Healing Care?

Rehabilitation of female Turkish and Moroccan patients with chronic pain from a family perspective

Thesis to obtain a Master’s degree in Medical Anthropology

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Foreword

With this thesis, I finalize the Amsterdam Master’s of Medical Anthropology course (AMMA). The modules and the whole process of research have been intensive and continuously marked with deadlines, but I feel it has given me a firm foundation in the interesting fields of anthropology and social science research.

Hereby I like to thank the people who have assisted me directly or indirectly in finalizing this thesis. First, I like to thank the families who participated in the research for allowing me a glimpse in their personal lives. Their thoughts and experiences provided me with many insights and form the basis of this thesis. I am grateful to the Jan van Breemen Instituut for affording me the opportunity to conduct the research with relatives of patients who attend this centre. In specific, I like to thank Dr Jos Dekker for facilitating the process of obtaining ethical approval, and Emmanuel Scheppers for his support as a colleague anthropologist and researcher.

My academic supervisor, Els van Dongen, has been great in encouraging me in times of doubt, and her comments and feedback on my ideas and work have been inspiring. I am grateful for her faith in my capabilities.

I like to thank my dear friend Ellen Jansman, for both her emotional support and her critical comments on my research ideas and thesis. In addition, I thank my English and Irish friends, James Benson and Jean Sullivan, for their last minute efforts to proofread the thesis.

In a research about family care, I naturally think of the care I receive from my family and I am specifically grateful to my parents for encouraging me to follow my aspirations. Last, but not least, I thank my boyfriend Juan Carlos Gonzalez. This year has been a challenge for him as well and I appreciate his endless concern, attention and support. He has shared my enthusiasm and worries, and additionally his common sense frequently offered refreshing insights in the subject.

Amsterdam, August 2004
Ingrid Sturkenboom
CHAPTER 1

Introduction

This thesis describes a study of chronic pain and rehabilitation of female Turkish and Moroccan patients from a family perspective. The topic derives from a combination of my personal interest in the field of rehabilitation, disability, culture and families along with the practical considerations whilst seeking for a research setting.

Working as an occupational therapist in the field of rehabilitation medicine in Tanzania raised my awareness that concepts of disability, independence and normalization have different meanings in different contexts. Working and living in ‘non-western’ cultural setting made me challenge my own personal and cultural biases and the norms of values inherent to (western) rehabilitation medicine. My wish to better understand this concept of culture in relation to health, illness and disability made me choose to follow a medical anthropology course, of which this research and thesis are the final products.

Considering The Netherlands is a multicultural and multi-ethnic society, I was curious to explore how people from another cultural background to me, would interpret and give meaning to chronic illness or disability, and rehabilitation. In specific, I was interested to gain insight in the perspective of the family. Dr Jos Dekker, the secretary of the working party of transcultural rehabilitation informed me of a research project taking place at The Jan van Breemen Instituut, where he works as a rehabilitation physician. This research, called IDEAL, addresses issues relating to utilization of rehabilitation services by Turkish and Moroccan migrants with chronic low back pain (see appendix I for overview of IDEAL). Dr Dekker agreed a study on the family perspective on rehabilitation could add valuable insights to the running project and I gained ethical approval to conduct the study.

However, due to delay in the recruitment of participants for the IDEAL research, there were also no participants via this project for my study. Therefore, I adjusted the sampling criteria by widening the diagnosis of chronic low back pain to any chronic pain condition and accepting patients from all stages of rehabilitation.
Problem statement

Medical rehabilitation aims to enhance autonomy and participation in society for individuals who suffer long-term disabilities (Cardol 2001). By engaging in rehabilitation, patients train their abilities and/ or learn strategies to enable participation in their daily activities and life roles. Rehabilitation programmes endeavour to be client centred (ibid). This includes the notion that goals and methods of treatment are tailored to how the patient perceives his/ her needs, and not to how the professionals perceive the patient’s needs. Nevertheless, research suggests expectations and goals for rehabilitation often vary between professionals and the patient concerned and this may impede the quality and effectiveness of client centred care (Playford et al 2000; Sumsion & Smyth 2000).

The study of Thomas et al in which obstacles in rehabilitation for migrants were explored, suggests expectations and goals for rehabilitation between migrants and professionals are different. Thomas et al proposed that this discrepancy is mainly due to the fact that health professionals and migrants have different notions on who is responsible for illness and treatment. Rehabilitation professionals utilize models for treatment that assume an active involvement of the patient to work on his problems. In contrast to this, migrants are perceived to utilize external explanatory models for illness and subsequently expect a solution for the problem to be provided by the professional (Thomas et al 1999).

Whilst there is an abundance of research reflecting the perspectives of health professionals regarding the perceived ‘problematic’ service delivery to migrants, there is still a need to gain more insight in the perspectives of the migrants themselves. Specifically, how do migrants perceive and experience chronic conditions, healing options and the role of rehabilitation? Such studies would benefit both migrant groups themselves and health care professionals in respect of a more effective delivery of client centred health care. For the study described in this thesis, I did not choose to focus specifically on the perspective of individual patients, but more on the perspective of family members involved in the patients’ care at home.

The relevance of the perspective of family members derives from social network theories within sociology and anthropology. These theories indicate the influence of the social

1 In this research I use the term migrant for people who in Dutch terms are classed as ‘allochtoon’. Although there are many different notions within Dutch society of who is classed allochtoon, I use the definition as indicated by ‘Centraal Bureau voor Statistiek’ (CBS). They define as allochtoon a Dutch resident who is not born in The Netherlands (first generation), or whose parents (or one of the parents) are born in a foreign country (second generation) (CBS, 2003). They also differentiate between ‘western’ and ‘non-western’ migrants, with the latter being people from Turkey, Africa, Latin-America or Asia (but not Japan or Indonesia) (CBS 2003).
network of the patient on the recognition of illness, the meaning given to illness and expectations for care and treatment (Kleinman 1980; Kinlay 1981; Pescosolido 1991). Kleinman (1980) contends that the social network forms the popular sector of health care and provides the largest amount and most continuous support and care to a patient. Of this social network, family members are generally most involved or influential in the care at home in case of illness (Wersch & Uniken Venema 1993; Reysoo 1999; Potting 2001). Families have their own values, attitudes and beliefs on illness and health, which shape beliefs regarding particular illnesses of a family member. These beliefs lead to perceived care needs with expectations of what interventions or actions might be appropriate to deal with the illness situation. Additionally, when a person is chronically ill and disabled, people who care about, and care for this person are likely to notice an impact of this illness on their lives as well. To paraphrase Kleinman (1988:249): disease affects single individuals, but the illness incorporates his social circle. The impact on family members in turn influences their response to the illness and care. These theories lead to the conclusion that illness and response to illness are dynamic, continuously interactive social processes in which the ill person and the family members are all potential victims and social actors.

Moreover, as stated before, rehabilitation aims to enhance participation in society and rehabilitation professionals expect active involvement of the patient. Rehabilitation is a learning process, which is enforced when the patient is engaged in daily activities. Thus, learning does not only take place in direct intervention with the professionals, but specifically in the interaction with the social network and the home environment (Finkenflugel 1999). Considering the nature and aim of rehabilitation, I thus ascribe importance to the role and perceptions of the family for the effectiveness of rehabilitation. Therefore, I have endeavoured to explore the social context of rehabilitation and specifically give voice to family members to represent their perspective on the illness, treatment and care of their chronically ill relative.

Because of the original opportunity to conduct my research parallel to a project at the Jan van Breemen Instituut, the sample population is defined as Turkish or Moroccan patients with a chronic pain condition. Although there is no registration by ethnicity, patients from Turkish or Moroccan descent are perceived to be two of the largest migrant groups attending the Jan van Breemen Instituut with chronic pain complaints (Scheppers 2003). Available demographic data for 2003 for the region suggests this could be correct: 33 percent of the total population in Amsterdam comprises of non-western migrants and 25 percent of these are Moroccan and 15 percent are Turkish (CBS 2003).
Despite advances in pain management, pain remains difficult to treat and the amount of people with disability because of chronic pain conditions continues to grow worldwide (Driessen 2002). Although pain is a universal phenomenon, the actual pain experience, expression and subsequent care vary greatly between individuals. Socio economic and socio demographic position, cultural and religious values, personality and personal life history all influence the way pain is understood, expressed and responded to (Kleinman et al 1992; Bendelow 1993; Driessen 2002). These differences can be perceived more prominently when people are from different cultural backgrounds. For example research findings suggesting that Turkish and Moroccan patients express pain in a more elaborative way utilising a different body of metaphors for pain in comparison to native Dutch people (Eppink 1990; Driessen 2002). In a cross-cultural setting this can lead to confusion, misunderstanding and stereotypical interpretations. Consequently, discrepancies may arise in expectations for care and treatment.

Furthermore, I focus this study on family members of female patients. In traditional Turkish and Moroccan culture there is a strong role division between men and women (Van Es 1995; Abraham 1996; Yerden 2000) As women are mainly responsible for domestic tasks, I assume an illness affecting a woman’s productive role would have a greater impact on family life at home. Reysoo (1999) found in her study on health care seeking of Moroccan women, that child-rearing women do not give in to illness quickly as an inability to perform their women’s roles might lead to social marginalization and might jeopardize marriage. These factors might not only influence illness behaviour, but might also influence the family member’s perspective on illness and disability, and expectations for care and treatment. Considering the small-scale nature of this study, and the possibility that rather different considerations might apply to male rather than female patients I have elected to restrict my study to a target group of female patients.

Understanding the manner in which family members understand and influence rehabilitation may lead to advantages for deliverers and receivers of health care services. It could fairly be said that there is a lack of insight into how Turkish and Moroccan families of female patients understand, perceive and respond to chronic pain and pain rehabilitation programmes. I address this omission in this thesis.
Research objective

The overall objective of this study is to explore the perspectives of family members regarding rehabilitation of female patients of Moroccan or Turkish descent with a chronic pain condition.

The following four research questions guided the fieldwork:

1) What are the family members’ perceptions of the illness of their relative?
2) What are thoughts and expectations of the family member regarding healing options for the chronic pain condition?
3) What are perceptions of the role and prospects of rehabilitation?
4) What do family members perceive as their role in the care of a person with chronic pain?

This anthropological study expands on and deepens the medical perspective, which generally only considers or treats the individual patient out of the social context. Therefore, I hope that findings of this research will not only enhance insight into family members’ perceptions on rehabilitation in relation to chronic pain and family care, but can also identify for rehabilitation professionals the additional value of the family perspective when analysing care needs and planning interventions. In relation to medical anthropology, I hope that this study can modestly support or add to theories of pain and family care in a cultural context.

Outline of the thesis

The above problem statement and research objective have introduced the concepts of chronic pain, migrants, rehabilitation and family care. In chapter two, I further elaborate on these concepts specifically in relation to my particular perspective as to their relevance for this study. Chapter 3 describes the methodology of this study and reflects on its process and limitations. Following this, chapter four provides a short description of the Jan van Breemen Instituut and its aims and methods for chronic pain conditions. The chapter also includes a brief assessment of the professionals’ own viewpoints on the role of the family in rehabilitation.

In the following four chapters, findings arising from the visits to families are presented and interpreted. Herein, references are made to findings or concepts in the literature where
appropriate. In every chapter, a different research topic is addressed. In chapter 5, the perceptions on the illness are the central focus. It addresses the questions of how family members describe and interpret the condition, how they know the person is in pain and what they see as the causation of suffering. Chapter 6 describes what family members perceive as appropriate healing options and what they expect regarding improvement of the situation. Perceptions of the role of rehabilitation in healing are discussed in this chapter as well. Chapter 7 specifies the impact of the illness for the family member concerned. The final of these four chapters looks at perceptions of the role of family care in coping with the illness.

An overall discussion and conclusion in relation to the research objective is given in chapter 9. Additionally, this chapter reflects on some of the assumptions made for this research. The thesis concludes with a chapter on recommendations, both for practice and for further research.

Note:
Although I dislike the term 'patient' for someone within a home environment, this term is used for the ill female person in this thesis, in order to keep a clear distinction for the reader between the female person with the chronic pain condition, and her relatives who participated in the study. These relatives will be referred to as ‘family members’ or ‘participants’.
CHAPTER 2

Migrants, chronic pain, family and family care:
A conceptual framework

This thesis concerns Turkish and Moroccan migrants, chronic pain, rehabilitation and the role and perceptions of family members. In this chapter, some relevant background to these subjects and concepts is given. Additionally, it highlights the perspective with which I approach these concepts in my study. The chapter will start with general discourses on migrants and health care in The Netherlands. Then the understanding and meaning of chronic pain is addressed. Lastly, I focus on difficulties in defining the concepts of family and family care. Rehabilitation as a general concept has been addressed in the introduction and rehabilitation in the Jan van Breemen Instituut will be described in chapter four. Therefore, this concept will not be discussed separately in this chapter.

Turkish and Moroccan migrants

Significant immigration of Turkish and Moroccan people into The Netherlands started during the 1960's. The driving force was largely the recruitment of men for manual labour (Van Dijk & van Dongen 2000; Van Es 2000; Van Beelen 2004). Initially only the men came and the immigration was seen as a temporary phenomenon, however later many of the men brought over their wives and children and their stay in The Netherlands became permanent (ibid). Currently, Moroccan and Turkish migrants constitute nearly forty percent of the total amount of non-western migrants in The Netherlands (CBS 2003).

Decades of research and debates related to non-western migrants and health care has lead to the conclusion that healthcare provision for migrants is seen as problematic. The focus of research has been on three main areas: differences in health status, problems in accessibility of services and the actual utilization of care (cf Havenman & Uniken Venema 1996; RVZ 2000; Van Veen et al. 2003; Wolffers & Van der Kwaak 2004).

The main drive for research originated from the side of (biomedical) health care professionals. They are generally dissatisfied with the interaction with migrant patients and the
effectiveness of care and, moreover, perceive that migrants’ use of certain health care services is inappropriate (cf RVZ 2000; Van Veen et al 2003). Factors that can contribute to these ‘problems’ are found to be multiple, but recurrent themes are language barriers, cultural differences, and the migrant’s lack of medical knowledge about the body and medical systems.

Recently there has been more debate about the concept and role of cultural differences. The main critique from the field of social sciences is that culture is often seen as a static reified concept, whereas culture is highly dynamic and is influenced by the wider sociocultural and political context and the personal life world (Vermeulen 1992; Van Dijk 1998). Concerning migrants, cultural values and ideas are influenced to greater or lesser extent by Dutch values and ‘traditional’ ethnic values and this changes over time. Moreover, stereotyping ‘the’ migrant groups distracts attention from the genuine diversity of attitudes to health and sickness both between and within migrant groups. These differences are sometimes more prominent than differences between migrants and the native population (Van Duursen et al 2002).

Another criticism is that professionals see culture as something of the ‘other’. They lack appreciation of a) their own cultural values/norms and b) the fact that the health care system is a cultural system (Kleinman 1980; Van Dijk 1998; Van Duursen et al 2002; Wolffers & Van der Kwaak 2004). Values and norms are embedded in the professional conduct, the organization of care, the objectives and the methods used. For example the culture of rehabilitation, based on the ideology of individual autonomy, and participation, can be seen as a specific western adaptation to disability (Anderton et al 1989; Finkenflugel 1999). Objectives and effectiveness of service are evaluated according to these concepts and therefore there is little scope for diverse ideas on disability, autonomy or participation. Perceiving culture as something of the other combined with perceiving the other culture as a problem in health care provision can result in blaming the migrants for the failing health care system (Van Dijk 1998).

For this thesis, I adopt the perspective that cultures are dynamic and diverse, and that rehabilitation medicine itself is a cultural system, as central notions.

Chronic pain

Pain is essential for human survival and is a fundamental part of human nature (Bates 1996; Van der Geest 1998; Driessen 2002). In an historical account, Driessen (2002) outlines how
since the 20th century pain has become more and more medicalised and placed within the biomedical model. Through this, the originally more magical and religious concept of pain shifted to an empirical and rational concept. This has had several implications for understanding and responding to pain.

In the biomedical discourse the meaning of pain is subject to the Cartesian human duplex vision, in which aetiology of pain is classified as a symptom of underlying somatic or psychological dysfunction (Kleinman et al 1992; Bendelow & Williams 1996; Driessen 2002). Although the recognition of psychosomatic illnesses suggests clinicians acknowledge an interaction between mind and body, many of the actions of staff in pain clinics show a continued belief in mind-body dualism (Bates et al 1997).

The biomedical discourse on pain has also constructed the concepts of acute and chronic pain, which are value laden. Acute pain, often organic, has a warning function for potential or actual harm to the body. It is a symptom of disease; it can be controlled and as such reflects the successes of biomedicine. In contrast, chronic pain is ambiguous and poorly understood: it has no biological function, does not respond to biomedical intervention and as such threatens the credibility of biomedicine (Good 1994a; Honkasalo 2001). The International Association of the Study of Pain classifies chronic pain as pain that persists longer than six months, past the normal time of healing and/or failed to respond to the usual forms of biomedical interventions (Bates & Rankin-Hill 1994; Bates et al 1997). In my study, I use this cut off point of six months of pain as the criteria for patients of my sample. For some patients of my sample there will be an underlying physical disease explaining the enduring symptom of pain; for others there might not be a prove of underlying organic pathology, which is also labelled in biomedicine as 'non-specific pain'.

In terms of the mind-body dichotomy, psychological processes are thought to maintain chronic pain (Kleinman et al 1992; Vlaeyen et al 1996). Explanations from the psychological model use the notion of secondary gains, learned behaviour and dysfunctional cognitive thinking patterns (ibid). For example, sympathy and increased attention or nurturance of the family can reinforce pain behaviour. Pain behaviour can also be used to deflect other emotional or social problems or may be used to manipulate relationships or responsibilities (Kleinman et al 1992).

Pain management programmes are based on these psychological notions and enforce behavioural and cognitive strategies to enable a positive adaptation to pain (Vlaeyen et al 1996; Wittink & Hoskins Michel 2002). Successful patients are considered those who are motivated to 'work on their problems' and adapt successfully to the pain in a way that they
express minimal pain behaviour and function as normal as possible in life (Bates & Rankin-Hill 1994; Jackson 1994; Bendelow et al 1997).

Within social science literature on pain, the emphasis is on the sufferers’ search for the meaning of the illness and the lived experience of pain. Kleinman (1988), Good (1994a), and many interpretive anthropologists suggest this meaning is expressed in the illness narratives of sufferers. However, although pain is an individual inner experience, essentially subjective and private, the pain experience lies at the intersection of body, mind and life world of the individual and is intersubjective (Kleinman et al 1992). The pain experience is shaped by and shapes the ‘life world’ of the sufferers and affects those around them (Kleinman et al 1992). This interaction in constructing meaning and experience of pain is an important background for my study, whereby I focus on the narratives from the family members.

Family and family care

As explained in the introduction of the thesis, the focus of my research is the perspective of family members. However, the concept of family and who is a family member can have different meanings in different cultures and contexts. Depending on age, social class and culture, individuals can define their family differently.

Potting (2001) points out that what is meant by the term family depends on who asks about it and the context it refers to. In some situations, the term family refers to the people sharing a household. Within traditional Turkish and Moroccan culture, three generations may share a household reflecting the importance of the extended family (Abraham 1996; Yerden 2000). However, in recent times this has evolved into a state where living within a nuclear family is common. This is both for families in Turkey and Morocco and for migrant families in the Netherlands (ibid).

In other situations, the term family refers to the group of persons connected with each other through biological ties or legal procedures (e.g. marriage) (Potting 2001). However, the way people themselves define their family can be based more on the responsibilities and expectations attached to being family.

Family relationships are fundamentally social, prescribing norms of behaviour for members...to say that someone is a family member is to accept social rules defining
obligations which different family members owe to each other (Marsh and Arber 1992: 10 as quoted in Potting 2001: 32)

Therefore, the concept of family is socially and culturally constructed. To avoid discussion and confusion on who is classed family or not, and who therefore can be or not be eligible to participate in my study on the family perspective, I will leave the determination of this to the patient. A family member of the patient is therefore anyone who she considers as a family member.

Norms and values within family life shape notions of family obligations and expectations, and these are the basis of care for family members in case of illness. In the chapter on family care (chapter 7), I will describe traditional Turkish and Moroccan ideas and attitudes towards family care and contrast these with the statements of family members participating in this research. In general, it is suggested in the literature that traditional Moroccan and Turkish cultural values stress the importance of family relations in giving and receiving practical support in case of illness (Leeflang 1991; Wersch & Uniken Venema 1993; Abraham 1996; Yerden 2000). It is important to realize, however, that the mere existence of family or other social network ties does not necessarily guarantee support. Ahmad & Atkin (1996: 51) warn against the stereotype of the virtuous caring families of migrants as "it ignores both diversity of perspectives and behaviour within an ethnic group and the similarities across ethnic groups". Socio-economic and demographic factors may influence the willingness and ability to provide care.

According to Potting (2001) it is difficult to distinguish what is part of 'normal' family care and what is specific care for the ill person. Additionally, what constitutes care is diverse and complex. Family care can involve emotional care and instrumental care. It can include tasks that promote the functioning or well-being of the ill individual, and tasks to ensure continuity of family life. It can be care that enforces dependency and sickness identity of the ill person, or care to promote normalisation in functioning. Considering the diversity and complexity of family care, I share Potting’s viewpoint and leave the participants of the study to describe and define what they perceive as care for their ill family member.
CHAPTER 3

Methodology

The objective and research questions set out in the introductory chapter warrant certain methodological choices, which I will address in the present chapter. Transparency of the methodology deployed “allows the reader to assess the intellectual strengths and weaknesses, the biases, and the conscientiousness of the researcher” (Rubin & Rubin 1995: 85) and with this judge the credibility of the study. Therefore, this chapter not only provides insight on how the research was conducted, but also reflects on the process and the limitations of the study.

Study type

As indicated the main objective is to explore the perspective of family members regarding rehabilitation and care of female patients of Moroccan or Turkish descent with a chronic pain condition. To gain an insight into a particular person’s perspective, I explored their notions, beliefs and expectations in an open manner through in depth interviews and conversations. Therefore, this study is qualitative and descriptive in nature.

Sampling

As stated in the background to the study in chapter one, the ‘recruitment site’ of the Jan van Breemen Instituut was mainly chosen for reasons of feasibility, namely to gain access to family members of patients who have experienced rehabilitation. Since the ethical committee of Slotervaart Hospitals had agreed the initial research proposal, permission was granted to approach patients and their families registered by The Jan van Breemen Instituut. Originally, the recruitment of research participants would have been via a running research project involving Moroccan and Turkish people with chronic low back pain. However, as indicated in the background to the study, this proved impracticable and resulted in a change in both the sampling criteria and recruitment method.
Finally, I aimed to include in my study family members of six to ten female patients of Moroccan or Turkish descent with a specific or non-specific condition causing chronic pain. These patients could be still in treatment in the Jan van Breemen Instituut or recently have been discharged. The sample size of six to ten patients was determined by the number of available and willing participants and time constraints. My aim was to focus on one or two family members of each patient. The family members could be any relatives involved in the care of the patient in the home environment. This means they assist, supervise or take over activities or roles the patient would have performed herself if feeling well; or they have an important role in making decisions concerning care and treatment or in providing emotional support. These persons are more likely to have an impact on the perspective of the patient and the situation of care at home.

Considering there is no registration of patients by ethnicity, potential participants could not be identified reliably through the administration of the Jan van Breemen Instituut and thus, I had to depend on the willingness of therapists to identify potential participants among their caseload. I was introduced to the therapists in a team meeting and following this written information about the research was sent to them. After several reminders and directly approaching individual therapists, I received the names of sixteen patients during my fieldwork period.

The next step was to contact these patients. Most researchers in the field of migrant studies report difficulty in recruiting Turkish or Moroccan research participants (Abraham 1996; Reysoo 1999) However, Çinibulak (2003) found a personal approach most effective in recruiting Turkish women for health research. Therefore, I chose to contact patients in person. If possible, I approached the women still attending the Jan van Breemen Instituut after their appointment time. The patient could get a first impression of the researcher and have a face to the name. I explained the research, gave the information letter (see appendix II) and checked willingness to participate. In the explanation I stressed the wish to speak to them and a family member who is involved in their care at home. In case the next appointment was not due for some time, or when the patient had already been discharged, I telephoned the person.

Although time consuming, this method proved to be effective. Of the thirteen patients contacted, eight families were willing to partake in the research whereas five families declined. Reasons given by the latter group were: family members are unwilling to participate because they are too busy (two cases); the patient feels misunderstood by her family and does not want to talk about it (one case) and patient sees no point talking about it as she is disillusioned by rehabilitation (one case). In one case, the woman had agreed to participate, but
changed her mind after talking to her children. Considering the nature of the reasons given, interviews with these families would have been interesting, but unfortunately, I did not manage to change their minds.

At the time of my first visit, I explained the research again, provided the information letter if they had not as yet received this and gave opportunity to ask any questions or express any concerns about the research. Once in the homes of people, I sensed it would be inappropriate to introduce a written consent form. My concern was this would create unnecessary suspicion, too formal an atmosphere and more distance between the participants and me. However, all participants have provided verbal agreement for the interviews after explanation of the aim, procedure and privacy rights. I have sent a report of the conversation to the people who wanted this.

**Brief profile of the participants**

Although a brief introduction of each family would be insightful, for reasons of privacy and anonymity, I limit this overview to some general characteristics of the participants. Table 1 summarizes some of these characteristics per case.

The group of participants was diverse and comprised of people from two Moroccan and six Turkish families. In one family, I spoke to two sisters who both fitted the criteria of the research as patients and family members. They both were females with chronic pain complaints who attended the Jan van Breemen Instituut and they both were involved with each other’s care.

The patients were aged between 22 and 81 and the range of medical conditions as reported in the medical notes of the patients was: pain following polyneuropathy, arthritis, fibromyalgia and undiagnosed non-specific pain. Table 1 on the next page provides an overview of the cases and reflects the participating family members I spoke to during the visits.

All patients had experienced some form of rehabilitation at the Jan van Breemen Instituut. However, they had not all received comprehensive rehabilitation, but only involvement of the doctor and maybe one other discipline. Five patients were still in treatment at the time of my fieldwork and four had recently been discharged.
Apart from the two sisters who were both ill, there were two other families, in which the participating husband of the female patients also suffers from chronic pain and attends or had attended the Jan van Breemen Instituut.

Following the definition of CBS generation classification of migrants, seven of the nine female patients are first-generation migrants and the remaining two are second-generation. Regarding level of education, five of the nine female patients have had at least secondary education, either here in The Netherlands (four women) or in country of origin (one woman).

Table 1 Basic profile sample group

<table>
<thead>
<tr>
<th>Case</th>
<th>Age group patient</th>
<th>Ethnic background</th>
<th>Country of birth patient</th>
<th>Pain condition</th>
<th>Visit 1</th>
<th>Visit 2</th>
<th>Visit 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>65+</td>
<td>Moroccan</td>
<td>Morocco</td>
<td>Neuropathic pain</td>
<td>Patient Daughter in law</td>
<td>Son Daughter in law</td>
<td>N/a</td>
</tr>
<tr>
<td>2</td>
<td>35-49</td>
<td>Turkish</td>
<td>Turkey</td>
<td>Non-specific chronic pain</td>
<td>Patient Husband Son</td>
<td>Patient Husband Daughter in law</td>
<td>N/a</td>
</tr>
<tr>
<td>3</td>
<td>65+</td>
<td>Turkish</td>
<td>Turkey</td>
<td>Arthritis</td>
<td>Patient Grandson Daughter</td>
<td>N/a</td>
<td>N/a</td>
</tr>
<tr>
<td>4</td>
<td>20-34</td>
<td>Turkish</td>
<td>The Netherlands</td>
<td>Arthritis</td>
<td>Patient Partner Mother Father Brother</td>
<td>N/a</td>
<td>N/a</td>
</tr>
<tr>
<td>5</td>
<td>50-64</td>
<td>Turkish</td>
<td>Turkey</td>
<td>Non-specific chronic pain</td>
<td>Patient Husband</td>
<td>Patient Husband</td>
<td>Husband</td>
</tr>
<tr>
<td>6</td>
<td>20-34</td>
<td>Turkish</td>
<td>The Netherlands</td>
<td>Non-specific chronic pain</td>
<td>Sister Patient</td>
<td>Sister Patient</td>
<td>N/a</td>
</tr>
<tr>
<td>7</td>
<td>35-50</td>
<td>Turkish</td>
<td>Turkey</td>
<td>Fibromyalgia</td>
<td>Patient Sister</td>
<td>Patient Sister</td>
<td>N/a</td>
</tr>
<tr>
<td>8</td>
<td>20-34</td>
<td>Moroccan</td>
<td>Morocco</td>
<td>Arthritis</td>
<td>Patient Husband</td>
<td>Patient Husband</td>
<td>N/a</td>
</tr>
<tr>
<td>9</td>
<td>35-50</td>
<td>Turkish</td>
<td>Turkey</td>
<td>Fibromyalgia</td>
<td>Patient Husband</td>
<td>Husband</td>
<td>N/a</td>
</tr>
</tbody>
</table>

Throughout the remainder of the thesis, all patients and participants have fictitious names and additional contextual information for each case will be provided where needed.
Data collection: process and methods

The data collection took place over a period of six weeks in May and June 2004. The participants were visited at their homes during which I conducted in-depth interviews.

My aim had been to visit all families at least twice. This would provide me with the opportunity to use the first visit to speak to both patient and relative, establish rapport and address the main topics. In the second visit, I could then focus more on the family member and draw upon themes and questions arisen from the first visits. Due lack of availability of the participants, I did not succeed to do this second visit in two cases. In one case, I had the opportunity to meet a family member for a third time (see table 1).

In all cases, I was invited in the living room where the patient and one or more of her family members would be. During the initial visit, mainly the patient and one relative were present during the whole conversation. Other family members might walk in and out, provide drinks and sometimes join for a small part of the conversation.

The focus of the interviews was on the perceptions and experiences regarding: the illness of the relative, the treatment in general, rehabilitation in specific, and the role of the family in care and rehabilitation. Appendix III gives a complete overview of the topic list for the first interviews. As the research addresses a health problem, which is both current and historical for the participants, I addressed past experiences and current notions and expectations.

The style of interviewing was open and loosely structured. During the first visit, I usually asked the participant(s) to first give an account of the illness. Following this, I asked different questions, related to what they had said and related to my research questions. Therefore, the sequence of the topics was flexible. This way, the interviews were more natural and flowed more conversationally. Moreover, the sequence in which topics came up, the emphasis the participants put on certain topics compared to others, and who brought them up were useful for my analysis. For example, between the patient and her relative, the person who spoke best Dutch would always ‘dominate’ the conversations during the first visit.

In contrast, I was more directive in the second interviews, by specifically asking the opinion of certain participants, who had not given their opinion in the first interview. Additionally, I brought in certain topics related to specific themes and new topics that had started to come to the surface in the preliminary analysis. Only in a few cases, I got the opportunity to speak to the family member without the presence of the patient, which shed a different light
on some sensitive issues, like sexuality and frustration with certain characteristics or behaviour of the patient.

With permission of the participants, most interviews (eleven) were recorded with a MP-3 voice recorder. In three interviews, I had not asked to record and took brief notes instead. These were all first visits taking place early on in the fieldwork period, when I had been more focused on making the people feel comfortable to talk and familiarize myself with the interview situation. Later on, I became skilled in finding the right moment to ask if I could record the interview. In one interview, the recording had failed due to a technical error.

I observed the social and environmental context to place the verbal responses in context. For the purpose of my research, I was attentive for non-verbal communication and observed the interactions between family members and the patient and the role family members take in the care of the patient during my presence. After the visits, the recordings or notes were transcribed into word documents.

Besides the data collected from visits, I looked in the medical notes after the first visit, to get the ‘formal’ medical diagnosis and to get an impression of what kind of disciplines had been involved in the care of the patient. I preferred not to get these details before the first visit, so as not to prejudge the situation before hearing the perceptions of the family. However, after the first visit I found it useful to look at the medical notes so as to contextualise the accounts of the participants regarding the perceptions on the illness and perceptions of rehabilitation. My personal preference was to avoid delving too deeply in the case notes, nor to discuss the professionals’ perceptions on the individual’s case. The reason for not doing this is that the focus of my research is the perspective of the family and not an exercise in comparison between the perspectives of the family and health professionals.

However, I did have two discussion meetings with health professionals. One meeting was with two social workers and one with three occupational therapists. The aim was to get background information on the role of family in rehabilitation in the Jan van Breemen Instituut. Topics discussed were: what they considered the role of family in rehabilitation to be, if and how they involved families in the rehabilitation process and what, from their experience, the involvement and role of Turkish and Moroccan families in pain rehabilitation is.
Data analysis

The data obtained during the conversations with the participants form the basis for the analysis. As indicated in the above section, I obtained some additional background and contextual information. This mainly assisted in putting the comments of the participants into a broader context and in providing the background information on the setting of the research.

Following each visit, I re-read the transcribed data and reflected on what had been said and by whom. For each family, I prepared an additional document, in which relevant data was ordered under the three broad categories of perceptions on illness, perceptions on treatment/rehabilitation and perceptions on the role of the family. This followed the organization of the main research questions. Although the chronological aspects of the conversation are not visible in this topic-oriented document, it made it easier to compare and contrast data of different families and elicit gaps in data. This helped to prepare the follow up visit and ‘find’ some of the themes.

Moreover, after each visit, I reflected on the process of the visits and the interviews. I specifically reflected on methodology, approach and my position as researcher and person. For example, I tried to relate my comments and questions to the kind of responses I got from the participants. In a later section, I will comment on the effects on validity of data in relation to my role as a researcher.

As indicated above, some preliminary analysis took place during fieldwork and guided the topics for the second interviews. The cyclical and interactive process of analysis and data collection is characteristic of ethnographic research (Spradley 1980). The ongoing cyclical process of analysis also helps to establish when the data collection is complete and a saturation point is achieved (Rubin & Rubin 1995). This would be “when narratives repeat the same events and the same variety of interpretations” (Rubin & Rubin 1995: 73).

The topic-oriented documents, the original transcriptions and reflection notes were all used for analysis. I followed steps of the qualitative data analysis process as described by Le Compte and Schensul (1999) and Spradley (1980). Within the categories of perceptions on illness, perceptions on rehabilitation/treatment and perceptions on the role of the family, I labelled the data with key words and key phrases for main ideas and experiences expressed. By comparing and contrasting these codes within and between categories of one family and within and between families, themes ‘emerged’. In appendix IV an overview is given of the codes used. The next challenging step was to detect linkages and relationships between themes and to link these to theoretical concepts and literature. Due to the limited scale of the
study and the diversity of the research group, I am aware of the limitations in interpreting the data. This will be discussed in the following section.

Validity and credibility of the study

The quality of qualitative research is judged by its validity and credibility. Validity can be threatened at various stages of the research process: in sampling, in data collection and in analysis (Hardon et al 2001: 203). As Patton (1990: 461) poses: “the credibility of qualitative enquiry is especially dependent on the credibility of the researcher because the researcher is the instrument of the data collection and the centre of the analytic process”. In the following account, I highlight some potential biases in the study and the way I have tried to minimize these.

Sampling bias

There were many recruitment stages before reaching the family members I aimed to include in the study, and at each stage, the selection was made by someone with his/her own perspective. The patients attending the Jan van Breemen Instituut are already a selective group. Then the therapists made a selection of potential participants. Subsequently, the patient had a choice in participating and then she would ask or select a family member. Therefore, I do not consider the final group of participants to be representative of the whole target group. Likewise, due to time constraints, the focus of the study was on one to two family members of each patient, which is not representative of the overall family perspective.

As stated in the sampling criteria, I aimed to speak to family members who were involved in the instrumental or emotional care of the patient at home. In most cases, I feel I did speak to a person relevant for the care of the patient. However, in some cases, the choice of participant was based more on who is considered best in representing the family to ‘outsiders’, either because of the position of the man in the house, or because of language ability.

Both the family members and the group of patients were diverse. The patients had varied diseases, were in varied phases of their illness and were at different stages of rehabilitation. This is important to consider in the analysis and interpretation of the data. The heterogeneity of the selected group in combination with the small sample size, may account for the variety in responses on the topics and means the results cannot be generalized.
Bias in data collection and analysis

Personal characteristics like age, gender, ethnicity and personality can affect the impression people have of the researcher; the level of rapport and subsequently the data collected (cf Silverman 2000). I tried to build rapport by being friendly, non-judgmental and respectful, and by showing genuine interest in their situation. From the data obtained, I have the impression most participants trusted me. They were willing to talk and some shared very personal experiences with me. The fact I am female and an outsider from their social network, might have had a positive effect. In spite of this, my own ethnic background biased data in another way. For example, I noticed they would often introduce the concept of ‘cultural values’ as overarching explanation for their behaviour and ideas. They would have statements like: “but that is cultural”, or “in Turkish culture...” This might not have happened so explicitly if I would have been from the same cultural background.

Another personal factor influencing the research is my background as rehabilitation professional. On the one hand, this experience made it easier to understand the medical terminology and the rehabilitation process. It also helped in communicating with the therapists. On the other hand, in the conversations with the families, I had to continuously remind myself not to take things for granted. This became easier in the course of the fieldwork.

Additionally, my attachment to the Jan van Breemen Instituut for this research forms a potential bias. I had contacted people via the Jan van Breemen Instituut and referred to this when explaining the research. This was positive for legitimizing the research purpose and gaining acceptance for participation. Nevertheless, the association of the research and me with the rehabilitation unit could affect their responses regarding perceptions on rehabilitation. People might avoid criticism, or decide to complain more in the hope for change. I attempted to limit this response bias by clearly explaining I am student and researcher and not staff, and by clarifying that all information would be treated anonymously and would not affect treatment of the patient.

Regarding communication, four of the patients had limited ability to speak Dutch and the family member would translate. In some situations, this went well, but in other situations, I doubted the objectivity or completeness of the translations. For example, the patient would give a long reply and the family member would translate it to me in a few words. This affects the validity of these data. However, my emphasis was not on the perspective of the patient herself, but more on the perspective of the family member. Therefore, the data of the patient herself were less relevant for my research anyway. In three cases, the patient had a better ability to communicate in Dutch than the participating family member, and subsequently
intervened in the accounts of the other person or dominated the conversation in the first interview. In the second interviews, however, I was more directive in letting the family member speak for himself. In some cases, I had the opportunity to speak to the family member alone.

Language ability also affected the way in which ideas and experiences were formulated and expressed. Frequently interviewees would apologize for their inability to express to me what they felt due to their limited vocabulary. In some cases, this has affected the richness of the discourses. However, I frequently asked for clarification and tried to give feedback to the participants of what I had understood from his or her account, to confirm I had understood them correctly. For the transcriptions, I had to paraphrase some of the sentences to make them more fluent. Besides that, I translated the Dutch narratives into English for this thesis. Whilst I endeavoured to correctly represent the meaning of the accounts, I recognise that some form of translation bias is inevitable.

I am aware that the presence of the patient during most visits influenced the data gathered and especially in cases where the patient was very involved in the interview, I did not obtain a 'pure' family perspective. However, this problem was inherent to the research methodology. For ethical reasons, I did not consider it appropriate to gain access to family members via the patient and then ask the patient to leave the room. The occasions where I had opportunity to speak to the family member by himself, I noticed the conversations had a different content and tone. However, in the other interviews, I gained valuable information about the interaction between patient and family member, which has been used to put the responses in context.

A major limitation is the lack of opportunity for participant observation or 'hanging around' in the home environment. Data from these kinds of observations would have been a valuable addition to the interview data. Unfortunately, this was not realized in this small-scale research. The visits were not spontaneous, but arranged meetings. For them, I was a visitor in their private home with a purpose of interviewing and subsequently there were certain expectations and behaviours from both sides. Although I might have shifted in their perception from an unknown formal visitor to an interested friendly visitor, I remained some kind of visitor. Therefore, I cannot expect to have observed normal family life or normal family interactions. My analysis, therefore, is mainly based on people's accounts and narratives.

Finally, following the analysis I do not consider that I have been able to achieve saturation point in data collection. Time constraints did not permit me to get a larger sample size nor to do more follow up visits. Thus, the analysis and conclusions need to be seen as tentative.
The Jan van Breemen Instituut

Considering that the patients’ and their families’ experiences of rehabilitation have been mainly through treatment at Jan van Breemen Instituut, a description of the centre with its aims and methods is relevant and is set out in this chapter. In addition, the role of the family in rehabilitation from the perspective of rehabilitation professionals is given. Information has been gathered from the general information brochure and a work document of the Jan van Breemen Instituut and through discussion with health professionals.

Rehabilitation at the Jan van Breemen Instituut

The Jan van Breemen Instituut is a regional health care centre in Amsterdam, covering a population of 1.2 million people. It specialises in the diagnosis, treatment and rehabilitation of rheumatological conditions. Additionally, patients with neurological impairments, and patients with chronic pain can follow a rehabilitation programme here.

The aim of the Jan van Breemen Instituut is to work together with the patient towards recovery and increased independence in activities and participation in society. The Jan van Breemen Instituut offers assessment, treatment, coaching and advice to adults and children on an outpatient basis. The main medical disciplines in this centre are: rheumatology, rehabilitation medicine, physiotherapy, podotherapy, occupational therapy, speech therapy, social work and psychology.

A guiding principle for care provision in the Jan van Breemen Instituut is to put the patient centrally within the care process, as part of client centred practice. This means they strive to deliver not only patient friendly care, but also have a mutual understanding of each other’s needs and responsibilities. Goals and objectives for treatment should be suited to the patient’s individual needs and formulated jointly between patient and professional.

Most treatment takes place on an individual basis. However, the Jan van Breemen Instituut also offers group programmes for information provision, discussion and/or exercises. Relevant examples for this research are: the pain management group, arthritis group and
fibromyalgia group. Therapists comment that due to practical considerations, only people with sufficient skills in communication in Dutch join the group programmes.

Considering the variety of diagnosis of the sample group for my research, I will not outline the specific aims and methods for each diagnostic group in detail. However, regarding fibromyalgia and chronic pain syndrome, the aim is mainly to learn to live with the pain, as there is no effective medical treatment to control the symptoms. Patient learn pain management strategies, which include learning to balance task demands with body capabilities (belasting en belastbaarheid) and learning to change thinking patterns and behaviours that reinforce the pain. The perspective is that by managing the pain, patients can increase successful participation. Balancing task demands with body capabilities is also important for patients with arthritis. Additionally, arthritis patients can learn to use specific strategies and adaptations, which help to protect the joints from further damage, increase independence and manage fatigue.

The family and the rehabilitation process

Rehabilitation professionals consider the patient's social and physical environment important as it provides the context in which the patient functions. Nevertheless, treatment sessions take place in the centre, away from the home environment. The way rehabilitation professionals try to elicit information about the social context is by questioning the patient about it. For example, questions regarding available social support, work, and roles at home.

In view of the fact there is recognition that the patient is part of a social context and participation is influenced by the social context, I asked two social workers and three occupational therapists to outline the involvement of the family in the rehabilitation process at the Jan van Breemen Instituut.

The social workers are not involved with all patients attending the Jan van Breemen Instituut for rehabilitation. When they do see patients, however, they state their approach is system oriented, denoting a focus on the patient and his/her social network. Concretely this means that in some cases, they might ask the partner to join a session; and in other cases, they might give patients specific home exercises to do, like exercises to ask for help and be more assertive. The latter implies the responsibility is for the patients to change their position in relation to their social environment.
The notion that it is the patient’s responsibility to change within his/her environment is the reason given by the occupational therapists for not involving family members in treatment systematically. The treatment is in principle focused on the individual and there are no guidelines to involve family members in occupational therapy sessions. Except for in the interdisciplinary group programme for arthritis and fibromyalgia patients: in this programme is one scheduled partner afternoon. Then the partner and/or other significant others are invited to join the patient’s group session. Otherwise, in individual sessions, when the patient asks, he or she can bring a family member, but it is not actively encouraged. Unless the patient cannot speak Dutch: then a family member is asked to attend for translation. The above practice of involving family in treatment sessions also applies for physiotherapy.

When I asked the social workers how, in their experience, family members of female patients of Turkish and Moroccan take up their role in rehabilitation, they suggested that for most cases, the family is not actively involved in rehabilitation and the patient ‘has to do it herself’. The family members’ expectations that the professionals will heal the patient are given as main reason for this lack of involvement. Regarding their role at home, the rehabilitation professionals perceived that either the family members will take over all activities, or they leave the patient to do everything. Both occupational therapists and social workers stressed, however, the differences in response to illness, rehabilitation and care depend on age and educational level of the person.

**Summary**

The aim of rehabilitation at the Jan van Breemen Instituut is to enhance the patient’s participation in activities at home and in the wider society. The individual patient is responsible to carry over and apply strategies learned and exercises done. In most cases, the family members are only minimally involved in actual treatment sessions. Rehabilitation professionals suggest that family members of female patients of Turkish and Moroccan descent more often misconceive their therapeutic role than family members of native Dutch patients.
CHAPTER 5

"The woman is sick"

In this chapter I present and discuss findings arising from conversations with participating family members and patients about the illness of the patient. I particularly focus on how participants describe and interpret the condition, how they know the person is in pain and what they see as the causation of the suffering. These aspects are central to a proper understanding of a patient's response to pain. The first part of the chapter discusses descriptions and communication of the patient's pain, the second part the explanatory models for the illness. A brief summary is given at the end of each section.

The visibility of the invisible pain

Becoming or being ill is often a social process. Illness needs to be communicated to people around in order to mobilize care and support (Helman 2001). The expression of pain, the 'pain idiom' is a result of cultural and social learning and will be shaped by the values and ideologies of the family and the wider community (Van der Geest 1998). Many factors like age, social status, cultural background, gender and personality can influence when and how people express pain (Bendelow 1993; Bates & Rankin-Hill 1994; Bendelow & Williams 1996; Van der Geest 1998).

Pain is intrinsically impossible to describe and language will always prove to be inadequate (Schott 2004). Schott remarks this is specifically the case in pain that the sufferer and his or her 'audience' have never experienced before. Resorting to metaphors is considered the only option available to render the indefinite and baffling pain sensations more concrete. As Lakoff and Johnson (1980: 193) conclude: a "metaphor is one of our most important tools for trying to comprehend partially, what cannot be comprehended totally....it is imaginative rationality". Expressing pain metaphorically might help to make sense of the experience and make this experience to some extent insightful for others.

Interestingly, in my study, very few family members give metaphoric detail to reflect the kind of pain of their relative. In describing the pain, they refer to location and some to the
fluctuating nature. The fact that there is pain appears to be the only relevant issue. For example, Myra has had a specific pain for over 20 years. Her husband, Achmed, stated:

Achmed: She has pain everywhere. The breasts and the chest are also painful. When I touch her a little bit she has pain. All the bones are painful.

Researcher: How would you describe the kind of pain? What will she tell you?

Achmed: I don’t know. [pause] I will ask her. [Achmed talks to Myra in Turkish, she replies and he translates to me]

In the past 10-15 years, it felt like hammer and stabbing and it comes and goes. Now it comes from here [points to his neck] and it presses very hard and it stays. Myra: Very hard here [points to her neck]. It walks like this [makes a circular movement along the body]. It kills me really.

Achmed: That is a saying. When it comes, it is like death.

Researcher: Does she tell you normally what the pain is like?

Achmed: No to be honest, I don’t want to know. The moment we talk the pain becomes big. If we don’t talk about it the pain remains small. That is my idea, I don’t know. Then you are busy with other things.

Myra qualifies her experience of pain. She expressed the sensation of pain in metaphors of a ‘hammer’, ‘stabbing’ and ‘pressing’ and ‘it kills me’, illustrative of pain as something or someone violently attacking the body. She also indicated the fluctuation and moving character of the pain by stating it ‘comes and goes’, it ‘walks’ and it ‘stays’. However, Achmed did not make those sensory qualifications when he describes his wife’s condition. In fact, he had to ask her at the time of the interview how she would describe it. He reasons that he does not want to know, as talking about it might make the pain worse. Obviously, this last statement has implications for structuring appropriate support and will be discussed later. For now, what is important is that communication about pain in the family does not necessarily take place in highly descriptive accounts. ‘She tells me she has pain’ can be sufficient. Selma and Zeyneb, two sisters who both have chronic pain conditions, underline this point. They suggest there is no need to explain details of pain to each other or to other family members.

Selma: Maybe because the family ties are so close you don’t need to say so much. You can feel something is wrong with someone.

Zeyneb: We are immediately there. Maybe it is because we are sensitive for each other’s needs. Maybe that is why it was never discussed. I was ill recently and everyone comes round to help.

Selma: You feel if there is something you can count on them. But they don’t talk about those things much. They just accept it.

Zeyneb: They say ‘Oh you are sick, how bad. What can I do?’

Selma: They don’t ask for details. What is wrong and why? I only told you [refers to her sister] a little bit, but even then you play it down, not to feel sorry for yourself. Or you overdo it a bit, if you need some help. You say: ‘I have pain, here and there pain’. You don’t explain details, but just ‘I have pain’.
This seems to be in contrast with statements from the literature that the invisibility and subjectivity of the pain experience is a major obstacle for gaining credibility and understanding from people around (Kleinman et al 1992). However, Selma had indicated earlier in the interview that the moment she received a diagnosis of fibromyalgia, she was relieved: “The pain is really there and there is no need to defend myself”. Additionally, both sisters stress not only the importance of a diagnosis from the doctor, but also the importance of medication as a proof to others in a Turkish community for being ill. The more medication a person has, the more they can demonstrate they have something wrong with them. It is a visible cue to others, a symbol of illness. This is in line with what Van der Geest and Whyte (1989) suggest to be the metaphoric and metonymic function of medicines. The concreteness of medicines makes an inchoate experience like pain more understandable as an ‘it’, something that is there and can be treated. Medicines also refer to ‘the authority that knows best’.

One of the ‘charms’ of medicines is that, even removed from their medical context, they retain a potential connection to it. The medicines have a metonymic association with medical doctors who prescribe them, with medical science that forms their ultimate ground (Van der Geest & Whyte 1989: 359).

From the accounts given by patients, I detect an important difference between getting recognition that you are ill and that you cannot do certain things and getting people to understand what the experience is like. The patients are specifically concerned about their credibility and do not consider it possible for another person to understand what their specific pain is like. Similarly, the family members all state their inability to feel the pain of the other. Maybe that is why exact descriptions of pain are less important. Although some participants allege others might not believe or understand the condition of the person, none of the participating family members expressed any doubt themselves that their relative is in pain. Maybe this has been a salient criterion for willingness to participate in the interviews.

Not only verbal expression, but also specific movements, postures and behaviour can be an expression of pain (Driessen 2002). Family members refer more to these non-verbal, visible aspects of pain expression when they are asked how they know their relative is in pain. Facial expressions, posture, movement and inactivity are the signs picked up on. The following fragments illustrate this.

Jamila (daughter of Naima): She will tell us, but in fact, we know when she cannot sleep in the night.
Erkhan (husband of Fatma): My wife will tell me, but I will also see it in her face. She does like this ...[pulls a screwed up face]. And then she won’t do anything; just lies on the coach.

Selma (sister Zeyneb): I look at little things, like when she puts on her coat. I look whether she uses her other hand to assist. That kind of things I pay attention to. But I don’t say anything about it. I say that for the first time now. I observe [...] As sister you are very aware of the situation of your youngest sister. You pick up signals with your heart not with your head. I can see when she moves strangely. You can express it in words, but I can see it. I see her and maybe because I have experience of it, I am more sensitive for it. Things like how she sits down. I see how she sits and think: okay today is not such a good day. And then I wait to see whether she starts complaining.

In this last account, Selma suggests she has experience with pain herself and therefore she can pick up signals more easily. In the other two situations where the husbands of the women also suffer chronic pain, the men underline it is easier to understand the situation of their wife, as they know what it is like to be in pain.

Hasan (husband of Sevgi): I can see it. When she is well, she moves easily and is eager to do things. When she has pain she does not feel like anything and she lies on the coach. Because I have the same, I can understand better that you can’t do things when you are in pain.

Inactivity is an important indicator for being sick. This was also found in studies by Reysoo (1999) and Leeflang (1991), in which both Moroccan and Turkish women define sickness as being unable to carry out their daily tasks.

In sum, the above findings suggest that family members have no exact notion on the type or sensory experience of pain of their relative, but they do have ideas on the location of the pain. Family members do not consider it important to know exactly what the pain is like. Knowing the relative is in pain is enough. Indicators for knowing the person is in pain are mainly based on visual cues like body language, behaviour (inactivity) or medicines. These cues form a visualisation of the invisible pain for family members, and seem more important in communication of pain than descriptive accounts of the experience.

Diversity and multi causality

As suggested above, all participants agreed their relative is in pain and is ill. According to Kleinman (1980), people will always struggle to find out what is wrong and ask the question
of ‘why me’ or ‘why her/him’? Illness narratives indicating an explanation for the illness shape not only the meaning of the illness but also guide the choice of intervention or response to an illness episode. The accounts of non-professionals are referred to as the lay understanding of illness (Helman 2001). Gwyn (2002) refers to the limitation of the dichotomous distinction between expert and lay interpretations of illness and disease. The lay understanding of illness is formed by several different and often conflicting sources, which can include professional discourses and ‘folk’ models (ibid). Kleinman (1980) notes that lay explanations are often partly outside of awareness and that they can be vague and have multiple meanings.

As the group of patients was varied in the type of pain conditions experienced, the duration of illness and age, it is not surprising the responses of family members to questions relating to the explanatory models of the illness are diverse. Interestingly, when the family members were asked where the pain comes from, they all first gave an account of the doctor’s opinion. Then later on in the conversation, other notions might come to the surface. This might be a reflection of Kleinman’s statement of the lay explanation being partly outside of the person’s awareness. Therefore, the person might not consider the comments made to be an explanation for the illness. Alternatively, it might reflect what people perceive to be the hierarchy of whose opinion is more valuable and ‘truthful’, the biomedical expert or the ‘lay’ opinion.

To illustrate the accounts ‘lay’ explanations, I give an example of the illness narrative regarding Myra, who suffers longstanding pain in her whole upper body. Achmed’s response to the question where the pain of his wife comes from, was as follows:

Achmed: Yes, who knows, the doctors don’t know.
Myra: High blood
Achmed: We haven’t heard a name for it. We have only heard all the pain comes from here [points to joints on his body], but we don’t know.
Researcher: What is the relation between high blood and pain for you?
Achmed: When she has high blood then she gets headache, heavy headache. Yesterday she had headache the whole day and now she is tired.
Researcher: So the high blood leads to headache?
Achmed: That is what we think. It can have many causes.

[...]
Achmed: In the past we were with a whole family. A house full. Then she used to get headache. Not just for a few hours or a day, but it stayed.
Myra: the headache started when I was thirty. It started with headache here [points at the front of her head]. Not now. Now it is here [points at the back of her neck] It presses and pricks. Not good.
Achmed: She came in 1973, but the headache had started before that. She used to get headache, but not so badly. We get headache from stress or thinking, but it goes away when there is a solution for the problem, after some hours or a day. In
the past it was like that, but when she came here it stayed more...Now age also plays a role I think. When she was young it was different.

In the third meeting when I was alone with Achmed he said:
Achmed: my wife is not so happy here. When she came, the children were still in Turkey, because I wanted them to do primary school there. Maybe that was the wrong decision. She was very unhappy and started to have more headaches. Then once the children were here, she was a bit happier, but it is never her home.

Additionally, he indicates that good and bad things might just happen:
Achmed: People experience positive and negative things. Like a mirror. The front can be positive and the back can be negative. That is logical. You don't know what might happen. You can get an accident, stomach problem, heart problem; the hospitals are full with them. [...] The illness has no purpose, it can just happen.

These accounts about Myra reflect different explanations and meanings, with the dominant notion being her unhappiness or psychological stress. This feeling of never feeling at home and home sickness is well documented in the literature as a source of psychological stress for the first generation migrants (cf Graafsma & Tiekema 1987; Stronks 2004). Besides this, the explanatory model for Myra includes notions of ageing and ‘just bad luck’. Noticeable in this discourse and in some of the others is that people relate and link symptoms to each other. In this case, it was high blood [pressure, I.S.] and headache. In other accounts, other relations mentioned are: difficulty in breathing and pain in the neck and the back, headache and sensitivity for pain in other body parts, or weakness of the shoulder muscles and pain in the back.

Family members of four patients mention physical or psychological stress from work as the reason for the start or the worsening of the condition. Like in the case of Fatma, a Turkish lady with chronic non-specific pain. Her husband frequently referred to the fact they had to do hard physical labour as migrants, which resulted in health problems. Concerning his wife’s pain in her hand he stated:

Erkhan: Of the hand, it is from working. She worked in the flowers. Because everyone has to prepare a hundred or two hundred bunches for the auction. All the women have to work hard. Everyone has to. One makes a hundred; the others have to make a hundred. One makes two hundred than the others have to do that. If someone makes hundred then the boss will ask you why you only make ninety, you know. There is a lot of pressure.

The other people who referred to physical or psychological stress from work were younger and did not relate it to the fact they had to work hard as migrants, but just blamed the nature of the work. Therefore, in most of the accounts on stress and work, people refer to demands, expectations and reasons that lie outside the person. Only one participant, Hasan, considers the main cause of the stress of his wife not to be external, but the result of her being a perfec-
tionist and having a 'busy personality'. Important to mention for the context is that he has chronic pain as well, in combination with depression and he explains his wife’s illness in the same way he explains his own illness. The following fragments of the conversation with him illustrate this.

Hasan: I think she used to think and do too much. She tried to do everything. Recently she is a little less busy, but the problems don’t go away.

Researcher: What happens with the body when a person is too busy?

Hasan: When I compare it with myself. When I think a lot I get dizzy and tired and I don’t feel like doing anything. I have no energy, the battery is empty. No power. [...] My wife can’t sit down. Every time she has the feeling she has to do something. That is in her person. I used to be the same. I was always busy and wanting to do something [...] It is like a car with a 1 litre engine, which tries to perform like a 2 litre engine car. When we do that we wear out; the battery is empty. We have to accept we are a 1 litre car. Now we have to recharge.

Hasan uses the metaphor of the empty battery to depict their conditions. This metaphor fits the body-as-machine concept, which is commonly used in western societies and is often reinforced by the way health professionals explain problems in health (Helman 2001). Not only is Hasan’s body-as-machine account congruent with western notions of imagining ill health, he also indicates they are responsible for the empty battery themselves, which is the basis of many of the self-management strategies in intervention in The Netherlands.

Another big category of explanations for illness was climate conditions: the damp and the cold. The difference in climate conditions between The Netherlands and Turkey or Morocco is often referred to. For some people the cold might have caused the illness in the first place, for others the cold made the illness worse. Explanatory models referring to hot and cold factors are well described in anthropological literature and are persistent in some form many parts of the world (cf Greenwood 1981; Peeters 1986; Helman 2001). In these theories, hot or cold foods or environmental factors are thought to cause an imbalance in the body, resulting in hot or cold illnesses. None of the participants, however, referred to food as a factor. All the notions about cold related to climate. Mohamed states the effect of the cold. His wife ( Rachida) has recently been diagnosed with arthritis.

Mohamed: The problem from rheuma comes from the cold. When you have a lot of cold in your body.

Rachida: He means there are some people who live in the cold weather, but can’t stand it.
Mohamed: When cold enters your body for 1, 2, or 15 years, then you get rheuma. When you are young, you go out with a T-shirt in the cold. When you do this for years then you get a cold in your body.

Rachida: What he means is that you don’t notice it at that moment, but later you notice.

Mohamed: You have to prevent this by eating well and dressing warmly.

In the above account, Mohamed and Rachida classify people in persons who can stand the cold and persons who cannot. Herewith they appear to refer to a personal vulnerability to get ill. This notion of vulnerability was also evident in a statement of Erkhan, which refers to familial or heredity vulnerability: “She is not the only one. In the family is allergy, asthma, you know many illnesses.” This partly explains for him why is wife is also sick.

So far, all the accounts of illness explanations have been naturalistic. Literature on health and illness beliefs of Moroccan and Turkish people suggests there can also be personalistic or religious reasons for disease (cf Peeters 1986; Hoffer 1997; Reysoo 1999). None of the participants referred to these notions spontaneously. Therefore, I asked some of the participants specifically. Only one participant indicated his elderly mother has the idea that bad spirits have possibly caused her illness, as the doctor could not find a cause. The son himself does not think that, but he respects the ideas of his mother. Regarding religion, most of the patients themselves indicate God is not accountable for disease. He does not make you ill, but everything in life has a purpose or a meaning. They say a verse in the Koran suggests that illness might be a test of God for the people he loves most to see how you can handle it, but that is for extreme cases (Mohamed, Selma, Zeyneb). They mention religion does play a role in providing emotional support, but this will be addressed in the section of healing options.

To summarize this section of the chapter about family members’ notions on causation of the illness of their relative, it can be stated that there is a wide variety of explanatory models both for each case and between cases. Factors involved are mainly external and naturalistic, like physical stress, ageing, psychological stress due to external demands, and climate. Some of the factors mentioned, like climate change and unhappiness or homesickness are attributable to migration. Few participants mentioned internal factors like personality, or personal/familial vulnerability. Regarding supernatural notions, only one participant mentioned the influence of evil spirits and he reflected the perspective of his elderly mother. Although some participants referred to the fact everything has a purpose and meaning in life and only God knows this purpose, they do not consider Him accountable for causing illness. For some participants getting ill ‘just happens’.
CHAPTER 6

Healing options

In this chapter, I address participants' ideas on healing. What is needed to improve the situation for the patient? What intervention has occurred or is planned? What is the perceived effectiveness of this intervention? In particular what is the role of rehabilitation in healing? These questions have been addressed in the conversations with the patients and their family members. The various responses reflect not only the patients' and family members' ideas on actual treatment options, but also show their attitude to the role of professional healthcare and the role of patient and family in illness management. Additionally the responses demonstrate perceptions regarding expectations of the healing process.

The chapter will initially cover an indication of the role of the doctor, patient and family in searching for effective healing strategies. An outline of perceived healing options follows. This includes a discussion on what people consider rehabilitation to be. Notions of hope and hopelessness will then be explored in relation to expectations for improvement, before concluding the chapter with a summary.

Actively searching

Most people had been to see various doctors before attending the Jan van Breemen Instituut. The doctor plays a central role in the intervention narratives of patients and their family members. "The doctor says" is a frequent starting line of the accounts, reflecting the authoritarian knowledge and position of the doctor. Most often, participants referred to the specialist and not to the general practitioner, as the specialist would have carried out the assessments and is perceived to have most knowledge. It may then appear that people take a mere passive role in the search for treatment and accept whatever is said. However, this is not always the case as will be illustrated in the next paragraphs.

With reference to faith in biomedicine in The Netherlands, it is interesting to note that in almost all cases, the patients have visited or intend to visit a (biomedical) doctor in their country from origin. They all like to get a second opinion either on the illness or on appropri-
ate treatment. Often family in Turkey or Morocco advise patients to visit particular medical specialists. The visit can also follow from the success stories heard from others, or be based on their own experiences with treatment. An account of Gulnair, a young Turkish woman, who recently had been diagnosed with arthritis, illustrates this. As the interview with her was not recorded, her comments are paraphrased from notes taken during the interview:

She feels she was “neglected” by the general practitioner. He had not sent her to the right specialist when she first had the problems. “Maybe if he had sent me to the rheumatologist last year, I would feel better now.” In July she plans to go to Turkey and visit a doctor who specialises in rheumatology and was recommended to her by her family there. “Maybe he can suggest other treatment options. Here they can only help me to a certain point. They can’t take away the pain. Maybe the doctors in Turkey can.”

The two sisters Zeyneb and Selma, who have both grown up in The Netherlands, stated that healthcare can be good in Turkey, depending on the quality of the hospital.

Selma: *In my environment there are already three cases proving that the treatment there and the after care there are a lot better. However, you have to put it into perspective. There are second-class hospitals and you can’t expect much from them. But A, the first class, that is...*
Zeyneb: *REAL first class.*

Selma explained at length her experience with the Turkish healthcare and the sisters indicated what they consider to be better in Turkish healthcare. This included: a thorough and complete body scan for diagnosis instead of only focusing on the original complaint; speedy processes and timely results; the availability of more effective medication and the focus on healing rather than on paperwork. This was best described in the comment of: “They take the bull by the horns” (Zeyneb).

When I asked Achmed whether their family in Turkey advises on treatment for his wife he replied:

*Yes, that is always the case. When we are on holiday, they might for example tell us about someone who had a headache and who went to a particular doctor, and now the headache is gone. Then we also go to this doctor. Naturally, we do that. Maybe the doctor is better. But the reason for the headache might be different. After 3 or 4 weeks holiday the pain is less... Maybe, because she can relax more here [points to his head] and it is a warm climate.*

Achmed linked the expected effectiveness of treatment not only with the skills of the doctor or the success stories of others, but also with what he considers to be the causes of his wife’s illness: unhappiness and the cold climate in The Netherlands.
The above accounts demonstrate the idea held by some that doctors and/or procedures and treatment options in Turkey may be better than in The Netherlands. Seeking treatment in Turkey can also offer another potential option for treatment and as such may be just another avenue to try. In the Netherlands they depend on referrals from the general practitioner to see a specialist, whereas in Turkey it can be the patient’s own decision. Therefore, if they can afford to go and see a specialist in Turkey, it is easy to get a second opinion. It cannot do any harm and is a source of hope.

Three participants mentioned the use of the internet as an additional way to find out about illness and treatment. For example, Hasan mentioned that his wife Sevgi, who is disappointed that the doctor here only prescribed paracetemol, surfs the internet for other possible medications. He stated:

*She has a lot of knowledge about medication. She is clever with that. She sometimes looks on the internet for certain medicines. She researches this. She does not just accept something the doctor says.*

Sevgi’s attitude reflects a critical stance to the authority of the doctor and a belief that she can take an active role herself in researching other suitable medications. It gives her some independent control in managing the pain. Her level of education and her familiarity with the Dutch health care system may explain Sevgi taking this active investigative role. The other two participants who use the internet are in a similar position as Sevgi in respect of level of education.

The use of the internet as a source of information for patients, and the effects of this on patient-doctor communication and patient-doctor relationships have been researched in The Netherlands (cf Van der Kraan 2001; Van Rijen 2002). However, specific references to internet use and migrant patients are not available in the published literature. Nevertheless, information technology is likely to become increasingly important in allowing migrant patients to search for other healing options, apart from those recommended by their doctor.

As may be seen from the preceding, people are actively searching for healing options. The doctor’s opinion is important, but is not always accepted, with people often searching for second opinions. In their search for healing options, people are guided by own experiences, the experiences or advice of others in their social network, and their perceptions on the causes of their illness. For some, the internet is a source of information. Additionally, religion and
feelings of hope or hopelessness can play a role in the motivation to search for treatment. This will be further discussed later in this chapter. Firstly, various treatment options put forward by either the patient or the family member(s) are outlined.

**Medication**

Study participants mentioned medication most frequently as a healing option. This finding is not surprising, considering the fact that medication provides visual evidence of illness, as referred to in chapter five. Regarding the healing power of medication, Van der Geest and Whyte (1989) argue that medicines are perceived by many people as a physical substance to effectively combat the entity of illness residing in the body (Van der Geest & Whyte 1989). The taking of medication provides individuals with feelings of control where combating their illness is concerned (ibid).

Mostly, the participants see medication not as a cure, but as a means of controlling the pain. However, some do not consider the type of medications given to be effective.

- **Achmed (husband of Myra):** Every year she uses thousands of paracetemol, but it only reduces the pain a little bit.

- **Erkhan (husband of Fatma):** We both use painkillers. It is not great, but maybe without medication it would be worse.

The ineffectiveness of prescribed medication drives some of the patients to self-medicate. For example, Sevgi uses other pain medication, as she is disappointed with the paracetemol prescribed by the doctor. Selma also started self-medicating when the doctor could not offer any other medication options. The following fragment of a conversation with Selma herself illustrates this:

**Researcher:** How do you deal with the pain?
**Selma:** You learn to deal with it. Your life goes on. I have to work. How often can you take off sick leave? Then you take a lot of medication (slik je je suf aan medicijnen). Sometimes you think I am a walking pharmacy. [laughs] For all kinds of pain I had something with me.

**Researcher:** So you are a pain medication expert?
**Selma:** [laughs] Yes really! You start to self medicate. Even when your GP says 'now this is the last thing I can give you. If this doesn’t help then I can’t help you’ then you start doctoring yourself. Then I discovered –I take this for half a year...
now that there is a good migraine medication, which takes away my muscle ache. By putting the brain at rest, it gets less pain signals.

For Selma, medication is an alternative to resting for controlling her pain. It allows her to continue to be active and function normally. However, the problem is that the human body gets used to the medication in question and the medication then becomes less effective. To use Selma’s words:

All those things you take have an expiry date. When you start, they work really well and then you get a set back when they don’t work anymore.

Achmed has also noticed this where his wife is concerned, and he compares this reduction in efficacy of medication to drug use.

Myra used to get injections in her wrist to reduce the pain. Now the doctor has stopped this.

Achmed: They did injections, not for a few times, but for some years. It is like with alcohol or drugs. First, you need a small glass of alcohol and you get drunk. Then you can drink a whole bottle and still you are not drunk. That is what happens with the injections with her body. Initially it helped but later it did not help. Later she got tablets. Dr G said ‘these are good tablets but many people get stomach problems.’ She [refers to his wife] said ‘I take them.’ They did help for a while, 3 years, and she did not get stomach problems. Later they did not help anymore. Your body gets used to it. Like injections for heroin. Now Dr G is away and the young Doctor gave the armband [refers to a splint which immobilizes the hand, I.S.]

Pharmaceuticals, therefore, are important for both patients and family members as a means of controlling pain. Nevertheless, they are regarded as only being effective for a limited period. The doctor is perceived to play a role in the prescribing of medications. However, it seems the doctor does not deal effectively with helping patients to cope with the fact that some medications may not be suitable or effective. When patients are dissatisfied, they may revert to trying out other medications themselves.

Rest versus exercise.

In chapter two, it has been mentioned that resting or inactivity of the female indicates to her family members that she is sick. Some participants also suggested that rest and/or relaxation may aid recovery from illness.
Researcher: *What is needed to improve the situation?*
Hasan: *I don’t know. I think if she doesn’t think so much and doesn’t work so much. But she can’t sit down. Every time she has the feeling she needs to do something. That is in her person. I used to be the same. I was always busy and wanting to do something. But now I don’t feel like doing anything.*

[...] 
Researcher: *So you think your wife should rest more?*
Hasan: *Yes and take domestic help. She needs someone who can do all those things. She needs to rest to recharge the battery.*

He then adds that whoever undertakes the domestic tasks must complete these to his wife’s standards or otherwise she will still complete these tasks herself.

Hasan, who considers his wife’s illness to be a result of her nature of always being busy, sees resting as a choice his wife has to make in order to get better. By this he meant resting of body and mind. “She has to learn to let go”, he frequently stated. His own pain and fatigue are also relieved when he rests, whereas they increase as a result of movement or exercise. Therefore, as in the explanatory model for the illness, he refers to his own experiences and sees rest and relaxation as the only options to allow his wife to recover.

The other participating husband, who himself is ill, and who sees ‘wear and tear’ and overwork as the main reason for their illnesses, considers a combination of rest and gentle movement as best for his wife’s well-being. Here, physical and mental well-being are considered:

Erkhan (husband of Fatma): *If she does things slowly (rustig aan) then the pain is less. Rest helps.*

Erkhan also explains his wife has a splint to keep her hand still, to let it rest, in order to reduce the pain. Her son sometimes gives her a massage. This helps to relax the neck muscles, but only for a short time. They go for a short walk every day to get some fresh air. He says: *When we sit at home, we get a headache. We need some fresh air.* He explains they are both outdoor people, who cannot stay inside. He himself has major problems when he is in a closed place for some time. Then he starts to panic. He says it is the same for his wife.

However, family members’ ideas on the benefit of rest or exercise for the patient were not always based on their own experiences of rest or physical exercise in illness. For some of them, feedback of the patient was important. In the first interview, Mohamed had not yet joined his wife in going to treatment sessions. Although his wife mentioned in our conversation to be positive about gentle exercise, Mohamed’s comment about physiotherapy exercise was: “*but you say it gives you pain in your foot.*” He interpreted his wife’s previous comments to him about the increase in pain associated with exercise as evidence that exercise and movement are not useful in promoting the healing process. By the time of the second inter-
view, however, his wife's condition had improved and Mohamed had been to a physiotherapy
session with his wife. His subsequent comment on exercise was:

Mohamed: I am not a doctor, but if she exercises then she will improve. Sport is
like a medicine. It is a way to heal. Sport is important.
Rachida: Too much, or too intensive is not good.
Mohamed: But three times a week or so.

This change in attitude to the effect of physical activity shows that attitudes to healing options
are dynamic and change according to exposure, experiences and results.

Through contrasting the study participants' statements on rest and movement with my
own (professional) perception of therapeutic activity, an additional interpretation can be
made. In my previous work as occupational therapist, I often used daily activities therapeuti­
cally with patients. From Mohamed's statements and comments from other participants it
appears that when they refer to movement as a healing option, they see it mainly in the form
of a specific exercise or sport. Engaging in daily activities like housework or personal care
was not mentioned as potentially therapeutic. Instead, family members consider refraining
from (certain) domestic activities to be important in pain reduction.

Warmth

Although not all participants regarded the cold climate in The Netherlands as an actual cause
of the illness, all indicated that coldness aggravates the pain. Therefore, all participants men­
tioned the positive effect of heat in increasing mobility and reducing pain.

Narratives of participants suggest that patients need to spend time in the warmer cli­
mates of Turkey or Morocco. Additionally, some participants mentioned the importance of
specific sources of heat, combined with minerals, available within these countries, such as hot
sand and hot springs. They stated that these treatment options are particularly beneficial for
rheumatic conditions. Hot sand treatment is only available in Morocco. Hot springs are pre­
sent in both countries. Mohamed and Rachida explain the use of hot springs and hot sand in
Morocco:

Researcher: Is there anything else you feel you can do for healing?
Mohamed: She wants to go to South Morocco. Because there is a lot of sun. There
are some places for the disease of rheuma- a kind of desert.
Rachida: There are some places where there are-I have never been there. I only
hear it from others- there are specialists who have experience with these kind of
complaints, rheuma complaints. Many people with rheuma go there. And they lie in the sand. They bury themselves in the sand, with only the head sticking out. The sand is hot of the sun and this helps for the complaints, because rheuma is something from the damp. The sand is dry and warm. The people with the speciality about this will indicate: where exactly, for how long, how many days you can use it, whether you need to go there the whole year or just a few weeks or days. Do you need to do just your feet or legs or your whole body. It depends on your complaints. They also check things like your heart and asthma. Because then maybe you cannot use it. They advice.

Researcher: Who tells you about this?
Rachida: You hear it from the people in the south.

[Then Mohamed explains how the disease of rheuma is a disease caused by coldness (see previous chapter)]

Rachida: If it is possible I like to go. You need a good car, with ventilation. It is 40-50 degrees there. You really need to prepare it well. We live in the North of Morocco, so then it is still a long way to travel. It takes about two days. You don't go alone but with other family members, so you have to arrange food and hotel for them as well. It is expensive and we can't manage it now. But we hope to go next year, if we are still alive.

The last part of the above account indicates that choice of treatment option is not only determined by attitudes to the effectiveness of the treatment, but also depends on the availability and ease of accessing the treatment in question. Regarding the hot springs they mentioned:

Mohamed: The water is natural; it comes out of the ground
Rachida: It is spring water with sulphide. People with various complaints go there [...] It is very hot water. It is divided in two person rooms with two baths or one person room or a public bath. For me it was too hot. There is some cold water to cool it down.

Most participants regarded thermal springs as a beneficial form of treatment. However, for two patients with asthma, it was regarded as unsuitable, as such treatment may aggravate their breathing problems.

In the ‘cold and damp’ climate of the Netherlands, patients try to avoid getting cold by dressing warmly and avoiding drafts in the house.

Achmed (husband of Myra): The warm climate in Turkey is important. The pain is less in Turkey.
Researcher: And here?
Achmed: She is quickly cold. If I open the door for some fresh air, she wants to close it.

Jamila (daughter of Naima): My mother wraps her arm in a cloth to keep it warm.
Despite these strategies for keeping warm, participants still regarded visiting Turkey or Morocco to be more beneficial.

**Religion**

As stated in the previous chapter, religion was not mentioned spontaneously when talking about health and illness. When asked specifically, most family members and patients regarded religion as providing a potentially beneficial form of support. The way this benefit was derived differed from person to person. Most mentioned the supportive value of praying and reading the Koran.

Zeyneb: ...Now when I pray I get comfort and support. What I can't get somewhere else. What you can't tell anyone you can say the invisible who is present all the time.

Mohamed and Rachida also clearly explained the role of religion in support or healing for them:

Researcher: *Does religion play a role in illness and health?*
Mohamed: *When you read the Koran all the time.*
Rachida: *There have been moments that I was emotionally not good. I had pain, my foot was swollen. I started to have pains everywhere: in my stomach, in my back. When I read the Koran, it becomes quieter. You get a good feeling inside. You get stronger.*
Mohamed: *It gives a good emotional feeling inside and when you feel well inside, then you can cope better with illness.*

[...]
Mohamed: *In the Koran is a verse saying that God does not want to hurt anyone. Therefore, we can't say God makes us sick. But the other way round. If we are sick, God can help us to get better. He can help us.*
Rachida: *Sometimes people use other things than medication, like the hot sand or the hot springs. There are different ways that people can seek for healing, but God can help with this. It says God helps you, but you need to do something for it. You have to search.*
Mohamed: *You can't sit at home and wait.*
Rachida: *It is your destiny what you get in life. But you have to try your best. Religion helps to accept the situation more. I thank God and ask him to help me. I have hope he can help me in some way. No-one knows this. That is the purpose of life. God sees how do you do things, how you accept what you have. He gives you a hand - figuratively speaking. I compare my condition with other ill people and then I am thankful I don't have it so badly. So it is a support, else it breaks you. You don't get much attention from others in this busy life, so God's support is helpful.*
Like Zeyneb, Rachida referred to the constant support from God, unlike support from fellow human beings, which may not always be available. Additionally, Rachida and Mohamed postulated that God is supportive in healing, but that individuals are responsible for searching for healing options. This commitment to search for healing is also mentioned in literature about Islam ethics in relation to health care (cf Pranger 1997). This might be an important reason for the active searching attitude reported at the start of this chapter. For some, this means just going to see a doctor.

Erkhan: *Religion has nothing to do with our illnesses. It only helps for the moral. In the Koran it says you have to go to the doctor when you are ill. For some people this is different, but for us it is like that.*

Religion does not provide support for everyone. In the cases of Sevgi and Hasan for example, they are both ill, but they both have different opinions about the role of religion.

I ask about the role of religion in healing. Hasan shakes his head. He does not think religion plays a role. Sevgi says it does for her. She feels better after praying. She feels he understands her and she gets support from her religion. Nevertheless, eventually she has to learn to deal with it herself. He can only support her.

Based on participants responses it may be concluded that faith, praying and the personal relationship with God may provide individual sources of support. For most patients religion resulted in feelings of strength, tranquility and comfort. Religion helps patients accept their situation, but also demands them to take responsibility for seeking *external* healing options.

**Rehabilitation**

As indicated in chapter 4, the aim of the Jan van Breemen Instituut is to work with patients to aid recovery and to increase independence in activities and participation in society. For chronic pain conditions, the focus is on *learning to live with the pain*, implying mainly a behavioural change to improve functioning despite the presence of pain. This research seeks to ascertain family members perception of rehabilitation as a healing option. However, most family members do not talk very much about rehabilitation.

Three family members were actively involved in joining the treatment sessions the patient, either because of their own interest in attending or in order to translate between professional and patient. These three individuals were aware of the aims of the exercises suggested
by the rehabilitation professionals and even spoke of their awareness of the rehabilitation process in encouraging independence. For example Said, the son of Naima is actively involved in his mother’s rehabilitation programme and explained the input of occupational therapy:

Said: ... *The wheelchair, the toilet, the shower,* - but this has not been installed yet - how she should lie in bed, advice for pulling up the blanket [he demonstrates the movement] if you can’t with your hands how you sew on a loop, so you can do it with your fingers or your whole hand, how she can open the tap, lift a glass, pick up a fork, ...and that really went a lot better.*

Researcher: *So you tried this at home?*

Said: *Yes the last weeks she was independent with eating; only tearing the bread in pieces she could not do. But when you give her a fork or spoon and put it on the table, she picks it up herself and starts eating.*

It is important in understanding the above statement, to realise that Naima’s functioning is not only limited by pain, but also by severe weakness of her arms. The suggested strategies are to compensate for this weakness. Interestingly though, Naima’s own expectations of rehabilitation are different. According to her son Said, she engages in the ‘exercises’ but sees her involvement in the rehabilitation process as necessary to obtain her doctor’s permission to go to Morocco.

Said: *She wants to get better...She wanted to try her best so that if we would go to Dr X, the specialist that he would say to her: ‘now you can go on holiday, you have tried your best. [we laugh]. Yes, she really wanted to go on holiday and that is why she has had a blow now, because she can’t go.*

Other family members are aware that their relative attends the Jan van Breemen Instituut, but they did not provide details on questions regarding the type of treatment received or the aims of the treatment. They indicated not to know these specifics. The conversations held give the impression that many family members see it as something that happens there and/ or something that only concerns the patient. Rehabilitation is associated with exercise, massage, going to see the specialist (for medication), ‘having a talk’ and provision of orthoses or adaptive equipment. The following statements reflect aspects of the above:

Achmed was not aware of the word rehabilitation, so I specifically asked what the aim of the treatment is at the Jan van Breemen Instituut.

Achmed: *We go to Jan van Breemen to see the doctor. I go with her because of the language. He looks in the file. What has been done in the past? How did it go and then maybe he tries something different...now the doctor sent us to get a band for her hand. When I ask about exercise, he says: The GP has sent her for massage to the physiotherapy.*
Hasan was not aware of the word rehabilitation either. When his wife says “Jan van Breemen”, he said: “Oh yes you [refers to his wife] go to the hospital for therapy.” In the second meeting when his wife is away he said: She went to the hospital. I think to talk with the psychologist...I don’t know what else she does there. She has the appointments. I don’t ask her all the time where she is going. When I ask she maybe gets angry.

In some interviews, patients would subsequently explain what they do at the Jan van Breemen Instituut. For example, Sevgi, who had just had introductory sessions for the therapies, explained her understanding of the aims of her rehabilitation:

*I will learn to listen to my body and stay within the limits. I will learn how to deal with the pain.*

This statement illustrates the concept of rehabilitation and individual responsibility promoted at the Jan van Breemen Instituut. However, not all patients are clear on the aims of rehabilitation. Gulnair has just started rehabilitation. When I asked her the aim of this she said:

*I don’t know. I get massage and I do some exercise on the treadmill. They try to help me, but to a certain point. They can’t take away the pain.*

It can be concluded, that ideas and knowledge of rehabilitation vary between patients and between patients and their family members, with family members tending to be less aware of what happens in rehabilitation than the patients. It is another option the patient can try to get better and it happens there, meaning in the hospital.

**Hope and hopelessness**

When talking with family members about healing options and expectations for health improvement, the themes of hope and hopelessness emerged. The difficulty with discussing expectations is that expectations are linked to ideas about ‘what will happen in the future’ and some participants said not to think about the future.

*Daughter of Naima: I don’t think about the future. You don’t know. But we hope she will get better soon.*

For the family members, the notion of hope is linked with complete recovery and searching for interventions to heal the condition of the ill relative. Although all participants refer to a
doctor’s statement that the condition is chronic and therefore will stay, some still hope for recovery.

Ali (Gulnair’s fiancée): _The doctor has said that the pain will stay, but she has to get better and I think she can._

Mohamed (husband of Rachida): _I am an optimistic person. I can’t say what it will be like, but I have a lot of hope she gets better. With medication and sports she can get better._

For both these men, their partners had only recently (in the past six months) been diagnosed with the condition, are young and have just started rehabilitation. Although they acknowledge the doctor has said the condition is chronic, they may not yet regard the illness as chronic. The fact that treatment has just started may provide some hope. The uncertainty of the future provides hope for improvement. The patients themselves refer to stories they have heard of others who recovered from illness, which may be regarded as ‘stories of hope’.

The above optimism is in contrast to the statements of partners of two women of middle age who have had their condition for a long time and who had tried various interventions without success.

Achmed (husband of Myra): _... They can’t take away the pain; she has to live with it. That is what it means I think._

Researcher: _What does this mean for you?_

Achmed: _We have no choice (het kan niet anders). If the doctor can help than we would like this. We want everything to be okay but we can’t. We have to try to live like that._

[...]

_The pain has been for so long already and it only gets worse. She has tried many things and nothing helps. Now it has become normal. It is how it is._

Erkhan (husband of Fatma): _...That is difficult, the future, I don’t know. Can get worse, or stay the same. Yes, I want it to get back like before, but that is not possible._

[...]

_If someone has an operation, then you can take away the problem and it is over. But the woman can’t have an operation. The illness lives with you, you know.... We try to live like that, you can’t do otherwise (je kan niet anders)._”

These accounts indicate feelings of resignation and hopelessness. This is reflected in their ideas for healing options. They mainly referred to the need for monitoring by the doctor, rest and medication to control the pain. The need to live with the pain has a negative connotation
in their perception. It is something they have no choice about, or any control over as there is nothing else that can be done. With reference to this notion of lack of control, I conclude this section with an illustrative metaphor of Hasan regarding his own illness:

*I compare it with a piece of paper in the wind. I feel like that. I can’t fight against the wind. I just go with it. I give in.*

**Summary**

This chapter has provided an overview of the participants’ perspectives on healing options for their ill relatives. Most family members mentioned medication, warmth, rest or exercise as appropriate healing options. The perceived causes of illness determine what family members consider appropriate treatment, as do experiences of the effectiveness of certain treatments as well as the phase and duration of the illness. Family members who themselves have chronic pain referred to their own experiences in relation to illness management and linked this to what they think is appropriate for their relative. The doctor’s opinion plays an important role in the search for healing, but people might go to different doctors to get second opinions when they have no faith in what the doctor says or prescribes as treatment. In that respect people are active in their search for healing and this search seems to be motivated by religious notions and feelings of hope.
Impact of the illness: “moeilijk”

As seen in the previous two chapters, family members have ideas on the patient’s illness and ideas and expectations regarding healing. However, chronic illness and its consequences impinge not only on the life of the patient, but also affect the family as a unit and the individual family members. Corbin and Strauss (1988) refer to the strain on family members to rebalance family- and individual life and to accommodate illness. This can influence the family member’s experience of illness, and in turn might affect the response towards the patient.

‘Moeilijk’ (difficult) is the word frequently used by participants in conversations about the illness and the impact of illness on their lives. However, what is ‘moeilijk’ about it for the family members? How does the illness affect their lives? The responses to these questions are addressed in this chapter.

Loss and change

Chapter eight will elaborate on who provides care and why. The following section in this chapter, however, examines the impact of being a carer.

Of all the cases in this study, only one patient, Naima, receives help with personal activities like feeding, toileting, showering. In addition to dependency for personal care, Naima’s family members also worry Naima might faint or fall.

Jamila (daughter of Naima): She cannot stay home alone. We don’t have any rest, we think about her. [...] I am here in the day. Then when I go home at night, I phone again [to her sister in law, I.S.] to find out how she is doing.

As family members perceive that Naima requires total care and is at risk, 24-hour care is needed and this obviously affects the lives of the family members involved. The provision of this care becomes a central organizing principle for family life. They have to re-prioritize time
and duties and they have to deal with emotions of fear and worry. Additionally, Naima’s illness resulted in a loss of some of her previous contributions to family life:

Said (son of Naima): *She used to be housewife. She helped us in the house and looked after the children (ze was oppas oma). We made use of this. My wife works for homecare three times a week.*

Researcher: *How do you manage this now?*

Said: *My sister also works for homecare and they do it alternately, so they arrange it like that with the children.*

Naima’s loss of her role as housewife and caretaker of the children means a change of roles is required for others in Naima’s family. The complete or partial inability to carry out domestic tasks is an important consequence of the illness for many families. Some participants, however, implied this is mainly a difficulty for the patient herself: she feels dissatisfied for not meeting her own role perceptions. For example:

Achmed (husband of Myra): *When I ask her to help her, she says no. Sometimes she phones her daughters, but I don’t think she asks enough for help. She keeps trying herself.*

Researcher: *Why is that you think?*

Achmed: *I think she thinks it is her work and she will not feel good if someone else does it. But I never asked her why. It is what I think.*

Hasan, who himself has a chronic illness, mentioned that one consequence of his wife’s illness is her inability to care for him. Hasan himself had been ill for a long period prior to his wife’s illness, and therefore had been used to her helping him:

Hasan (husband of Sevgi): *Now my wife is also sick it is more difficult. We both need help. I can’t ask her to help me, I used to be able to ask her, but now I can’t. For example, if I need water I get it myself.*

In the other family, where the husband was ill (Erkhan), his wife had been ill for a long time prior to her husband’s illness. This meant that the role of his wife as the carer had not been established. Therefore, Erkhan did not perceive his wife’s illness as being associated with the loss of his carer. Instead, he was more frustrated by his own inability to help her.

As well as an inability to perform normal activities within the home setting, illness may also prevent the ill member of the household going out to work which impacts on the rest of the family members. Seven of the female patients used to have a job before they became ill. Only three have returned to work part-time. This has financial consequences for the family, especially when the loss of job is long-term.
Hasan mentioned that his and his wife’s roles in society are also affected by their illnesses, as they are unable to carry out community activities in the same manner as they previously had done. In his opinion, this has had an impact on how the community perceives them now. This in turn affects how Hasan feels. To illustrate this in his words:

**Researcher:** Your wife said last time that you both used to do a lot for other people and that now you can’t. How do you experience this?

**Hasan:** That gives me pain. When I worked, I had my own company and earned quite well. Everyone always came to borrow money. I could not say no. [...] When you say no, people think badly about you. Therefore, we always try to do well. When I became sick and poor, people still expect you can help them. Then people think we don’t care about them. This gives me pain.

For paperwork they always came to my wife. When she now says she can’t help, then they say ‘she does not want to help me’. The people don’t consider and understand our situation.

Illness was also noted to affect people’s social life, with some patients’ partners mentioning that they now missed doing as many social activities with their spouse. Pain and fatigue limit the patient’s ability to enjoy going out, which results in their partner doing more things on their own or socialising less. For example, when Gulnair’s fiancée was asked what the impact of the illness is for him he said:

**Ali (paraphrased):** We don’t go out. She can’t and I am not allowed to go out myself, because she does not like that.

**Gulnair (paraphrased):** But I am also often in a bad mood, because I am tired and frustrated. And I direct this to him (reageer dit op hem af).

**Ali (paraphrased):** Yes but I am used to that and I can take direct my frustration to the boxes at work.

As can be seen from the second part of the above, partners may experience negative behaviour from their spouse, because of their spouse feeling frustrated and tense because of their illness. Although it has not been explored in depth, two other partners commented that there had been an increase in the number of arguments occurring in the household, due to the feelings of frustration associated with the illness. Both of these partners were also ill themselves and therefore their own illnesses and their wife’s illnesses impacted on family life and relationships.

One husband found the loss of his wife as a sexual partner to be a major problem. He raised this as an issue when spoken to alone. The following account is paraphrased from notes taken during and after the conversation, as it was not audio-recorded.
As I told you last time, my wife has pain in her chest and breasts (titties). Therefore, I cannot touch the parts that are nicest about the women. Every time I try to touch her she doesn’t want me to, as she has pain. I do not like to force her, because I don’t want my wife to have pain. However, I have my needs as a man. That is natural. I need to be able to do nice things (gezellige dingen) with a woman. This is already for 15 years and that is a long time. Now I meet other women and have sex with her. I want to touch ‘the nice parts of a woman’. Not every day, but maybe every fortnight. Not a fixed relationship, but different women.

Not everyone was so open about this issue. When sexuality was addressed with other husbands however, they agreed that their wife’s illness had an impact on sexual activity. For two of the husbands this was not such a problem as they were ill themselves and therefore less interested in sexual activity. One of them responded:

That is difficult. For me it is not much of a problem. Sometimes we do things naturally, automatically. We are not in control. Sometimes I don’t think about it at all. I use medication as well [mentions type] and these medications make you feel lonely. You don’t want anything. You have no drive to do things. So I don’t think much about it. I only think about getting well and getting a normal life. I don’t think of private things. For my wife it is the same. Normally I leave her in control. When she feels like it, because she is also sick and tired. When she is tired, I can’t ask her anything. But life is difficult.

For another partner, whose wife’s illness has only recently been diagnosed, as the pain experienced varies, their level of sexual activity varies, but they seem to be accepting of this.

Summary

The narratives of family members show that loss and a change in the normal activities carried out in the home are some of the main impacts of illness. The female in the household being the one who is ill, may mean the partial or complete loss of a carer for the children and for anyone else who is ill in the home. The financial income of the family, their participation in social events and activities are also affected. Illness may also affect sexual activity between partners. These all place emotional demands on family members and practical adjustments will be required. The exact nature and extent of the losses and change for the family varies. It appears to be influenced by many factors including: the type and severity of the functional limitations of the patient, the duration of the illness, the previous roles of the patient and the nature of the relationship between the family member and the patient.
CHAPTER 8

"We care"

This chapter outlines the findings from the final topic area of this research, namely the family’s perspective on their role in treatment and care. Responsibility for the day-to-day management of a chronic condition and its effects on family life rests largely with the patient and her family. Ideas and feelings about the illness and treatment as described in the previous chapters, may be determinants of the roles family members take in the care and treatment of the patient. Additionally, norms and values on care and the availability of human resources may influence care roles.

The nature of the tasks performed by family members is first presented. This is followed by a discussion on who provides what care, and on what basis family members provide care. The chapter concludes with a brief summary.

Care activities

As mentioned in the previous chapter, only one lady receives assistance from her family with personal activities such as showering, dressing, feeding and toileting. The carrying out of domestic activities is the form of care provided most often by family members, with family members assisting with shopping, cleaning and/or cooking. The activities undertaken and the extent to which these tasks are undertaken vary between households. In some families, the woman still undertakes most activities and asks family members to do tasks such as dusting, hovering and shopping. In other families, all domestic activities are undertaken by other family members, thereby freeing the patient from such tasks. The latter situation tends to occur only where there is another woman available to assist.

Apart from these activities, other caring roles were elicited from the conversations, as being undertaken by family members. For example, some family members advise the patient to rest or to go to the doctor. In situations where the patient does not speak Dutch, a family member accompanies them to their various medical and therapy appointments to act as a translator. Said (the son of Naima) aptly illustrates this with the comment: 'I am her ears and
mouth'. He could have added 'and her legs', because his sister explained how he has to carry his mother up stairs and also has to wheel her in her wheelchair. He assumes great responsibility in his mother's care and helps his mother to decide on the best treatment options and filters information from the doctors to protect her.

Said: *And then, as her child, you need to tell your mother certain things. And I love her. It is really difficult to tell certain things to your mum. You always keep things behind. Not to upset her. So she will be more tranquil. [Explains she might need an operation]. If I would tell her now then she would get worse, then I will make her worry again.*

This fragment clearly shows the emotional element of 'caring for' the other person in the sense of feelings of concern, dedication and attachment in addition to the pure practical element (cf Van der Geest 2002). Potting (2001) in her work on family care for the elderly in The Netherlands, underlines the intermingling of instrumental, emotional and relational aspects of care as a specific characteristic of care by family members. Family relationships are per definition personal relationships, which have a history and involve positive and/or negative emotional elements. These impact on what care is given and how it is given.

Said's involvement in healing is also reflected in the fact that he encourages his mother to use the strategies she has learned and to do her exercises and he is actively involved in all the treatment sessions at the Jan van Breemen Instituut. In contrast to this, most other family members did not express this as their role. They might provide transport to the Instituut or attend sessions to translate, but only as a matter of necessity: *'I go with her because of the language'* (Achmed, husband of Myra). When I asked Hasan whether he is involved in treatment he responded:

Hasan: *No I don't go with her, unless she asks me. What can I do? She knows best herself...She will tell me about it when she wants to.*

Hasan does not feel he can do much to contribute to his wife's healing. He may advise her to leave the cleaning for the day and tries to do some of the practical tasks for her. Yet, he said that because he has chronic pain himself, he understands that his wife cannot undertake certain tasks when she is in pain. This element of understanding is mentioned by the other three fellow sufferers and can be seen as a form of emotional care. For example, Erkhan commented:

Erkhan (husband of Fatma): *We understand each other. If one has pain, then maybe you say 'difficulty', but I have the pain myself as well, so we have to help each other. [...]*
Researcher: How can you help each other?
Erkhan: My daughters in law help with the housework. I can’t do much. We only give each other some moral. Go for a little walk, sit together.

However, what does ‘giving each other moral’ or as others mentioned ‘giving emotional support’ mean exactly? It does not seem to refer to talking about the experience of pain. As mentioned in chapter five, most participants considered talking about the pain as either not needed or unhelpful. According to Achmed talking about it only focuses the attention on it and makes the pain seem worse. Selma and Zeyneb, who said they give each other emotional support, stated they do not like to talk about the pain with each other, as they do not want to feel sorry for themselves. They help each other with practical tasks where possible and enjoy each other’s company. Comments from Naima’s family members also suggest the only thing they can do is offer practical support and company. Therefore, emotional support seems to mainly take the form of showing understanding for the situation by providing practical support or by ‘being there’. In addition, advice and ‘stories of hope’ that others can give, is considered helpful care by those patients who have only recently been diagnosed. A comment of Rachida related to the care role of her mother, father and siblings illustrates this.

Rachida: They support me in some way. They say: ‘don’t worry, it will get better’, or they give stories of other people who have been healed. Even when you know in your head it will never get better, it is good.

In summary, the role of the family in healing and care mainly takes the form of offering practical support, allowing the person to rest, and providing advice and company. The participants’ level of optimism determines how receptive they are to giving or receiving advice.

Who cares?

The inability of the women to perform either personal and/or domestic activities requires practical adjustment and assistance. The previous section outlined the kinds of care activities the participants perform for the patient. In this section, I elaborate on the findings on who provides this care in terms of age, gender and relationship to the patient and why particular people provide this care.

In his book Zorgen om zorg, Yerden (2000) describes the traditional Turkish norms and values where the provision of care to the sick and dependent elderly is concerned. He states that elderly first generation migrants are reluctant to use professional carers and tend to rely
on carers within the family. The son and his wife should provide complete care for the parents, according to Yerden. This is known as *bakim* and it involves domestic care, personal care and financial care. When intimate personal care is required, such as washing or toileting, this should preferably be done by someone of the same sex as the person in need of care. Extended family members are expected to provide *yardim*, which means some help with practical issues such as shopping, finances or translations. Nevertheless, following his research amongst Turkish families in the Netherlands, Yerden concluded there is a shift in this care model. Norms about who should provide care are changing in the younger generation and there is often an inability of the younger generations to fit traditional care roles in the current life-context in The Netherlands. Yerden found that *bakim* may also be provided by daughters instead of daughters in law. Moree (2003) states in a review article on family care for migrant groups that norms and values for family care in Moroccan traditional culture are similar. However, literature on migrants and family care is all focused on care of the elderly or care of handicapped children and not on the care of younger chronically ill adults. In this study sample, there were four of the nine female patients who were younger, married and had no adult children to provide *bakim*. Considering this, and the fact that care models are dynamic, variations on the above traditional notions on care were to be expected.

Apart from one case where there was formal domestic assistance, none of the other participants mentioned practical help from someone outside the immediate family. Other people like friends or neighbours visit or phone, but do not assist with household activities. Rachida and Mohamed assumed the lack of involvement from others in their social network is a consequence of life in The Netherlands:

Rachida: *I find that a characteristic of life here in The Netherlands. Everyone lives for himself or herself. There is little support from others. Everyone has their own work, their own house, their own life, so to say. I get visitors, but even for the visitors you have to prepare things, make coffee. The visitors you get for a little while, they don’t help you. You get more work from them [laughs]. I find that a contrast with what I see in Morocco. When you are ill then the whole family is around you. Every day there is someone else with you.*

Mohamed: *Not only family. Also neighbours and friends or colleagues.*

Rachida: *You are helped from A to Z. I understand it and you have to accept it. Life is like that here. Everyone is busy. You have no time for the other.*

In all cases, family members who live in the same house or family members who live nearby provide most of this care. According to the findings in this study, the rule of the thumb seems to be, the further away the less involved. Statements such as “I live nearby so I can help”, or “they live far away so they don’t help so much” were common. For those people living fur-
ther away the support provided involved the provision of advice about visiting certain doctors and telling the ‘stories of hope’. For family members still living in Turkey or Morocco this is the only role undertaken.

Distance is not the only factor determining who assists with what. Gender, age and ability of the family member and the extent of their involvement in other activities are also important. Naima, who needs assistance with personal care, receives this only from other women, being her daughter and daughter in law. Domestic activities are also performed by women, unless there is no other woman in the house or available from elsewhere to help. For example, in the case of Fatma, her daughter lives in the same house, but works during the day. Therefore, one of her daughters in law, who lives nearby comes to do the cooking and cleaning. However, Erkhan mentioned he used to help with cooking until he became ill. Regarding men doing housework he stated:

Erkhan: In the past man works, wife is at home. Now it is different for many people. Men do household activities together with the wife. When I was healthy, I helped cooking. I can do it because I had been alone here for 9 years. Some people can’t cook.

The same applies to the younger couple Rachida and Mohamed. Although Rachida considers domestic activities to be her job when she feels well enough, Mohamed is happy and able to help.

Rachida: There has been a time where he had to do everything. Not that he did everything, but all the necessary things for the day. Not the big clean, but hovering, cooking, laundry, shopping. I see it like this: naturally, the man does not look after the household -not his role-, but he can do the necessary daily things. Now I do more myself again. He didn’t think like I am not a woman so I don’t do it, no. It was nice and clean in the kitchen and he cooked.

Mohamed: Now it is not a problem, because we are the two of us. When there are children, it will be difficult. Then there is a lot of work.

Researcher: Was this new for you?
Mohamed: For 4 years I had lived by myself. In my country, I studied at the university and I had to cook, clean and wash.
Rachida: So he knows everything. When I look at things that I think need to be done, they are good. I don’t need to tell him what to do. He can see it himself.

From the above, it appears that Rachida is very appreciative of the assistance from her husband and this is likely to motivate him to help. This is not the case for two households where male family members also try to help with domestic tasks, but there efforts are not considered ‘good enough’ and they asserted this lack of appreciation stops them from undertaking do-
mestic activities and may a source of tension. To illustrate this, the example of Hasan and Sevgi is used.

Sevgi and Hasan have three teenage children, all sons. Sevgi commented in the first interview how she regrets not having any girls, as they would have been more able to help. She also noted not to expect much of the children, as “children are so busy with their own activities nowadays.” (Sevgi) Additionally, she also stated that besides shopping her husband could do little in the house: “He can only make an egg” (Sevgi).

In the second visit, I am alone with Hasan and then he said: 
*She does the things in the house more. When everything is clean and tidy, then she has more rest and is happier. That is the difference of her character and mine. For me once a week cleaning the house is normal. When she does not feel well I say ‘just leave the house’, or ‘we do it together when you feel better’ and she says no, she wants to do it. Then she complains I don’t help her. When I feel well I can help, but when I don’t feel well I can’t help. She can’t wait. When I help it is not good, when I don’t help it is not good. This is strange. She can’t let go.*

[...] The children don’t help much, very little. They can’t do anything. Sometimes my son will hover, but he does it quickly and it is not what she wants. She wants it very exact. Everyone has to do it the way she does it, but no-one does it that way.

Researcher: Will she ask the children?

Hasan: *She often asks them to help. Sometimes the children do, but after that when she does not like it and they don’t want to do it anymore. It is the same for me. I really try to do it well, so she will say it is good, but she keeps telling me ‘do that there etc’. That is for me also a burden. She keeps telling us. She can’t just be quiet and think okay maybe the next time they will do better. She has to let go. She should leave us. She wants to keep control. Then it is difficult.*

It is of note, however, that men appear to be ‘willing’ to assist with domestic tasks. Scott and Wenger (1995), and Potting (2001) argue in relation to gendered care in European cultures that traditional divisions of tasks considered appropriate for men and women are often “abandoned in the face of necessity” (Scott and Wenger 1995: 171). The same principle might apply for Turkish and Moroccan families and this might explain the assumed domestic role of the men in this study.

**Why we care**

As indicated above, necessity may be a reason for providing care. Necessity comes from the notion of obligation to care and not having an alternative. All of the participating husbands regard it as their marital duty to look after their wife. For example, Erkhan stated:
Erkhan (husband Fatma): *If you marry then it means you help. You cannot say you are sick now I get divorced. That happens. Dutch and Turkish people now as well divorce a lot. This is a problem.*

The understanding and helpful attitude displayed by the husbands seems to contrast with the worry expressed by Moroccan women in the study of Reysoo (1999), that an inability to fulfil role expectations may jeopardize marriage. However, as Erkhan mentioned: *“that happens.”*

Apart from the sense of marital duty, according to traditional Turkish and Moroccan values, family members are supposed to help each other, as they are members of the same group. As Selma and Zeyneb stated:

Selma: *You feel that if there is something, you can count on them. But they don’t talk about feelings that much. There is a network and that is nice. You phone them and they come. Even my youngest brother comes when you need him.*

Zeyneb: *Yes not for a cup of coffee, but if something needs to be done, he is there for you.*

In the case of care for parents, the attitude of general family duty plays a role, as do norms and values of reciprocity and respect for elderly (Abraham 1996; Yerden 2000). Family members of the older patients often explicitly mentioned the traditional cultural values.

Erdal (grandson of Hatice, paraphrased): *In Turkish culture, family looks after the elderly and ill people. We just want my grandmother to have a good life now.*

The case of Naima further illustrates this. This elderly lady lives with her son Said, who feels responsible for her care. Both Said’s wife and Naima’s daughter, who lives in the same neighbourhood, provide the personal care for Naima. When I asked Said why he had decided to look after his mother he stated:

Said: *It has always been my wish to look after her. I have had such a good upbringing. Also my father. The two of them. [Tells a long anecdote indicative of the tolerance and good care of his parents]*

My mother is used to it that we do things for her. It is in our blood. If our parents are older we don’t let them do anything, we do it all for them. I think when my children get older that they won’t do that [we all laugh]*

Said: *No seriously, we are still in that culture, in between, but when my children get older they say ‘you know we have our own children, our own family, there is a nursing home and we come to visit you every day’. That is what they will do. I see that. I wouldn’t say that to my mother.*

The desire to look after his mother as a sign of appreciation for his upbringing demonstrates the idea of reciprocity. Reciprocity implies a bi-directional exchange, a give and take of resources. In case of caring for children, this expectation of receiving back care is delayed:
suspended reciprocity. Van der Geest (2002) discussed reciprocity in relation to care of the elderly in Ghana and noticed as well that the care elderly people get is a measure of the care they gave to their children when they were young.

However, as the above indicates, ideas of appropriate care for elderly parents are expected to change amongst the younger generation. In other cases, I noted that expectations for care might also change amongst first generation migrants. For example, Erkhan and Fatma are both ill and parents of adult children. His daughters in laws and sons help with the care now. When I asked him about his future expectations for care he said:

Erkhan: Yes I don’t know. If something happens later, I don’t know. At this moment, he helps. Later they might have a problem, the children go to school, they have worries, and maybe for them it will also be difficult.

Erkhan: We consider outside help when the children can’t help us. We have no choice. The children need to think of their own future. Some Turkish people expect that the children will look after them. For me this is not the case. If they do good things with their life, I am happy.

He suggests he will not be resentful when his children are unable to provide the care he requires, but he is aware that his expectations are in contrast to those of other Turkish people.

Summary:

This chapter addressed perceptions of family members on family care. It may be concluded, that family care patterns and care activities vary and cannot be predicted or captured by a set care model. Nevertheless, it appears that input from the family in healing and care is mainly focused on offering practical support to allow the patient to rest and to keep the household running. Different members of the family may provide different kinds of support depending on their relationship to the patient and the constraints such as distance, time and abilities. Although the preference is for women to do domestic activities, in some cases men may be required to take on this role. Providing advice and company are also forms of support that family members can offer for the well being of the patient.

The reasons for caring for elderly and sick family members are based on values of marital duty, family obligation, reciprocity and respect. However, this research has shown that these values may have a different meaning in different contexts and may change over time.
CHAPTER 9

Reflection, discussion and conclusions

The preceding chapters provided an outline and interpretation of the findings for each topic area of the research. In this chapter, I return to the overall research objective and discuss what can be concluded about the family perspective on rehabilitation of female patients of Turkish or Moroccan descent with chronic pain. This is divided into the perspective on chronic pain and the perspective on chronic pain rehabilitation. In the second part of the chapter, I reflect on assumptions made prior to undertaking this research and which influenced the choice of research topic. Firstly, the use of the social network theory for this study will be addressed, and then the relevance of concentrating on female patients and Turkish and Moroccan patients will be reflected on. The relevance of this study for medical anthropology is highlighted in the section ‘concluding remarks’.

The issue of chronic pain

In contrast to acute pain, which is seen as a symptom of disease and can be managed, the ‘function’ of chronic pain is ambiguous and poorly understood by biomedicine (Good 1994a; Jackson 1994; Honkasalo 2001). This study addressed the meaning family members give to the chronic pain condition of their relative.

The patients involved in this research study all had longstanding pain. For some there was a diagnosed underlying disease such as arthritis, for others there was no measurable or rational physiological underlying disease found. Nevertheless, most participants suggested there was something wrong with the body of their relative: the body is damaged through ageing, work, coldness, personal or hereditary vulnerability. Therefore, the pain is interpreted as something negative, as a symptom of disease and as a symptom of a malfunctioning body. In the case where a husband considered his wife’s personality to be responsible for the illness, something was still perceived to be wrong with the body: “the battery is empty” (Hasan). Additionally, Achmed, who considered psychological stress, caused by unhappiness to be the
main reason for his wife’s pain still advises his wife to go to the doctor to review her medication. Pain, therefore, is perceived mainly as a physical and medical problem.

Although a medical diagnosis and a prescription of medication confirmed the presence of illness, none of the participants expressed any doubt that the person was ill. This issue of credibility, which is often a concern for patients who suffer from chronic pain, does not seem to be an issue for the participating family members. They can see that the person is not well: the pain is visible in body language and behaviour. This visibility of pain adds a concept to previous anthropological work on pain that has mainly used discourse analysis to elicit the expression and experience of pain for sufferers (cf Kleinman et al 1992; Good 1994a). As findings from this study suggest, verbal communication and discussion on the pain are less relevant between patient and family. Participating family members indicated that they derive more meaning from the patient’s behaviour and from visual cues such as facial expression, posture, movement and inactivity, than from verbal communication. They respond by the provision of care. Studies that seek to gain understanding of pain idioms should therefore not only rely on discourse analysis, but also on observation.

Returning to the issue of credibility, I assume it is important that family members know the person from before the illness and therefore can judge the credibility of the person’s illness behaviour. However, in reality not all family members of patients with chronic pain will be understanding and acknowledging of the illness, despite the findings from this study. The specific sample used for the purposes of this study, as indicated in chapter three, is likely to be biased.

Findings suggest that what family members consider appropriate healing options for the chronic pain condition of the patient is not only subject to their explanatory models for the illness, but also to experiences of previous treatment and the phase and duration of the illness. Medication, warmth, rest or gentle exercises were mentioned most often. When religion plays a role in healing it is mainly in the form of encouraging the patient to be active in searching for healing options and in providing comfort and moral support.

In the early stage of the chronic pain condition, family members are still hopeful that there will be a cure, whereas in those cases in which the patient has suffered pain for a long time and has tried many things without effect, the family members experience feelings of resignation. This seems to link with theories on phases of grieving, and different modes of adjustment to chronic illness (cf Radley & Green 1987; Corbin & Strauss 1988).
Most family members perceived the person as sick and therefore in need of rest and may provide assistance with performing activities at home. I expect that the response to providing instrumental care is unlikely to have been very different in the cases of other (chronic) illnesses. In the majority of cases assistance involved taking over (certain) household activities. Despite preferences for who should provide what care, care provision is not completely predictable. Distance, time and physical capability are influencing factors.

Rehabilitation of chronic pain conditions

In the Jan van Breemen Instituut, rehabilitation is focused on the individual. The social situation is considered an important contextual factor, but family members are only minimally involved in the actual rehabilitation sessions. Health professionals in the Jan van Breemen Instituut suggested that patients need to change their coping strategies and illness behaviour. Making these changes is their responsibility. This means the patient should inform family members of the rehabilitation process, translate the rehabilitation message to the home environment and subsequently apply it. Findings from this research suggest that unless family members were actively involved in the process through their own interest, their ideas and values on rehabilitation are not congruent with those of rehabilitation professionals, and are likely not to be the same as those of patients.

The aim of rehabilitation for chronic pain in the Jan van Breemen Instituut is that patients ‘learn to live with the pain’. This is supposed to have a positive meaning in the sense of improving functioning and being to some extent in control of the symptoms. Patients need to learn to listen to their bodies and apply strategies to balance task demands with body capabilities (belasting en belastbaarheid). However, as indicated in the section on hope and hopelessness in chapter six, some participating family members talk about the ‘need to live with the pain’. They see this as an indication there is no hope that the situation will improve and they just have to adapt by changing roles and activities.

Comments from most of the participating family members imply rehabilitation is a form of treatment taking place there. The role of the family in dealing with the illness was mainly in the form of taking over activities when necessary, rather than enabling the patient to grade activity in manageable steps or encouraging the patient to use alternative strategies, as proposed by rehabilitation professionals (cf Vlaeyen et al 1996). Admittedly, not all of the patients in the sample had received comprehensive rehabilitation and some had only just started rehabilitation. This variation in exposure might partly explain the lack of awareness or in-
volvement of family members. However, it may be argued that just because the rehabilitation professionals instruct the patient in the rehabilitation setting does not mean that this results in the translation of the message to the home environment. Therefore, rehabilitation professionals must strive to actively involve family members in the rehabilitation process.

The relevance of the social network theory

The reason for focusing on the family of patients had been the idea that biomedical healthcare only sparsely addresses the social network. The illness experience has often been seen as individualistic rather than reciprocal. The relevance of eliciting the family perspective was guided by the theory that family members help to shape meaning of illness and influence expectations for care and treatment (cf Kleinman 1980; Kinlay 1981; Pescosolido 1991). Moreover, family members are often involved in and affected by the illness of the individual and this shapes their perceptions. Although I did not focus in this study in particular on how and to what extent the perspective of family members influences the perspective of patients and vice versa, the findings from this study endorse the social network theory.

The patients in the study were all part of a family network, even though in some instances this network is divided between people in the Netherlands and people in Turkey or Morocco. By giving advice or stories of hope and by helping with activities, the illness is acknowledged and this involvement influences the experience of the illness for the patient. Even if family members do little for the patient or understand the illness differently from her, this is likely to affect the experience for the patient. Although most family members saw it as the responsibility of the patient to go to the doctor and seek healing, they had their own ideas about the illness, treatment and how the situation should be managed at home. Additionally, participating family members had all noticed, to varying degrees, the impact of the illness on their lives.

As mentioned in the limitations of the study, the perspectives of the family in the conversations have merged to a more or lesser extent with the perspective of the patient. Although the tone and content of accounts changed when only the partner was spoken to, the merging of perspectives may indicate that we cannot elicit a single perspective. In daily life, there is verbal and nonverbal interaction between family members and meaning is continuously shaped and reshaped through these interactions.
What about the sick woman?

Another choice within the research topic had been to look at female patients. My assumption was that an illness affecting the woman’s productive role generally has a more practical impact on family life at home. I based this assumption on literature on gendered role division in Turkish and Moroccan families (cf Van Es 1995; Reysoo 1999). The woman is mainly responsible for taking care of the household and raising the children and it was expected that significant disruption to normal family life would be found when the woman was unable to perform these roles. This would require adjustment on behalf of other family members. The impact of the illness on family members has indeed been confirmed in the participant’s narratives. However, as outlined, this impact not only includes the reduced ability to perform domestic activities, but also other important losses such as the spouse not having a partner for socialising or a sexual partner.

Additionally, it was assumed that the expectations around roles may pressurize women to continue working despite their illness. For the participating families, the impression was given that the women would remain more active when there was no other woman available to take over the domestic duties. Interestingly though, comments from some of the partners in this research suggest that they do not demand this, advise their wife to rest and are willing to take over some of these activities. However, they find that the woman does not like to ask, or that the woman would not be satisfied about their input. This raises the question as to whether this role expectation of the ‘always capable domestic woman’ is maybe more imposed by the women themselves or by the wider community than by their husbands at home.

A last reflection relating to gender concerns the woman’s position relative to the man of the house. In traditional Turkish and Moroccan culture, women have an inferior position compared to men and men present the family to the outside (Abraham 1996; Yerden 2000). Researchers have therefore avoided interviewing women in the presence of men (cf Leeflang 1991; Wersch & Uniken Venema 1993). In four of the conversations, this power imbalance was affirmed. The man would dominate the conversation and the woman said very little. In all those cases, the women were older and had not mastered the Dutch language. However, in three of the seven situations where men and women were together in the conversation, the women dominated the conversation and voiced their opinion strongly. At times the husband or partner had to be addressed specifically to obtain his opinion. The most obvious evidence of ‘power reversal’ was in the conversation with Hassan, who stated he worries his wife gets
angry with him when he asks her things (see page 46). Women in power at home can therefore also apply to Moroccan and Turkish families, even when the woman is ill.

The focus on Turkish or Moroccan migrants

As indicated in the background to the study, my interest in eliciting the perspective of people from a different culture stemmed from experiences abroad, whereby I noticed the concepts of rehabilitation, autonomy, independence and individual responsibility have a different meaning. In The Netherlands, the difference in culture between non-western migrants and people of Dutch descent is often presented as a problem and given as reason for failing health care for migrants (Van Dijk 1998).

Reflecting on the conversations and the outcome of this study which focused on Turkish and Moroccan migrants, it may be concluded that the family members have different ideas on treatment and rehabilitation compared to Dutch rehabilitation professionals. However, this may be more a reflection of a difference in perspective between the rehabilitation professionals and families, than migrant families and Dutch families. While working part-time as a home care nurse assistant for disabled and chronically ill people, who were mainly Dutch, this last year, I noted the difference in attitudes to independence in the home environment compared to what rehabilitation professionals endeavour in rehabilitation settings. Sometimes, people do not want to try themselves. They prefer to be assisted. Independence is not desired by all.

The notion that Turkish and Moroccan migrants often have religious or supernatural explanatory models of chronic disease (cf Pecters 1986; Hoffer 1997; Reysoo 1999), is not enforced by the vast majority of naturalistic explanatory models for the disease given by the participants in this study. Admittedly, perceptions on the source of the illness and source of healing were external in nature for most family members. This has been referred to by professionals as a 'problem', as patients do then not take individual responsibility for healing and adopt a passive role when they are being treated (Thomas et al 1999). However, from the perspective of family members going to the doctor, or going to visit a hot springs is not a sign of passivity, but taking responsibility for healing. Additionally, resting is considered as an appropriate act to avoid further damage and encourage healing.

Regarding family care, cultural values and norms, resulting in an obligation to look after 'vulnerable' family members, were found to be important for the participating Turkish and
Moroccan migrants. However, variations to the traditional care model were found for some of the families in my study. Participants also felt that it was likely that care models will change even more for the next generation. These variations are a result of practical difficulties associated with fulfilling this ideal, and the changing meaning of family care or gender relations. Therefore, the dynamic nature of culture and the importance of context need to be emphasized.

Concluding remarks

The contribution of the findings to rehabilitation medicine will be stated in 'recommendations for practice' in the next chapter. These concluding remarks address the contributions of this study to medical anthropology. Based on the discussion, reflections and conclusions, it may be stated that this study has mainly affirmed certain anthropological theories and concepts.

The conclusions assert that people's practices and perceptions are not only subject to general cultural values and norms, but also to the specific context. This applies to perceptions on family care, gender roles, illness and treatment. With this, these findings challenge some of the stereotypes that persist regarding 'the' Turkish and Moroccan migrants. Additionally, the study suggests that a medical system like rehabilitation medicine is a culture with its own values, norms and practices. This confirms anthropological theories of cultures of professional health care systems (cf Kleinman 1980; Kleinman 1986; Good 1994b).

Finally, regarding exploring the pain idiom, this chapter has presented the argument that interpretations of pain idioms should not only rely on discourse analysis, but also on observation.
CHAPTER 10

Recommendations

Recommendations for practice

Some general recommendations for rehabilitation professionals can be inferred from the conclusions of the previous chapter. These are as follows:

1. Rehabilitation professionals need to realize that the ‘rehabilitation culture’ is a specific culture, which is not necessarily shared by patients or their families. Conscious awareness of taken-for-granted personal and professional norms and values is important to appreciate other people’s norms, values and expectations.

2. Rehabilitation professionals need to involve the family actively in rehabilitation if they expect the patient to apply the rehabilitation concept at home. The focus on the individual is not sufficient. Actively involving family members should include encouraging family members to ask questions, providing them explanations, as well as asking their perceptions on the situation and the role they are able to or wish to play in rehabilitation.

3. The context and uniqueness of each patient’s situation should be kept central in the rehabilitation process, as there is no blueprint of cultural values and norms for patients of Turkish and Moroccan descent.

Ideas for further research

The conversations with the families and the research topic have been inspiring. As the preceding chapters have shown, the research findings provided insights in the family perspective on chronic pain and rehabilitation, but it also raised new questions. Some of these may be interesting to explore further. With a brief description of these research ideas, this thesis will be concluded.

In the previous chapter, it was argued that differences in notions on rehabilitation might more reflect a difference in perspective between the rehabilitation professionals and families, than between migrant families and Dutch families. This hypothesis could be explored further in a comparative study.
From the analysis, it seems that the phase of the illness may determine to some extent expectations for healing and impact of the illness on family members. This study only provides a ‘snapshot’ of the family member’s perspective within a six weeks period. A longitudinal study in which some families are followed in time may be interesting, to explore how perceptions on illness and treatment and adjustment within the family change over time.

It was surprising to have three of eight families in the study sample in which the participating family member of the patient also had a chronic pain condition. This raises the question as to whether this is a coincidence, or whether there are many families, in which this is the case. If so, what could be contributing factors? Additionally, these ‘fellow sufferers’ implied they could understand the situation of the patient better. They also referred to their own experiences when talking about appropriate illness management for the patient. It may be interesting to explore the role of the ‘fellow sufferer’ in providing support and care further.

Due to time limitations, this study only explored the perspective of one or two family members of each patient. A study that includes all involved family members may provide better insight in the diversity of perspectives within a family, and how this affects coping with the sickness of the relative. Within such a study, the perspective of younger children in the family could be added to provide insight in their role in care and healing.
APPENDIX I

Brief overview ideal study

The IDEAL research project is based on the impression of rehabilitation physicians that migrants with chronic back pain often stop intervention immediately after, or soon after, the first consult with the rehabilitation physician. The contributing factors to explain this perceived problem of utilization of rehabilitation services are the focus of attention in that research project (Scheppers 2003).

IDEAL stands for Interculturalisatie: Diagnostische Evaluatie bij Allochtone patiënten met Lage rugklachten. The project runs from March 2003 for a four-year period and is conducted as part of the research theme chronic back pain within the section ‘rehabilitation medicine’ of Zorg Onderzoek Nederland (ibid).

The groups under study are Turkish and Moroccan patients with chronic pain who are referred for an outpatient rehabilitation programme in The Jan van Breemen Instituut. The reasons for the choice of these groups are the high prevalence of chronic back complaints among Turkish and Moroccan patients, and the fact they form the largest groups of migrant patients referred to the Jan van Breemen Instituut (ibid).

The IDEAL study mainly addresses possible conflicting perspectives and concentrates on: the doctor-patient interaction, the perspective of the patient, the perspective of the rehabilitation physician and the organizational and structural aspects of care provision in the rehabilitation facility (ibid).
APPENDIX II

Information letter to patients (in Dutch)

Amsterdam, (date) 2004

Geachte mevrouw (name)

U bent naar het Jan van Breemen Instituut gekomen om wat aan uw klachten te doen. Leven met chronische pijn is moeilijk. Methoden om hier iets aan te doen kunnen altijd worden verbeterd. Voor deze verbetering is het nodig dat men uw mening en behoeften kent. Daarvoor zou ik, in het kader van mijn opleiding, graag de rol van uw familie en netwerk willen onderzoeken. Wat zijn hun ideeën? Hoe kijken zij tegen revalidatie aan? En natuurlijk: hoe zien zij uw situatie?

U kunt een waardevolle bijdrage leveren en ik vraag u om die reden deel te nemen aan mijn onderzoek. Ik wil graag met u en een paar leden van uw familie een paar keer praten over pijn en revalidatie. Die gesprekken duren ongeveer anderhalf uur. Het spreekt vanzelf dat alles wat u of uw familie zegt anoniem blijft. Uw naam en die van uw familie worden nergens vermeld. Ik hoop dat u beslist mee te doen. Ik zal dan binnenkort contact met u opnemen om een afsprak te maken.

Hoogachtend

Ingrid Sturkenboom
Studente medische antropologie

(Telephone contact details researcher)
APPENDIX III

Topic list interview

Introduction (to participant, patient and other relevant relatives present)

- Express appreciation for offering opportunity to talk, be there
- Explain again purpose, procedure research
- Explain rights (voluntary participation, allowed to ask questions, allowed to stop tape, able to withdraw or stop at any point) and issue of confidentiality/ anonymity of data.
- Check whether participant has understood everything and still consents to partake in research.

General information:

- Participant’s relationship to patient
- Participant’s age, education/ work, living situation, own perceived health status, own family situation
- Family: migration history: (when, from where, reason)

Characteristics social network of the patient

Can include: family, friends, neighbours, and other community members- in The Netherlands or from abroad.

- Who is involved with the patient? What is their relationship to the patient
- What is the nature of the contact? What is frequency of the contact? How important is the contact

Perceptions on health status of the patient and the consequences

- Detailed description of the condition of the patient as perceived by participant: what is the problem, where is it located, when did it start, how has it developed, notions on what caused the condition/ explanatory model.
- Consequences: how serious is the pain at the moment, how does it impact on patient’s ability to function, how does it impact on the family, what does this mean for the patient and for the family, what does it mean for the participant her/himself?
- Expectations for change in the health status
Perceptions on family care

- Ideas on role of family in care and healing
- Who is involved with what in relation to patient’s care or patient’s previous roles? (see also characteristics of social network)
- Description of participant’s own involvement (what, when, how often)
- Participant’s experience and feelings of involvement in care

Perceptions on rehabilitation

- Understanding + meaning of the concept rehabilitation
- Expectations of rehabilitation for the patient (goals, methods)
- Participant’s experiences of rehabilitation for the patient to date (goals, methods, difficulties/successes)
- Perceptions on the role of the patient and family in rehabilitation: what rehab unit expects of family, what participant feels family can/cannot do

Perceptions on health care (for all other health care than rehabilitation)

- Ideas regarding possible health care options for chronic pain
- Tried treatments or methods by patient for dealing with the pain apart from rehabilitation: (where, for what reason, experience, effectiveness)

Observation: Impression of:

- Living conditions/home environment: general impression of space and objects
- Interaction patient and participant: frequency, content, nature, who initiates, emotions/feelings apparent in interaction (through verbal and non-verbal messages)
- Level of participation of patient in family life: inclusion in conversation or decision making, actions taken by patient, activities performed by patient.
- Role of family members in care of the patient: practical and emotional support given, encouraging patient to engage in activities, encouraging patient to take rest
APPENDIX IV

Analysis scheme

The following table provides an overview of the code labels for variables and themes elicited from the fieldwork data. In the first column the topic is given, in the second column the code labels and sub-codes labels (the sub-codes are listed after the colon)

<table>
<thead>
<tr>
<th>PERSONAL AND SOCIAL CONTEXTUAL DATA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain condition patient</td>
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<td></td>
</tr>
<tr>
<td>Rehabilitation treatment status</td>
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<tr>
<td></td>
</tr>
<tr>
<td>Age group patient</td>
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<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td>Ethnicity patient</td>
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<tr>
<td></td>
</tr>
<tr>
<td>Country of birth patient</td>
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<tr>
<td></td>
</tr>
<tr>
<td>Country of birth participating family member</td>
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<tr>
<td></td>
</tr>
<tr>
<td>Relationship of family member to patient</td>
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<td></td>
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<tr>
<td>Health status participating family member</td>
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<tr>
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</tbody>
</table>
| Household                          | Patient with partner only: no children, children living out  
|                                  | Patient with partner and child(ren): with school-age children, with adult children  
|                                  | Patient living in with son and his family  
| Home environment                 | House  
|                                  | Flat/ apartment  
|                                  | Access without stairs – or - Access with stairs  
| **ILLNESS PERCEPTIONS**          |  
| Onset                            | Sudden onset or gradual onset  
|                                  | Recent onset (up to 1 year ago) – or - Onset Long time ago  
| Description illness              | Not knowing diagnosis - or - Knowing diagnosis  
|                                  | Description in location of pain  
|                                  | Description in sensory quality or no description of sensory quality  
|                                  | The doctor says  
| Symptoms                         | Pain Location: Specific location - or - Whole body  
|                                  | Pain pattern (time): continuous pain, fluctuating pain  
|                                  | Fatigue  
|                                  | Weakness  
|                                  | High blood  
|                                  | Concentration problems  
| Communication about the illness   | Can see: facial expression, inactivity, movement, posture, medication  
|                                  | She tells  
|                                  | Not talking about it  
| Explanatory model                | The doctor says  
|                                  | We don't know  
|                                  | Religion: God not accountable  
|                                  | Linking symptoms  
|                                  | Climate: coldness, damp  
|                                  | Physical stress: work  
|                                  | Ageing  
|                                  | Emotional stress: unhappiness, work pressure  
|                                  | Personality  
|                                  | Familial vulnerability  
|                                  | It can just happen  
|                                  | Supernatural cause: spirits  

| Impact of illness for me/us | Change of roles  
|                           | Re-prioritising time  
|                           | Loss of person doing household activities  
|                           | Loss care taker children  
|                           | Loss carer for self  
|                           | Impact on sexual relationship  
|                           | Reduced social activity  
|                           | More arguments  

**HEALING OPTIONS**

| Expectations for change | Not thinking of future  
|                        | Not knowing/ uncertainty  
|                        | Hope: expecting recovery, expecting improvement  
|                        | No hope: acceptance, resignation, need to live with it, lost faith  
|                        | Fear/ worry  

| Searching for healing | Actively searching: going to doctor, obtaining second opinion doctor  
|                       | - Turkey or Morocco, obtaining family advice, searching internet  
|                       | - Awaiting appointments  

| Healing options | Medication  
|                 | Rest  
|                 | Movement: exercise, walking  
|                 | Warmth: visiting Turkey/ Morocco, hot springs, hot sand, clothing  
|                 | Role religion: moral support, encourage care seeking  
|                 | Traditional healer: spirit healer, herbs  
|                 | Operation  

| Concept of rehabilitation | Adaptations: splint, wheelchair  
|                          | Medication  
|                          | Seeing the specialist  
|                          | Going for a talk  
|                          | Advice  
|                          | Exercise  
|                          | Massage  
|                          | There - or - Here and there  

| Effectiveness of treatment options | Improvement - or - No effect - or - Worse  
<p>|                                   | Faith - or - No faith |</p>
<table>
<thead>
<tr>
<th><strong>FAMILY CARE</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content of care</strong></td>
</tr>
<tr>
<td>Housework: cleaning, cooking, shopping, laundry</td>
</tr>
<tr>
<td>Facilitating treatment: translation, transport, encouraging exercise</td>
</tr>
<tr>
<td>Assistance personal care</td>
</tr>
<tr>
<td>Mobility: taking for a walk, assist on stairs</td>
</tr>
<tr>
<td>Advice</td>
</tr>
<tr>
<td>Protection</td>
</tr>
<tr>
<td>Moral support: being there/ company, understanding, acceptance, fellow sufferer, stories of hope</td>
</tr>
<tr>
<td><strong>Who cares</strong></td>
</tr>
<tr>
<td>Partner: husband, fiancée</td>
</tr>
<tr>
<td>Child: son, daughter</td>
</tr>
<tr>
<td>Parent: mother, father</td>
</tr>
<tr>
<td>Sibling: sister, brother</td>
</tr>
<tr>
<td>Daughter in law</td>
</tr>
<tr>
<td>Grandson</td>
</tr>
<tr>
<td><strong>Reason for care</strong></td>
</tr>
<tr>
<td>Cultural expectation: family obligation, marital duty, reciprocity</td>
</tr>
<tr>
<td>Cultural change</td>
</tr>
<tr>
<td>Necessity</td>
</tr>
<tr>
<td>Ability to help- or- Inability to help</td>
</tr>
<tr>
<td><strong>Experience of care</strong></td>
</tr>
<tr>
<td>Happy to help/ satisfaction</td>
</tr>
<tr>
<td>Frustration: feeling unable, no appreciation</td>
</tr>
</tbody>
</table>
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Summary

Family members of patients potentially play an important role in rehabilitation. Ideas and attitudes towards illness, healing, family care and gender roles can shape family members’ perspectives on chronic pain and rehabilitation. As there is a lack of insight into how Turkish and Moroccan families understand, perceive and respond to chronic pain and pain rehabilitation programmes, this thesis seeks to address this.

Family member’s perceptions on illness, treatment (including rehabilitation) and care have been explored through in-depth interviews in the home setting of the patient. Eight families were included in the study, of which two were Moroccan families and six were Turkish families. A total of seventeen interviews were conducted. Data analysis involved coding data obtained from the conversations, eliciting themes and linking these to the broad categories of perceptions on the illness, perceptions on treatment and perceptions on family care. These categories form the basic structure for the presentation of the findings of this thesis.

The findings suggest that the family members all acknowledge the patient is experiencing pain and that the invisible pain may be visible in body language, behaviour (inactivity) or by the taking of medicines. These visible cues seem more important in communication for family members than descriptive accounts of the experience. In all cases, pain is considered a symptom of a malfunctioning body. Various explanatory models are given for each case and between cases. Factors involved are mainly external and naturalistic, such as physical stress, ageing, psychological stress due to external demands, and climate. Few participants mentioned internal factors like personality, or personal/familial vulnerability. For some participants getting ill ‘just happens’. Participants referring to religion stated everything has a purpose and meaning in life and only Allah knows this purpose, but they do not consider Him accountable for causing the illness. Religious ideas and practices mainly provide moral support and encourage people to be active in the search for healing.

Relatives of patients regarded medication, warmth, rest or gentle exercise to be appropriate treatment options. Most family members had little idea what the aim or content of rehabilitation treatment is for their relative. Rehabilitation happens there, meaning in the hospital.
Family members of patients who have suffered from chronic pain for a long time were not hopeful there would be any improvement in the condition. Feelings of resignation and 'the need to live with it' were prominent in their accounts. In contrast, family members of patients only recently diagnosed with the chronic condition, were hopeful that the patient would recover.

The role of family members in illness management lies mainly in providing advice and providing instrumental care by taking over or assisting in domestic activities. For some participants instrumental care also involved providing transport to the health service facility and providing translating services in consultations with health professionals. Different members of the family may provide different kinds of support depending on their relationship to the patient and the constraints of distance, time and abilities. Traditional role divisions can change in face of necessity. Values of marital duty, family obligation, reciprocity and respect are the basis for providing care, but as the findings of the research affirm these values can have a different meaning in different contexts and may change over time.

The main recommendation made for practice is that rehabilitation professionals need to actively involve the family in the rehabilitation process, if they expect the patient to apply the rehabilitation concept at home.