

## “Now we have lost everything”

### Asylum seekers in the Netherlands and their experiences with health care

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*Een kwalitatieve analyse van de verhalen van 22 asielzoekers over hun gezondheid en hun ervaringen met de Nederlandse gezondheidszorg bracht aan het licht dat zij ontevreden zijn met de geboden zorg. Ze klagen erover dat ze niet gehoord worden, afgescheept worden en slecht behandeld worden. De asielzoekers verklaren veelal hun ervaringen in termen van discriminatie. Bij de analyse van deze verhalen over de gezondheidszorg dient rekening gehouden te worden met vier elementen: de algemene maatschappelijke uitsluiting die asielzoekers ervaren, de feitelijke toegang tot de zorg, de competentie van de zorgverleners en het wereldbeeld van de asielzoekers.*

*[asielzoekers, gezondheidszorg, discriminatie, Nederland]*

“Is this humanity? We came here to live in freedom, to see the human side of life!” said the twenty-five year old asylum seeker from the Middle East,<sup>1</sup> speaking below his breath. He had been extensively discussing his illness and his encounters with health care providers here in the Netherlands. How he tried in vain to convince his general practitioner to prescribe him the proper medicine. He only received a prescription for a painkiller (Paracetamol). Didn’t the specialist in his land of birth prescribe him a special medicine after his cerebral haemorrhage five years ago? Why did the doctors in the Netherlands act otherwise? Was it because he was a Muslim?, he added rhetorically. After a short period of silence the other three asylum seekers in the room responded with stories of experiences. They were thoroughly puzzled by how Dutch health care operated. Moreover, they wondered why they were treated differently than natives and denied proper health care. One man concluded: “We don’t know our rights. We must exercise our rights. We have fled; we have been fighting for our rights. Now we have lost everything.”

This discussion took place during a focus group meeting, which was a part of our research we conducted in a reception centre for asylum seekers. The stories told by the asylum seekers about their experiences fit in the picture that the scarce literature about this subject also paints. Refugees and asylum seekers feel that their doctors do not take them seriously. They also feel misunderstood, mistreated and discriminated against.

How must we interpret their narratives about health and health care? In this article we will provide elements for a frame of reference for the analysis of these stories and elucidate the way in which asylum seekers make sense of these experiences.

### **The research: Making sense of experience**

This article is based on data from the first part of our research among asylum seekers in a Dutch reception centre. This research started in September 2000 and will last two years. The objective of the research is to describe and analyse how asylum seekers make sense of their experience. The principal research questions are: Which present observations, expectations or memories do asylum seekers interpret as problematic and threatening? How do they deal with these experiences? What do they perceive as supportive? What coping strategies do they apply? This research does not focus on the actual health problems of asylum seekers, nor on their experiences with health care, but has a broader scope, namely all critical incidents they have to deal with during their stay in the centre. The information we gathered concerning health issues can be seen as 'collateral information'.

The research 'Making sense of experience' is financed by the health insurance company that is in charge of the implementation of the health insurance regulations for asylum seekers. The goal of the research is to provide the aforementioned health insurance company and the Dutch mental health care system with basic information about the way asylum seekers approach and cope with health problems. The main objective is to improve the Dutch mental health care facilities. A team consisting of a psychologist/social worker, a psychologist/psychotherapist, a paediatrician and a medical anthropologist is conducting the research. Two are Dutch natives, one was born in Hungary and the other in former Yugoslavia.

The research can be classified as interpretative, while the methodology is qualitative and exploratory. We used open interviews, focus groups and (participant) observation to gain insight into the lives of asylum seekers. The conversations were in Dutch, French, English, and Servo-Croatian. In one case, the assistance of a professional interpreter was needed.

The management of the centre offered us the use of a small room during the first research period which lasted from March until July 2001. It was formerly used as a shed, but is has now been refurbished as a cabin in which one could live. One of the researchers stayed overnight in the centre at least once a week. The researchers became as familiar an element of the asylum centre as possible in the limited period of time. We noticed in their reactions to our presence, which were hospitable and friendly.

We selected respondents by snowball sampling, but mostly we took advantage of occasional and incidental contacts around the centre to introduce ourselves. After a general introduction meeting, which was attended by fifty asylum seekers and a first round of interviews with five key persons, as identified by the reception team of the centre, we started to visit the centre on a regular base.

We became acquainted with asylum seekers during organised activities in the recreation room, such as a sewing-group for women, and in the courtyard of the reception centre where mostly men were sitting in the sun and talked to one another. In the beginning, we initiated contact with the asylum seekers, but as the research progressed, they gradually began to initiate conversations with us. Eventually, they determined the time, length, place and content of our discussions. The researchers observed and listened to what they had to say. They followed the flow of the conversation that the asylum-seeker dictated and avoided asking questions in a structured way that would steer respondents to another topic.

Such encounters took place in their units, in the recreation room, in the courtyard and in our own cabin. Some encounters were casual, short and superficial, but we spoke with most of the respondents intensively and at length several times. We stopped adding new respondents when we reached a point of saturation in this stage of the research.

### **The asylum seekers**

The research population consisted of 285 persons, twelve years and older, who actually lived in the reception centre itself. None of the 52 registered asylum seekers living outside of the centre, mostly families, were included in the research.

In the four months that we were at the centre, we spoke to 48 asylum seekers. These 31 men and 17 women ranged from 12 to 54 years old. They hailed from the major theatres of war and human rights violations i.e. the Balkans, Middle East, Eastern and Western Africa, the former Soviet Union. A comparison of the sample group to the total population of asylum seekers in the centre by age and country of birth made clear that they were a representative selection. Women were, however, slightly underrepresented.

In general, the respondents had been waiting for a long time, up to six years, for a decision about their asylum request. The majority of them had already been informed by the Immigration and Naturalisation Board (IND) that a residence permit would be denied. They challenged this decision with a juridical procedure. Only one respondent, an Afghan man had successfully received a temporary residence permit during our stay in the centre. Some respondents had received a temporary residence permit before the research started, but they were still living in the centre because of lack of housing.

Twenty-two of the asylum seekers spontaneously mentioned health complaints and experiences with Dutch health care. Some just touched on the subject, while others spoke at length. This article is mainly based on the interviews with those 22 respondents. The other 26 respondents did not mention health complaints, but they also did not refer to good health explicitly. We do not know why they did not discuss health issues. Were they healthy? Had they had good experiences with health care? Did the importance of the topics that they did discuss during the interviews outweigh that of health? Were there cultural or personal barriers to talk about these issues? Did the interview circumstances invite some of them to speak more openly about their health than others? We did not ask so we do not know.

## **The context: The world asylum seekers live in**

### *Procedure and general overview*

In 1999, approximately 40,000 asylum seekers entered the Netherlands. Upon arrival, they had to report to one of four main registration centres. If their request for asylum is not dismissed and access to the asylum procedure is granted, the asylum seeker is transferred to one of the investigation centres. The first extensive interview with an officer of the Immigration and Naturalisation Board takes place in one of these centres. In these large centres there is little privacy. One is not allowed to do any kind of work, except inside the centre. Asylum seekers who are granted residence in the Netherlands while waiting for the outcome of the asylum procedure are transferred to one of the more than the one hundred smaller reception centres, most of them far from any major city. In this stage they are able to follow Dutch courses and are allowed to work up to twelve weeks a year. After they are granted a residence permit, it takes about six months before they are given regular housing in one of the Dutch cities.

On January 1, 2000, 64,700 asylum seekers were registered in reception centres. In 1998, the average length of stay in these centres was 20 months. Another research showed that in 1999 6,000 asylum seekers had resided there for more than three years. The measures implemented to speed up the asylum procedure to date have not resulted in a substantial reduction of this period. In the period between 1992 and 1997, 50 % of all asylum seekers were granted a residence permit on various grounds, often after lengthy juridical procedures of appeal. A recent change in the law has tried to decrease the length of the asylum procedure to six months. The Department of Justice expects that approximately 30 % of the asylum seekers will eventually get a (temporary) residence permit.

In the last five years the quality and variety of the facilities offered by the reception centres have decreased. Presently, the basic objective is to provide each asylum seeker a 'sober but humane' reception. This means that the centres provide only lodging and limited educational and recreational facilities. For other facilities (e.g. health care, socio-cultural activities, sport) asylum seekers have become more and more dependent upon the community around the reception centre. Asylum seekers are expected to take initiatives themselves. They are supposed to be self-reliant. Each adult receives 40 Euros per week, in addition to the food and clothing that the centre provides.

The research took place in one such reception centre, host to 323 asylum seekers, located in a small village in the immediate vicinity of a large town. The centre has a professional reception team who take care of the housing conditions and organise a few educational and recreational activities. A team of trained volunteers offers information and guidance about the juridical procedures. Finally, there is a medical team in the centre who focuses on collective prevention (TB-screening, health education) and operates as a gatekeeper to the Dutch health care system (general practitioner, hospitals). Asylum seekers can consult nurses of this team who are supervised by a medical doctor. Local general practitioners and the health care facilities in the nearby town provide curative care. In most reception centres, the migration police has its own office. All of the adult residents must check in with them every week.

### *Sharing room with strangers*

The centre consists of seven two-level block buildings, each containing five or six units, four rooms, a bathroom and kitchen to a unit. Usually eight asylum seekers reside in. Residence is decided without consideration for nationality or region of origin, so persons from different places and cultural backgrounds often share one room. Respondents often report tensions between the residents. Tensions stem from differences in nationality, religion, ethnic group, clans, life styles and diet. The strict rules about interaction between single Muslim men and women are difficult to obey and are an important source of tension. "No freedom, no privacy", according to a woman living in a unit with her two children, two other women and four single men. Eight persons between 12 and 42 years of age, representing five different nationalities and three religions live together in one unit. A man from the Middle East states:

We are having a difficult time here. What is happening with our families, the IND does not know. We are coming here to be healed. What we find here are eight people under one roof. (...) Stress becomes chronic here. You don't heal easily. My roommate was a fighter. Now he cries. In our culture, men don't cry. (...) That is the life of a refugee.

### *Limited access to work and education*

There are limited possibilities for asylum seekers to attend education or to work. "Without the paper (residence permit), every door is locked." There are facilities in the centre to teach Dutch, English, and how to operate personal computers. Access is limited though, for the lessons in Dutch can only be attended by asylum seekers who have not received a negative decision about their request for asylum. A majority of the asylum seekers get at least one negative decision. Possibilities for work are limited to voluntary work in the centre (managing the creche or the bar in the recreation room), incidental seasonal work (harvesting fruit), and irregular jobs (distributing newspapers).

### *Social exclusion*

It has been observed that asylum seekers are to a high extent excluded from Dutch society. We already mentioned the limitations for work and education, but the exclusion occurs also in social activities. Language barriers, limited financial means and geographical distance reduce the possibilities for interacting with and socialising with the Dutch residents. This exclusion is reflected in the experiences of the asylum seekers we met in the reception centre. Furthermore, media stories about high criminality among asylum seekers and about an influx of 'economic' refugees contribute to an increasingly negative image.

## **Looking through the eyes of the asylum seekers**

The majority of respondents emphasised the heaviness of their life as asylum seekers. They talked about pain, grief, loneliness, idleness, about the loss of relatives, friends, culture, the tensions in the relationship with the Dutch surrounding community, with other asylum seekers, and about the lack of answers to their many questions: why me, why this, why now? Recurrent topics or themes were the inscrutable asylum procedure, their uncertain future, the emptiness of their present existence, lack of support, discrimination and the feeling of being denied a human status.

### *Puzzling procedures*

The asylum procedure is a puzzling phenomenon for most of the respondents. It lacks transparency and seems to work without reason, but be based on chance, like a lottery. Many times the question ‘Why?’ resonated in the conversations. Why are some people rejected and others not? Why do some have to wait so long and others don’t? After years of attending courses in Dutch why do some people learn that they have to leave? Why do people help you and then kick you out? Why don’t they say immediately that you cannot obtain a residence permit? It doesn’t make sense to them; they feel toyed with. A woman from the former Soviet Union, wonders:

Why do people have to wait so long? Why such a long time? That drives people mad. If there are five thousand persons, 99 percent becomes crazy. Why does the Netherlands need so much crazy people? Crazy people cannot work. If I wait for ten months, I lose interest. Why don’t they say right away: Go to another country. This makes you sick.

### *Fear of future*

The lack of perspective and uncertainty about the board’s results is also recurrent. Who will be the next to be deported by the police? With a few words a young man made a crucial point: “In every asylum seeker’s mind there is a burden: what will happen tomorrow?”

### *Empty existence*

Asylum seekers often do not understand the procedure, fear the results of the murky proceedings, and in the meanwhile, their life is empty. The daily life of asylum seekers is mainly filled with waiting, thinking and worrying. Many asylum seekers complain of being bored. “Every day is the same!” Only a minority of the respondents consider themselves sufficiently engaged in meaningful activities. For the majority the stay in the centre, sometimes for six years or more, is experienced as a waste of time. The words of a man from the former Soviet Union echo the dull rhythm and meaninglessness of everyday life.

Nine o'clock. Stand up take a shower. Back to my room. My roommate sleeps. To the kitchen. Someone in the kitchen. Wait. Back to my room. My roommate sleeps. I cannot do anything. Go to the kitchen. I want milk. No more milk. Make coffee. No milk for coffee. Back to my room. My roommate sleeps. Watch TV. Eat. I eat, but don't understand why I eat. I cook. I feel good when I cook, when there is someone to cook for. Evening. I went one evening to the club. What can you do there without money? Drink a glass of beer sitting alone. I know I'm nothing. No home, no work, no money, no love.

### *Loss of supportive networks*

Even the contact with other asylum seekers from the same region is limited. The social support offered by fellow companions in times of distress is marginal. People often expressed feelings of extreme loneliness. "If I should die in Somalia, people should say: 'Salah is dead. We knew the man.' Here nobody would mourn for me", said one man who does not even trust his own fellow clansmen in the centre anymore. One woman from the former Soviet Union states:

I'm not an animal. I don't want to stay in the Netherlands, because I'm alone. (...) I have lost my job, my loved ones. Now I have nothing. And one day I will kill myself. (...) My soul is crying.

Occasionally, asylum seekers get help from residents living in the same unit. Life in the reception centre is to a high degree individualised. Former social networks mostly have vanished and only a few relatives or trustworthy friends, if any, are available to support them. The asylum seekers therefore heavily depend on the Dutch volunteers working in the centre, occasional Dutch friends, acquaintances and official authorities. A woman from the former Soviet Union, explains her life in the centre to us:

People don't help you here. Only if you turn crazy. (...) My husband is ill. (...) I'm ill. I go to the mental health care, to the hospital. I'm tired. Very tired. People worry much here. They cannot forget their problems. They don't understand them. No one can understand. What can we do? Listening to music for a while. Waiting, waiting, waiting.

Though contact with the Dutch environment outside of the centre is minimal, it is often very important. One middle-aged man from the Middle East met and chatted with some Dutch locals in a nearby pub. "I feel to be just a bit of the man I used to be. I'm so pleased with myself." When he met them a second time, they greeted him and called him by name. This, too, was gratifying.

### *Negative reactions*

The asylum seekers often mentioned experiences with discrimination by the general population or official authorities. One East African man said:

(Dutch) people don't know what is the matter with asylum seekers. They are badly informed. They think we steal their jobs, that we come here for the money. There is discrimination and rejection.

One Middle Eastern boy was asked by a group of Dutch youngsters what he was doing with the bike he was riding. When he told them that it was his own bike, they reacted with disbelief. He was dismayed and angry to be wrongly regarded as a bicycle thief.

### *Turned into an object*

The sub-standard living conditions, the numerous unanswered questions and other depressing experiences made the asylum seekers feel dehumanised, like second-rate civilians or even animals "They only see the black side, the white side they don't see," according to a young man from the Middle East. Not being treated as a fellow human proved to be a painful experience. An older woman concluded:

There is no humanity. If the Dutch speak about asylum seekers, they talk as if we are not human beings. There is a lot of pain. It hurts. Nobody can feel it. No one likes to be a stranger, to be without money or house and to beg. I feel as though I am lost in the ocean.

Lots of talk was generated about being discriminated against, being used, being treated as merchandise, animals, objects or dossiers. One of the male respondents from Eastern Africa had a conspiracy theory:

The government is making business with asylum seekers. They get money from Geneva. They put them in a small room, and some are allowed to go to school. After a few years the asylum seekers are sent away and new ones come.

Other asylum seekers are convinced that the response of the authorities is a deliberate strategy to destroy them psychologically. All of these statements point to experience in which human status is denied.

## **Reactions to the experiences**

How do the asylum seekers react to these feelings and experiences? Confronted with discrimination, exclusion, rejection, uncertainty, lack of perspective and seemingly uncontrollable powers and procedures, some asylum seekers feel helpless and powerless.

There are organisations in the Netherlands that combat discrimination. There, people can look for their rights. But if the government is the one who discriminates? Where can you go to? To Kofi Anan? (young man from the Middle East).

Asylum seekers respond differently to their situations. Some asylum seekers withdraw into their own familiar world or create a new one, and lock the outer world out. Others lock out the past and focus only on the present. They occupy themselves with small-



scale, meaningful activities, such as raising their children or voluntary work within the centre. Others make plans for an escape route: marrying a Dutch resident, leaving for another country or becoming part of the shadow-world of illegal residents in the Netherlands. Some seek comfort in their faith, while others sink into passivity. Some remain in chaos, wondering what has happened to them, repeating “Why?” without getting an answer. And finally, in the minds of a few of them suicidal thoughts arise.

But there are also some asylum seekers who try to fight the outside world, look for allies and eventually engage in battle. A young woman from the former Yugoslavia told us that a general practitioner referred her to a specialist after she had informed a Dutch friend working for a newspaper about her plight. This resulted in the publication of an article and made the doctor change his mind according to her. She said:

I can fight for myself and my husband and children. I fight for myself and for my health. The others don't. They are afraid, I'm not. If they will not help you, tell them to write it down. I know what I can do with such a letter. Then they will help you, because they know that you are in your right.

Most of the asylum seekers are well aware of the most valuable weapons for their battle: knowledge of the Dutch language, Dutch friends, familiarity with their rights, a network of supportive family and friends, engagement in meaningful activities and relationships and the ability to imagine alternative futures.

The respondents often did not appear to use one fixed strategy. The man who mentioned Kofi Anan expressed his ultimate powerlessness but he also did fight; the battle-ready woman from former Yugoslavia felt helpless when she saw the limited results of her energy-consuming battles. Strategies change with time and context, some asylum seekers have more flexible strategies than others.

### **Health complaints and their resolution**

Of the 22 respondents who commented on health problems, many mentioned pain in the back, shoulders, stomach, kidneys, intestines, and/or head. Others mentioned specific diseases, such as diabetes, urethral infection and dental caries. Furthermore, they complained about concentration problems, sleeping problems, dizziness, heavy sweating and worry. ‘Having a full head’ was a complaint we often heard. One man said:

In the past my head was empty. I could think. Now it is always full. I cannot concentrate and learn well. It keeps me awake at night.

Some respondents mentioned more psychological ills, such as anger, fear, depression, desperation, confusion, loss of motivation and perspective in life, and even suicidal thoughts. One man from Eastern Africa stated that in the six years he has spent as an asylum seeker, he has developed many health complaints. “Psychic complaints, which all have to do with my head. My life is ruined. This is no good.” The respondents connected their complaints with the circumstances of their life: separation from their families and culture, scant human contact and uncertainty about the future. Health problems

proved to be intertwined with existential questions. In just a few words, a young woman from former Yugoslavia depicted the phases that asylum seekers go through:

First there is relief. Then problems appear. With the children, with your health. You are worrying. That makes you crazy. You cannot understand what it is to be an asylum seeker. Time here is lost time. We have no future.

How do the asylum seekers explain the causes of their health complaints? A recurrent theme in the narratives of asylum seekers is the worsening of their health after arrival in the Netherlands. "My hair turned grey in the Netherlands. In the beginning I had one cane, now I need two. I'm ruined psychologically. Why do they treat the disabled so badly in the Netherlands?", a middle aged man with a history of torture and imprisonment repeated over and over again. He and others made clear that they see a causal relationship between their failing health and their life as an asylum seeker.

We noticed that the asylum seekers themselves made distinctions based on the aetiology of the sickness. When we closely regarded the remarks and stories of the respondents, a threefold classification of supposed causes arises.

First there are health complaints which are seen as consequences of bodily failure, such as a toothache. These health problems are considered more or less 'normal'. Secondly, there are health complaints associated with present life conditions. This category refers to psychic and psychosomatic complaints, most of them directly linked to the prolonged stay in the reception centre, the seemingly endless and unpredictable asylum procedures and the interaction with a new and unknown environment. Thirdly, there are complaints associated with previous life conditions i.e. the life before flight. This category refers to the consequences of human rights violations in the home country, such as imprisonment and torture, of the flight itself, as well as to pre-existing somatic disorders. In some cases the respondent mentioned that these health complaints already existed in the home country, but has worsened during the stay in the Netherlands.

In general, the respondents see most of their health problems as a consequence of being an asylum seeker and living in the reception centre with little or no future prospects. In all but one case, causes connected with the here-and-now situation outweighed those connected with the then-and-there explanations. As respondents spoke about their failing health, they accentuated recent causes of their complaints. A middle aged man from the Middle East said: "I try to get better, but my problems are chronic, because they are affected by the problem of (being separated from) the family." The flight to another country did not reduce his problems, but instead created even more.

### **The use of health care facilities**

When discussing health care, respondents referred mostly to contact with general practitioners, medical specialists and hospitals. Only five of the 22 asylum seekers mentioned contact with mental health care providers. Dutch mental health facilities are relatively unknown to asylum seekers and are seen as only a last resort. One respondent explained that he avoided seeking mental health care because it is used by some asylum

seekers to facilitate the juridical. A middle-aged woman who was denied a permit to stay in the Netherlands was told by her lawyer that she had two options remaining to avoid deportation: “To go to the RIAGG (outpatient mental health care) or to marry.”

In general, asylum seekers rely heavily on the formal medical system, the regular health care facilities. The informal sector of health care (lay referral system) is practically not available in the reception centre.

### **Experiences with health care**

Our respondents shared many stories with us about other asylum seekers which script unfolded similarly. An asylum seeker has a health complaint, the severity of which is misjudged by the doctor. The result is the loss of a limb or the life of the patient. One representative anecdote:

An asylum seeker with a complaint of the body went to the doctor, who only gave him Paracetamol. The next day he was dead. In his home country they might have treated him worse, but he would be alive.

Some asylum seekers had neutral or even positive experiences with the Dutch health care. Negative encounters however dominated the stories that the asylum seekers told us spontaneously. Most grievances focused around the medical team in the reception centre and the general practitioner. Although they have quite different tasks (collective prevention versus individual curative care) the asylum seekers mention them in one breath. Three often intertwined themes arise from the stories about their contact with these representatives of Dutch health care: not being heard, feeling put off and treated badly.

We will concentrate on the medical team, the general practitioner and dental care. We do not discuss experiences with mental health care at length, because in all but two cases we heard only limited and fragmented information. The meagre information that we did hear indicated disappointment with the mental health care that was provided, with the exception of one male respondent, who was very satisfied with the help and support he received.

#### *Not heard*

Respondents complain that they have to wait too long before they are heard. It took too much time before the doctor acted in what they perceived to be the correct manner. They interpreted this as a sign of disinterested. A Northern African man complained that he asked to be referred to a specialist for more than two years because he suffered from kidney stones. He was told that “the medical team in the reception centre only gives medicine.” An asylum seeker from Eastern Africa who wanted a medical check because of the torture he has endured was told that referral was not necessary. He no longer goes to the medical team. An asylum seeker from the Far East, with a radiating pain in his shoulders and back, was told by a staff member of the medical team that pain

is part of life. Eventually the physiotherapist referred him to the hospital, where he underwent surgery.

### *Feeling put off*

Some felt put off by doctors or that health care providers did not fulfil their expectations. Far too often, after presenting their complaints, asylum seekers were sent away without getting the assistance they felt to be necessary. They are well aware that Dutch health care, with its highly developed medical technology, can offer much. The disappointing experiences with health care partly reflect cultural differences in perceptions of adequate care.

What makes them feel put off? Firstly, respondents expect that the care for severe somatic complaints provided in the country of origin will be continued in the Netherlands. It is incomprehensible to them that medication is not continued in the same way it was at home, or that diagnosis is at debate. The prescription of Paracetamol has become a symbol for the lack of interest of and the rejection by the health care system. It marks the underestimation of the severity of the complaint. For asylum seekers, Paracetamol stands for failed assistance. In other cases the asylum seekers were not prescribed what they thought was correct. A young woman from the Balkans with a “ruined back due to the war” complained that the physiotherapist only offered her sport exercises, while what she needed was massage.

Secondly, patients feel put off when they are not immediately referred to a specialist or hospital. As many asylum seekers come from countries where a direct consultation with specialists is the normal way of seeking help, they are dismayed to be confronted with a medical team and general practitioners who function as gatekeepers to more specialised health care. Asylum seekers perceive them as a barrier to entering the door of the health care system, a lock that prevents them from reaching the necessary care.

Finally, opinions of the centre medical team or general practitioner are sometimes contradicted by specialists. When finally, after a long waiting period and perhaps assistance from Dutch friends and acquaintances, a referral takes place, and a medical intervention is considered necessary by the specialist, the suspicions of the patient are confirmed. In the opinion of the asylum seeker, this proves that the medical team or general practitioner had indeed denied the patient access to proper care. Only an intervention resulted in the provision of the wanted care.

### *Treated badly*

The third theme is closely connected to the previous ones and deals with being treated badly or incorrectly. The asylum seekers feel neglected and deserted by health care providers. These feelings are strengthened by their experience as an asylum seeker in other situations. The general opinion is that the medical team let them hang on a string because they don't refer if asked. “The medical team always says: ‘Come back tomorrow’,” a woman from former Yugoslavia argued. Much criticism is directed towards the appointment system. “If you are five minutes late, they don't help you. You have

to wait another week for a new appointment,” according to a woman from the former Soviet Union.

A lot of stories criticize dental care, which, they say, is limited to cleaning and the pulling of teeth. Several asylum seekers complain that their disparate treatment (when compared to that of Dutch people) has led to an unnecessary loss of teeth. According to one woman, who was a dentist herself, they waited too long to help her so she lost a tooth. Another young woman from the Balkans said:

There is one dentist for an hour a week for four hundred asylum seekers. They look, clean the teeth, and do nothing.

### **Research and literature compared**

Because little research has been done, existing literature offers us only limited information about the way refugees and asylum seekers perceive and experience health care (see literature references). Results are based on small-scale research with at most several dozen refugees or asylum seekers. The information available is fragmented, anecdotal and restricted to specific groups of asylum seekers or refugees.

This available information, scant as it may be, corroborates with the information that our research has found, especially in terms of experiences with general practitioners. Refugees and asylum seekers notice an impersonal distance between them and the general practitioner, limited consultation time, little interest in personal backgrounds or present living conditions and lacking investigation of the body for serious somatic causes of illness. Kramer (1999) concluded that the uncertainty about the results of the asylum procedure predominate previous experiences before the flight. His respondents criticised doctors for paying no attention to their present stressful life situation or for only paying attention to their traumatic past. While only somatic complaints are presented, the patients themselves often do relate them to their life circumstances in present and past. Finally, Bartels & Haayer (1995) noticed the reluctance of refugee women in their contacts with male doctors.

The general practitioner fails to meet expectations. For instance, he is not prescribing effective medicine, but only a common painkiller (Paracetamol). This observation leads to bitter remarks of refugees. “We are used to getting medicine if we are ill, but here we get Paracetamol. In the Netherlands they cure everything with Paracetamol” (Logghe 1998: 50). “They even prescribe Paracetamol for pinching shoes” (Huijbregts & Van Tienhoven 1999: 11).

There is one area in which our findings diverge from those of others. In the research of Van den Brink (1996) the Somalian refugees had a better opinion of health care, although they too remain critical towards the general practitioner. They didn’t feel discriminated or mistreated, but rather misunderstood. It is important to note that they all had residence permits. Although based on only a few small-scale researchers, one could argue that the absence of a legal status could lead to a more negative view of health care, about which feelings of discrimination or mistreatment are expressed.

## Discussion

How do we interpret these findings? How do we explain the feelings those who are misunderstood, mistreated or discriminated against? How should we read the narratives of these asylum seekers? It is important to remember that these stories are fluid. The images, interpretations, explanations and strategies of the asylum seekers change in time and context. This flexibility could prove to be an effective way of coping. Some asylum seekers have experimented with several 'story books', while some seem to have stuck with one. As Goodman (2001: 185) states: "The narrated experience is multi-layered, and gives itself to (creative) readings by all participants; specifically it allows patients (and caregivers) to entertain, play and struggle within themselves over competing versions and possible explanations of the illness."

This has consequences for the research too. Narratives are created the moment they are spoken (cf. Bilu 2000: 14). As a consequence, the context of the research is important to understand in order to grasp the meaning of the narrative. The research itself may have encouraged respondents to focus on their negative experiences with health. We offered a megaphone to the respondents to express their general feelings, evoking the narratives. The research is one of the few opportunities for them to let the outside world glimpse the living conditions and, by extension, the distress of the refugees. In another context the narratives might have been different.

The narratives about misunderstanding, mistreatment, discrimination, not being heard, feeling put off and treated badly can be analysed against four different backgrounds. Four levels of analysis, which come together to form a pyramid-like structure, can be distinguished. All four must be taken into account in the analysis of the health narratives of the asylum seekers.

First of all, the level of societal exclusion is at the base. Directly or indirectly, asylum seekers are separated from the rest of the population. They experience exclusion on juridical, economic, financial, geographical and ideological grounds, resulting in an overall feeling of being discriminated against and even dehumanised.

Secondly, at the level of health insurance, some regulations do result in an unequal accessibility to health care provisions. Though the public health insurance fund provides asylum seekers with a similar package as Dutch natives, there are some exceptions. Asylum seekers have limited access to dental care. Adults are only entitled to emergency dental care. Unlike the Dutch natives they cannot insure themselves additionally for more extended dental care, including restoration of caries-affected teeth.

Thirdly, at the level of the provision of care, individual health care providers often lack expertise and cultural competence, which leads to substandard care. Furthermore straightforward discrimination may occur. The popular image of asylum seekers as demanding patients who take too much time and ask help for minor or non-medical problems also plays a role. These attitudes often are communicated non-verbally and effect the way asylum seekers perceive health care. Furthermore, the general tendency in Dutch health care is to analyse non-somatic health problems of asylum seekers either in terms of traumatisation focussing on individual psychic reactions to events in the past, or in terms of reactions to juridical or existential problems which are considered

beyond the realm of health care providers. This causes a rise in feelings of neglect or denial of the political and social dimension of human rights violations experienced and of present pathogenic living conditions in the centre.

Finally, at the level of the health care consumer, the asylum seekers extrapolate general experiences to health care. They interpret situations and actions of health care providers that do not make sense to them as proof of unequal access or discrimination. To use a medical term, their general world-view infects their interpretation of health care. Cultural differences in perception of adequate care also play a role. Asylum seekers are confronted with a seemingly familiar health care system but with an unfamiliar perspective. Dutch medical culture is characterized by complaint-oriented communication, reliance on the self-healing capacity of the body and prevention of somatic fixation by minimizing referral to specialists and prescribing medication as little and light as possible. Reacting from a perspective based on a different medical culture, asylum seekers can interpret the way health providers act to mean they are intentionally withholding proper care from them.

A final remark concerns the observation that so many asylum seekers spoke in terms of discrimination, injustice and dehumanisation. Jerome Frank's concept of demoralisation (cf. Stoffer 2001) possibly offers a key to the analysis of these narratives. According to Frank demoralisation is a state of mind that is a consequence of the person's conviction that he or she cannot solve a problem that is invalidating him or her to such an extent that it cannot be ignored. Their mission in life is doomed to fail. This situation is characterised by discouragement, shame, fear and a feeling of alienation. The problem for asylum seekers is the ongoing threat of being expelled, of having to return to an environment of war and human rights violation. This threat is overwhelming, anonymous, and in the end, asylum seekers feel it can not to be influenced. In this context they feel they have become objects, numbers or dossiers. The threat blocks their mission to escape the violence and start a new and safer life. This demoralisation has a disastrous effect on their problem solving capability.

In trying to regain a sense of mastery, the asylum seekers create an idiom of distress to contain the problem, a language they know very well from their respective pasts. Their position as an asylum seeker has forced other aspects of their person (ethnicity, culture, age, gender) into the background. Now only the bare existence, the basic right to be and live here, counts. Life experience is explained from this sole perspective. We can consider this language that the asylum seekers have developed to be a language of injustice, dehumanisation and discrimination, and a protest against inhuman living conditions. But it is also an attempt to neutralize the demoralisation. It also explains the essence of the world asylum seekers live in: the exclusion from a meaningful social life and material goods in the Netherlands. As they already saw themselves as victims of war and human rights violations, they restore or maintain continuity by interpreting their present existence from the same perspective, thereby holding on to a proven strategy.



## Notes

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1 To protect the privacy of the respondents, age and country of origin are indicated in general terms.

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