REFUGEES AND GENERAL PRACTITIONERS – PARTNERS IN CARE?

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REFUGEES AND GENERAL PRACTITIONERS

PARTNERS IN CARE?

C.Titia Feldmann

Refugees and general practitioners
Partners in care?

Vluchtelingen en huisartsen
Bondgenoten in de zorg?

Proefschrift ter verkrijging van de graad van doctor aan de Universiteit van Tilburg op gezag van de rector magnificus, prof.dr. F.A. van der Duyn Schouten, in het openbaar te verdedigen ten overstaan van een door het college van promoties aangewezen commissie in de aula van de Universiteit op woensdag 20 december 2006 om 14.15 uur

door

CARLA TITIA FELDMANN

geboren op 19 februari 1946 te Amsterdam

PROMOTORES:

Prof.dr.J.M.Bensing
Prof.dr.A.de Ruijter

OVERIGE COMMISSIELEDEN:

"May everyone who was driven from his country by poverty or necessity and came to live in this city, through God's will find so much abundance and wealth that he will forget his former country."

(Plea by Koy Konboro, ruler of Djenné, 13th century. Cited in exhibition 'Djenné', National Museum of Ethnology Leiden, July 2001.)

"Dat een ieder die door armoede en nood uit zijn land verdreven is en in deze stad is komen wonen, hier door God zoveel overvloed en rijkdom zal vinden dat hij zijn oude vaderland zal vergeten."

(Smeekbede van Koy Konboro, heerser van Djenné, 13de eeuw. Geciteerd in tentoonstelling 'Djenné', Rijksmuseum voor Volkenkunde te Leiden, juli 2001.)

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CHAPTER 1 - GENERAL INTRODUCTION

Since the late nineteen-eighties an increasing number of refugees[1] have come to the Netherlands, on a temporary basis or to stay. The majority of them arrive on their own initiative and must forward a request for asylum to the Dutch government. As long as the Dutch authorities are dealing with this request, they are 'asylum seekers' in the Netherlands and they live in accommodations provided by the Dutch government. This process can take years.

For most people arriving as refugees the Dutch healthcare system is foreign and organised very differently from the system they were used to at home. During their stay in the reception centres, run by the state-funded Central Organisation for the Reception of Asylum Seekers (COA), refugees come into contact with the 'regular' Dutch healthcare system through intermediaries of the medical team in the centre. It is only after they leave the centre and settle in their own houses, that they start dealing with Dutch providers of healthcare independently.

The 'refugee experience' can broadly be divided in three stages: stage one is tearing oneself loose from a known environment that has become threatening and hostile; stage two the journey of travelling to another destination; stage three reconstructing a new life in that new place. In between stages two and three, there may be a prolonged period of uncertainty because of asylum procedures, which means that the start of stage three is postponed. This study has focused on stage three: how do people proceed to reconstruct their lives, from a situation characterised by loss of autonomy and loss of social identity, in an environment that demands learning a great number of new skills? Technically speaking, refugee status ends at the moment a person aquires the nationality of another country. She or he becomes a citizen of the new country, with full citizen's rights. In this study the term refugee will mostly be used, for the sake of brevity and clarity, though in many cases 'former refugee' would be more correct.

Little is known about how refugees fare in their contacts with the Dutch healthcare system, once they settle in their own house. Volunteers of the Dutch Council for Refugees provide support to refugees during the first two years of their integration into the municipality where they settle, often including an introduction to a general practitioner (GP).

Dutch sources indicate refugees do not always get the help they think they need(van den Brink, 1996; Jukema and Wilts, 1996; Bartels, 2003). Most problems seem to be experienced in contact with GPs (Vera, 1998; Pree, 1998). This is not surprising, as the Dutch healthcare system is a primary-care oriented system (Starfield, 1994) - like the British and Scandinavian systems - as opposed to healthcare systems in most countries where refugees originate. Higher degrees of dissatisfaction with healthcare were found among former refugees (Bartels, 2003), than among other groups in society.

Internationally, some qualitative studies have been conducted in countries of resettlement, eliciting refugees' views on their health (Kopinak, 1999) and use of health care (Barrett et al. 1998; Searight, 2003; Lipson, 1991). The rarity of studies voicing the views of resettled

[1] A refugee, as defined in the Treaty of Geneva, 1951, adapted in the Protocol of New York, 1967, is "any perosn who owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence is unable or owing to such fear unwilling to return to it."

refugees themselves has been mentioned both in the Netherlands (Ingleby, 2003) and internationally (Ager, 2000).

Former refugees also tend to be more 'foreign' to Dutch providers of healthcare than other migrant groups. They originate from countries that most Dutch people know little about. Earlier migrants to the Netherlands – mostly from former colonies or recruited as labour migrants – predominantly settled in the large cities. Working with these migrants has been a challenge to providers of healthcare, involving a learning process that is still going on (Spruit, 1986; Uniken Venema et al. 1995; Foets et al. 2004). Because of the Dutch government policy to spread refugees equally in all municipalities, they find themselves in places where so far few migrants have settled. This means that the last fifteen years an increasing number of healthcare providers have been confronted with patients of non-Dutch origin.

GPs mention problems with refugees' inadequate knowledge of the Dutch healthcare system and the role of the GP in it, and with the complexity of demands refugees make on them (van der Aalst et al. 1996). Some studies have been conducted dealing with experiences of GPs providing care to asylum seekers still living in reception centres in the Netherlands (Hogendorp, 2002; van Oort et al. 2003). No other studies have been found dealing with experiences of GPs providing care to former refugees who had settled in Dutch municipalities and become part of the practice population in different cities, small towns and villages in the Netherlands. These indications of uneasiness and a lack of satisfaction on both sides provided the original inspiration for this study.

The aim of the study

The aim of this study is to explore the reflections, perceptions and opinions of former refugees and GPs in the Netherlands concerning their encounters. The aim is not to arrive at a 'generalised thruth' based on the evidence of numbers, but to gain an insight into how interaction processes are perceived and reflected on by both parties, and learn from the confrontation of their perspectives.

The principal question is: which factors lead to success or failure in the way a working relationship develops between a refugee patient and a GP/ care provider, viewed from the perspective of both refugees and GPs?

A number of questions have to be addressed, in order to fulfill this aim. What are refugees' expectations from GPs? How do they reflect on their encounters with GPs? What problems did they meet, and what explanations do they give for these problems? How, on the other hand, do GPs reflect on their work with refugees? What problems do they encounter and how do they deal with these problems? What are the common grounds between the refugees' perspectives and the GPs' perspectives? What are the differences? How can an insight into common grounds and differences contribute to a better cooperation between refugees and GPs?

Theoretical framework

This study will tap from different disciplines and theoretical frames of reference, exploring how they can help to understand and interpret the findings presented in a number of chapters.

Paradigms for evaluating the health and prospects of refugees in countries of resettlement have shifted from a 'trauma-oriented approach' (Mollica et al. 1987; Mollica, 2001; Kinzie and Frederickson, 1984) to a 'resilience-oriented approach' (Ahearn, 2000; Eastmond, 1998; Eastmond, 2000; Watters, 2001; Muecke, 1992; Kopinak, 1999). Instead of being defined as victims, refugees began to figure in research studies as active agents in their own lives, authors warning that "It is important to acknowledge the resilience of individuals and communities and not label people with diagnoses that may add to their stigma and powerlessness" (Burnett and Peel, 2001).

Ahearn coined the term 'Psychosocial wellness of refugees', defining it as consisting of 'the ability, independence, and freedom to act and the possession of the requisite goods and services to be psychologically content' (Ahearn, 2000). It cannot be denied though, that forced migration is a major life event, demanding adaptation to a new environment, learning of new skills and coming to terms with past experiences. Paying attention only to health complaints and past experiences of violence is too limited an approach (Hondius et al. 2000). Muecke (Muecke, 1992) demands attention for refugees' experiences with extreme change. Watters strongly advocates giving a central role to refugees themselves in articulating their needs as far as service priorities are concerned (Watters, 2001).

One central focus of this study is the 'health seeking process' (Chrisman, 1977) as it is experienced by the refugees. Chrisman demanded attention for the different ways in which different cultural groups define symptoms, take up the role of being sick, consult lay people, hold beliefs about health and illness, and function in their social networks. The nature of the 'health seeking process' necessarily changes with the process of moving to another country. Known and trusted sources of information and support are in most cases no longer available, new resources have to be found and a relationship built with them (Helman, 1996; Zola, 1973). Resettled refugees' beliefs about health and illness may change.

The other focus is the 'care delivery process' as it is experienced by GPs, in this case especially in relation to former refugees from Somalia and Afghanistan. General practice in the Netherlands 'encompasses all conditions, problems and questions concerning illness and health from all people, irrespective of age, sex, or any other characteristic of the person concerned' (Nederlands Huisartsen Genootschap (NHG) *[Dutch Society of General Practitioners]* , 2004). General practice is supposed to deal with people in their context, but western medicine is still strongly based on 'mind-body dualism' (Mayou and Sharpe, 1997), despite Engel's plea already in 1977 (Engel, 1977) for a biopsychosocial model, including social, psychological and behavioural dimensions.

Kleinman (Kleinman, 1980) has described the consultation between a doctor and their patient as an interaction between 'Explanatory Models'. This interaction presents many opportunities to misunderstand each other, even if patient and doctor speak the same language. Explanatory models concern ideas about the cause, reason for onset at a certain moment, expected course and required treatment of a certain complaint (Kleinman, 1982), but also general perceptions about health and illness. Kleinman (Kleinman, 1980) argued that the degree of cognitive disparity between a care provider and a patient is directly related to healthcare outcomes. Research by other scholars (Leventhal and Cameron, 1987; van Wieringen et al. 2002; May et al. 2004) has underlined this argument.

Explanatory models and frames of reference are not static entities. They are the provisional results of a continuous process of interaction between different agents, in this case resettled refugees and their new environment (van Dijk and van Dongen, 2000; Eastmond, 2000; Berry, 1992). "The migrant culture is a pluri-form culture, an in-between culture, between the country of origin and the host country" (van Dijk and van Dongen, 2000). The same

applies to former refugees, after they have lived in their new country for some time (Eastmond, 2000).

Communication has been recognised as a key process in delivering and receiving care. Research on communication in healthcare has produced valuable insights. Helman (Helman, 1984) distinguished the communication code (the explicit medium that is used), the internal context of both parties, like explanatory models, prejudices, earlier experiences, and the external context like the physical and social setting.

Communication in healthcare, involving doctors and patients with different cultural backgrounds, has so far more often focused on 'traditional' migrant groups than refugees. Van Dijk made the statement that 'culture was often used as an excuse' for the failure of providers to provide adequate care (van Dijk, 1998). It was found that mutual understanding was less often reached between doctors and non-Dutch parents than between doctors and Dutch parents (van Wieringen et al. 2002; Harmsen, 2003). Consultations between Dutch GPs and patients of non-Dutch origin were found generally to be of shorter duration than consultations with patients of Dutch origin (van den Brink-Muinen et al. 2004).

Some areas can be expected to yield a particularly interesting focus for the aim of this study, to confront the views of refugee patients and GPs with each other. These are the areas of 'somatisation' or physical complaints without an apparent diagnosis, and gender, especially in opposite gender situations between Islamic refugee women and male doctors.

Earlier research has shown that 'somatisation' or the presentation of physical complaints without an apparent medical explanation (medically unexplained physical symptoms or MUPS) may be an important part of the illness presentation by refugee patients, especially in primary healthcare (Lin et al. 1985; Lipson and Omidian, 1992; Hondius et al. 2000; Harris and Maxwell, 2000).

Methodology

The aim of the study - with its focus on the processes of health seeking and providing care – required collection of reflections, perceptions and opinions, both from refugees and GPs. Since we were also interested in the time dimension in these processes, we chose a qualitative design, based on in-depth interviews, for eliciting the views of both refugees and GPs.

Refugees in the Netherlands are not a homogeneous community. They originate from many different countries, and live in municipalities spread over the country, as intended by government policy. The study had to focus on a limited number of groups, in order to obtain results that could possibly be linked to cultural or political backgrounds.

Through VON (Vluchtelingen Organisaties Nederland, *Refugee Organisations in the Netherlands*) cooperation was obtained from the Afghan and Somali community organisations. Both are among the four largest refugee communities in the Netherlands (Klaver et al. 2005) and have a substantial presence. By the end of 1997, there were about 24,000 refugees from Somalia and about 17,000 refugees from Afghanistan living in the Netherlands. By Juanuary 2006 the number of Somali's had decreased to around 19,800; the number of Afghans in the Netherlands had increased to around 30,000 (Centraal Bureau voor de Statistiek, Voorburg/ Heerlen, June 2006). Although the two groups have the Islamic religion in common, their cultural backgrounds and political experiences are quite different (see Appendix I).

The intention was to reach participants of varying ages (but not younger than eighteen), and educational levels, living in their own houses in a variety of geographical locations, after a total stay in the Netherlands of at least three years.

Some remarks have to be made on the issue of language. I made a choice in the beginning that I did not want to exclude people from participating in the study based on their proficiency in a foreign language. I was equally interested in the opinions and experiences of people with limited language skills. They might well be the elderly or otherwise more vulnerable people, definitely not less in need of healthcare. People who were approached as participants were given a choice of whether to do the interview in Dutch or in their own language.

Two teams were formed, one Afghan and one Somali, the first researcher being part of both teams. The Afghan team included three Afghan women, who in turn acted as cultural intermediaries, interpreted during interviews and explained issues where necessary. The Somali team included two Somali women, fulfilling the same functions in the interviews with Somali participants who chose to give the interview in their own language. The assistant researchers were selected for their good language and communication skills, knowledge of the specific terminology and commitment to the aim and methodology of the research. Participants in ten Afghan interviews and three Somali interviews spoke with the first researcher alone in Dutch, because they felt their Dutch was good or sufficient.

Possible participants were approached through the community organisations, through personal networks of the assistant researchers and through people working for the Dutch Council for Refugees. Later some participants volunteered after hearing about the research from other participants. Where possible, selective sampling was used – in order to achieve the desired variety in age, educational level and geographical locations of participants.

Twenty-four interviews were held involving thirty-six Afghan participants: twelve couples of husband and wife, nine women alone and three men alone. Twenty-three participants had acquired the Dutch nationality, thirteen had a refugee or humanitarian permit. Seven Afghan participants lived in a major city, eighteen in smaller towns and eleven in villages. The twenty-five Somali interviews involved thirty participants: sixteen women alone, five couples and four men alone. Twenty-eight Somali participants had aquired Dutch nationality, two had a refugee or humanitarian residence permit. Nineteen Somali participants lived in a major city, seven in smaller towns and four in villages.

The interview always started with an introduction by the researcher, guaranteeing anonymity and carefully checking for informed consent to the taperecording of the interview. A topic list was used in a flexible way, starting from the participants' experiences with healthcare in their country of origin, their health during the last period in their own country and during their escape, their arrival in the Netherlands and subsequent experiences with healthcare. Participants were also asked to reflect on their present situation in the Netherlands and on what health means to them. At the end of the interview, participants were asked for their recommendations concerning the subject of the study.

Since it is not known which GPs provide care to Somali and Afghan refugee patients, a random sample of 325 GPs from the national database of Dutch GPs were approached with information about the study and an invitation for an interview. Fifty GPs responded to this invitation; twenty-three with a refusal, twenty-two because they did not have patients of Afghan or Somali origin in their practice, and one with no explanation. Of the twenty-seven GPs who agreed to the interview, six withdrew at a later stage because of time constraints.

Three more GPs were approached via personal contacts and agreed to give an interview. Among the participating GPs, the fifty-plus age group and GPs practising in urban health centres or group practices were over-represented – though these factors were considered when taking the original sample.
The GPs were offered a choice between an interview on location in their own practice, and an interview by telephone. A senior medical student, coached by the researcher, conducted twenty-two of the GP interviews, twelve by telephone and ten on location. The first researcher conducted three interviews on location, one of which was a follow-up interview to clarify some issues.

A topic list for the GP interviews was designed with advice from an advisory board consisting of Afghan, Somali and Dutch experts, making use of the results of the refugee interviews. Topics addressed were the perceptions the GPs had of refugees in their practice and illnesses they were presenting, possible problems they were encountering in the process of assisting their refugee patients, and the way they were dealing with these problems. The GPs were also asked to compare their experiences working with refugee patients and with other patients of non-Dutch origin.

A verbatim transcript was made of all interviews. One of the assistant researchers checked the translation of each refugee interview that was not held in Dutch. On close reading of the text, the researcher assigned codes to text fragments, using the WinMAX 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. A methodologist specialising in qualitative research read the GP interviews and six of the refugee interviews, and helped to validate the codes assigned. The coding process and subsequent inductive analysis, starting with some extreme cases, were the subject of intensive discussions between the researcher, her supervisors and co-authors. At a later stage, peer examination by an external researcher helped to sharpen and focus the interpretive process.

Structure of the thesis and research questions

Chapter 2 deals with the Somali interviews, introducing a conceptual framework for analysis and interpretation of the narratives. The interview material contains both personal experiences of health care, and stories participants heard from important others, like family members or friends. Since both appeared to be important in the formation process of participants' opinions and reflections, both are included in the analysis. The principal question addressed is: which frames of reference play a role in the way an individual refugee's relationship to the Dutch healthcare system, and in particular the GP, develops over the course of time?

Chapter 3 presents an analysis of the Afghan interviews, relating the conceptual framework to personal characteristics and assets (age, education, languages spoken) and social resources (other people providing information and/or support) of the participants. The following questions are dealt with:

- 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 in the process?
- What personal and social resources were useful to them?
- How can we explain differences among participants' experience of healthcare and their interpretations of this experience?

In Chapter 4, results are presented of interviews with GPs in different cities, small towns and villages in the Netherlands, about their experiences assisting refugee patients originating from Afghanistan and Somalia. Leading questions in this chapter are:

- What perceptions do the GPs have of the Afghan and Somali refugees and the problems they present?
- How do the GPs address the problems of the refugees and what difficulties do they encounter in this process?

In chapter 5, results of refugee interviews and GP interviews are confronted with each other, focusing on an issue that figured prominently in both refugee and GP interviews: physical complaints without an apparent medical explanation.
Questions addressed in this chapter are:

- What are the refugees' perspectives on health, illness and mental worries?
- What are their expectations from doctors?
- What are their problems dealing with Dutch doctors?
- What are the GPs' perspectives on medically unexplained physical symptoms presented by their refugee patients?
- What strategies do the GPs use to address these complaints?
- What can we learn by comparing the refugees' and GPs' perspectives with each other?

Chapter 6 deals with another issue that came out as a point of concern in both refugee interviews and GP interviews: gender in the consulting room. The points of view of female refugee participants are compared with views of mostly male doctors.
The following questions are dealt with:

- What is the variety of opinions among the refugee women on the issue of preference for a GP's gender?
- What are the experiences of the women when they express their preference?
- How do GPs deal with same-gender preference in an opposite-gender situation?

Chapter 7 offers a summary, and reflections on the methodology, theoretical framework and results of the study. The chapter ends with general conclusions and recommendations for practice, policy and future research.

Reference List

Ager, A. (2000) Psychosocial programs. Principles and practice for research and evaluation. In: Ahearn, F.L., (Ed.) *Psychosocial wellness of refugees. Issues in qualitative and quantitative research*, pp. 24-38. New York / Oxford: Berghahn Books]

Ahearn, F.L.Jr. (2000) Psychosocial wellness. Methodological approaches to the study of refugees. In: Ahearn, F.L.Jr., (Ed.) *Psychosocial wellness of refugees. Issues in qualitative and quantitative research*, pp. 3-23. New York / Oxford: Berghahn Books]

Barrett, B., Shadick, K., Schilling, R., Spencer, L., Rosario, S., Moua, K. and Vang, M. (1998) Hmong/Medicine interactions: Improving cross cultural health care. *Family Medicine* **30**, 179-184.

Bartels, K. (2003) Gezondheid van (voormalig) vluchtelingen in Almere [Health of former refugees in Almere]. ZON-MW, The Netherlands, (Ed.) ZON-MW.

Berry, J.W. (1992) Acculturation and adaptation in a new society. *International Migration Quarterly Review* **30**, 69-89.

Burnett, A. and Peel, M. (2001) Asylum seekers and refugees in Britain. The health of survivors of torture and organised violence. *British Medical Journal* **322**, 606-609.

Chrisman, N.J. (1977) The health seeking process: an approach to the natural history of illness. *Culture, Medicine and Psychiatry* **1**, 351-377.

Eastmond, M. (1998) National discourses and the construction of difference: Bosnian Muslims in Sweden. *Journal of Refugee Studies* **11**, 161-181.

Eastmond, M. (2000) Refugees and health: ethnographic approaches. In: Ahearn, F.L.Jr., (Ed.) *Psychosocial wellness of refugees: issues in qualitative and quantitative research*, 1 edn. pp. 67-87. New York / Oxford: Berghahn Books]

Engel, G.L. (1977) The need for a new medical model: a challenge for biomedicine. *Science* **196**, 129-136.

Foets, M., van Vree, F.M. and van der Kemp, A. (2004) Interventions to promote intercultural adaptation of Dutch health care. *Ethnicity and Health* **9**, S27-28.

Harmsen, J.A.M. (2003) When cultures meet in medical practice. Improvement in intercultural communication evaluated. [Dissertation]. Erasmus University Rotterdam.

Harris, K. and Maxwell, C. (2000) A needs assessment in a refugee mental health project in North-East London: extending the counselling model to community support. *Medicine, conflict and survival* **16**, 201-215.

Helman, C.G. (1984) The role of context in primary care. *Journal of the Royal College of General Practitioners* **34**, 547-550.

Helman, C.G. (1996) Culture, health and illness. An introduction for health professionals. 3rd edition edn, Butterworth-Heinemann.

Hogendorp, J. (2002) Huisartsen zonder grenzen [General practitioners without borders]. Groningen, The Netherlands: Medische Opvang Asielzoekers Noord Nederland.

Hondius, A., van Willigen, L.H.M., Kleijn, W.C. and van der Ploeg, H.M. (2000) Health problems among Latin American an Middle-Eastern refugees in The Netherlands: relations with violence exposure and ongoing sociopsychological strain. *Journal of Traumatic Stress* **13**, 619-634.

Ingleby, D. (2003) Kennisontwikkeling [*Development of knowledge]*. In: Grotenhuis, R., (Ed.) *Van pionieren tot verankeren. Tien jaar gezondheidszorg voor vluchtelingen. [From the pioneer phase to the anchoring phase. Ten years healthcare for refugees]*, pp. 48-75. Utrecht: Stichting Pharos]

Jukema, J.S. and Wilts, N.P. (1996) Gezondheidszorg door de ogen van vluchtelingen [Healthcare through the eyes of refugees]. Zwolle, The Netherlands: Patiënten/consumenten Platform Zwolle.

Kinzie, J.D. and Frederickson, R.H. (1984) Post traumatic stress disorder among survivors of Cambodian concentration camps. *American Journal of Psychiatry* **141**, 649-650.

Klaver, J., Mateman, S. and Tromp, E. (2005) Vluchtelingenwerk Integratiebarometer. Een onderzoek naar de integratie van vluchtelingen in Nederland. Amsterdam: Regioplan,

nr.1295.

Kleinman, A. (1980) Patients and healers in the context of culture. Berkeley: University of California Press.

Kleinman, A. (1982) Psychiatric consultation-liaison service. In: Chrisman, m.N.J. and Marettzki, T.W., (Eds.) *Clinically applied anthropology; anthropologists in health science settings*, pp. 83-115. Dordrecht: Reidel Publishing Company]

Kopinak, J.K. (1999) The health of Bosnian refugees in Canada. *Ethnicity and Health* **4**, 65-82.

Kuckartz, U. (1998) WinMAX 97. Scientific text analysis for the social sciences. Berlin, Germany: BSS (Büro für Softwareentwicklung und Sozialforschung).

Leventhal, H. and Cameron, L. (1987) Behavioral theories and the problem of compliance. *Patient Education and Counseling* **10**, 117-138.

Lin, E.H.B., Carter, W.B. and Kleinman, A.M. (1985) An exploration of somatization among Asian refugees and immigrants in primary care. *American Journal of Public Health* **75**, 1080-1084.

Lipson, J. (1991) Afghan refugee health: some findings and suggestions. *Qualitative Health Research* **1**, 349-369.

Lipson, J.G. and Omidian, P.A. (1992) Health issues of Afghan refugees in California. *The Western Journal of Medicine* **157**, 271-275.

May, C., Allison, G., Chapple, A., Chew-Graham, C., Dixon, C., Gask, L., Graham, R., Rogers, A. and Roland, M. (2004) Framing the doctor-patient relationship in chronic illness: a comparative study of general practitioners' accounts. *Sociology of Health and Illness* **26**, 135-158.

Mayou, R. and Sharpe, M. (1997) Treating medically unexplained physical symptoms; Effective interventions are available. *British Medical Journal* **315**, 561-562.

Mollica, R.F., Wyshak, G. and Lavelle, J. (1987) The psycho-social impact of war trauma and torture on South east Asian refugees. *American Journal of Psychiatry* **144**, 1567-1572.

Mollica, R.F. (2001) Assessment of trauma in primary care. *JAMA* **285**, 1213

Muecke, M.A. (1992) New paradigms for refugee health problems. *Social Science and Medicine* **35**, 515-523.

Nederlands Huisartsen Genootschap (NHG) *[Dutch Society of General Practitioners]* (2004) Concretisering. Huisartsenzorg en huisartsenvoorziening. Concretisering toekomstvisie Huisartsenzorg 2012. Utrecht, the Netherlands:

Pree, P. (1998) Over de kloof [Across the gap]. Amsterdam: VluchtelingenWerk Nederland.

Searight, H.R. (2003) Bosnian immigrants' perceptions of the United States health care system: A qualitatve interview study. *Journal of Immigrant Health* **5**, 87-93.

Spruit, I. (1986) Health care for laborer immigrants: perceptions of problems. In: M.Colledge, H.v.G.P.G.S., (Ed.) *Migration and Health*, Copenhagen: WHO]

Starfield, B. (1994) Is primary care essential? *The Lancet* 1129-1133.

Uniken Venema, H.P., Garretsen, H.F.L. and Maas, P.J.v.d. (1995) Health of migrants and migrant health policy, The Netherlands as an example. *Social Science & Medicine* **41**, 809-818.

van den Brink, G. (1996) "Je moet niet stoormaken jouw dokter". Somalische vluchtelingen in de Nederlandse gezondheidszorg ['You should not disturb your doctor'. Somali refugees in Dutch health care] *Thesis*. University of Amsterdam, The Netherlands.

van den Brink-Muinen, A., van Dulmen, A.M., Schellevis, F.G. and Bensing, J.M. (2004) Tweede Nationale Studie naar ziekten en verrichtingen in de huisartspraktijk. Oog voor communicatie: huisarts-patient communicatie in Nederland. [The Second Dutch National Survey of General Practice. An eye for communication: GP-patient communication in The Netherlands.]. Utrecht, The Netherlands: NIVEL.

van der Aalst, A., Amptmeijer, W. and Groenendijk, F. (1996) Huisarts en de zorg voor vluchtelingen; een onderzoek in de regio Zuid-Oost Utrecht [The general practitioner and the care for refugees; a study in the south-east Utrrecht region]. Utrecht, The Netherlands: GGD Zuid-Oost Utrecht.

van Dijk, R. (1998) Culture as excuse: the failure of health care to migrants in the Netherlands. In: S.van der Geest, A.R., (Ed.) *The art of medical anthropology*, pp. 243-251.

van Dijk, R. and van Dongen, E. (2000) Migrants and health care in The Netherlands. In: P.Vulpiani, J.M.C.E.v.D., (Ed.) *Health for all, all in health. European experiences on health care for migrants*, pp. 47-68. Perugia: Cidis/ Alisei]

van Oort, M., Deville, W. and de Bakker, D. (2003) Monitoring huisartsenzorg aan asielzoekers. Utrecht: NIVEL.

van Wieringen, J.C.M., Harmsen, J.A.M. and Bruijnzeels, M. (2002) Intercultural communication in general practice. *European Journal of Public Health* **12**, 63-68.

Vera, P. (1998) Dan is je spiegel gebroken. [Then your mirror is broken]. Tilburg, The Netherlands: BOZ.

Watters, C. (2001) Emerging paradigms in the mental health care of refugees. *Social Science and Medicine* **52**, 1709-1718.

Zola, I.K. (1973) Pathways to the doctor - From person to patient. *Social Science and Medicine* **7**, 677-689.

CHAPTER 2

SOMALI REFUGEES' EXPERIENCES WITH THEIR GENERAL PRACTITIONERS: FRAMES OF REFERENCE AND CRITICAL EPISODES

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SOMALI REFUGEES' EXPERIENCES WITH THEIR GENERAL PRACTITIONERS: FRAMES OF REFERENCE AND CRITICAL EPISODES

Abstract

The results are presented 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 actual situation in The Netherlands appears to be a more significant frame of reference than healthcare as it was known in Somalia. There is a general narrative in the Somali communities that healthcare in The Netherlands is not good for Somali's and feelings of being discriminated against appear to be common. Stories about medical calamities circulating within the communities illustrate and enhance this perception. Consulting practitioners in neighbouring countries is a frequently taken escape route.

The individual narratives show a more varied picture. Critical episodes can be identified, where encounters with GPs have had either a positive or 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 issues, building or undermining trust. Depending on their personal experiences, participants identify with the general narrative, or keep some distance from it.

Keywords: (Somali) refugees, general practitioners, critical episodes, trust, feelings of discrimination, general narrative.

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 stories, then you don't trust Dutch healthcare 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 healthcare. "Us" is our small research team, consisting of a middle-aged female Dutch doctor, the researcher, and a female Somali assistant researcher, also 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 over 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 to spread new migrants and prevent larger concentrations in the major cities.

Different Dutch sources indicate that refugees do not always get the help they think they need. The role of the GP in particular – who takes a central position in Dutch healthcare – is often not appreciated (van den Brink, 1996; Vera, 1998; Pree, 1998) . Some regard the GP more as a stumbling stone on their way to "real" medical care. Problems mentioned are a feeling of not being respected or taken seriously by GPs, and of physical complaints too often being 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 and Allotey, 2003) . In several countries, migrant populations have been found to be less healthy than the rest of the

population (Sundquist, 1993; Sundquist, 1995; Iglesias et al. 2003; Bollini and Siem, 1995; van Dijk and van Dongen, 2000).(Iglesias et al. 2003; Kopinak, 1999; Bollini and Siem, 1995; van Dijk and van Dongen, 2000) A range of relevant issues has emerged, including ethnic stereotyping (Kleinman, 1977), cultural stereotyping (van Dijk, 1998), ethnic differences (Sundquist, 1993; Sundquist, 1995; Iglesias et al. 2003) economic differences (Sundquist, 1995), the "health seeking process" (Chrisman, 1977) and "medical gossip"(Suls and Goodkin, 1994) .

The voices of migrants themselves are less often heard in the international literature. In this article, we present an analysis of interviews with Somali participants, focusing on their experiences with healthcare in the reception centres where they stayed as asylum seekers, and with the GPs they met after they 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 way an individual refugees' relationship to the Dutch healthcare system, and in particular the GP, develops in the course of time? A train of thought will be presented in which the satisfaction or dissatisfaction with the available care is seen as resulting 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

Cooperation was provided by Somali 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 Somali language. A list of topics was compiled with advice from different 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, i.e. 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. 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, some participants volunteered for an interview after hearing about the study from other participants. 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, with different levels of education, different ages and varied family structures. Our aim was, in the first place, to elucidate the dynamics of a process.

Group of participants

Table I gives an overview of characteristics of the 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 have lived in the Netherlands for between six and fifteen years. Their ages ranged from 24 to 68. All were Muslims.

The educational level of the participants varied: 11 participants had completed academic or vocational education; 13 had completed secondary education, five only had

primary education and one woman was illiterate. Twenty participants were unemployed, seven were employed, one young man was a fulltime student, two participants were over 60 years of age.

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

(*Insert table 1 around here)*

Data generation

A qualitative research method with in-depth, semi-structured interviews was used (Glaser and 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 in their experience.

All interviews were recorded on tape, with the consent of the participants, mostly in their homes, in two cases 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. Twenty-two interviews took place in the Somali language, with one of the assistant researchers interpreting. 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. 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 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 spent 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 healthcare?

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 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 form 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: "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 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 analytical process, we assigned the label "critical episode" (CE) to this type of opinion-shaping experience with a healthcare professional.

The critical episode label refers to a series of events during a period of time, which the interviewees mentioned 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 different interviews and each episode was scored on whether the participant related it to the attitude or to the professional behaviour of the healthcare 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.

Results

Healthcare in Somalia before 1991

Up to the present day, traditional and modern medicine exist side by side in Somalia, both in the cities and in rural areas. All our participants were primarily oriented towards modern – western – medicine in their home country. Most participants 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 healthcare, especially in their younger years. One man, who 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 the consultation of 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 not an impediment: 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 to choose 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 about diagnosis and treatment. Doctors in Somalia not only prescribed 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 stated it is not good to always be given strong medication: the drug may not be effective in the case of serious disease.

Arriving in the new country

The first encounters our participants had with the Dutch healthcare 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 healthcare 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 healthcare are free for asylum seekers who generally don't have resources. With a few exceptions, the full package of healthcare is available. Screening for lung tuberculosis is compulsory within two weeks of arrival. In order to facilitate the access of asylum seekers to the regular healthcare system, medical teams are stationed in the reception centres. These teams provide the arriving refugees with information on health and healthcare 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 healthcare providers, especially GPs. Inhabitants report to the nurse of the reception centre with questions or problems concerning their health. The nurse refers to the GP for further diagnosis and treatment. None of our participants stayed in a reception centre for more than 18 months.

Arrival in the new country meant safety and security on the one hand, but also disorientation and loss of known identity. What stands out in many stories is a high degree of experienced vulnerability and helplessness in this initial stage. Women who 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 states 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 more newcomers. They have lived in The Netherlands for six up to fifteen years.

A striking element in 24 out 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 healthcare. Stories about experiences with healthcare 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 mention specific calamities, concerning people whom they personally know: a Somali person in a coma and later severely disabled after anaesthesia for a minor operation; a small child that 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 one 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: *"When you hear this type of stories and you don't get attention yourself, how can you have trust?"*

Because of its "omnipresence" in virtually all interviews, we labelled this phenomenon the "general narrative". Participants made a strong link between this "general narrative" and a lack of trust in Dutch healthcare 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

Though almost all participants mention the problems many of their compatriots have with Dutch healthcare and GPs in particular, individual participants take different positions when they refer to the general narrative. Participants in 18 interviews take a distance from it, referring to problems other people have, participants in six interviews identify with the general narrative. Mrs S13: "*Dutch doctors are among the best doctors in the world, but they are not interested in us."* In one interview the participant did not mention other people's experiences with healthcare. The question arises 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 healthcare, 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. Mostly these were episodes where the participants felt particularly vulnerable or their existence felt threatened due to a health problem (either their own or that of a close relative). Examples of critical episodes related by participants are: experiencing disturbing physical symptoms or 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 functioning. The first encounter with a new health professional was mentioned by many participants as a critical episode.

The episode comprises the problem itself, what the participant thought about the problem at that time, the encounter with healthcare 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 may 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 healthcare provider acted in their opinion. Attitude and communication aspects, as experienced by the participant, were differentiated from task-oriented 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 differs; between one and four. Some critical episodes had not ended at the moment 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 healthcare.

Competence to use the Dutch healthcare system and trust in the general practitioner emerged as central issues in the evaluation participants gave of episodes in their narrative. As a result of a critical episode, a participant felt either more competent or more helpless to use the new healthcare 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-oriented performance in 21 cases and confidence-inspiring communication in 14 cases. In three CEs, both task-oriented 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 discourse 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 healthcare was restored, after an earlier experience with a new GP who 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-oriented performance

Mr S21 described how in the village where he lived before with his wife and children, he 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 has diabetes, phoned the hospital and made sure he was admitted for initial treatment.
The way 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."
The carefully formulated words of a soft-spoken Somali woman, mrs. S08, sitting in her apartment in a major city in the Netherlands. The curtains of her flat are drawn, leaving only shaded light to pass through. She is wearing a colourful traditional dress with green headtie. 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, medication for her depression, addressing 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 was referring to information she 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 that now. That it is better to preserve the antibiotics for those occasions when the child really needs it, otherwise the child can unnecessarily become allergic to it.
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 looking after her sick child.

- Doctor does more than expected

Some participants related years later with great appreciation how a doctor did more than they expected, and in that way showed 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 real 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-oriented performance as inadequate. In 23 cases, the way the healthcare 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 a lack of interest on the part of the professional, or the professional not taking 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 a good advice."* Meeting no interest or recognition from this healthcare 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 eldest 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, rounding up with the question, when were they 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 left in her memory: a healthcare 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 pregnancy, she delivered her child prematurely with a very serious infection. The child had to remain hospitalised for two years and had a very bad start. Mrs S05 felt the obstetrician did not take 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 twenties at the time of the interview, is 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 hespoke the Italian language 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 in improvement. So far he had refused to send her to a specialist, which she has been asking for several times over. 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 in the healthcare 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 neither trusted their 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 in 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 in between them. And when the patient is ready telling his complaints, the doctor writes a prescription at once. That surprises me. He does not go to touch the patient, where is the pain? I miss that no physical examination is done. That was the first impression I had about Dutch doctors."

- Generalising attitude

Mr.S25 related a period when he had many physical complaints, stomachaches, bowel complaints, headaches and visited his GP very regularly. 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 13 participants offering explanations for their own negative experiences or those of others, six felt discrimination against them as a group (Somalis, refugees, foreigners, dark people) was the main reason. Mrs S13 was clear in her statement. She thought 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 makes a direct link between attention and trust. None of her experiences had given her reason to start trusting her GP.

Two participants thought it is mainly because of 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 a 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 different strategies in situations where they felt they were not receiving the health care they needed.

- Direct confrontation

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

- Taking a personal advocate

Asking a compatriot, and preferably one with a higher professional training in the field of healthcare, to accompany her or him to the next encounter with the care provider, was mentioned by two participants.

- Change to another healthcare professional

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

- Consulting a healthcare professional in another European country

Finding an escape route and travelling to a neighbouring country for medical care seems to be the most often used strategy. Many Somalis have relatives in other European countries, so it is not very difficult for them to arrange an encounter 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 perseverence in finding the cause of a problem were highly appreciated. Mrs S13: "*German doctors, they hook and crook – they don't let you go until they have found what is wrong with you",* according to one of our participants. Six participants mentioned consulting doctors in another European country for a health problem of themselves or a close family member. Many more quote other Somalis who have done so.

Discussion

The frame of reference our participants are constantly referring to when interpreting their experience with general practitioners, is their actual situation in The Netherlands as refugees from Somalia. They are reflecting on a period of six to fifteen years, comparing their present situation to 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 doctors not taking their patients seriously and are often placed in a context of discrimination. Feeling discriminated 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 a widespread lack of trust in Dutch healthcare 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 type of stories circulating in migrant communities in other countries (Manderson and Allotey, 2003); (Suls and 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 why the general narrative has an overwhelmingly negative content and what is its function in the Somali community. Suls and Goodkin (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 into the 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 to a great extent exists 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)

From the personal narratives it becomes clear 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 healthcare system developed in the course of time. 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, mostly felt competent to find their way in Dutch healthcare and also trust their GP. The GP had become a trusted ally. Trust is used here as it was defined by Misztal (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 healthcare system and did not trust their GP. The GP had become an obstacle for them in healthcare. 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) An explanation may be that once trust in the available healthcare system has broken down, the route to a healthcare 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, the attitude and the interpersonal communication were described as the most decisive factors by participants. A bad outcome health-wise was linked to a lack of interest on the part of the professional concerned. Qualifications attributed to professionals who have generated trustwere : a friendly attitude; radiating interest; being prepared to give attention to the patient as a person with individual needs. A professional who takes enough time, who examines his patient well, explains his findings and then gives advice or prescribes a treatment, and who 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 obtain an answer to the question 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 was acceptable, if one is convinced the doctor has given serious attention to the person and the problem and then concludes that medication is not necessary.

Nieuwhof and Mohamoud (Nieuwhof and Mohammoud, 2000) related the importance Somalis attach to the personal qualities of relationships, to their nomadic

background and a general mistrust against institutions. Bloemen (Bloemen, 2000) advocated some 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 et al, (Barrett et al. 1998) who interviewed Hmong (refugee) patients in the United States about their encounters with healthcare 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 healthcare setting is not specific for Somalis or for refugees in general. Straten, Friele & Groenewegen (Straten et al. 2002) found in a large-scale research study among Dutch patients "trust in the patient focus of healthcare providers" to be the most important dimension of public trust in healthcare. Kinnersley e.a. (Kinnersley et al. 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 and Campbell, 1997).(Jung et al. 1998; Mechanic and Meyer, 2000; Sixma et al. 1998; Wensing 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 the number one cause at the root of fatal medical errors (Clancy, 2005). Serious attention is a prerequisite for trust, especially in the medical situation. And trust is conditional for believing the doctor and for a fruitful cooperation between doctor and patient.

References

Barrett, B., Shadick, K., Schilling, R., Spencer, L., Rosario, S., Moua, K. and Vang, M. (1998) Hmong/Medicine interactions: Improving cross cultural health care. *Family Medicine* **30**, 179-184.

Bloemen, E.J.J.M. (2000) Huisarts en vluchteling [General practitioner and refugee]. In: W.J.H.M.van den Bosch/ P.E.H.Treffers, (Ed.) *Vluchtelingen [Refugees]*, Houten, The Netherlands: Bohn Stafleu Van Loghum]

Bollini, P. and Siem, H. (1995) No real progress towards equity: health of migrants and ethnic minorities on the eve of the year 2000. *Social Science and Medicine* **41**, 819-828.

Chrisman, N.J. (1977) The health seeking process: an approach to the natural history of illness. *Culture, Medicine and Psychiatry* **1**, 351-377.

Clancy, F. (2005) The blame game. *Minnesota Medicine* **88, electronic edition October 2005**,

de Freitas, C. (2005) 'Health has no borders': Cape Verdian immigrants in The Netherlands and the transnational quest for health care across Europe. *Internation Journal of Migration, Health and Social Care* **1**, 19-36.

Fisseni, G. (2004) German GPs' most serious errors: causal and protective factors. In: WONCA/ NHG, (Ed.) *Quality in Practice, WONCA Europe Regional Conference* , pp. 127 Utrecht, The Netherlands: WONCA/ NHG]

Glaser, B.G. and Strauss, A.L. (1967) The discovery of grounded theory: Strategies for qualitative research. New York: Aldin Publishing Company.

Iglesias, E., Robertson, E., Johanssen, S.E., Engfeldt, P. and Sundquist, J. (2003) Women, international migration and self-reported health. A population-based study of women of reproductive age. *Social Science and Medicine* **56**, 111-124.

Jung, H.P., van Horne, F., Wensing, M., Hearnshaw, H. and Grol, R. (1998) Which aspects of general practitioners' behaviour determine patients' evaluations of care? *Social Science and Medicine* **47**, 1077-1087.

Kangas, B. (2002) Therapeutic itinaries in a global world: Yemenis and their search for biomedical treatment abroad. *Medical Anthropology* **21**, 35-78.

Kinnersley, P., Stott, N., Peters, T.J. and Harvey, I. (1999) The patient-centredness of consultations and outcome in primary care . *British Journal of General Practice* **49**, 711-716.

Kleinman, A. (1977) Depression, somatization and the new cross-cultural psychiatry. *Social Science & Medicine* **11**, 3-10.

Kopinak, J.K. (1999) The health of Bosnian refugees in Canada. *Ethnicity and Health* **4**, 65-82.

Kuckartz, U. (1998) WinMAX 97. Scientific text analysis for the social sciences. Berlin, Germany: BSS (Büro für Softwareentwicklung und Sozialforschung).

Manderson, L. and Allotey, P. (2003) Storytelling, marginality, and community in Australia: How immigrants position their difference in health care settings. *Medical Anthropology* **22**, 1-21.

Mechanic, D. and Meyer, S. (2000) Concepts of trust among patients with serious illness. *Social Science and Medicine* **51**, 657-668.

Miles, M.B. and Huberman, A.M. (1994) Qualitative analysis. An expanded sourcebook. Thousand Oaks: Sage.

Misztal, B.A. (1996) Trust in modern societies. Cambridge, New York: Polity Press.

Nieuwhof, A. and Mohammoud, A.A. (2000) Communicatie, sleutel tot participatie. De Somalische gemeenschap in Nederland. [Communication, key to participation].

Den Haag: Ministerie van Binnenlandse Zaken en Koninkrijksrelaties.

Pree, P. (1998) Over de kloof [Across the gap]. Amsterdam: VluchtelingenWerk Nederland.

Reason, J. (2000) Human error: models and management. *British Medical Journal* **320**, 768-770.

Rees Lewis, J. (1994) Patient views on quality care in general practice: literature review. *Social Science and Medicine* **39**, 665-670.

Safran, D.G., Taira, D.A., Rogers, W.H., Kosinski, M., Ware, J.E. and Tarlov, A.R. (1998) Linking primary care performance to outcomes of care. *Journal of Family Practice* **47**, 213-220.

Searight, H.R. (2003) Bosnian immigrants' perceptions of the United States health care system: A qualitatve interview study. *Journal of Immigrant Health* **5**, 87-93.

Sixma, H.J., Spreeuwenberg, P.M.M. and van der Pasch, M.A.A. (1998) Patient satisfaction with the general practitioner. A two level analysis. *Medical Care* **36**, 212-229.

Straten, G.F.M., Friele, R.D. and Groenewegen, P.P. (2002) Public trust in Dutch health care. *Social Science & Medicine* **55**, 227-234.

Suls, J.M. and Goodkin, F. (1994) Medical gossip and rumour. Their role in the lay referral system. In: R.F.Goodman, A.B.-Z., (Ed.) *Good Gossip*, pp. 85-99. Kansas: University of Kansas Press]

Sundquist, J. (1993) Ethnicity as a risk factor for consultations in primary health care and out-patient care. *Scandinavian Journal of Primary Health Care* **11**, 169-173.

Sundquist, J. (1995) Ethnicity, social class and health. A population-based study on the influence of social factors on self-reported illness in 223 Latin America refugees, 333 Finnish and 126 South European labour migrants and 841 Swedish controls. *Social Science and Medicine* **40**, 777-787.

Thom, D.H. and Campbell, B. (1997) Patient-physician trust: an exploratory study. *The Journal of Family Practice* **44**, 169-176.

van den Brink, G. (1996) "Je moet niet stoormaken jouw dokter". Somalische vluchtelingen in de Nederlandse gezondheidszorg ['You should not disturb your doctor'. Somali refugees in Dutch health care] *Thesis*. University of Amsterdam, The Netherlands.

van Dijk, R. (1998) Culture as excuse: the failure of health care to migrants in the Netherlands. In: S.van der Geest, A.R., (Ed.) *The art of medical anthropology*, pp. 243-251.

van Dijk, R. and van Dongen, E. (2000) Migrants and health care in The Netherlands. In: P.Vulpiani, J.M.C.E.v.D., (Ed.) *Health for all, all in health. European experiences on health care for migrants*, pp. 47-68. Perugia: Cidis/ Alisei]

Vera, P. (1998) Dan is je spiegel gebroken. [Then your mirror is broken]. Tilburg, The Netherlands: BOZ.

Weiss, R.S. (1994) Learning from strangers. The art and method of qualitative interview studies. New York: Free Press.

Wensing, M., Jung, H.P., Mainz, J., Olesen, F. and Grol, R. (1998) A systematic review of the literature on patient priorities for general practice care. Part 1: description of the research domain. *Social Science and Medicine* **47**, 1573-1588.

Wu, A.W. (2000) Medical error: the second victim. *British Medical Journal* **320**, 726-727.

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.	W	35	15	None	M secondary W secondary	Large city
S25	Dutch cit.	M	36	13	Employed	Higher	Large city

CHAPTER 3

AFGHAN REFUGEES IN THE NETHERLANDS AND THEIR GENERAL PRACTITIONERS: TO TRUST OR NOT TO TRUST?

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AFGHAN REFUGEES IN THE NETHERLANDS AND THEIR GENERAL PRACTITIONERS: TO TRUST OR NOT TO TRUST?

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 article 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 experience 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 experience 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.

Keywords: (Afghan) refugees, The Netherlands, general practitioner, trust, critical episodes, personal resources, social resources, prejudice.

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 article 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 1980's, 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 1970's. They have settled in towns and villages spread 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 1970's and 1980's, 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, 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 article we shall focus on four questions:

1. What are participants' frames of reference, in respect of health care and what is their definition of health?
2. How did participants try to solve their health-related problems and what was their experience of the process?
3. What personal and social resources were useful to them?

4. How can we explain differences among participants' experience of health care and their interpretation of their experience?

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.

Two Afghan women were selected via personal contacts 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 health care 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, with 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 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 only had 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, 13 had a refugee or humanitarian residence permit. Seven participants lived in a major city, eighteen in smaller towns and eleven in villages.

(Insert Table 1 around here)

Data generation

A qualitative research method with in depth, semi-structured interviews was used (Glaser and 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 dimension and the time dimension in their experience.

All interviews were recorded on tape, with the 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 health care 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 health care. 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 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 examination 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 health care 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 health care 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. So experiences with urban health care 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. Health care 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 health care 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 helped themselves with herbs 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. Meaning of health 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 experience with health care 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 health care 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. But all participants who were interviewed after September 2001 mentioned this period as very emotionally disturbing and often enhancing complaints like headache.

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 side of a health care 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 her child with a cold; unfriendly remarks about Dutch language skills towards a recently arrived woman.

- *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, by 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, for the first time got the proper treatment for her depression, said: 'I cannot make my voice heard here', which for her was partially a question of language, but partially also a question 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 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 given, 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 a 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 gets 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 mentioned 'worrying too much' spontaneously as a cause of illness. But 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 tranquilisers 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.

(Insert table 2 around here)

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 voluntary work.

He got 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 health care 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 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 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 suddenly died 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 moved very fast 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 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 was recently operated on her gallbladder, 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 don't 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. But 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. For her social resources she generally depended on her husband.

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, that 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 health care.

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 of 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 health care 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 more 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 later she got 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, 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 don't 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 more applicable. Trusted social resources were often not available.

Social resources

From our interviews we learnt, that health and health care 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. 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 personality. In the view of the participants, the stories they hear from other Afghans about health care 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 'contact persons' of 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, change to another professional or change the interpretation of a professional's behaviour. Interesting 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 made the connection 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 treated 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 less personal resources and who also used Dutch social resources less frequently.

Discussion

The design of our study allowed us to get an 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 ‘sense making’ process, 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 subject’, both with 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 health care, (Edwards et al. 2004) not linked to a health care 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}(Vera, 1998; van den Brink, 1996; Logghe, 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 health care. 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 'wellbeing' 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 health care in Afghanistan - with a free choice which doctor to consult and a direct access to medical specialists - being the common frame of reference to 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 in 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 disposition, and the choices they make 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 health care circulating in the Afghan community.

Several authors mention negative stories about health care, 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 health care 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 of the participants with health care. These experiences cannot be completely separated from their other experiences in the Netherlands. The participants with the most negative health care experiences stressed their feelings of being discriminated against as foreigners in general. Health care 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 health care professionals. The same personal and social resources that are helpful in the health care 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 health care institutions less effectively serve certain groups in society. It can be considered common knowledge that health care professionals are human beings who may make mistakes and do not always behave friendly. The question is, whether refugees - or perhaps people with a non-Dutch background in general - run a greater risk than other users of health care, to be 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 upon 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 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 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 the history taking 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 health care.

Apparently our participants do not differ basically from other patients around the world in what they expect from doctors. But 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.

References

Barrett, B., Shadick, K., Schilling, R., Spencer, L., Rosario, S., Moua, K. and Vang, M. (1998) Hmong/Medicine interactions: Improving cross cultural health care. *Family Medicine* **30**, 179-184.

Bartels, K. (2003) Gezondheid van (voormalig) vluchtelingen in Almere [Health of former refugees in Almere]. ZON-MW, The Netherlands, (Ed.) ZON-MW.

Beiser, M. (1991) The mental health of refugees in resettlement countries. In: Adelman, H., (Ed.) *Refugee Policy: Canada and the United States*, pp. 425-443. Ontario, Canada: York University]

Beiser, M. and Hyman, I. (1997) Refugees' time perspective and mental health. *American Journal of Psychiatry* **154**, 996-1002.

Bensing, J., Schreurs, K. and de Rijk, A. (1996) The role of the general practitioner's affective behaviour in medical encounters. *Psychology and Health* **11**, 825-838.

Bracken, P.J., Giller, J.E. and Summerfield, D. (1995) Psychological responses to war and atrocity: the limitations of current concepts. *Social Science and Medicine* **40** , 1073-1082.

Dingwall, R. (2001) Contemporary legends, rumours and collective behaviour: some neglected resources for medical sociology? *Sociology of Health and Illness* **23**, 180-202.

Eastmond, M. (2000) Refugees and health: ethnographic approaches. In: Ahearn, F.L.Jr., (Ed.) *Psychosocial wellness of refugees: issues in qualitative and quantitative research*, 1 edn. pp. 67-87. New York / Oxford: Berghahn Books]

Edwards, C., Staniszweska, S. and Crichton, N. (2004) Investigation of the ways in which patients' reports of their satisfaction with healthcare are constructed. *Sociology of Health and Illness* **26**, 159-183.

Eisenbruch, M. (1991) From post-traumatic stress disorder to cultural bereavement: diagnosis of Southeast Asian refugees. *Social Science and Medicine* **33**, 673-680.

Gau, D., Pryce-Jones, M. and Tippins, D. (1989) Satisfactory Practice. *Health Services Journal* **99**, 1464-1465.

Gernaat, H.B.P.E., Malwand, A.D., Laban, C.L., Komproe, I. and de Jong, J.T.V.M. (2002) Veel psychiatrische stoornissen bij Afghaanse vluchtelingen met verblijfsstatus in Drenthe, met name depressieve stoornis en posttraumatische stressstoornis. *Nederlands Tijdschrift voor Geneeskunde* **146**, 1127-1131.

Glaser, B.G. and Strauss, A.L. (1967) The discovery of grounded theory: Strategies for qualitative research. New York: Aldin Publishing Company.

Granovetter, M.S. (1973) The strength of weak ties. *American Journal of Sociology* **78**, 1360-1379.

Harris, K. and Maxwell, C. (2000) A needs assessment in a refugee mental health project in North-East London: extending the counselling model to community support. *Medicine, conflict and survival* **16**, 201-215.

Jerusalem, M. and Mittag, W. (1995) Self-efficacy in stressful life transitions. In: Bandura, A., (Ed.) *Self-efficacy in changing societies*, pp. 177-201. New York: Cambridge University Press]

Karlsen, S. and Nazroo, J.Y. (2002) Agency and structure: the impact of ethnic identity and racism on the health of ethnic minority people. *Sociology of Health and Illness* **24**, 1-20.

Kinnersley, P., Stott, N., Peters, T.J. and Harvey, I. (1999) The patient-centredness of consultations and outcome in primary care . *British Journal of General Practice* **49**, 711-716.

Kleinman, A. (1995) Pitch, picture, power: the globalization of local suffering and the transformation of social experience. *Ethos* **60**, 181-191.

Kopinak, J.K. (1999) The health of Bosnian refugees in Canada. *Ethnicity and Health* **4**, 65-82.

Kuckartz, U. (1998) WinMAX 97. Scientific text analysis for the social sciences. Berlin, Germany: BSS (Büro für Softwareentwicklung und Sozialforschung).

Lipson, J. (1991) Afghan refugee health: some findings and suggestions. *Qualitative Health Research* **1**, 349-369.

Logghe, K.L.R. (1998) De verschillen kun je niet wegpoetsen. (You cannot eradicate the differences.). Tilburg, The Netherlands: BOZ en Palet. BOZ, Tilburg.

Manderson, L. and Allotey, P. (2003) Storytelling, marginality, and community in Australia: How immigrants position their difference in health care settings. *Medical Anthropology* **22**, 1-21.

Miles, M.B. and Huberman, A.M. (1994) Qualitative analysis. An expanded sourcebook. Thousand Oaks: Sage.

Misztal, B.A. (1996) Trust in modern societies. Cambridge, New York: Polity Press.

Muecke, M.A. (1992) New paradigms for refugee health problems. *Social Science and Medicine* **35**, 515-523.

Pearlin, L., Lieberman, M.A., Menaghan, E.G. and Mullan, O.T. (1981) The stress process. *Journal of Health and Social Behaviour* **22**, 337-356.

Rees Lewis, J. (1994) Patient views on quality care in general practice: literature review. *Social Science and Medicine* **39**, 665-670.

Safran, D.G., Taira, D.A., Rogers, W.H., Kosinski, M., Ware, J.E. and Tarlov, A.R. (1998) Linking primary care performance to outcomes of care. *Journal of Family Practice* **47**, 213-220.

Searight, H.R. (2003) Bosnian immigrants' perceptions of the United States health care system: A qualitatve interview study. *Journal of Immigrant Health* **5**, 87-93.

Sixma, H.J., Spreeuwenberg, P.M.M. and van der Pasch, M.A.A. (1998) Patient satisfaction with the general practitioner. A two level analysis. *Medical Care* **36**, 212-229.

Stewart, M.A. (1995) Effective physician-patient communication and health outcomes: a review. *Canadian Medical Association Journal* **152**, 1423-1433.

Stoffer, R. (2001) Demoralisatie en de mislukte missie. In de voetsporen van Jerome Frank. [Demoralisation and the failed mission. Following Jerome Frank's footsteps]. *Tijdschrift voor psychotherapie* **27**, 366-380.

Thom, D.H. and Campbell, B. (1997) Patient-physician trust: an exploratory study. *The Journal of Family Practice* **44**, 169-176.

Uniken Venema, H.P., Garretsen, H.F.L. and Maas, P.J.v.d. (1995) Health of migrants and migrant health policy, The Netherlands as an example. *Social Science & Medicine* **41**, 809-818.

van den Brink, G. (1996) "Je moet niet stoormaken jouw dokter". Somalische vluchtelingen in de Nederlandse gezondheidszorg ['You should not disturb your doctor'. Somali refugees in Dutch health care] *Thesis*. University of Amsterdam, The Netherlands.

van den Tillaart, H., Olde Monnikhof, M., van den Berg, S. and Warmerdam, J. (2000) Nieuwe etnische groepen in Nederland. Ubbergen, The Netherlands: Tandem Felix.

van Dijk, R., Bala, J., Öry, F. and Kramer, S. (2001) "Now we have lost everything"; asylumseekers in The Netherlands and their experiences with health care. *Medische Antropologie* **13**, 284-300.

Vera, P. (1998) Dan is je spiegel gebroken. [Then your mirror is broken]. Tilburg, The Netherlands: BOZ.

Watters, C. (2001) Emerging paradigms in the mental health care of refugees. *Social Science and Medicine* **52**, 1709-1718.

Weick, K.E. (1995) Sensemaking in organizations. California, London: Sage.

Weiss, R.S. (1994) Learning from strangers. The art and method of qualitative interview studies. New York: Free Press.

Wensing, M., Jung, H.P., Mainz, J., Olesen, F. and Grol, R. (1998) A systematic review of the literature on patient priorities for general practice care. Part 1: description of the research domain. *Social Science and Medicine* **47**, 1573-1588.

Table 1

CHARACTERISTICS OF AFGHAN PARTICIPANTS

Afghan Participants	**Legal position**	**Man (M)/ Woman (W)**	**Age**	**Years in NL**	**Employment** M = man W = woman	**Education upon arrival** (M)an/ (W)oman	**Type of community**
A 01 **pilot interview**	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 **Secondary trust** **Secondary disillusionment** **Primary disillusionment**
Primary trust

N=3 N=7 N=8 N=3

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[6] (PR): L = low, A = average, H = high
Use of social resources: old (O) or new (N).

[6] 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.

CHAPTER 4

GENERAL PRACTITIONERS AND REFUGEE PATIENTS: DEALING WITH UNEXPLAINED PHYSICAL SYMPTOMS. A QUALITATIVE STUDY

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GENERAL PRACTITIONERS AND REFUGEE PATIENTS: DEALING WITH UNEXPLAINED PHYSICAL SYMPTOMS. A QUALITATIVE STUDY

How this fits in

GPs providing help to refugees often feel pressured by language barriers and complexity of problems. In addition to language problems, dealing with unexplained physical symptoms is the main constraint mentioned by GPs in this study. Effective strategies include:

1. Investing in the relationship with refugees from the start.
2. Approaching each (refugee) patient as an individual, not as a representative of a group.
3. Following an open, biopsychosocial approach relating to medically unexplained physical symptoms.

ABSTRACT

Background
GPs providing help to refugee patients often feel pressured by language barriers and complexity of problems.
Objective
To explore GPs' experiences in working with Afghan and Somali refugee patients.
Design of study
From a random sample of 325 GPs practicing in different regions in the Netherlands, 21 volunteered for an interview. Three more GPs were interviewed via personal contacts.
Setting
The Netherlands.
Method
Qualitative analysis of transcripts of semi-structured interviews.
Results
Most urban practices have adapted their organisation to deal with increasing numbers of foreign-born patients over the years. Refugee patients profit less from these changes than the larger groups of earlier migrants. GPs see a clear distinction between their refugee patients and other patients of non-Dutch origin - mostly migrant workers - specifying the losses and violence refugees have experienced, their higher educational levels and associated better language skills.
With the exception of language problems, dealing with medically unexplained physical symptoms is the most important constraint for the GPs. They have developed different strategies for dealing with the refugees' supposed 'stress-related complaints', ranging from a predominantly somatic approach to a consequent biopsychosocial approach.
Conclusions
The doctors who have most experience working with refugee patients, stress the importance of investing in the relationship with refugee patients right from the beginning and approaching each (refugee) patient as an individual, not as a representative of a group. An open, biopsychosocial approach seems to work well for these doctors in dealing with medically unexplained physical symptoms presented by refugee patients.

Keywords
General practitioner; refugees; medically unexplained physical symptoms; qualitative research.

INTRODUCTION

In this article we present the results of a qualitative study among Dutch GPs, providing care to Afghan and Somali refugee patients in the Netherlands. Refugees from Afghanistan and Somalia are two of the larger groups, with around 37.000 and 21.000 respectively by January 2005, among approximately 250.000 refugees of 80 different nationalities living in The Netherlands. Since the late 1980s an increasing number of GPs have been faced with patients of non-Western origin in their practices.

As is the case in the UK, the GP in the Netherlands has a central position in health care. As a result of the regulated reception system for asylum seekers, there are no structural access problems to health care for asylum seekers and refugees. There are, however, such problems for failed asylum seekers and illegal migrants. General practices in the UK vary in their attitudes towards refugee patients [1]. This sometimes results in less than optimal accessibility to basic care.[2] [3-5] GPs mention a range of problems in providing care to refugees. Language problems, resulting in time-consuming consultations, are the most common.[6]

Dutch studies of general practice care for immigrant patients (refugees are often not distinguished from other groups), produced the following results:

- Consultations with patients of non-Western origin do not, on average, last longer than consultations with Dutch patients, but patients of non-Western origin consult their GPs more often.[7]
- GPs give less information to patients of non-Western origin.[8]
- Reciprocal understanding is less often achieved in consultations between GPs and the non-Western parents of sick children, than between GP and Dutch parents.[9]
- Self-assessed poor health is substantially more prevalent among non-European immigrants.[10]
- GPs experience consultations with patients of non-Western origin more often as burdensome, because of communication problems and patients' extra need for information.[11]

We decided to study the perspectives of GPs providing care to refugees, as part of our research into Afghan en Somali refugees' experiences with Dutch health care. We chose a qualitative method in order to bring out differences in approach between GPs, and to generate insight into the meaning of these differences.[12] Our research questions were:

1. What perceptions do the GPs have of the Afghan and Somali refugees and the problems they present?
2. How do the GPs address the problems of the refugees and what difficulties do they encounter in this process?

METHOD

Design and participants

Since we did not know which GPs provided care to Somali and Afghan refugee patients, we approached a random sample of 325 GPs from the national database of Dutch GPs. We invited them by letter for an interview. Fifty GPs responded to this invitation; 23 with a refusal, 22 who did not have patients of Afghan or Somali origin in their practice; and one without explanation. Of the 27 GPs who agreed to the interview, six withdrew at a later stage, because of time constraints. Three more GPs were approached via personal contacts and agreed to an interview.

We conducted 24 interviews, in the Fall and Winter of 2003-2004, twelve by telephone and the same number face-to-face. A senior male medical student, coached by the first author, who is a

female former GP, carried out 22 interviews; the first author did three interviews, one of which was a follow up interview to clarify specific issues. The interviewer took notes during 21 of the interviews, which were written up shortly afterwards. Three interviews plus the follow-up interview were recorded on tape with permission of the GP and a verbatim transcription was made.

The interview included questions about the characteristics of the GP and the practice, numbers of refugees and patients of non-Western origin, and was further structured around open questions on problem presentation by the refugee patients and the process of assisting them. We added one question asking the GP to make a comparison between the refugee patients and other patients of non-Dutch origin. Most interviews lasted between 35 to 50 minutes; three were longer, 60 to 90 minutes.

Among the 24 participating GPs, 17 were men and 7 women, a ratio similar to that of practising GPs in the Netherlands in 2003 (NIVEL, national database). In respect of other characteristics, the group was not representative: GPs under 40 years of age (36% of GPs in the Netherlands) were under-represented (12%); GPs aged 50 and above (19% of GPs in the Netherlands) were over-represented (42%). GPs from highly urbanised areas were also over-represented, as were GPs working in group practice and health centres – 50% in the participating group, 30% of GPs in the Netherlands. Fifteen of the 24 participating GPs worked four days or more in their practices, 9 GPs less than four days. All participating doctors except one were of Dutch origin.

Twenty-one GPs had more than five years experience working with Afghan and Somali refugees, some up to 10 or 15 years. Most doctors had both groups in their practice, three only one of the two. The number of Somalis ranged between 3 and 250 per practice, the number of Afghans between 3 and 60. The practices varied widely in percentage of patients of non-Dutch origin: from 97% in highly urbanised practices to 1% in rural practices.

Analysis

The first author initially analysed and coded the transcripts, using the WinMAX software program [13] to organise the data and facilitate retrieval. The second and last authors also read the interviews and the codes were discussed between the authors. A short profile was written for each doctor, linking interview results to doctor- and practice variables. In a first round, rough codes were assigned for the doctors' perceptions of the refugee groups; the problems the refugee patients presented to them; the way the doctors dealt with these problems and the constraints they met. Dealing with stress-related complaints emerged as a key issue. Analysis then focused on the strategies the doctors said they used to deal with this type of problems, attaching sub-codes to elements of the strategies and linking these to the degree of satisfaction that the doctors expressed or perceived in the refugees. We also looked at doctor and practice characteristics in relation to the strategies chosen.

RESULTS

Refugees and other migrants

The GPs in the urban practices had more experience dealing with patients of non-Western origin than GPs in less urbanised areas. They had often adapted their practice organisation to these groups, making more use of interpreters and cultural intermediaries, mostly for the patients of Turkish and Moroccan origin, the most numerous of the migrant groups in the Netherlands.

The GPs were aware of differences between the refugees and other migrant groups. They mentioned the experiences of violence and loss that characterise refugees as well as their higher

educational qualifications. The refugees tended to learn Dutch faster and more often spoke another European language, such as English or French. Despite this, 16 GPs mentioned the language barrier as a constraint. Family members and especially children were more often used to overcome the language barrier, than the available interpreting service, in the case of refugees.

Description of problems

The doctors rarely mentioned infectious diseases. Exceptions were tuberculosis, sexually transmitted diseases and hepatitis, mostly among people of Somali origin. Eight doctors mentioned relationship problems, gynaecological complaints, unwanted pregnancies and sexual abuse among Somali women.

Virtually all GPs mentioned physical complaints to which they could not attach a diagnosis as an important and characteristic part of the illness presentation by refugees. They referred to pains in joints and muscles, headaches, abdominal pains and backache as 'psychosomatic complaints', 'somatisation' or 'stress-related complaints'. The doctors related these complaints either to the present situation of the refugees or to their experiences of violence in the past. Some doctors noticed that the presentation of this type of complaints decreased when the social situation improved, because the refugee patient received a residence permit, found a job or started on an educational course.

> Dr.15: (referring to refugees in general) "Almost always physical complaints, like headaches, pains in muscles and joints […], sleeping problems, pains in the wrists or the back. This is more an expression of a psychological problem. Less well-educated patients of non-Dutch origin […], more often present these complaints. It is the same thing for less well-educated Dutch people. The lower the educational level, the more difficult it is to deal with the complaints. A good insight into the illness (on the patient's part) is half of the cure."

Though this type of problem is mentioned in connection to refugees in general, it is more often associated with Afghan refugee patients than with Somali refugees.

In this article, we focus on the way the doctors say they try to deal with what they generally call the 'stress-related complaints' of their refugee patients. For reasons of objectivity, we shall use the more neutral term 'medically unexplained symptoms'.

Dealing with medically unexplained symptoms

The GPs seem to use different strategies to deal with medically unexplained symptoms of their refugee patients. The strategies have a number of components, which we briefly want to present here.

- *Investing in the relationship*

Investing in the relationship with refugee patients at an early stage is considered important by a majority of the GPs. The fifteen doctors, who say they invest in a good relationship with their refugee patients at an early stage, see this investment as a basis for dealing with this type of problems. Working part-time did not prevent the doctors from investing in the relationship with their refugee patients; six of the nine part-time doctors did invest in it.

> Dr. 03: "Creating trust is an important aspect, to show that you are interested in the person, not only in the disease; to show that you want to know something about the context. Sometimes it is difficult to find time for it in a busy practice, but I see it is a worthwhile investment. […] For refugees, where do you come from, how did you get here? […] I ask

about shocking events, specifically why they came to The Netherlands, whether they have family here and where the family is. […] You should not do that when they have already been in the practice for six months. You have to separate it from the presentation of a problem. […] This is what I decided by trial and error."

The GPs who have most experience working with refugees stress the importance of meeting each refugee patient as an individual, not as a representative of a group.

Dr.24: "Looking at Afghan and Somali refugees: you always have to approach people as individuals. You can only go on 'experience' to a very limited extent with certain groups. That complicates matters, but also makes it easy. You can just as well say, I'll wait and see who comes in. And whatever his or her story, I can always listen. [..] Nowadays I sometimes just lean back in my chair and let people tell their story. [….] What works well for me, is to approach each patient as a human being, independent of his skin colour or where you think he or she comes from. Just listen to the complaint and approach it in as unprejudiced a way as possible. […]"

Nine GPs seem to invest less energy and time into the relationship with their refugee patients, but refer them in an earlier stage for either diagnostic procedures or mental health care. They speak about their refugee patients in a more 'distant' way, stressing cultural differences, 'strangeness' of complaints, lack of education and differences in thinking about health. They are more often (but not always) the doctors with fewer than 10 Somali and/or Afghan refugee patients in their practice and fewer years of experience working with them.

- Explaining

Twelve doctors mention explaining as their main strategy, four of them as part of a bio-psychosocial approach. They try to explain to the patient what the complaint does or does not mean, but they feel hampered by the language barrier. They often encounter resistance to their explanations. Some doctors attribute this to lack of insight on the patient's part, or to different cultural paradigms. They associate education and intelligence in their patients with a better insight into illness.

Dr.08: (referring to Afghan patients) "They accept psychological and psychosomatic complaints less than physical complaints. They had a good job in Afghanistan and here it is difficult for them to find a good job. […] I listen and show compassion. I explain a lot about psychological complaints. They are very intelligent people, they understand our Dutch way of helping."

Most doctors, who invest less in the relationship with their refugee patients, also seem to invest less in giving explanations.

- Extra diagnostic procedures

Ten out of 24 doctors say they refer their refugee patients, or patients of non-Dutch origin in general, more often for diagnostic procedures, than their Dutch patients. These referrals can be part of broader strategies and are also mentioned by doctors who do invest in the relationship with their refugee patients. They mention pressure from the patients (most often), non-acceptance of

explanations without such a procedure but also uncertainty in the doctor's mind and the wish to wind up the consultation as reasons for the referrals.

> Dr.03: "Extra diagnostic procedures are requested, because they (refugees, later expanded to people of non-Dutch origin in general) often suspect some specific cause of their complaint and they put great trust in diagnostic procedures. So you request that procedure, as a sort of transaction. […] You do this, in part, because you suspect illness. […] Partly too, I think, to wind up the consultation. […] In the beginning I tried to explain in words alone, but that did not work. I saw them coming back, so I took another route. […] But I think we are also afraid sometimes that refugees could have unfamiliar types of diseases. That we could miss something (mentions tuberculosis and Vitamin D deficiency)."

- Keeping to a somatic approach

Four GPs state they keep to a somatic approach as much as possible, among them the three doctors with less than five years experience in working with refugees. They connect their preference for this strategy to either language problems or a supposed inadequate insight on the part of their refugee patients, and often a combination of both. If the somatic approach does not work, they refer their patient to a social worker or the mental health care service. Doctors following this strategy seem to do so as an alternative to personally investing in the relationship with their refugee patients. Three of them also express feelings of powerlessness in helping refugee patients.

> Dr.04: (referring to refugees in general) "The patient often has difficulty making the translation between physical complaints and a psychological cause. […] I keep as much as possible to a somatic approach. The patient interview is often difficult because of the language barrier; so I request more diagnostic procedures. Some problems resolve themselves in the course of time."

- 'Fishing' for the cause

Five GPs say they focus on uncovering 'the cause' of the problem - in this context they mostly refer to traumatic experiences in the past -, usually after a somatic approach has not provided an explanation for the complaint. The 'fishing strategy' therefore is different from the bio-psychosocial approach referred to later. Our material does not provide insight into how effective these doctors were in their efforts, except for the frustrations some of them voice.

> Dr.09: (referring to refugees in general) "I talk a lot with the patients. Sometimes I cannot get to the root of the problem. I try to trace the cause. Sometimes I give symptomatic medication."

- Consultation with or referral to social work or mental health care

Eighteen doctors mention referral to social work or (specialised) mental health care, mostly as part of a broader approach. Twelve GPs refer to these professionals after investing in the relationship themselves. Six GPs seem to refer without investing themselves, among them the three doctors with less than five years experience working with refugees. The others don't mention these referrals.

- Biopsychosocial approach

Eight GPs state they follow a biopsychosocial approach in dealing with 'stress-related complaints' of their refugee patients. These doctors seem most satisfied with the approach they have developed, sometimes in the course of many years. Only two of them express feelings of powerlessness.

> Dr.24: "I tell people; I am a doctor with a bio-psychosocial approach. I look at both physical and psychological causes and I like to talk openly about that. I tell people they can decide for themselves whether certain things should be written down or not. […] I purposely do it this way. Because if you talk too much about psychological aspects, people, not only Somali's, say that there is really something wrong with me, doctor. [...] This feeling, that physical complaints must have a physical cause, Somali's certainly have that. But the longer I work as a doctor, the more I wonder whether this is something specific for other cultures. […] I think increasingly that it is something intrinsically human, this feeling that 'I have a physical complaint, so there must be something wrong with my body. […] And I must say, the longer I work as a GP, I don't want to become nihilistic, there are definitely differences between groups in how they approach their body, but I think sometimes the differences are exaggerated. […] This biopsychosocial approach does justice to how people feel. […] There are people who tell me, doctor, I am very tense these days, with many problems..."

- Supposed satisfaction of refugee patients

Most doctors felt the refugee patients were satisfied. Seventeen doctors thought their Afghan patients were satisfied, two doubted whether they were and two knew they were not. Three doctors did not have Afghan patients in their practice.
Eleven doctors thought their Somali patients were satisfied, 10 doctors were not sure, two doctors knew their Somali patients were not satisfied. One doctor did not have patients of Somali origin. We cannot know the extent to which the impressions of the doctors matched with the real degree of satisfaction among the refugee patients. The doctors gave different arguments for their suppositions that the patients were satisfied: receiving presents, recommendations to other refugee patients, lack of negative comment, patients coming back easily, or patients who did not come back. Ten GPs reported more problems dealing with Somali patients, because of their occasionally demanding behaviour.

At the end of the interview, we asked the participating GPs whether they had tips for colleagues, on how to deal with their refugee patients successfully. The most striking tips are presented in Box I.

DISCUSSION

Summary of main findings

Our study gives a picture of how GPs in different parts of The Netherlands provide care to refugee patients settled in their practice area, and of difficulties they encounter in this process. There is a striking similarity in the way the doctors describe the social situation and illness presentation by their refugee patients. The GPs consider the presentation of physical complaints without a medical explanation as a central and difficult to handle characteristic of the illness presentation by these patients. For this reason we focused our analysis on this issue, distinguishing different strategies the doctors said they were using, and tried to distil some 'best practices' that might be useful for colleagues.

Strengths and limitations of the study

The GPs we were able to interview are a (self) selected sample of Dutch GPs: besides having Somali and/or Afghan refugee patients in their practice, they were sufficiently interested in them to volunteer for an interview on this subject. Older GPs, urban GPs and GPs working in group practices and health centres were over-represented in our sample. The advantage of our non-representative sample may have been that it provided us with a number of valuable 'best practices'.

Several authors have mentioned negative stereotyping, in association with patients presenting with medically unexplained symptoms.[14 15] Our study did not yield evidence of doctors negatively stereotyping refugee patients for this reason. It is possible that GPs with more negative attitudes have not participated in the study. The participating GPs varied widely in numbers of refugee patients in their practice, and number of years they have been working with them. The strategies they said they used to deal with unexplained physical symptoms also varied, as did the degree of satisfaction the doctors expressed with their strategy.

Comparison with the literature

The most experienced doctors specify investing in the relationship with refugee patients at an early stage, and showing interest in their context as the primary tools for working successfully with refugees. Leaning back in one's chair, focusing on each individual with an open mind is considered more important, than detailed knowledge of different groups. This accords with the advice of Burnett and Peel, who also stressed the importance of trust building [16].

Dealing with medically unexplained physical symptoms of patients is one of the central challenges for general practitioners.[14] It is a difficult terrain, on which, in the worst case, both doctor and patient start feeling progressively helpless. Doctors try on a daily basis to reassure patients with unexplained physical symptoms. Explaining is an important part of this reassurance or 'normalisation' process.[17] Reassurance without an explanation is found not to be effective. Neither is an explanation that does not relate to the patient's concerns. There is no reason to think that this will be different for refugee patients.

The doctors who said they followed a biopsychosocial approach seemed most satisfied with their results, also because, in their view, it related best to the patient's point of view. In the view of the authors, these doctors provided the 'best practices', based on long years of experience, working with impressive numbers of refugee patients. Fairhurst and May found that doctors were most satisfied with consultations in which they felt they knew the patient and related to the patient's presentation.[18]

Our finding that a considerable number of doctors acknowledge referring patients of non-Dutch origin more often for diagnostic procedures is in keeping with other studies.[19] Supposed pressure from the patient's side is most often given as an argument. In view of the results of other studies,[20-22] showing that doctors do not always pick up patients' agendas,[23] one can raise the question whether in all cases, the pressure came from the patient.

Implications of the study

Investing in the relationship with refugee patients right from the beginning, showing interest in the individual and her/his circumstances and background, provides a basis for dealing with medically unexplained physical symptoms. The way an initial interview can best be integrated into practice, needs further study. An analytic approach to strategies GPs actually use in dealing with medically unexplained physical symptoms of their (refugee) patients, may be helpful in advancing the quality of care for patients with this type of problems.

REFERENCES

1. Jones D, Gill P. Refugees and primary care: tackling the inequalities. Br Med J 1998; 317:1444-6.

2. Grant C, Deane J. Stating the obvious: factors which influence uptake and provision of primary health services for refugees. Brixton Refugee Health Project. Department of Public Health & Health PolicyLondon: Lambeth, Southwark and Lewisham Health Authority, 1995.

3. Reeves M, de Wildt G, Murshali H *et al*. Access to health care for people seeking asylum in the UK . Br J Gen Pract 2006; 56:306-8.

4. Kmietowicz Z. Doctors turn away refugees, conference told. Br Med J 2001; 323:653.

5. Jones J. Asylum seekers in UK receive poor health care . Br Med J 2000; 320:1492.

6. Ramsey R, Turner S. Refugees' health needs. Br J Gen Pract 1993; 43:480-1.

7. van Lindert H , Droomers M, Westert GP. Tweede Nationale Studie naar ziekten en verrichtingen in de huisartspraktijk. Een kwestie van verschil: verschillen in zelfgerapporteerde leefstijl, gezondheid en zorggebruik. [The Second Dutch National Survey of General Practice. A matter of difference: differences in self-reported life style, health and use of care.]. Utrecht, The Netherlands: NIVEL, 2004.

8. van den Brink-Muinen A, van Dulmen AM, Schellevis FG, Bensing JM Editors. Tweede Nationale Studie naar ziekten en verrichtingen in de huisartspraktijk. Oog voor communicatie: huisarts-patient communicatie in Nederland. [The Second Dutch National Survey of General Practice. An eye for communication: GP-patient communication in The Netherlands.]. Utrecht, The Netherlands: NIVEL, 2004.

9. van Wieringen JCM, Harmsen JAM, Bruijnzeels M. Intercultural communication in general practice. European Journal of Public Health 2002; 12:63-8.

10. Westert GP, Schellevis FG, de Bakker DH, Groenewegen PP, Bensing JM, van der Zee J. Monitoring health inequalities through general practice: the Second Dutch National Survey of General Practice. European Journal of Public Health 2005; 15(1):59-65.

11. Bruijnzeels MA, de Hoop TSW, Voorham AJJ. Etnische herkomst van patienten en werkbelasting van de huisarts [Ethnic origin of patients and general practitioners' workload]. Huisarts & Wetenschap 1999; 42(6):254-8.

12. Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. Br Med J 1995; 311:42-5.

13. Kuckartz U. WinMAX 97. Scientific text analysis for the social sciences. Berlin, Germany: BSS (Büro für Softwareentwicklung und Sozialforschung), 1998.

14. Wileman L, May C, Chew-Graham CA. Medically unexplained symptoms and the problem of power in the primary care consultation: a qualitative study. Fam Pract 2002; 19(2):178-82.

15. Raine R, Carter S, Sensky T, Black N. General practitioners' perceptions of chronic fatigue syndrome and beliefs about its management, compared with irritable bowel syndrome: qualitative study. Br Med J 2004; 328:1354-6.

16. Burnett A, Peel M. Asylum seekers and refugees in Britain. Health needs of asylum seekers and refugees. Br Med J 2001; 322:544-7.

17. Dowrick C, Ring A, Humphris G, Salmon P. Normalisation of unexplained symptoms by general practitioners: a functional typology. Br J Gen Pract 2004; 54:165-70.

18. Fairhurst K, May C. Knowing patients and knowledge about patients: evidence of modes of reasoning in the consultation? Fam Pract 2001; 18(5):501-5.

19. Cardol M, van Dijk L, de Jong JD, de Bakker DH, Westert GP. Tweede Nationale Studie naar ziekten en verrichtingen in de huisartspraktijk. Huisartsenzorg: wat doet de poortwachter? [The Second Dutch national Survey of General Practice. General practice: what does the gatekeeper do?]. Utrecht, The Netherlands: NIVEL, 2004.

20. Ring A, Dowrick C, Humphris G, Salmon P. Do patients with unexplained physical symptoms pressurise general practitioners for somatic treatment? A qualitative study. Br Med J 2004; 328:1057-60.

21. Ring A, Dowrick CF, Humphris GM, Davies J, Salmon P. The somatising effect of clinical consultation: What patients and doctors say and do not say when patients present medically unexplained physical symptoms. Soc Sci Med 2005; 61:1505-15.

22. Little P, Dorwerd M, Warner G, Stephens K, Senior J, Moore M. Importance of patient pressure and perceived pressure and perceived medical need for investigations, referral and prescribing in primary care: nested observational study. Br Med J 2004; 328:444-6.

23. Salmon P, Dowrick CF, Ring A, Humphris GM. Voiced but unheard agendas: qualitative analysis of the psychosocial cues that patients with unexplained symptoms present to general practitioners. Br J Gen Pract 2004; 54 :171-6.

Box I

Tips for colleagues

Dr. 12: “Be open and forget your prejudices. You don’t really need specialised knowledge to be able to help refugees well.”

Dr.24: “Let somebody speak for 1½ minutes (at the beginning of a consultation), before you start interfering.”

Dr.23: “Let them feel that for you every person is equal and show interest in their specific problems.”

Dr.01: “You have to address the actual social situation first, before coming to old traumas. An empty stomach has no ears.”

Dr.07: “Refugees are often quite willing to talk about their experiences. But you have to ask the right questions. Not how was the war, but what happened to you?”

Dr.22: (referring to refugees in general) “We involved some of the first refugees (in the 1970’s) in an advanced professional training for the regional GPs. That was a very impressive training, hearing from them what was important to them. Show that their narratives mean something to you. But don’t only focus on the past, look at the situation as a whole. What are their expectations for the future, what can we contribute to that?”

Dr.17: “Take this group seriously, beware of pitfalls. They can have normal, serious ailments.”

CHAPTER 5

‘WORRIES ARE THE MOTHER OF MANY DISEASES’; GENERAL PRACTITIONERS AND REFUGEES IN THE NETHERLANDS ON STRESS, BEING ILL AND PREJUDICE

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‘WORRIES ARE THE MOTHER OF MANY DISEASES’:

GENERAL PRACTITIONERS AND REFUGEES IN THE NETHERLANDS ON STRESS, BEING ILL AND PREJUDICE

Abstract

Objective: To confront the views of refugee patients and general practitioners in the Netherlands, focusing on medically unexplained physical symptoms (MUPS).

Methods: The study is based on in depth interviews with refugees from Afghanistan (n=36) and Somalia (n=30). Additionally semi-structured interviews were conducted with 24 general practitioners. Text fragments concerning the relationship between mental worries and health or physical ailments were subject of a secondary analysis, the results of which are presented.

Results: Medically unexplained physical symptoms were a key issue for both refugees and GPs. The GPs saw MUPS as a significant part of the illness presentation by refugee patients. Refugees felt GPs were often prejudiced, too readily using their difficult background as an explanation for physical symptoms. A ‘general narrative’ circulating in the refugee communities undermines trust. The GPs applied different strategies in dealing with MUPS presented by their refugee patients. A ‘human interest strategy’ is distinguished from a ‘technical strategy’. The results are discussed in the wider context of the literature on MUPS and patient satisfaction.

Conclusion: No fundamental difference in paradigms was found between refugees and GPs as to the negative influence worries and bad experiences can have on health. For a fruitful cooperation to develop, based on trust, GPs need to invest in the relationship with individual refugees, and avoid actions based on prejudice.

Practice Implications: The importance of (a lack of) trust is underestimated in medical practice. Phenomena undermining trust are often out of sight for practitioners. Critical reflection is needed on the strategies practitioners employ to deal with MUPS.

Keywords: refugees; general practitioners; medically unexplained physical symptoms; prejudice; trust; stereotyping; medical error.

1. Introduction

> Mrs. A22: 'GPs think that we Afghans always have psychological problems. That we come from a Third World country where there was war and we have suffered a lot and therefore we are all mad or psychologically ill. That is not true. Of course we have suffered a lot of misery, but this is another story. A gallstone has nothing to do with a psychological problem. […] GPs here think that all our problems are psychological.'

Mrs. A22 is one of the Afghan women we interviewed for our research on the experiences of Dutch healthcare by refugees from Afghanistan and Somalia. The refugees in this study actually are 'former refugees': they have got a permit, they have settled in municipalities spread over the country, and have been busy building a new life for themselves for several years.
Since the general practitioner has a central role in Dutch healthcare and everybody living in the Netherlands is supposed to be on the list of a GP, we decided also to interview general practitioners about their experiences working with refugees from Afghanistan and Somalia, exploring their perceptions of refugees' problems and illness presentation, and the way they were dealing with these problems. The results of the refugee interviews and the GP interviews separately are being published elsewhere [1-3].

Virtually all GPs we interviewed mentioned the presentation of medically unexplained physical symptoms (MUPS) as an important part of the illness presentation by their refugee patients, and many of them acknowledged meeting difficulties in managing these complaints.

> Dr. 18 (referring to the illness presentation of Afghan refugees): 'Many backaches and stomach complaints are — according to me — expressions of psychological problems, but I cannot put my finger on it. […] They think in different paradigms, they deal differently with illness, they see another connection between body and mind, more focused on the physical complaints.'

It seems both refugee patients and GPs have a problem here. Since the issue of physical complaints without an apparent medical explanation emerged as an important subject from both refugee and GP interviews, we decided to make it a central focus in our analysis. In this article we present the results of this analysis. The following questions will be addressed:

- What are the refugees' perspectives on health, illness and mental worries?
- What are their expectations from doctors?
- What are their problems dealing with Dutch doctors?
- What are the GPs' perspectives on medically unexplained physical symptoms presented by their refugee patients?
- Which strategies do the GPs use to address these complaints?
- Which problems do they encounter while assisting refugee patients with this type of complaints?
- What can we learn by confronting the refugees' and GPs' perspectives with each other?

We shall place our findings in the wider context of research on MUPS in general practice.
The doctors used different terminologies: 'somatisation', 'psychosomatic complaints', or 'stress-related complaints'. For our own analysis, we shall keep to the designation 'medically unexplained (physical) symptoms'. The other terms will frequently appear, however, when quoting others. Before presenting our study, we shall give a brief outline of the literature concerning MUPS.

Dealing with MUPS is a frequently occurring challenge for general practitioners — and not only in relation to refugee patients. Depending on the source and definition used, between 15 to 20% of consultations in general practice concern patients presenting with physical symptoms without apparent organic disease. Exploring the field of literature on this subject [4-6], the reader is confronted with different terminologies used by different practitioners (psychiatry, general medicine, general practice) and scholars (medicine, anthropology, psychology). Our search therefore included the terms 'somatisation', 'somatoform disorders', and 'somatic fixation'.

In a review article Burton [4] gave the following definitions, which we quote here, because we think they contribute to semantic clarity:

- Medically unexplained physical symptoms (MUPS): physical symptoms for which no clear or consistent organic pathology can by demonstrated, although organ dysfunction may be an integral part of the symptoms;
- Somatisation: the process by which patients with psychological distress (as measured by psychiatric diagnostic interview or questionnaire) present physical symptoms to their doctor;
- Somatoform disorder: presentation of a specified number of physical symptoms without organic cause in the absence of other major psychiatric diagnosis; this includes DSM-IV Somatisation Disorder, considered part of the psychiatric domain [7], requiring presentation of at least eight out of 40 symptoms and an age of onset before 30 years.

Somatic fixation (not dealt with by Burton) points to the process going on between the 'somatising' patient and the doctor trying to heal [8,9] .

The literature confirms 'somatisation' or 'physical complaints without diagnosis' as being an important part of the illness presentation by refugees in different countries and situations [10,11] . Hondius and Van Willigen [12] found a correlation between the number of physical complaints and a history of physical torture. Lin's [13] findings among Asian refugees and immigrants in a US primary care situation point to an association between 'somatisation' and a high social burden in combination with lack of resources — both material, social, and personal. Refugees had a higher rate of somatisation than immigrants.

Coker [14] collected and analysed narratives from over 100 Southern Sudanese refugees living in Cairo and presenting with physical symptoms at a special clinic. The refugees told their stories, consistently interweaving physical sensations with their experiences of exile, loss, and marginalisation. Coker advocates listening to these narratives as 'a message about the existential crisis in which their (the refugees') community is embroiled.'

Burton [4] concludes his review article saying that "The notion that most MUPS are the result of a single process of somatisation (particularly the somatisation of mental distress), […] is no longer supported by the evidence. There is now good evidence that physiology, personality, life experiences, health cognitions, and interactions with healthcare professionals are all important, and any new paradigm needs to include them."

The interaction and communication between doctors and patients have become central issues in the research on MUPS. From the comparison of three qualitative studies, May et al. [15] demonstrated that differences between doctor and patient about the interpretation of the presented complaints are an important source for conflict. General practitioners express frustration and

powerlessness when dealing with this type of complaint [16]. Negative stereotyping of patients can play a role [17], and doctors often have wrong ideas about patients' explanatory models [18]. Patients employ their own tactics to convince the doctor of their point of view [19]. Doctors with a higher perceived workload, lower job satisfaction, and a lack of training in communication skills reported higher numbers of 'heartsink patients' in their practices [20].

Somatisation in general practice was found to be associated with damaging earlier life events, often unknown to the general practitioner [21,22] . Mollica [23] advocates the systematic assessment of the impact of traumatic life experiences in new primary care patients, especially refugees.

Management of MUPS has been another focus of study: what do GPs do and which strategies work? Kuyvenhoven [24] identified three parameters for quality of performance by GPs: attention paid to somatic aspects, patient orientation, and prevention of unnecessary harm, i.e. superfluous prescriptions and referrals. She was able to construct profiles of GPs in which more patient orientation correlated with less risk of unnecessary harm. Later observational studies have tried to clarify the dynamics of why GPs order physical interventions. Ring et al. [25] demonstrated from audio taped consultations that patients with unexplained physical symptoms often did not directly request physical interventions — but the GPs felt pressurised by the style of presentation. GPs were found to offer little effective explanation or empathy in consultations with patients presenting MUPS [26].

Burton [4] found few studies concerning treatment of MUPS in primary care. Recognising and treating depression [27] and cognitive behavioural therapy [28] have appeared to be promising. Blankenstein [29] found reattribution to be a promising approach. In the refugee and trauma literature, body-oriented treatments are advocated, but they have mostly been developed in a mental healthcare setting [30,31] . The statement in 1997 that 'Effective interventions are available' for treating medically unexplained physical symptoms [32] had apparently not yet become common knowledge in 2005 [33].

Having outlined the 'state of the art' above, we return to our interview material in order to explore how our results relate to the state of the art and possibly shed some new light on it.

2. Methods

2.1 Procedure

Since little research has been done eliciting refugees' views on the way the healthcare system serves them in countries of resettlement, we set up an open ended, explorative study to learn about their frames of reference, expectations and experiences concerning health and healthcare. Elements from grounded theory [34,35] were used in designing the study, during data collection and in the analytical process.
We held 25 in depth interviews with refugees from Somalia, involving 30 participants, and 24 with refugees from Afghanistan, involving 36 participants. The refugees were approached through self-organisations, volunteers of the Dutch Council for Refugees and personal networks. In a later stage some participants volunteered for an interview, after hearing about the study from other participants.
The participants lived in different municipalities in The Netherlands. The interviews lasted between one and a half to two hours and were conducted by the first author (a female, former

general practitioner) with the help of a female Somali or Afghan assistant researcher interpreting and, where necessary, explaining issues. At different stages, two Somali women and three Afghan women were involved as assistant-researchers. All of them had academic education and were committed to the subject of the research. One of the Afghan women was a professional interpreter. All assistant researchers were fluent in Dutch and in their own language, had good knowledge of the specific terminology and strong communication skills. They were also important as 'cultural intermediaries' and assisted in developing a trust-based relationship with the participants. Eight of the Somali participants and nine of the Afghan participants were approached by the assistant researchers and therefore known to them. Ten Afghan interviews and three Somali interviews were conducted directly in Dutch by the first author alone. All interviews were recorded on tape with the consent of the participants and a verbatim transcription was made.

A topic list was designed with advice from refugee experts, and used in a flexible way, following the line of thought of participants. The topic list was adapted during the process of data collection, adding issues that appeared to be important during the interviews, such as 'stories heard from others'.
The first part of the interviews focused on participants' experiences with healthcare in their country of origin. In the second part they were asked to speak about their situation and health in the Netherlands, naturally leading to their experiences with healthcare. The narratives focused on their experiences with general practitioners. At the end of the interview participants were asked to formulate what health and illness mean to them, what their ideas are about causes of illness, and they were invited to make their own additions and recommendations.

In a later stage we interviewed 24 GPs with Somali and/or Afghan refugee patients in their practice. Twenty-one of them responded to our letter of invitation, which was sent to a non-selective sample of 325 Dutch GPs in different (urban and rural) areas of the country. Three more GP interviews were realised through personal contacts. The GPs were therefore not the GPs of the refugees we had interviewed. In the developmental stage of the research we briefly considered the possibility of trying to interview refugees and GPs in pairs. We dropped this idea almost immediately, because of the expectation, and urgent advice we were given, that refugees will refuse to give an interview or not speak freely if they were asked whether their GPs could be interviewed later.

The GP interviews had a semi-structured character with open-ended questions. A senior medical student conducted 22 of the interviews, coached by the first author. The first author carried out three interviews, one of which was a follow-up interview to clarify specific issues. Twelve of the GP interviews were conducted by telephone and the other twelve face-to-face, according to the doctor's preference. The interviewer took notes during the interviews and elaborated on them conscientiously immediately afterwards. Three GP interviews were recorded on tape with the consent of the doctor and transcribed verbatim.

2.2 Groups of participants

Afghan refugees

Thirty-six Afghan participants took part in 24 interviews (a husband and wife giving an interview together are counted as two participants); twelve couples, nine women alone, and three men alone. Their ages ranged between 18 and 66 years, and they had lived in the Netherlands for between three and 13 years. All participants were Muslims. The level of education of the participants varied; twelve had completed academic or higher vocational education, 16 a

secondary or lower vocational education, seven had received only primary education, and one elderly woman was illiterate.

Sixteen participants were unemployed, nine were employed, four were receiving some sort of training, three were doing voluntary work, and four were over 60 years of age. Twenty-three participants had acquired Dutch nationality, 13 had a refugee or humanitarian residence permit. Seven participants lived in a major city, 18 in a smaller city, and 11 in a village. Young, unmarried men were under represented among our participants, as compared to the Afghan population in the Netherlands [36].

Somali refugees

Thirty Somali participants took part in 25 interviews (a husband and wife giving an interview together are counted as two participants); sixteen women have been interviewed alone or in the presence of small children, five women together with their husbands, and four men alone. Their ages ranged between 24 and 68 years, and they had lived in the Netherlands for between six and 15 years. All participants were Muslims. Eleven participants had completed academic or higher vocational education, 13 secondary or lower vocational education, five had received only primary education, and one woman was illiterate.

Sixteen participants, mostly women, were busy looking after their families, five female participants and two male participants were engaged in paid work, two men were over 60 years of age, one of whom was active in voluntary work, and one young man was a fulltime student. Apart from two women, all Somali participants had acquired the Dutch nationality. Nineteen participants lived in a major city, seven in a smaller city, and four in a village. Young, unmarried men were under represented among our participants, as compared to the Somali population in The Netherlands [36].

General practitioners

Among the 24 participating GPs, 17 were male and seven were female — a ratio similar to that of practising GPs in The Netherlands in 2003. The participating group was atypical in other characteristics: GPs under 40 years of age (36% of GPs in the Netherlands) were under represented and GPs aged 50+ (19% of GPs in the Netherlands) were over represented. GPs from strongly urbanised areas were also over represented, as were GPs working in group practices and health centres — 50% in the participating group, 30% of GPs in The Netherlands.

Fifteen of the 24 participating GPs worked four days or more in their practices, nine GPs less than four days. Except for one, all GPs were of Dutch origin. Twenty-one GPs had more than five years experience working with Afghan and Somali refugees, some up to ten or 15 years. Most participants had both groups in their practice and three had only one of the two. The number of Somalis ranged between three and 250 per practice, the number of Afghans between three and 60. The practices varied widely in their percentage of patients of non-Dutch origin: from 97% in strongly urban practices to 1% in rural practices.

2.3 Analysis

The first author analysed and coded the transcripts of the refugee interviews, using the WinMAX software program [37] 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 and the recoding of textfragments. After initial coding and cross-sectional comparison, a schematic presentation in short quotes was made of each refugee interview [1,2] . Using this method facilitated analysis along the time axis. In a process of constant comparative analysis, starting from some extreme cases, the refugee narratives were analysed. Personal experiences appeared to be intermingled with stories about other people's experiences. In the personal narratives 'critical episodes' could be distinguished, encounters with healthcare providers that left a positive or a negative mark in the participant's memory [1,2] . Participants also provided explanations for their negative experiences. The feeling of 'not having been taken seriously' by a healthcare provider was central in negative critical episodes. Explanations provided were mostly based on perceived prejudice or lack of interest from the provider's part.

The GP interviews were analysed and coded in the same way. A short profile was written for each doctor, linking interview results to doctor and practice variables. In an initial analysis, rough codes were assigned for the doctors' perceptions of the refugee groups, the problems the refugees presented to them, the way they dealt with these problems, and the constraints they met [3].

Dealing with MUPS emerged as one of the central themes in both the refugee and the GP interviews. In order to explore this topic further, we performed a secondary analysis of our interview data, both refugee interviews and GP interviews, introducing the code 'body and mind', which was attached to all statements concerning this theme. Further content analysis linking refugee statements to GP statements revealed agreements, disagreements, and bottlenecks, which form the body of this article.

3. Results

The perspectives of refugees and general practitioners are presented successively in the next section, under content headings derived from the analytical process.

3.1 Perspectives of refugees

3.1.1 General narrative vs. personal narratives

The refugee participants frequently interspersed their personal narrative with stories they had heard from others - friends or family members - in their respective communities about experiences with healthcare. Instead of discarding these 'second-hand' stories, we gratefully accepted and analysed them. In contrast to the variety of the personal narratives, the 'second-hand stories' had an overall negative content of prejudice, lack of good care for foreigners or refugees, and professional mistakes (sometimes with severe consequences). These stories functioned as a sort of shared backdrop — either contrasting with the personal narrative or underlining it.

We introduced the concept of ‘general narrative’ for this phenomenon, which was identified in both the Afghan and Somali refugee communities.

3.1.2 Refugees’ concepts of health and illness

Both Afghan and Somali participants, when asked to describe what health means to them, used terms like ‘the most valuable thing a human being can have’ and related it to physical functioning, as well as social, emotional, and mental functioning, and autonomy: to be able to think well, to radiate happiness, to work, to walk around and eat well, to relate to others, and to be independent. Exceptions were two young Afghan participants (A13 and A25), who specifically referred to health as ‘something in the body’ or the absence of physical impairments.

Illness, on the other hand, was referred to as ‘the worst’ and associated with loss of independence. The terminologies used by Somali and Afghan participants were strikingly similar and pointed to a comprehensive concept of health, in which autonomy was a central characteristic.

3.1.3 Causes of illness — mental worries

We asked all participants what, in their view, are causes of illness. Both Afghan and Somali participants mentioned a wide range of possible causes: climate and environment, bad food or lack of food, the will of God, lifestyle items like alcohol, drugs, and smoking, lack of hygiene, infections and ‘bad’ sexual contacts, lack of physical exercise, or too much physical strain. The single most frequently mentioned item, though, was mental worries or ‘thinking too much’ because of loneliness, unemployment, war experiences, loss of family members, being separated from family, or not being able to support family members in bad situations. Participants in 21 out of 24 Afghan interviews spontaneously mentioned this item, husband and wife agreeing completely in the interviews with couples.

> Mrs. A02: ‘Nerves play a role; the cause of physical complaints, thousands of complaints, lies in psychological problems.’ ‘We have a saying,’ her husband adds, ‘that worries are the mother of many diseases. […] This expression is part of the culture of our country, a proverb of our older men, of our ancestors.’

There seems to be a difference between generations. Mr. and Mrs. A02, quoted here, belonged to the middle-aged generation and considered the notion of the link between worries and illness as part of their cultural heritage. Mrs. A25, who is much younger and arrived in the Netherlands at the age of 19, said that before leaving her country she was not aware of the influence of emotional problems on the body, but she discovered it from her own experience.

Among the Somali participants there was less general agreement about worries or living in a bad situation as a causes of illness: participants in 15 out of 25 interviews mentioned it. This still makes ‘worries’ the single most mentioned cause of illness, also by Somali participants. But contrary to the Afghan participants, Somali participants saw this as a new discovery, as part of their experience as exiles.

> Mrs. S09: ‘But about the mental problems and illness, that I learnt here. I never heard that in Somalia. […] [In Somalia] I have never seen someone who is ill because of stress or fear. […] Maybe Somalia was an open country. People have their own family and they have more contact. I think in Somalia they don’t have stress.’

The comprehensive concept of health was reflected in the way participants, both of Somali and Afghan origin, described their (ill) health in specific situations in the past or in the present. The present situation, i.e. the perception of self and others as persons not being able to fully participate in the new society and therefore unable to re-establish autonomy, was also described in terms of illness, by both Somali and Afghan participants:

> Mrs. S15: 'Many refugees from Somalia are what we call 'outpatients'. Everybody is ill because of the situation, especially the men. They are sitting at home and they are not used to sitting at home. […] There is no job for them here. That makes people ill.'

3.1.4 Personal responsibility — strategies to stay healthy

First and foremost participants felt responsible for their own health and situation. They were active in their endeavours to keep themselves healthy and sound. Being careful in the choice of food, being meticulous with hygiene, and taking regular physical exercise were mentioned by almost all of them.

Both Somali and Afghan participants mentioned a range of strategies to cope with their worries and bad memories: indulging in activities, praying, doing sports or other physical activity, listening to music, trying to think positively, talking with friends or family. Many participants combined different strategies.

Sharing the burden of worries by talking with family members or friends was the most frequently mentioned strategy, both by Afghans (10) and Somalis (17). But it was also a disputed strategy:

> Mrs. A24 (a 29-year-old mother of two): 'In the beginning I thought it was good to talk about my experiences. But after two or three years in The Netherlands I noticed I became angrier and sadder when I talked about it. All these memories came back into my mind. Therefore I tried to forget everything. And each time these memories come back, I do something to forget. In this way I helped myself a lot. Four or five years ago, these memories jumped on me five times a day, nowadays only once a week. […] The memories have a very bad influence on my life; they catch my joy of life. I don't want to live again.'

3.1.5 Expectations from doctors

Recognising that participants view health as a very valuable entity, closely linked to autonomy, and actively try to stay healthy, our next question was: what do participants expect from doctors, especially general practitioners? It is clear from the interviews that a doctor is primarily expected to address physical complaints; that is considered to be his expertise. You don't go to a doctor to discuss your problems:

> Mr. A13: 'I never talked with anybody about my stress and pain, because I knew that it is part of my life. When you have left your country, you have to fight the pain and the stress. […] Keep yourself busy with other things, with other people, playing football, studying, reading.'

But participants consider it important that a doctor shows interest in their person and their background.

> Mr. A08: 'I don't think the doctor can help you to get a job. His job is the health of the patient. […] But it is important that the doctor knows something about the background of the patient. He should know which things influence the health of the patient, in his country of origin and here.'

Kind words as a welcome are considered very important:

> Mrs. A20: 'When you sit with a doctor and you hear kind words, that has an influence on your nerves, on your body. You start feeling better, healthier, than when the doctor is angry. It is all psychology.'

Anxiety about symptoms is an important motive to visit the GP, and the first need the participants expressed is the need to know the cause of the symptom. They expect a thorough physical examination. Fears related to symptoms can be very specific:

> Mr. A15: 'Sometimes I get this idea that perhaps when I was so much under pressure, because of the strokes on my head (he refers to torture during his stay in prison in Afghanistan), that perhaps that is the cause of my headaches. […] And sometimes I think, if no real examination is done, I cannot have certainty what causes this headache. First there must be a diagnosis [of] where it comes from. Now I don't watch TV, I don't worry about anything, only about my health, and still this headache remains the same.'

Several participants expressed the wish to be part of the discussions with the doctor on how their problem can best be addressed:

> Mr. A16: 'I would want the doctor to say: *You are my client. We have five minutes to discuss and find a solution together*. Correct and accept each other. That is the right way.'

These expectations don't seem extraordinary: a positive, welcoming attitude, recognition and adequate examination of the physical complaint, resulting in an explanation that deals with specific fears, and an exchange of views on how to proceed. Still, a lot of complaints about Dutch GPs are circulating in both the Afghan and the Somali refugee communities. So what is going wrong?

3.1.6 Refugees' problems with doctors

Our analysis of both personal narratives and the 'general narrative' shows that refugees have problems with doctors who they feel don't take them or their complaints seriously: there is fear of misjudgement. Stories circulate in both the Afghan and the Somali communities about physical symptoms that for a long time were misjudged by doctors and in the end appeared to be caused by a serious physical disease.

> Mrs. S24: 'Somali people don't trust Dutch doctors. […] For instance, my friend, she died last week in this neighbourhood. She had a terrible headache for almost five years. She visited her GP several times, he sent her to the hospital for a photo. Nothing was found. Later she went into a coma because she had a tumour in her head. She died shortly after. And other Somalis hear that a young woman died like that. How can you have trust

if you hear something like that? Somebody who lives in Europe and has a headache for five years, then suddenly dies. Like somebody living in the jungle without a doctor.'

Participants want to be approached as individuals, not as representatives of a group. With the understanding that they have suffered many bad experiences and that these can influence their present state of health, like Mrs. A22 quoted at the beginning of this article, they feel doctors focus too much on this 'refugee experience' at the cost of open-minded attention to what is wrong with the individual patient:

> Mr. S25: 'What angered me most was his generalising attitude that blocks everything: this person comes from Somalia, so he is traumatised.'

Paracetamol has become a metaphor by itself in refugee narratives. It is not so much the paracetamol as a medicament that is blamed, but it has become an unappreciated replacement for serious professional attention and human recognition.

Tranquillisers, more or less the counterparts of paracetamol, also figured in a number of narratives as substitutes for real professional interest in the patient:

> Mrs. A09: 'After those nine months in the reception centre, I came to my house. […] It started with headaches and pains in my neck and shoulders and body. […] During two or three years I went to see the doctor and I got tranquillisers and sleeping tablets. And the doctor said: *because you are here in a foreign country and you have gone through a lot of experiences, these are normal reactions because of the problems you have had in the past*. For two or three years I got these tablets. […] Until I told the doctor: *I don't want to take the tablets again*. One becomes addicted to them.'

Some participants felt they are too often identified with their past experiences of war and oppression, and that attention to their present situation and struggle is lacking:

> Mr. A12: '[…] I want to move forward. […] Maybe I have experienced a lot of bad things, but I don't want to talk about these bad things again. If I go back to these problems that I left behind, that drives me mad.'

3.2 The general practitioners' perspective

The GPs we were able to interview probably were more positively inclined towards refugee patients than the average Dutch GP: they were prepared to make the extra investment of giving an interview concerning this relatively small group in their practice. The general tone of the interviews was one of interest and commitment, though sometimes mixed with feelings of insufficiency and powerlessness. We did not come across statements with a discriminatory content.

3.2.1 General practitioners on refugee problems

With presentation of medically unexplained physical symptoms being such a central issue in the experience of the participating GPs, we focused our analysis on problem definitions they gave, difficulties they met, and management strategies they had developed. The GPs connected the

presentation of a wide spectrum of physical complaints to the situation their refugee patients were living in, and also to their past experiences:

> Dr.14: 'The Somali's don't root well in The Netherlands. […] Evident physical complaints; besides that, psychosocial and psychosomatic complaints, like headache, stomach ache, as a cover on top of the bad situation in which they are. They feel unhappy. […] Restrained anger about their bad social situation.'

The doctors made a link to the level of education, not only for refugee patients, but also for other patients of Dutch and non-Dutch origin: people with less education more often present with this type of complaint, according to the participating GPs.

The supposed 'difference in paradigms' has been mentioned before when quoting Dr.18 in the introduction of this article. We now proceed to present an overview of management strategies as they arose from our GP interviews.

3.2.2 How doctors deal with refugee problems

From our interview data we can roughly make a division between fifteen doctors who said they invest in the relationship with their refugee patients, and nine others who seemed to do this less. We labelled the two strategies 'human interest strategy' and 'technical strategy'.

The 'human interest' GPs were more often older, had a longer experience of working with refugees, sometimes expressed a special interest in working with these groups, and had larger groups of refugee patients in their practice.

The nine GPs following a 'technical strategy' spoke about their refugee patients in a more 'distant' way, stressing cultural differences, 'strangeness' of complaints, lack of education, and differences in thinking about health. They were more often (but not always) the doctors with fewer than ten Somali and/or Afghan refugee patients in their practice and fewer years of experience working with them.

Both the 'human interest strategy' and the 'technical strategy' can take different varieties. Some components appeared in both strategies. Ten out of the 24 GPs we interviewed expressed feelings of powerlessness when dealing with these types of problems in their refugee patients.

3.2.3 Human interest strategy

i. Investing in the relationship

The fifteen doctors who said they do invest in the relationship with refugee patients, saw this investment as a necessary basis for dealing with unexplained physical symptoms.

> Dr. 03: 'Creating trust is an important aspect, to show that you are interested in the person, not only in the disease; to show that you want to know something about the context. Sometimes it is difficult to find time for it in a busy practice, but I see it is a worthwhile investment. […] For refugees, where do you come from, how did you get here? […] I ask about shocking events, specifically why they came to The Netherlands,

whether they have family here and where the family is. […] You should not do that when they have already been in the practice for six months. You have to separate it from the presentation of a problem. […] This is what I worked out by trial and error.'

The GPs who had the most experience working with refugees stressed the importance of meeting each refugee patient as an individual, not as a representative of a group.

> Dr. 24: 'Looking at Afghan and Somali refugees, you always have to approach people as individuals. You can only go on 'experience' to a very limited extent. […] That complicates matters, but also makes it easy. You can just as well say, *I'll wait and see who comes in, and whatever his or her story, I can always listen*.'

ii. Biopsychosocial approach

Eight GPs stated they follow a biopsychosocial approach in dealing with the 'stress-related complaints' of their refugee patients. These doctors seemed most satisfied with the approach they had developed, sometimes in the course of many years. They also felt their refugee patients were satisfied. Only two of these GPs expressed feelings of powerlessness.

> Dr. 24: 'I tell people I am a doctor with a biopsychosocial approach. I look at both physical and psychological causes and I like to talk openly about that. […] I purposely do it this way. Because if you talk too much about psychological aspects, people, not only Somalis, say that *there is really something wrong with me, doctor*. […] This feeling, that physical complaints must have a physical cause, Somalis certainly have that. But the longer I work as a doctor, the more I wonder whether this is something specific for other cultures. […] This biopsychosocial approach does justice to how people feel. […] There are people who tell me: *doctor, I am very tense these days, many problems*….'

iii. 'Fishing' for the cause

Another strategy we distinguished is the 'fishing strategy'. The GP starts fishing for a psychological cause after somatic causes have been excluded — in this context the GPs mostly referred to traumatic experiences in the past. The 'fishing strategy', therefore, is different from the bio-psychosocial approach. Five participating GPs said they follow this strategy: three of them as part of a 'human interest strategy', two of them as part of a 'technical strategy'. These doctors did not appear to be very successful in their efforts; they expressed feelings of powerlessness more often than doctors who followed a 'biopsychosocial approach' right from the beginning.

3.2.4 Technical strategy

Keeping to a somatic approach

Four GPs stated they keep to a somatic approach as much as possible, three of them had less than five years experience in working with refugees. They connected their preference for this strategy to either language problems or a supposed inadequate insight on the part of their refugee patients, and often a combination of both. Doctors following this strategy seemed to do so as an alternative to personally investing in the relationship with their refugee patients. Three of them expressed feelings of powerlessness in helping refugee patients.

> Dr. 04 (referring to refugees in general): 'The patient often has difficulty making the translation between physical complaints and a psychological cause. […] I keep as much as possible to a somatic approach. The patient interview is often difficult because of the language barrier, so I request more diagnostic procedures. Some problems resolve themselves in the course of time.'

The other 'technical strategy' GPs combined the somatic approach with explaining, fishing, or referrals to a mental healthcare service or social worker, without really investing in the relationship themselves.

3.2.5 Elements that occur in both 'human interest' and 'technical' strategies

i. Explaining

The doctors mainly used language as an instrument: explaining what the complaint does or does not mean, but they felt hampered by the language barrier. Twelve doctors mentioned explaining as their main strategy, four of them as part of a biopsychosocial approach. They appreciated education and intelligence in their patients and associated this with a better insight into illness.
They often encountered resistance to their explanations. Some doctors attributed this to a lack of insight on the patient's part or to different cultural paradigms. Doctors who invested less in the relationship with their refugee patients also seemed to invest less in giving explanations.

ii. Extra diagnostic procedures

Ten out of 24 doctors said they refer their refugee patients, or patients of non-Dutch origin in general, for diagnostic procedures more often than their Dutch patients. These referrals can be part of broader strategies and were also mentioned by doctors who did invest in the relationship with their refugee patients. Pressure from the patient was most often given as an argument, but also uncertainty in the doctor's mind, and the wish to wind up the consultation:

> Dr. 03: 'In the beginning I tried to explain in words alone, but that did not work. I saw them coming back, so I took another route. […] But I think we are also afraid sometimes that refugees could have unfamiliar types of diseases. That we could miss something… (mentions tuberculosis and Vitamin D deficiency).'

iii. Consultation with or referral to social work or mental healthcare

Eighteen doctors mentioned consultation with or referral to social work or (specialised) mental healthcare, mostly as part of a broader approach. Twelve 'human interest' GPs refer to these professionals after investing in the relationship themselves. Six GPs seemed to refer without investing themselves, among them the three doctors with less than five years experience working with refugees. The others did not mention these referrals.

4. Discussion and conclusion

4.1 Discussion

Contrary to our expectations refugees and GPs generally speaking share the view that worries and bad experiences can have a negative influence on health. There seems to be a difference, though, between Afghan participants and Somali participants. Whereas the concept of worries influencing health was presented to us as part of Afghan cultural heritage, Somali participants saw it as part of their exile experience. Of course at the level of the individual consultation a difference in 'explanatory models' [38] may exist which, if not clarified, will prevent that 'mutual understanding' [39] is reached. Our design of reflective interviews with refugees and GPs, not engaged with each other, does not allow us to say anything about individual consultations. The phenomenon of doctors not being aware of their patients' explanatory models has already been pointed out by Helman in 1985 [18].

If paradigms do not differ fundamentally between refugees and GPs as far as the possible relationship between worries and health is concerned, then where is the problem?
The refugee participants feel they are too readily being identified with their traumatic past experiences and present hardships, at the cost of open-minded attention to their individual needs at a certain moment. The general narrative provides a body of evidence that this can lead to professional mistakes with sometimes-dramatic consequences, and therefore adds to the feeling in refugee patients that they have to be 'on their guard' when consulting a doctor. The trust, which is basic to a successful medical consultation, is not there. Innes et al. [40] described the consultation as a 'complex, adaptive system', composed of 'networks of agents'. Complex decision-making arises when agreement and certainty have to be traded for. The general narrative from the refugee community and earlier personal negative experiences are typical 'agents' in the 'network' of refugee patients that play a role in undermining trust, but which are unknown to the doctor. They are part of the 'internal context' [41] of the refugee patient.

Our refugee participants are very clear that first and foremost they need serious and unprejudiced attention for the physical aspects of their problem. If the doctor fails to acknowledge the physical complaint and to empathise with the underlying anxiety, explanations will not lead to accepted reassurance [19, 42, 43]. Anxiety and uncertainty related to physical symptoms are generally important driving forces for consulting a health professional [44,45]. Though doctors are aware of the risk of missing a serious disease, our interview data creates the impression that they tend to be more focused on preventing unnecessary harm by limiting interventions. Recently, Klein [46] analytically underlined the risk of doctors taking wrong decisions based on prejudice, stereotype, or overconfidence. Our minds have the tendency to be more focused on information that fits our pre-existing expectations rather than on conflicting information. Klein advises that it can be helpful to make a habit of seeking the opinion of colleagues.

We distinguished two mutually exclusive main strategies the GPs were applying: a 'human interest strategy' and a 'technical strategy'.
The GPs employing a 'technical strategy' speak in a rather 'distant' way about their refugee patients, emphasising cultural differences, 'strangeness' of complaints, and differences in paradigms: probably reflecting their difficulty in 'connecting' to these patients. They experience a 'cultural distance' [47]. For them, the refugee patients remain 'generalised others' [48]. It seems likely that a technical strategy, combined only with explanations and/or referrals, and without investment in the relationship, leads to dissatisfaction on the part of refugee patients, and often also on the part of the GP.

The GPs applying the 'human interest strategy' seemed more satisfied with their approach, especially if they combined it with a systematic biopsychosocial approach. Satisfaction on the

part of the GP implied their belief that the refugee patients were satisfied. Fairhurst and May [49] related GPs' satisfaction with consultations to their communication and reasoning style. The GPs were more satisfied with consultations where they felt they had 'connected' to the patient, resulting in 'inductive knowledge' of patients, rather than 'deductive knowledge' based on mere facts.

There is an interesting and heartening parallel between what refugees expect from doctors, according to our interview data, and what we tend to call the 'best practices' of the GPs. Interest in the person and her/his background, showing a welcoming attitude, serious and careful history taking plus a physical examination, seeking agreement on possible explanations, and further discussion on the course to follow figure in both refugees' expectations and doctors' best practices. This strategy is in line with recommendations in the MUPS literature [4]. Asking about the way refugee patients deal with their situation and worries may be a useful addition, and helps to shift the 'locus of control' partially back to the patient [50], creating an atmosphere of joint responsibility [51].

The literature on MUPS relates requests for diagnostic interventions to 'perceived patient pressure' [25, 52]. GPs often miss cues to start discussing psychosocial issues [53, 54] . Ring et al.[26] concluded that the focus of attention should be more on a doctor's tendency to offer somatic interventions and neglect psychological cues, than on special characteristics of patients. Our interviews illustrate that GPs sometimes consciously order diagnostic interventions to wind up the consultation or because they feel unable to communicate in another way.

The question arises as to how far refugee patients are different from other patients in general practice. In a review of studies concerning patient views on quality of care in general practice, Rees Lewis [45] concludes that nearly all studies emphasise communication as one of the aspects of a consultation most indicative of quality in the eyes of the patient. From his meta-analysis, the following emerge as the top four items (in order of significance) correlating with general satisfaction:

- GP gives enough information
- Like GP as a person
- GP spends enough time on consultation
- GP has good medical skills

Looking at these items and having listened to our refugee participants, but also reflecting on the wider MUPS literature, we can conclude that communication tuned to the individual patient is of central importance, together with clinical competence. Safran et al.[55] found in a large survey among primary care patients that not only satisfaction but also self-reported health improvements correlated strongly with integration of care, thoroughness of physical examination, communication, comprehensive knowledge of patients, and trust. Patients, refugees or otherwise, want and need professionally competent doctors with good interpersonal skills.

4.2 Conclusion

Surprisingly, no fundamental difference in paradigms was found between refugees and GPs as to the negative influence worries and bad experiences can have on health. But refugees felt GPs were often prejudiced towards them, too easily bringing up psychological explanations for their physical complaints. A 'general narrative' circulating in the refugee communities, with an overall negative content of prejudice, lack of good care for foreigners or refugees, and professional mistakes with serious consequences, undermines trust. General practitioners were not aware of

this ‘internal context’ of their refugee patients. For a fruitful cooperation to develop, based on trust, GPs need to invest in the relationship with individual refugees, and avoid statements or actions based on stereotypes and prejudice. There is a heartening parallel between refugees’ expectations and GPs’ best practices.

More qualitative and quantitative research is needed to assess whether a ‘general narrative’ phenomenon also exists in other refugee communities, and how widespread it is.
Systematic introduction and evaluation, first qualitatively and later quantitatively, of an introductory consultation with new refugee patients could establish the value and best elaboration of this extra investment in general practice.
Direct observation, visual registration and later (qualitative) analysis of consultations between general practitioners and refugee patients, combined with eliciting refugees’ expectations and level of trust before the consultation, and both the GPs’ and the refugees’ assessments afterwards, can help to raise awareness of possibilities for improvement in specific practices.

4.3 Practice implications

We feel our findings have the following implications for practice:

- Early investment in the relationship with new refugee patients may be crucial to establishing a basis of trust and dealing with unexplained physical symptoms effectively.
- Asking (refugee) patients about their situation and the way they are dealing with it, separate from the complaint that is being presented, helps to create an atmosphere of joint responsibility.
- A physical complaint always deserves a thorough physical examination.
- The tendency to stereotype refugee patients may be a serious pitfall for practitioners.
- Critical reflection by practitioners is needed on strategies they employ for dealing with unexplained physical symptoms.
- Professional errors by medical practitioners have a long life circulating as part of the ‘general narrative’ in refugee communities, undermining trust. A more open climate when dealing with professional mistakes, especially towards the patients involved and their relatives, may help to address this phenomenon.

Privacy

For privacy reasons, all personal identifiers have been removed from this manuscript.

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Reference List

[1] Feldmann CT, Bensing JM, de Ruijter A, Boeije HR. Somali refugees' experiences with their general practitioners: frames of reference and critical episodes. [submitted for publication]].

[2] Feldmann CT, Boeije H, Bensing JM, de Ruijter A. Afghan refugees in the Netherlands and their general practitioners: to trust or not to trust? Sociol Health Illn [accepted for publication].

[3] Feldmann CT, Mol SSL, Bensing J, de Ruijter A, Boeije H. Dutch general practitioners and refugee patients: dealing with unexplained physical symptoms: A qualitative study. [submitted for publication].

[4] Burton C. Beyond somatisation: a review of the understanding and treatment of medically unexplained physical symptoms (MUPS). Br J Gen Pract 2003; 53:231-9.

[5] Mumford DB, Devereux TA, Maddy PJ, Johnston JV. factors leading to the reporting of 'functional' somatic symptoms by general practice attenders. Br J Gen Pract 1991; 41:454-8.

[6] Peveler R, Kilkenny L, Kinmonth AL. Medically unexplained physical symptoms in primary care: a comparison of self-report screening questionnaires and clinical opinion. J Psychosom Res 1997; 42:245-52.

[7] Escobar JI, Gara MSRC, et.al. Somatisation disorder in primary care. Br J Psychiatry 1998; 173:262-6.

[8] Grol R. To heal or to harm. The prevention of somatic fixation in general practice. London: Royal College of General Practitioners, 1981.

[9] Biderman A, Yeheskel A, Herman J. Somatic fixation: the harm of healing. Soc Sci Med 2003; 56:1135-8.

[10] van Willigen LHM, Hondius AJK, van der Ploeg HM. Health problems of refugees in The Netherlands. Trop Geogr Med 1995; 47(3):118-24.

[11] Adams KM, Gardiner LD, Assefi N. Healthcare challenges from the developing world: post-immigration refugee medicine. Br Med J 2004; 328:1548-52.

[12] Hondius A, van Willigen LHM, Kleijn WC, van der Ploeg HM. Health problems among Latin American an Middle-Eastern refugees in The Netherlands: relations with violence exposure and ongoing sociopsychological strain. J Trauma Stress 2000; 13(4):619-34.

[13] Lin EHB, Carter WB, Kleinman AM. An exploration of somatization among Asian refugees and immigrants in primary care. Am J Public Health 1985; 75(9):1080-4.

[14] Coker EM. "Traveling pains": Embodied metaphors of suffering among Southern Sudanese refugees in Cairo. Cult Med Psychiatry 2004; 28:15-39.

[15] May C, Allison G, Chapple A *et al*. Framing the doctor-patient relationship in chronic illness: a comparative study of general practitioners' accounts. Sociol Health Illn 2004; 26(2):135-58.

[16] Wileman L, May C, Chew-Graham CA. Medically unexplained symptoms and the problem of power in the primary care consultation: a qualitative study. Fam Pract 2002; 19(2):178-82.

[17] Raine R, Carter S, Sensky T, Black N. General practitioners' perceptions of chronic fatigue syndrome and beliefs about its management, compared with irritable bowel syndrome: qualitative study. Br Med J 2004; 328:1354-6.

[18] Helman CG. Communication in primary care: the role of patient and practitioner explanatory models. Soc Sci Med 1985; 20(9):923-31.

[19] Salmon P. Patients who present physical symptoms in the absence of physical pathology: a challenge to existing models of doctor-patient interaction. Patient Educ Couns 2000; 39:105-13.

[20] Mathers N, Jones N, Hannay D. Heartsink patients: a study of their general practitioners. Br J Gen Pract 1995; 45:293-6.

[21] Portegijs PJM, Jeuken FMH, van der Horst FG, Kraan HF, Knottnerus JA. A troubled youth: Relations with somatization, depression and anxiety in adulthood. Fam Pract 1996; 13:1-11.

[22] Mol SSL. Trauma, life events and PTSD; a challenge for patients and family doctors [thesis]. Maastricht, The Netherlands: Unigraphic, 2002.

[23] Mollica RF. Assessment of trauma in primary care. JAMA 2001; 285:1213.

[24] Kuyvenhoven MM. Quality of performance of general practitioners confronted with patients' non-specific complaints. Utrecht: Elinkwijk BV, 1988.

[25] Ring A, Dowrick C, Humphris G, Salmon P. Do patients with unexplained physical symptoms pressurise general practitioners for somatic treatment? A qualitative study. Br Med J 2004; 328:1057-60.

[26] Ring A, Dowrick CF, Humphris GM, Davies J, Salmon P. The somatising effect of clinical consultation: What patients and doctors say an do not say when patients present medically unexplained physical symptoms. Soc Sci Med 2005; 61:1505-15.

[27] Morriss RK, Gask L, Ronalds C, e.a. Clinical and patient satisfaction outcomes of a new treatment for somatised mental disorders taught to general practitioners. Br J Gen Pract 1999; 49:263-7.

[28] Lidbeck J. Group therapy for somatization disorders in general practice: effectiveness of a short cognitive-behavioural treatment model. Acta Psychiatr Scand 1997; 96:14-24.

[29] Blankenstein NAH. Somatising patients in general practice; reattribution, a promising approach [dissertation] . Amsterdam: PrintPartners Ipskamp, 2001.

[30] Rothschild B. The body remembers. New York. London: W.W.Norton & Company, 2000.

[31] Levine PA, Frederick A. Waking the tiger. Berkeley, California: North Atlantic Books, 1997.

[32] Mayou R, Sharpe M. Treating medically unexplained physical symptoms; Effective interventions are available. Br Med J 1997; 315:561-2.

[33] Rosendal M, Olesen F, Fink P. Management of medically unexplained symptoms. Includes diagnosis, specific treatments , and appropriate communication. Br Med J 2005; 330:4-5.

[34] Glaser BG, Strauss AL. The discovery of grounded theory: Strategies for qualitative research. New York: Aldin Publishing Company, 1967.

[35] Weiss RS. Learning from strangers. The art and method of qualitative interview studies. New York : Free Press, 1994.

[36] van den Tillaart H, Olde Monnikhof M, van den Berg S, Warmerdam J. Nieuwe etnische groepen in Nederland. Ubbergen, The Netherlands : Tandem Felix, 2000.

[37] Kuckartz U. WinMAX 97. Scientific text analysis for the social sciences. Berlin, Germany: BSS (Büro für Softwareentwicklung und Sozialforschung), 1998.

[38] Kleinman A. Patients and healers in the context of culture. Berkeley: University of California Press, 1980.

[39] van Wieringen JCM, Harmsen JAM, Bruijnzeels M. Intercultural communication in general practice. European Journal of Public Health 2002; 12:63-8.

[40] Innes AD, Campion PD, Griffiths FE. Complex consultations and the 'edge of chaos'. Br J Gen Pract 2005; 55:47-52.

[41] Helman CG. The role of context in primary care. J R Coll Gen Pract 1984; 34:547-50.

[42] Dowrick C, Ring A, Humphris G, Salmon P. Normalisation of unexplained symptoms by general practitioners: a functional typology. Br J Gen Pract 2004; 54:165-70.

[43] Kessler D. Normalisation: horrible word, useful idea. Br J Gen Pract 2004; 54:163-4.

[44] Cameron L, Leventhal EA, Leventhal H. Symptom representations and affect as determinants of care-seeking in a community-dwelling, adult sample population. Health Psychol 1993; 12(3):171-9.

[45] Rees Lewis J . Patient views on quality care in general practice: literature review. Soc Sci Med 1994; 39:665-70.

[46] Klein JG. Five pitfalls in decisions about diagnosis and prescribing. Br Med J 2005; (330):781-4.

[47] Redmond MV. Cultural distance as a mediating factor between stress and intercultural communication competence. International Journal of Intercultural Relations 2000; 24:151-9.

[48] Wallace AFC. Culture and Personality. 2 edition. New York : Random House, 1970.

[49] Fairhurst K, May C. Knowing patients and knowledge about patients: evidence of modes of reasoning in the consultation? Fam Pract 2001; 18(5):501-5.

[50] Jones R. Irritable bowel syndrome:management of expectations and disease. Br J Gen Pract 2004; 54:490-1.

[51] Bensing JM, Verhaak PFM. Somatisation: a joint responsibility of doctors and patients. Lancet 2006; 367(February 11):452-4.

[52] Little P, Dorwerd M, Warner G, Stephens K, Senior J, Moore M. Importance of patient pressure and perceived pressure and perceived medical need for investigations, referral and prescribing in primary care: nested observational study. Br Med J 2004; 328:444-6.

[53] Salmon P, Dowrick CF, Ring A, Humphris GM. Voiced but unheard agendas: qualitative analysis of the psychosocial cues that patients with unexplained symptoms present to general practitioners. Br J Gen Pract 2004; 54 :171-6.

[54] Levinson W, Gorawara-Bhat R, Lamb J. A study of patient clues and physician responses in primary care and surgical settings. JAMA 2000; 284(8):1021-7.

[55] Safran DG, Taira DA, Rogers WH, Kosinski M, Ware JE, Tarlov AR. Linking primary care performance to outcomes of care. J Fam Pract 1998; 47(3):213-20.

CHAPTER 6

DEALING WITH GENDER PREFERENCES IN THE CONSULTING ROOM: ISLAMIC REFUGEE WOMEN AND DUTCH GPS

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DEALING WITH GENDER PREFERENCES IN THE CONSULTING ROOM: ISLAMIC REFUGEE WOMEN AND DUTCH GPS

Abstract

Objectives To explore the opinions of refugee women with an Islamic background on their preference for a GP's gender, their experience when they express their preference and the way GPs deal with same-gender preference in an opposite-gender situation.
Design A qualitative **s**tudy based on in-depth interviews with refugees of Somali and Afghan origin living in the Netherlands, and with Dutch GPs working with refugee patients from Somalia and/or Afghanistan. The material presented here is based on a sub-selection from the total material, i.e., the quotes dealing with the gender issue are taken from interviews with both refugee women and GPs.
Setting Multiple-entry snowball samples of Afghan and Somali refugees living in different municipalities in the Netherlands, and a selective sample of GPs practising in different regions and assisting Afghan and/or Somali refugee patients.
Results
Both Afghan and Somali refugee women expressed a variety of opinions about preference for gender of their care provider, even in intimate situations. More Somali than Afghan women said that the gender of the practitioner was not an issue for them. The experiences of the women, when they expressed their preference, also differ. One woman did not express her preference, but did not respond to an invitation for a cervical smear test. Five of the male GPs we interviewed felt the gender issue was a constraint for them in assisting Islamic refugee women. They found different solutions.
Conclusions
Dealing with gender preferences should start from an open discussion with individual patients, not from assumptions based on a woman's religion and ethnicity.

Keywords: general practitioner / gender preference / Islamic women / refugee women / primary care

Introduction

Gender is an important aspect of the professional but often intimate encounters that take place in the consulting rooms of medical practitioners. It may influence both the access and the outcome of healthcare, possibly in different degrees for different groups in society. Little is known about how medical practitioners actually deal with situations involving gender preferences expressed by women of different backgrounds.

In our qualitative study concerning the experiences of Afghan and Somali refugees in the Netherlands, all of them with an urban Islamic background, gender was one of the aspects that figured prominently in the narratives of the women we interviewed. General practitioners we interviewed about their experiences of providing care to refugees mentioned the gender aspect as one of the constraints in being good GPs for some of their refugee patients.

As in many countries the proportion of female practitioners has increased in the medical workforce, there is more possibility for patients' gender preferences to be honoured.[1] On the other hand, medical training focuses on "neutralising differences"[2]: professional socialisation is supposed to counteract increasing differences among medical students. Research has focused on patient preferences and on differences in communication styles. Patient preferences are related to the type of medical encounter: same-sex gender preferences are mostly expressed for encounters involving intimate examinations or discussion of sensitive problems. [3-5]The preferences of women patients figure more frequently in the literature than those of men, probably because women's reproductive role and common screening procedures necessarily involve more frequent intimate procedures.

In most surveys in western countries, a varying majority of women does not express a strong gender preference, even for gynaecologic or obstetric procedures.[6-11] In a Dutch household survey, Kerssens et al.[5] found 20% of women respondents expressed a same-gender preference for general practitioners; 42% of women respondents expressed preference for a female gynaecologist and 45% for a female midwife. In the same survey 16% of male respondents expressed a preference for a male GP. In a Spanish survey, 50–60 % of patients expressed a same-gender preference for a consultation involving genital complaints, women more frequently than men.[12] In a survey involving patients at an obstetrics and gynaecology clinic in the US, Chandler et al.[13] found that 52% of patients expressed a preference for a female practitioner, but only 35% ranked gender as one of the top two factors for selecting a provider. On the other hand, abused women in a US study based their choice to disclose or not to disclose the abuse while visiting their doctor, more on her or his attitude – caring, easy to talk to, protective – than on gender.[14]

The findings among Islamic populations tend to be different, though not unequivocal. In a survey involving a mixed population in the US,[15] almost 90% of Muslim women expressed a preference for a female provider of obstetric/gynaecological services, as opposed to 74% of Hindu women and 55–60% of women belonging to other religions. Only a minority of the women felt strongly about their preference. In a survey among patients attending obstetric and gynaecological services in the United Arab Emirates, 86.4% of the respondents expressed a preference for a female physician. The reasons given for this preference were embarrassment (90%), religious beliefs (74%) and cultural traditions (45%).[16] From an interview study among women with an Islamic background living in Australia, the possibility to choose a female provider of antenatal care, as well as better information about procedures, were highlighted as points for attention.[17]

Participation in screening procedures can be negatively influenced by women's considerations about modesty and gender. Rajaram et al. found this to be the case for participation by Asian-Islamic women in breast cancer screening in the US.[18] Patients of female physicians were shown to have higher rates for breast and cervical cancer screening in Minneapolis, US.[19]

In this article we present the results of our interviews with Somali and Afghan refugee women and with general practitioners as far as the gender aspect is concerned. We shall deal with the following questions:

1. What is the variety in opinions among the women on the issue of preference for a GP's gender?
2. What are the experiences of the women when they express their preference?
3. How do GPs deal with same-gender preference in an opposite-gender situation?

Method

In our qualitative study exploring participants' experiences with healthcare in the Netherlands, we conducted 24 in-depth interviews with refugees from Afghanistan, involving 21 Afghan women [20]. Twelve Afghan women were interviewed together with their husbands, nine alone. Twenty-five interviews with refugees from Somalia living in the Netherlands involved 21 Somali women [21]. Seven Somali women were interviewed together with their husbands and 14 alone. The participants lived in different municipalities in the Netherlands, for between 3 and 15 years. A topic list was used, but handled in a flexible way. The topics covered experiences with healthcare in the country of origin and experiences after arrival in the Netherlands. The gender aspect was not one of the principle topics, but appeared to be an important part of the narratives. The narratives contained many stories about experiences with general practitioners. The interviewer verified for each story whether a male or a female practitioner was involved, if that was not immediately clear from the beginning. All interviews were recorded on tape with the consent of the participants, and a verbatim transcription was made of each interview. A "gender of practitioner" code was assigned to each section dealing with gender aspects, both opinions and actual experiences of the participants, using the WinMax programme.[22] All gender-related quotes were analysed, and opinions, preferences and experiences distinguished for Afghan and Somali participants.

We interviewed 24 Dutch general practitioners, 17 men and 7 women, about their experiences of assisting Afghan and Somali refugee patients. They were not the GPs of the refugees we interviewed. The interviews covered the views of the GPs on the situation and illness presentation of their refugee patients, the way they dealt with problems presented to them and the constraints they met. The GPs had their practices in different parts of the country and their experiences dealing with refugee patients and other migrant groups varied in length. Gender-related quotes were assigned a separate code during the analysis and related to the gender of the practitioner concerned.

Results

Gender preference

The gender of a provider was an issue in 11 out of 21 interviews with Somali women and 14 out of 21 interviews with Afghan women. Seven Somali women said the gender of the general practitioner did not matter to them: a doctor is a doctor. Six of these women were interviewed alone. In one case, the husband was present and agreed. Four Somali women said their body was

forbidden territory for any man except their husband, except in an emergency, for religious reasons. Two of these women were interviewed alone, two together with a husband.

All the Afghan women who gave an opinion on this issue expressed a gender preference. Eleven of them said it was easier to have a female GP, especially when intimate examinations were involved, but they were not very adamant about their preference. In seven of these interviews, the husband was present. Two others linked their opinion to their circumstances, such as being in a foreign country without a husband. Three women stated they should not be intimately touched by a strange man, except in an emergency. In two of these interviews, the husband was present.

Experience when expressing preference

Three of the four Somali women who expressed a strong preference for a female GP actually had a male GP. Two of them had the possibility to make an appointment with a female doctor for intimate examinations. The third woman said she did not show up for a cervical smear test because her doctor was a man, but she had not discussed this with him. Neither had she asked for a female GP, because practices were very full in the city where she lived.

Four of the Afghan women who expressed a same-gender preference had a female GP. Four other women said their GP referred them to a female gynaecologist on their request. Three Afghan women were patients in a dual practice, where they could easily arrange an appointment with a female doctor if they wished. Two women recounted how their male GP had become very angry when they asked to be referred to a female practitioner for a gynaecological examination. For both these women, this was a very shocking experience, especially as the doctors involved had made negative inferences about their Islamic background and their duty to adapt to European cultural standards. One woman related how her male GP, when she consulted him about lower abdominal complaints and requested referral to a gynaecologist, insisted that he should examine her first, in his role as GP. She asked for some time to think about it, and came back after a week for the examination – because she decided she could trust him.

GPs on gender issues

Five of the 17 male GPs we interviewed mentioned gender issues as a constraint in dealing with Islamic refugee women. They felt they missed certain issues because the women didn't want to bring them up, and therefore they could not be good GPs for these women. As for the practical side, the GPs had either instructed their practice assistant to perform the examination while retiring behind a curtain themselves, or they referred the woman to a female colleague or gynaecologist. Female GPs, on the other hand, felt refugee women confided certain problems more easily to them, but they also came across shame in discussing sex-related issues.

Discussion

Although our groups were small, we think our findings are interesting. If doctors tend to see themselves as neutral,[2] this does not automatically mean that their patients are also prepared to see them as neutral. Our findings go beyond the domain of general ideas or assumptions, and also beyond the social desirability of doctors always being well-mannered professionals. The women we interviewed gave their views on this issue spontaneously, as part of their narrative about their experiences with healthcare. The variety of their opinions, even within relatively small groups of women with an Islamic background from Afghanistan and Somalia, is a warning against easy generalisations about how to approach certain "groups". A focus-group study among Somali women living in Minnesota, US, also demonstrated a variety of opinions on the gender preference

issue, 15 out of 27 women preferring a female provider, and only three basing their opinion on religious conviction.[23]

We cannot provide an explanation for the difference we found between the Afghan and Somali women. More Afghan women than Somali women were interviewed together with their husbands. This may or may not have influenced the opinions expressed. Most women who expressed a same-sex gender preference did so using the argument that they "felt more comfortable", identifying themselves primarily as women, or women in a refugee situation, and not so much as Islamic women. The length of stay in the Netherlands and the level of education did not differ much between the Afghan and Somali women. Of course, the limited size of our groups does not allow any further conclusions about gender preferences among Somali or Afghan women more generally.

In international surveys, Islamic women express a same-sex preference when choosing a care provider more often than western women, especially if intimate procedures are involved.[15;16] This does not mean that all women with an Islamic background should be assumed to hold that same preference. Patients are individuals who can be approached and asked openly about their preferences.[17;23] Respectful asking in itself may contribute to clearing the atmosphere.

Female care providers are not always available in western countries, and to a much lesser degree in countries of origin. According to the women we interviewed, in the case of an emergency Islam is pragmatic: the life and health of the woman are more important than the gender issue. The Taliban regime in Afghanistan was a dramatic exception, virtually excluding women from access to healthcare.

The usual practice in most western countries, and also in the Netherlands, is that gender preferences should be accommodated where possible. The wording of the invitational letter for the cervical screening procedure in the Netherlands indicates that the woman can express her preference for a female practitioner. But apparently not all GPs are aware of this wording, or they do not agree with it. Our interview results evoke the question of how much it is the task of general practitioners to try and mitigate the gender preferences of Islamic women. Doing this through an emotional outburst can only be qualified as unprofessional behaviour. Accommodating gender preferences may greatly enhance adherence to preventive screening procedures and thus quality of care.

It is clear that many western women also have gender preferences, though they may feel very strongly about these preferences less often. The gender preferences of patients necessarily have to be seen from the perspective of the availability of female professionals. They are more represented in certain specialties (paediatrics) than in others (surgery).[1] Female practitioners also more often work part time than do male medical practitioners,[1;24] reducing the actual availability of female doctors. The number of women entering the medical field has greatly increased in recent years in many countries.[1] In the Netherlands, female GPs made up 34% of the GP workforce in 2006, but most of them work in group practices, health centres and dual practices, resulting in unequal availability of women practitioners in different parts of the country. On the other hand, gender sensitivity in dealing with delicate issues and an open attitude to let patients bring forward their points of view[25] do not need to be the prerogatives of female practitioners.

Reference List

1. Allen I. Women doctors and their careers: what now? *British Medical Journal* 2005;**331**:569-72.

2. Beagan BL. Neutralizing differences: producing neutral doctors for (almost) neutral patients. *Social Science and Medicine* 2000;**51**:1253-65.

3. Ackerman-Ross FS,.Socha N. Close encounters of the medical kind: attitudes toward male and female physicians. *Social Science and Medicine* 1980;**14A**:61-4.

4. Ahmad F, Gupta H, Rawlins J, Stewart DE. Preferences for gender of family physician among Canadian European -descent and South-East Asian immigrant women. *Family Practice* 2002;**19** :146-53.

5. Kerssens JJ, Bensing JM, Andela MG. Patients' preference for health professionals' gender. *Social Science and Medicine* 1997;**44**:1531-40.

6. Vondruska-Bendert K, Steiner RA, Buddeberg C, Haller U. [Gynecological examination: perceptions, fears and expectations of polyclinic patients]. *Gynakologie und geburtshilfe Rundschau* 1995; **35**:20-5.

7. Plunkett BA, Kohli P, Milad MP. The importance of physician gender in the selection of an obstetrician or a gynecologist. *American Journal of Obstetrics and Gynecology* 2002;**186**:926-8.

8. Patton DD, Bodtke S, Horner RD. Patient perceptions of the need for chaperones during pelvic exams. *Family Medicine* 1990;**22**:215-8.

9. Lund JD, Rohrer JE, Goldfarb S. Patient gender preferences in a large military teaching hospital. *Obstetrics and Gynecology* 2005;**105**:747-50.

10. Howell EA, Gardiner B, Concato J. Do women prefer female obstetricians? *Obstetrics and Gynecology* 2002;**100**:827-8.

11. Fisher WA, Bryan A, Dervaitis KL, Silcox J, Kohn H. It ain't necessarily so: most women do not strongly prefer female obstetrician-gynaecologists. *Journal of Obstetrics and Gynaecology Canada* 2002.

12. Delgado A, Martinez-Canavate T, Garcia V, Frias J, Rueda T, Morata J. [Patient preference and stereotype about the gender of family physician]. *Atencion Primaria* 1999;**23**:268-74.

13. Chandler PJ, Chandler C, Dabbs ML. Provider gender preference in obstetrics and gynecology: a military population. *Military Medicine* 2000;**165**:938-40.

14. McCauley J, Yurk RA, Jenckes MW, Ford DE. Inside "Pandora's box": abused women's experiences with clinicians and health services. *Journal of General Internal Medicine* 1998;**13**:549-55.

15. Zuckerman MNN, Feldman J, McCalla S, Minkoff H. Determinants of women's choice of obstetrician/ gynecologist. *Journal of Womens Health and Gender Based Medicine* 2002;**11**:175-80.

16. Rizk DE, El-Zubeir MA, Al-Dhaheri AM, Al-Mansouri FR, Al-Jenaibi HS. Determinants of women's choice of their obstetrician and gynecologist provider in the UAE. *Acta Obstetrica Gynecologica Scandinavica* 2005;**84**:48-53.

17. Tsianakas V,.Liamputtong P. What women from an Islamic background in Australia say about care in pregnancy and prenatal testing. *Midwifery* 2002;**18**:25-34.

18. Rajaram SS,.Rashidi A. Asian-islamic women and breast cancer screening: a socio-cultural analysis. *Women Health* 1999;**28**:45-58.

19. Lurie N, Margolis KL, McGovern PG, Mink PJ, Slater JS. Why do patients of female physicians have higher rates of breast and cervical cancer screening? *Journal of General Internal Medicine* 1997;**12**:34-43.

20. Feldmann CT, Boeije H, Bensing JM, de Ruijter A. Afghan refugees in the Netherlands and their general practitioners: to trust or not to trust? *Sociology of Health and Illness* [accepted for publication].

21. Feldmann CT, Bensing JM, de Ruijter A, Boeije HR. Somali refugees' experiences with their general practitioners: frames of reference and critical episodes. [submitted for publication]].

22. Kuckartz, U. WinMAX 97. Scientific text analysis for the social sciences. 98. Berlin, Germany, BSS (Büro für Softwareentwicklung und Sozialforschung).

23. Wissink L, Jones-Webb R, DuBois D, Krinke B, Ibrahim Q. Improving health care provision to Somali refugee women. *Minnesota Medicine* 2005;**88, electronic edition February 2005**.

24. Bensing JM,.van den Brink-Muinen A. Gender differences in practice style: a Dutch study of general practitioners. *Medical Care* 1993;**31**:219-29.

25. van den Brink-Muinen A, Bensing JM, Kerssens JJ. Gender and communication style in general practice; differences betweeen women's health care and regular health care. *Medical Care* 1998;**36**:100-6.

7. FINAL CHAPTER

7.1 SUMMARY

Chapter 1 contains a general introduction. Refugees from outside Europe are a relatively new group in the Netherlands. Unlike earlier migrants who predominantly live in the bigger cities, they have settled in municipalities all over the country as a consequence of government policy. Indications of refugees being dissatisfied with healthcare, and GPs experiencing problems assisting refugee patients inspired this study. The aim of the study was to compare the perspectives of refugees and general practitioners in the Netherlands, and learn from the confrontation of their perspectives. A theoretical framework is outlined, drawing on different disciplines and fields of knowledge.

A qualitative method with in-depth interviews was chosen, aiming to gain an insight into experiences, considerations and reflections of both individual refugees and individual GPs.

Chapter 2 presents the first results of twenty-five interviews with participants from Somalia (n=30) living in different places in the Netherlands, varying in ages and educational backgrounds. The personal narratives of the interviewees were analysed in episodes of contact with health care. Episodes that in retrospect had been of specific importance to the participants were labelled 'critical episodes'. In this way, chains of critical episodes were constructed, and individual critical episodes were analysed. Critical episodes left either a positive mark or a negative mark in the memory of the participant, and were articulated as such. A positive mark meant that trust in the healthcare provider had increased after the critical episode, while a negative mark led to a decrease in trust. The core characteristics of negative critical episodes were not getting attention, and a feeling of not being taken seriously.

GPs figured in all the narratives of Somali participants. The narratives of individual interviewees or couples showed a good variety, ranging between gratitude and satisfaction with past or present GPs on one side, to dissatisfaction and frustration among other participants. A way out of an unsatisfactory relationship with a health care provider was often sought abroad, in another European country, where family relations help to provide access. German doctors especially were praised by Somali interviewees, for their professional thoroughness.

Almost all interviewees, however, hinted at negative experiences other refugees from Somalia had had with Dutch healthcare. Because of its omnipresence in the narratives, this phenomenon was labelled the 'general narrative'. The tone of the general narrative is: Dutch healthcare is good, but not for us. We, as Somali's, refugees, foreigners, are not taken seriously. Professional errors are interpreted as resulting from lack of interest and lack of attention on the part of the professional, based on a prejudiced or discriminatory attitude.

The general narrative also embodies medical errors that have happened to other Somali's, and in some cases other people of foreign origin, personally known to the interviewees: physical symptoms that were not recognised in time as signs of an underlying fatal disease; small children dying of dehydration, after the worried parents visited a healthcare professional several times; people being left handicapped after anaesthesia for a minor operation.

The interviewees took different positions referring to the general narrative, either identifying with it or taking a distance from it. The position they took depended on their personal experiences with healthcare in the Netherlands, and especially the recent experiences with their GP.

Earlier personal experiences with healthcare in the Netherlands, and stories heard form others about their experiences with Dutch healthcare, were more often used as a frame of reference during the interviews than experiences with healthcare in Somalia. Expectations of care providers as formulated by our Somali participants did not substantially differ from expectations of users of primary healthcare as found in the international literature.

Chapter 3 contains the results of twenty-four interviews with thirty-six participants of Afghan origin, living in different places in the Netherlands and varying in age and educational background.

The general narrative phenomenon was also found among the Afghan participants and pointed to a body of narratives with a generally negative content circulating in the Afghan community. Elements of the Afghan general narrative were found to a large extent to be congruent with the content of the Somali general narrative: feelings of lack of attention and not being taken seriously by care providers, based on prejudice. Along with a supposed prejudice against foreigners, the prejudice towards refugees having physical complaints because of psychological problems was mentioned by Afghan participants. The GP as the central figure in healthcare evoked mistrust among some Afghan participants: how can one doctor deal with so many different types of complaints and diseases? Participants with the most negative critical episodes identified most strongly with the general narrative.

The critical episode concept was also used to analyse the Afghan personal narratives, and yielded a good variety. The chains of individual critical episodes were then analysed in relation to the participants' personal and social resources. Personal resources were operationalised as a combined score of age, education and European languages spoken on arrival. Social resources were differentiated in 'known' (family and Afghan friends) and 'new' (mostly Dutch) social resources.

Participants with more personal resources more often made use of new social resources and more often had positive critical episodes after initial negative critical episodes. They succeeded in discussing their problem with a healthcare professional or changing to another provider.

The results of the refugee interviews are discussed against the background of the international literature on patient satisfaction and communication in healthcare. The needs and expectations expressed by the refugee participants did not basically differ from the needs and expectations of other clients of healthcare, as they have found their way into the international literature.

Chapter 4 presents the results of the qualitative analysis of semi-structured interviews with twenty-four Dutch GPs assisting (former) refugees from Somalia and/ or Afghanistan in their practices. They were not the GPs of the participants in the refugee interviews. From a random sample of 325 GPs practising in different regions in the Netherlands, twenty-one volunteered for an interview. Three more GPs were interviewed via personal contacts. The GPs varied in age, sex, type of practice organisation, number of refugees, years of experience and numbers of people of foreign origin in their practices, but they were not a representative sample of GPs in the Netherlands. Older GPs and GPs practising in urban group practices were over-represented.

Most urban practices have adapted their organisations to deal with increasing numbers of foreign-born patients over the years. Refugee patients profit less from these changes than the larger numbers of earlier migrants.

GPs see a clear distinction between their refugee patients and other patients of non-Dutch origin - mostly migrant workers - specifying the losses and violence that refugees have experienced, their higher educational levels and associated better language skills.

Despite their generally better language skills, GPs still experience language problems while assisting refugee clients. The availble interpreting service is rarely used. Alongside the language problems, the GPs most often mentioned dealing with medically unexplained physical symptoms as a difficult challenge in assisting refugee patients. They had developed a variety of strategies for dealing with the refugees' supposed 'stress-related complaints', ranging from a predominantly somatic approach to a consequent bio-psychosocial approach.

The doctors who had most experience working with refugee patients, emphasised the importance of investing in the relationship with refugee patients right from the beginning and approaching each (refugee) patient as an individual, not as a representative of a group. The GPs who invested in the relationship with refugee patients from the beginning and applied a consequent biopsychosocial strategy when dealing with unexplained physical symptoms, seemed most satisfied with their approach.

In **chapter 5** a confrontation of refugee interviews and GP interviews is presented, focusing on physical complaints without an apparent diagnosis, 'medically unexplained physical symptoms' or MUPS. From the interviews, MUPS appeared to be a key issue for both refugee patients and GPs, but from quite different angles.

The refugee interviewees, both from Afghanistan and Somalia, gave a comprehensive definition of health, relating it to physical, emotional, and mental functioning, as well as to autonomy. Participants in twenty-one out of twenty-four Afghan interviews spontaneously mentioned 'worries' or 'thinking too much' as a cause of illness. So did participants in fifteen out of twenty-five Somali interviews, making 'worries' the single most frequently mentioned cause of illness in both Afghan and Somali refugee interviews. Most Afghan participants considered this notion of worries as a cause of illness as part of their cultural heritage. Somali participants saw it as a new discovery and part of their existence in exile.

The refugee interviewees primarily felt responsible for their own health and situation. They were active in their endeavours to keep themselves healthy and sound, through careful choice of food, meticulous hygiene and regular physical exercise. Both Somali and Afghan participants mentioned a range of strategies to cope with their worries and bad memories. Doctors were primarily expected to address physical complaints. That is considered to be their expertise. Physical complaints elicit fear and insecurity, but also interfere with daily functioning, and therefore threaten autonomy. Anxiety about symptoms is an important motive to visit the GP, and their first need is to know the cause of the symptoms. The interviewees found it important that a doctor shows interest in their person and their background, and displays a welcoming attitude. They want to be approached as individuals, not as representatives of a group. They need recognition and adequate examination of their physical complaints, resulting in an explanation that deals with specific fears, and an exchange of views about how to proceed.

The problem arising from the refugee interviews is one of feeling approached on a prejudiced basis. Refugees feel GPs too readily use their difficult situation and experiences as an explanation for physical symptoms, based on stereotyped ideas about refugees as a group. There is a general narrative circulating in both Afghan and Somali refugee communities with an overall negative content of prejudice, lack of good care for foreigners or refugees, and professional mistakes, sometimes with severe consequences. This general narrative is the evidence of a weak basis of trust between the refugee communities and care providers.

The GPs saw MUPS, mostly designated as 'stress-related complaints' or 'psychosomatic complaints' as a significant part of the illness presentation by their refugee patients. They connected the presentation of a wide spectrum of physical complaints to the situation their refugee patients are living in, and also to their past experiences. They expressed difficulty, in many cases, in dealing with this type of complaint. They developed different strategies to deal with these complaints of their refugee patients, and mentioned different levels of satisfaction about their approach. The strategies, as discussed by the doctors in the interviews, could roughly be divided into a 'human interest strategy' and a 'technical strategy'. The most elaborate 'best practices' came from GPs who said they follow a biopsychosocial approach, combined with a 'human interest strategy'. They emphasised the importance of investing in the relationship with refugee patients right from the beginning, and felt they were able to connect to the patients and their worries, at the same time recognising and attending to the physical pains and problems.

The results of the study are discussed in the wider context of the literature on MUPS and patient satisfaction. The best practices brought up by some GPs seemed to fit well with the expectations and needs as expressed by the refugee participants.

The core problem identified from the interviews is not so much a fundamental difference in paradigms between GPs and refugee patients, at least not as far as definitions of health and the influence of worries on health are concerned. The problem is rather a lack of trust, based on phenomena that are out of sight for practitioners. Besides that inadequate communication probably plays a role. For fruitful cooperation to develop, GPs need to invest in the relationship with individual refugees, and avoid actions based on stereotypes and prejudice. Critical reflection is needed on the strategies practitioners employ to deal with MUPS.

In **chapter 6**, the focus is on gender, more specifically the gender preferences as expressed by the refugee women, their experiences when they express their preference and the way GPs deal with same-gender preference in an opposite-gender situation. Male GPs we interviewed mentioned the gender aspect as one of the constraints in being good GPs for some of their refugee patients. The material presented here is based on a sub-selection from the total material, i.e., the quotes dealing with the gender issue are taken from interviews with both refugee women and GPs.

Both Afghan and Somali refugee women expressed a variety of opinions about preference for gender of their care provider, even in intimate situations. More Somali than Afghan women said that the gender of the practitioner was not an issue for them. All the Afghan women who gave an opinion on this issue expressed a gender preference, especially where intimate examinations were involved. Most of them were not very adamant about their preference, using phrases such as'it is easier to have a woman'. Four Somali women and three Afghan women were stricter in their preference, though still exempting cases of emergency.

Not all women who expressed preference for a female GP actually had a female GP. Some were patients in a dual practice, where they could easily make an appointment with a female colleague.

Some others were referred to a female gynaecologist on their request. One woman did not express her preference, but did not respond to an invitation for a cervical smear test. Two women related how their male GP became very angry when they asked to be referred to a female practitioner for a gynaecological examination.

Five of the male GPs we interviewed mentioned gender issues as a constraint in dealing with Islamic refugee women. They felt they missed certain issues because the women didn't want to bring them up, and therefore they could not be good GPs for them. As for the practical side, the GPs had either instructed their practice assistant to perform the examination while they themselves retired behind a curtain, or they referred the woman to a female colleague or gynaecologist.

The results are discussed in the context of the literature on gender preferences in medical situations. In international surveys, Islamic women express a same-gender preference when choosing a care provider more often than western women. This does not mean that all women with an Islamic background should be assumed to hold that same preference. Dealing with gender preferences should start from an open discussion with individual patients, not from assumptions based on a woman's religion and ethnicity.

7.2 REFLECTIONS

On the method used

The aim of this study was to explore the reflections and opinions of refugees and general practitioners in the Netherlands on the way they meet and deal with each other, in their full variety, and gain an insight into processes at hand, also paying attention to the historical dimension. In order to achieve this aim and make people's voices heard, a qualitative design based on in-depth interviews was needed.

A qualitative study based on interviews is a laborious and time consuming design. There is a long delay between the original interviews and the results becoming visible. Other qualitative methods, such as focus groups (Omidian, 2000) or making an inventory of opinions within an institutional setting (MacMullin and Loughry, 2000) can yield quicker results.

What focus group interviews cannot produce is the variety of individual opinions, reflections and perceptions, and the history behind these opinions. They tend to produce the general narrative. Health and illness in the end are individual experiences, though strongly connected with being part of a family and a community (Kopinak, 1999; Lipson, 1991). This latter notion fostered the choice for the interview design.

The qualitative design as we used it, eliciting people's memories of events in the recent and less recent past, evokes the question of the relationship between memory and 'truth'. The researcher being part of the discussion, in fact eliciting the narrative there and then, can only deal with the material the participant is prepared to share and in the way it is presented. The narrative takes shape, depending on how much the researcher keeps to her own 'agenda', the topic list, or decides to follow the associations of the interviewee that may stray away from the structure of the topic list (Leydesdorff, 2004).

The interview itself becomes part of a 'sensemaking process' (Weick, 1995; Geertz, 1973; de Ruijter, 1996). With growing experience I found that following the associations of the interviewee was much more fruitful than strictly keeping to the topic list. In this way the participant came up with what was really important to her or him. Adding some questions such as 'how?', 'why?', 'explain more', 'was that always your opinion?', helped to clarify issues. Participants may have had their reasons for bringing up certain issues and leaving out others. Human memory is believed to be unreliable. It is impossible to know whether the events participants related really happened the way they told them. My position is that the only choice a researcher in this type of study has is to accept everything a participant says as 'real'. That is, truth as it is perceived by the participant, the perception or image the event has left in her or his memory, knowing that the perception may have been influenced by later experiences and stories heard from other people.

It was unavoidable that the sampling procedure that was used led to a selection of refugee participants. Trust appeared to be a decisive factor in the decision to participate – trust in the person of the intermediary. Single young men, numerous among first generation refugees, were under-represented. Other channels would have been needed to reach them.

Originally the scenario was that possible participants would be approached by the community organisations, with a preliminary explanation about the aim and practicalities of the research.

Then, after an initial agreement, one of the assistant researchers would phone the possible participant, give additional information if necessary and make an appointment if the person agreed to give an interview. It appeared that in this way too many people were waiting for each other, and we decided to start using a more direct network approach, via assistant researchers and people working for the Dutch Council for Refugees and other personal contacts.

Intermediaries got refusals for different reasons, such as negative associations with the word interview (reminiscent of the interview with the immigration service), fear that the general practitioner might hear about what they said, and lack of time. A recommendation for future researchers could be to use the word 'discussion' rather than the word 'interview', in order to avoid associations with the immigration service interview. Lack of time was mostly an argument given by people who had a job, selectively decreasing the number of employed participants in the study.

More women than men participated in the study, especially from the Somali side. This may be connected with the subject of the study. Health is a subject that is more discussed among women than among men, both with Afghans and Somalis. In families it is mostly the women who are in charge of health matters. Men prefer to discuss politics.

More Afghan than Somali interviews became 'discussion groups' as described by Omidian (Omidian, 2000), a husband and wife taking part together, adding to each other's words and sometimes correcting each other, which often appeared to be fruitful for the discussion. The presence of the assistant researcher in most cases helped to break the initial uneasiness, especially if the participant knew the assistant researcher. The assistant researchers also played a role as 'cultural intermediaries', explaining issues to two sides, which was very valuable. There was one case though, where a possible participant refused the interview at the last moment because of the assistant researcher – apparently distantly known, but not trusted.

The GPs who took part in the study were not the GPs of the refugee participants. A scenario of interviewing 'pairs' of refugees and GPs was dropped at an early stage, because of the expectation and also urgent advice from experts that refugee participants would refuse to give an interview, and certainly not speak openly, if they knew that their GP would also be approached for an interview.

The GPs we did interview were not a representative sample of GPs in the Netherlands. Older GPs and GPs practising in group practices or health centres in an urban environment were over-represented. Since we chose to approach the GPs separately from the refugees who were interviewed, there was no way of knowing which GPs had Afghan and/ or Somali refugee patients in their practices. The GPs may have had many other considerations in their decisions as to whether or not to take part in the study, besides having refugee patients in their practices. The GPs who were approached through personal networks obviously were approached because of their known positive attitude towards, and long experience working with, refugees.

The results of the GP interviews can therefore not be considered to represent the whole scope of attitudes, perceptions and strategies among GPs in the Netherlands working with refugee patients. Our procedure did however result in bringing out some best practices, and in exposing an interesting variety in perceptions and strategies among GPs.

General reflections

Perhaps one of the most remarkable findings of this study is that refugees' expectations from GPs do not basically differ from what other patients in the Netherlands and internationally expect from their doctors: a doctor who takes them seriously, listens to their story very well, performs a careful physical examination and gives clear information about considerations, possibilities for further diagnostics and treatment. In an international review of studies dealing with patients' views on quality of care, Rees Lewis (Rees Lewis, 1994) concluded that "patients do not seem to make a clear distinction between technical skills and interpersonal skills of doctors".

Nearly all studies emphasised communication as one of the aspects of a consultation most indicative of quality of care from patients' perspective. Bensing (Bensing, 1991; Bensing et al. 1996) found in a quantitative analysis of videotapes the affective behaviour of GPs correlated positively with room for the patient and the professional quality of the consultation as judged by a panel. In a review of studies on quality of physician-patient communication and patient health outcomes, Stewart (Stewart, 1995) found a positive relationship in most of the reviewed studies. So good communication is not only appreciated by patients, it also contributes to better outcomes of care.

The refugees in this study, with one or two exceptions, did not make a distinction between the interpersonal skills and technical skills of the doctors they encountered. Interpersonal skills, including friendliness and a welcoming attitude, tended to be used as a measure of whether a particular doctor was sufficiently interested in them to be trusted. The participants were emphatic that the doctor has to listen to them very well, in order to be able to take the right direction and apply the right knowledge to their case. Moreover, professional errors that the participants related or heard about from others tended to be blamed on lack of interest on the part of the doctors. In this context it is interesting to refer to a highly regarded malpractice attorney, cited by Clancy (Clancy, 2005), who called 'not listening to the patient' the number one cause for missing a diagnosis of myocardial infarction.

The refugee participants in most cases did not doubt the technical skills of Dutch doctors. The doctor's certificate seemed to be perceived as a guarantee for quality. In a way, the refugee participants took us back to the basic rule of medicine; that it starts and ends with the patient. Applying evidence-based medicine is a great goal to continue pursuing, but the right evidence needs to be applied to the right patient. In order to do that, careful communication is indispensable – making communication the bridge between evidence-based medicine and patient-centred medicine (Bensing, 2000).

Trust came out as a key concept from the refugee interviews. Trust is conditional for accepting a doctor's explanations, accepting proposals for treatments that are different from what was expected, and for adhering to treatment plans. The need to build a trusting relationship when assisting refugee patients has been stressed by many authors and practitioners (Burnett and Peel, 2001; Firling, 1988; Lipson and Omidian, 1992; van der Veer, 2003; Lipson and Omidian, 1992). It is important for providers of healthcare to realise that different elements in refugees' experiences may have undermined trust.

Trust may be an under-researched area of healthcare organisation (Green, 2004), but interest in it seems to be undergoing a revival. Misztal (Misztal, 1996) defined trust as follows: "to believe that results of somebody's intended action will be appropriate from our point of view". In an instrument designed to measure public trust in healthcare (Straten et al. 2002), 'trust in the patient focus of health care providers' came out as the most decisive dimension. Public trust

appeared to be determined both by personal experience and experience of friends in this study. Trust has been linked to outcomes of care (Safran et al. 1998), and lack of trust to delay in reporting serious illness (Malterud, 2005). There can be little doubt that trust is a useful, probably indispensable ingredient in the practice of healthcare.

But how to establish trust? The refugee interviews in this study first and foremost point to the attitude and interpersonal conduct of the doctor. The welcoming smile, as a sign of readiness and attention, and showing an interest in the person and their context. In his exploratory study on patient-physician trust, Thom (Thom and Campbell, 1997) also made the observation that "a good bedside manner is not just a desirable amenity, it is essential to providing competent care".

In primary care, an introductory consultation may be a very valuable tool, as also indicated by experienced GPs in this study. Of course the question can be raised as to whether a special and longer introductory consultation should only be offered to special categories of new patients, or to all of them. For new refugee patients, at least some extra topics need to be included, like the country of origin, reason for and year of departure, whereabouts of family, present socio-economic situation, and earlier experiences with healthcare. Preferably the topics for such an introductory consultation should be developed in dialogue with experts from refugee communities.

The 'general narrative' that was mentioned by virtually all refugee participants we interviewed may point to a relatively low level of institutional trust in Dutch healthcare (Straten et al. 2002) in the respective communities. Of course the small number of participants involved in this study does not allow generalisations. Further research is needed to know whether the negative general narrative phenomenon is present in the whole networks of Afghan and Somali refugees, possibly also networks of other refugee and migrant groups. The fact however that it was so often mentioned leads to the consideration that it may be significant.

Then the question arises as to what the 'general narrative' means. Looking at Chrisman's model of the 'health seeking process' (Chrisman, 1977), the general narrative is part of the 'social dimension' the refugee patients live in, but belonging to the 'internal context' as described by Helman (Helman, 1984) and therefore will usually be out of sight for the doctor consulted. Its negative influence on trust will be stronger, the more the individual refugee patient identifies with the general narrative, because of earlier negative experiences and living mostly within the network of the 'own group'.

A feeling of living in a marginalised position in the Dutch society may strengthen identification with the general narrative. Other authors have mentioned 'contemporary legends' (Dingwall, 2001) or 'medical gossip' (Manderson and Allotey, 2003) circulating in more or less marginalised groups in other countries. These stories have a more 'legendary' character than the stories making up the general narrative in this study. The function of the stories as 'narratives of mistrust', warning against possible threats from outside, at the same time strengthening internal cohesion, may well be parallel. They can however also be interpreted as signals that people want to help improve the quality of services (Manderson and Allotey, 2003).

The position former refugees take in a society, after having been admitted and living there for some time, is the result of an interaction process that starts from the moment of arrival and continues for many years. An interaction process between an individual or family, the larger community of 'fellow countrymen and women' already present, and the 'mainstream society', as also discussed by Eastmond (Eastmond, 1998): "With its emphasis on trauma, and in the absence of viable opportunities for economic and social integration, the receiving society seems to offer a

sick role and a pathologised identity. However, from the refugees' perspective, the major concern in their everyday lives is rather the active reconstitution of 'normal life', which means recovering a sense of economic independence and control over their lives." Ghorashi (Ghorashi, 2005) makes the same argument, referring to the Dutch context: "The image of helplessness is stronger in highly regulated states: the system changes the active, adult self into passive client. If you cannot be active, you become prisoner of the past". The percentage of (former) refugees depending on social security is estimated between 38-57% in the Netherlands (Klaver et al. 2005).

Refugees in this study were also adamant about their priority to re-establish an active and economically independent life, except for people who felt that, because of their age, the future was only for their children. Autonomy and economic independence were considered to be part of a holistic concept of health, absence of this independence a factor contributing to illness. Kopinak (Kopinak, 1999) got a similar holistic definition of health from Bosnian refugees in Canada, Lipson (Lipson, 1991) from Afghan refugees in the US and Eastmond from Bosnian refugees in Sweden (Eastmond, 1998). Barudy referred to the need for 'reorganisation of the social identity' as one of the tasks awaiting political refugees resettling in a foreign country (Barudy, 1989). In a philosophically written book review in the British Medical Journal, Marmot (Marmot, 2003) drew the attention of a broad medical readership to the link between autonomy, self-esteem and health.

It should be a priority for receiving societies to support former refugees in their endeavours to re-establish autonomy and economic independence. A recent report by the Dutch Council for Refugees (Klaver et al. 2005) demonstrates that a lot of work remains to be done in this regard.

The position refugees, or other migrant groups for that matter, take in a new society does not develop in a simple linear way. In many western societies, the discourse has taken a much sharper edge the last five years – polarising 'us' and 'them', blaming problems on 'the other'. Refugees in the Netherlands have taken their share of this uneasiness. The societal debate also involves the issues of 'solidarity' and choices to be made between belonging 'here' or belonging 'there'. This study illustrates that in most cases life in a 'diaspora' situation involves both here and there – refugees and migrants live transnational lives. Nearly always there are (perceived) responsibilities and obligations towards family members in the country of origin or elsewhere. Being in a strong position makes it possible to fulfil these responsibilities; being in a weak position adds to feelings of powerlessness and failure.

This study demonstrates that the position refugees take towards Dutch healthcare results from an interactive process between personal needs, choices as to where to present those needs, (perceived) reactions from care providers, sources of information used, actions taken when results were not perceived as satisfactory, and how this whole 'episode' is processed later on in a continuing interpretive process.

Many studies emphasise the importance of supportive contacts with family and other people from the 'own group' for the prospects of refugees in a new country (Beiser, 1991; Kopinak, 1999). The results of this study additionally point to the importance of 'new contacts', for getting access to new information and starting to understand a new society. Granovetter, referring to 'weak ties' as opposed to the 'strong ties' that usually exist within particular groups, wrote: "Weak ties […] are here seen as indispensable to individuals' opportunities to their integration into communities..." (Granovetter, 1973). Establishing these ties is a two-sided process, requiring an active, outreaching approach from both the receiving society and the resettling refugee. Personal assets such as a young age, good education, speaking a European language help the refugee in this process. Dutch society has formalised part of the outreaching process, in the work of the

Dutch Refugee Council, which was mentioned as invaluable by many refugee interviewees. Informal contacts with neighbours or other Dutch people, who became trusted friends, were also very important in individual cases.

The way care providers come forward in the first place to welcome them as new and 'foreign' clients, is often perceived with anxiety by refugee patients. One reason for this anxiety is that providers of healthcare are in charge of matters of life and death. The 'question at stake' (Kleinman, 1995) is not only 'What is going to happen to me now?', but also 'What will happen to me when my life is really in danger?' The other reason for anxiety is the high 'moral authority' generally attributed to medical professionals. If a doctor behaves in an unfriendly or prejudiced way, this has a stronger impact than the same behaviour from another person.

The 'critical episode' concept, as it arose from our analytical process, appeared useful in structuring the refugee narratives. The design of the study was not originally geared towards the use of the 'critical incident technique' (Flanagan, 1954), as Jung e.a. (Jung et al. 1998) did in their study exploring patients' evaluations of GPs' behaviour. For future researchers, this may well be a fruitful approach, possibly narrowing down the scope and length of interviews. The term 'episode' instead of 'incident' might have the advantage of including longer periods of time and successive stages of an interaction process. It has a more neutral connotation than the word 'incident', which tends to evoke the association that something has gone very wrong.

The 'critical episode' concept could also be useful in everyday practice, for instance in dealing with personal continuity (Schers, 2004), or as a 'silent alert' in the mind of a GP. Schers found that the importance patients attached to continuity in the person of the care provider depended on the reason for encounter. Personal contiuity was considered most important in the case of hospital admissions for serious conditions, and when other serious life events were at hand. In a qualitative study Tarrant (Tarrant et al. 2003) found patients prioritised continuity with the same provider in case of complex and longterm problems, or problems that involved emotional concerns – all examples of critical episodes. A silent question in the mind of the practitioner as to whether 'this consultation might represent a critical episode for the patient' could help to foster the extra attention needed at a certain moment, in an always busy practice schedule.

The issues of prejudice and stereotyping figure prominently in both the general narrative and in negative critical episodes of individual participants – much more prominently than the issue of 'culture'. This can come as a surprise to advocates of 'interculturalisation' of healthcare institutions. Refugees seem to be concerned with the way providers of healthcare perceive them, and feel these perceptions could mean a risk to the way they are served by providers, and eventually to their health.

Cultural differences, in the sense of differences in perceptions and beliefs about health, differences in 'explanatory models' (Kleinman, 1980) can be dealt with, once they can be verbalised and exchanged – possibly resulting in better mutual understanding (Harmsen, 2003; van Wieringen et al. 2002). This study leads to the supposition that doctors sometimes make wrong assumptions about refugees' explanatory models, a phenomenon that also has been demonstrated by Helman (Helman, 1985) in a study involving primary care patients, doctors and nurse practitioners.

Prejudice and stereotyping belong to another domain. They are usually not verbalised, at least not in the medical context, but may play an important role in the decision-making process. This has been demonstrated in a number of studies by Zola (Zola, 1973), Helman (Helman, 1985) and Wissink (Wissink et al. 2005), to name just a few. They belong to the 'internal context' (Helman,

1984) of care providers, as much as the perception, expectation or fear of prejudice may belong to the 'internal context' of the refugee patient.

Refugees perceived different types of prejudice: on one hand a prejudice against foreigners, refugees, black people; the perception that, because of their looking different and speaking differently, they were not receiving full attention and optimal care from providers. On the other hand the perception that GPs too easily tended to attribute physical complaints to their difficult situation and experiences as refugees. This emphatically formulated concern of the refugee participants, along with with virtually all GPs naming 'stress-related complaints' as characteristic of the illness presentation by their refugee patients, made the issue of 'medically unexplained physical symptoms' a central focus in this study.

Many authors have referred to refugees presenting physical problems, mostly using the term 'somatisation', that doctors related to their suffering, bad living conditions and feelings of powerlessness (Lin et al. 1985; Lipson, 1991; van Willigen et al. 1995; Eastmond, 2000; Harris and Maxwell, 2000; Coker, 2004; Junod Perron and Hudelson, 2006). Coker (Coker, 2004) introduced the term 'embodied metaphors of suffering'. Kleinman (Kleinman, 1995) wrote about 'bodily idioms of distress' he encountered in Chinese patients with psychological wounds from their experiences of political violence during the Cultural Revolution.

Apparently refugees do present bodily idioms of their distress to GPs, and possibly they do so more often than other people. But being a refugee does not diminish the *a priori* probability of developing a serious medical condition. Refugees are worried about their physical symptoms, as are most other people who present physical pains and ailments to their doctors. In this study I have chosen to use the term 'medically unexplained physical symptoms' (MUPS), as it sounds neutral and does not imply a judgment about cause or diagnosis. There is a vast body of literature on MUPS in general practice, leading to the insight that MUPS may be better understood as bodily idioms of distress also in non-refugee patients in general practice (Portegijs et al. 1996; Mol, 2002). Presentation of chronic functional gastrointestinal disorders has been linked to a poor quality of life (Guthry and Thompson, 2002).

In the general MUPS literature, the dispute between the worried patient and the doctor who cannot find a medical textbook diagnosis to apply, and wants to avoid further medicalisation, also takes a central position (Wileman et al. 2002; May et al. 2004; Jones, 2004). Communication between patients and care providers was found to be a decisive issue (Salmon et al. 2004; May et al. 2004; Ring et al. 2005; Rosendal et al. 2005). A quest for good strategies for diagnosis and treatment has been going on for some time. Burton (Burton, 2003) concluded from an extensive review that a holistic approach is needed, including physiology, life experiences and interactions with care providers, avoiding stigmatising the patient. Some promising strategies are available (Morriss et al. 1999; Burton, 2003; Blankenstein, 2001; Rothschild, 2000; Levine and Frederick, 1997) but don't seem to be widely applied yet (Burton, 2003; Mayou and Sharpe, 1997).

A striking impression while exploring this field of knowledge, so central in primary healthcare, is how separated studies concerning refugees are from studies concerning other patients – even though basically the same phenomena are being dealt with. There seem to be different scientific compartments for refugees and for other patients, hindering a mutual cross-pollination that could be very fruitful. Body-oriented treatment strategies e.g. (Rothschild, 2000; Levine and Frederick, 1997) that have been applied in mental health settings for refugees are hardly mentioned in primary healthcare settings (Landsman-Dijkstra et al. 2006).

One of the problems GPs experience, with both refugee patients and patients with MUPS in general, is powerlessness. It is one of the recurring themes in the MUPS literature (Mathers et al. 1995; Wileman et al. 2002; May et al. 2004) and is also expressed by the GPs who participated in this study. Confronted with the reality of refugees' lives, GPs tend to feel overwhelmed, by complexity and by the impossibility of changing the context of their patients. I think +dealing with experiences of powerlessness is an issue that deserves more attention in medical education and advanced professional training than it gets nowadays.

7.3 CONCLUSIONS AND RECOMMENDATIONS

Conclusions

In the communities of both Afghan and Somali refugees in the Netherlands there is a general narrative of distrust against Dutch healthcare, especially the GP. The core of this narrative is a feeling of not being taken seriously by GPs because of stereotyping and prejudice.

Medical errors may have a long life, becoming part of the collective memory of refugee groups in society. More so, when they have not been openly discussed with the patient or the relatives involved.

Trust is a key concept for the fruitful cooperation between GPs and refugee patients. Establishing a trusted relationship may require some extra investment by the GP, which can best be made at an early stage.

The 'critical episode' concept is a useful tool in analysing and interpreting a biographical narrative of experiences with healthcare. A critical episode is an episode that in hindsight has been of special significance to the narrator, because of the seriousness of the presented problem, the way the care provider behaved, the outcome of the episode, or a combination of these elements.

Refugees tend to identify with the general narrative in their community after negative critical episodes, and to take a distance from it after positive critical episodes.

Use of Dutch social resources and sources of information helps refugees to change an unsatisfactory situation with a care provider.

Refugees both from Afghanistan and from Somalia see worries or difficult living circumstances as a possible cause of illness, but they think GPs too easily come up with a psychological explanation for their physical complaints.

GPs see 'stress-related complaints' or 'medically unexplained physical symptoms' as an important part of the illness presentation by their refugee patients, and have difficulties communicating about these complaints with refugees. They sometimes make wrong assumptions about their refugee patients' frames of reference concerning health and illness.

A 'biopsychosocial approach' (Engel, 1977), in which the physical complaint is carefully investigated, at the same time giving attention to worries and living circumstances, offers the best prospect for relieving possibly stress-related complaints.

Among refugee women with an Islamic background a variety of opinions exists about preference for gender of care providers. Dealing with gender preferences should start from an open discussion with individual patients, not from assumptions based on ethnicity or religion.

Refugees don't differ from other patients in their expectations of GPs. They first and foremost want to be taken seriously and approached as individuals, not as representatives of a group.

Recommendations

For healthcare professionals

A friendly, welcoming attitude should be the norm in the practice of healthcare.

Make use of the available 'instant' telephone interpreting service, whenever language is expected to be a barrier in the communication with refugee patients, after checking this with the patient.

An introductory consultation in which, besides the medical history, also the country of origin, year and reason of departure, present socio-economical situation, whereabouts of family members and experience with healthcare in the Netherlands so far are discussed, is a valuable investment when a refugee (family) registers as (a) new patients in general practice.

A silent question in the mind of the practising GP as to whether the problem being presented might be part of a critical episode for the patient could be helpful in focusing attention during a busy practice session.

Asking refugee patients what is worrying them and how they deal with their worries can be a useful strategy in dealing with 'unexplained physical symptoms'. Focus on the present context first. Never skip the primary physical examination.

Try to be aware of the role unconscious prejudice can play in the decision-making process. Consulting an experienced colleague in a situation that evokes feelings of powerlessness or irritation may prevent errors.

Medical errors need to be dealt with in an open way by healthcare professionals, also when refugee patients are involved.

Approach every patient as an individual, not as a representative of a group. Refrain from uttering generalising statements about any group.

A question about gender preference should be part of an open discussion with individual patients.

For further research

More research needs to be done into the 'general narrative' phenomenon in refugee communities, and possibly other migrant communities.

A 'critical episode technique' may be a useful approach for future researchers into the history of people's experiences with healthcare.

For policy makers

An introductory consultation for new refugee patients (and possibly other new patients with complex histories) should be funded as an extra activity in general practice by medical insurance companies.

More attention needs to be given to the position (former) refugees take in the Dutch society. Refugees' 'natural inclination' to strive for the re-establishment of economic independence should be supported more effectively.

Refugees should not be pathologised and not be identified with a victim role, in order to prevent them from becoming prisoners of their past.

Dealing with feelings of powerlessness deserves more attention in medical education and advanced professional training.

Information about fatal medical incidents needs to be gathered and analysed on a national scale, stratified for the nationality and language skills of the patient involved, giving special attention to communication aspects.

Proactively dealing with the diversity of users should be an issue on the policy agenda of all healthcare organisations and institutions in the Netherlands, including the professional organisations of GPs.

Reference List

Barudy, J. (1989) A programme of mental health for political refugees: dealing with the invisible pain of political exile. *Social Science and Medicine* **7**, 715-727.

Beiser, M. (1991) The mental health of refugees in resettlement countries. In: Adelman, H., (Ed.) *Refugee Policy: Canada and the United States*, pp. 425-443. Ontario, Canada: York University]

Bensing, J. (1991) Doctor-patient communication and the quality of care. *Social Science and Medicine* **32**, 1301-1310.

Bensing, J. (2000) Bridging the gap. The separate worlds of evidence-based medicine and patient-centered medicine. *Patient Education and Counseling* **39**, 17-25.

Bensing, J., Schreurs, K. and de Rijk, A. (1996) The role of the general practitioner's affective behaviour in medical encounters. *Psychology and Health* **11**, 825-838.

Blankenstein, N.A.H. (2001) Somatising patients in general practice; reattribution, a promising approach [dissertation] . Amsterdam: PrintPartners Ipskamp.

Burnett, A. and Peel, M. (2001) Asylum seekers and refugees in Britain. Health needs of asylum seekers and refugees. *British Medical Journal* **322**, 544-547.

Burton, C. (2003) Beyond somatisation: a review of the understanding and treatment of medically unexplained physical symptoms (MUPS). *British Journal of General Practice* **53**, 231-239.

Chrisman, N.J. (1977) The health seeking process: an approach to the natural history of illness. *Culture, Medicine and Psychiatry* **1**, 351-377.

Clancy, F. (2005) The blame game. *Minnesota Medicine* **88, electronic edition October 2005**,

Coker, E.M. (2004) "Traveling pains": Embodied metaphors of suffering among Southern Sudanese refugees in Cairo. *Culture, Medicine and Psychiatry* **28**, 15-39.

de Ruijter, A. (1996) Betekenisconstructie en sturing in een complexe wereld *[Constructing meaning and management in a complex world]*. In: Gastelaars, M. and Hagelstein, G., (Eds.) *Management of meaning. Managing and organising as processes of attributing meaning.*, pp. 10-23. Utrecht: ISOR]

Dingwall, R. (2001) Contemporary legends, rumours and collective behaviour: some neglected resources for medical sociology? *Sociology of Health and Illness* **23**, 180-202.

Eastmond, M. (1998) National discourses and the construction of difference: Bosnian Muslims in Sweden. *Journal of Refugee Studies* **11**, 161-181.

Eastmond, M. (2000) Refugees and health: ethnographic approaches. In: Ahearn, F.L.Jr., (Ed.) *Psychosocial wellness of refugees: issues in qualitative and quantitative research*, 1 edn. pp. 67-87. New York / Oxford: Berghahn Books]

Engel, G.L. (1977) The need for a new medical model: a challenge for biomedicine. *Science* **196**, 129-136.

Firling, K. (1988) The Afghan refugee client. *Journal of Counseling and Development* **67**, 31-34.

Flanagan, J.C. (1954) The critical incident technique. *Psychological Bulletin* **51**, 327-358.

Geertz, C. (1973) The interpretation of cultures. New York: Basic Books.

Ghorashi, H. (2005) Agents of change or passive victims: the impact of welfare states (the case of the Netherlands) on refugees. *Journal of Refugee Studies* **18**, 181-198.

Granovetter, M.S. (1973) The strength of weak ties. *American Journal of Sociology* **78**, 1360-1379.

Green, J. (2004) Commentary: Is trust an under-researched component of healthcare organisation? *British Medical Journal* **329**, 384

Guthry, E. and Thompson, D. (2002) Abdominal pain and functional gastrointestinal disorders. ABC of psychological medicine. *British Medical Journal* **325**, 701-703.

Harmsen, J.A.M. (2003) When cultures meet in medical practice. Improvement in intercultural communication evaluated. [Dissertation]. Erasmus University Rotterdam.

Harris, K. and Maxwell, C. (2000) A needs assessment in a refugee mental health project in North-East London: extending the counselling model to community support. *Medicine, conflict and survival* **16**, 201-215.

Helman, C.G. (1984) The role of context in primary care. *Journal of the Royal College of General Practitioners* **34**, 547-550.

Helman, C.G. (1985) Communication in primary care: the role of patient and practitioner explanatory models. *Social Science and Medicine* **20**, 923-931.

Jones, R. (2004) Irritable bowel syndrome: management of expectations and disease. *British Journal of General Practice* **54**, 490-491.

Jung, H.P., van Horne, F., Wensing, M., Hearnshaw, H. and Grol, R. (1998) Which aspects of general practitioners' behaviour determine patients' evaluations of care? *Social Science and Medicine* **47**, 1077-1087.

Junod Perron, N. and Hudelson, P. (2006) Somatisation: illness perspectives of asylum seeker and refugee patients from the former country of Yugoslavia. *BMC Family Practice* **7**, 10.1186/1471-2296-7-10

Klaver, J., Mateman, S. and Tromp, E. (2005) Vluchtelingenwerk Integratiebarometer. Een onderzoek naar de integratie van vluchtelingen in Nederland. Amsterdam: Regioplan, nr.1295.

Kleinman, A. (1980) Patients and healers in the context of culture. Berkeley: University of California Press.

Kleinman, A. (1995) Writing at the margin. Discourse between anthropology and medicine. Berkeley/ Los Angeles/ London: University of California Press.

Kopinak, J.K. (1999) The health of Bosnian refugees in Canada. *Ethnicity and Health* **4**, 65-82.

Landsman-Dijkstra, J.J.A., van Wijck, R. and Groothof, J.W. (2006) Improvement of balance between work stress and recovery after a body awareness program for chronic aspecific psychosomatic symptoms. *Patient Education and Counseling* **60**, 125-135.

Levine, P.A. and Frederick, A. (1997) Waking the tiger. Berkeley, California: North Atlantic Books.

Leydesdorff, S. (2004) Subjectiviteit en levensgeschiedenis, oral history in historisch perspectief [*Subjectivity and biography, oral history in perspective]*. 43-79. Amsterdam: Meulenhoff.

Lin, E.H.B., Carter, W.B. and Kleinman, A.M. (1985) An exploration of somatization among Asian refugees and immigrants in primary care. *American Journal of Public Health* **75**, 1080-1084.

Lipson, J. (1991) Afghan refugee health: some findings and suggestions. *Qualitative Health Research* **1**, 349-369.

Lipson, J.G. and Omidian, P.A. (1992) Health issues of Afghan refugees in California. *The Western Journal of Medicine* **157**, 271-275.

MacMullin, C. and Loughry, M. (2000) A child-centered approach to investigating refugee children's cencerns. In: Ahearn, F.L.J.E., (Ed.) *Psychosocial wellness of refugees. Issues in qualitative and quantitative research*, pp. 194-207. New York / Oxford: Berghahn Books]

Malterud, K. (2005) Humiliation instead of care? *The Lancet* **366**, 785-786.

Manderson, L. and Allotey, P. (2003) Storytelling, marginality, and community in Australia: How immigrants position their difference in health care settings. *Medical Anthropology* **22**, 1-21.

Marmot, M. (2003) Self esteem and health. *British Medical Journal* **327**, 574-575.

Mathers, N., Jones, N. and Hannay, D. (1995) Heartsink patients: a study of their general practitioners. *British Journal of General Practice* **45**, 293-296.

May, C., Allison, G., Chapple, A., Chew-Graham, C., Dixon, C., Gask, L., Graham, R., Rogers, A. and Roland, M. (2004) Framing the doctor-patient relationship in chronic illness: a comparative study of general practitioners' accounts. *Sociology of Health and Illness* **26**, 135-158.

Mayou, R. and Sharpe, M. (1997) Treating medically unexplained physical symptoms; Effective interventions are available. *British Medical Journal* **315**, 561-562.

Misztal, B.A. (1996) Trust in modern societies. Cambridge, New York: Polity Press.

Mol, S.S.L. (2002) Trauma, life events and PTSD; a challenge for patients and family doctors [Dissertation]. Maastricht, The Netherlands: Unigraphic.

Morriss, R.K., Gask, L., Ronalds, C. and e.a. (1999) Clinical and patient satisfaction outcomes of a new treatment for somatised mental disorders taught to general practitioners. *British Journal of General Practice* **49**, 263-267.

Omidian, P. (2000) Qualitative measures and refugee research. The case of Afghan refugees. In: Ahearn, F.L.Jr., (Ed.) *Psychosicial wellness of refugees. Issues in qualitative and quantitative research*, New York / Oxford: Berghahn Books]

Portegijs, P.J.M., van der Horst, F.G., Proot, I.M., Kraan, H.F., Gunther, N.C.H.F. and Knottnerus, J.A. (1996) Somatization in frequent attenders of general practice. *Social Psychiatry and Psychiatric Epidemiology* **31**, 29-37.

Rees Lewis, J. (1994) Patient views on quality care in general practice: literature review. *Social Science and Medicine* **39**, 665-670.

Ring, A., Dowrick, C.F., Humphris, G.M., Davies, J. and Salmon, P. (2005) The somatising effect of clinical consultation: What patients and doctors say and do not say when patients present

medically unexplained physical symptoms. *Social Science and Medicine* **61**, 1505-1515.

Rosendal, M., Olesen, F. and Fink, P. (2005) Management of medically unexplained symptoms. Includes diagnosis, specific treatments , and appropriate communication. *British Medical Journal* **330**, 4-5.

Rothschild, B. (2000) The body remembers. New York. London: W.W.Norton & Company.

Safran, D.G., Taira, D.A., Rogers, W.H., Kosinski, M., Ware, J.E. and Tarlov, A.R. (1998) Linking primary care performance to outcomes of care. *Journal of Family Practice* **47**, 213-220.

Salmon, P., Dowrick, C.F., Ring, A. and Humphris, G.M. (2004) Voiced but unheard agendas: qualitative analysis of the psychosocial cues that patients with unexplained symptoms present to general practitioners. *British Journal of General Practice* **54**, 171-176.

Schers, H. (2004) Continuity of care in general practice [*Dissertation Radboud University Nijmegen, the Netherlands]*. Wageningen: Ponsen en Looijen.

Stewart, M.A. (1995) Effective physician-patient communication and health outcomes: a review. *Canadian Medical Association Journal* **152**, 1423-1433.

Straten, G.F.M., Friele, R.D. and Groenewegen, P.P. (2002) Public trust in Dutch health care. *Social Science & Medicine* **55**, 227-234.

Tarrant, C., Windridge, K., Boulton, M., Baker, R. and Freeman, G. (2003) "He treats you as a person not just like a number". How important is personal care in general practice? *British Medical Journal* **326**, 310-312.

Thom, D.H. and Campbell, B. (1997) Patient-physician trust: an exploratory study. *The Journal of Family Practice* **44**, 169-176.

van der Veer, G. (2003) In de spreekkamer van de GGZ hulpverlener [*In the consulting room of the mental health professional]*. In: Grotenhuis, R., (Ed.) *Van pionieren tot verankeren. Tien jaar gezondheidszorg voor vluchtelingen. [From pioneer phase to anchoring phase.Ten years healthcare for refugees.]*, Utrecht: Stichting Pharos]

van Wieringen, J.C.M., Harmsen, J.A.M. and Bruijnzeels, M. (2002) Intercultural communication in general practice. *European Journal of Public Health* **12**, 63-68.

van Willigen, L.H.M., Hondius, A.J.K. and van der Ploeg, H.M. (1995) Health problems of refugees in the Netherlands. *Tropical and Geographical Medicine* **47**, 118-124.

Weick, K.E. (1995) Sensemaking in organizations. California, London: Sage.

Wileman, L., May, C. and Chew-Graham, C.A. (2002) Medically unexplained symptoms and the problem of power in the primary care consultation: a qualitative study. *Family Practice* **19**, 178-182.

Wissink, L., Jones-Webb, R., DuBois, D., Krinke, B. and Ibrahim, Q. (2005) Improving health care provision to Somali refugee women. *Minnesota Medicine* **88, electronic edition February 2005.**,

Zola, I.K. (1973) Pathways to the doctor - From person to patient. *Social Science and Medicine* **7**, 677-689.

7. LAATSTE HOOFDSTUK

7.1 SAMENVATTING

Hoofdstuk 1 biedt een algemene inleiding op het onderwerp vluchtelingen en huisartsen in de Nederlandse samenleving.
Vluchtelingen uit landen buiten Europa vormen een relatief nieuwe groepering in Nederland. In tegenstelling tot eerdere migranten die vooral in de grotere steden wonen, hebben zij zich in alle Nederlandse gemeenten gevestigd, als gevolg van het spreidingsbeleid van de Nederlandse overheid. Signalen van onvrede over de Nederlandse gezondheidszorg bij vluchtelingen en van ongemak en onzekerheid bij Nederlandse huisartsen waren aanleiding tot dit onderzoek. Doel van het onderzoek was, de perspectieven van vluchtelingen en huisartsen met elkaar te confronteren en te leren van deze confrontatie. Er wordt een theoretisch kader geschetst, puttend uit verschillende wetenschappelijke disciplines en referentiekaders.

Gekozen is voor een kwalitatieve methode van onderzoek, in de vorm van diepte-interviews, om inzicht te kunnen krijgen in ervaringen, overwegingen en reflecties van zowel individuele vluchtelingen als individuele huisartsen.

Hoofdstuk 2 bevat de eerste resultaten van 25 interviews met 30 personen afkomstig uit Somalië, wonend in verschillende plaatsen in Nederland, met uiteenlopende achtergrond qua leeftijd en opleiding. De persoonlijke verhalen van de geïnterviewden zijn geanalyseerd in episodes van contacten met de gezondheidszorg. Episodes die achteraf bezien van bijzondere betekenis zijn geweest voor de geïnterviewde, kregen een label ‘kritische episode’. Op deze wijze werden uit het interviewmateriaal ketens van ‘kritische episodes’ geconstrueerd. De individuele kritische episodes zijn inhoudelijk geanalyseerd. Een kritische episode liet een positieve of een negatieve indruk achter in het geheugen van de geïnterviewde en werd als zodanig geformuleerd in het interview. Een positieve indruk leidde tot een toename van vertrouwen in de betreffende hulpverlener, een negatieve indruk tot een vermindering van vertrouwen. Geen aandacht krijgen, zich niet serieus genomen voelen door een hulpverlener, waren de belangrijkste kenmerken van negatieve episodes.

Huisartsen figureerden in alle verhalen van de Somalische geïnterviewden. De interviews vertoonden onderling een grote verscheidenheid, uiteenlopend van dankbaarheid en tevredenheid jegens huidige of eerdere huisartsen, tot ontevredenheid en frustratie. Een uitweg uit een onbevredigende relatie met een hulpverlener werd dikwijls in het buitenland gezocht, via familieleden in een ander Europees land.

Vrijwel alle geïnterviewden noemden negatieve ervaringen van andere vluchtelingen uit Somalië met de Nederlandse gezondheidszorg. Omdat dit fenomeen in overeenkomstige bewoordingen in alle verhalen terugkeerde, kreeg het in de analyse de naam ‘general narrative’ of ‘algemeen verhaal’. De strekking van het algemene verhaal is: de Nederlandse gezondheidszorg is goed, maar niet voor ons. Wij, Somaliërs, vluchtelingen, vreemdelingen in het algemeen, worden niet serieus genomen. Medische fouten worden geïnterpreteerd als gevolgen van gebrek aan belangstelling, gebrek aan aandacht van de kant van de hulpverlener, als gevolg van een bevooroordeelde of discriminerende houding.

Verhalen over medische fouten die gemaakt zijn in de behandeling van persoonlijk bekende andere Somaliërs of mensen van buitenlandse afkomst, maken deel uit van het algemene verhaal:

lichamelijke verschijnselen die niet tijdig werden herkend als signalen van een levensbedreigende ziekte; kleine kinderen die stierven door uitdroging nadat verontruste ouders meerdere malen een hulpverlener hadden bezocht; mensen die gehandicapt raakten na een narcose voor een kleine operatie.

De geïnterviewden namen verschillende posities in, in relatie tot het algemene verhaal: zij identificeerden zich ermee, of ze namen er afstand van, afhankelijk van hun persoonlijke ervaringen met de Nederlandse gezondheidszorg, in het bijzonder de recente ervaringen met hun huisarts.

Eerdere ervaringen met de Nederlandse gezondheidszorg en verhalen van anderen over hun ervaringen werden vaker aangehaald als referentiekader tijdens de interviews, dan ervaringen met de gezondheidszorg in Somalië. De verwachtingen die de Somalische geïnterviewden formuleerden ten aanzien van hulpverleners verschilden niet wezenlijk van de verwachtingen van andere gebruikers van eerstelijns gezondheidszorg zoals die uit de internationale literatuur naar voren kwamen.

Hoofdstuk 3 bevat de resultaten van 24 interviews met 36 personen afkomstig uit Afghanistan, wonend in verschillende plaatsen in Nederland en met uiteenlopende achtergrond qua leeftijd en opleiding.

Het fenomeen van het ‘algemene verhaal’, het ‘general narrative’, werd ook aangetroffen in de Afghaanse interviews, met een overwegend negatieve inhoud. De elementen van het Afghaanse ‘algemene verhaal’ kwamen grotendeels overeen met de inhoud van het Somalische ‘algemene verhaal’: het gevoel onvoldoende aandacht te krijgen en niet serieus genomen te worden door hulpverleners, als gevolg van vooroordelen. Behalve van een verondersteld vooroordeel jegens mensen van buitenlandse afkomst, maakten Afghaanse deelnemers veelvuldig melding van een verondersteld vooroordeel bij huisartsen dat vluchtelingen vooral lichamelijke klachten hebben ten gevolge van hun psychologische problemen. De spilfunctie van de huisarts in de Nederlandse gezondheidszorg was reden tot wantrouwen bij sommige Afghaanse geïnterviewden: hoe kan één dokter de verantwoordelijkheid op zich nemen voor de afhandeling van zoveel verschillende soorten klachten en ziekten? Geïnterviewden met de meest negatieve kritische episodes identificeerden zich het sterkst met het ‘algemene verhaal’.

Het concept van de ‘kritische episodes’ is ook gebruikt om de persoonlijke verhalen van de Afghaanse geïnterviewden te analyseren, en leverde een brede verscheidenheid aan verhalen op. De ketens van individuele kritische episodes zijn vervolgens geanalyseerd in relatie tot de persoonlijke en sociale ‘hulpbronnen’ van de geïnterviewden. De persoonlijke hulpbronnen werden geoperationaliseerd in een gecombineerde score van leeftijd, opleiding en spreekvaardigheid in een Europese taal bij aankomst. Sociale hulpbronnen werden onderscheiden in ‘bekende’ (familie en Afghaanse vrienden) en ‘nieuwe’ (vooral Nederlandse) hulpbronnen.

Geïnterviewden met meer persoonlijke hulpbronnen maakten vaker gebruik van nieuwe sociale hulpbronnen, en meldden vaker positieve kritische episodes na eerdere negatieve kritische episodes. Zij slaagden erin hun problemen te bespreken met een hulpverlener of van hulpverlener te veranderen.

De resultaten van de interviews met vluchtelingen worden besproken tegen de achtergrond van de internationale literatuur over patiënt-tevredenheid en communicatie in de gezondheidszorg. De behoeften en verwachtingen zoals uitgesproken door de vluchtelingen, verschilden niet wezenlijk

van de behoeften en verwachtingen van andere cliënten in de gezondheidszorg, zoals die hun weg hebben gevonden in de internationale wetenschappelijke literatuur.

Hoofdstuk 4 beschrijft de resultaten van de kwalitatieve analyse van semi-gestructureerde interviews met 24 Nederlandse huisartsen over hun dienstverlening aan (voormalige) vluchtelingen uit Somalië en Afghanistan. De geïnterviewde huisartsen waren niet de huisartsen van de geïnterviewde vluchtelingen. Uit een aselecte steekproef van 325 huisartsen in verschillende regio's in Nederland die werden aangeschreven en uitgenodigd voor een interview, reageerden 21 huisartsen positief. Nog drie huisartsen konden worden benaderd via persoonlijke contacten. De man/vrouw verdeling onder de geïnterviewde huisartsen kwam overeen met de verdeling onder praktizerende huisartsen in Nederland ten tijde van de interviews. Qua leeftijd, praktijkorganisatie en vestigingsplaats waren zij niet representatief. Oudere huisartsen, huisartsen uit grote steden en huisartsen werkzaam in groepspraktijken of gezondheidscentra waren oververtegenwoordigd. De huisartsen verschilden onderling sterk in de aantallen vluchtelingen in hun praktijk, aantal mensen van buitenlandse afkomst in de praktijk en het aantal jaren dat zij ervaring hadden met vluchtelingen. De meeste praktijken in de grote stad hadden hun organisatie in de loop van de jaren aangepast aan een cliëntenbestand waarvan mensen met een niet-Nederlandse achtergrond een steeds groter deel waren gaan uitmaken. De getroffen voorzieningen waren vooral afgestemd op de eerdere migrantengroeperingen en minder op vluchtelingen.

De huisartsen maakten een duidelijk onderscheid tussen hun vluchteling-patiënten en andere patiënten met een niet-Nederlandse achtergrond – overwegend arbeidsmigranten. Zij noemden daarbij de verliezen en geweldservaringen van de vluchteling-patiënten, het hogere opleidingsniveau van de vluchtelingen en daarmee samenhangende betere taalvaardigheid.

Ondanks de genoemde betere taalvaardigheid, maakten de huisartsen veelvuldig melding van taalproblemen bij de hulpverlening aan vluchteling-patiënten. Van de beschikbare tolkendienst werd weinig gebruik gemaakt. Na taalproblemen, werd de behandeling van lichamelijke klachten zonder duidelijke fysieke oorzaak het meest frequent gemeld als probleem in de hulpverlening aan vluchteling-patiënten. De huisartsen hadden verschillende strategieën ontwikkeld voor de behandeling van de veronderstelde 'stress-gerelateerde klachten' van hun vluchteling-patiënten, uiteenlopend van een overwegend 'somatische' benadering, tot een consequente biopsychosociale benadering, waarin aan lichamelijke, psychische en sociale factoren gelijktijdig aandacht werd besteed.

De huisartsen die de meeste ervaring hadden in het werken met vluchtelingen, benadrukten het belang van vroegtijdig investeren in het opbouwen van een relatie met vluchteling-patiënten en het benaderen van iedere vluchteling-patiënt als een individu, niet als een vertegenwoordiger van een groep. De huisartsen die vanaf de start investeerden in de relatie met hun vluchteling-patiënten, bijvoorbeeld door het voeren van een apart kennismakingsgesprek, en die handelden volgens een consequente biopsychosociale strategie in geval van onverklaarde lichamelijke klachten, leken het meest tevreden over hun benadering.

Hoofdstuk 5 biedt een confrontatie van de interviews met vluchtelingen en de interviews met huisartsen, waarbij lichamelijke klachten zonder duidelijke diagnose centraal staan: medisch onverklaarde lichamelijke klachten (MOLK). Deze MOLK bleken op grond van de interviews een essentieel onderwerp te zijn, zowel voor de vluchtelingen als voor de huisartsen, maar vanuit verschillende invalshoeken.

De geïnterviewde vluchtelingen, zowel uit Somalië als uit Afghanistan, gaven een integrale definitie van gezondheid, verwijzend naar het lichamelijke, het emotionele en het geestelijke functioneren, maar ook naar autonomie. Deelnemers in 21 van de 24 Afghaanse interviews noemden spontaan 'zorgen' of 'teveel denken' als oorzaak van ziekte, evenals deelnemers in 15 van de 25 Somalische interviews. 'Zorgen' waren daarmee de meest genoemde oorzaak van ziekte in interviews met zowel Afghaanse als Somalische vluchtelingen. De meeste Afghaanse geïnterviewden beschouwden deze opvatting over 'zorgen' als oorzaak van ziekte als deel van hun cultureel erfgoed. De Somalische geïnterviewden zagen deze visie als een nieuwe ontdekking en deel van hun bestaan in ballingschap.

De geïnterviewde vluchtelingen voelden zich primair zelf verantwoordelijk voor hun gezondheid en situatie. Zij probeerden actief de eigen gezondheid te bevorderen, door zorgvuldige keuze van voedsel, nauwgezette hygiëne en geregelde lichamelijke activiteit. Zowel de Somalische als de Afghaanse geïnterviewden meldden verschillende strategieën om minder last te hebben van hun zorgen en slechte herinneringen. Van dokters wilden zij in de eerste plaats aandacht voor hun lichamelijke klachten. Dat is de expertise van de dokter. Lichamelijke klachten veroorzaken angst en onzekerheid, maar interfereren ook met het dagelijks functioneren en vormen daardoor een bedreiging voor de autonomie. Ongerustheid over symptomen is een belangrijke drijfveer om de arts te bezoeken, en de eerste behoefte is om de oorzaak te weten van de klachten. De geïnterviewde vluchtelingen vonden het belangrijk dat de dokter belangstelling toont voor hun persoon en hun achtergrond, en hen vriendelijk welkom heet. Zij wilden als individuen benaderd worden, niet als vertegenwoordigers van een groep. Zij wensten erkenning en een adequaat onderzoek van hun lichamelijke klachten, resulterend in een verklaring die aansluit op specifieke ongerustheid, en een uitwisseling van gezichtspunten over de vraag hoe verder te gaan.

Het probleem dat uit de interviews met vluchtelingen naar voren komt, is dat men dikwijls het gevoel had op bevooroordeelde wijze benaderd te worden door huisartsen. Vluchtelingen hadden het gevoel dat huisartsen te lichtvaardig hun moeilijke situatie en ervaringen aangrepen als verklaring voor hun lichamelijke symptomen, op basis van stereotype ideeën over vluchtelingen als groep. Binnen de gemeenschappen van zowel Afghaanse als Somalische vluchtelingen circuleert een 'general narrative', een algemeen verhaal met een overwegend negatieve inhoud van vooroordelen en gebrek aan goede zorg voor vluchtelingen en andere mensen van buitenlandse afkomst, en medische fouten met soms ernstige gevolgen. Dit 'algemene verhaal' is een blijk van een zwakke vertrouwensbasis tussen de gemeenschappen van vluchtelingen en Nederlandse hulpverleners.

De huisartsen zagen MOLK, door hen meestal aangeduid als 'stress gerelateerde klachten' of 'psychosomatische klachten' als een significant deel van de ziektepresentatie door hun vluchteling-patiënten. Zij legden een verbinding tussen een breed scala aan lichamelijke klachten en de situatie waarin hun vluchteling-patiënten leven, met hun ervaringen uit het verleden. De huisartsen gaven aan het omgaan met dit soort klachten in veel gevallen als een probleem te ervaren. Zij hadden verschillende strategieën ontwikkeld en verschilden in de mate van tevredenheid over hun benadering. De strategieën zoals de dokters die in de interviews beschreven, konden grofweg worden onderverdeeld in een 'human interest' strategie en een 'technische strategie'. De meest uitgewerkte 'best practices' kwamen van huisartsen die aangaven dat zij een 'biopsychosociale benadering' combineerden met een 'human interest' strategie. Zij benadrukten hoe belangrijk het is vroegtijdig te investeren in het opbouwen van een relatie met vluchteling-patiënten, en hadden het gevoel dat zij aansluiting konden vinden bij de vluchteling-patiënten en hun zorgen, waarbij gelijktijdig aandacht werd gegeven aan de lichamelijke pijnen en problemen.

De resultaten van het onderzoek worden besproken in de bredere context van de internationale literatuur over MOLK (MUPS) en patiënt-tevredenheid. De ‘best practices’ zoals beschreven door sommige huisartsen, lijken goed aan te sluiten bij de verwachtingen en de behoeften van de geïnterviewde vluchtelingen.

Het uit de interviews geïdentificeerde kernprobleem is niet zozeer een fundamenteel verschil in paradigma’s tussen huisartsen en vluchtelingen, althans niet wat betreft de definitie van gezondheid en de mogelijke invloed van zorgen op de gezondheid. Het kernprobleem is een gebrek aan vertrouwen bij vluchtelingen, op grond van fenomenen die zich afspelen buiten het gezichtsveld van de huisartsen. Daarnaast speelt waarschijnlijk tekort schietende communicatie een rol. Om een vruchtbare samenwerking te laten ontstaan, moeten huisartsen investeren in het opbouwen van een vertrouwensrelatie met individuele vluchtelingen, en handelingen die gebaseerd zijn op stereotypen en vooroordelen vermijden. Handelingsstrategieën van huisartsen wat betreft het omgaan met medisch onverklaarde lichamelijke klachten behoeven kritische reflectie.

In **hoofdstuk 6** komen voorkeuren ten aanzien van de sexe van hulpverleners aan de orde, in het bijzonder de voorkeuren van vrouwelijke vluchteling met een Islamitische achtergrond, hun ervaring wanneer zij uiting geven aan die voorkeur en de wijze waarop huisartsen omgaan met uitgesproken voorkeuren. Geïnterviewde mannelijke huisartsen gaven aan dat het sexe-aspect een van de beperkingen was die het hun moeilijk maakten een goede huisarts te zijn voor hun vluchteling-patiënten. Het materiaal dat in dit hoofdstuk wordt gepresenteerd is een subselectie uit het totale interviewmateriaal, namelijk de passages uit zowel de interviews met huisartsen als de interviews met vluchtelingen waarin het sexe-aspect aan de orde komt.

Zowel de Afghaanse als de Somalische vrouwen verschilden onderling in hun voorkeuren voor de sexe van een hulpverlener, zelfs bij intieme onderzoeken. Meer Somalische dan Afghaanse vrouwen zeiden dat de sexe van een hulpverlener voor hen onbelangrijk was. Alle Afghaanse vrouwen die zich uitspraken over dit onderwerp, gaven aan, een voorkeur te hebben voor een vrouwelijke hulpverlener, in het bijzonder voor intieme onderzoeken. De meesten van hen waren niet heel uitgesproken in hun voorkeur; zij gebruikten termen als: ‘het is makkelijker een vrouw te hebben voor dat onderzoek’. Vier Somalische vrouwen en drie Afghaanse vrouwen waren meer strikt in hun voorkeur – waarbij nog steeds een uitzondering werd gemaakt voor acute situaties.

Niet alle vrouwen die voorkeur hadden voor een vrouwelijke huisarts, hadden feitelijk ook een vrouwelijke huisarts. Sommigen van hen waren patiënt in een duo-praktijk, waar zij gemakkelijk een afspraak konden maken met een vrouwelijke collega. Anderen werden op hun verzoek verwezen naar een vrouwelijke gynaecoloog. Een vrouw sprak haar voorkeur niet uit, maar gaf geen gehoor aan de uitnodiging voor een bevolkingsonderzoek op baarmoederhalskanker. Twee vrouwen vertelden hoe hun mannelijke huisarts erg boos werd toen zij vroegen om een verwijzing naar een vrouwelijke arts voor een gynaecologisch onderzoek.

Vijf van de geïnterviewde mannelijke huisartsen meldden sexe-gerelateerde onderwerpen als een probleem in de hulpverlening aan vrouwelijke vluchtelingen met een Islamitische achtergrond. Zij hadden het gevoel dat zij bepaalde onderwerpen misten, omdat de vrouwen daar niet mee kwamen, en dat zij daardoor geen goede huisarts konden zijn voor deze vrouwen. Als praktische oplossing hadden deze huisartsen ofwel hun praktijkassistente geïnstrueerd om het onderzoek uit te voeren, waarbij zij zich achter een gordijn terugtrokken, of ze verwezen de vrouw naar een vrouwelijke collega of een gynaecoloog.

De bevindingen worden besproken tegen de achtergrond van de internationale literatuur over sexevoorkeuren in medische situaties. In internationale onderzoeken geven Islamitische vrouwen vaker dan westerse vrouwen aan een voorkeur te hebben voor een hulpverlener van hetzelfde geslacht. Dit betekent niet dat ervan uit gegaan moet worden dat alle vrouwen met een Islamitische achtergrond een dergelijke voorkeur hebben. Omgaan met sexevoorkeuren zou moeten starten vanuit een open gesprek met individuele patiënten, niet vanuit aannames, gebaseerd op de religie of de etniciteit van een vrouw.

7.2 OVERWEGINGEN

Over de gebruikte methode

Het doel van dit onderzoek was de reflecties en meningen van vluchtelingen en huisartsen in Nederland over de manier waarop zij elkaar ontmoeten en met elkaar omgaan, in al hun verscheidenheid te exploreren, en inzicht te krijgen in de processen die spelen, en daarbij ook aandacht te besteden aan de historische dimensie: hoe veranderen meningen in de loop van de tijd? Om dit doel te bereiken en de stemmen van mensen te laten horen, was een kwalitatief onderzoek nodig, gebaseerd op diepte-interviews.

Kwalitatief onderzoek, uitgaande van interviews, is een arbeidintensieve methode. Er is een lang tijdsverloop tussen de oorspronkelijke interviews en het moment dat de resultaten zichtbaar worden. Andere kwalitatieve methoden, zoals focusgroepen (Omidian, 2000) of een inventarisatie van meningen in een institutionele setting (MacMullin and Loughry, 2000) leveren sneller resultaten op.

Wat interviews met focusgroepen niet opleveren, is de verscheidenheid aan individuele meningen, reflecties en inzichten, en het verhaal achter deze meningen. Focusgroepen zullen eerder het 'algemene verhaal', de 'general narrative' opleveren. Gezondheid en ziekte zijn in laatste instantie individuele ervaringen – hoewel sterk verbonden met de familie, de gemeenschap waarvan een individu deel uitmaakt (Kopinak, 1999; Lipson, 1991). Deze overwegingen hebben geleid tot de keuze voor interviews met individuen of echtparen.

De kwalitatieve methode zoals we die hebben toegepast, houdt in het oproepen van herinneringen van mensen aan gebeurtenissen in het nabije en minder nabije verleden. Daarmee komt de vraag op naar de relatie tussen herinneringen en de 'waarheid'. De onderzoeker maakt deel uit van de discussie, roept in feite het verhaal ter plaatse op. De onderzoeker kan slechts gebruik maken van het materiaal dat de geïnterviewde bereid is te delen, op de manier waarop deze het aanreikt. Het verhaal neemt vorm aan, afhankelijk van de wijze waarop de onderzoeker vasthoudt aan haar eigen 'agenda', de lijst van te bespreken onderwerpen, of besluit om de associaties van de geïnterviewde te volgen, die kunnen afwijken van de voorgenomen structuur (Leydesdorff, 2004).

Het interview zelf wordt deel van een proces van 'betekenisgeving' (Weick, 1995; Geertz, 1973; de Ruijter, 1996). Met het toenemen van mijn onderzoekservaring, merkte ik dat het volgen van de associaties van de geïnterviewde vruchtbaarder was, dan het strak vasthouden aan de onderwerpenlijst. Op die manier vertelde de geïnterviewde datgene wat echt van belang was voor haar of hem. Het stellen van een paar vervolgvragen zoals hoe, waarom , kunt u dat toelichten, was dat altijd uw mening, volstond dan om zaken duidelijk te krijgen.
De geïnterviewden kunnen hun redenen hebben gehad om bepaalde onderwerpen naar voren te brengen, andere weg te laten. Het menselijk geheugen heet onbetrouwbaar te zijn. Het is onmogelijk te weten of de gebeurtenissen waarover de geïnterviewden vertelden, werkelijk op die manier hebben plaatsgehad. Mijn positie is dat de onderzoeker in dit soort onderzoek geen andere keuze heeft dan alles wat een geïnterviewde zegt, als waar en werkelijk te accepteren. Het gaat over de werkelijkheid zoals de geïnterviewde die heeft waargenomen, de indruk of het beeld dat die waarneming in haar of zijn geheugen heeft achtergelaten. Die indruk kan in de loop van de tijd veranderd zijn, onder invloed van latere ervaringen en verhalen van andere mensen.

Het was onvermijdelijk dat de gebruikte wervingsmethode tot een selectie van de geïnterviewde vluchtelingen leidde. Vertrouwen bleek een doorslaggevende factor in de beslissing om wel of niet medewerking te verlenen aan een interview – vertrouwen in de tussenpersoon. Alleenstaande jonge mannen – talrijk onder de eerste generatie vluchtelingen - waren ondervertegenwoordigd in dit onderzoek. Om hen te bereiken hadden andere kanalen moeten worden gebruikt.

Het oorspronkelijke scenario was dat mogelijke participanten zouden worden benaderd door de zelforganisaties van vluchtelingen, met een korte uiteenzetting over het doel en de organisatie van het onderzoek. Na een eerste positieve reactie zou een van de assistent-onderzoeksters de mogelijke participant telefonisch benaderen, zonodig meer toelichting geven en een afspraak maken als de persoon in kwestie instemde met een interview. Het bleek dat op deze wijze teveel mensen op elkaar wachtten. Daarom is besloten over te gaan tot een meer directe netwerk-benadering, via de assistent-onderzoeksters, via medewerkers van vluchtelingenwerk en andere persoonlijke contacten.

De intermediairen kregen weigeringen om verschillende redenen, zoals negatieve associaties met het woord interview (associatie met het interview met de Immigratie- en Naturalisatie Dienst, IND), angst dat de huisarts over het interview zou horen en gebrek aan tijd. Een aanbeveling voor toekomstige onderzoekers zou kunnen zijn om liever het woord ‘discussie’ te gebruiken dan het woord ‘interview’, teneinde associaties met het IND interview te vermijden. Tijdgebrek was vooral een argument voor mensen met een baan – waardoor selectie kan zijn opgetreden ten gunste van mensen zonder werk.

Meer vrouwen dan mannen hebben deelgenomen aan het onderzoek, vooral van de Somalische kant. Dit kan te maken hebben met het onderwerp van het onderzoek. Gezondheid is een onderwerp dat meer in de kring van vrouwen dan in de kring van mannen wordt besproken, zowel door Afghanen als door Somaliërs. In gezinnen heeft meestal de vrouw de centrale rol wat betreft gezondheid en ziekte. Mannen praten liever over politiek.

Meer Afghaanse dan Somalische interviews werden ‘discussie groepen’ in de zin zoals beschreven door Omidian (Omidian, 2000), doordat man en vrouw samen deelnamen aan het interview, elkaar aanvullend, soms corrigerend, wat vruchtbaar bleek voor de discussie. De aanwezigheid van de assistent-onderzoekster hielp in de meeste gevallen om de initiële ongemakkelijkheid te doorbreken, vooral als de geïnterviewde de assistent-onderzoekster kende. De assistent-onderzoeksters vervulden ook een waardevolle rol als culturele intermediairen, waarbij zij naar twee kanten bepaalde onderwerpen toelichtten. Een keer kwam het voor dat een deelnemer die reeds had toegezegd, op het laatste moment het interview weigerde, vanwege de persoon van de assistent-onderzoekster – blijkbaar uit de verte bekend, maar niet vertrouwd.

De deelnemende huisartsen waren niet de huisartsen van de geïnterviewde vluchtelingen. Een eerder scenario om ‘koppels’ van vluchteling en huisarts te interviewen werd in een vroeg stadium verlaten, vanwege de verwachting en ook het dringende advies van experts, dat vluchtelingen geen medewerking zouden willen verlenen, en zeker niet open zouden spreken, als zij wisten dat hun huisarts later zou worden benaderd voor een interview.

De geïnterviewde huisartsen vormden geen representatieve steekproef van praktizerende huisartsen in Nederland ten tijde van de interviews (2003). Oudere huisartsen en huisartsen werkzaam in stedelijke groepspraktijken en gezondheidscentra waren oververtegenwoordigd. Door de keuze de huisartsen te benaderen onafhankelijk van de geïnterviewde vluchtelingen, was het niet mogelijk te weten welke huisartsen Somalische en/ of Afghaanse vluchtelingen in hun praktijk hadden. De huisartsen kunnen allerlei overwegingen gehad hebben om wel of niet deel te

nemen, afgezien van het wel of niet hebben van vluchtelingen in hun praktijkpopulatie. De huisartsen die via persoonlijke contacten werden benaderd, waren vanzelfsprekend huisartsen van wie bekend was dat zij een positieve houding tegenover vluchtelingen hadden en langdurige praktijkervaring in het werken met vluchtelingen.

De resultaten van de interviews met huisartsen zullen daarom niet het hele scala vertegenwoordigen aan houdingen, inzichten en strategieën van Nederlandse huisartsen die met vluchteling-patiënten werken. De gekozen procedure heeft wel een aantal 'best practices' opgeleverd en een interessante verscheidenheid aan inzichten en strategieën van huisartsen.

Algemene overwegingen

Misschien is een van de meest opvallende bevindingen van dit onderzoek wel, dat de verwachtingen die vluchtelingen hebben van huisartsen niet wezenlijk verschillen van wat andere patiënten, in Nederland en internationaal, van hun dokters verwachten: een dokter die hen serieus neemt, goed naar hun verhaal luistert, een zorgvuldig lichamelijk onderzoek doet en duidelijke informatie geeft over zijn bevindingen en mogelijkheden voor verdere diagnostiek en behandeling. In een internationaal overzicht van onderzoeken naar de meningen van patiënten over de kwaliteit van zorg, concludeerde Rees Lewis (Rees Lewis, 1994) dat "patiënten geen duidelijk onderscheid maken tussen technische vaardigheden en interpersoonlijke vaardigheden van dokters".

Uit bijna alle onderzoeken kwam communicatie naar voren als een van de meest doorslaggevende aspecten van kwaliteit vanuit het gezichtspunt van de patiënt. Bensing (Bensing, 1991; Bensing et al. 1996) vond in een kwantitatieve analyse van videobanden dat het affectieve gedrag van huisartsen positief correleerde met zowel de ruimte voor de patiënt als de professionele kwaliteit van het consult, beoordeeld door een panel van huisartsen. In een overzicht van onderzoeken naar de samenhang tussen de kwaliteit van de arts-patiënt communicatie en subjectieve verbetering van de gezondheid van de patiënt, vond Stewart (Stewart, 1995) een positieve relatie in de meeste onderzoeken. Goede communicatie wordt dus niet alleen gewaardeerd door patiënten, maar draagt ook bij aan betere resultaten van de zorg.

De vluchtelingen in dit onderzoek maakten, met een of twee uitzonderingen, geen onderscheid tussen de interpersoonlijke en de technische vaardigheden van de dokters met wie zij te maken hadden. Interpersoonlijke vaardigheden, inclusief vriendelijkheid en een verwelkomende houding, werden gebruikt als maatstaf om te beoordelen of een bepaalde dokter voldoende in hen geïnteresseerd was om hem te kunnen vertrouwen. De geïnterviewde vluchtelingen benadrukten dat de dokter goed moet luisteren, om in staat te zijn de juiste richting te kiezen en de juiste kennis toe te passen in hun geval. Anderzijds werden medische fouten waar deelnemers mee te maken hadden gehad, of waarover zij van anderen hadden gehoord, meestal geweten aan gebrek aan interesse van de betreffende dokter. In dit verband is het belangwekkend een zeer gerespecteerde Amerikaanse advocaat, gespecialiseerd in medisch tuchtrecht en geciteerd door Clancy (Clancy, 2005) aan te halen, die stelde dat niet luisteren naar de patiënt de voornaamste oorzaak is van het missen van de diagnose hartinfarct.

De geïnterviewde vluchtelingen trokken in de meeste gevallen de technische vaardigheden van Nederlandse artsen niet in twijfel. Het artsdiploma leek gezien te worden als een garantie voor kwaliteit. In zekere zin brengen de geïnterviewde vluchtelingen ons terug naar de grondregel van de geneeskunde: geneeskunde begint en eindigt bij de patiënt. Het toepassen van 'evidence based medicine', geneeskundig handelen op basis van wetenschappelijk onderbouwde keuzes en

methoden, is een groot goed om te blijven nastreven, maar de juiste 'evidence' moet op de juiste patiënt worden toegepast. Om dat te bereiken, is zorgvuldige communicatie onmisbaar – waarmee communicatie de brug blijkt te zijn tussen 'evidence based medicine', wetenchappelijke geneeskunde en 'patient-centred medicine', patiëntgerichte geneeskunde (Bensing, 2000).

Vertrouwen kwam als het centrale concept naar voren uit de interviews met vluchtelingen. Vertrouwen was een voorwaarde om uitleg van een dokter te accepteren, om behandelvoorstellen te accepteren die afweken van wat men verwachtte, en om mee te werken aan behandelplannen. De noodzaak om een vertrouwensrelatie op te bouwen in de hulpverlening aan vluchtelingen is door veel auteurs en hulpverleners benadrukt (Burnett and Peel, 2001; Firling, 1988; Lipson and Omidian, 1992; van der Veer, 2003). Het is belangrijk dat hulpverleners zich realiseren dat verschillende elementen in de voorgeschiedenis van vluchtelingen hun vertrouwen kunnen hebben ondermijnd.

Vertrouwen is mogelijk een weinig onderzocht gebied binnen de gezondheidszorg (Green, 2004), maar de belangstelling ervoor lijkt toe te nemen. Misztal (Misztal, 1996) definieerde vertrouwen als volgt: "de overtuiging dat de resultaten van de actie die iemand beoogt in ons voordeel zullen zijn." In een meetinstrument dat werd ontworpen (Straten et al. 2002) om het vertrouwen van consumenten in de gezondheidszorg te meten, bleek het 'vertrouwen dat hulpverleners het belang van de patiënt beogen' het meest doorslaggevende aspect te zijn. Het algemene vertrouwen bleek in dit onderzoek zowel bepaald te worden door eigen ervaringen als door de ervaringen van vrienden en bekenden. De resultaten van zorg in individuele gevallen bleken mede afhankelijk van het aanwezige vertrouwen (Safran et al. 1998); gebrek aan vertrouwen leidde tot uitstelgedrag bij het melden van ernstige ziekten (Malterud, 2005). Er bestaat weinig twijfel dat vertrouwen een nuttig, waarschijnlijk onmisbaar, element is in de praktijk van de gezondheidszorg.

Wat is ervoor nodig om vertrouwen op te bouwen? De interviews met vluchtelingen in dit onderzoek wijzen allereerst naar de houding en het interpersoonlijke gedrag van de dokter. De vriendelijke lach, als teken van bereidheid en aandacht; het tonen van belangstelling voor de persoon en zijn context. In zijn explorerende onderzoek naar het vertrouwen tussen patiënt en arts, kwam Thom tot de uitspraak (Thom and Campbell, 1997) dat "een zorgvuldige bejegening niet alleen een aantrekkelijke eigenschap is, maar essentieel voor het bieden van goede zorg".

In de eerstelijns gezondheidszorg kan een kennismakingsgesprek met nieuwe vluchteling-patiënten een zeer waardevol middel zijn, zoals huisartsen in ons onderzoek aangaven. Natuurlijk kan de vraag worden opgeworpen of een speciaal en langer kennismakingsgesprek alleen aan specifieke categorieën van nieuwe patiënten moet worden aangeboden, of aan alle nieuwe patiënten. Voor nieuwe vluchteling-patiënten moeten tenminste een aantal extra onderwerpen deel uitmaken van het kennismakingsgesprek, zoals het land van herkomst, de reden voor vertrek, de verblijfplaatsen van familieleden, de huidige sociaal-economische situatie, en eerdere ervaringen met de gezondheidszorg in Nederland. Onderwerpen voor een dergelijk kennismakingsgesprek moeten bij voorkeur in dialoog met experts uit gemeenschappen van vluchtelingen worden ontwikkeld.

Het 'algemene verhaal' of 'general narrative' waarvan bijna alle geïnterviewde vluchtelingen melding maakten, zou kunnen wijzen op een laag niveau van 'institutioneel vertrouwen' in de Nederlandse gezondheidszorg binnen de desbetreffende gemeenschappen van vluchtelingen. Het kleine aantal deelnemers dat bij dit onderzoek was betrokken, laat vanzelfsprekend geen generalisaties toe. Meer onderzoek is nodig om te weten te komen, of het 'general narrative' fenomeen in de volledige netwerken van Afghaanse en Somalische vluchtelingen aanwezig is,

mogelijk ook in de netwerken van andere vluchtelingen- en migrantengroepen. Het feit dat er zo vaak melding van werd gemaakt, geeft aanleiding tot de veronderstelling dat het van belang is.

Vervolgens komt de vraag op, wat het 'algemene verhaal' betekent. Met Chrismans (Chrisman, 1977) model voor het 'health seeking process' oftewel 'model voor hulp zoeken' voor ogen, maakt de 'general narrative' deel uit van de 'sociale dimensie' waarin de vluchtelingen leven, maar behoort tot de 'interne context' zoals door Helman (Helman, 1984) beschreven en blijft daardoor meestal onzichtbaar voor de dokter die wordt geraadpleegd. De negatieve invloed op het vertrouwen is sterker, naarmate de individuele vluchteling-patiënt zich meer identificeert met de 'general narrative', vanwege eerdere negatieve ervaringen en/of een leven vooral binnen de beslotenheid van de eigen groep.

Het gevoel binnen de Nederlandse samenleving in een gemarginalseerde positie te verkeren kan de identificatie met de 'general narrative' versterken. Ook andere auteurs hebben melding gemaakt van 'hedendaagse legenden' (Dingwall, 2001) of 'medische roddel' (Manderson and Allotey, 2003) die circuleren in min of meer gemarginaliseerde groepen in verschillende landen. Die verhalen hebben een meer 'legendarisch' karakter dan de verhalen die in dit onderzoek de 'general narrative' vormden. De functie van de verhalen, als 'verhalen van wantrouwen', die waarschuwen tegen mogelijke bedreigingen van buiten en tegelijkertijd de interne samenhang versterken, zou heel goed overeen kunnen komen. De verhalen kunnen ook worden opgevat als signalen dat mensen de kwaliteit van de dienstverlening willen helpen verbeteren (Manderson and Allotey, 2003).

De positie die (voormalige) vluchtelingen innemen in een samenleving, nadat ze zijn toegelaten en enige tijd hun leven hebben opgebouwd, is het resultaat van een interactieproces dat begint op het moment van aankomst en vele jaren doorgaat. Een interactieproces tussen een individu of een gezin, de grotere gemeenschap van landgenoten die al aanwezig is en de samenleving van het gastland als geheel, zoals ook beschreven door Eastmond met betrekking tot Zweden (Eastmond, 1998): "Met zijn nadruk op trauma, en het ontbreken van levensvatbare mogelijkheden voor economische en sociale integratie, lijkt de ontvangende samenleving vooral een rol als zieke en een gepathologiseerde identiteit te bieden. Vanuit de invalshoek van vluchtelingen is de grootste prioriteit in het dagelijks leven echter het actieve herstel van een 'normaal leven', wat zoveel inhoudt als het herstel van economische onafhankelijkheid en controle over het eigen bestaan." Ghorashi houdt eenzelfde betoog, verwijzend naar de Nederlandse context (Ghorashi, 2005): "Het beeld van hulpeloosheid is sterker in sterk gereguleerde landen: het systeem verandert het actieve, volwassen zelf in een passieve cliënt. Als je niet actief kunt zijn, word je een gevangene van je verleden." Het percentage (voormalige) vluchtelingen dat afhankelijk is van een uitkering, wordt in Nederland geschat tussen 38 en 57% (Klaver et al. 2005).

De vluchtelingen in dit onderzoek legden sterk de nadruk op hun prioriteit om een actief en economisch onafhankelijk bestaan op te bouwen – afgezien van de mensen die in verband met hun leeftijd het gevoel hadden dat de toekomst slechts aan hun kinderen was. Autonomie en economische onafhankelijkheid werden gezien als onderdelen van een holistisch gezondheidsconcept, afwezigheid daarvan als factoren die ziekte konden veroorzaken. Kopinak (Kopinak, 1999) verkreeg van Bosnische vluchtelingen in Canada eenzelfde holistische definitie van gezondheid, evenals Lipson (Lipson, 1991) van Afghaanse vluchtelingen in de Verenigde Staten en Eastmond van Bosnische vluchtelingen in Zweden (Eastmond, 1998). Barudy had het over de noodzaak voor politieke vluchtelingen die zich hervestigden in een vreemd land een 'nieuwe sociale identiteit op te bouwen' (Barudy, 1989). In een filosofisch geschreven boekbespreking in het British Medical Journal vroeg Marmot (Marmot, 2003) de aandacht van een breed medisch lezerspubliek voor het verband tussen autonomie, zelfrespect en gezondheid.

Het zou een prioriteit moeten zijn voor hervestigingslanden om (voormalige) vluchtelingen te ondersteunen bij hun pogingen om economisch onafhankelijk te worden en hun autonomie te herstellen. Een recent rapport van VluchtelingenWerk Nederland (Klaver et al. 2005) laat zien dat er wat dit betreft nog veel werk te doen is in Nederland.

De positie die vluchtelingen, maar ook andere migrantengroepen, in een nieuwe samenleving innemen, ontwikkelt zich niet volgens een simpele rechte lijn. In veel westerse samenlevingen heeft het maatschappelijk debat de laatste vijf jaar een veel scherpere toonzetting gekregen, waarbij een polarisatie is opgetreden tussen 'wij' en 'zij', en de problemen aan ' de ander' worden toegeschreven. Vluchtelingen in Nederland hebben hun deel meegekregen van de toenemende polarisatie. Het maatschappelijke debat gaat ook over kwesties van 'solidariteit' en keuzes die gemaakt zouden moeten worden tussen 'hier' thuis te zijn of 'daar' bij te horen. Dit onderzoek illustreert dat in de meeste gevallen het leven in een 'diaspora' situatie zowel over 'hier' gaat als over 'daar': vluchtelingen en migranten leven transnationale levens. Bijna altijd voelt men zich verantwoordelijk tegenover familieleden in het land van herkomst of elders. Wie zelf in een sterke positie verkeert, kan deze verantwoordelijkheden aan; in een zwakke positie verkeren betekent extra gevoelens van machteloosheid en mislukking.

Dit onderzoek laat zien dat de positie die vluchtelingen innemen ten aanzien van de Nederlandse gezondheidszorg, het resultaat is van een interactieproces tussen persoonlijke noden, keuzes waar aan te kloppen met die noden, (ervaren) reacties van hulpverleners, geraadpleegde bronnen van informatie, acties die werden ondernomen in geval eerdere resultaten als onbevredigend werden ervaren, en hoe deze hele episode later werd verwerkt in een voortgaand interpretatieproces.

Veel onderzoekers benadrukken het belang van steunende contacten met familie en andere mensen van de 'eigen groep' voor de vooruitzichten van vluchtelingen in een nieuw land (Beiser, 1991; Kopinak, 1999). De resultaten van dit onderzoek wijzen daarenboven op het belang van 'nieuwe contacten', om toegang te krijgen tot nieuwe informatie en begrip op te bouwen hoe de nieuwe samenleving werkt. Granovetter (Granovetter, 1973) schreef over 'zwakke banden' (weak ties) , in tegenstelling tot de 'sterke banden' zoals die gewoonlijk bestaan binnen bepaalde groepen: "Zwakke banden […] worden hier beschouwd als onmisbaar voor de vooruitzichten van individuen om te integreren in samenlevingen, …". Het aangaan van dergelijke banden is een tweezijdig proces en vereist een actieve benadering 'met uitgestrekte hand', zowel vanuit de ontvangende samenleving als vanuit de vluchteling die zich hervestigt. Persoonlijke 'hulpbronnen' zoals een jonge leeftijd, een goede opleiding, het spreken van een Europese taal, helpen de vluchteling bij dit proces. De Nederlandse samenleving heeft de 'uitgestrekte hand' deels geïnstitutionaliseerd, in het werk van VluchtelingenWerk Nederland, dat door veel van de geïnterviewde vluchtelingen als buitengewoon waardevol werd genoemd. In individuele gevallen waren contacten met buren of andere Nederlandse mensen die vertrouwde vrienden werden, ook van doorslaggevend belang.

De manier waarop een hulpverlener zich opstelt tegenover hen als nieuwe cliënten van buitenlandse afkomst, wordt door veel vluchtelingen met angstige spanning tegemoet gezien. Een reden voor deze angstige spanning is dat hulpverleners onmisbaar zijn in zaken van leven en dood. De 'kwestie waar het over gaat' (Kleinman, 1995) is niet alleen: "wat gaat er nu met mij gebeuren?", maar ook: "Wat zal er gebeuren als mijn leven echt in gevaar is?"
De tweede reden voor angstige spanning is de hoge 'morele autoriteit' die aan medische professionals wordt toegeschreven. Als een arts zich onvriendelijk of bevooroordeeld gedraagt, brengt dit een sterkere schok teweeg, dan hetzelfde gedrag van een willekeurige andere persoon.

Het begrip ‘kritische episode’ zoals dit naar voren kwam uit ons analytische proces, bleek waardevol om de individuele verhalen te structureren. Het onderzoek werd niet primair opgezet volgens de ‘critical incident technique’ (Flanagan, 1954), zoals Jung e.a. (Jung et al. 1998) deden in hun onderzoek naar de wijze waarop patiënten het gedrag van hun huisartsen evalueerden. Voor toekomstige onderzoekers zou dit een vruchtbare benadering kunnen zijn, waardoor de interviews meer doelgericht gehouden kunnen worden. De term ‘episode’ kan als voordeel hebben boven de term ‘incident’ dat het over een langere tijdsperiode kan gaan en over verschillende stadia in een interactieproces. Bovendien heeft de term ‘episode’ een meer neutrale gevoelswaarde dan het woord ‘incident’, dat meteen de associatie oproept dat er iets fout is gegaan.

Het concept ’kritische episode’ zou ook nuttig kunnen zijn voor de dagelijkse praktijk, bijvoorbeeld daar waar het gaat over het omgaan met persoonlijke continuïteit (Schers, 2004), of als een ‘stil alarm’ in het hoofd van een huisarts. Schers concludeerde in zijn proefschrift dat het belang dat patiënten hechtten aan continuïteit in de persoon van de hulpverlener, samenhing met de reden voor het contact. Persoonlijke continuïteit werd het meest van belang geacht als er sprake was van een ziekenhuisopname voor een ernstige aandoening of als andere ingrijpende gebeurtenissen aan de orde waren. Tarrant (Tarrant et al. 2003) vond in een kwalitatief onderzoek dat patiënten vooral hechtten aan persoonlijke continuïteit in geval van complexe en langdurige problemen, of bij problemen met een sterk emotionele lading – alle voorbeelden van ‘kritische episodes’. Een ‘stil alarm’ in het hoofd van de huisarts of ‘dit consult voor de patiënt een kritische episode zou kunnen zijn’, zou kunnen helpen om op het moment dat dat noodzakelijk is, wat extra aandacht op te brengen in een altijd druk spreekuurprogramma.

De begrippen ‘vooroordeel’ en ‘stereotypering’ waren nadrukkelijk aanwezig zowel in het algemene verhaal of ‘general narrative’, als in de negatieve kritische episodes van individuele geïnterviewden – veel nadrukkelijker dan het begrip ‘cultuur’. Dit kan als een verrassing komen voor de pleitbezorgers van de ‘interculturalisatie’ van instellingen voor gezondheidszorg. Vluchtelingen blijken zich zorgen te maken over de wijze waarop hulpverleners hen zien, en zij hebben het gevoel dat deze zienswijze een risico kan inhouden voor de wijze waarop hulpverleners hen helpen, en uiteindelijk voor hun gezondheid.

Culturele verschillen, in de zin van verschillen in opvattingen over gezondheid, verschillen in ‘verklaringsmodellen’ (Kleinman, 1980) kunnen onderwerp van discussie zijn, als ze worden uitgesproken en uitgewisseld, waardoor mogelijk een beter wederzijds begrip ontstaat (Harmsen, 2003; van Wieringen et al. 2002). Dit onderzoek wekt de indruk dat dokters soms tot verkeerde aannames komen over de verklaringsmodellen van vluchtelingen. Helman (Helman, 1985) vond een dergelijk fenomeen in zijn onderzoek onder patiënten, artsen en verpleegkundigen in de eerstelijns gezondheidszorg.

Vooroordeel en stereotypering behoren tot een ander domein. Zij worden meestal niet uitgesproken, althans niet in een medische context, maar kunnen een belangrijke rol spelen in het besluitvormingsproces. Dit is aangetoond in meerdere onderzoeken, onder andere door Zola (Zola, 1973), Helman (Helman, 1985) en Wissink (Wissink et al. 2005), om er slechts enkele te noemen. Stereotypen en vooroordelen behoren tot de ‘interne context’ (Helman, 1984) van hulpverleners, evenals de waarneming, de verwachting of de angst voor vooroordelen kan behoren tot de ‘interne context’ van de vluchteling-patiënt.

De geïnterviewde vluchelingen meldden verschillende soorten vooroordelen: aan de ene kant een vooroordeel jegens vreemdelingen, vluchtelingen, donkere mensen; de indruk dat zij, omdat ze er anders uitzagen, anders spraken, niet de volle aandacht en geen optimale zorg kregen van de kant

van hulpverleners. Aan de andere kant waren zij van mening dat huisartsen te gemakkelijk geneigd waren lichamelijke klachten toe te schrijven aan hun moeilijke situatie en ervaringen als vluchtelingen. Deze met grote nadruk door de geïnterviewde vluchtelingen geformuleerde angst, in combinatie met de door vrijwel alle geïnterviewde huisartsen als karakteristiek voor vluchtelingen genoemde presentatie van 'stress-gerelateerde klachten', was aanleiding om het onderwerp 'medisch onverklaarde lichamelijke klachten' tot een centraal thema te maken in dit onderzoek.

Veel auteurs maken melding van het feit dat vluchtelingen frequent lichamelijke klachten presenteren; meestal wordt in dit kader de term 'somatisatie' gebruikt, door artsen in verband gebracht met lijden, slechte leefomstandigheden en gevoelens van machteloosheid (Lin et al. 1985; Lipson, 1991; van Willigen et al. 1995; Eastmond, 2000; Harris and Maxwell, 2000; Coker, 2004; Junod Perron and Hudelson, 2006). Coker (Coker, 2004) introduceerde de term 'embodied metaphors of suffering', misschien het beste te vertalen als 'in het lichaam neergeslagen lijden'. Kleinman (Kleinman, 1995) schreef over de 'bodily idioms of distress', het idioom van het lichaam om lijden te ervaren, dat hij tegenkwam bij Chinese patiënten die onuitgesproken psychologische en persoonlijke wonden hadden door hun ervaringen met politiek geweld tijdens de Culturele Revolutie.

Blijkbaar presenteren vluchtelingen inderdaad lichamelijke idiomen van hun lijden aan huisartsen, en mogelijk doen zij dat vaker dan andere mensen. Maar vluchteling zijn vermindert de à priori kans op het krijgen van een ernstige lichamelijke aandoening niet. Vluchtelingen maken zich zorgen over hun lichamelijke verschijnselen, zoals de meeste mensen die lichamelijke pijnen en klachten aan hun dokters presenteren. In mijn analyse heb ik ervoor gekozen de term 'medisch onverklaarde lichamelijke klachten' te gebruiken, omdat zij neutraal klinkt en geen oordeel inhoudt over de oorzaak of de diagnose. Er is een grote hoeveelheid literatuur over 'medisch onverklaarde lichamelijke klachten' (MOLK) in de huisartspraktijk, die tot het inzicht leidt dat MOLK wellicht ook in niet-vluchteling patiënten beter begrepen kunnen worden als een lichamelijk idioom voor lijden aan het leven (Portegijs et al. 1996; Mol, 2002). Presentatie van chronische functionele maag-darm klachten is in verband gebracht met een zelf ervaren lage kwaliteit van leven (Guthry and Thompson, 2002).

In de algemene literatuur over MOLK (MUPS) staat de discussie centraal tussen de ongeruste patiënt en de dokter die geen diagnose kan stellen en verdere medicalisering wil vermijden (Wileman et al. 2002; May et al. 2004; Jones, 2004). Communicatie tussen patiënten en hulpverleners bleek een beslissend aspect te zijn (Salmon et al. 2004; May et al. 2004; Ring et al. 2005; Rosendal et al. 2005). De zoektocht naar goede strategieën voor diagnose en behandeling loopt al lange tijd. Burton (Burton, 2003) concludeerde uit een uitvoerige literatuuranalyse dat een holistische aanpak nodig is, met oog voor fysiologische aspecten, levenservaringen en interacties met hulpverleners, maar zonder patiënten te stigmatiseren. Er zijn veelbelovende strategieën beschikbaar (Morriss et al. 1999; Burton, 2003; Blankenstein, 2001; Rothschild, 2000; Levine and Frederick, 1997), maar die lijken nog weinig te worden toegepast (Burton, 2003; Mayou and Sharpe, 1997).

Bij het exploreren van dit terrein van kennis, van zulk centraal belang in de eerstelijns gezondheidszorg, valt op hoe weinig verbinding er is tussen onderzoeken onder vluchtelingen en onderzoeken onder andere patiënten – hoewel het in de grond over dezelfde fenomenen gaat. Er lijken afzonderlijke wetenschappelijke compartimenten te zijn voor vluchtelingen en voor andere patiënten, die een wederzijdse kruisbestuiving in de weg staan. Van lichaams-georiënteerde behandelstrategieën bijvoorbeeld (Rothschild, 2000; Levine and Frederick, 1997) die binnen de

geestelijke gezondheidszorg voor vluchtelingen worden toegepast, wordt binnen de eerstelijns gezondheidszorg nauwelijks melding gemaakt (Landsman-Dijkstra et al. 2006).

Een van de problemen die huisartsen ervaren met zowel vluchteling-patiënten als patiënten met medisch onverklaarde lichamelijke klachten in het algemeen, is machteloosheid. Machteloosheid is een van de terugkerende thema's in de MUPS literatuur (Mathers et al. 1995; Wileman et al. 2002; May et al. 2004) en wordt ook aangegeven door huisartsen die voor dit onderzoek zijn geïnterviewd. Geconfronteerd met de werkelijkheid van het leven van hun vluchteling-patiënten, lijken huisartsen zich overweldigd te voelen door de complexiteit van de context waarin deze mensen leven en de onmogelijkheid die te veranderen. Ik denk dat omgaan met gevoelens van machteloosheid een onderwerp is dat meer aandacht behoeft in de medische opleiding en de bijscholing van artsen, dan het nu krijgt.

7.3 CONCLUSIES EN AANBEVELINGEN

Conclusies

In de gemeenschappen van zowel Afghaanse als Somalische vluchtelingen in Nederland circuleert een ‘algemeen verhaal’, ‘general narrative’, van wantrouwen jegens de Nederlandse gezondheidszorg, in het bijzonder de huisarts. De kern van dit verhaal is het gevoel, niet serieus genomen te worden door huisartsen als gevolg van stereotypering en vooroordelen.

Medische fouten kunnen een lang leven hebben en deel gaan uitmaken van het collectieve geheugen van vluchtelingengroepen in de Nederlandse samenleving, destemeer wanneer zij niet openlijk besproken zijn met de betrokken patiënt of de familie.

Vertrouwen is essentieel voor een vruchtbare samenwerking tussen huisartsen en vluchteling-patiënten. Het opbouwen van een vertrouwensband kan een extra investering vragen van de huisarts, die het beste in een vroeg stadium gedaan kan worden.

Het begrip ‘kritische episode’ is een nuttig hulpmiddel bij het analyseren en interpreteren van biografische verhalen over ervaringen met gezondheidszorg. Een kritische episode is een episode die, achteraf bezien, van bijzondere betekenis is geweest voor de verteller, vanwege de ernst van het gepresenteerde probleem, de wijze waarop de hulpverlener reageerde, het resultaat van de episode of een combinatie van deze elementen.

Vluchtelingen neigen er toe zich te identificeren met het ‘algemene verhaal’ in hun gemeenschap na negatieve kritische episodes en er afstand van te nemen na positieve kritische episodes.

Gebruik maken van Nederlandse sociale contacten en informatiebronnen helpt vluchtelingen om verandering te brengen in een onbevredigende situatie met een hulpverlener.

Vluchtelingen uit Afghanistan en Somalië zien zorgen en moeilijke leefomstandigheden als mogelijke oorzaken van ziekte, maar zij zijn van mening dat huisartsen te makkelijk geneigd zijn een psychologische verklaring te geven voor hun lichamelijke klachten.

Huisartsen zien ‘stress-gerelateerde klachten’ of ‘medisch onverklaarde lichamelijke klachten’ als een belangrijk onderdeel van de ziektepresentatie door hun vluchteling-patiënten. De communicatie over deze klachten met vluchtelingen ervaren zij als moeizaam. Zij hebben soms een verkeerd beeld van de referentiekaders van hun vluchteling-patiënten ten aanzien van gezondheid en ziekte.

Een ‘biopsychosociale benadering’ (Engel, 1977) met zorgvuldig onderzoek van de lichamelijke klacht en gelijktijdige aandacht voor zorgen en leefomstandigheden, biedt de beste vooruitzichten voor verlichting van mogelijk stressgerelateerde klachten.

Onder vrouwelijke vluchtelingen met een Islamitische achtergrond bestaat een scala aan meningen aangaande voorkeur voor de sexe van hulpverleners. Omgaan met sexevoorkeuren dient te beginnen met een open discussie met individuele patiënten, niet met aannames gebaseerd op etniciteit of religie.

Vluchtelingen verschillen niet van andere patiënten in hun verwachtingen van huisartsen. In de allereerste plaats willen zij serieus genomen worden en als individuen benaderd, niet als vertegenwoordigers van een groep.

Aanbevelingen

Voor hulpverleners

Een vriendelijke, verwelkomende houding zou de norm moeten zijn in de praktijk van de gezondheidszorg

Maak gebruik van de beschikbare, 'instant' telefonische tolkendienst in situaties waarin taal naar verwachting een barrière zal vormen in de communicatie met vluchteling- patiënten – na overleg hierover met de patiënt.

Een kennismakingsgesprek waarin, naast de medische voorgeschiedenis, ook het land van herkomst, de reden van vertrek, de huidige sociaal-economische situatie, de verblijfplaatsen van familieleden en eerdere ervaringen met de gezondheidszorg in Nederland aan de orde komen, is een waardevolle investering als een vluchteling (gezin) zich als nieuwe patiënt(en) komt inschrijven in de huisartspraktijk.

Een 'stil alarm' in het hoofd van de praktizerende huisarts of het probleem dat een patiënt presenteert mogelijk deel uitmaakt van een 'kritische episode' voor deze patiënt, zou een nuttig hulpmiddel kunnen zijn om de aandacht te richten tijdens een druk spreekuur.

Een vraag aan vluchteling-patiënten waar zij zich zorgen over maken en hoe zij met hun zorgen omgaan, kan een goede strategie zijn in geval van 'onverklaarde lichamelijke klachten'. Richt uw aandacht eerst op de actuele context. Sla het lichamelijke onderzoek nooit over.

Tracht u bewust te zijn van de rol die onbewuste vooroordelen kunnen spelen in het besluitvormingsproces. Het raadplegen van een ervaren collega in situaties die gevoelens van machteloosheid of irritatie oproepen, kan fouten helpen voorkomen.

Omgaan met medische fouten vraagt een open benadering, ook jegens vluchteling-patiënten.

Benader iedere patiënt als individu, niet als vertegenwoordiger van een groep. Onthoud u van generaliserende uitspraken over groepen.

Een vraag naar eventuele voorkeur voor de sexe van een hulpverlener moet deel uitmaken van een open discussie met individuele patiënten.

Voor verder onderzoek

Er is meer onderzoek nodig naar het 'general narrative' fenomeen in gemeenschappen van vluchtelingen, en mogelijk andere gemeenschappen van migranten.

Een ‘kritische episode techniek’ kan een zinvolle benadering zijn voor toekomstige onderzoekers naar verhalen over individuele ervaringen met gezondheidszorg.

Voor beleid

Een kennismakingsgesprek voor vluchteling-patiënten (en mogelijk voor andere patiënten met een complexe voorgeschiedenis) die zich nieuw inschrijven in een huisartspraktijk zou als extra activiteit moeten moeten worden betaald door zorgverzekeraars.

Er is meer aandacht nodig voor de positie van (voormalige) vluchtelingen in de Nederlandse samenleving. De ‘natuurlijk neiging’ van vluchtelingen om te streven naar herstel van economische onafhankelijkheid dient meer effectief te worden ondersteund.

Vluchtelingen dienen niet te worden gepathologiseerd en niet geïdentificeerd te worden met een slachtofferrol, teneinde te voorkomen dat zij gevangenen worden (of blijven) van hun verleden.

Omgaan met gevoelens van machteloosheid verdient meer aandacht in de opleiding en bijscholing van artsen.

Fatale medische incidenten dienen op landelijk niveau verzameld en geanalyseerd te worden, gestratificeerd naar de nationaliteit en taalvaardigheid van de betrokken patiënt en met speciale aandacht voor communicatie aspecten.

Proactief omgaan met de diversiteit in achtergronden van gebruikers dient een onderwerp te zijn op de beleidsagenda van alle gezondheidszorgorganisaties en - instituten in Nederland, inclusief de beroepsorganisaties van huisartsen.

Reference List

Barudy, J. (1989) A programme of mental health for political refugees: dealing with the invisible pain of political exile. *Social Science and Medicine* **7**, 715-727.

Beiser, M. (1991) The mental health of refugees in resettlement countries. In: Adelman, H., (Ed.) *Refugee Policy: Canada and the United States*, pp. 425-443. Ontario, Canada: York University]

Bensing, J. (1991) Doctor-patient communication and the quality of care. *Social Science and Medicine* **32**, 1301-1310.

Bensing, J. (2000) Bridging the gap. The separate worlds of evidence-based medicine and patient-centered medicine. *Patient Education and Counseling* **39**, 17-25.

Bensing, J., Schreurs, K. and de Rijk, A. (1996) The role of the general practitioner's affective behaviour in medical encounters. *Psychology and Health* **11**, 825-838.

Blankenstein, N.A.H. (2001) Somatising patients in general practice; reattribution, a promising approach [dissertation] . Amsterdam: PrintPartners Ipskamp.

Burnett, A. and Peel, M. (2001) Asylum seekers and refugees in Britain. Health needs of asylum seekers and refugees. *British Medical Journal* **322**, 544-547.

Burton, C. (2003) Beyond somatisation: a review of the understanding and treatment of medically unexplained physical symptoms (MUPS). *British Journal of General Practice* **53**, 231-239.

Chrisman, N.J. (1977) The health seeking process: an approach to the natural history of illness. *Culture, Medicine and Psychiatry* **1**, 351-377.

Clancy, F. (2005) The blame game. *Minnesota Medicine* **88, electronic edition October 2005**,

Coker, E.M. (2004) "Traveling pains": Embodied metaphors of suffering among Southern Sudanese refugees in Cairo. *Culture, Medicine and Psychiatry* **28**, 15-39.

de Ruijter, A. (1996) Betekenisconstructie en sturing in een complexe wereld *[Constructing meaning and management in a complex world]*. In: Gastelaars, M. and Hagelstein, G., (Eds.) *Management of meaning. Managing and organising as processes of attributing meaning.*, pp. 10-23. Utrecht: ISOR]

Dingwall, R. (2001) Contemporary legends, rumours and collective behaviour: some neglected resources for medical sociology? *Sociology of Health and Illness* **23**, 180-202.

Eastmond, M. (1998) National discourses and the construction of difference: Bosnian Muslims in Sweden. *Journal of Refugee Studies* **11**, 161-181.

Eastmond, M. (2000) Refugees and health: ethnographic approaches. In: Ahearn, F.L.Jr., (Ed.) *Psychosocial wellness of refugees: issues in qualitative and quantitative research*, 1 edn. pp. 67-87. New York / Oxford: Berghahn Books]

Engel, G.L. (1977) The need for a new medical model: a challenge for biomedicine. *Science* **196**, 129-136.

Firling, K. (1988) The Afghan refugee client. *Journal of Counseling and Development* **67**, 31-34.

Flanagan, J.C. (1954) The critical incident technique. *Psychological Bulletin* **51**, 327-358.

Geertz, C. (1973) The interpretation of cultures. New York: Basic Books.

Ghorashi, H. (2005) Agents of change or passive victims: the impact of welfare states (the case of the Netherlands) on refugees. *Journal of Refugee Studies* **18**, 181-198.

Granovetter, M.S. (1973) The strength of weak ties. *American Journal of Sociology* **78**, 1360-1379.

Green, J. (2004) Commentary: Is trust an under-researched component of healthcare organisation? *British Medical Journal* **329**, 384

Guthry, E. and Thompson, D. (2002) Abdominal pain and functional gastrointestinal disorders. ABC of psychological medicine. *British Medical Journal* **325**, 701-703.

Harmsen, J.A.M. (2003) When cultures meet in medical practice. Improvement in intercultural communication evaluated. [Dissertation]. Erasmus University Rotterdam.

Harris, K. and Maxwell, C. (2000) A needs assessment in a refugee mental health project in North-East London: extending the counselling model to community support. *Medicine, conflict and survival* **16**, 201-215.

Helman, C.G. (1984) The role of context in primary care. *Journal of the Royal College of General Practitioners* **34**, 547-550.

Helman, C.G. (1985) Communication in primary care: the role of patient and practitioner explanatory models. *Social Science and Medicine* **20**, 923-931.

Jones, R. (2004) Irritable bowel syndrome: management of expectations and disease. *British Journal of General Practice* **54**, 490-491.

Jung, H.P., van Horne, F., Wensing, M., Hearnshaw, H. and Grol, R. (1998) Which aspects of general practitioners' behaviour determine patients' evaluations of care? *Social Science and Medicine* **47**, 1077-1087.

Junod Perron, N. and Hudelson, P. (2006) Somatisation: illness perspectives of asylum seeker and refugee patients from the former country of Yugoslavia. *BMC Family Practice* **7**, 10.1186/1471-2296-7-10

Klaver, J., Mateman, S. and Tromp, E. (2005) Vluchtelingenwerk Integratiebarometer. Een onderzoek naar de integratie van vluchtelingen in Nederland. Amsterdam: Regioplan, nr.1295.

Kleinman, A. (1980) Patients and healers in the context of culture. Berkeley: University of California Press.

Kleinman, A. (1995) Writing at the margin. Discourse between anthropology and medicine. Berkeley/ Los Angeles/ London: University of California Press.

Kopinak, J.K. (1999) The health of Bosnian refugees in Canada. *Ethnicity and Health* **4**, 65-82.

Landsman-Dijkstra, J.J.A., van Wijck, R. and Groothof, J.W. (2006) Improvement of balance between work stress and recovery after a body awareness program for chronic aspecific psychosomatic symptoms. *Patient Education and Counseling* **60**, 125-135.

Levine, P.A. and Frederick, A. (1997) Waking the tiger. Berkeley, California: North Atlantic Books.

Leydesdorff, S. (2004) Subjectiviteit en levensgeschiedenis, oral history in historisch perspectief [*Subjectivity and biography, oral history in perspective]*. 43-79. Amsterdam: Meulenhoff.

Lin, E.H.B., Carter, W.B. and Kleinman, A.M. (1985) An exploration of somatization among Asian refugees and immigrants in primary care. *American Journal of Public Health* **75**, 1080-1084.

Lipson, J. (1991) Afghan refugee health: some findings and suggestions. *Qualitative Health Research* **1**, 349-369.

Lipson, J.G. and Omidian, P.A. (1992) Health issues of Afghan refugees in California. *The Western Journal of Medicine* **157**, 271-275.

MacMullin, C. and Loughry, M. (2000) A child-centered approach to investigating refugee children's cencerns. In: Ahearn, F.L.J.E., (Ed.) *Psychosocial wellness of refugees. Issues in qualitative and quantitative research*, pp. 194-207. New York / Oxford: Berghahn Books]

Malterud, K. (2005) Humiliation instead of care? *The Lancet* **366**, 785-786.

Manderson, L. and Allotey, P. (2003) Storytelling, marginality, and community in Australia: How immigrants position their difference in health care settings. *Medical Anthropology* **22**, 1-21.

Marmot, M. (2003) Self esteem and health. *British Medical Journal* **327**, 574-575.

Mathers, N., Jones, N. and Hannay, D. (1995) Heartsink patients: a study of their general practitioners. *British Journal of General Practice* **45**, 293-296.

May, C., Allison, G., Chapple, A., Chew-Graham, C., Dixon, C., Gask, L., Graham, R., Rogers, A. and Roland, M. (2004) Framing the doctor-patient relationship in chronic illness: a comparative study of general practitioners' accounts. *Sociology of Health and Illness* **26**, 135-158.

Mayou, R. and Sharpe, M. (1997) Treating medically unexplained physical symptoms; Effective interventions are available. *British Medical Journal* **315**, 561-562.

Misztal, B.A. (1996) Trust in modern societies. Cambridge, New York: Polity Press.

Mol, S.S.L. (2002) Trauma, life events and PTSD; a challenge for patients and family doctors [Dissertation]. Maastricht, The Netherlands: Unigraphic.

Morriss, R.K., Gask, L., Ronalds, C. and e.a. (1999) Clinical and patient satisfaction outcomes of a new treatment for somatised mental disorders taught to general practitioners. *British Journal of General Practice* **49**, 263-267.

Omidian, P. (2000) Qualitative measures and refugee research. The case of Afghan refugees. In: Ahearn, F.L.Jr., (Ed.) *Psychosicial wellness of refugees. Issues in qualitative and quantitative research*, New York / Oxford: Berghahn Books]

Portegijs, P.J.M., van der Horst, F.G., Proot, I.M., Kraan, H.F., Gunther, N.C.H.F. and Knottnerus, J.A. (1996) Somatization in frequent attenders of general practice. *Social Psychiatry and Psychiatric Epidemiology* **31**, 29-37.

Rees Lewis, J. (1994) Patient views on quality care in general practice: literature review. *Social Science and Medicine* **39**, 665-670.

Ring, A., Dowrick, C.F., Humphris, G.M., Davies, J. and Salmon, P. (2005) The somatising effect of clinical consultation: What patients and doctors say and do not say when patients present medically unexplained physical symptoms. *Social Science and Medicine* **61**, 1505-1515.

Rosendal, M., Olesen, F. and Fink, P. (2005) Management of medically unexplained symptoms. Includes diagnosis, specific treatments , and appropriate communication. *British Medical Journal* **330**, 4-5.

Rothschild, B. (2000) The body remembers. New York. London: W.W.Norton & Company.

Safran, D.G., Taira, D.A., Rogers, W.H., Kosinski, M., Ware, J.E. and Tarlov, A.R. (1998) Linking primary care performance to outcomes of care. *Journal of Family Practice* **47**, 213-220.

Salmon, P., Dowrick, C.F., Ring, A. and Humphris, G.M. (2004) Voiced but unheard agendas: qualitative analysis of the psychosocial cues that patients with unexplained symptoms present to general practitioners. *British Journal of General Practice* **54**, 171-176.

Schers, H. (2004) Continuity of care in general practice [*Dissertation Radboud University Nijmegen, the Netherlands]*. Wageningen: Ponsen en Looijen.

Stewart, M.A. (1995) Effective physician-patient communication and health outcomes: a review. *Canadian Medical Association Journal* **152**, 1423-1433.

Straten, G.F.M., Friele, R.D. and Groenewegen, P.P. (2002) Public trust in Dutch health care. *Social Science & Medicine* **55**, 227-234.

Tarrant, C., Windridge, K., Boulton, M., Baker, R. and Freeman, G. (2003) "He treats you as a person not just like a number". How important is personal care in general practice? *British Medical Journal* **326**, 310-312.

Thom, D.H. and Campbell, B. (1997) Patient-physician trust: an exploratory study. *The Journal of Family Practice* **44**, 169-176.

van der Veer, G. (2003) In de spreekkamer van de GGZ hulpverlener [*In the consulting room of the mental health professional]*. In: Grotenhuis, R., (Ed.) *Van pionieren tot verankeren. Tien jaar gezondheidszorg voor vluchtelingen. [From pioneer phase to anchoring phase.Ten years healthcare for refugees.]*, Utrecht: Stichting Pharos]

van Wieringen, J.C.M., Harmsen, J.A.M. and Bruijnzeels, M. (2002) Intercultural communication in general practice. *European Journal of Public Health* **12**, 63-68.

van Willigen, L.H.M., Hondius, A.J.K. and van der Ploeg, H.M. (1995) Health problems of refugees in the Netherlands. *Tropical and Geographical Medicine* **47**, 118-124.

Weick, K.E. (1995) Sensemaking in organizations. California, London: Sage.

Wileman, L., May, C. and Chew-Graham, C.A. (2002) Medically unexplained symptoms and the problem of power in the primary care consultation: a qualitative study. *Family Practice* **19**, 178-182.

Wissink, L., Jones-Webb, R., DuBois, D., Krinke, B. and Ibrahim, Q. (2005) Improving health care provision to Somali refugee women. *Minnesota Medicine* **88, electronic edition February 2005.**,

Zola, I.K. (1973) Pathways to the doctor - From person to patient. *Social Science and Medicine* **7**, 677-689.

Appendix I. COUNTRIES OF ORIGIN

Afghan diaspora

Afghanistan is a landlocked, mountanous country in the centre of Asia. Since 1973 the country has known a more or less continuous situation of internal warfare, where different factions, backed up by different external forces, have fought armed conflicts.

The exodus of Afghans started in the 1970s, after a coup ended the monarchy. Large numbers of civilians have left the country, and found a more or less temporary refuge in neighbouring countries. Smaller numbers of Afghans have found their way to Europe and the United States. They were in the first place urban intellectuals who were threatened and victimised by different regimes, but also people who were resettled in third countries from refugee camps.

Afghans in the Netherlands are mostly urban people who came on their own initiative, fleeing from a situation that was personally threatening to them, and who had the means and the connections to make it to a further destination. They have fled from different repressive regimes (communist, Mujahideen, Taliban) and therefore have different political backgrounds. After the Taliban regime was forcefully terminated by American bombs, the number of Afghans trying to enter the Netherlands has drastically dropped.

By January 2006 more than 37,000 people of Afghan origin (source: CBS) were living in the Netherlands, 2,634 (source: COA) of them still as asylum seekers in a reception centre. About 30,000 people of Afghan origin live in municipalities of different sizes, spread over the country. They are not a conspicuous community in the Netherlands.

Somali diaspora

Somalia is a country in the Horn of Africa with a coastline of over 3,000 km, protruding into the Indian ocean and the Gulf of Aden. Somalia has known a number of violent and long-lasting conflicts, with neigbouring countries and among different internal groups. Substantial exodus movements of Somalis have produced large camp settlements in neighbouring countries, such as Kenia and Ethiopia.

Exodus movements to European countries and the United States started from the late 1980s into the greater part of the 1990s. The Netherlands received the first refugees from Somalia in 1984.They became a conspicuous group from 1989. In 2000 about 28,700 Somalis were living in the Netherlands. Though they were housed in municipalities all

over the country, they have gradually formed communities in a number of cities, such as Tilburg, The Hague, Rotterdam and Utrecht. Since the late 1990s, a movement has started of Somalis from the Netherlands to England and the United States. In 2006, their number in the Netherlands fell to 19,800 (source CBS).