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## Afghan refugees in The Netherlands and their general practitioners: to trust or not to trust?

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### ABSTRACT

In-depth interviews with Afghan refugees living in the Netherlands about their experience of health care, have led to a series of narratives. This chapter focuses on the relationship between the refugee-patients and their general practitioners (GPs) from the participants' point of view. It was possible to distinguish four different types of narrative, by analysing the individual interviews into critical episodes. Building trust was identified as the crucial issue. A number of possible explanations are given for the differences found. Links are made to participant expectations in respect of health and health care and to their personal and social resources.

The GP has a key role in the Dutch healthcare system, but is a novel phenomenon for refugees arriving from Afghanistan. The development of a relationship of trust is sometimes compromised by negative personal experience and also by stories relating such experiences circulating in the Afghan community.

The elements that constituted positive and negative episodes and led to the development or undermining of trust were identified in the narratives. Negative experiences tended to be interpreted as a sign of prejudice on the part of the health care professional.

The findings of this study are discussed in the wider context of research into patient priorities in general practice.

### INTRODUCTION

*'I was lucky to meet the right people at the right time; I don't know where I would have been otherwise'*, says Mrs A25, a 29-year-old woman of Afghan origin. She is one of the participants interviewed, as part of a research program designed to clarify and understand the experience of Afghan and Somali refugees in the Netherlands with the Dutch health care system.

In this chapter we present an in depth analysis of interviews with Afghans, living in various towns and villages in the Netherlands, focusing on their experiences with health care at the

reception centres to which they were assigned as asylum seekers, and with the GPs they met after they had settled in a home of their own.

Since the late 1980s some 30,000 people from Afghanistan who had fled from different regimes there have come to the Netherlands. Afghan refugees form one of the larger groups among the more than 200,000 who have found refuge in the Netherlands since the 1970s. They have settled in towns and villages distributed throughout the country. This is pursuant to Dutch government policy designed to prevent large concentrations of new immigrants in major cities.

The prospects for refugees in respect of health and livelihood when resettled far away from their homes have been the subject of a growing body of research and publications. Paradigms have been shifting (Watters, 2001; Muecke, 1992) from a strong emphasis on traumatic experience in the country of origin, and possible consequent psychiatric symptomatology in the 1970s and 1980s, to a more holistic approach that includes cultural bereavement (Eisenbruch, 1991) and the resilience of people, using their personal and social resources (Beiser, 1991; Beiser and Hyman, 1997). This has meant a shift in focus from refugee pathology to refugee health (Muecke, 1992) and from looking at refugees as victims to acknowledging their strength, resilience and capacity to change.

Beiser (Beiser, 1991) presented a model, based on Pearlin's (Pearlin et al. 1981) stress-process theory, in which he saw the mental health of refugees in their new country, at a certain point in time, as an outcome of pre-migration stress, post-migration stress, personal resources, social resources and socio-demographic characteristics. Beiser took the position that what happens to people after they enter a country of permanent asylum probably has a greater effect on their mental health during the first two to three years of resettlement than everything that happened to them before. Bracken et al. (Bracken et al. 1995) came to the same conclusion. Separation from the family and unemployment came out as strong post-migration stressors (Beiser, 1991; Beiser and Hyman, 1997).

Beiser referred to several factors as personal resources and assets in the resettling process. These were hardiness, sense of control, ethnic pride, time perspective, and level of acculturation. These factors may be assumed to coincide partially, in conceptual terms, with what others (Jerusalem and Mittag, 1995) have called "a sense of personal efficacy", which "seems to reduce the likelihood of negative appraisals of stressful life demands, and as a consequence, [...] provide protection against emotional distress and health impairments". Age, sex, education and ethnicity were grouped as socio-demographic characteristics that could influence the health of resettling refugees in the model Beiser presented.

Social resources can be subdivided as close confiding relationships (like that between man and wife) on one hand, and social support from the ethnic community or society at large on the other (Beiser and Hyman, 1997). Refugees who settle in a country without the support of a partner and/ or an ethnic community seem to be more at risk.

Successful and reliable contacts with health care can be seen as an important part of the new social resources to be acquired by refugees. In case of emergency, adequate action by a health care professional can mean the difference between life and death. Adequate access to appropriate health care has been positioned as one of the factors determining the incidence and prognosis of disease among migrant groups (Uniken Venema et al. 1995).

Various – international and Dutch – sources indicate that refugees resettling in the West do not always get the help they think they need from health care professionals. Bosnian refugees in the US mentioned difficulties in getting access to health care, because of bureaucratic procedures and attitudes (Searight, 2003). Interviews with Hmong refugees in the United States about their interactions with care providers (Barrett et al. 1998) pointed to shortcomings such as lack of time, stereotyping and insufficient information about cultural backgrounds. Refugees in London complained about GPs dismissing difficult minor problems like stomachache and headache, by saying "This is just in your mind" (Harris and

Maxwell, 2000). A quantitative study among resettled refugees from different backgrounds in the Netherlands showed that 50% of these refugees were not satisfied with their treatment by the GP (Bartels, 2003). Afghan refugees in a study carried out by Gernaat and Malwand (Gernaat et al. 2002) expressed little confidence in Dutch health care.

In our study, we are not focusing on the health of refugees as assessed by others, but we are looking at how participants view their own treatment by health care institutions. We believe our method of reflective interviews with individuals or families can shed some light on differences and dynamics that tend to disappear in focus group interviews.

In this chapter we shall focus on four questions:

What are participants' frames of reference in respect of healthcare and what is their definition of health?

How did participants try to solve their health-related problems and what was their experience of the process?

What personal and social resources were useful to them?

How can we explain differences among participants' experiences of healthcare and their interpretations of their experiences?

## RESEARCH METHODS

### Procedure

Cooperation was provided by Afghan organisations via the VON (Refugee Organisations in the Netherlands). An introduction was written, to be used as a handout for potential participants and translated into the two languages used in Afghanistan, Dari and Pashto. A list of topics was compiled with advice from different experts, some with academic expertise and some with inside knowledge of the Afghan community.

Via personal contacts two Afghan women were selected as assistant researchers. These assistant researchers were selected on the basis of their special skills, i.e. fluency in Dutch and their own language, knowledge of the specific terminology, good communication skills and insight into and understanding of the aim and the methodology of the research. The assistant researchers were also important as 'cultural intermediaries' and assisted in developing a trust-based relationship with the participants. Another assistant researcher joined later.

Potential participants were approached via several agencies, including the refugee-organisations, a local division of the Dutch Refugee Council and some personal contacts. At a later stage, snowball sampling was used. In order to avoid selection bias as much as possible, it was made clear to all intermediaries that we were interested in both positive and negative experience of the healthcare system. The criteria for inclusion as participants were that those selected had lived in the Netherlands for three years or more and in their own homes for at least a year. Care was taken to include participants living in different parts of the country, in larger and smaller municipalities, at different levels of education, different ages and varied family structures.

The 24 Afghan interviews were carried out by the first author – a middle-aged, female medical doctor – with or without one of the assistant researchers in two periods: between September 2000 to July 2001 and between June 2002 to May 2003. The break was the result of the departure of one of the assistant researchers and was later extended because of the impact of the terrorist attacks in the United States and the bombing of Afghanistan on the Afghan community in the Netherlands.

## Group of participants

Table 1 gives an overview of characteristics of the 36 participants in 24 interviews. A husband and a wife giving an interview together are counted as two participants. Twelve couples, nine women and three men were interviewed. Their ages ranged from 18 to 66. They had lived in the Netherlands between three and thirteen years. All were Muslims.

The educational level of the participants varied: 12 had completed academic or vocational education; 16 had completed secondary education, seven had only attended primary education and one elderly woman was illiterate. Sixteen participants were unemployed, nine were employed, four were receiving some sort of training and three were doing voluntary work; four were over 60 years of age.

Twenty-three participants had acquired the Dutch nationality, while 13 had a refugee or humanitarian residence permit. Seven participants lived in a major city, eighteen in smaller towns and eleven in villages.

## [TABLE 1]

### Data generation

A qualitative research method with in-depth, semi-structured interviews was used (Glaser and Strauss, 1967; Weiss, 1994). This method created room for explanations, and let the interviewees develop their views and feelings. At the same time, light could be shed on the biographical dimension and the time dimension in their experience.

All interviews were recorded on tape, with the knowledge and consent of the participants in their homes. Whenever an answer did not seem to match the question during the interview, the question was rephrased, to prevent misunderstanding. The interviews lasted between 1½ and 2½ hours, including the introduction, pauses and time for reflection at the end. Fourteen interviews took place in the Dari language, with one of the assistant researchers interpreting. Ten interviews were held in Dutch by the first author alone. The assistant researchers identified with the project and became part of the team, greatly enhancing the quality of the study and helping to prevent misunderstanding.

The first part of the interview focused on the experience of the participants with healthcare in their country of origin, and how they felt their health had been influenced by the last period in their country and by experience during their escape.

In the second part, participants were asked to talk about their situation and health in the Netherlands, naturally leading to their experience of healthcare. Time was taken to go through different types of experience, more or less chronologically, as the participants recalled them. How did they approach their problems, what contacts were useful to them and what stories did they hear from others about health and health care?

### Analysis

The first author made a verbatim transcription of all interviews, and one of the assistant researchers checked the translation. On close reading of the text, the researcher/ first author assigned codes to text fragments, using the WinMAX software programme (Kuckartz, 1998) to organise the data and facilitate retrieval. The use of the software programme enhanced the consistency of the coding process and facilitated cross-sectional comparison. The last author, reading and coding three interviews, helped to validate the codes assigned. The coding process and subsequent inductive analysis, starting with some extreme cases, was the subject of intensive discussion between the authors. At a later stage peer review by an external researcher helped to sharpen and focus the interpretive process.

Positive and negative comments on GPs were distinguished and the constituent elements of such comments were analysed in a process of ongoing comparative analysis. It was observed that interview participants often used earlier experience, and in some cases, the experience of others, on which to base their opinions. During the inductive process, we assigned the label

'critical episode' (CE) to this type of opinion-shaping experience with a healthcare professional.

The label critical episode refers to a series of events during a period of time, which the participant mentioned in the interview as having been of special significance to her/him, in a positive or a negative way. Examples of critical episodes related by participants were: experiencing disturbing physical symptoms; being pregnant in an unknown environment; serious or disfiguring illness of a child; the start of a chronic illness; experiencing mental problems that undermine normal functions. The first encounter with a new health professional came out as a critical episode in many interviews.

A data matrix was constructed of all critical episodes from the different interviews and each episode was scored on whether the participant related it to the attitude or to the professional behaviour of the health care professional, or to both (Miles and Huberman, 1994). The outcome of the episodes was coded for the health of the person involved and for the gain or loss of trust in the professional.

A score for personal resources was attributed to each participant, based on age, educational level and knowledge of a European language at the time of arrival in the Netherlands.

Comparative youth (under 30) was considered to be an advantage, and an age above 50 a disadvantage in the resettlement process. If a husband and a wife were interviewed together, the highest of their two scores for personal resources was attached to the narrative.

Since the focus of this study was on health and the use of health care, we were interested which social resources participants were using to get information about health care and solve their health-related problems. The social resources were differentiated and coded as 'known social resources', i.e. mostly family and friends already known at home, or 'new social resources': new Dutch contacts.

## RESULTS

### Frames of reference

To understand the meaning of critical episodes for participants, some insight into their frames of reference is a basic requirement. One frame of reference is the healthcare system people were used to in their own country. Another frame of reference is formed by their ideas about health and illness. Since these items were discussed by all participants more or less in the same way, they will be described here as a common background to the personal narratives, which will be presented in the next section.

#### 1. Healthcare in Afghanistan

All our participants were city dwellers in their country of origin and belonged to an average or above average socio-economic class. Three participants spent part of their youth in a village. Three moved from one city to another, away from the immediate scene of war. Experiences with urban healthcare in Afghanistan were a common frame of reference to our participants, though in different periods, depending on their age and the moment they left the country.

Since the Russian invasion in 1979, Afghanistan has been in a more or less continuous state of civil war. Healthcare was functioning reasonably well during the communist regime, at least in the cities, and did not deteriorate too much yet during the reign of the *Mujaheddin*. A complete breakdown occurred when the Taliban took over in 1996. Many more healthcare professionals fled the country and women were denied access to even basic facilities.

Hospitals were mainly concentrated in the cities. People from the villages had to come to the city if they needed more advanced health care than a Tabib, a herbal specialist,

could provide. In the cities too, many people consulted a Tabib or treated themselves with herbal remedies for different complaints, before consulting a medical doctor. The knowledge of medicinal herbs was passed on in the families of traditional healers from father to son. Elderly women had enough common-sense knowledge about herbs to advise their daughters and daughters-in-law how to treat their sick children. Mullahs were consulted by the more religious families, especially in the villages, and asked to read Koran and pray for God's blessing for the sick person.

Nine participants mentioned treatment at home with herbs by their mother before being taken to a doctor. Most of them did the same thing with their own children. If the illness did not respond favourably to this treatment, or if it looked very serious from the onset, the child was taken to a doctor.

The choice of what doctor to see was free, but usually a family consulted the same doctor. Hospital care was free of charge, but doctors who were working in the hospital had their private clinics in town in the afternoon. If the patient was not able to come to the clinic, the doctor could be requested to pay a home visit. The patient made a choice whether to consult the 'family doctor' or to consult a more specialised doctor directly (for a skin disease or a throat infection). Outside the hospital, the patient had to pay for the consultation and for the medication. Participants emphasised the importance of the free choice they had, which doctor to consult. There was a definite competition between doctors: the more medication and the quicker the referral, the better the doctor. Drugs, including antibiotics, could also be purchased without a prescription. Some participants emphasised that the way doctors saw medicine as business, was not always to the advantage of the patients.

## 2. What health means to participants

We asked participants, at the end of the interview after a basis of trust had been established, what health meant to them. It appeared that health had a very wide and comprehensive meaning for most of our participants. They described it in terms of: "being able to think well", "being able to do everything you want", "being able to enjoy life", "being independent" and "being in charge of yourself".

Two points were striking in these definitions of health:

1. Most participants made no distinction between what Western medicine refers to as 'mental' and 'physical' health. Only two participants related health specifically to the body.
2. An immediate connection seemed to be made between health and 'autonomy', in the sense of being able to look after yourself and those who depend on you.

As for illness, participants made a clear distinction between a "simple illness" that can easily be cured, and a serious illness that takes over your life and makes you dependent. One participant stated: "You can better be dead, than suffer from that type of illness."

When asked for causes of illness, participants in 21 out of 24 interviews named "thinking too much" or "worrying too much" as an important cause of illness. Other causes that were mentioned were the climate, infections, lack of hygiene and bad eating habits.

## Personal narratives - central themes in the critical episodes

In the 24 interviews, 84 critical episodes (CEs) concerning experiences with healthcare in the centre for asylum seekers and with general practitioners were identified. Of these 84 CEs, 37 had a positive outcome for the participant and 47 had a negative outcome. A negative critical episode always affected the trust in the healthcare professional in a

negative way. In some instances, the health of the participant or a family member was also – sometimes seriously – affected.

There were no systematic differences between the phase I and the phase II interviews in the sense of more negative or more positive assessment of health care. However all participants who were interviewed after September 2001 mentioned this period as very emotionally disturbing, often enhancing complaints like headaches.

From the cross-sectional analysis of our interview material, some central themes emerged that were either the ‘thorns’ or the ‘jewels’ in the critical episodes of our participants. Not surprisingly, the ‘jewels’ were often the opposites of the ‘thorns’ – leading to either trust or disillusionment.

#### *Friendliness versus rudeness*

Many participants emphasised the importance of friendliness on the part of a healthcare professional. “If you meet a doctor with a smiling face, you start feeling better at once.” Another young woman said: “We don’t have anybody here. It is very important that the doctor is friendly.”

Rudeness, impatience and anger were part of several negative critical episodes: anger about a request to see a female practitioner for a gynaecological problem; impatience towards a young and worried mother bringing in her child with a cold; unfriendly remarks about Dutch language skills towards a woman who had arrived recently.

#### *- Perceived personal interest versus not feeling taken seriously or not being heard*

Feeling or not feeling that one is being taken seriously is at the heart of most critical episodes. The feeling of being taken seriously breeds trust, when there is a doctor who listens to you, takes time with you, carries out a physical examination, and gives a good explanation. This contrasts with the experiences of other participants who felt their message did not get through. A female participant, Mrs A06 who, after ten years, received the proper treatment for her depression for the first time, said: “I cannot make my voice heard here”, which for her was partially a question of language, but partially also an issue of perceived discrimination.

#### *- Sharp diagnosis and swift action versus illness gets too old*

A young woman, Mrs A24, related how, after an earlier negative episode, the GP in her new place of residence took ample time for the first consultation with her, listened to her story very well and suggested that her continuous emotional instability might be due to an overactive thyroid gland – which actually turned out to be the case. This episode became the turning point in her life in the Netherlands. After she started treatment of her thyroid condition, she was able to face her new life.

The woman who developed a bleeding stomach ulcer during her stay in the reception centre and was immediately referred to the hospital for treatment, retained a strong feeling of trust from this critical episode. She remarked that she would have been dead had she still been in Afghanistan.

On the other hand, our material contains several stories about a long delay before a referral to a specialist was granted, or before an active treatment was started by the GP, which in the end turned out to be very necessary, according to the participant. Examples are a teenage boy with deteriorating eyesight, another boy with serious acne not responding to treatment and a young child suffering dehydration as a result of continuous vomiting.

The expression that “*they let your illness become very old here*” was used by several participants, referring to general practitioners, as opposed to the way doctors in Afghanistan treat their patients. It refers to the feeling among many participants that an illness should be treated in an early stage, before it has time to become serious.

#### *Unjustified psychological explanation*

Unjustified psychological explanation of physical complaints is a recurring theme both in the personal narratives by our participants and in stories they have heard from others, accompanied by sometimes-gruesome examples of how the doctor was proved to be wrong in the end.

Many participants do acknowledge a relationship between mental worries and health or illness. Participants in 21 out of 24 interviews spontaneously mentioned “worrying too much” as a cause of illness. However they feel general practitioners are too often prejudiced about (Afghan) refugees having psychological problems.

#### *Long-term treatment with tranquilisers and/ or sleeping tablets*

Several women gave highly negative reports about long-term treatment with tranquilizers and/or sleeping tablets and expressed a fear of becoming addicted. They perceived this type of treatment as revealing a lack of interest in them and their circumstances, on the part of the GP.

#### **Different types of personal narratives**

There appeared to be considerable variety in the narratives of different participants. In order to get closer to the roots of these differences, a schematic presentation in short quotes was made of the complete narrative of each participant, later structured into the constituent critical episodes. We connected the narratives to the personal resources of the participants and the social resources they mentioned in using to solve their health problems.

In this way the time dimension became visible and four different types of narratives could be distinguished: positive CE only, negative CE in the past but positive appreciation now, negative CE only and the last type with positive CE in the past but negative appreciation now. We provided each type of narrative with a motto:

- positive CE only – ‘primary trust’
- negative CE in the past but positive appreciation now – ‘secondary trust’
- negative CE only – ‘primary disillusionment’ and
- positive CE in the past but negative appreciation now – ‘secondary disillusionment’.

Table 2 gives an overview of different types of personal narratives, and of the positive and negative critical episodes mentioned, the social resources used and personal resources, according to the scoring system.

#### **[TABLE 2]**

In the following section we present four short biographies to illustrate each type of narrative. Each biography is directly based on the interview material, focusing on the critical episodes.

##### *Primary trust*

Mr A08 is a man in his late fifties with an academic education, who used to work in the Ministry of Health in his own country. He speaks English well and has learnt a reasonable amount of Dutch. He feels unhappy that he has never been able to use his

qualifications, since he came to the Netherlands with his wife and teenage children, seven years before the interview.

His own critical episode was when he arrived in the reception centre with a continuous, excruciating pain in his stomach, which had been with him during the last months of his escape. The doctor in the first centre looked after him very well and referred him to the hospital for further exploration of his complaints. It appeared he had multiple and recurring kidney stones and he has been getting treatment ever since.

When he started having breathing problems recently, his GP first treated him with an inhaler, but referred him to a specialist when this did not help him enough. He has not experienced negative critical episodes.

Mr A08, with his good command of English and university education, scores average in our system of 'personal resources': age was not on his side. He has made many new friends, both Dutch and other nationalities, and keeps himself busy with volunteer work.

He received good professional help when he needed it and he trusts he can always get the help he needs – also because he has background medical knowledge himself and he is able to communicate in different languages, both English and Dutch.

Mr A08 hears many complaints about healthcare and GPs from other Afghans, but he does not identify with these stories. In his view, all Afghans in the Netherlands are psychologically ill, because they are separated from their families and have lived in a war zone for such a long time. Their situation is worse because they are unemployed and have become dependent on social security.

He does not believe that GPs should be solving social problems. Doctors should concern themselves with health problems. But he thinks doctors in Europe lack information about the backgrounds of refugees from Afghanistan, and refugees lack information about the Dutch health care system. He has worked as a volunteer in a refugee organisation for several years, providing information about health and health care to his countrymen. He thinks people should be encouraged and supported to do something useful with their abilities, instead of just sitting at home, dependent on social security.

### *Secondary trust*

Mrs A25 is a modern young woman who speaks Dutch fluently. The first author interviewed her alone in Dutch. She relates how she arrived in the Netherlands nine years before the interview, a twenty-year-old widow with a daughter aged two, after a long and hazardous journey. She had just entered university in Afghanistan when the war invaded her life and the family had to flee. Her husband died suddenly in that same period. Looking back, she is surprised how strong she was during that period. She was the one the family – her parents, brothers and sisters – relied on to bargain their way through during the escape, because she could speak English. No time to think, no time to feel pain. In the end, she and her daughter were the first to arrive in Europe.

In the reception centre for asylum seekers, she broke down. She could not sleep and she had terrible headaches. Nothing like that ever happened to her before and she did not understand what was wrong with her. Finally she had found security and she was so tired – then why couldn't she sleep? She went to see the doctor in the centre, who gave her paracetamol for her headache. The tablets helped to relieve her pain, so she went back to get more when they finished. The doctor told her it was not a good idea to continue using painkillers; that her body was reacting to the stress of the difficult period she had been through and maybe what she really needed was some relaxation. He offered to treat her with acupuncture. To her surprise, she noticed that helped her a lot: it made her body relax and she could sleep the night after the treatment. This opened her eyes to the relationship between physical complaints and mental stress. She is still grateful to this doctor, who took an interest in her as a person and helped her to start understanding her problems in another

way. As a result of this critical episode she felt less helpless. Her fear and tension, increased by awful episodes during her escape, decreased.

She had to transfer to another centre where she was given a small room with her daughter. She believed that this second centre was very unsafe and felt imprisoned in her room. Her fears, sleeplessness, nightmares and headaches returned – also because she had not heard from her parents. She received tranquilisers, sleeping tablets and later antidepressants from the doctor in the centre. Looking back, she realises that the medication made her feel intoxicated and ‘stoned’. By then she had started learning Dutch in the centre and she made good contact with the Dutch teacher, who invited her to the home of his parents. These people became aware of her disturbed state of mind and expressed their alarm at all the medication she was taking at her young age. She became alarmed herself and told the doctor that she did not want to continue taking the medication. Maybe she could get another type of therapy? This experience revived her mistrust. She felt this doctor was not interested in her. She calls his attitude bureaucratic and even wondered whether he wanted to poison her.

She was lucky to receive her refugee status quickly and focused on getting out of the centre as soon as possible. She found a room to live in, with the help of Dutch friends, and later settled in an apartment with her daughter. Once that was achieved, she felt she could start a new life: learn Dutch and then pick up on her education. But she broke down again, crying for hours every evening and night and was not able to concentrate.

She consulted her new GP and started telling him her story but broke down in tears. He listened to her and did not need too much time to understand her problem. He asked her permission to refer her to a psychologist. She agreed and the therapy worked out very well for her, helping her to give a meaning to some of her awful experiences and to get back control of her life. Since then she made rapid progress learning the new language. She started studying and later working. She learnt to trust people again and made new friends.

Mrs A25 described in the interview how she changed in the way she consulted a doctor. In the beginning, she was very surprised, even shocked, when a doctor asked her what she thought about the situation herself. She was used to doctors as authority figures who tell their patients what to do. In the course of her years in the Netherlands, she has learnt about the system and its options and she often comes up with a proposal herself.

She does not know where she would have been if her first Dutch friends had not warned her about the medication. They helped her to come out of her zombie-like state in the centre before she became addicted. After five years, her parents, brothers and sisters joined her in the Netherlands. In her view, this family reunion helped her to find peace in her new environment.

Mrs A25 is clear in her narrative, that on her arrival in the Netherlands she was stressed and exhausted, but she also found it difficult to trust people, because of her experience during the escape. The first practitioner she met won her trust, because of his friendliness and the personal interest he took in her. In her experience with the second practitioner she did not perceive these qualities, and she interpreted the way the medication influenced her functioning as a possible poisoning. It is not clear from her story whether her own mood at that particular moment made it more difficult for the second practitioner to gain her trust. She used her personal resources and new social resources to confront the practitioner and emerged from the negative episode, which otherwise could have lasted much longer. The third practitioner apparently struck the right note and won her trust. Her trust in the health care system and in her GP was restored.

Mrs A25 knows many Afghan refugees in the Netherlands who do not feel they are being taken seriously by their GP and do not think he wants to help them. Her mother, who recently had a gallbladder operation, is an exception and is full of praise for the treatment she received. Mrs A25 is skeptical about the stories she hears from other Afghans. In her view,

most of them stick to their physical complaints and don't want to hear any psychological explanations. Consulting a psychologist is associated with insanity by most of her compatriots. She feels communication is an important part of the problem. People don't understand the explanation the doctor gives, but do not say that they do not understand and are left with their unresolved questions and problems.

#### *Primary disillusionment*

Mr & Mrs A21 were interviewed together. Their handicapped daughter, two years old, was lying on a bed in the sitting room during part of the interview, breathing with difficulty. Mr A21 has lived in the Netherlands for 12 years and speaks Dutch well. Mrs A21, who is a medical doctor and arrived in the Netherlands eight years after her husband, also understands Dutch, but expresses herself less easily.

Mr A21 had a difficult start in Holland. In a period when he developed an obsessive syndrome as a result of fear and loneliness, he did not receive support from his GP in the small town where he lived. Volunteers from the Dutch Refugee Council helped him to pick up his life and become active. He later moved to another town, learnt the language, started working and took some courses. He had a male GP during that period, but no critical episodes.

Following the arrival of his wife, he changed to a female GP. Mrs A21 became pregnant and gave birth to a daughter. The daughter appeared to be handicapped at birth. The GP visited them only once after the birth of this daughter and said she could not help the girl, when the father brought her for consultation because of respiratory problems. The daughter had to undergo a series of operations in a teaching hospital. Mr and Mrs A21 felt they had been abandoned by their GP in this period – another negative critical episode.

Mrs A21 became pregnant again and delivered a healthy daughter. At the age of six months this new baby girl became ill with a very high fever. The father was in the hospital with the older girl and Mrs A21 was at home alone with the baby. She took the baby to the GP and told her that the baby cried when she lifted her legs and that she could not lift her head. The GP, in the mother's story, examined the baby in the pram and said, there is nothing seriously wrong with her. Small children can have these high fevers and she should give her paracetamol. The mother phoned the GP again and again, because the fever did not go down and the baby was vomiting. Nobody came.

Finally, on the third night, a locum came and diagnosed meningitis. He phoned a pediatrician and said the mother had to take her child to the hospital. He refused to call an ambulance. The neighbours took her to the hospital with the baby. There it appeared the child was so desperately ill that she had to be taken to the intensive care department of a teaching hospital. The child survived, but is now severely handicapped: she can only move her eyes, smile a bit and move her limbs in an uncoordinated way.

Both Mr and Mrs A21 are convinced this happened to their child because they are foreigners. They feel very bitter. So far they have not filed a complaint against the GP concerned. Mr A21 is talking to a lawyer to prepare a case. They have changed to another GP, who has given them a lot of support, since their daughter came back home. However their trust in the Dutch health care system has broken down irreparably and their life is overshadowed by the consequences of this episode.

Mr A21's personal resources were good when he arrived: he was in his twenties, he could express himself in English and had some education. He had been working and was also studying, but he had to stop because of the problems with their children. Mrs A21 had an even higher-level of education when she came, but she did not speak English and she was over thirty. She generally depended on her husband for her social resources.

Mr. and Mrs A21 have lost trust in Dutch health care. They came with high expectations about health care in an industrialised society like the Netherlands. They turned to professional health care with their health problems, but were seriously disappointed. The

first GP Mr A21 met did not show any interest in his person or his problem. At that time, his new social resources helped him to stand on his own feet.

Mr and Mrs A21 interpreted the tragic episode, which ruined the life of their child and their family, as a sign of discrimination, not as a mistake by a professional that could have happened to anyone. Mr. and Mrs A21 are completely disillusioned about Dutch healthcare.

#### *Secondary disillusionment*

The first author and assistant researcher interviewed Mrs A23 while she was alone at home. Now in her early thirties, Mrs A23 started out as a child refugee, when her family took refuge in a neighbouring country. Because she was not allowed to go to school there, she lost her chance at a secondary education. She married young and later returned to Afghanistan with her husband and first child. When the situation became too threatening for them, the husband decided they should go to Europe. She felt she was a healthy woman up till then. The family had lived in the Netherlands for eight years at the time of the interview.

For Mrs A23, this has been a period of adversity and bad health. In the reception centre, she felt she received good healthcare for herself and her family. An interpreter was available, so she was able to communicate. During her stay in the centre she suffered from headaches and later migraine. When she developed serious heartburn, she was referred to a specialist, examined and treated well, in her view.

After leaving the reception centre, the family was assigned an old house in a major city where she felt afraid and isolated. Because neither she nor her husband spoke a European language, they had great difficulty locating the first addresses they needed. Their contact with the Dutch Refugee Council only materialised after two weeks. They wanted to register for a language course at once, but there was a one-year waiting list. Mrs A23 was only able to take the course two years later, because of an intervening pregnancy and later problems in finding someone to look after her child. The GP she consulted did not help her and she felt he was not interested in her problems.

After four years, the family succeeded in moving to another place, where they had a nice apartment, closer to some Afghan people they knew. Mrs A23 developed headaches, pains on the right side of her jaw, neck, arm and trunk. She consulted her GP frequently. He gave her tranquilisers and sleeping tablets, which she felt were not helping her.

Mrs A23 misses her family. She feels she is no longer the woman she used to be. She feels guilty towards her children because she often shouts at them and "*makes small problems very big*". She wants to be a normal mother and is afraid that her children will suffer later from her problems now. Her doctor first referred her to a social worker and she later received educational assistance in dealing with her children. But she feels her doctor just wanted to get rid of her and was not interested in her. Her situation has not improved. She feels helpless in her situation and hardly has any contacts with Dutch people. Though she speaks some Dutch, she does not feel her knowledge is sufficient for easy communication. She has tried to switch doctors, but said this was not possible in the small municipality where she lived.

The year before the interview she also developed abdominal complaints. She noticed that her stomach was swelling but her doctor kept her on the same regime of tranquilisers and antacids. It was a locum who finally discovered that there was a huge swelling in her upper abdomen, which an ultrasound image revealed as a chronically inflamed and blocked gall bladder. At the time of the interview, she was on the waiting list for an operation.

Mrs A23 scored low on personal resources in our 'system', even though she was young. Her social resources are mainly her family – living in other countries – and some friends she knew from Afghanistan.

Mrs A23 does not trust her GP. In fact, after her first positive experiences during her stay in the reception centre, she feels nobody, her GP-included, has wanted to listen to her.

She is one of the participants who said that a long-lasting relationship with a GP deteriorated over the years, the GP becoming more and more unfriendly. Limited personal resources, missing the support from her family and no access to new social resources may have prolonged her suffering.

In Mrs A23's view, all Afghans have the same problem. Their GP does not take them seriously. She thinks doctors treat refugees differently and they do not dare to behave like that towards their Dutch patients, because Dutch patients are better informed.

We assessed Mrs A23's narrative as one of secondary disillusionment.

#### *Personal and social resources*

In their own country the people we define as refugees here, were individuals who were functioning independently, on different levels and with different 'personal resources', in the middle of their own social environment or 'social resources'. On arrival in the new country, part of their acquired personal resources, like language, diploma's, knowledge of social structures and codes were suddenly no longer applicable. Trusted social resources were often not available.

#### *Social resources*

From our interviews we learnt that health and healthcare are subjects frequently discussed among Afghan women, but much less among men. In the interviews with couples, the women mostly took the lead – probably for this reason. The exceptions were two interviews that took place in Dutch, because of the participants' preference, and the man appeared to be much more fluent in the Dutch language, and one interview in Dari with a couple in which the man obviously was the dominant partner. In the view of the participants, the stories they hear from other Afghans about healthcare in the Netherlands are always negative – not being taken seriously by doctors; missed diagnoses and late referrals. Because of the one-sided content of these 'stories from others', we called this phenomenon the 'general narrative'.

Participants conveyed these stories to us in different ways, either identifying themselves with the stories (Mr and Mrs A21, Mrs A23) or distancing themselves from them – Mr A08. and Mrs A25.

Knowing how general the 'general narrative' is, one can understand that the 'social resources' newly arriving refugees turn to make a difference. Information from social resources helps to create positive or negative expectations, confirms or challenges personal experience or puts it in a specific context. Afghan social resources will come up with different interpretations from Dutch social resources.

Our participants differed in that respect – to the extent that some said they only consulted the family (even when abroad) about health-related matters, whereas others only consulted Dutch people. From our analysis we saw, that the 'secondary trusters' were all people who had regular contacts with Dutch people and were using them as sources of information, often in combination with 'old' known social resources. The 'new social resources' could be contacts persons from the Dutch Refugee Council, neighbours or other friends.

It was clear from the narratives of many of the 'secondary trusters' that the new social resources had been helpful to either change the course of action of a professional, help change to another professional or change the interpretation of a professional's behaviour. An interesting note in this context is the account of a lady who said that in the beginning she did not like her (male) GP, because he was not very friendly and she assumed that he did not like foreigners. When she heard from her Dutch neighbour that the doctor behaved the same way to her, she concluded this must be his character and she decided to stay with him, because she and her husband felt the doctor took their health problems very seriously.

### *Personal resources*

In our analysis it was striking that the participants who mentioned negative critical episodes in the past and positive critical episodes later – the ‘secondary trusters’ – generally had high or average scores on personal resources. Mrs A25 is an example. From her narrative it is evident that her personal resources helped her to start exploring new social resources at an early stage. Speaking a European language (English or German) at arrival was definitely helpful for the participants who did, according to their own stories. They succeeded in making themselves understood right from the start, without depending on others. The only participants with low personal resources in the ‘secondary trust’ category had strong day-to-day support from a close family member with higher personal resources.

Participants losing trust, after a more positive start, were more often participants with more limited personal resources and who also used Dutch social resources less frequently.

## **DISCUSSION**

The design of our study allowed us to gain in-depth insight into the views of the Afghan participants. They have been “making sense” (Weick, 1995) of their lives in the Netherlands and their encounters with health care as part of their life. The interviews we held can be seen as a step in this process of making sense of their lives, possibly also influenced by the role participants attributed to the researcher – as a safe intermediary to make their voices heard. The fact that the researcher and the assistant researcher were women seemed to facilitate the discussion of this ‘women’s subject’, among both female and male participants. Many participants expressed appreciation for the time we took to listen to and understand their stories.

Our design is different from designs mostly used to study patients’ satisfaction with healthcare, (Edwards et al. 2004) not linked to a healthcare institution or focused on people with specific problems. This is probably the reason why participants were also prepared to express negative opinions. Very few participants gave direct feedback to a care provider and none of them filed a complaint. The ‘critical episodes’ arose from the analysis of our interviews: participants mentioned events that had been important to them over the years. We did not intentionally focus on specific incidents, as Gau with his ‘critical incident technique’ did in a focus group context (Gau et al. 1989), and mentioned by Rees Lewis (Rees Lewis, 1994) in his review of studies concerning patient views on quality of care. Our results give some food to Sixma’s supposition (Sixma et al. 1998) based on the analysis of a large dataset, that concentrating on the number and type of incidents between GPs and patients might be a fruitful method of gaining insight into possible causes of decreasing patient satisfaction.

The personal narratives of our participants showed more variety than the findings of some other authors – mostly derived from focus group interviews with refugees living in Dutch society (Pree, 1998; Vera, 1998) – might lead one to expect. This is probably a direct result of the method used. We interviewed our participants individually or as couples – so they would feel free to mention their own experience and opinions differing from those of others. Focus group interviews often tend to produce a ‘dominant narrative’, in this case concordant with what we called the ‘general narrative’.

The variety of the narratives shows that we succeeded in our aim of preventing selection bias, in the sense of interviewing only people with negative or positive stories about healthcare. The educational levels of our participants were more or less in line with educational levels of the Afghan population in the Netherlands (van den Tillaart et al. 2000). More women than men were interviewed and the group of young unmarried men, quite prominent in the Afghan group in the Netherlands, is poorly represented. This could be a

result of self-selection, in the sense that people who make little use of health care institutions – like young men – did not volunteer for an interview about health care, as opposed to (young) women, who tend to be the ‘caretakers’ in the family, also responsible for health matters. Since our aim was to analyse the experiences of people who did make use of health care institutions, we think the lack of unmarried young men in our study group does not diminish the value of our results.

As for our first question about the participants’ frames of reference: the participants emerged from our interviews as people actively involved in the process of establishing themselves in their new country and constructing a meaningful future for themselves (and their children) as autonomous human beings. In this quest process, health is a crucial asset and health disturbances were often viewed with great apprehension. The descriptions of health our participants gave us, as an integral ‘well-being’ also encompassing ‘autonomous functioning’ agrees with the findings of other authors, who interviewed (Afghan and Bosnian) refugees in resettlement countries. (Lipson, 1991; Kopinak, 1999). Eastmond (Eastmond, 2000) found the same inclusive concept of health among Bosnian refugees in Sweden.

Urban healthcare in Afghanistan – with a free choice of which doctor to consult and direct access to medical specialists – being the common frame of reference for all our participants, the central and unavoidable position of the Dutch general practitioner induced feelings of helplessness and dependence in many participants, especially in the beginning.

The results of our study show that this ‘forced relationship’ between the Afghan refugee patient and the Dutch GP does not always work. Throwing up Kleinman’s (Kleinman, 1995) basic question “What is at stake here?” we feel, from analysing the interviews and comparing the different narratives, that the answer should be: trust-building. Did the participants trust that in case of a serious, life-threatening event, they would get the help they needed? This is trust as described by Misztal (Misztal, 1996): “To trust is to believe that results of somebody’s intended action will be appropriate from our point of view.” Connecting this to the definition of health the participants gave us, it is maintained that help should be given with respect for autonomy and be directed towards restoration of control.

The question that interests us is, why over the course of time, some participants developed trust in the Dutch system and others did not. This was the question we focused on in this part of our study. Our concept of ‘critical episodes’ and the categorisation of the narratives as different types of chains of critical episodes helped us to find some answers to this question.

We have distinguished four types of personal narratives, the ‘primary trust’ type, the ‘secondary trust’ type, the ‘primary disillusionment’ type and the ‘secondary disillusionment’ type. Apparently a good start is not enough for a lasting trust and a bad start does not mean that everything is lost. Positive changes in trust were often, but not always, linked to a change of professional. Sometimes a ‘mistake’ could be forgiven when a professional was prepared to talk about it openly, and the participant dared to speak out. These were rare occasions in our material. Likewise, negative changes in trust were often linked to a change of professional. Since the same participants spoke differently about their experiences with consecutive practitioners, the differences in behaviour and attitudes between practitioners are at least a factor to be taken into consideration.

We have looked at ‘social resources’ not only as sources of support, like Beiser (Beiser, 1991) in his model, but also as sources of information, as ‘bridges to the surrounding society’ (Granovetter, 1973). We assume there is a link between the personal

resources people have at their disposal, and the choices they make as to which social resources to use. People with more personal resources (education, knowledge of a European language and comparative youth in a combined score) used a wider variety of social resources – including Dutch social resources – and were more likely to change an unsatisfactory relationship with a general practitioner in a positive direction.

In our analysis we noticed that the trust-building process is not only based on the chain of personal experiences, but also on stories heard from others. We came across a phenomenon we labelled the ‘general narrative’: a complex of negative stories about healthcare circulating in the Afghan community.

Several authors mention negative stories about healthcare, circulating among refugee groups. Van Dijk (van Dijk et al. 2001) links the narratives of refugees in a reception centre for asylum seekers in Holland to demoralisation (Stoffer, 2001) based on feelings of societal exclusion. Most refugees coming to Holland start their new life from such a reception centre – and thus may come across this type of stories. But according to our participants, the shaping of the ‘general narrative’ continues outside the centres.

Manderson and Allotey (Manderson and Allotey, 2003) came across stories with a strong ‘alert’ content circulating in an immigrant community in Australia. The stories were vehicles for a lack of trust among people who were feeling marginalised – but could also be used in efforts to improve healthcare for the people concerned. Dingwall (Dingwall, 2001) sees contemporary legends with a medical connotation as valuable resources for medical sociology and places them in the framework of unequal power relations between medical professionals and the non-professionals.

The content of the ‘general narrative’ among Afghan refugees in the Netherlands is very much in line with the content of the negative critical episodes we encountered in our interviews. It is clear that these negative experiences will at their turn feed back into the ‘general narrative’. Our observation that participants who felt disillusioned about the help they got from their general practitioner identified with the general narrative, whereas participants who had developed trust tended to distance themselves from it, makes this all the more likely.

In our study we focused on the experiences that the participants had with healthcare. These experiences cannot be completely separated from their other experiences in the Netherlands. The participants with the most negative healthcare experiences stressed their feelings of being discriminated against as foreigners in general. Healthcare professionals are seen as important representatives of a society. A negative attitude or negative behaviour on the part of these representatives may leave a very strong impression. On the other hand, negative experiences in other social situations may lead to more negative interpretations of the behaviour of healthcare professionals. The same personal and social resources that are helpful in the healthcare situation are probably helpful in the whole process of building a future in a new country.

In this context, it is interesting to mention Karlsen and Nazroo (Karlsen and Nazroo, 2002) who, through careful factor analysis of the Fourth National Survey of Ethnic Minorities in Britain, showed strong independent relationships between health and experiences of racism, perceived racial discrimination and class. Their implication is that experienced or perceived racism is a chronic stress factor, which as such could undermine health. An additional explanation might be that healthcare institutions less effectively serve certain groups in society. It can be considered common knowledge that healthcare professionals are human beings who may make mistakes and do not always behave in a friendly manner. The question is, whether refugees – or perhaps people with a non-Dutch

background in general – run a greater risk than other users of healthcare of being confronted with professional mistakes and prejudiced behaviour.

Our participants mentioned positive critical episodes as episodes in which the professional involved displayed a friendly, open attitude, showed patience and took enough time, gave a good explanation or took swift action in dealing with the presented problem. Here of course the question arises how much the priorities of the refugee patients we interviewed differ from those of other patients.

A review of the literature on patient priorities for general practice care (Wensing et al. 1998) provides striking similarities: humaneness, competence, shared decision-making, enough time and ‘informativeness’ are at the top of the list of patients’ priorities in general. Kinnersley (Kinnersley et al. 1999) found ‘patient-centredness’ to be statistically significantly associated with patient satisfaction, in a comparative study of patients consulting 143 different British GPs. Rees Lewis (Rees Lewis, 1994) identified interpersonal skills on the part of the practitioner as the most consistently named item of value to patients across a number of studies.

How important is being a ‘competent and friendly doctor’? Is anything more at stake than just that? An impressive number of studies have been conducted to answer this question. The quality of the doctor’s affective behaviour was found strongly to correlate with the overall quality of the consultation (Bensing et al. 1996). A large survey in the United States (Safran et al. 1998) defined “patients trust in their physicians” and “physicians’ comprehensive (‘whole person’) knowledge of patients” as the variables most strongly associated with patients’ tendency to follow the doctors’ advice. Thom (Thom and Campbell, 1997) concluded from a focus group study that a good bedside manner is essential to providing competent care and breed trust. Stewart (Stewart, 1995) found from a review study that the quality of communication, both in taking a history and in the discussion of the management plan, positively correlated with patient health outcomes. In short, the results of all these studies lead towards the conclusion that friendliness and interpersonal skills are not just ‘the nice wrapping’, but an integral part of good-quality healthcare.

Apparently our participants do not differ basically from other patients around the world in what they expect from doctors. However, they live in a situation that may make it more difficult for them to develop trust. Realising that earlier experiences and stories circulating in certain communities may undermine the building of trust can sensitise practitioners to the importance of a first encounter or other critical episode for a refugee patient.

## TABLES

Table 1 *Characteristics of Afghan participants*

<i>Afghan Participants</i>	<i>Legal position</i>	<i>Man (M)/ Woman (W)</i>	<i>Age</i>	<i>Years in NL</i>	<i>Employment M = man W = woman</i>	<i>Education upon arrival (M)an/ (W)o man</i>	<i>Type of community</i>
A 01 <i>pilot interview</i>	permit	W	69	2	None	None	Large city
A 02	permit	M + W	45, 41	4	None	M higher, W secondary	Village
A 03	permit	M + W	59, 56	4	None	M none, W primary	Village
A 04	permit	W	39	4	None	Secondary	Village
A 05	permit	W	48	3	None	Higher	Small town
A 06	Dutch cit.	M + W	50, 43	10	M not, W employed	M Higher, W secondary	Small town
A 07	Dutch cit.	W	66	9	None	Secondary	Small town
A 08	Dutch cit.	M	57	7	Volunteer	Higher	Large city
A 09	Dutch cit.	W	47	10	Employed	Primary	Village
A 10	permit	W	66	4	None	None	Small town
A 11	permit	M	18	3	Student	Primary	Small town
A 12	Dutch cit.	M + W	45, 35	8	M + W employed	M + W higher	Village
A 13	Dutch cit.	M	31	10	Employed	Secondary	Small town
A 14	permit	M + W	43, 28	3	In training	M higher, W secondary	Small town
A 15	permit	M + W	38, 33	5	None	M higher, W secondary	Village
A 16	Dutch cit.	M + W	45, 44	8	M studying, W volunteer	M higher, W secondary	Small town
A 17	Dutch cit.	M + W	63, 45	M 6, W 8	None	M secondary, W secondary	Large city
A 18	Dutch cit.	M + W	63, 52	9	None	M + W primary	Large city
A 19	Dutch cit.	M + W	50, 51	9	M none, W employed	M secondary, W higher	Town
A 20	Dutch cit.	M + W	44, 40	12	M + W employed	M secondary, W secondary	Town
A 21	Dutch cit.	M + W	40, 35	M 13, W 5	None	M secondary, W higher	Small town
A 22	Permit	W	38	5	None	Higher	Village
A 23	Dutch cit.	W	36	8	M employed, W none	Primary	Large city
A 24	Dutch cit.	W	29	7	M student, W employed	M higher, W university student	Large city
A 25	Dutch cit.	W	29	9	Employed	University student	Town

Table 2 24 Afghan interviews, critical episodes (CE), personal resources, use of social resources Critical episodes concerning the medical team in the reception centre or a general practitioner

No CE GP N = 3			Secondary trust N = 7				Secondary disillusionment N = 8				Primary disillusionment N = 3				Primary trust N = 3			
Part nr	PR	SR	Part nr	Nr CE neg/pos	PR	SR	Part nr	Nr CE pos/neg	PR	SR	Part nr	Nr CE	PR	SR	Part nr	Nr CE	PR	SR
A04	A	O	A12	1/4	H	N	A02	1/3	A	O + N	A06	4	A	O + N	A05	2	A	O
A07	L	O	A13	1/1	H	O + N	A03	3/1	L	O	A21	4	H	O + N	A08	2	A	N
A11	A	N	A14	1/4	A	N	A09	1/3	L	O + N	A22	6	A	O + N	A10	1	L	O
			A17	3/3	L	O + N	A15	2/2	H	O + N								
			A20	1/2	A	O + N	A18	1/3	L	O + N								
			A24	2/2	H	N	A19	1/3	A	O + N								
			A25	1/2	H	N	A23	4/5	L	O								
							A16	1/3	A	O + N								

Critical episodes (CE) nr. (+) / nr (-)

Personal resources score<sup>1</sup> (PR): L = low, A = average, H = high

Use of social resources: old (O) or new (N).

<sup>1</sup>The score was obtained by adding up subscores 0, 1 or 2 for age (50+ = 0, 30–49 = 1, 15–29 = 2), knowledge of European language upon arrival (not = 0, a bit = 1, well = 2) and education upon arrival (none or primary only = 0, finished high school = 1, finished higher education = 2). A total score of 0, 1 or 2 was designated as low, 3 and 4 as average, 5 and 6 as high.

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