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Somali Refugees' Experiences with their General Practitioners: Frames of Reference and Critical Episodes

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ABSTRACT

The article presents the results of a qualitative study based on in-depth interviews with Somali refugees living in The Netherlands, on their experiences with general practitioners (GPs). The central question is: what are the frames of reference participants use to interpret their experiences? The current situation in The Netherlands appears to be a more significant frame of reference than health care as it was known in Somalia. There is a general narrative in the Somali communities that health care in The Netherlands is not good for Somalis, and feelings of being discriminated against appear to be common. Stories of medical calamities circulating within the communities illustrate and enhance this perception. Consulting practitioners in neighbouring countries is a frequent escape route.

The individual narratives show a more varied picture. Critical episodes can be identified, in which encounters with GPs had either a positive or a negative outcome for the individual. The content of positive and negative episodes is analysed. The personal attitude and communication skills of the practitioner appear to be central to building or undermining trust. Depending on their personal experiences, participants identify with the general narrative or keep some distance from it.

INTRODUCTION

'Dutch doctors are good, but they don't want to give us attention [...] Each time you don't get attention and you hear this type of story, then you don't trust Dutch health care again.'

A 46-year-old Somali woman is telling us about her experiences with doctors since her arrival in The Netherlands in 1993. She also mentions stories she has heard from other Somalis concerning their experiences with Dutch health care. 'Us' is our small research team, consisting of a middle-aged female Dutch doctor, the researcher and a female Somali assistant researcher, also a medical doctor by education

but not practising in The Netherlands. The assistant researcher speaks Dutch fluently and translates and explains when necessary.

Since the late 1980s, around 28,000 Somali people who fled the war and violence in their country have come to The Netherlands. Somalis form one of the larger groups among more than 200,000 refugees, originating from more than 140 different countries, who have been housed in The Netherlands since the 1970s. They have settled in municipalities all over the country, in accordance with the policy of the Dutch Government of dispersing new migrants to prevent larger concentrations in the major cities.

Various Dutch sources indicate that refugees do not always get the help they think they need. In particular, the role of the GP, who has a central position in Dutch health care, is often not appreciated (van den Brink, 1996; Vera, 1998; Pree, 1998). Some regard the GP more as a stumbling block to 'real' medical care. Problems mentioned are a feeling of not being respected or taken seriously by GPs and that physical complaints are too often explained as psychological. Among refugees, stories circulate about missed diagnoses and wrong treatments (Vera, 1998; Pree, 1998).

A study of the international literature reveals that we are not dealing with a specifically Dutch phenomenon (Searight, 2003; Manderson & Allotey, 2003). In several countries, migrant populations have been found to be less healthy than the rest of the population (Sundquist, 1993, 1995; Iglesias et al, 2003; Bollini & Siem, 1995; van Dijk & van Dongen, 2000). A range of relevant issues have emerged, including ethnic stereotyping (Kleinman, 1997), cultural stereotyping (van Dijk, 1998), ethnic differences (Sundquist, 1993, 1995; Iglesias et al, 2003), economic differences (Sundquist, 1995), the 'healthseeking process' (Chrisman, 1977) and 'medical gossip' (Suls & Goodkin, 1994). Differences in access to health care may explain part of the variety found in the state of health of different groups (Sundquist, 1993).

The voices of migrants themselves are less often heard in the international literature. In this article, we present an analysis of interviews with Somali (former) refugees, focusing on their experiences with health care in the reception centres where they stayed as asylum seekers and with the GPs they met after they had started living in a house of their own. Our leading question in this qualitative study is: which frames of reference play a role in the development over time of an individual refugee's relationship with the Dutch health care system, in particular with the GP? We will argue that satisfaction or dissatisfaction with the available care results from a process of continuous re-interpretation by the individual participant of her or his own health history and that of immediate relatives, against the background of relevant frames of reference.

RESEARCH METHODS

Procedure

Co-operation was provided by Somali organisations via the VON (Refugee Organisations in the Netherlands). An introduction was written, to be used as a hand-out for potential participants, and translated into the Somali language. A list of topics was compiled, with advice from various experts, some with academic expertise and some with inside knowledge of the Somali community.

Two Somali women were selected via personal contacts as assistant researchers, on the basis of their special skills: fluency in Dutch and their own language, knowledge of the specific terminology, good communication skills and understanding of the aim and the methodology of the research. They took turns in assisting during the interviews. The assistant researchers were also important as 'cultural intermediaries' and assisted in developing a trust-based relationship with the participants.

Potential participants were approached via several agencies, including the refugee organisations, a local division of the Dutch Council for Refugees 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 experiences of the health care system. The criteria for inclusion as participants were having 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, with different levels of education, different ages and varied family structures, thus maximising variety by selective sampling of interviewees.

Participants

Table 1, opposite, gives an overview of the characteristics of 30 participants in 25 interviews. A husband and a wife giving an interview together are counted as two participants. Sixteen women, five couples and four men were interviewed. They had lived in The Netherlands for between six and fifteen years and their ages ranged from twenty-four to sixty-eight. All were Muslims.

The educational level of the participants varied; eleven participants had completed academic or vocational education, thirteen had completed secondary education, five had only primary education and one woman was illiterate. Twenty participants were unemployed, seven were employed, one young man was a full-time student and two participants were over sixty years of age.

Twenty-eight participants had acquired Dutch nationality, and two had a refugee or humanitarian residence permit. Nineteen participants lived in a major city, seven in smaller towns and four in villages.

Data generation

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

The first author conducted all the interviews. In 22 cases one of the assistant researchers interpreted to and from Somali. All interviews were recorded on tape with the consent of the participants. Most were conducted at home, though two were carried out in an office environment at the request of the participant. Whenever an answer did not seem to match the question during the interview, the question was rephrased to prevent misunderstanding. The interviews lasted between one and a half and two and a half hours, including the introduction, pauses and time for reflection at the end. The assistant researchers identified with the project and became part of the team, greatly enhancing the quality of the study and helping to prevent misunderstandings. Three interviews were held in Dutch by the first author alone. The interviews took place between November 2000 and May 2003.

The first part of the interview focused on the experience of the participants with health care in their country of origin, and how they felt their health had been influenced by their last period in that 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 up to their experience of health care. Time was spent in going 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 the Dutch parts of all the 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 win MAX software programme (Kuckartz, 1998) to organise the data and facilitate retrieval. The use of the software program 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 in opinions about health care, was the subject of intensive discussion between the authors. At a later stage, peer examination by an external researcher helped to sharpen and focus the interpretive process.

The interviews contained both narratives about participants' own experiences and stories participants had heard from others, mostly family members or good (Somali) friends. Instead of disregarding these second-

hand narratives, we decided to make them part of our analysis with a separate label of 'general narrative'. The elements constituting the general narrative were coded and analysed separately.

In the personal narratives, positive and negative comments were distinguished, and the constituent elements of such comments were analysed and compared 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 as a basis for their opinions. During the analytical process, we assigned the label 'critical episode' (CE) to this type of opinion-shaping experience with a health professional.

[TABLE 1]

The critical episode label refers to a series of events during a period of time which the interviewees mentioned in the interview as having been of special significance to them, in a positive or a negative way. A data matrix was constructed of all critical episodes from the interviews, and each episode was scored on whether the participant related it to the attitude or to the professional behaviour of the health professional, or to both (Miles & 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.

RESULTS

Healthcare in Somalia before 1991

Traditional and modern medicine still exist side by side in Somalia, both in the cities and in rural areas. All our participants were primarily orientated towards modern – Western – medicine in their home country. Most participants had lived in the capital, Mogadishu, and belonged to the higher socio-economic class before they fled the country. Three lived in other cities. One man was born in a rural area but later moved to Mogadishu. The oldest participants reported more experiences with traditional health care, especially in their younger years. One man, who had started his life in a nomadic family and later followed academic education, never saw a doctor until he moved to the city at the age of eight.

Many participants mentioned the use of traditional homecare measures, preceding the consultation of a doctor. Young mothers took advice from older women in the family on how to treat their children's illnesses. Sometimes a traditional healer was consulted, in addition to consultation with a doctor. Elderly male family members were often called in to read the Koran for a sick person, in order to ask for God's blessing.

Participants emphasised the freedom they had to consult the care provider of their choice at the moment they chose to do so. Still, they mentioned a strong tendency to keep to the same doctor as much as possible for the same family member. Lack of money was an impediment to some degree. The hospital was free, and if you needed money to buy medication or see a doctor in his practice, there was the family to support you. Families with more money had more options open to them.

A key reason for choosing to consult a particular doctor was the amount of time and the measure of serious attention he devoted to his patients. Our participants portrayed Somali doctors as listening very well to their patients, doing a thorough physical examination and giving a good explanation of the diagnosis and treatment. Doctors in Somalia prescribed not only a lot of medication, but also strong medication such as antibiotics. Antibiotics were often prescribed together with vitamins. One notion many of our participants brought up is that a disease should be treated at an early stage, before it becomes very serious. On the other hand, some participants said that it is not good always to be given strong medication; the drug might then be ineffective in the case of serious disease as a result of too frequent use.

Arriving in the new country

The first encounters our participants had had with the Dutch health care system took place in the reception centres where they stayed as asylum seekers. Since all of them arrived before 1996, we are referring to the period 1991–1995. Before presenting the content of their reflections, it is necessary to elaborate briefly on

the organisation of health care for asylum seekers in The Netherlands. Since 1987, the Dutch Government has provided for the basic needs of people who have filed an asylum request. Housing in reception centres, food and, later, money to buy food, and access to health care are free for asylum seekers, who generally lack resources. With a few exceptions, the full package of health care is available. Screening for lung tuberculosis is compulsory within two weeks of arrival.

In order to facilitate the access of asylum seekers to the standard health care system, medical teams are stationed in the reception centres. These teams provide the arriving refugees with information on health and health care matters, offer and perform an examination of the actual health status of every individual and function as links (bridge-builders) between the new arrivals and Dutch health care providers, especially GPs. Inhabitants report to the nurse at the reception centre with questions or problems about their health. The nurse refers to the GP for further diagnosis and treatment. None of our participants had stayed in a reception centre for more than 18 months.

Arrival in the new country meant safety and security on the one hand, and also disorientation and loss of familiar identity. What stands out in many stories is a high degree of experienced vulnerability and helplessness in this initial stage. Women who had arrived alone with their children, in particular, described in strong words how they felt lost, suffering from uncertainty and physical and mental problems, not knowing where to go. Mrs S16 says the following about the period when she arrived in The Netherlands in the early 1990s.

'I had a good life in Somalia, until I had to flee. I was a working woman, I had my own house and everything. In the centre, I felt helpless. I missed my country, I missed my family, my friends, my possessions. I really felt isolated. I became somebody who does not have freedom again, who is dependent on others.'

The general narrative

At the moment of the interview, participants are no longer newcomers. They have lived in The Netherlands for between six and fifteen years.

A striking element in 24 of the 25 Somali interviews is the reference participants make to problems that other Somalis, all Somalis, most Somalis, in some cases 'all refugees' or 'all foreigners' have with Dutch health care. The collection of these stories heard from others we labelled the 'general narrative', because of its rather monotonous character. Stories about experiences with health care circulating in the Somali network, as related by our participants, are mostly negative. The stories are about doctors who don't examine their patients well enough, who don't give the right medication, who don't take refugees or foreigners seriously and/or refuse to refer their patients to a specialist in time. Paracetamol crops up in many stories about doctors in The Netherlands.

'This is a country of paracetamol. I can buy paracetamol myself. I don't need to go to the doctor for that.'

Participants also mentioned specific calamities concerning people whom they know personally: a Somali person in a coma and later severely disabled after anaesthesia for a minor operation, a small child who died of dehydration because the general practitioner underestimated the severity of the situation, a young man who died of a disseminated tumour in his neck, after having been told for a year by his GP that he was too young to have a malignancy, a young woman who died of a brain tumour after suffering from serious headaches for five years and being told several times by different doctors that nothing was wrong with her head. Mrs S17 said:

'When you hear this type of story and you don't get attention yourself, how can you have trust?'

Participants made a strong link between this 'general narrative' and a lack of trust in Dutch health care that seems to have become rooted in the Somali community. The general narrative was used as a shared frame of reference by most participants while narrating their personal experiences.

Individual participants – taking position

Although almost all the participants mention the problems many of their compatriots have with Dutch health care, and GPs in particular, individual participants take different positions when they refer to the general narrative. Participants in 18 interviews distance themselves from it, referring to problems other people have, while participants in six interviews identify with the general narrative. Mrs S13 said:

'Dutch doctors are among the best doctors in the world, but they are not interested in us'.

In one interview, the participants did not mention other people's experiences with health care. The question arises of why people take these different positions. To clarify this issue, we continue with the presentation of participants' personal narratives.

Personal narratives – critical episodes

From the stories participants tell about their encounters with health care, it appears that, in retrospect, certain episodes have been of special significance to them. We have labelled these 'critical episodes'. The critical episode (CE) qualification has been given by the researcher to a series of events during a period of time which participants mentioned in the interview as having been of special significance to them. These were mostly episodes where the participants had felt particularly vulnerable, or that their existence was threatened because of a health problem (either their own or that of a close relative). Critical episodes related by participants include experiencing disturbing physical symptoms or being pregnant in an unknown environment, serious or disfiguring illness of a child, the start of a chronic illness and experiencing mental problems that undermine normal functioning. The first encounter with a new health professional was mentioned by many participants as a critical episode.

The episode was analysed in terms of the problem itself, what the participant had thought about the problem at that time, the encounter with health care providers concerning the problem, the evaluation of the encounter by the participant afterwards and the outcome of the episode for the health of the participant or the relative concerned. An episode might comprise several encounters. Participants talked about the episode as a positive or negative experience in hindsight. During the interview, care was taken to obtain as much clarity as possible about the meaning participants attributed to the different aspects of the episode. Thus the outcome as far as their health was concerned – improvement, no improvement or damage – could be distinguished from the way the health care provider acted (in their opinion). Attitude and communication aspects, as experienced by the participant, were differentiated from task-orientated actions such as performing physical examinations, writing prescriptions or referrals to a specialist.

Some critical episodes, as related, had a dramatic impact on people's lives; others seemed trivial in the eyes of an outsider. For each participant, a chain of critical episodes could be constructed. The number of critical episodes per participant varied between one and four. Some critical episodes had not ended by the time of the interview, or had left a lasting effect on people's lives. In the following section, some cases will be described, focusing on participants' experiences with primary health care.

Competence in using the Dutch health system and trust in the general practitioner emerged as central issues in participants' evaluation of episodes in their narrative. As a result of a critical episode, a participant felt either more competent or more helpless in using the new health care system. Competence is described in words like 'now I know where I am, I know my way, I know what to do'.

INDIVIDUAL EPISODES

In 25 interviews, participants mentioned 38 positive critical episodes and 44 negative critical episodes. We shall elaborate on positive and negative CEs separately.

Positive critical episodes

Of 38 positive CEs, participants mentioned confidence-inspiring, task-orientated performance in 21 cases and confidence-inspiring communication in 14 cases. In three CEs, both task-orientated performance and communication were mentioned.

Welcoming attitude in introductory consultation

Mrs S09 related how her second GP arranged a special introductory consultation to get to know her, and asked her about her history and background. The conversation took place in English, which both parties could speak with ease. The doctor also gave her very useful information about her diabetes and about how to adjust her lifestyle.

She greatly appreciated this doctor's interest in her as a person. Her confidence in Dutch health care was restored, after an earlier experience with a new GP who had ended a first consultation within two minutes. She started seeing her GP as an important ally; she got attention, recognition and information. Though she had one bad experience, Mrs S09 now feels competent and trusts her GP.

Proactive, task-orientated performance

Mr S21 described how in the village where he had lived before with his wife and children, he had complained to his GP about feeling tired and drinking and urinating a lot for a few days. The doctor immediately examined his blood, told him that he had diabetes, phoned the hospital and made sure he was admitted for initial treatment. The way in which the doctor dealt with his problem inspired trust.

Obvious human interest during family crisis

'When you are ill, a good general practitioner is half of your life.'

These are the carefully formulated words of a softspoken Somali woman, Mrs. S08, sitting in her apartment in a major city in The Netherlands. The curtains of her flat are drawn, letting only shaded light to pass through. She is wearing a colourful traditional dress with green head tie. Her toddler son has cried himself to sleep. The female doctor she has in the major city where she lives almost literally saved her life when she was going through a family crisis, being abused by her husband and sinking into a depression. Her doctor supported her by listening to her with an open mind, giving her advice, prescribing medication for her depression, speaking to the husband and inviting her for frequent visits.

Giving effective information about illness

Mrs S08 stressed the importance of good information.

'If you get the key to your illness, that is half of your cure.'

She is referring to information she had received about her depression. At first she did not understand what was wrong with her, until her doctor explained to her and gave her an information leaflet to read. She was greatly relieved, learning that she was not the only person with this type of problem, that it can happen to anyone, Somali, Dutch or otherwise. The doctor helped her to restore control over her life. She felt a stronger and more competent person afterwards.

When Mrs S08 consulted her new GP with a coughing, feverish child, the doctor examined her son thoroughly, then prescribed some cough syrup and asked her to give the child a lot to drink and some paracetamol, if needed. The doctor added that it would be easy for her to prescribe antibiotics, but that the child did not need them now, that it is better to preserve the antibiotics for those occasions when the child really needs it, otherwise the child can unnecessarily develop an allergy to them (the GP may actually have spoken of resistance, not allergy). Mrs S08 told us this was the first time that she understood why her child does not always get antibiotics when he has a fever. Now that she has been given an explanation, she trusts her doctor. The new information has helped her to feel more competent in looking after her sick child.

Doctor does more than expected

Some participants related years later, with great appreciation, how a doctor had done more than they expected, and in that way showed her or his concern and interest. Mrs S15 described one such episode.

'I went to the doctor because I had some sort of flu. The doctor told me: 'This is flu. You have to drink a lot and take paracetamol'. I followed his advice, but later it became worse. I developed a terrible throat ache, I could not drink anything, I could not swallow. Then I phoned him to make an appointment, but he just came and visited me at home. He saw that I had a really bad throat infection and he gave me antibiotics. Then I got better.'

She felt she could rely on her doctor.

Negative critical episodes

Of 44 negative critical episodes, participants in 20 cases evaluated the task-orientated performance as inadequate. In 23 cases, the way the health professional communicated was the main problem. In one case, the participant mentioned both communication and task performance as inadequate. But on closer analysis, participants in most cases thought that lack of interest on the part of the professional, or the failure of the professional to take them or their complaint seriously, was at the root of what they saw as inadequate task performance.

No interest during first consultation

Mrs S09 related how she first met her new GP in her new place of settlement after leaving the reception centre. She walked into his office, carrying her medical file and her history of a murdered husband and an uprooted life. The doctor hardly looked at her or her file and just wrote out a prescription for the tablets she was using for her diabetes. After two minutes she found herself outside again. She was shocked, and thought he did not even want to know what was wrong with her.

'I did not give him the medical file, because he was not interested. My expectation was somebody who will be open to me, like doctors in Africa. Somebody who gives good explanation and good advice.'

Meeting no interest or recognition from this health professional made her feel rejected as a person and thrown back into her helplessness as a newcomer.

Negative approach during first consultation

Mrs S13 related how the first doctor she came across after settling in her own house in a major city, reacted to her at their first encounter. 'What are you?' he asked this educated and colourfully dressed woman with two children. The elder daughter, who had started learning the language, translated for the mother and translated back that they were human beings. Next the doctor asked whether they had had tuberculosis or skin diseases, ending with the question of when they were going back to Somalia. She told the doctor, in English, that this was none of his concern. Was he a doctor or an immigration official? Though the event dated back more than eight years, she related it with a vividness that illustrated the deep mark it had left in her memory: a health professional who met her with hostility and seemed to reject her as a person. After this experience, she did not dare to consult her doctor for a year and finally requested her medical insurance company to assign her to another GP.

Professional fails to pick up signal

Mrs S05 had a very bad experience with her first pregnancy. From the fifth month of pregnancy, she had the experience of losing fluid and told her obstetrician about it several times. The obstetrician told her nothing serious was wrong and did not take action. At eight months pregnant, she delivered her child prematurely with a very serious infection. The child had to remain in hospital for two years, and had a very bad start. Mrs S05 felt that the obstetrician had not taken her signal seriously because she was a foreigner and did not know her way around.

Problem does not respond to treatment, professional refuses referral

Ms S03, single and in her late 20s at the time of the interview, was in the middle of a critical episode. She had been visiting her doctor, a male doctor in a health centre in a major city, for two years with the same, but gradually worsening, complaint of backache, vaginal discharge and urinary tract infections. She liked this doctor, because he spoke Italian well, which was her second language. But she was discontented because the doctor had been giving her different courses of antibiotics without proper physical examination and without resulting improvement. So far he had refused to send her to a specialist, which she had requested several times. Being examined by a male doctor was not a problem for her. At the time of the interview, she felt desperate and very worried about her health. She felt she was not getting adequate treatment, while her condition was worsening.

Mrs S10 called her present GP an obstacle to health care for herself and her children. She had been consulting him two or three times a month for almost four years, because of her youngest daughter's skin problems. The skin problem did not respond to treatment, the mother was desperate and the doctor got angry when she insisted on being referred to a specialist.

These two participants felt very helpless at the time of the interview and did not know how to solve their problems. It was obvious that neither trusted her GP.

No physical examination

Mrs S16 complained to the doctor in the centre about her headaches and sleeplessness. She was prescribed paracetamol and sleeping medication. Because the doctor did not physically examine her, she did not feel reassured and continued worrying about her condition.

Later, Mrs S16 visited the GP in her first place of residence, a village in the North of the country, with complaints of headaches and back pain. She received paracetamol again, without a physical examination. Mrs S16 had concluded that Dutch doctors are strange.

'I was surprised here. The doctor and the patient, there is a table between them. The patient speaks, the doctor listens, yes, yes. Maybe the patient points, I have pain here and here. He sits here and the patient there and that table is between them. And when the patient has finished describing his complaints, the doctor writes a prescription at once. That surprises me. He does not go to touch the patient, where is the pain? There is no physical examination and I miss it. That was the first impression I had of Dutch doctors.'

Generalising attitude

Mr S25 related a period when he had many physical complaints (stomach-aches, bowel complaints, headaches) and visited his GP frequently. Many years later, he was still angry because of the way his doctor communicated with him then.

'He used to tell me, that is because you come from Somalia. People from Somalia have all these complaints, because of the situation there. Maybe he was right, but that was not what I needed then [...] That generalising attitude is what still makes me angry.'

Mr.S25 wanted to be approached as an individual person, not to be defined as a member of a group.

Explanations for negative experiences

Of the thirteen participants offering explanations for their own negative experiences or those of others, six thought that discrimination against them as a group (Somalis, refugees, foreigners, dark people) was the main reason. Mrs S13 was clear in her statement. She thinks that Dutch doctors are among the best doctors in the world, but they are not interested in her or other Somali people.

'The way in which Dutch doctors receive you, at the moment you enter, you are dead. You don't have feelings any more [...] Whether I die today or tomorrow, or I get better, is the same to him. That is the feeling I have [...] Sometimes I wonder why he is a doctor. Maybe he is engaged in other things. I don't

think he is a bad person, but he is not interested in me or my complaints. I don't want to complain, but my right is that my doctor listens to me and gives attention to my problems [...] If he really listens to us and gives us attention, then he knows what is wrong with us and he does not need to refer us to the specialist or to prescribe medication. But only if he listens really well. If we know and feel that he gives us attention, then we trust what he tells us.'

Mrs S13 made a direct link between attention and trust. None of her experiences had given her reason to start trusting her GP.

Two participants thought it was mainly for financial reasons or medical insurance regulations. Maybe the medical insurance did not allow doctors to give good care to refugees. Three mentioned both grounds. Differences in culture and language and lack of information on physical health matters on the part of Somali patients were also mentioned as causes of problems.

Finding a way out

Our participants used various strategies in situations where they felt that they were not receiving the health care they needed.

Direct confrontation

Four participants mentioned confronting a professional directly when they felt they were not properly treated. Two participants said they had avoided going to see the doctor for quite a long time after a confrontation.

Taking a personal advocate

Two participants mentioned asking a compatriot, and preferably one with higher professional training in the field of health care, to accompany her or him to the next encounter with the care provider.

Change to another healthcare professional

Two participants had changed to another doctor. Two other participants said they did not dare to do so, for fear of negative consequences.

Consulting a health care professional in another European country

Finding an escape route and travelling to a neighbouring country for medical care seems to be the strategy used most often. Many Somalis have relatives in other European countries, so it is not very difficult for them to arrange an appointment with a doctor in Germany or Luxembourg. Germany appears to be the most popular destination for consultation outside the Netherlands. Our participants were unanimous in their praise for German doctors; their attentive and respectful attitude and their perseverance in finding the cause of a problem were highly appreciated. According to Mrs S13,

'German doctors, they hook and crook – they don't let you go until they have found what is wrong with you'.

Six participants mentioned consulting doctors in another European country for their own health problem or that of a close family member. Many more quoted other Somalis who had done so.

DISCUSSION

The frame of reference to which our participants refer constantly when interpreting their experience with general practitioners is their current situation in The Netherlands as refugees from Somalia. They are reflecting on a period of six to fifteen years, comparing their present situation with their pre-flight situation, where they were autonomous citizens in their own country, able to make their own choices. There is a 'general narrative' in the Somali community of not being taken seriously and not receiving enough attention from care providers. Stories about professional mistakes, with sometimes serious consequences, are linked to claims that doctors do not take their patients seriously, and are often placed in a context of

discrimination. Feeling discriminated against as a group (Somalis, refugees, dark people, people with little money) is part of the general narrative. The general narrative provides evidence that there is widespread lack of trust in Dutch health care among people of Somali origin in The Netherlands. The results of our research are in keeping with the findings of other authors (van den Brink, 1996; Vera, 1998; Pree, 1998) in this respect.

The content of the general narrative has some characteristics in common with the types of story circulating in migrant communities in other countries (Manderson & Allotey, 2003; Suls & Goodkin, 1994):

narratives of misdiagnosis, perceived unnecessary treatment, inappropriate tests and interventions, medical mischief, negative outcomes and poor clinical care.

None of our participants mentioned positive 'medical gossip'.

This raises the question of why the general narrative has an overwhelmingly negative content and what its function is in the Somali community. Suls and Goodkin (1994) see 'medical gossip' as an 'attempt to provide assurance or to express alarm'. In the Dutch context, a function of 'maintaining a state of vigilance', possibly also strengthening internal solidarity, seems likely, related to feelings of not being fully accepted in Dutch society. The results of this research so far create the impression that positive personal experiences – though they definitely occur – are less likely to be incorporated into the general narrative. Realising that the content of the general narrative consists to a great extent of professional mistakes that have been made, but not discussed with the people directly involved, stresses the importance of a more open attitude in dealing with mistakes (Fisseni, 2004; Reason, 2000; Wu, 2000).

It is clear from the personal narratives that individuals position themselves differently in relation to the general narrative, depending on their personal experiences.

The introduction of the concept of 'critical episodes' has allowed us to see some patterns in the way participants' relationship to the Dutch health care system had developed over time. Most participants who related a chain of positive critical episodes, and those who related a mixed chain with a negative critical episode only in the past, felt competent to find their way in Dutch health care and also trusted their GP. The GP had become a trusted ally. Trust is used here as it was defined by Misztal (1996).

To trust is to believe that results of somebody's intended action will be appropriate from our point of view.

They keep some distance from the general narrative.

Participants who related a chain of negative critical episodes, or a mixed chain with a negative critical episode in the present, did not feel competent as users of the health care system and did not trust their GP. The GP had become an obstacle to health care for them. These participants tended to identify with the general narrative.

The trend to consult a doctor in another country has been mentioned by other authors for different groups (Kangas, 2002; de Freitas, 2005). The explanation may be that, once trust in the available health care system has broken down, the route to a professional in another country via international family links is more easily accessible than finding another doctor in the place of residence.

In all critical episodes where a GP was involved, participants described attitude and interpersonal communication as the most decisive factors. A bad outcome in health terms was linked to lack of interest on the part of the professional concerned. Qualifications attributed to professionals who had generated trust were a friendly attitude, radiating interest and being prepared to give attention to the patient as a person with individual needs. A trusted professional takes enough time, examines the patient well, explains his findings and then gives advice or prescribes a treatment, and knows his limitations. This is what participants expect from doctors, based on their experiences in Africa, where personal attention is the most

valuable asset a doctor has to offer, in an environment with limited technical possibilities. Since we are relying on participants' memories and their interpretation of these memories, possibly coloured by recent experiences, we cannot know whether Somali doctors in fact were so kind and understanding. Participants have noticed at an early stage that Dutch doctors are more restrictive in prescribing medication than doctors in their own country. Not receiving medication is acceptable, if one is convinced that the doctor has given serious attention to the person and the problem and then concluded that medication is not necessary.

Nieuwhof and Mohamoud (2000) related the importance Somalis attach to the personal qualities of relationships to their nomadic background and a general mistrust of institutions. Bloemen (2000) advocated extra investment by GPs in building a trusting relationship with refugees in general, in order to reach out to people whose confidence in fellow human beings may have been damaged by experiences of loss and violence. Barrett and colleagues (1998), who interviewed Hmong (refugee) patients in the United States about their encounters with health care providers, came up with 'be kind and have a positive attitude' as their number one recommendation – somewhat to their own surprise.

The emphasis on the importance of the interpersonal qualities of relationships in a health care setting is not specific to Somalis or to refugees in general. In a large scale research study among Dutch patients, Straten and colleagues (2002) found 'trust in the patient focus of health care providers' to be the most important dimension of public trust in health care. Kinnersley and colleagues (1999) have demonstrated a significant and positive correlation between patient satisfaction and patient-centredness in a large-scale British analysis of audiotaped GP consultations for new episodes. Findings of other authors point in the same direction (Thom & Campbell, 1997; Jung *et al*, 1998; Mechanic & Meyer, 2000; Sixma *et al*, 1998; Wensing *et al*, 1998; Thom *et al*, 1998; Safran *et al*, 1998; Rees Lewis, 1994). Apparently, the attitude of the doctor is, in many cases, also decisive for Dutch or British patients.

On the other hand, not listening to patients has been found to be the main cause of fatal medical errors (Clancy, 2005). Serious attention is a prerequisite for trust, especially in the medical situation. And trust is indispensable for believing the doctor and for fruitful cooperation between doctor and patient.

TABLE

Table 1

Characteristics of Somali participants

	Legal position	Man (M)/ woman (W)	Age	Years in NL	Employment	Education	Type of community
S01	Dutch cit.	M + W	45, 32	7	None	Secondary	Large city
S02	Dutch cit.	M + W	28, 28	8	Both employed	M secondary W primary	Large city
S03	Permit	W	28	8	Employed	Primary	Large city
S04	Dutch cit.	M	67	6	None	Higher	Large city
S05	Dutch cit.	W	35	10	None	Secondary	Village
S06	Dutch cit.	M	68	7	Volunteer	Higher	Small town
S07	Dutch cit.	W	55	8	None	Higher	Large city
S08	Dutch cit.	W	28	7	None	Secondary	Large city
S09	Dutch cit.	W	51	6	Employed	Higher	Large city
S10	Dutch cit.	W	33	9	None	Higher	Large city
S11	Dutch cit.	M	24	9	None	Student	Large city
S12	Dutch cit.	W	49	10	None	Secondary	Large city
S13	Dutch cit.	W	45	9	None	Secondary	Large city
S14	Dutch cit.	W	40	9	None	Higher	Large city
S15	Dutch cit.	M + W	59, 45	M 6 W 9	None	M+W higher	Village
S16	Dutch cit.	W	45	9	Employed	Higher	Large city
S17	Dutch cit.	W	46	8	Employed	Secondary	Large city
S18	Dutch cit.	W	54	9	None	Secondary	Small town
S19	Dutch cit.	M + W	58, 52	7	None	M higher W secondary	Small town
S20	Dutch cit.	W	35	6	None	Primary	Small town
S21	M Dutch cit. W permit	M + W	44, 33	6	None	M primary W illiterate	Small town
S22	Dutch cit.	W	36	10	None	Secondary	Village
S23	Dutch cit.	W	29	12	None	Primary	Large city
S24	Dutch cit.	M + W	35	15	None	M secondary W secondary	Large city
S25	Dutch cit.	M	36	13	Employed	Higher	Large city

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