under pressure. The employees may become stressed, angry, irritable, prejudiced, indifferent, withdrawn from the relationship, conflict-creating, confused, or impatient.

Many situations are exacerbated by intra-cultural conflicts (intra-staff disagreements, i.e. staff disagree on attitudes, values, and patient approach) about what is happening and how to tackle it. Disagreements between the employees (often ethnic Danes) are transferred to a cross-cultural conflict. In reality, however, the escalation of conflict starts as an ethnic Danish conflict. The disagreement is reflected in ambiguous and disjointed information, unclear social rules, or internal disagreements about relationships with patients. Stressed relatives withdraw despairingly. They cannot figure it out, and none of the health professionals try to engage in understanding the problem with professional curiosity. On the contrary, the employees' interaction is characterized by arbitrariness and a lack of professionalism: making something seem odd, as well as tropicalisation (e.g. problems one does not understand must be rooted in exotic explanation and rituals), cultural arguments, and pseudo-religious assumptions replace a professional cross-cultural approach to patients and caregivers.

Bilingual patients and relatives often find it difficult to engage in critical dialogue about staff generalisations (and many of them are internalised after many years of experience). It takes communicative strength to argue your way out of a generalization. Prejudice and bias are often more evident than the staff themselves are aware of, and this in itself can be provoking and challenging to patients and relatives.

Conflicts between staff and patients can arise for several reasons, one of the most frequent being language barriers, but in special cases the political attitude of staff towards refugees may also block a professional approach toward the patient. Conflict management in cross-cultural contexts is always based on the patient's history; where the patient comes from; what language the patient speaks; what family and networks exist; whether the patient has experienced war; whether there are any signs or symptoms of anxiety or stress; what the patient's perception of the condition and illness is. If the patient is already disqualified as a person and human being due to refugee/immigrant status, then the patient's background information will never be obtained, and this provides fertile ground for further misunderstandings with conflict potential.

Case 4

This case occurred in connection with a request from another Danish hospital whose staff needed help dealing with a patient with a different ethnic background. Reportedly, the patient was uncooperative, demanding, and dissatisfied. At a ward visit, it turned out that the patient did not understand Danish but could, according to the staff, speak fairly good English - a language that only some of the department staff mastered, while others only had a minimal vocabulary. Consequently, the communication between staff and patient often consisted of one-way communication with short command-like messages from the staff to an insecure and anxious patient who had no family or close network in Denmark. The patient had fled the war in Somalia and had undergone severe, traumatic experiences in his childhood. The combined English language of the staff was so poor that it created conflicts. Firstly, the staff's professional English vocabulary was inadequate (contrary to the staff's own opinion). Furthermore, they had created a command language (Get up! Move! Drink your water!) that sounded like harsh soldier language, which caused anxiety and stress in the patient due to his background (with which the staff had not familiarised themselves).

Conflict management also entails helping staff to become aware of their own prejudices. Most often, prejudices emerge as unconscious actions that can quickly become a whole department's culture, where no one questions whether the patient receives an equal and caring approach, care, or treatment. Thus, health professionals who believe that refugees/immigrants should not be in the country at all are challenged in their professional skills, which is why conflict management will always require a reproach and making the staff aware of their own attitudes and prejudices towards the patient.

You are the wisest in your native language, and you are best at being ill in your native language. Symptoms, perceptions of illness, and behaviour during illness are coded in the native language at a very young age. If the key conversations about the patient's illness are conducted without an interpreter, the seed is planted for a series of disagreements and misunderstandings that will be experienced as 'cross-cultural conflicts', but in reality, it starts with the staff not being professional in their dialogue concerning key information. Patients and relatives see it as discrimination and a wilful act on the part of the staff. The often-ambiguous information they receive when there is no interpretation is perceived as unprofessional, and this increases the risk of conflict.

When as a patient or caregiver one is excluded from a dialogue about the key diagnosis/ treatment because there is no interpretation, there is a shift to an anxiety-driven focus on errors and shortcomings when you do not understand the content, you can only respond to what you can see; when you do not understand the reasoning for the decisions and actions of the staff, then they automatically become mistakes. A transfer to another professionally quite relevant department can be seen as a rejection or that

the doctors have given up and are now just referring the problem elsewhere. Therefore, the early small and insignificant signs of misunderstandings or disagreements must be directly taken up and a dialogue about what the problem is should be encouraged.

Many people unknowingly raise their voices towards patients in conversations marked by language barriers. The patient, however, may see this as 'scolding', direct orders, or an expression that the doctor/nurse believes the patient is disabled (without that being the intention).

In many non-Danish cultures, there is a conversation ethic that says you let the professional speak first and finish speaking before you (as expected) get to speak as a relative. The staff often misunderstand this and think that the patient has no comments, and so they end the conversation at the very moment the patient or relatives are allowed to speak according to their code. It is noted that the patient consents ... but they don't. You remain polite in a conversation and wait for your turn. It is important to be clear about when the patient should contribute with questions and comments because the rules may differ from those the patient is used to.

In 1983, Berlin and Fowkes created a clinical mnemonic to avoid cross-cultural misunderstandings (1321):

- L** Listen (listen to the patient's problem)
- E** Explain (explain to the patient the perception of the problem)
- A** Acknowledge (acknowledge the problem and any differences in perceptions)
- R** Recommend (suggest options)
- N** Negotiate (negotiate the best option with the patient)

In 2000, Levine and Gotlieb formulated the following mnemonic (1349):

- E** Explain (let the patient talk about his/her problem)
- T** Treatment (what treatment has the patient tried)
- H** Healers (from whom has the patient sought advice)
- N** Negotiate (negotiate a common acceptable solution)
- I** Intervention (joint action)
- C** Collaboration (work with all relevant people to support the solution)

21.3. Frequent challenges with ethnic minority patients and relatives

One of the most frequent 'points of contention' in hospital wards is that the staff feel that the patients' relatives 'make too much noise'. Instead of professional curiosity and dialogue, strict demands are very quickly placed on the number of relatives allowed in the ward, who can talk to whom, people are told off, and the 'kid gloves come off'. The individual reaction patterns of the employees become clear: Some are 'triggered' by an incident or a remark and start to scold; others become frightened and withdraw, while others try to be welcoming and to smooth things out. The cause of the conflict or unfriendly atmosphere never becomes clear to the patient or relatives, and the very different, often contradictory or ambiguous; reactions of the staff create even more confusion, which contributes to further conflict situations. The unresolved values and policies of the staff in relation to the unfamiliar social behaviour end up being part of the cause of the conflict continuing unchecked.

So, what would be good to know? Based on analyses of the conflicts in which the MHC has been involved, discussions with experienced interpreters, and patient experiences, the following tools can be used to prevent or de-escalate conflicts:

- Survival strategies are learned when one is two years old (in families with many children born at short intervals, 'survival techniques' are taught as soon as you have a younger sibling; you have to fight loudly for any love, care, and help).
- 'If it goes, it goes' approach (in low-resource countries you have to fight hard for help, and anything goes).
- 'You have a duty to defend your body' (you have been given the body as a gift, a loan, and you must take care of it and defend it by all means - otherwise you are a bad person).
- Frightened people react unexpectedly (sick people can react unexpectedly if they become very afraid. The same applies to the relatives if they cannot get an overview or understand what is happening. Some people who are afraid become silent and isolate themselves, while others lash out, make demands, and try to get attention by raising their voice).
- '*What will other people think?*' (a social code that requires a patient and his or her relatives to defend the sick person or requires everyone in the patient's social network to visit and defend the sick person - even if they are not normally next of kin, they must nevertheless behave to avoid being subjected to the same social code).
- Experience of being humiliated or disregarded (some relatives have previously experienced being humiliated, rejected, or neglected according to their own or the patient's needs and are therefore determined that it will not happen again).
- Patient/relatives are used to misunderstandings because they rarely experience interpreter assistance. The patient and relatives are therefore extra vigilant and 'super aware' of errors, misunderstandings, and misinformation.
- Bulldozer psychology: Patients and relatives have experienced that doctors and nurses do not understand their needs anyway. (*'You can't understand it anyway. I don't expect you to understand, so I'm just going to push until I get my needs met.'*)

21.4. What stresses patients (and thus increases the risk of disagreements)?

What is routine for a health care professional can be a dramatic life change for the patient. For most people, encountering the health care system will be a relatively rare occurrence, and most situations are completely new to the patient. The social codes are hard to learn during first-time events, and the patient's own reactions will often be unpredictable (and incomprehensible, even to themselves and their relatives).

Patients have no frame of reference the first time they are seriously ill, and it takes considerable time before they 'learn' or adopt a frame of understanding. Decisions often need to be made where there is no 'right of cancellation' (amputation, transplantation, side effects from chemotherapy, etc.).

Effective treatments are often associated with greater or lesser risk of side effects, complications, or serious subsequent illnesses. Information to the patient, therefore, involves a risk assessment of what may cause severe anxiety in the patient and relatives. If you as a patient have insufficient insight into the basis of the decision, you may have doubts, ask more questions than other patients would and demand more details or special treatment, or make ambivalent statements that the staff find difficult to understand and which may initiate a conflict.

21.5. Illness interpretation

You learn to vomit, have a stomach ache, and be afraid in your native language. Even bilingual people can get into trouble if they get sick because they often have only their native language as a basis for conversations about emotions, illness, life, and death. All values and concepts linked to symptoms and illness are coded very early in life, and their meanings are negotiated in one's native language. Initial conversations about medical history, examinations, differential diagnoses, and life with illness should be offered with interpreter assistance in order to establish a good medical history and ensure that key concepts, examinations, and treatments are understood. If health professionals fail to recognise that bilingual patients may have interpretation needs, it can create fertile ground for misunderstandings and conflicts. Many conflicts start during important talks in the absence of interpreter assistance.

Higher education does not mean that the relatives necessarily understand more complex treatments, complications, or side effects. Misunderstandings easily arise if information is omitted because it is assumed that the patient's level of education makes the information redundant or banal.

When one parent who speaks 'a little Danish' is informed, it does not equate to the other parent being informed. If children or adolescents are used as interpreters, they will often have trouble translating because the messages are more complex than the adults think or because many children have an extremely poor vocabulary in their parents' native language. These children have learned only simple, everyday vocabulary while in Denmark, which is insufficient for a medical interview.

21.6. Culturally based turn-taking in a conversation

How to start a conversation, when to bring up the key point of the conversation, taking turns, the significance of pausing, and who gets the last word are culturally determined and guided by context. The structure of the conversation affects understanding: If the goal of the conversation is clear from the start, the process of building arguments through a presentation of background information can ensure that the recipient understands and uses the subsequent information correctly. You ensure a common framework of understanding through the structure of the argument. You have to agree on the structure and intent of the conversation very early in a conversation so that information is used correctly.

It may be a good idea to understand the varieties of social conversation codes that often cause misunderstandings. In many societies, it is expected that other people will be *allowed space* to speak. In Denmark, patients from these cultures may *wait in vain*, whereas the health professional perceives a *lack of questions* as a sign of (tacit) acceptance. In reality, the patient is waiting for signs that the patient has been given formal permission to speak. It could be rude to say something unsolicited, and if the health professional does not ask and invite the reluctant patient, then the patient will not interfere in a conversation.

Pauses have very different cultural significance and can cause ambiguity. The length of the pause is culturally determined and signals in different ways whether you are still thinking or have finished talking. The patient may be thinking about long pauses: *'Did I say something completely wrong?'* Or about very short pauses: *'Why does the doctor interrupt all the time?'*

In some cultures, you have to *wait to get to the point* until the end of what you want to say. Some people get *straight to the point*, while others *indirectly touch on* the heart of the matter in mere glimpses that are scattered throughout the conversation. According to Danish conversation culture, we may tend to *get straight to the point* right at the beginning of the conversation. However, this may cause misunderstandings if the patient expects the conclusion to come at the end of the conversation. The patient 'does not hear' what is said at the beginning because culturally, from the patient's point of view, the beginning of the conversation is often courtesy phrases and less important information. If there is no agreement on when the key point of the conversation is presented, it can lead to conversations being misunderstood 100 % (if you constantly expect the conclusion to come at the end), or it may make the

doctor's messages appear messy and unprofessional (because the impression is that the information is given in a scattered and random fashion and not at the end of the conversation).

The tone of voice is also culturally coded. Whether the tone goes up or down when we ask for help or information can create many misunderstandings. The placement of words is also important. We expect the words to come in a certain sequence, which is why we experience more misunderstandings when people use the word order from their native language.

Many misunderstandings or conflicts arise because the participants in the conversation think that they are referring to the same thing, e.g. 'a good contact', 'a good mother', 'Call if it gets acute.' Shifts in reasoning level can create misunderstandings because they can be perceived as a direct accusation, '*I am in favour of equality*', is countered by, '*How can you be when you always do the cooking at home?*' Another example is the phrase, '*Have you thought about going back to your home country?*' which may be meant as a friendly attempt to get the patient to describe where they envision their future but gets perceived by the patient as being unfriendly. An opening question such as, '*How is it going?*' which is mostly a greeting, can trigger a very long detailed explanation about the children, the finances, the spouse, and problems with the social worker.

21.7. Stereotypes start conflicts

A particular problem in cross-cultural conversation is the use of generalisations and stereotypes, which often creates conflicts. The individual experiences such generalisations as disempowerment and dehumanisation. Mastering the language and negotiation competencies are important for the individual's ability to speak up against or clarify the generalisations they experience. If the patient is unable to talk their way out of the generalisation or is not encouraged to engage in a critical dialogue, they feel powerless and demotivated, and this can end in anger, disappointment, and unnecessary conflicts.

Stereotypes are necessary to orienting ourselves in the world. The real world is in every way too big, too complex, and too fleeting for direct acquaintance between people and their surroundings. However, stereotypes require openness, and if the openness disappears, we get in trouble: absolutes and stereotypes are not flexible enough to capture the real people who populate this world. Humans live very diverse lives. Paradoxically, everybody thinks that *their way* of seeing things is the only natural and right way for humans and that other ways are reprehensible or erroneous. Each human being lives egocentrically rooted in their historical moment, their society, and their physical environment: *locked inside a bubble of their own experienced reality and in their own knowledge*. As an employee of the health care system, you need to be aware of the difference between your own reality and the patient's reality - and that some of the differences are found in different values, routines, prejudices, and dislikes. Knowing them, talking about them, and reducing their influence on the conversation can avoid serious conflicts and misunderstandings.

21.8. Changed decision-making patterns in families

If the head of a family dies or loses standing due to severe illness, the family pattern changes and decision-making processes are disrupted. The oldest boys suddenly have a huge responsibility with which they have no experience and their negotiating skills may not be quite developed yet, but the family sees them as the natural 'heirs' as the heads of the family. The pressures of family and networks may make the young men use language and rhetoric with conflict potential with the healthcare professionals. Often, the older family members do not realize what the young people say to the staff and cannot moderate their demands or language.

Children learn faster than adults and have better language control than their parents. In a digitised public sector, children's experiences with the Internet and computers give them an additional head start over parents. The disrupted and unfamiliar family pattern where the children have 'adult skills' can

cause conflicts both within the family and in relation to employees in public/local services, who often make convenient but ambivalent use of children as interpreters, social workers, lawyers, and spokespeople, even in very tense conversations.

21.9. Emergency telephone communication with patients without an interpreter

Advice no. 1: Listen carefully to what is said and be particularly aware of these points:

1. Avoid interrupting.
2. Do not ignore what the caller did not understand; it may be important and relevant.
3. Be aware that what the caller says could be very different from what the caller really wanted to say.
4. Be aware of the caller's possible language errors that may interfere with the meaning (word choice, incorrect synonyms, adjectives, grammar).
5. Ask the caller to repeat incomprehensible expressions or phrases, letting the caller rephrase them while giving the recipient a chance to hear the word or phrase again.
6. Find out whether the caller is physically with the patient or has been asked to call by people who are with the patient.

Advice no. 2: The recipient must ensure mutual understanding and be particularly aware of these points:

1. Repeat, rephrase, and check any information that is potentially important.
2. Avoid answers like 'mm-hmm' or 'OK'.
3. Avoid perceiving the caller's 'mm-hmm' or 'OK' as if they have understood your information.
4. Use follow-up and control questions to ensure mutual understanding.
5. Perceive general expressions as ambiguous and unreliable - be specific and simple.

Advice no. 3: The recipient must adjust his/her language depending on the feedback received from the caller, so be particularly aware of these points:

1. Be articulate: speak clearly and definitely.
2. Use simpler words if the caller does not understand what you are saying.
3. Avoid words that have two or more meanings.
4. Avoid metaphors or local idioms.
5. Avoid unnecessary words (fillers, colloquialisms).
6. Ask one question at a time, and give one piece of information at a time.
7. Be clear in relation to, who, what, and where.
8. Be clear: instructions are instructions; questions are questions.
9. Control the process, stick to simple language, and be clear about what the plan is with your questions and information.

Advice no. 4: The recipient must provide relevant and adequate information, so be particularly aware of these points:

1. Say, what you will do and what the caller should do, and repeat it.
2. Avoid stopping the conversation when you need to look something up, talk to a colleague, or call elsewhere without informing the caller.

3. If you do something (request an ambulance, etc.), tell the caller what you are doing and who should do what in this case. Say where the ambulance will take the patient. Repeat.
4. Inform the caller one more time about the reasons for your questions and information.

21.10. Other types of conflicts

Be aware of 'reverse' conflicts with bilingual healthcare professionals who frequently experience derogatory comments from patients (often only in private, which contributes to prolonging conflicts).

Case 5

A former mercenary is hospitalized with confusion and weight loss. He appears very extroverted and seems clear in his attitudes and values, but he comments very intimidatingly on the appearance and behaviour of the staff. The nurses on one evening shift are predominantly dark-skinned, and several of them are bilingual. The patient refuses to be 'cared for by such (N-word)'. Management only became aware of the conflict after many clashes between the patient and the staff and when staff indicated that they would report the patient to the police for racism. The patient was told to comply with the hospital and departmental policy in this matter, and the problem was not reported to the police. The patient was found to have brain tumours and subsequently developed a good relationship with staff.

Many bilingual health professionals can recount instances of 'a little everyday racism'. One young nurse was ordered by a patient to go wash her hands several times at the sink until the patient told the nurse that she had unclean hands that could not be washed.

During the swine flu epidemic of 2009, the Danish Health Authority opted out of targeted campaigns for ethnic minorities despite the potential misunderstandings and high alertness. As a result, minority communities instead had to seek information about the epidemic and vaccination from unregulated Internet websites. This resulted in the spreading of generalised and highly counter-productive misinformation about the epidemic and vaccination, which created a heated and conflicted atmosphere: *'The epidemic was started by the Americans', 'the virus was spread by pigs' 'the vaccine contained pig protein' and most seriously 'ethnic minorities were deliberately not being vaccinated' and 'the vaccine was only for ethnic Danes.'* The same distrust and misinformation spread around the vaccine for human papilloma virus because it was initially launched as a vaccine that protected girls from sexually transmitted diseases and that they should get the vaccine before becoming sexually active.

In unfamiliar situations, structures, rules and routines can prove counter-productive, if they are followed too rigidly. Pragmatic decisions may be justified in critical, but unfamiliar, situations as the following case illustrates:

Case 6

In connection with the war in Libya, the Danish government offered to fly a number of war-injured soldiers to Denmark for treatment in Danish hospitals in 2011 and 2012. A small group of these soldiers were admitted to Odense University Hospital, where an existing department was converted into a special department manned partly by new staff for this purpose. The soldiers came from hospitals in their home country and were therefore isolated for fear of spreading antibiotic-resistant bacteria. The Libyan soldiers behaved in a challenging manner towards the staff. Not only were they clearly psychologically affected by being isolated, they were also demanding, they were stressed, and they spoke out loudly according to the staff. The soldiers ignored the smoking bans, which caused serious conflicts. The cleaning staff felt mistreated by the soldiers, and several of them refused to go into the department to clean. The MHC was asked to review the situation. It was found that the soldiers were upset that they could not talk to each other, they wanted to smoke, they disliked the food they were offered, and they needed

an interpreter. The soldiers had contacted the Libyan ambassador, who was willing to bear all the expenses related to the treatment. A permanent interpreter was then established for the day shift, and the interpreter agreed to provide food for the soldiers from a local Middle Eastern restaurant. After conversations with the soldiers, it became evident that they had a need for conversations about their war experiences, and an Arabic-speaking psychologist was called in. The psychologist found that one of the soldiers had serious mental health problems and that the other soldiers were so afraid of him that they did not dare be alone with him. The psychologist began conversations with the soldiers. A steering committee under the hospital management for the soldiers' treatment subsequently decided to lift individual isolation and replaced it with cohort (joint) isolation, and since the department was a special department anyway, an exception was granted to the soldiers to be allowed to smoke on the balcony. The department had to be completely cleaned after the completion of the treatment anyway.

This case also illustrates that hospital managers should get involved quickly and effectively if there is a need to temporarily circumvent guidelines that are otherwise considered mandatory.

21.11. General advice and guidance

- Take a step forward - be curious and appreciative, ask and say what you feel, perceive, and experience. Try to understand the patient's situation and anxiety, and clear up any misunderstandings.
- Clarify and adjust expectations for the interviews, examinations, and treatment.
- Say something if your boundaries have been violated, but indicate where your boundaries are BEFORE they are violated, not afterwards.
- Ask for support and help from management. Do not 'tuck it away' or bring it home. Do not try to solve difficult problems on your own.
- Obtain agreement and form common policies among the staff, ensure clear communication paths, reduce interfaces, and simplify information channels.
- If you sense high alertness in a patient or relatives, it is important not to perpetuate it: the perpetuating behaviour must be identified and stopped. If the situation lasts too long, it gets internalised and becomes the 'norm' or 'routine' and can be difficult to reduce; the roles get distributed and the high stress level is established as 'baseline'. Often these are individual employees who are malefactors that are 'conflict-ready intensifiers' who also 'whip up a certain mood'. It requires a systematic approach to identify them. The same applies to individual relatives: who is looking for dialogue and who is looking for conflict? Who is the formal and who is the informal spokesperson of the family?
- Beware of instinctive readiness reactions that are often based on prejudices and generalisations that rarely fit.
- Guilt, shame, and professional pride can challenge and disrupt, or replace, professionalism. When your pride and professionalism takes a hit, it can shake something existential: *'Am I the one who is wrong? Am I doing anything right? Am I good at anything?'* Do not battle with this alone. Talk to the hospital psychologist or ask your department management for help. Talk to colleagues and managers about difficult situations.
- If you would like inspiration for questions and questioning techniques, use the Cultural Question Guide (see the link under sources).

21.12. Factors concerning patients or relatives that need to be addressed early and systematically

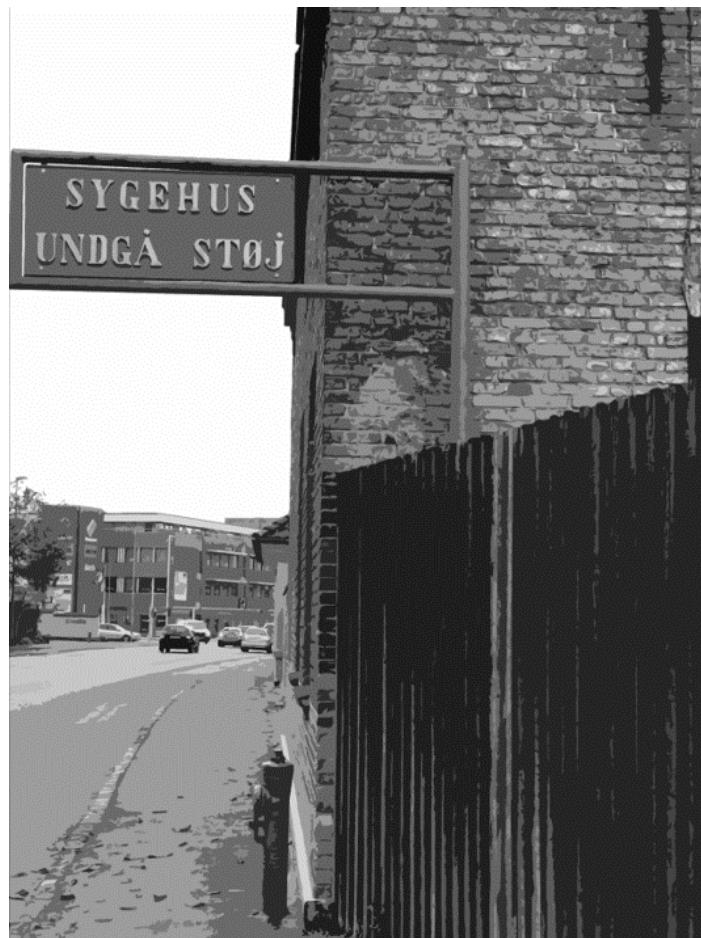
- Previous incidents and experiences with the hospital system in the home country (violent hospital stays, operations)
- Previous incidents and experiences with the hospital system in Denmark (errors, misunderstandings, rejections)
- Great sadness, loss (cognitive overload, guilt, and shame)
- Family conflicts (cognitive overload, guilt, and shame)
- Conflicts with other people from the same ethnic group (stigma, exclusion, loneliness, compliance)
- Who makes the big decisions in the family, and who influences those who make the big decisions?
- Finances (the integration benefit is lower than the standard cash benefit and is equivalent to the student grant; are there any outstanding loans?)
- Religion and culture (outlook on life, attitudes to illness and death, rituals, and spiritual care).
- Basis of residency (temporary, humanitarian, permanent, or Danish citizen)
- War trauma, PTSD, mental illness (stress, anger, dissociation, flight, 'indifference', distorted somatic symptoms)
- Note that personality changes/disorders can contribute to unnecessary conflicts (also among the staff!)
- The basic: What is important to you? Is there anything you are particularly afraid of, which we should know about?

21.13. Remember

1. Use an interpreter - not just for the patient's sake.
2. Make the interpreter part of the conversation - the interpreter is not only a tool but also a cultural bridge builder.
3. Not only can interpreters translate, they can also mediate in situations where values and routines collide. An interpreter who understands a conflict can resolve it, can communicate rules and frameworks, and can lower the level of conflict.
4. *Use the interpreter* to ensure equality in the contact and a common framework - the native language is the key and the yardstick to understanding.
5. Step up and be curious - say it out loud if you are in doubt or unsure.
6. What did I not understand? What did the patient not understand? How do we solve it?
7. Do not scold - even a casual remark can hurt and permanently damage a good relationship.
8. Trust is like paper - once it is crumpled it never gets nice again.
9. *All humans are rational according to their own terms.* Examine the terms before you question the solution.
10. Don't solve a problem you don't understand - seek insight into the root cause/the mechanism.
11. If you do not give yourself time for the patient, the patient will take your time - *give yourself time to create trust.*
12. You'll never win a cultural guessing game - instead, *ask and gain respect.*

13. Common agenda! *Continuously obtain partial conclusions* during the interview, and ask the patient to keep a *'record of decisions'*.
14. Continuously reflect with colleagues and managers about difficult situations - create a common understanding and approach.
15. Relations and context are important: find out who is best to talk to in the given relationship and context, and who among the staff is best at this particular situation.
16. In the case of complex examinations or treatments: Calm down! Slow down. Include the patient and relatives at every step, prepare the next step well, let the patient and relatives have a successful experience before moving on to the next step. Ask directly about anxiety, fear, problems, and misunderstandings. Make sure all messages are received correctly before moving on.
17. If you are not successful after three attempts, try twice again.
18. Look like you want to understand and help the patient and the relatives.
19. Don't be put off by cultural or religious differences. Show a positive curiosity and don't be afraid to refer to others if you cannot answer questions, give help, or solve problems.
20. Be open to interdisciplinary help and have contact information on any external resources that can help support spiritual and religious needs.

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23. About the Migrant Health Clinic

The Migrant Health Clinic (MHC) was established in 2008 as an interdisciplinary outpatient clinic within the Department of Infectious Diseases, Odense University Hospital. The clinic is not intended to serve all migrant patients. The clinic receives patients with long-term complex conditions who have various language barriers, patients with persistent compliance failures, or patients needing interdisciplinary coordination for examinations and treatments. A further purpose of the clinic is to document, alleviate, and prevent the health consequences of unequal access to health due to language barriers, poor or no schooling, stereotypes, assumptions, prejudice, lacking ethnic competencies among health professionals, and the organisational barriers created by the standard health care system regarding particularly vulnerable patient groups. The clinic is not a substitute for other areas of specialisation, but it aims to assist and strengthen the areas of specialisation in cross-cultural and complex areas. Since its start, the clinic had served about 2500 patients. This book is based on collected experiences and the related scientific literature.



A case-based textbook on the blind clinical spots in the encounter with ethnic minority patients in the Danish healthcare system. Refugees, immigrants, and migrants are not a uniform patient group, but are still often met by group biases, prejudice and generalizations that can lead to misdiagnosis, increase the risk of side effects and complications which all complicates a life in exile that is already marked by many major challenges and obstacles. Languages and values associated with illness are coded at a young age in the home country and in the mother tongue, which has crucial for approach and communication with or without an interpreter. The textbook is primarily aimed at doctors, medical students, and other health professionals, but can be read and used by anyone working with the health of refugees and migrants. The book highlights typical mistakes and frequent misunderstandings and describes tools that can be used by anyone who works with the health of ethnic minorities in prevention, communication, diagnostics, treatment, and rehabilitation. The book is based on clinical experiences from the Migrant Medicine Clinic at Odense University Hospital.