

# **Dementia**

## **among elderly Moroccan immigrants in the Netherlands**



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Master Thesis Social & Cultural Anthropology

Department of Social Sciences

VU University Amsterdam

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‘Doctors, usually male and in white coats carrying stethoscopes exist at one level; nurses usually female and in uniform represent another. The task of the patient is to learn to read the signs, accept the symptoms and understand the symbols which, correctly read, reveal the limits not only of healing ability but of power and control derived by the individual from his/her category and its permitted level of information’.

(Frankenberg 1980: 198)

## Preface

When I started the pre-master programme Social and Cultural Anthropology at the VU University in September 2008, I had no clear idea what knowledge I would gain and experiences I would have during the course of this study. I had finished my bachelor of applied sciences in occupational therapy<sup>1</sup> and decided that it was time for something new, something challenging. In the course of time my life started changing; I moved to Amsterdam, I finished the pre-master courses with satisfactory grades and I was hired as a part-time occupational therapist at the Slotervaart hospital. As an occupational therapist working in a hospital in Amsterdam, health care for immigrants is an important part of my work. I focus on the diagnostics phase of determining cognitive problems with elderly members in society. As the number of elderly members of ethnic minorities is increasing, it seemed necessary for me to know more about their specific characteristics and wishes with regard to elderly health care. This was the trigger for me to focus my pre-master thesis on the problems experienced by Turkish and Moroccan elderly (Rijkers, 2009) and this master thesis on dementia among elderly Moroccan immigrants in the Netherlands. These subjects allowed me to combine my former education, my work as an occupational therapist and my study Social and Cultural Anthropology.

Without the support of the Slotervaart hospital, it would not have been possible to conduct this research. For this I thank Jos van Campen, who supported me during the process, and the members of the Medical Ethical Commission, who approved this study. Also special thanks to my colleagues, who always inspired and motivated me. Furthermore I would like to thank all the employees and volunteers of the projects I visited, for allowing me to do participant observation and supporting me in my search for respondents. Of course I would like to say special thanks to all my respondents and their family members for participating in this research and for opening up to me about this sensitive topic. I would like to thank Edien Bartels, Ellen Bal and Anna Ligthart for their critical feedback on the research plan, the research and this thesis. Last but not least I want to thank Casper for listening to all my stories, for motivating me to continue despite misfortune, for correcting my English and for always standing by my side. Due to the support of all of them I did not face too many obstacles and experienced a very interesting and good time conducting this research and writing this thesis.

Amsterdam, June 2010

Caroline Rijkers

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<sup>1</sup> Occupational therapy is the art and science of enabling engagement in everyday living, through occupation; of enabling people to perform the occupations that foster health and well-being; and of enabling a just and inclusive society so that all people may participate to their potential in the daily occupations of life (Townsend & Polatajko 2007:372). Occupation refers to everything that people do during the course of everyday life. Each of us has many occupations that are essential to our health and well-being.

## **Executive summary**

This qualitative anthropological research focused on dementia among Moroccan immigrants in the Netherlands. Previous studies on this topic are limited and fail to focus on dementia among Moroccan immigrants in the Netherlands. Therefore, the research presented in this thesis may be considered to be unique. The research question is as following: How is dementia experienced by elderly Moroccan immigrants in the Netherlands suffering from dementia, their family members and by health care professionals?

A total of eight Moroccan families were included in this research, of which seven elderly suffering from dementia were interviewed, as well as eighteen family members. Although all respondents were diagnosed with dementia, they do not seem to acknowledge it. Their family members do, but most of them expressed having difficulties dealing with dementia and its symptoms. The diverse symptoms of dementia, and in particular the character changes, make it hard for family members to provide proper care.

This research furthermore concluded that the Moroccan elderly suffering from dementia feel at home in the Netherlands. The most important aspect of home to them is the presence of family members. Although, this does not mean that they do not think about their past lives in Morocco. Due to dementia, they started living more and more in the past, repeating stories about ‘those days’. They do not forget their past and their home country, though they do not express a will to return to Morocco, because of the presence of their family members in the Netherlands.

To offer migrants the pleasant old day they deserve, it is not only important that migrant families know how to adapt to the new situation with dementia, but also that the Dutch health care system takes action in this area. Health care professionals are becoming increasingly aware of the lack of cultural specific facilities for elderly members of ethnic minorities. Studies have shown that this target group makes less use of health care facilities for the elderly, such as day-care, professional home care and nursing homes. However, it appears that the wishes regarding such facilities for elderly from ethnic minorities are increasing. I state specific facilities, because the situation of these elderly is specific as well. Most of them do not speak the Dutch language (anymore) and their cultural background differs from Dutch elderly.

Elderly with cognitive problems are stigmatized in many cultures, among others in the Moroccan community in the Netherlands. Denial, shame and sensitivity are three important aspects related to dementia which places it within the taboo atmosphere. If dementia can be removed out of this atmosphere, discussing the subject will be easier and support can be offered to both patient and care givers. Due to the findings that the elderly and their family members tend to do nothing after the diagnosis is set, assistance is often not asked. To overcome these obstacles it was concluded that it is important to provide culturally sensitive, specific health care for elderly suffering from dementia.

## Samenvatting

Dit kwalitatieve, antropologische onderzoek richtte zich op dementie onder oudere Marokkaanse migranten in Nederland. Er zijn slechts een gering aantal studies bekend over dit onderwerp en deze richten zich niet specifiek op dementie onder Marokkaanse migranten in Nederland. Hierdoor kan het gepresenteerde onderzoek als uniek beschouwd worden. De onderzoeksvraag luidde als volgt: Hoe wordt dementie ervaren door oudere, dementerende Marokkaanse immigranten in Nederland, hun familieleden en door professionele zorgverleners?

In totaal werkten acht Marokkaanse families mee aan het onderzoek, waarbij er zeven ouderen met dementie geïnterviewd werden en achttien familie leden. Ook al was bij alle respondenten de diagnose dementie gesteld, de ouderen erkenden dat niet allemaal. De meeste familieleden erkenden het wel, maar uitten moeilijkheden over de omgang met de (symptomen van) dementie. De uiteenlopende symptomen van dementie, met name de veranderingen in karakter, maakten het moeilijk voor de familieleden om goede zorg te bieden.

Een andere conclusie van dit onderzoek was dat de Marokkaanse ouderen met dementie zich thuis voelen in Nederland. Voor hen is het belangrijkste aspect van thuis de aanwezigheid van familieleden. Dit betekent echter niet dat zij helemaal niet meer aan hun vroegere leven in Marokko denken. De dementie zorgt ervoor dat ze meer in het verleden gaan leven en verhalen van vroeger vaak herhalen. Hun verleden en hun vaderland zullen zij niet snel vergeten, maar zij gaven aan niet terug te willen keren omdat hun familieleden hier in Nederland wonen.

Om ook oudere migranten een goede oude dag te bieden, is het niet alleen belangrijk dat migrantenfamilies weten hoe zij om moeten gaan met dementie, maar ook dat Nederlandse zorgverleners actie ondernemen. Professionele zorgverleners zijn zich steeds meer bewust van het gebrek aan specifieke voorzieningen voor ouderen van etnische minderheden. Onderzoek laat zien dat deze doelgroep minder gebruik maakt van zorgvoorzieningen voor ouderen, zoals dagopvang, professionele thuiszorg en verzorgingshuizen. Anderzijds wordt het duidelijk dat de wensen van deze groep ouderen voor cultureel specifieke voorzieningen er wel degelijk zijn. Ik zeg hier cultureel specifieke voorzieningen, omdat de situatie van deze ouderen ook specifiek is; velen spreken de Nederlandse taal niet (meer) en ze hebben een andere culturele achtergrond dan Nederlandse ouderen.

Ouderen met cognitieve problemen worden gestigmatiseerd in vele culturen, onder meer in de Marokkaanse gemeenschap in Nederland. Ontkenning, schaamte en emotionaliteit zijn drie belangrijke aspecten gerelateerd aan dementie, die het onderwerp in de taboe sfeer plaatsen. Als dementie uit deze sfeer kan worden gehaald zou het gemakkelijker worden om over het onderwerp te praten en steun kan gegeven worden aan de oudere en de familieleden. Een van de bevindingen is dat ouderen en hun familieleden de neiging hebben om na de diagnose niets te ondernemen, zij zullen niet snel om hulp vragen. Cultureel specifieke zorg is nodig om deze obstakels te overwinnen.

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## 1. Introduction

I find myself sitting on a large sofa, with my knees touching the large round wooden table in front of me and my bare feet on the soft carpet. To my right sits a young Moroccan woman, wearing fashionable clothes and not wearing a headscarf. She is the youngest daughter of the man and woman in front of me. The man has a grey beard and he wears black trousers and a dark-coloured sweater. If he is not spoken to directly, he just stares into the room. His wife wears a long dress over some other clothes, she does wear a headscarf and talks lively with her daughter in Arabic. The daughter translates the conversation for me to Dutch. The mother talks about Morocco and about the time she came to her husband in the Netherlands. She tells me stories about the first years here in the Netherlands, how lonely and terrified she felt those years. Her husband was working in Utrecht, sometimes for more than 10 hours a day. She knew no one and without him she could not do anything, she sat at home. She tells how the times have changed, nowadays she knows many neighbours, has many friends and her Dutch is reasonable. Her husband was diagnosed with Parkinson's disease in 2002 and since then his health has declined; he has tremors in both hands, walking is difficult due to muscle rigidity and bradykinesia and he suffers from Parkinson's related dementia. At this moment in time, the man rarely leaves the house anymore and his daily activities are very limited. He tells me that he experiences fewer problems in Morocco, mainly due to the climate. I ask him if he would rather be in Morocco than in the Netherlands, but he insures me that that is not the case. He does not want to live in Morocco without his children and grandchildren, as they are of high importance to him. The man and wife still go to Morocco for holidays, but the number of weeks they stay declines each year (case of Mr. El Amrani).

This Moroccan family described above is an illustration of my research population. During my field research period, I stayed in Amsterdam (the Netherlands) and focused on dementia among elderly Moroccan immigrants. The book *Marokkanen in Nederland, de pioniers vertellen* (Moroccans in the Netherlands, the pioneers describe; Cottaar, Bouras & Laouikili 2009) provides an illustrative background of the Moroccan immigrants who came to the Netherlands in the sixties and seventies, depicting their stories and experiences of among others work, religious life and family reunification. It clearly describes the route to my research topic, as in time the Moroccan immigrants decided to stay permanently, making the Netherlands their new physical home. Although, as they aged and their memories declined due to dementia, it might be the case that their minds would return to Morocco.

An important aspect of this research is feelings of home and belonging. Everyone needs a place to call home, where they can always return to and feel safe. 'As a basic human need, sense of belonging as connectedness is important to the individual, family and community' (Hill 2006:212). But it is unknown where elderly Moroccan immigrants suffering from dementia feel at home. Which aspect of home and belonging do the elderly ascribe as the most important? Where is their home? Does the dementia influence these feelings?

‘Epidemiological studies worldwide show that about 20 to 30 percent of those aged 65 and over suffer from at least one mental disorder’ (Gallo & Lebowitz, 1999; in Werner & Heinik 2008:93). Dementia affects one in twenty people over the age of 65, with the prevalence doubling every five years between 65 and 95 years (Iliffe & Manthorpe 2002:243). Since every person is not only unique, but also affected differently by dementia, no two persons will experience symptoms that develop in precisely the same way. Among some early symptoms that can be determined, such as memory loss, difficulty performing familiar tasks, problems with language, disorientation and a loss of initiative (Alzheimer’s Disease International), declining memory, especially short-term memory, is the most common early symptom. People with ordinary forgetfulness can still remember other facts associated with the thing they have forgotten, for example they may briefly forget their next-door neighbour’s name but they still know the person they are talking to is their next-door neighbour. A person with dementia will not only forget their neighbour’s name but also the context. Expressing this by means of a metaphor: ‘Whereas the normal person gradually exchanges old planks in her boat of knowledge and personality for new ones while sailing the sea of life, the person with progressive dementia is steadily losing planks without any replacements. Initially the shape of the boat stays the same, but as time goes by it disintegrates into smaller and smaller pieces, each floating separately in a sea of lost memories’ (Holm 2001:153).

Since the symptoms will worsen, eventually people with dementia start living in the past, as they forget things that happened in the recent history. ‘People who develop dementia often gradually realize something is wrong. [...] Many experience feelings of fear, insecurity, confusion or disbelief when they start to realize “something is wrong”. [...] Feelings of being useless, becoming a burden for others, resulting for some in feelings of concern for their partner, are common, which emphasises the importance of others’ (de Boer et al. 2007:1026-1029).

Several risk factors can be determined that increase the probability of developing dementia. On the one hand there are factors that you cannot change, such as high age, family history and genetics. On the other hand are risk factors that you can control, including high blood pressure, high cholesterol, diabetes, smoking and heavy alcohol use. There are also controllable aspects that increase the risk for developing diabetes, high blood pressure and cholesterol, which in turn may increase the risk of developing dementia. These include being overweight or obese, lack of physical activity and an unhealthy diet. On the basis of these controllable risk factors, it can be said that the elderly Moroccan immigrants in the Netherlands have a high risk on developing dementia. Especially the women, who, in general, lack physical activity and are often overweight have a higher chance of developing diabetes, high blood pressure and high cholesterol, and as a result have an increased risk on developing dementia.

## **1.1 Research questions**

The aim of this research is not only to give a voice to elderly Moroccan immigrants suffering from dementia and their family members, but also to illustrate the potential influence of the illness experience on feelings of home and belonging. The third voice in this research is that of the health care professionals. These health care professionals are of particular importance, because they can provide another viewpoint on the experiences of the elderly, as well as on the provided and needed health care. The following research question and sub-questions are formulated.

How is dementia experienced by elderly Moroccan immigrants in the Netherlands suffering from dementia, their family members and by health care professionals?

- How is dementia experienced by elderly Moroccan immigrants in the Netherlands suffering from dementia, and how does it relate to their feelings of home and belonging?
- How is dementia experienced by their family members?
- How is dementia among elderly Moroccan immigrants experienced by health care professionals?

Experience can be defined as how reality presents itself to our consciousness (Bruner 2001:266). In this research, the word is meant in the broadest sense, since it entails obtaining knowledge through perceiving, observing, feeling and doing. Experiences cannot be observed by others, as they are individually bounded, so in-depth interviews are necessary.

## **1.2 Social and scientific relevance**

The first generation of Moroccan immigrants in the Netherlands is aging and consequently they suffer from old-age-related illnesses. Since dementia is one of those illnesses, it will occur more often within the Moroccan community. It seems important to know more about the experiences of dementia among this population, in order to adapt the care and informational services. This phenomenon is also noticed by De Vries, as she conducted a masters' research on dementia and care among Turkish elderly immigrants in 2007. She concludes: 'The new situation that is appearing in the Netherlands requires adaptation from different areas. For the first time migrant families have to cope with the care for family members with dementia, while professional health care has to deal with elderly people with a different cultural/ethnic background' (De Vries 2007: 9). An early diagnosis is important, because it allows those with dementia and their family to engage with support services and plan for their futures. 'These actions can prevent the significant psychological distress that people with dementia and close supporters may experience, and provide knowledge about the availability of medical and psychosocial support that improves morale' (Ilfie & Manthorpe 2002:244).

An extensive literature study showed that other researches focusing on dementia in ethnic minorities, focused on the family members instead of the elderly. For example, the research on

dementia and care among Turkish immigrants in the Netherlands included only family members because of pragmatic reasons. De Vries explains that the reason was two folded; firstly family members are more accessible and communication is easier, and secondly it is expected that they will identify changes among the elderly sooner than the elderly themselves (de Vries 2007:25). As a result, the perception of the elderly themselves stays under exposed. Old persons, as they become increasingly dependent upon their children and their society, must struggle to be heard' (Cohen 1995:331). The number of studies focussing on the perspective of the elderly suffering from dementia is relatively small. Even though, 'there is increasingly knowledge that people with dementia are able to express views, needs and concerns and several researchers have stressed the importance of incorporating the subjective experience of people with dementia in research in order to better meet their needs for care' (de Boer et al. 2007:1022). The article of de Boer et al. provides an overview of the available academic literature on the perspective of dementia patients.

Whitehouse et al. explain that the 'cultural-historical and phenomenological perspectives on disease formulated in anthropology can enrich our understanding of the experience of ageing and, in specific societies, of the meaning and significance of cognitive changes that range from momentary forgetfulness to a diagnosis of Alzheimer's disease' (Whitehouse et al. 2005:320). Iliffe & Manthorpe conclude that the experience of dementia is not only influenced by socio-economic status, education and religion, but also by culture and adaptation to migration (Iliffe & Manthorpe 2002:249). Although the *disease* dementia may not differ between societies or ethnic groups, the experiences of *illness* and *sickness* may. These concepts are derived from Kleinman (1980), Frankenberg (1980) and Richters (1996), and will be explained in chapter two.

Feelings of home and belonging among diverse groups on the other hand have been the subject of many anthropological researches in the recent years. For example, the book '*Conceptualizing Home*' written by Bozkurt in 2009, which relates to the feeling of home and belonging among Turkish families in Germany. De Bree et al. (de Bree et al., 2009) conducted research on the same feeling of Dutch Moroccan return migrants and abandoned children in North-eastern Morocco. At the University of Groningen, Stock currently is conducting a PhD research on the feelings of home and belonging of the second generation of Moroccan immigrants in the Netherlands. Nonetheless, the question 'how does the process of aging influence the feelings of home and belonging' remains unanswered in academic literature. Bozkurt mentions the first generation of Turkish immigrants, though she focuses more on the second and third generation.

What I think this research can contribute is awareness about how dementia is experienced within the Moroccan community in the Netherlands. In addition, knowledge of the feelings of home and belonging of the Moroccan elderly suffering from dementia is important as they are often lost in their world and are looking for 'home'. But what does 'home' mean for them?

### **1.3 Thesis outline**

This thesis contains four essential parts; the theoretical framework, the research setting and methodology, results of the data analysis and a conclusion. The theoretical foundation gives a critical review of the relevant research literature, and defines the key terms and concepts in connection with the research question; anthropology of aging, explanatory models and home & belonging. In chapter three, the research setting and methodology is depicted, explaining the broader research background. In chapters four, five and six the research findings will be presented, following the three sub questions. Chapter four will focus on the voice of the elderly Moroccan immigrants suffering from dementia and on their feelings of home and belonging. Chapter five focuses on the voice of the family members and chapter six on the voices of health care professionals with a Dutch or Moroccan background. The results will be depicted in detail and discussed in a wider theoretical relevance. The thesis ends with a conclusion, which will be followed by the references and appendices.

## 2. Theoretical Framework

This chapter presents the theoretical framework, upon which the research of this thesis is conducted. First this research is placed within the anthropology of aging. The second paragraph provides a detailed description of explanatory models, focusing on the dimensions of disease, illness and sickness. The third paragraph focuses on home and belonging. A conclusion is presented in paragraph four.

Figure 1 depicts the composition of this chapter; anthropology of aging is the overall theoretical framework of this research. Patients, family members, health care professionals are part of society and are the different actors. Patients and their family members experience the *illness*, health care professionals focus mainly on the bio-medical *disease* and together in society, the social experience of *sickness* is created. *Illness* and *disease* may both influence *sickness*, though the influence of illness seems less than that of *disease*. Since elderly, who suffer from dementia, might experience changes in home and belonging as their thoughts will return to the past in Morocco, home and belonging is the final important aspect. It is questioned in this thesis whether *illness* has influence on feelings of home and belonging.

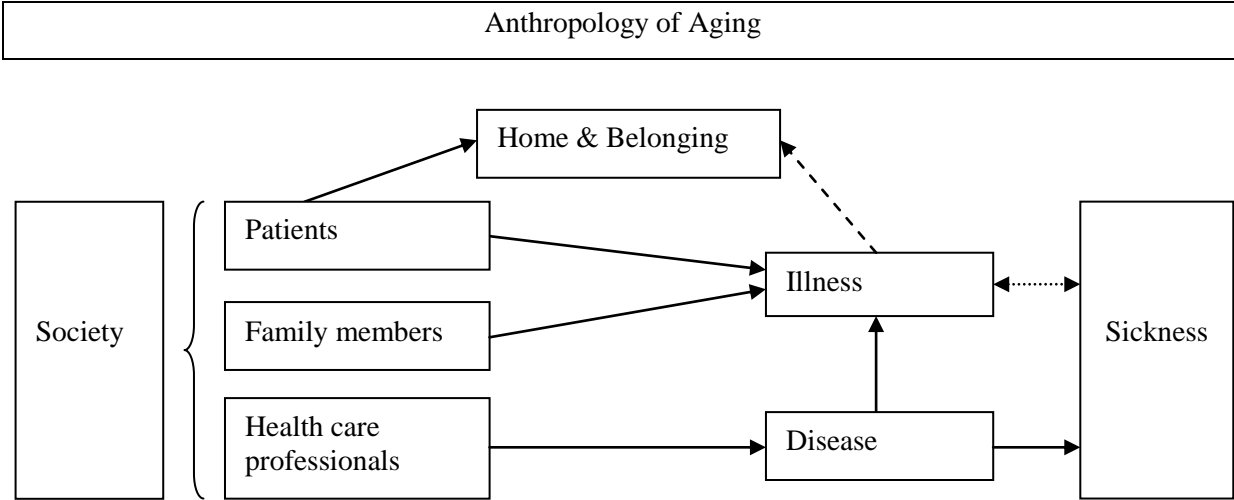


Figure 1: Overview of the theoretical framework

## **2.1 Anthropology of aging**

Anthropology is a broad profession, with several distinctive branches. One of the less common branches is anthropology of aging, also called geroanthropology. An increasing share of anthropological research is focusing on concepts of age (Infeld 2002:xvi). The anthropology of aging seeks to understand aging as a social and biological process and does not focus primarily on the end product of aging but looks to elders as active participants and creators of the meaning and experience of later life (Solimeo, 1999). This research is part of anthropology of aging, as it focuses on the effects of aging among migrants.

According to Fry, a challenge for a theory of aging is to disentangle what is universal from what is specific and locally based (Fry 2002:12). Aging is universal, but old age can be experienced differently by people from different cultural backgrounds. Dementia is universal as well, though it seems that the experiences are not universal. Holmes and Holmes state that anthropologists believe that problems of understanding relating to old age must be analyzed only in terms of the cultural context in which they occur. Furthermore they explain the relativist approach, which warns that one society's solutions to their aging problems cannot be generated to all other societies. To other societies, with different basic values and institutions, these solutions could be unsuccessful (Holmes & Holmes 2002:31-32). Migrants with a Moroccan background in the Netherlands can experience old age (and in addition dementia) in a different way than elderly with a Dutch background. In addition, differences between aging in Morocco and aging in the Netherlands ought to be specified. Elderly in the Netherlands are expected to have agency and be 'active elders', although in general this is not the way Moroccan elderly age. Can this be explained by the differences in the experience of disease and health?

## **2.2 Explanatory models**

Kleinman has his own ideas concerning interculturalisation. He argues that in the context of culture, the study of patients and healers, and illness and healing, must start with an analysis of health care systems (Kleinman 1980:25). He focuses on three interrelated subjects that represent the core of his study: illness experiences, practitioner-patient transactions and the healing process. His theories clarify that differences exist between how people experience sickness and health, due to differences in social and cultural background. The foundation for this theory is that people in general use different explanatory models to rationalize the cause of disease. Kleinman describes the health care system in the same way that political, religious or kinship systems are analyzed. He argues that in all societies, health care activities are more or less interrelated. The totality of these interrelationships is called the health care system. Patients and healers are basic components of such systems and are embedded in specific configurations of cultural meanings and social relationships. They cannot be understood apart from this context. Illness and healing are also part of the system of health care (ibid:24-26).



Kleinman distinct the concepts disease and illness; disease is the dysfunction of biological and/or psychological processes. This concept fits into the biomedical approach used in many western countries and it focuses on curing or controlling the disease. The concept of illness refers to the individual experiences of the disease and the societal reaction to the disease. 'It is the way the sick person, his family and his social network perceive, label, explain, valuate and respond to disease' (ibid:88).

Frankenberg makes a distinction between disease and illness as well. With disease he means 'a biological or pathological state of the organism whether or not it is socially or culturally recognized, and whether or not the patient and his/her advisers, lay or professional, are aware of its existence' (Frankenberg 1980:199). With illness he means 'the patient's consciousness that there is something wrong (about which in disease terms he/she may or may not be technically correct)' (ibid:199). Frankenberg argues that the model of Kleinman is biased. He presents the concept of sickness, 'the social consciousness of disease', as the missing factor. Frankenberg explains: 'By using the concept of illness, we enable the physician to see how his view differs from the patient – and how he can impose his cure. The concept of sickness enables us all including physicians to see more clearly the significance of, for example, the maleness and the whiteness together with the class position of the physician and the femaleness, blackness and subordination of the patient' (ibid:199).

Richters has written a comprehensive commentary on Kleinman's theory (Richters 1996). She states that when a doctor does not look further than the disease-model, it will be a one-way communication, the doctor explaining the disease to the patient, who just listens. The doctor has the power; the patient seems to be powerless. Instead, if the illness and sickness models are applied, the power discrepancy will decrease or even disappear. The patient will be able to tell his or her experience of the disease, rather than only listening to the explanation of the disease by the doctor. This makes the patient an active partner, instead of a passive listener.

### 2.2.1 The disease dimension of dementia

'Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment' (World Health Organization ICD-10, 1992). The most common type include Alzheimer's disease, vascular dementia, mixed dementia, dementia that may occur with Parkinson's disease or as a result of severe head injury of anoxia. 'It has been said that dementia is both the most under diagnosed and most over diagnosed condition in older people. It is under diagnosed when severe cognitive losses are erroneously considered to be a normal part of aging. Cultural factors play a large role in this under diagnosis when loss of functional abilities is considered the social norm. Dementia is over diagnosed when other potentially reversible conditions are overlooked. In an adult with cognitive losses, a correct diagnosis

is both possible and important. Reversible causes of cognitive and functional impairment should be carefully considered' (Yeo & Gallagher-Thompson 2006:106).

Every person is unique and dementia affects people differently - no two people will have symptoms that develop in exactly the same way. An individual's personality, general health and social situation are all important factors in determining the impact of dementia on him or her. The most common early symptoms of dementia, according to Alzheimer's Disease International are:

- Memory loss. Declining memory, especially short-term memory, is the most common early symptom of dementia.
- Difficulty performing familiar tasks. People with dementia often find it hard to complete everyday tasks that are so familiar we usually do not think about how to do them. A person with dementia may not know in what order to put clothes on or the steps for preparing a meal.
- Problems with language. Occasionally everyone has trouble finding the right word but a person with dementia often forgets simple words or substitutes unusual words, making speech or writing hard to understand.
- Disorientation to time and place. We sometimes forget the day of the week or where we are going but people with dementia can become lost in familiar places such as the road they live in, forget where they are or how they got there, and not know how to get back home. A person with dementia may also confuse night and day.
- Misplacing things. A person with dementia may put things in unusual places such as an iron in the fridge or a wristwatch in the sugar bowl.
- Changes in personality. A person with dementia may seem different from his or her usual self in ways that are difficult to pinpoint. A person may become suspicious, irritable, depressed, apathetic or anxious and agitated especially in situations where memory problems are causing difficulties.
- A loss of initiative. At times everyone can become tired of housework, business activities, or social obligations. However a person with dementia may become very passive, sitting in front of the television for hours, sleeping more than usual, or appear to lose interest in hobbies.

Derived from the website of Alzheimer's Disease International

There have been a number of cross-cultural epidemiological studies on dementia, for example in China (Ikels, 1998), Japan (Henderson & Traphagan, 2005) and India (Cohen, 1995). Pollitt examines dementia in a Western context, 'the evidence for its universality and for social and cultural differences in its manifestations' (Pollitt 1996:305). Although researches on the topic of dementia in non-Western areas are limited, he suggests that it is universal, though it may manifest itself differently and at different rates. An important problem that arises during research on the topic in non-Western areas is that the citizens do not recognize dementia (or its criteria) as such. Pollitt emphasises that the

interpretation of dementia may vary within different cultural contexts (ibid:316). He concludes that definitions of mental disorder and abnormality in old age are culturally variable, as are definitions of old age itself. All societies appear to distinguish between normal and abnormal old age. However the ways in which the distinctions are drawn vary greatly. 'It is clear that there is still much to be learned about the complex interaction between the experience of ageing and the onset of dementia, both in our own society and in others' (ibid:305).

'Although many gaps in our knowledge remain, it has become increasingly clear that dementia phenomenology and prevalence differs by ethnic/cultural group' (Yeo & Gallagher-Thompson 2006:87). A few characteristics of Moroccan elderly influence the prevalence or the estimation of the prevalence of dementia among Moroccan elderly. First of all, the prevalence estimations in the Netherlands are based on the Dutch population. The Moroccan population differs in the sense of age structure and the division between men and women. In general, there are more elderly Moroccan men than women. Second it is important to note that the health situation of Moroccan elderly differs from Dutch elderly. Reasons for this are their work circumstances in the past, the prevalence of diabetes and heart failure and their low socio-economic status. According to Goudsmit, all these factors can influence the prevalence of dementia (Goudsmit 2007:14-15).

### 2.2.2 The illness dimension of dementia

Illness refers to the individual experiences of a disease. 'An anthropological approach to illness is one that tries to get to the very essence of our concepts of self, other, illness and wellbeing by examining their manifestations in cultures all over the world' (Hashmi 2009:207). Important questions concerning this concept are: How does a patient define the complaints, what are his/her experiences and how does he/she explain the complaints. The advantage of seeing dementia not only as a biomedical disease, is described by Henderson as following: 'The benefit is the ability to consider it *not* as a disease or series of symptoms, but also as a category of differentiation, discrimination, and ascription of cultural values that shapes the experience and interpretation of functional decline in old age' (Henderson & Traphagan 2005:272).

Ikels illustrates how elderly people in the Chinese region Guangzhou experience the symptoms associated in the West with dementia, such as memory loss, confusion, inappropriate behaviour, personality changes and physical decline. In the first stages of the disease, Chinese elderly would not experience these symptoms as distressing or disabling. In comparison, American elderly would probably panic, fearing what might come next. According to Ikels, three important reasons for this could be relevant: beliefs about dementia, values, and situational variables specific to contemporary China. With this article, the author shows that the disease dementia is experienced differently in China than in the West, which is a difference in illness experience. I can relate this conclusion of Ikels to the situation of Moroccan elderly, since their recognition of dementia is limited as well. However, the Moroccan elderly are located in a Western country, with Western values and

beliefs. So although the illness experiences are alike to the Chinese elderly, the situations in which they occur differ. This subject will be further discussed in chapters four and five.

### 2.2.3 The sickness dimension of dementia

Sickness refers to the social experience of a disease, the explanation of the community. According to Frankenberg, ‘sickness through language, literature and “tale” precedes and survives individual disease, illness, personal consultation and legitimation’ (Frankenberg 1980:200). It involves not merely a cultural statement about what it means to be ill, but a social statement about sickness in process’ (Frankenberg 1980:205).

Beliefs about dementia may differ among ethnic groups. ‘Differences include beliefs that dementia is a normal form of aging or that dementia is a form of mental illness or a culture specific syndrome known as ‘worriation’ and spells. There may be beliefs that dementia is unavoidable, a result of fate, an imbalance in the body, and/or a retribution for sins of family or ancestors. Stigma and shame are often associated with dementia and demented family members may be hidden from the community. Accompanying this belief is the attitude that caring for a demented relative is a family responsibility’ (Flaskerud 2009:522).

An illustrative example about the experience of dementia in the society of Japan is depicted by Henderson and Traphagan, as they describe the Japanese version of senility, the moral concept *boke*, which may include symptoms of forgetfulness, disorientation, loss of interest or incontinence. Elderly Japanese citizens keep active as long as possible, in order to avoid becoming *boke*, because ‘if an individual becomes *boke*, the potential for burdening others, primarily family members, but also the society through use of government services, is increased’ (Henderson & Traphagan 2005:272). Rather than Alzheimer’s disease, it is the primary concept through which Japanese people think about cognitive decline in old age. As a result, they think about the moral consequences of becoming *boke*, instead of the biomedical symptoms. In Japan, people do not speak about the disease dementia, but about the sickness *boke*.

## **2.3 Home and belonging**

I expect that home and belonging is an important subject for the elderly Moroccan immigrants suffering from dementia, since, due to their declining memory, their home in the Netherlands could not feel as home anymore. I am interested to discover whether the illness dementia has influence on the feelings of home and belonging. Since no other authors focus on the combination dementia and feelings of home and belonging, this research aims at exploring the subject.

‘The concept of belonging refers to emotional attachment, about feeling at home and feeling safe’ (de Bree et al. 2009:12). Belonging is not directly linked to one place; people can feel they belong to more places. De Bree et al. describe this phenomenon of ‘dual belonging’ of Dutch Moroccan return migrant and abandoned children in Morocco. They conclude that Dutch Moroccan

children in Morocco do not exclusively construct feelings of home in the physical place they inhabit. The children also express feelings of belonging towards the Netherlands (ibid:12). ‘Home is a well known and broadly used signifier of belonging that is studied and discussed widely in social sciences, humanities and literature’ (Bozkurt 2009:19). Home is an ambiguous concept (Lam & Yeoh 2004:142), because each individual may conceive of home differently, it may not only change in meaning and relevance over a person’s lifetime, but also in meaning for different cultures and societies (Magat 2008:120-121). Bozkurt describes it as a multi-dimensional and dynamic concept that refers to emotional, spiritual, social, cultural, territorial and political *self-location* over time and space (Bozkurt 2009:25). As I am specifically interested in where the elderly Moroccan immigrants suffering from dementia locate themselves, this concept of self-location is very useful for my research. Bozkurt also emphasises that home is not purely territorially bounded, for me this is important as well. I am particularly interested in what elderly Moroccan immigrants depict as the most important aspect of this self-location. Do they have the ability to return to the current situation and locate themselves in the Netherlands; Are they caught in the context of their past in Morocco due to the effects of dementia? Do they even locate themselves territorially or is it more culturally, emotionally or socially bounded? Important in this context is the influence of family members and professionals as well. Do others have influence on the self-location of the research population and in what way?

### 2.3.1 Home-making and return migration

Different authors write about the process of home-making, which happens as the migrants construct and mystify the past (Bozkurt 2009, Hannerz 2002, Stock 2009). Bozkurt emphasises that ‘the experience of dislocation and the sense of absence strengthen the efforts to reconstruct the lost home by unmaking change, difference, alienation and loss, and by mystifying the past’ (Bozkurt 2009: 37-38). She explains that among Turkish migrants in Germany, ‘processes of collective imagination and home-making are reported to take place in the meetings of the ethnic community in new localities, during which a home-like atmosphere was created with familiar smells, tastes and sounds, supported by visual materials as well as cultural practices, exercise of rituals and traditions, and through oral communications’ (ibid:39). These are reported to contribute to migrant’s efforts to recover a sense of community and belonging abroad. I can imagine that elderly immigrants suffering from dementia will even stronger mystify the past, therefore this concept might be of particular importance.

Bozkurt furthermore describes that the first generation Turkish immigrants in Germany picture Turkey as an ‘airy and luminous place’ (ibid:97-116). Regardless of the growing estrangement, they see Turkey as an ideal location and influence their children’s and grandchildren’s perception of home and the homeland. What Bozkurt does not describe is whether the Turkish immigrants think of return migration. If they picture Turkey as an ideal location, why would they stay in Germany? Bozkurt’s interviewees highlighted the importance of the presence of family and the ethnic community. ‘Some emphasise that the existence of co-ethnics in Germany provides a sense of security and enables the

maintenance and celebration of ethnic and cultural references' (ibid:114). She explains that 'despite the mystification of the homeland and a recurrent emphasis on the wish for return, some practical reasons such as high quality of social and health services, retirement benefits, and family members residing in Germany keep them from an absolute return and lead to a solution in form of commuting between two countries' (ibid:115). However, Bozkurt interviewed relatively healthy first generation Turkish immigrants. She has no data on the influence of illnesses such as dementia.

Return migration is the process of people returning to their country or place of origin after a significant period of time in another country or region (King 2000:8). De Bree describes that in this definition return can be associated with the idea of temporary settlement in the host country followed by permanent (re) settlement in the country of origin. This implicates that return migrants are eventually going 'home' to their country of origin. But are they really coming home? De Bree argues that return migration is not an easy process. She mentions in her thesis: 'Although all of them returned voluntarily and remained in contact with Morocco during their years abroad, they felt some kind of alienation upon return' (De Bree 2007:28). All of her respondents after return, perceived the Netherlands in a much more positive way than Morocco, which obviously makes feelings of home problematic.

## **2.4 Discussion and conclusion**

Since the biomedical explanation of the disease dementia is already clear, this research focuses on the illness and sickness among elderly Moroccan immigrants in the Netherlands. Especially illness, defined as the experience of a disease by the patient and his or her family, is of specific significance. Since the three concepts are interrelated, all influence another, though not at the same level. Illness for example is likely to be influenced by disease, though disease is only limited influenced by illness. An important question that arises out of this is: *Would more knowledge of the disease influence the illness?* According to the Alzheimer's Association it would: 'Since knowledge is an important factor influencing behaviour, a lack of knowledge can be experienced as a barrier to appropriate help seeking. In the context of dementia, both early recognition and successful interventions can be facilitated by appropriate knowledge of the disease and the utilization of relevant services' (Alzheimer's Association 2009:235, Jang, Kim & Chiriboga 2010:420). Increased knowledge of the disease could result in early recognition and successful interventions, which could in turn influence the illness experience.

Another interesting question concerns the combination of the concept of disease and feelings of home and belonging is: *Can feelings of home and belonging be influenced by a disease?* I think it can, because the experience of a disease can make people think differently about other aspects, for example home and belonging. This research tends to show the influence of dementia on feelings of home and belonging of elderly Moroccan immigrants in the Netherlands.

The theoretical foundation of this thesis was three-folded, with the anthropology of aging, explanatory models and home and belonging. Anthropology of aging is used to set the scene for this research. The focus of the second paragraph is on explanatory models introduced by Kleinman (1980) and discussed by Frankenberg (1980) and Richters (1996). It explains the differences between the concepts of disease, illness and sickness. Furthermore it is expected that home and belonging is an important subject for the elderly Moroccan immigrants suffering from dementia, since their home in the Netherlands could not feel as home anymore. As shown before, the aim of this research is actually two-sided. On the one hand I tend to explore the experiences of dementia among Moroccan immigrants and on the other hand I strive to discover whether dementia influences the feelings of home and belonging. The following chapter focuses on the research setting and methodology.

### **3. Research setting and methodology**

This chapter focuses on the research setting and methodology. Problems and challenges will be described, as well as the background of the respondents and a personal reflection on the research. The first paragraph focuses on the research setting, highlighting the background information, access to the research population and an overview of the respondents. The second paragraph focuses on the research methods: participant observation, qualitative in-depth interviews and conversations with key-informants. This chapter finishes with a short conclusion.

#### **3.1 Research setting**

The research is conducted in and around Amsterdam (the Netherlands) from January 2010 to April 2010. The research population consists of elderly Moroccan immigrants in the Netherlands, who suffer from dementia. The main reason for this was an almost complete absence of this population in the academic medical literature, since an extensive literature study showed that other researches focusing on dementia in ethnic minorities, focused on the family members instead of the elderly. As a result, the perception of the elderly themselves stays under exposed.

##### 3.1.1 Background information

In the Netherlands, immigrants account for twenty percent of the total population (CBS Statline 2010). Turkey (11.4 percent), Morocco (10.4 percent), Suriname (10.2 percent) and the Dutch Antilleans (4.1 percent) are the main countries of origin of immigrants (ibid.). In the upcoming decennia the number of members of ethnic minorities will increase from 3.36 million in 2010 to approximately 4.8 million (29 percent of the total population) in 2050 (CBS 2010). The most important causes of this growth are the relative young age structure of the first generation, the expected high migration balance and the relative high number of children. The amount of elderly Moroccan immigrants will also increase in the future. In April 2010, an expected 13.3 percent of the Moroccan immigrants are aged fifty or older (ibid.). The majority lives in one of the four large cities (Amsterdam, Rotterdam, The Hague and Utrecht).

In the 1960's and 1970's thousands of labour migrants from among other countries, Morocco arrived in the Netherlands to help rebuilding the country after the Second World War. The Dutch and the Moroccans expected that, in time, the guest workers would return to their home country. This certainly had consequences for their integration, for example the poor knowledge of the Dutch language. In the upcoming paragraphs a couple characteristics of Moroccan elderly will be discussed, which have influence on the problems they experience in their daily lives. Characteristics differ per country and area of birth, per cultural background and per family. It is impossible to give general characteristics that are important for all Moroccan elderly. The characteristics that will be highlighted in this paragraph thus cannot be generalized to all Moroccan elderly.



According to Schellingerhout, the socio-economic position of many of the Moroccan elderly is low. Older Moroccans generally have a low income (86 percent of Moroccan elderly have a low income, compared with 11 percent of the Dutch elderly) (Schellingerhout 2004:222). Through diverse circumstances (low education, type of occupation, economical changes, language problems) many of the Moroccan immigrants became unemployed or unable to work. The consequence is that relatively many elderly immigrants, amongst them many single women have to manage with a low income. In relation to their low socio-economic position the housing situation needs to be mentioned. Schellingerhout describes that Moroccan older persons relatively often live in homes with stairs, especially external stairs. He furthermore states that the fact that so many older Moroccans live in a home that is potentially unsuitable is striking, as they relatively frequently have mobility problems (ibid: 226).

During the conducted screenings with Moroccan elderly it became clear that they tend to be more oriented to the family and less oriented to the individual. The family structure tends to be patriarchal (Al-Krenawi & Graham 2000:11), as the man is seen as the head of the family and considered a powerful and charismatic figure. In most households it is the woman who has the influence within the household and the man has the influence in the outer world. Moroccan elderly women devote a lot of time and energy to managing the household. Above that, they honour the traditional cooking and derive pride out of it. The division of labour between men and women is in most households still traditional. Within the Moroccan community the elderly have a respected position, certainly in the maintenance of cultural and religious elements, for example by raising children and grandchildren. Moroccan elderly often live in a household with children. Part of this is caused by the fact that there is often an age difference between the husband and wife. Thirty percent of the Moroccan men are eleven or more years older than their wife (Schellingerhout 2004:224).

### 3.1.2 Access

In order to get access to the research population, I mainly made use of the medical records of the Slotervaart hospital. As an occupational therapist working in this hospital, I am involved in the diagnostics phase of determining dementia with elderly members of the society. During my work at the gerontology diagnostic centre, I meet elderly with diverse cultural backgrounds, since all of them receive an occupational therapy screening. After each screening of a Moroccan elderly, I asked them to cooperate in my research. After their agreement, an appointment was made to visit them at their home. This way, six respondents were included. The other two respondents were visiting day-care centre Darkom, one of the observation sites. In June 2009 I was invited to the opening of Darkom and this way I got to know the group leader. At this day-care centre, approximately eight elderly Moroccan women and three Moroccan men received day care, of whom two suffer from dementia. During my research I visited Darkom seven times, in order to do participant observation. Besides the observations

I asked the two women with dementia to participate in this research. They agreed and appointments were made with their daughters.

As I tended to recruit patients from my work at the Slotervaart hospital, I needed the approval of the Medical Ethical Commission of the Slotervaart hospital and the Jan van Breemen Institute. This is their way of safeguarding the patient's interests and privacy. In order to get the approval of this commission, I have written a research protocol, a patient information letter, an informed consent form and a questionnaire. The patient information letter and the informed consent forms can be found in appendix 1. On the 17<sup>th</sup> of December 2009 my research was officially approved by the commission; see the letter of approval in appendix 1.

Unfortunately I was not able to include respondents who did not know me via the Slotervaart hospital or Darkom, since those who were introduced to me by a key informant all refused to participate. It became clear that a certain kind of trust relationship is important to participate in research. It is difficult to find the Moroccan elderly, but it is even more challenging convincing them to participate. Despite all my efforts to find respondents elsewhere than at the hospital or Darkom, no additional respondents were found. I realise that my data might be biased due to this access problem. Most of the respondents knew me as an occupational therapist, or associated me to the hospital. This positioning might have influenced their answers and openness. My position as a health care professional might not only have negative effects, but also positive ones, as all respondents were willing to talk to me about the subject of dementia. It is possible that within another context, the respondents would not have been that willing.

Another bias in my research may be the fact that I only interviewed the family of one man who decided to return to Morocco. It would have been interesting to know more about their reasons for return and their experiences. In this thesis I only tell the story of Mr. Rabbae, who returned to Morocco after the diagnosis dementia, was set. I do think it is important and it might be a very interesting subject for further research, as the group of Dutch Moroccans returning to Morocco is increasing. Although, as De Bree states in her thesis, it is not the elderly who form the largest group to return, since 61 and 81 percent of all Moroccan male and female migrants, who emigrated between 1995 and 2004 from the Netherlands to Morocco, was younger than 50 years (De Bree 2007:18).

### **3.2 Research methods**

During the research, different research methods were used to answer the main research question. This can increase the reliability and validity of the results, since the data coming from different methods can be compared to each other. I made use of participant observation, qualitative in-depth interviews and conversations with key-informants. These methods showed themselves appropriate for getting the most, and best, information. I will now further clarify the methods used.

### 3.2.1 Participant observation

During the research, observations took place at the Slotervaarthospital, Moroccan day-care centre Darkom and at community centre the Karrewiel. In the following paragraph I will provide a short description of each setting.

At the geriatric day-clinic of the Slotervaart hospital, patients who are referred to the day-clinic by their General Practitioner, undergo a detailed screening of their health problems, both physical as cognitive. This screening involves a conversation with a gerontologist, cognitive tests, occupational therapy screening and multiple medical examinations like a CT scan and X-rays. In the research period, nine Moroccan elderly visited the day-clinic. During approximately seventy-five minutes I talked to them and their family via a professional interpreter and observed them during an acquainted activity (like making Moroccan tea, cooking a small meal or playing a typical Moroccan game). Eventually six elderly agreed to participate in my research, two patients refused and one patient did not have dementia. I observed the respondents both at the hospital and at their own houses.

Day-care centre Darkom is located within nursing home Riekerhof in Amsterdam Slotervaart and opens its doors Monday till Thursday from 10 am till 4 pm. It offers day-care facilities for elderly Moroccan men on Monday's and Wednesday's and for Moroccan women on Tuesday's and Thursday's. In order to take part in the activities, an indication of the CIZ (Central Indication services Care) is needed. For every elderly with a correct indication, Darkom receives an amount of money for food, articles and activities. The groups are led by a young Moroccan woman with an education in elderly care. Since many visitors are not able to speak Dutch, the common language in Darkom is Arab. Not only the language, but also the decoration of the room and the home-made 'halal' meals differ from Dutch day-care. The activities on the other hand, do not differ so much, as the elderly play games, participate in sports activities and the ladies conduct needlework. I have conducted participant observation at Darkom seven Tuesdays in a row, focussing mainly on the two women with dementia in the group.

Community centre the Karrewiel in Amsterdam East is an easily accessible building with room for all inhabitants of this city district. Within this community centre, diverse organizations and associations have their own place and function, among others COMAZ (the Moroccan elderly board). COMAZ is opened every day besides Saturday from 9 am to 7 pm. The elderly who visit COMAZ are all older than fifty-five and are either retired or in the unemployment law. COMAZ offers activities during the day for both men and women. During the day of my presence, the men are in the 'living room' and the women are in the kitchen where they attend a class in Arab this afternoon. The men are playing games which according to the chairman 'stimulate the brain', such as shuffle board, chess and domino. In addition, COMAZ offers informational gatherings to both males and female groups on a monthly basis.

### 3.2.2 Interviews

During in-depth interviews with the respondents, I planned to use different interview techniques in order to hear their narratives, opinions and ideas. My assumption was that the Moroccan elderly would have important objects in their houses which they would want to show to me, behind those important objects I expected to be rich narratives. With this enabling technique I hoped to collect information on what objects Moroccan elderly link to 'home' and what narratives belong to these objects. However, my respondents all told me that they were not materialistic and could not tell me stories about objects in their houses. The second technique I selected was photo-elicitation, as I hoped to hear the narratives behind the photos and the stories about their meaning of home. The respondents showed me photographs of different family members, weddings and parties and with these they showed me the importance of their family. However, not all interviewees had photographs in their houses or were willing to show them to me.

The methodological problems I experienced during my research can mostly be related to the research population. At first it is important to note that this population is extremely hard to reach and convince to participate in any research. Secondly it is difficult to interview respondents who have received little education and suffer from dementia. This meant that some respondents had a hard time understanding and answering my questions. Although I was familiar with the research population, my hopes and expectations were too high at the beginning of my research. Fortunately I was able to adapt them and still got useful information out of the interviews.

During the interviews, an ethnographic style was used. The interviews were open and structured on the basis of topics, see appendix 3. During them a family member was present to interpret questions and answers. Beforehand the respondents were asked if they preferred a professional interpreter or a family member. All elderly preferred a family member and thus no professional interpreters were hired. This choice may have improved the cooperation with the researcher and the trust relationship. Before the start of each interview, I explained the aim of the interview to the interpreter. The interpreter gave in turn a short resume to the respondent to check whether he/she understood the aim of the research. After the interview the respondent and the researcher signed the informed consent form, which is obligatory in medical research (see appendix 1).

Out of the interviews with eight respondents, four were male and four were female Moroccan elderly suffering from dementia. Table 1 depicts an overview of the respondents, describing their age, type of dementia, family situation, the city district in which they live and the family members whom I interviewed. A more detailed description of the respondents can be found in appendix 2. For privacy reasons, all respondents in this thesis are not mentioned by their real name. Since at least three respondents mentioned that they were in fact older than stated on their passport, it is important to note that the age of the respondents is not always trustworthy. This phenomenon is caused by the fact that in the past, birth was not registered in Morocco and often it was not clear how old someone exactly was.

	Age	Type of dementia	Family situation	City (district)	Interview with
Mr. El Yousfi	67	Alzheimer	Married 5 children	Amsterdam Old-South	Patient, wife, daughter
Mr. Ait Haddou	73	Vascular	Married 5 children	Amsterdam Osdorp	Patient, wife, son, daughter
Mr. El Amrani	62	Parkinson	Married 3 children	Amsterdam Slotervaart	Patient, wife, two daughters
Mrs. El Morabet	59	Vascular	Married 8 children	Amsterdam East	Patient, two daughters
Mrs. Ben Saleh	68	Alzheimer	Divorced 5 children	Amsterdam Osdorp	Patient, son, daughter
Mrs. El Yacoubi	65	Alzheimer	Married 8 children	Amstelveen	Patient, husband, three daughters
Mrs. El Tahiri	52	Alzheimer	Married 5 children	Leiden	Patient, daughter
Mr. Rabbae	†	Alzheimer	Married 3 children	Amsterdam	Widow, daughter

*Table 1: Overview of respondents*

Since Mr. Rabbae passed away in December 2009, I was not able to talk to him in person. However, I think that this case is of special value to this research, since Mr. Rabbae returned to Morocco after the diagnosis dementia was set in 2006. Since he lived more and more in the past due to his declining memory, the doctors had advised his family to return to Morocco. They expected that Mr. Rabbae would feel more at home in his birth region. Since none of my other respondents return migrated to Morocco, I think the experiences of his widow and daughter will enrich this research. Therefore I decided to include this family's story.

### 3.2.3 Conversations with key-informants

During my research I spoke with seventeen key-informants, in order to get an overall picture of dementia among Moroccan immigrants and to locate more respondents. All informants have experience with and/or knowledge of Moroccan elderly with dementia. Some were already part of my network, others were contacted by me after I read a publication and some were part of the networks of other informants and were introduced to me via snowball effect. Eight respondents have a Dutch background, nine a Moroccan. When quotations or opinions of a key-informant are mentioned in the text, this is made clear by a code. Informants have been given a letter code ranging from A to Q, with an additional letter d or m. These additional letters stand for the background of the informant, Dutch or Moroccan. Table one shows a short overview of the key-informants, more specific information can be found in appendix 4.

<b>Code</b>	<b>Function</b>
Ad	Gerontologist, Slotervaart hospital
Bd	Neuropsychologist, Slotervaart hospital
Cd	Staff member, Vilans
Dd	PhD student, RU Groningen
Em	Group leader, day-care centre Darkom
Fm	Chairman, home-care association Avicen Nurse practitioner diabetes care, Slotervaart hospital
Gm	Occupational Therapist, Cordaan
Hd	Gerontologist, Alzheimer Nederland
Ym	Chairman, board for Moroccan elderly COMAZ
Jd	Coordinator day-care centre, Flevohuis
Km	Chairman, home-care association Leven&Zorg
Ld	Visiting nurse migrant care, home-care association Thebe
Mm	Senior staff member, <i>Samenwerkingsverband Marokkaanse Nederlanders</i> (Association of Moroccan Dutchmen, SMN)
Nm	Chairman, foundation <i>Onze Hoop</i> (Our Hope)
Om	Project coordinator, commune for elderly above 50 Andalus
Pm	Senior project coordinator, Sefkat
Qd	Social Cultural Worker, Dynamo Chairman Alzheimer café Amsterdam East

Table 2: Overview of key-informants

### 3.3 Conclusion

In this chapter I have discussed the research setting and methodology. I have clarified the specific characteristics of the research population, as well as the situation they are in. I have shown how my position as an occupational therapist in the Slotervaart hospital gave me access to the Moroccan elderly suffering from dementia; in addition both the advantages and the disadvantages of this position were depicted. In the second paragraph I clarified the three research methods I used; interviews, conversations with key-informants and participant observation. With the combination of these three methods, the reliability and validity of the data was tested and ensured.

In the following three empirical chapters I will show how respectively the elderly themselves, the family members and the key-informants experience dementia. The *illness* dementia will thus be highlighted with examples from the patients and their family members. In chapter six, health care professionals will depict their view on the illness experience of Moroccan elderly in the Netherlands.

## **4. The voice of the elderly Moroccan immigrants suffering from dementia**

This chapter contains an analysis of the data on the experiences of the Moroccan elderly with dementia. It will answer the first sub-question of this thesis, namely: How is dementia experienced by elderly Moroccan immigrants in the Netherlands suffering from dementia, and how does it relate to their feelings of home and belonging? First the experienced symptoms, mentioned by the respondents, will be highlighted. The second paragraph focuses on the mental state of the elderly, which might be influenced by the disease. The third paragraph will provide information on the self-location of the Moroccan elderly suffering from dementia, focussing in particular on the importance of family members and return migration. The chapter ends with a short conclusion.

### **4.1 Experienced symptoms**

This paragraph will depict the symptoms of dementia the respondents mentioned in the interviews. Mr. Ait Haddou and Mrs. El Yacoubi told that they experienced no problems whatsoever. Mr. El Yousfi stated the following:

‘I do not have any complaints, everything goes alright. Sometimes, due to stress, I forget some things, but this is normal for my age and the rough life I have had. Usually when I go outside for a while, the forgetfulness disappears’.

Mr. El Amrani explained that he experiences increased forgetfulness and that his general practitioner mentioned that it is likely to be a part of the Parkinson’s disease. Mrs. Ben Saleh explains her complaints quite clearly.

‘I am forgetful. Once I made dinner, but forgot to shut down the gas. As a result, I almost caused a fire in the kitchen. And I forget where my house is; I am luckily to have such nice neighbours who bring me home when I am lost’.

Some respondents could name their physical complaints, but did not recognize the symptoms of dementia. Mrs. El Morabet for example complained of a constant warm feeling in her head, which was the fate of Allah according to her. Mrs. El Yacoubi has experienced continuous pain in the past fifteen years, the pain is worst in her head, back and knees. Since the pain is present the whole day, she is fairly limited in her daily life.

#### 4.1.1 Coping strategies

These examples show that the elderly had many difficulties in explaining their complaints. It might be the case that indeed they did not experience the symptoms themselves. Although it is more likely that they rather not talk about the symptoms, something might hold them back. Possible reasons for this could be acceptance of the symptoms as belonging to old age, shame towards the family, shame towards the professional or not admitting the cognitive decline. This phenomenon is also described in the review article by de Boer et al.: ‘Dementia obviously has a great impact on the lives of those affected. People have different ways of coping with the changes that are experienced’ (de Boer et al. 2007:1030).

De Boer et al. describe five coping strategies. The first is denial or avoidance, as some people are not able to accept the diagnosis and sometimes deny the symptoms. The second strategy is minimization and normalization, in which patients for example give priority to other problems, like physical complaints, or ascribe the dementia as normal for old age. Although, the authors describe, most patients try to continue their lives as best as possible. The fourth coping strategy is called compensating for the losses they experience. Patients for example make use of memory aids or do mind exercises. The last strategy described by the authors is coming to terms with dementia. ‘In order to come to terms with dementia people use a variety of coping mechanisms described above. Some express the importance of being informed of what is going on in order to be able to acknowledge and/or accept the diagnosis’ (de Boer et al. 2007:1032). The authors use different other articles to support this conclusion.

The coping strategies of my respondents can be linked to denial or avoidance (Mr. Ait Haddou and Mrs. El Yacoubi), minimization or normalization (Mr. El Yousfi, Mrs. El Morabet and Mrs. El Yacoubi) and continue living (Mr. El Amrani and Mrs. Ben Saleh). Remarkable is that none of the respondents uses compensating strategies, though this can be caused by their relative low education level and the illiteracy. Although, the most striking finding is that most respondents make use of the first two strategies. De Boer et al. describe that these strategies are often used to protect oneself from the outside world. It is likely that this is also the case in my research. As dementia is not well-known in the Moroccan community in the Netherlands, and the elderly might feel restrained to open up over the symptoms of dementia.

#### **4.2 Mental state**

As presented in the first paragraph, the symptoms of dementia are often not experienced, not expressed or ignored by the elderly Moroccan immigrants. However, it does seem to influence their general mental state, as many respondents seemed sad, discouraged and passive. For example Mrs. El Morabet, who feels lonely and isolated and would rather stay in bed the whole day. During the interview Mrs. El Morabet seems not interested in my questions. Occasionally she gives an answer, but most of the time her daughter does. The daughter thinks that her mother does see the cognitive



problems she has, and therefore becomes sad. Mother was always a busy woman, who took very good care of the household. Nowadays, she neglects the household and does not seem to enjoy anything anymore. Her daughter explains that this melancholy is the largest problem, the forgetfulness they can handle, but this change in character is heartbreaking.

This melancholy is also present in Mr. Ait Haddous' case. His daughter explains that he does not have interest in anything, he cannot enjoy anything anymore. The following quote illustrates Mr. Ait Haddous' feelings properly.

- Researcher: 'How are you doing?'
- Ait Haddou: 'No not good, but yes.'
- Researcher: 'No? How come?'
- Ait Haddou: 'No, not good.' [Continues in Arabic]
- Daughter: 'He does not feel well. He does not have any other answer. He is just not comfortable in his skin. He often states that he is ready for it, he is just waiting for his death.'
- Ait Haddou: 'No not good, not good. Just try, try, try, try. Think, think, think, but no, not good'.

Mr. Ait Haddou, a man who used to be full of energy and enthusiasm, who helped founding a mosque in Amsterdam Osdorp, who cared for his family and who knew so many people, now seems to have lost his spirit. One might notice that the burden of the forgetfulness leans hard on him. As he repeats the words 'try' and 'think', he seems to fight the forgetfulness without result. This feeling and the helplessness probably makes him feel sad and overwhelmed.

The daughter of Mrs. Ben Saleh notices changes in the mental state of her mother. Especially tiredness and unexpected events have a negative influence on her state of mind, as the daughter explained in the interview.

'She says: I was tired and she refers to her work again. She has, today she has, because yesterday was a tiring day for her, with the day-care. And the rhythm, the rest. When she is tired, you notice that immediately, as she will refer everything to the negative. The fatigue translates itself to negative thinking. When she has had a rough day, or witnessed something unpleasant, her mental state is also negative. At those times, you can say whatever you want, but she will keep the feeling she has got. It will not change'.

The daughter of Mrs. Ben Saleh furthermore described that her mother has difficulties accepting her old age. It is frustrating for her not being able to do things, not being able to do the things she used to do. The daughter tries to convince her mother that she still can do a lot, more than some other people. Mrs. Ben Saleh responds to her daughter with 'Yes, thank Allah that I can do something'.

### **4.3 Self-location**

Bozkurt describes home as a multi-dimensional and dynamic concept that refers to emotional, spiritual, social, cultural, territorial and political *self-location* over time and space (Bozkurt 2009:25). This self-location over time and space refers to where one places him or herself, where he or she feels at home. Seven respondents; Mr. El Yousfi, Mr. Ait Haddou, Mr. El Amrani, Mrs. El Morabet, Mrs. Ben Saleh, Mrs. El Yacoubi and Mrs. El Tahiri located themselves in the Netherlands. Although it appeared to be rather difficult to talk to the respondents about self-location nowadays, they expressed the presence of family members as the most important aspect of home.

#### 4.3.1 Narratives about the past

Mr. El Amrani came to the Netherlands in 1969 and worked for many years in Utrecht. During the interview he told a few stories about that time, when he had just arrived in the Netherlands. According to him, the Netherlands was like paradise then. Everyone was nice and it was safe. In those times you could just park your bike outside and it would not get stolen.

‘In former times, when we came here in the Netherlands, the Netherlands was like paradise’.

Many of my respondents had similar stories about their first years in the Netherlands. Mrs. Ben Saleh told me repeatedly of the time she worked in the ‘drop’ factory. She had a great time there, made many friends and learned the Dutch language. Although it was not always positive, Mrs. Ben Saleh also remembers negative experiences; walking home through the snow and ice and raising her five children all alone after the divorce of her second husband. Mr. El Yousfi told positive stories about his work at the flower auction in Aalsmeer and his very nice boss named Harrie. He had also worked in France and Germany, but the Dutch labour market suited him best.

These stories about many, many years ago are told by the respondents themselves. However, how well they respond on these questions, how difficult it is for them to answer questions about the recent past and the future.

#### 4.3.2 Importance of family members

The presence of close family members was emphasised by all respondents as very important. Mrs. Ben Saleh expressed this beautifully during the interview.

‘When my daughter is with me, I feel at home anywhere’.

For Mrs. Ben Saleh, her daughter with whom she has lived for four years is the most important thing in her life. She explains that if her daughter would move to Morocco or any other country, she would

go too. She would never be able to live on her own or with any of her other four children. Mr. El Amrani also emphasises that his family is at the base of his decision. He states:

I could not return to Morocco alone. If my family comes with me, than I would consider.

Though Mrs. Ben Saleh and Mr. El Amrani are reasonable and add to their answer that their children would never return, so they will not too. Mrs. El Yacoubi on the other hand is very clear that she will not return to Morocco.

‘No, my children are here, I stay. Holiday and then return home. My husband is here, children, friends. Only for holiday’.

As shown, family members are an important factor in elderly Moroccans self-location of home. This importance of family members can be caused either by the close family relationships or by a type of dependence of the elderly. This research does not make a distinction between these two possibilities, although this could be interesting in future research. The importance of family relationships is also stressed by de Boer et al.

#### 4.3.3 Thinking about Morocco

On open questions regarding home, I usually received a vague answer or just a gaze. To support her parents, the daughter of Mr. El Amrani explains the following:

If you would ask my parents to stay in Morocco for five or six months, they would say no. They could never stay in Morocco for such a period of time. [...] It is strange. They don't feel at home there, even though their sisters are there, their brothers are there. The mother of my mother is still alive and she lives there. But they don't feel treated there as family, because they have been in the Netherlands for so many years, say, broken up. It is really a holiday country for them.

Mrs. Ben Saleh states that she always dreams about Morocco, though she would never return definitely. Her daughter translates:

‘She says that she does think about Morocco when she goes to sleep, she dreams about it, but that she will not return definitely. She does not know anyone. “No I could never return to Morocco”. Since her children are here, she would not be able to live there’.

Not only Mrs. Ben Saleh, but also other respondents emphasised that they still think about Morocco a lot. Mrs. El Yacoubi described her thought about Morocco and in particular about her family, her

mother and a brother and a sister who are still in Morocco. She always had a hard time being away from them, though she would never return definitely.

‘Off course, I think of Morocco a lot. I think of my family, always see them too short. Yes is difficult here. Sometimes telephone, once a month with my family’.

Her daughter explains that mother calls her relatives in Morocco once a month to talk about everything that is happening. Although her mother has experienced difficult periods, mainly when a close family member passed away in Morocco and she could not be there with the funeral, she describes that mother could not return.

‘I do not think that mother could live in Morocco anymore. She is used to her freedom here. She is used to going to the mall and walk around. In Morocco she would not have such freedom’.

Mother agrees with her daughter and adds that she would be too lonely without her children and her grandchildren. She states that her children are here, so she will stay here too. She only returns to Morocco once a year for a six-week holiday.

#### 4.3.4 Return migration

Many Moroccan immigrants think of return migration. However, my respondents were all very clear about this, they would not return definitely. This finding is a contradiction to the findings of Bozkurt, as all of her first generation Turkish migrants emphasised that once they would definitely return to Turkey (Bozkurt 2009:114-116). All my respondents enjoyed staying in Morocco for a few weeks during the vacation, but six weeks or so was enough. The daughter of Mr. El Amrani depicted the following reasons for her parents to stay in the Netherlands.

I know my parents, we talk about it sometimes. You know, in the Netherlands arrangements are far better than in Morocco, for example the health insurance and taxes. In Morocco you can for example receive a payment letter which is based on nothing. And you better pay. And what they think too, if you need something new here, like a passport, you just go to the local authority. In Morocco that is terrible. You know, all those things make it that they prefer to stay here.

During this research, I came across one Moroccan family who did choose for return migration; Family Rabbæ. Since Mr. Rabbæ, who was diagnosed with Alzheimer’s dementia in 2003, passed away in December 2010, I heard this story from his wife and daughter.

Mr. Rabbae came as a guest worker to Germany in 1967 and a few years later he decided to move to Amsterdam, the Netherlands. His wife, who he married in 1950, stayed in Morocco and took care of their seven young children. In 1985, the whole family migrated to the Netherlands, to join their husband and father. In 1995, Mr. Rabbae retired and decided to spend more time in Morocco. Since then, he often travelled from Morocco to the Netherlands and the other way around. From 2002 onward, Mrs. Rabbae noticed some changes in the behaviour of her husband, as he became forgetful and more quickly irritated. She talked about this with her oldest daughter and then the diagnostic process begun.

In 2003, after the diagnosis was explained by the gerontologist, father was determined to return to Morocco. The doctors supported this wish, explaining to the family that he would probably feel more at home in Morocco. Certainly given the fact that his memory would decline even more, Morocco would be the best place for him to be. The family agreed to father's wishes and father and mother returned to Morocco, leaving their grown children in the Netherlands.

In the interview, Mrs. Rabbae describes that the first year in Morocco went well, as her husband was positive, met many friends and would stroll to the village all day. After this first year, the dementia increased and he started to do and say strange things. The care for father became more time and energy consuming. A maid was hired to support in the household, though this offered only temporarily relief. The wife had to look after her husband all hours a day. As she explained herself in the interview, she had to lock the doors to prevent him from wandering, she had to stimulate him to do anything, even eat. Though the nights were the worst according to Mrs. Rabbae, she had to be there as her husband woke up, for example to help him to the toilet. At night, his orientation was even worse and it had happened more than once that he urinated on a chair or fell asleep in the garden. Since no health care or support facilities were available in Morocco, mother was supposed to care for her husband all by herself.

After four years in Morocco, the health situation of Mr. Rabbae was decreased enormously, and his wife was overwhelmed by the amount of care. She could not do it anymore by herself, though still no professional support was possible. The children all lived in the Netherlands and could or would not return to Morocco. Instead, the family decided that it was best for everyone as father and mother would again return to the Netherlands. In 2007 Mr. and Mrs. Rabbae moved in with their oldest daughter. Professional home-care was hired to provide care for father in the morning and evening. An electronically adjustable bed, a wheelchair and a chair in the shower were arranged, which relieved the degree of care.

For a total of seven years, Mrs. Rabbae took care of her husband. The last two-and-a-half years when he was very ill, bedridden and while communicating with him was almost impossible. The home-care which was provided in the Netherlands was alleviation to her. She could now enjoy the moments with her husband again, without being responsible for the care.

This case shows that return migration might not be the best solution for elderly Moroccan immigrants with dementia. Although it is the place that often still exists in their memory, the minimum of available proper facilities. In Morocco, the family will be the only one responsible for the care giving. This might put an enormous weight on the shoulders of the family members. To Moroccan families, this could be considered not as a problem, since the amount of family members in general is large. As in this case, many family members lived in another country and the burden was carried by one person. This makes it all much more complicated.

#### **4.4 Discussion and conclusion**

Relating it all back to the question posed in chapter two: *Does a disease influence notions of home and belonging?* It can be said that the disease dementia does not directly influence notions of home and belonging. Although through the disease, Moroccan elderly are more and more dependent on their family members. A possible return to Morocco without their children is considered impossible, since then nobody will be present provide care. As a result, indirectly the two are connected. The illness dimension of dementia influences the family relationships and increases the dependence of the elderly; resulting in a difficult situation in which feelings of home and belonging are influenced largely by family relationships. A logical next question is: *Are the family relations the most important aspect of home and belonging?* In this research, it seems like it does. My respondents emphasise that the presence of family members is the most important aspect of home. It is considered more important than their longing for Morocco. The importance of the presence of family members and members of the ethnic community is also stressed by Bozkurt. However, she concludes that ‘Turkish emigrants in Germany dream of accomplishing the return journey which they have planned since their departure. They communicate this desire to their children as a will and a message about one’s real place to which one must return when it is time’ (Bozkurt 2009:116). Opposite to my respondents, her respondents seem to choose for the longing.

To conclude it can be said that Morocco will never disappear out of the minds of the Moroccan elderly. Though return migration is no option. Home to them is where their husband/wife, their children and grandchildren are. Notwithstanding the facts that most of them do not speak the Dutch language (anymore) and the loss of their most recent memories, return migration is no possibility. Off course they do not forget the past in Morocco, they still think and dream about it; they tell stories about the past to their children and grandchildren; and once a year they go for a holiday. They still mystify the past and long for Morocco, though they decide to stay because of the presence of their family members. My respondents experienced difficulties explaining their complaints. Only two mentioned dementia related symptoms, although they were all diagnosed with dementia. The cause of this can be found in the coping strategies of the elderly. The responses of my respondents can be subdivided in three coping strategies; denial or avoidance, minimization or normalization and continue living.

## **5. The voice of the family members**

This chapter will focus on the experiences with dementia of the family members of the Moroccan elderly. All respondents have been diagnosed with dementia, but how do their family members attribute meaning to this disease? Differences might occur in how family members experience the dementia, not only within and between Moroccan families, but also between Dutch and Moroccan families. A total of eighteen family members were interviewed and the results of the analysis will be depicted in this chapter. It is important to note that this chapter is both focussed on the disease as on the illness. One of the main reasons for this is that it occurred during the interviews that the daughters to whom I spoke focused more on the disease than on the illness. Therefore, especially paragraph one and part of paragraph two emphasises the disease dementia.

The chapter is divided into six paragraphs. First different biomedical symptoms of dementia, noticed by the family members will be described. Secondly the question whether dementia is seen as a taboo will be dealt with thoroughly. The third paragraph entails information on how family members deal with dementia and gender related differences are analysed. Finally, the fourth paragraph entails information on guidance and a short conclusion will be given in the fifth paragraph.

### **5.1 Symptoms of dementia**

As described in chapter two, dementia can entail several biomedical symptoms, which will not occur simultaneously in all cases. This paragraph focuses on the symptoms described by the different family members. The symptoms are organized by means of the biomedical disease symptoms described in paragraph 2.2.1 of this thesis.

#### 5.1.1 Memory loss

Family members support the assumption that memory loss is the most common symptom of dementia, since all of them mention memory loss (or in other words forgetfulness) as an important symptom. Memory loss involves the short term memory as well as the long term memory. However, events of the past are often remembered well until the dementia is severe. Many people with dementia can talk about their childhood and early life. The daughter of Mr. El Yousfi depicts the following short-term memory problems:

‘Father forgets what groceries to get if he is sent to the supermarket. Sometimes he forgets the Morning Prayer and other times he repeats the same prayer two times. It is difficult to have a normal conversation with father, because he constantly repeats himself and threads the story lose’.

Further on in the interview, she ensures me that I should not always believe her fathers' stories. Since he forgets what really happened, he creates his own narratives. So from time to time, Mr. El Yousfi lives in his own fantasy world as his daughter calls it.

Mr. El Morabet explains that the forgetfulness of his wife has increased the last two years. According to him she leaves the light on, forgets to shut the crane, asks the same questions over and over again, loses her belongings and loses money. Mrs. Ben Saleh moved in with her daughter after she forgot to turn off the gas and almost caused a fire in her house. Her daughter illustrates her mother's forgetfulness as following:

'This last year, mother constantly loses her belongings, is highly repetitive and forgets for example if she has eaten or conducted a prayer. She does remember things that happened in the past, for example stories about her mother and grandmother'.

The daughter of Mr. Ait Haddou also depicts two examples of her father's declining short term memory.

'The problem is that he does not remember whether he has eaten or not. You just heard it yourself. My mother said that he just ate, but he states that he has not. I know, he usually eats mandarins after dinner and when we arrived he was eating a mandarin. And now he says "yes I have had nothing to eat. I am dying of hunger here".'

'One time he came into the living room with his hands all black. We asked him what he had been doing, but he did not know. It turned out that he had disassembled the sink in the bathroom. But he did not know how or what'.

The dementia of Mr. Ait Haddou seems more severe than that of other respondents. This became clear during the interview, when his daughter explained that he even did not recognize his children all the time. At a given moment, she questioned the fact whether her father had even recognized her during the interview.

'He probably does not even know who I am. Do you know what shocked me just now? He said to me: 'If I do not understand her question, you are the interpreter'. That is why I was a bit shocked. I would really want to know who he thinks I am at this moment. O my god, I am losing it'.



### 5.1.2 Difficulty performing familiar tasks

Difficulty in performing familiar tasks can also be defined as apraxia. It often translates itself to the inability to recognize or use devices, such as Mr. Ait Haddou, who experiences difficulties controlling devices as the remote control, the water boiler and the stove. The daughter of Mrs. Ben Saleh mentioned examples of apraxia too.

‘She cannot operate the TV properly, so often she watches the same channel all day long. Cooking appears to be too complicated, she cannot oversee it and she does not know which devices to use’.

### 5.1.3 Problems with language

Patients may lose the ability to produce speech, to comprehend speech, to repeat, and to hear and read words in many nuanced ways; this can also be defined as aphasia. Mr. Ait Haddou has difficulties understanding language and finding the right words. This also became clear in the interview.

‘Oh I cannot do this. He does not give an answer to your question. [...] He is talking about years. He keeps on mentioning these numbers. I even notice when I ask him a question, even then, he does not answer the question. I think this is terrible. Not even when I translate the question in Arabic’.

I noticed aphasia with Mrs. Ben Saleh during my participant observation at day-care centre Darkom in three different ways. Firstly, Mrs. Ben Saleh mixes different languages (Arabic, Dutch and Spanish) and does not seem to notice it herself. In addition, she tells strange stories about herself, for example about a potential marriage with Jacques Chirac. And thirdly, I have noticed the childish language she often used. The other women at Darkom told me that Mrs. Ben Saleh was a bit crazy, while at the same time pointing with their finger to their forehead. Although they laughed about her strange stories and sometimes made fun of her, they also accepted her as such and helped her wherever possible.

### 5.1.4 Disorientation to time and place

Mrs. Ben Saleh often loses track of time (for example, she went to do groceries while the market was already closed) and is disoriented in space (for example, as she wakes up, she often does not know where she is and calls for her sons). In the interview, her daughter explains the disorientation:

‘At some moment in time she went outside and did not recognize the neighbourhood anymore. And yes than a neighbour ran into her and accompanied her home. Nowadays, if we are two doors further, than she knows, she looks around and recognizes the two large trees in front of our house. Then she recognizes these. But any further and she has no clue’.

Mr. Ait Haddou also experiences difficulties in orienting himself in the area, as a result he often gets lost. On my second appointment with this family, father was not present. Mother clarified to me that she had tried to stop him, though she had not been able to. When father wants to go outside, no-one can hold him. Since no-one knows where he is then, his family is worried about the terrible things that could happen to him.

‘Sometimes we do not even know where he is. You think that he went to the mosque, but you are never sure. I will admit to you, I just do not know. Sometimes my mother talks to neighbours and they tell her that they saw my father at the mosque. That might comfort me, but I still worry. Anyone can make use of him, it does not feel right’.

#### 5.1.5 Misplacing things

Family members of elderly suffering from dementia might find items in strange places. Just like the daughter of Mrs. El Tahiri explains.

‘Once I came to visit my parents and I went into the kitchen to get myself a glass of coke. It was then I discovered a diaper in the fridge. Mother denied that she was the one who had put it there, but we knew. A few weeks later my sister discovered a bottle of chlorine between the bottles of oil. Hopefully she had not used the chlorine as oil’.

Mr. El Yacoubi mentioned an example as well. He explained that a few weeks ago he went to Morocco for a short trip. His wife, who suffers from dementia, had been home alone for three weeks. As he returned, he found strange things all over the house. In the interview he gave one concrete example.

‘I saw that she had been busy cleaning our bedroom, the vacuum cleaner stood in the closet and a textile duster lay in the sink. I thought that was strange, because she always cleans a room and then puts everything away in the appropriate place’.

#### 5.1.6 Changes in personality

Changes in a person’s personality can mean an increase in suspicion, irritation, depression or anxiety. The daughter of Mr. Ait Haddou explained the following example.

‘Yesterday my father would go with my brother to the specialist. They drove by my house to bring my son home. Father was sitting in the car, but he refused to step out and come inside. I asked him: “Why would you not come to me? I am your daughter!” He said that he did not feel like it. It seems like he suffers from antipathy, I do not know. It seems like everything is strange to him’.

Sometimes a person may become more quickly irritated, especially in situations where memory problems are causing difficulties. The daughter of Mr. El Yousfi explains that talking to her father about his memory problems is difficult. He denies everything and then gets irritated because we accuse him of things he has never done. Mrs. El Yousfi experiences many difficulties with her husband's changes in personality. She states that she has the feelings she has lost her husband, he does not act as himself anymore. He is a totally different person, less sensitive and much sooner annoyed. She tells that her husband was always a nice, sensitive and handsome man. At the same time tears appear in her eyes and she covers her face in her hands.

#### 5.1.7 A loss of initiative

A decrease in or absence of emotion, interest or enthusiasm can also be defined as apathy. Patients with apathy lose the initiative and drive to perform their usual activities. Families report patients as showing loss of concern for daily events or even personal care, which can be distressing to them. Despite these issues, patients appear emotionally absent or unconcerned.

Mr. El Amrani suffers from Parkinson's disease and subsequently from dementia and apathy. His daughter explains that her father has become more passive in the last months. He used to visit the mosque daily, would go to the supermarket for small groceries and did some chores in and around the house. Since his Parkinson progressed, he lost his interest in doing chores and walking through the neighbourhood. His wife agrees with this, she describes that it is very difficult to motivate her husband to do something. If it was up to him, he would stay in bed for the whole day.

## **5.2 In the taboo atmosphere**

'In many cultures, elderly people with evident, long-term cognitive problems are stigmatised. This stigma may affect treatment-seeking behaviour, quality of life, and relationships within the family and the community' (Whitehouse et al. 2005:321). 'Studies show that the stigma attached to mental disorders prevents people from acknowledging their problem and seeking appropriate help, thereby limiting successful treatment and management. Furthermore, stigma affects not only the person with the mental disorder but also those surrounding the person, including family and professionals' (Werner & Heinik 2008:92). In addition, 'studies in the area of mental illness have shown that while stigma is common and detrimental for all society, its perception and effects are more intense among ethnic minorities' (Cohen et al. 2009:31). Although, Cohen et al. conclude that their study was the first in its kind to focus on the effect of ethnicity and culture on attitudes to people with dementia. They specifically focussed on the emotional reactions to persons with Alzheimer's dementia among Israeli Arab population of Israel.

The question whether dementia is a stigma or taboo among Moroccan immigrants in the Netherlands is hard to answer. It seems important to know what the family members of my respondents mean when they explain dementia as a taboo. After my interview with Mrs. El Yacoubi,

her two daughters talked to me about dementia. In a lively discussion, they explained to me how dementia might be seen in the Moroccan community.

- Daughter 1 'It is a taboo right'.
- Daughter 2 'Well, it is not a taboo, do you know what it is more likely. They say "ah it is old age". That is more it, you know sis. That is really it. When you ask those elderly Moroccans they will say, "ah it is part of life". Every one grows older. That is more it. It is not yet, they do not think old age is an illness'.
- Daughter 1 'Moroccans also do not admit easily that they mentally uh yes you know that their memory declines. They will not admit that easily'.
- Daughter 2 'You are right in that too'.
- Daughter 1 'Well, there is nothing wrong with me. I am still very well oriented". And yes they often deny that there is something wrong with them. Admitting that something is wrong, now that is uh yes that is commonly indeed a taboo'.
- Daughter 2 'Yes that is partly a taboo'.
- Daughter 1 'If you are a Moroccan with a depression they will say'
- Daughter 2 'Yes, but see'
- Daughter 1 'Depression is also a taboo'.
- Daughter 2 'Depressed then they just think uh that is not possible yes. But I think as regards Alzheimer that they more relate it to old age. It is part it, it is part of life, it belongs to the process and uh every human being grows older and every uh one forgets and the other do not. My father is still very sharp, he would never forget anything. And he has all those illnesses, but he is here [knocks on her head] still one hundred percent. He has everything; from diabetes to blood-thinning medicines yes father has really everything'.
- Daughter 1 'Yes'
- Daughter 2 'Asthma, yes everything you can imagine, he has got it'.
- Daughter 1 'Yes, diabetes in his eyes now'.
- Daughter 2 'Yes but he knows exactly where he left something'.
- Daughter 1 'That is also difficult for her, because she cannot top that. For him it is like, come on do you still not'.
- Daughter 2 'Do you still not know it'.
- Daughter 1 'That is for her. He should not do that anymore. Yes, but he is a very dominant man'.
- Daughter 2 'Yes, and dad is quickly irritated'.
- Daughter 1 'And he has no patience'.
- Daughter 2 'No patience'.
- Daughter 1 "And I have diabetes and I have this and that. Leave me alone"

- Daughter 2 'My mother has basically nothing. Yes she has got Asthma. No but she now has Alzheimer. But he thinks that she is fine physically. He still does not know what is wrong with her'.
- Daughter 1 'He still does not know what is wrong with her. He has no clue what it is. And he sits there every morning with all his pills, in the evening. In the morning an injection, in the evening. My mother, mom in fact nothing. I mean, furthermore she has nothing'.
- Daughter 2 'But that nothing, actually it is far worse what she has got'.
- Daughter 1 'It does influence everything she does in her daily life'.
- Daughter 2 'Yes, definitely'.

During my research, it became clear that dementia is a subject which people rather avoid. In the next sub-paragraphs, I will elaborate on three aspects of taboo, namely denial, shame and sensitivity. I will explain how these three aspects occurred in this research and conclude whether I think dementia is a taboo or not. Subsequently I will elaborate on two possible reasons why dementia might be seen as a taboo.

### 5.2.1 Denial

Total denial of the disease only occurred in the case of Mr. El Yousfi, as his family was convinced of the fact that father's situation had been caused by problems with his retirement savings. With the right medication and some rest, father would return to his 'old self' again, they thought. Especially his wife has many difficulties with the forgetfulness of her husband, she states that she has lost her husband, he is not himself anymore. The daughter told me the diagnosis of the doctor: dementia, but explained that they do not accept this diagnosis. The general practitioner of father had sent them to the hospital, because he was found by the police, walking down the freeway. But daughter does not believe that this has ever happened. According to her the police are not credible; her father has said that he was just walking around the neighbourhood. This example shows how the signs of dementia can be overlooked or ignored by family members. The daughter of Mr. El Yousfi, as well as other family members, was still in denial about the dementia. This case was the only one in which the whole family was in denial.

During the interviews I experienced that my respondents had more often difficulties talking to me about the subject than their family members. As explained in the first paragraph of chapter four, just Mrs. Ben Saleh acknowledged her forgetfulness and pointed it out as a problem. The other respondents did not, which indicates denial or perhaps shame. In the following section I will elaborate further on the specific topic of shame.

### 5.2.2 Shame

Feelings of shame can dominate the lives of family members. Different forms of shame can exist, such as shame on the disease, shame on the behaviour of the elderly or shame on the whole situation. Shame can result in the avoidance family members towards other people or the other way around. The daughter of Mr. Ait Haddou explained her feeling of shame as following,

‘O it is harsh, but sometimes I feel ashamed. Every time we do not know where he is, I am afraid that he has done something strange or dangerous. Like that time the police brought him home late at night. I could not look at them, I felt so ashamed. But we cannot keep an eye on him every moment of the day. We have our own job and families and my mother cannot stop him’.

This quote makes clear that her feelings of shame are increased by the fact that she cannot control her father’s behaviour. He needs to be looked over all day, but his daughter acknowledges that she cannot guarantee this. She has her own family, with three small children, and she cannot handle both. This shame of not being able to take care of your own father also emerged in the interview with the daughter of Mr. El Yousfi.

‘A couple weeks ago the neighbours of my parents talked to me about the behaviour of my father. They said to me “You are his daughter, go take care of your father”. That hurts me. Nobody will laugh at him, because than it will happen to them as well. But there is gossip, people talk about him behind his back. At the mosque too. I think that is terrible. They should mind their own businesses’.

Only the daughter does not acknowledge the fact that she cannot take proper care of her father. She feels ashamed that other people in the community think she does not do that. However, it is important to mention that the daughter of Mr. El Yousfi does not acknowledge the dementia either, so it seems quite obvious that she denies this as well.

### 5.2.3 Sensitivity

Dementia might be seen as a sensitive subject, a subject where people rather do not talk about, they share the taboo. The son of Mrs. Ben Saleh, whom I met at day-care centre Darkom, clearly did not want to talk to me about the subject. Each time I met him and tried to talk about the disease of his mother, he changed the topic of our conversation. One time, answering a question on the reason for his mother to visit Darkom, he said:

'My sister has sent my mother to this centre, I do not agree with her. She should be at home, with her family. I'm sorry, but you should talk to my sister about this. I cannot answer your questions, it is too confronting'.

Although he told many stories on other topics, his mother's disease made him feel uncomfortable. During the interview with his sister, she explained that her brother had indeed difficulties talking about the dementia to others. Since it was even for her hard to talk to him about this sensitive subject, she understood his reaction towards me. She explained further that she did feel comfortable talking about it, mainly due to her visits to an Alzheimer Café.

My respondents and their family members did not know anyone else in their community who has been diagnosed with dementia. They admit that they do not tell everyone either, for example the daughter of Mrs. El Tahiri,

'Not everyone needs to know. Only relatives and close friends know about the exact situation of my mother. All other people would not understand anyway, so why bother to tell them'.

To conclude it may be said that dementia is a sensitive topic, a topic which is rather avoided. It seems to be a shared taboo. All interviewees have different coping strategies. Some deny the presence of the disease; others are ashamed of it and rather hide it from the community. But does this really make it a taboo? We can continue to discuss about that. But one way or the other, dementia should be seen as a subject with some direct links to the taboo atmosphere. It evokes feelings that make people ashamed, uncertain or uncomfortable talking about it.

Except, how can a disease like dementia evoke such feelings that relate to a taboo? The first possibility might be the change within people, caused by the dementia. Elderly members of society who suffer from dementia turn into children, so to speak. As mentioned earlier in the paragraph, elderly suffering from dementia should be continuously looked after, just like children. Above that, dementia causes childish behaviour, such as saying everything that comes into mind whether it is appropriate or not. Elderly cannot take care of themselves anymore; as a result their children are obliged to act as parents for their parents. Boundaries between parents and children are crossed, which can cause many difficulties as avoidance and shame which in turn shows the way to the taboo atmosphere. A second possible reason might be that the relationship between the family and the community appears to be in danger. The change in personality might be noticed by the community, which will cause gossip, which was mentioned in the interviews as well. Not everyone in the Moroccan community will understand what dementia actually does with a person and how they should react. They might believe that the children do not care for their father or mother sufficiently. This might result in feelings of shame towards the community. Shame is a very powerful subject which prevents people from doing or saying particular things. Feelings of shame towards the community can result in denial or even hiding the elderly from society.

### 5.3 Dealing with dementia

Living with dementia is not easy, though having a family member with dementia is not easy as well. Many family members explained in the interview that they experienced difficulties dealing with their loved one. The daughter of Mrs. Ben Saleh depicts how she felt when the diagnosis was set.

‘In the beginning, yes Alzheimer. My mother suffers from Alzheimer. You know, yes off course I knew what Alzheimer was, but uh what it really does with a person and what you can expect. You do not know, because you are no expert’.

The daughters of Mrs. El Yacoubi explained that they had some difficulties reacting to their mother as well. Within a family of eight passionate children, it appeared quite difficult to react calmly without a discussion.

‘We also said “Mum, what are you doing?” and so on, you know. We did not know how to handle it or react uh either. It was very frustrating at some points. It was difficult, because we are all kind of direct. And the fact that you could not argue with her anymore or have a discussion. “Why did you do that?” “I did not do that”. “Yes you did”. ”No I did not”. Now we know that this did so, did not, could not work. We try to take it into account, but we are a very temperamental family and that is not going to change’.

During three interviews, family members got emotional. During the interview with Mr. El Yousfi, his wife and his daughter, the emotions got the overhand more than once. The family does not know what the forgetfulness and character changes are caused by, they believe that medicines will cure father. They do not seem to understand or accept that dementia is causing these changes in the behaviour of father. In addition, they also do not know how to handle father. Each time I ask Mr. El Yousfi a question and he starts with an answer, mother or daughter interrupt him with remarks as ‘He does not know the answer’ or ‘No that is not true, you have to tell it right’. Father became silent after these remarks and did not continue with his story. Mrs. El Yousfi and their daughter are having a tough time due to the health situation of their husband and father.

The family members of Mr. Ait Haddou are having a difficult time as well. They desire the best for their father, they would love to fulfil his wishes, but they acknowledge the fact that it is not always possible.

‘He worked so hard, tried so hard to accomplish something. He has built a house in Morocco, a large house for the whole family. But now he cannot enjoy it. The worst part is that we cannot let him go alone. In Morocco he would be laughed at and used. They would be able to exploit him for anything’.



### 5.3.1 Differences among family members

Two respondents mentioned that their family members did not think alike about the dementia. Mr. Ait Haddou is married and has two sons and three daughters. The eldest daughter of Mr. Ait Haddou described in the interview the following.

‘I can hardly believe it, that it has so far been. My mother neither. And each time I try to clarify to her little by little what is happening. It is still very tough for her. Is it already so far advanced and what do I have to do? How can I explain to her what is happening?’

The daughter of Mr. Ait Haddou also depicts how her brothers view the dementia and how they are handling the situation.

‘I think that my brothers have difficulties with it too, but boys are different huh. They tend to forget sometimes. And then I say, you cannot forget these things. Yes it is difficult. It is as.. Yes just like my brother who just rang, he said that our father is not ill at all. Yes if you do not ask him difficult questions. Ask him some intimate questions and see if he answers. And then my brother says ‘O seriously?’. Yes seriously. If you stay superficial in a conversation, than he will too. That he can, that is easy. They do not even see how badly he is doing.’

The daughter of Mrs. Ben Saleh describes this difference between daughters and sons as well.

‘Well I have a feeling that my brothers are not really conscious about it all. They know that she has Alzheimer, but uh no, they do not know how to respond properly. They have always been more subsided, for them it does not make a huge difference’.

These quotations might refer to gender specific associations of illness, in this case dementia. Females might be more interested in understanding issues relating to health and care than males. These differences might also have to do with the family structure, in which daughters are seen as responsible for the care of the parents. Since these relationships within the family are still considered to be important in the Moroccan community, daughters are often the contact person regarding care. In addition, daughters often have more intense contact with the parents and will thus have more knowledge about the situation. More knowledge might result in a better understanding and consequently a better way of dealing with the situation.

I found it quite remarkable that of all my conversations and interviews with families, I only shortly spoke to two sons. The first son I spoke to was present at the visit of his father to the day-clinic and although he was positive over my research, he directed me to his younger sister who, according to him, knew much more about that kind of things. I met the son of Mrs. Ben Saleh at Darkom, where he regularly came to visit his mother. Although I knew him already, during the interview only his sister

was present. As the daughters emphasize in the quotations that the perception of their brothers does differ from theirs, my observations confirm this.

## 5.4 Guidance

Guidance to dementia patients and their family members can be offered in diverse ways, for example by the General Practitioner, the gerontologist, a social worker, or by someone from a foundation like Alzheimer Nederland. In general it can be said that depending on the wishes and questions of the patient and family, the choice for which professional is made. Though, it is important to note that family members themselves have an important task in asking for guidance. In the case that family members do not ask questions or ask for help, it is difficult to provide guidance.

Two years ago, Mrs. Ben Saleh was diagnosed with dementia at the Slotervaart hospital. After the diagnostic phase, no additional guidance was arranged by the hospital. The daughter of Mrs. Ben Saleh experienced the following.

- Daughter            After the diagnosis, we did not receive any guidance from the hospital. I needed to figure it all out by myself. Because it has only been diagnosed and no further actions were taken.
- Researcher        And how did you solve that?
- Daughter            Well yes I did my best to figure things out myself. Uh I read a lot of information on Alzheimer and I visited some gatherings.
- Researcher        What kind of gatherings do you mean?
- Daughter            Yes you know, Alzheimer cafés. That helped me a lot. In the beginning, I had so many questions. Well yes. How does it develop? What is the prognosis? That type of questions. But directly after I heard the diagnosis, I was overwhelmed, and I did not have any questions for the gerontologist. With the time, the questions came.

This reaction of the daughter of Mrs. Ben Saleh appeared to be illustrative for more families. During the interviews with Mr. El Morabet, Mrs. El Tahiri, Mrs. El Yacoubi and Mr. Ait Haddou questions about dementia were asked. Since some respondents knew me via the Slotervaart hospital, they asked their questions to me, such as the daughter of Mrs. El Tahiri, who was very uncertain on what she could expect. The daughters of Mrs. El Yacoubi had many questions regarding the prognosis, the symptoms and the best way to react to their mother. It turned out that none of them had received professional guidance after the diagnosis. The daughter of Mrs. Ben Saleh appeared the only respondent who had visited an Alzheimer café, though otherwise guidance was quite limited.

Besides the daughter of Mrs. Ben Saleh, the daughters of Mrs. El Yacoubi searched on the Internet for information on dementia as well. Since the amount of information available was

enormous, they were not really satisfied after their search. Instead, it only made them more insecure, since they found some contradictory facts.

The family of Mr. El Morabet explained that they had received guidance, though more focussed on the Parkinson's disease in general. Specific information on Parkinson's related dementia was not offered to them directly. Despite this fact, the daughter explained that their social worker had prepared them well on the possible side effects of the Parkinson. So she knew who to turn to if problems arose, in case the dementia would worsen.

Concluding it might be said that the guidance of family members is not as it should be. Only one of the respondents was satisfied with the offered guidance, though additional guidance would be helpful in all cases. Family members were now stuck with all kinds of questions, not knowing where to turn to for help or answers. I argue that culturally sensitive health care facilities are needed.

## **5.5 Conclusion**

As mentioned in the previous chapter, the number of respondents who self-report symptoms of dementia is fairly small. Opposite, their family members could depict many symptoms of dementia relating to among others memory loss, disorientation, changes in personality and a loss of initiative. The illness experience of the family members thus differs somewhat from that of the patients. Since dementia is surrounded by denial, shame and sensitivity, it can be concluded that it is a subject within the taboo atmosphere.

Family members of respondents emphasised that they experienced difficulties dealing with dementia. Daughters are often worried and scared even that something terrible is happening to their parent. Sons on the other hand seem to ignore the signs; it seems that they are not quite conscious about the dementia. This difference can be caused by the family relationships within Moroccan families, as the daughters are often more involved in the care for the parents.

The final conclusion of this chapter is that cultural specific guidance is necessary in order to support all families with an elderly suffering from dementia. Appropriate guidance should begin with proper information by the General Practitioner or the gerontologist. The next chapter will depict the stories of some health care professionals working with or having knowledge over elderly Moroccan immigrants suffering from dementia.

## 6. The voice of health care professionals

During the research, professionals working with of having knowledge over Moroccan elderly suffering from dementia were interviewed and several projects were visited, this sixth chapter will contain an analysis of these data. Seventeen professionals agreed to a conversation about the subject of dementia among Moroccan elderly in the Netherlands. When quotations or opinions of a key-informant are mentioned in the text, this is made clear by a letter code, ranging from A to Q, with an additional letter d or m. These additional letters stand for the background of the informant, Dutch or Moroccan. The corresponding functions can be found in chapter three and appendix four.

The first paragraph of this chapter focuses on the position of Moroccans regarding dementia, explained by health care professionals with a Moroccan background. The second focuses on the underuse of health care facilities and the third on obstacles experienced by the health care professionals in offering guidance. The chapter closes with a short conclusion.

### 6.1 Position of Moroccans regarding dementia

As shown in the theoretical framework, neither in academic nor non-academic literature, information can be found on the position of Moroccans regarding dementia. During this research, professionals with a Moroccan background were asked what they thought the general position of the Moroccan community regarding dementia was. It can be said that most professionals highlighted the fact that dementia as a clinical syndrome is unknown. It is mostly seen as a part of the process of normal aging, everyone will experience it. Some professionals argued that dementia is seen as a form of craziness.

When I asked Mm whether he could explain how dementia is perceived in the Moroccan community in the Netherlands, he experienced difficulties in expressing his thoughts. He states that in the Berber language it is called '*itgaraf*'. In Arabic the word '*garifti*' is used, which means something like '*you become old and forgetful*'. The chairman of Avicen explains that in Morocco, the word Alzheimer is used as well. She explains that there is no literal translation of dementia or Alzheimer, so people might use Alzheimer instead.

#### 6.1.1 Taboo

In addition to the discussion whether dementia is a taboo or not in the previous chapter, I spoke to my key-informants about taboos. The word taboo was applied by Nm, chairman of foundation *Onze Hoop* (Our Hope), as he described the following.

'Among migrants, dementia is a topic which is surrounded by many constraints. Aging in general seems to be a taboo, let alone dementia. According to my opinion, taboos need to be broken'.

According to Nm, a taboo is defined as a subject which is off-limit, not discussable. He does not only perceive dementia as a taboo, but aging in general as well. Other key-informants did not distinguish dementia as a taboo; though they did mention the fact that dementia is a not an easy discussable subject within the Moroccan community.

Key-informant Fm, who is the chairman of Avicen and works as a nurse-practitioner diabetes care at the Slotervaart hospital, argues that dementia is still not seen as a clinical picture. She compares the position of dementia nowadays, to the position of chronic diseases, such as diabetes, ten years ago. Moroccans did not acknowledge the appearance of chronic diseases, although nowadays, it is embedded in the community and people perceive it as an illness. This has been a long process, which included many steps before awareness and acceptance was reached. Fm argues that as for dementia, the same process is now beginning. In addition she states that dementia is still a taboo within the Moroccan community, but she thinks that this will change in the upcoming years.

During the informational gathering 'What is dementia', the chairman of COMAZ (Moroccan elderly board in Amsterdam East), Ym, explained that dementia is seen by the elderly Moroccan men as something that is not likely to cross their path. He thinks that the Moroccan community still has to familiarize with many things, among others perceiving dementia as an illness and not as something that just belongs to the process of aging. Jd responded to this by noting that dementia is often not recognized as such, as it is considered normal when grandfather or grandmother become childish. Since it occurs often that the children by now have taken over the care for the elderly, symptoms are missed due to the fact that the elderly is already less active than normal.

A question that might come to mind is: *What do we win by breaking the taboo surrounding dementia?* By removing dementia out of the taboo atmosphere, discussing the subject will be easier and support can be offered to both the patient and the care givers. This will result in a decrease of helplessness and negative emotions with family members of elderly suffering from dementia. Knowledge of the disease, not only of the symptoms and the prognosis, but also how to deal with it and where to go for support, will improve the situation of elderly suffering from dementia and their family members.

### 6.1.2 Effects on family relationships

According to Hd, gerontologist of Alzheimer Nederland, there is a great lack of knowledge about the disease dementia. It is often thought of as a form of lunacy, a punishment by God or simply as a form of bullying by the elderly suffering from dementia. This lack of understanding is very hard for both the elderly and their families. People do not know how to react to strange actions, or how to respond to strange sentences.

Mm receives signals from the community that dementia is occurring more often. This is confirmed by members of MOBiN (Association for Moroccan Elderly in the Netherlands). Incomprehension over the situation and the disease causes such as loneliness and neglect, resulting in

tragic stories. Mm was clearly touched as he told the following story and explained that this type of events should not occur anymore in our modern society.

‘One of the members of MOBiN told me a story about an elderly Moroccan man living in Bergen op Zoom. This man suffered from dementia, though this was not acknowledged by his family. One day, his family had kicked the poor man out of their house. They claimed that their father was ‘crazy’, out of his mind and had therefore decided to disown him. I tried to understand, but I could not. How could you do something like that to your own father? But it shows that it is indeed happening, and that we should not close our eyes’.

This case is an example of what can happen as dementia is occurs in a Moroccan family. Tough we should not haste ourselves to any conclusions. We do not know the exact situation of the man and his family, for example their history. Perhaps father had always been a difficult man, and was this experienced by the family as an eligible reason to let him down. Family relations are important in this case. Men might be seen as head of the household, strict and dominant; women on the other hand, might be seen as caring and loving. With these family relations, decisions regarding care giving can differ when it regards father or mother. Children might be more open to care for their mother, than for their father. It is about the perception of their parents over the years. As might have occurred in Bergen op Zoom, that the children found a reason to disown their father, who at that point, could not defend himself anymore. This was not the case in my research, but it definitely could happen.

The preceding case kept on triggering my attention. *Can elderly suffering from dementia, still be held responsible for their behaviour?* Can one blame another for something he or she has done, when the behaviour is affected by dementia? Their behaviour does not fit the pattern; it is not their usual behaviour. Up to my opinion, you cannot blame an elderly suffering from dementia for his or her words or actions. The elderly themselves are not responsible, the disease is. Regarding to the case, the family members did hold their father responsible for his behaviour and see what happened. It might have been a totally different case as the family had acknowledged the dementia. Maybe they would have acted differently, but on the other hand, maybe they would not, regarding the family relations mentioned above.

The importance of the effect of existing family relationships and the social supports on the illness of people with dementia is described by Whitehouse et al. They argue that ‘attending to ethnic variations in family structure and responsibilities can help us understand how different groups address, with greater or lesser success, the challenge of old, cognitively impaired relatives’ (Whitehouse et al. 2005:323).

### 6.1.3 Acceptation and acknowledgment

Senior staff member of Sefkat, Pm, indicated that elderly immigrants appear to experience problems in accepting this new phase in their lives, the phase of old age. In many families social dilemma’s occur,

for example the doubt of children whether they can send their parents to care facilities, such as day-care.

‘People need to have the feeling that dementia can happen, but that they are able to do something with it. Nowadays dementia is kept behind closed doors, literally and metaphorically speaking’.

Dementia is under acknowledged in the Moroccan community and misbehaviour by family members does occur. Since the elderly suffering from dementia are kept out of society, Nm states that they are invisible.

‘Dementia is not acknowledged in many cases, as it is seen as part of the aging process, it relates to old age. Elderly Moroccans suffering from dementia are usually perceived as a handful and are mostly put off. Since the family feels ashamed, they are kept hidden from the community. In addition, the family takes over all the care and responsibilities, leaving nothing for the elderly themselves to do. Actually they are invisible’.

This invisibility is further explained by Nm as following:

‘Since physical and mental illnesses are seen as the Allah’s wish, they lead to an acceptance of the disease, which in addition closes the door. It is not noticed by the family, though elderly with dementia can live for many years, as a result the family does not care to find guidance or possibilities for the future. Diagnosis dementia; end of story’.

He also relates the invisibility to the acceptance of support and guidance. Due to the fact that the elderly and their family members tend to do nothing after the diagnosis is set, assistance is not often asked. This phenomenon will be discussed further in the following paragraph.

## **6.2 Use of health care facilities**

In 2004, Schellingerhout concluded that Moroccan elderly make less use of health care facilities than Dutch elderly (Schellingerhout 2004:31). The same conclusion was made after a small study of Sefkat conducted in 2007. This triggered them to find out whether the elderly wanted to make use of the facilities and this small-scaled research was conducted in 2008. Senior staff member Pm explained the following about the results.

‘The results showed that the elderly immigrants were indeed interested in the different health care facilities, but they simply did not know that they existed. We noticed a gap between the demands and the supplies, and we decided that we would attempt to make the gap smaller.

This has resulted in the establishment of a care home (*zorghuis*) for elderly Turkish and Moroccan immigrants and an Alzheimer tearoom in Den Bosch. The project is still in its early stages, so results cannot be given yet. Though, according to Pm the projects can already be called a success.

Nm explained in the interview that in the near future, things will change for the elderly, since the government is cutting in the finances for day-care facilities. As a result, indications are sharpened and elderly are more likely to receive a rejection from the CIZ (Centre for Indication premise of Care).

‘In the near future, things will only get more complicated for the elderly migrants, since rules and indications will be sharpened and the elderly have difficulties explaining the specific reason for them to need an indication. Because many of them will lose their indication, even more elderly immigrants will become isolated. The elderly themselves do not seem to be aware of this growing problem; they still believe that the government will take care of them. They still do not take initiatives and stay passive’.

Several reasons can be thought of why elderly Moroccans would need extra guidance, such as their poor understanding of the Dutch language, their unawareness over and underuse of health care facilities, as well as their lack of knowledge over symptoms, diseases and aging. Staff members of Sefkat concluded after an inventory research that many Turkish and Moroccan immigrants in the Netherlands had questions regarding dementia. Though, the elderly do not know who to turn to.

Monthly group information gatherings are held at COMAZ, separately for Moroccan elderly men and women. Ym, the chairman of COMAZ, seems to be very proud on these monthly meetings and talks lively about these. Since the meetings are a joint project of COMAZ, CIVIC, GGD and the Flevohuis, several topics related to health care, safety and community can be covered. In the spring of 2010, the following topics are on the agenda; diabetes, prostate problems, dietetics, safety in the neighbourhood and dementia. During all gatherings a professional interpreter is present to translate the information in Arabic. According to Ym, the reactions are positive.

‘During most meetings, the attendance is high and the responses of the elderly are very positive. They appreciate the verbal information in their own language, certainly since eighty-five percent is illiterate. The elderly are very grateful, because their knowledge about these topics is fairly limited’.

Key-informant Nm describes that the elderly do not perceive themselves as elderly. Their first response is often “No that is for the elderly, not for me”. They live with their minds in a previous era, as they stopped their mental clockwork once and now it seems to be broken. This phenomenon is similar with Dutch elderly, though they do have an easy access to many information resources. Information on diseases, provisions, health care and living arrangements need to be provided.



According to Nm, this information can best be provided in individual guidance, as group information gatherings are often perceived as uncomfortable. Within a group, the elderly are not open for new information, whereas with individual guidance the effects will be extended. Providing information in one's mother language seems to be very important. Once a topic has come up in a group everyone has some understanding for it the taboo is broken. But often the material is missing. Providing oral information is also very important. Providing information should already start at elementary schools. So children will know what is going on with their grandfather or grandmother.

Fm, chairman of Avicen and nurse-practitioner diabetes care, has many ideas how the obstacles can be conquered and facilities can be build. She emphasises a hands-on method, providing information and showing people the positive sides. In her function as chairman of Avicen, Fm comes across many Moroccan families who experience difficulties caring for their elderly father or mother. The employees of Avicen, who speak the language of the elderly, not only provide care, but also provide information and guidance. They are aware of all the possibilities, in contrast to many family members, and they tend to facilitate the best possible care. Fm knows that the number of requests for a cultural-specific nursing home is growing. For the last four years she is trying to convince others of the importance of such a home, although there are no results until now.

### **6.3 Conclusion**

This chapter focussed on health care professionals with a Dutch or Moroccan background, and their perceptions about dementia within the Moroccan community in the Netherlands. The health care professionals with a Moroccan background argue that dementia is not seen as a serious clinical picture. It is related to old age in general or, to craziness or it is simply ignored because of shame. The importance to bring dementia out of the taboo atmosphere is emphasised. Moroccan elderly use less health care facilities than Dutch elderly, the same stands for facilities regarding dementia support. However, it is important to inform and support the elderly and their family members adequately. Several reasons can be thought of why elderly Moroccans would need extra guidance, such as their poor understanding of the Dutch language, their unawareness over and underuse of health care facilities, as well as their lack of knowledge over symptoms, diseases and aging. Knowledge of the disease, not only of the symptoms and the prognosis, but also how to deal with it and where to go for support, will improve the situation of elderly suffering from dementia and their family members.

## 7. Conclusion

Dementia, which is a clinical syndrome, occurs mainly among the elderly, as advancing age is a serious risk factor. Since previous studies on this topic are not only limited, but also fail to focus on dementia among Moroccan immigrants in the Netherlands, the research presented in this thesis may be considered unique. This thesis focused on the experience of dementia of elderly Moroccan immigrants and their family members and on the point of view of health care professionals with a Dutch and Moroccan background. The research question was: *How is dementia experienced by elderly Moroccan immigrants in the Netherlands suffering from dementia, their family members and by health care professionals?* Three sub-questions are derived from this, and in the following subsections excerpts of the answers will be presented.

The first sub-question was: *How is dementia experienced by elderly Moroccan immigrants in the Netherlands suffering from dementia, and how does it relate to their feelings of home and belonging?* This research shows that Moroccan elderly suffering from dementia do not perceive their disease as such. Only two respondents identified forgetfulness as a symptom, others emphasised no complaints at all or only physical complaints. Although they were all diagnosed with dementia, they do not seem to acknowledge it. This phenomenon can also occur with Dutch patients, though on less extend. However, the symptoms do seem to influence the general mental state of the elderly, as many respondents appeared sad, discouraged and passive.

In relation to feelings of home and belonging it can be concluded that the Moroccan elderly suffering from dementia locate themselves with their families in the Netherlands. This importance of family members can be caused either by the close family relationships or by a type of dependence of the elderly. This research does not make a distinction between these two possibilities, although this could be interesting in future research. In the interviews, respondents mentioned that they still think about Morocco a lot and they tell stories of past times to their children and grandchildren. In a way, this mystification or in other words the process of romanticizing the past in Morocco is their way of dealing with home and belonging. They will not return migrate because of the presence of their family members in the Netherlands, though they cannot forget their past and their home country.

The second sub-question was: *How is dementia experienced by their family members?* A total of eighteen family members were interviewed and they could depict many examples corresponding to the following biomedical dementia symptoms; memory loss, difficulty performing familiar tasks, problems with language, disorientation to time and place, misplacing things, changes in personality and a loss of initiative. Elderly with cognitive problems are stigmatized in many cultures, among others in the Moroccan community in the Netherlands. Denial, shame and sensitivity are three important aspects related to dementia which places it within the taboo atmosphere. Studies show that a taboo prevents people from acknowledging the problem and seeking proper help, thereby limiting successful treatment and management. Most family members expressed a hard time dealing with

dementia and the symptoms. The diverse symptoms of dementia, and in particular the character changes, makes it hard for family members to provide proper care. Many respondents acknowledged that they experienced difficulties in dealing with the demented family member. More knowledge might result in a better understanding and consequently a better way of dealing with the situation. However, without sufficient guidance, obtaining more knowledge is difficult. As a result, guidance in general should be improved.

The third sub-question was: *How is dementia among elderly Moroccan immigrants experienced by health care professionals?* As shown in the theoretical framework, neither in academic nor non-academic literature, information can be found on the position of Moroccans regarding dementia. During this research, professionals with a Moroccan background were asked what they thought was the general position of the Moroccan community regarding dementia. Most professionals highlighted the fact that dementia is not seen as a clinical syndrome, since many people see it as normal aging. The subject is surrounded by the taboo atmosphere, which according to professionals needs to be broken. By removing dementia out of the taboo atmosphere, discussing the subject will be easier and support can be offered to both the patient and the care givers. Due to the fact that the elderly and their family members tend to do nothing after the diagnosis is set, assistance is not often asked. Although, it seems important to overcome obstacles and start culturally sensitive health care facilities. Health care professionals also mentioned the effects of dementia on family relationships. Due to the process of dementia, family relationships are likely to change; the parents become childish and the children are supposed to care for their parents.

I would like to close this Master's thesis with an article in the Volkskrant, 8<sup>th</sup> of June 2010: 'If we do nothing, in the future elderly suffering from dementia will roam the streets'. In this article, the director of Alzheimer Nederland emphasises the growing need for support for the families of elderly suffering from dementia. In the upcoming years, the number of dementia patients will double, though the number of health care professionals will remain the same. This might result in an even larger burden on the shoulders of informal caregivers, long waiting lists and insufficient professional guidance. Alzheimer Nederland does not accept this and stands up for the right of the elderly suffering from dementia and their family members. Adequate support of patients and caregivers with diverse backgrounds in the Netherlands is necessary.

Dementia is everywhere and it can happen to all elderly. But indeed, there are differences in how the dementia is recognized, handled and experienced. During the last three months I have been in a bumpy ride through the land of dementia among Moroccan elderly and it opened my eyes. I certainly hope that my research and my thesis will open the eyes of others too.

**Total word count: 24.975**

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Alzheimer's Association

<http://www.alz.org>

Alzheimer's Disease International

<http://www.alz.co.uk/alzheimers/symptoms.html>

CBS Statline

<http://www.cbs.nl/nl-NL/menu/cijfers/default.htm>

World Health Organization, ICD-10

<http://apps.who.int/classifications/apps/icd/icd10online/>

**Appendix 1: Approval Medical Ethical Commission**



## **Patient information letter (in Dutch)**

Betreffende het onderzoek naar de gevoelens van ‘thuis’ en ‘thuis zijn’ bij dementerende Marokkaanse migranten in Amsterdam.

Geachte heer/mevrouw,

Wij vragen u vriendelijk om mee te doen aan een medisch-wetenschappelijk onderzoek naar de gevoelens van ‘thuis’ en ‘thuis zijn’ onder dementerende Marokkaanse migranten in Amsterdam. U beslist zelf of u wilt meedoen. Voordat u de beslissing neemt, is het belangrijk om meer te weten over het onderzoek. Lees deze informatiebrief rustig door. Bespreek het met uw partner, vrienden of familie. Hebt u na het lezen van de informatie nog vragen? Dan kunt u terecht bij de onderzoeker, Caroline Rijkers. Op bladzijde 2 vindt u haar contactgegevens.

De onderzoeker is een master student antropologie aan de Vrije Universiteit te Amsterdam. Naast haar studie werkt zij als ergotherapeut in het Slotervaartziekenhuis te Amsterdam. Zij is met name geïnteresseerd naar de situatie van oudere migranten in Nederland. Het doel van haar master onderzoek is het achterhalen waar oudere Marokkaanse migranten zich ‘thuis’ voelen. Verlangen zij terug naar hun moederland Marokko of voelen zij zich thuis in Nederland? En hoe worden gevoelens van ‘thuis zijn’ versterkt? Binnen de antropologie zijn gevoelens van ‘thuis’ en ‘thuis zijn’ een belangrijk onderwerp voor onderzoek. Deze gevoelens worden beïnvloed door tijd en plaats. Op dit moment is er nog geen onderzoek uitgevoerd naar de invloed van dementie bij oudere migranten, hierdoor is dit huidige onderzoek zeker relevant.

Het onderzoek wordt uitgevoerd in de periode tussen januari en maart 2010. Het onderzoek bestaat uit één of na overleg meerdere bezoeken aan u en uw familie. Tijdens dit bezoek zal de onderzoeker met zowel u als uw familie praten. In totaal willen we ongeveer 10 families in het onderzoek betrekken. Na afloop van de gesprekken zal er een schriftelijke uitwerking naar u toegestuurd worden. U kunt dan reageren op de uitwerking, waarna deze nog veranderd kan worden. Indien gewenst kunt u de na afloop van het onderzoek de algemene resultaten toegestuurd krijgen. Dit zal de onderzoeker tijdens het bezoek met u bespreken.

Belangrijk bij deelname aan dit onderzoek is dat ook uw familie op de hoogte is van het onderzoek en toestemming geeft om deel te nemen. Dit omdat ook de familie bij het onderzoek betrokken zal worden.

U beslist zelf of u meedoet aan het onderzoek, deelname is vrijwillig. Als u besluit niet mee te doen, hoeft u verder niets te doen. U hoeft niets te tekenen. U hoeft ook niet te zeggen waarom u niet wilt meedoen. Als u besluit wel mee te doen, kunt u zich altijd bedenken en toch stoppen. Dit kan ook nog tijdens het onderzoek.

Omdat er aan het onderzoek geen risico's verbonden zijn, is er geen verzekering afgesloten.

Het onderzoek zal zo nauwkeurig mogelijk volgens plan verlopen. Maar de situatie kan veranderen, bijvoorbeeld door nieuwe informatie. Als dat zo is, bespreken we dat direct met u. U beslist dan zelf of u met het onderzoek wilt stoppen of doorgaan.

Tijdens het onderzoek zullen wij anoniem met uw gegevens omgaan. Na afloop van het onderzoek zullen de gegevens niet bewaard worden voor toekomstig onderzoek.

Dit onderzoek is goedgekeurd door de toetsingscommissie van het Slotervaartziekenhuis en het Jan van Bremen Instituut. Meer informatie over de goedkeuring vindt u in de Algemene brochure.

Als u nog vragen of opmerkingen heeft kunt u contact opnemen met de onderzoeker. Zij is bereikbaar op het telefoonnummer [REDACTED]. Wilt u graag een onafhankelijk advies over meedoen aan dit onderzoek? Dan kunt u terecht bij dr. Edien Bartels, docent antropologie aan de Vrije Universiteit te Amsterdam. Zij is bereikbaar op het telefoonnummer [REDACTED].

Met vriendelijke groet,

Caroline Rijkers

[REDACTED]

[Caroline.rijkers@gmail.com](mailto:Caroline.rijkers@gmail.com)

Bijlagen:

- Algemene brochure medisch-wetenschappelijk onderzoek met mensen
- Toestemmingsformulier
- Toestemmingsformulier wettelijk vertegenwoordiger (indien van toepassing)

## Toestemmingsformulier

Betreffende het onderzoek naar de gevoelens van ‘thuis’ en ‘thuis zijn’ bij dementerende Marokkaanse migranten in Amsterdam.

Ik heb de informatiebrief voor de proefpersoon gelezen. Ik kon aanvullende vragen stellen. Mijn vragen zijn genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.

Ik weet dat meedoen helemaal vrijwillig is. Ik weet dat ik op ieder moment kan beslissen om toch niet mee te doen. Daarvoor hoef ik geen reden te geven.

Ik weet dat sommige mensen mijn gegevens kunnen zien. Die mensen staan vermeld in de Algemene brochure.

Ik geef toestemming om mijn gegevens te gebruiken, voor de doelen die in de informatiebrief staan.

Ik vind het goed om aan dit onderzoek mee te doen.

Naam proefpersoon:

Handtekening:

Datum : \_\_ / \_\_ / \_\_

-----  
Ik verklaar hierbij dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de proefpersoon zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
Aanvullende informatie is gegeven door (indien van toepassing):

Naam:

Functie:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
\* Doorhalen wat niet van toepassing is.

Toestemmingsformulier wettelijk vertegenwoordiger (indien van toepassing)

Betreffende het onderzoek naar de gevoelens van ‘thuis’ en ‘thuis zijn’ bij dementerende Marokkaanse migranten in Amsterdam.

Ik ben gevraagd om toestemming te geven voor de volgende persoon, zodat hij meedoet aan dit medisch-wetenschappelijke onderzoek:

Naam proefpersoon:

Geboortedatum: \_\_ / \_\_ / \_\_

Ik heb de informatiebrief voor de proefpersoon gelezen. Ik kon aanvullende vragen stellen. Deze vragen zijn naar tevredenheid beantwoord. Ik heb voldoende tijd gehad om te beslissen of deze persoon meedoet.

Ik weet dat meedoen helemaal vrijwillig is. Ik weet dat ik op ieder moment kan beslissen dat deze persoon toch niet meedoet. Daarvoor hoef ik geen reden te geven.

Ik weet dat sommige mensen de gegevens van deze persoon kunnen zien. Die mensen staan vermeld in de Algemene brochure.

Ik geef toestemming om de gegevens te gebruiken, voor de doelen die in de informatiebrief staan.

Ik vind het goed dat deze persoon meedoet aan dit onderzoek.

Naam wettelijk vertegenwoordiger:

Relatie tot de proefpersoon:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
Ik verklaar hierbij dat ik deze persoon/personen volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de wettelijk vertegenwoordiger zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
Aanvullende informatie is gegeven door (indien van toepassing):

Naam:

Functie:

Handtekening:

Datum: \_\_ / \_\_ / \_\_

-----  
\* Doorhalen wat niet van toepassing is.

## Appendix 2: Detailed description of respondents

- Mr. El Yousfi is sixty-seven years old and lives with his wife and their two youngest sons in Amsterdam Old-South. Their two daughters and the eldest son are married and have moved out. A couple years ago Mr. El Yousfi experienced problems with his pension; as a result his pension was set to the minimum. According to the family, this event has totally changed him. After this, his memory declined rapidly and his character changed. In November 2009 Mr. El Yousfi was found by the police walking on the freeway, totally lost and confused. After this event, the General Practitioner referred him to the Slotervaarthospital. In January 2010 he was diagnosed with Alzheimer's disease.
- Mr. Ait Haddou is seventy-three years old and lives with his wife and their two sons in Amsterdam Osdorp. Their three daughters are all married and live elsewhere in Amsterdam. Mr. Ait Haddou is diagnosed with vascular dementia in 2009.
- Mr. El Amrani is sixty-two years old and lives with his wife in Amsterdam Slotervaart. Their three children (two sons and a daughter) are all grown-up, married and live elsewhere in Amsterdam. Approximately ten years ago he complained of a tremor in his right hand and muscle rigidity. He was diagnosed with Parkinson disease in 2002 and since then his health has declined. Nowadays he experiences tremors in both hands, walking is difficult due to muscle rigidity and bradykinesia and he suffers from Parkinson related dementia.
- Mrs. El Morabet is fifty-nine years old and lives with her husband and two youngest children in Amsterdam East. Her other six children moved out and live in the neighbourhood. She was diagnosed with Alzheimer's disease in 2009.
- Mrs. Ben Saleh is sixty-eight years old and lives with her daughter and her daughter's family in Amsterdam Osdorp. After the death of her first husband she remarried and in 1978 she migrated to the Netherlands with her second husband and their five children. After two or three years she divorced and was left alone with her five young children. Four years ago her health declined and she moved in with her daughter, son-in-law and their three children. Two-and-a-half years ago Mrs. Ben Saleh was diagnosed with Alzheimer's dementia.
- Mrs. El Yacoubi is sixty-five years old and lives with her husband and youngest child in Amstelveen. Seven of her eight children are all grown up and have their own houses. In February 2010 she was diagnosed with Alzheimer's disease at the hospital in Amstelveen.

- Mrs. El Tahiri is sixty-three years old and lives with her husband in Leiden. All of her children have families of their own and live in the neighbourhood. Mrs. El Tahiri came to the Netherlands in 1984, to reunite with her husband. Her husband is a traditional Muslim and as a result, she barely leaves the house. She was diagnosed with Alzheimer's disease in 2010 and additionally with a depression.
  
- Mr. Rabbae came as a guest worker to Germany in 1967 and a few years later he decided to move to Amsterdam, the Netherlands. In 1985, the whole family migrated to the Netherlands, to join their husband and father. In 1995, Mr. Rabbae retired and decided to spend more time in Morocco. In 2003 he was diagnosed with Alzheimer's disease, though he was determined to return to Morocco. In 2007 Mr. and Mrs. Rabbae returned to the Netherlands again and moved in with their oldest daughter. Professional home-care was hired to provide care for father in the morning and evening. An electronically adjustable bed, a wheelchair and a chair in the shower were arranged, which relieved the degree of care. Mr. Rabbae passed away in December 2010.

## **Appendix 3: Interview script/topic list (in Dutch)**

### **Algemene gegevens**

Naam: .....

Leeftijd: .....

Geboortedatum: .....

Geslacht: M/V

Burgerlijke staat: Gehuwd/Ongehuwd

Samenstelling huishouden: .....

Aantal kinderen: .....

Etniciteit: .....

Datum: .....

### **Introductie**

Ik ben een studente sociale en culturele antropologie van de Vrije Universiteit in Amsterdam en doe drie maanden onderzoek voor mijn studie. Ik ben geïnteresseerd in gevoelens van thuis van Marokkaanse oudere migranten. Wilt u meewerken aan het volgende interview over uw ervaringen en gevoelens? Graag zou ik het gesprek op band opnemen zodat ik het interview later kan uitwerken. Ik zal ervoor zorgen dat u niet te herkennen bent in de verslaglegging van mijn onderzoek, tenzij u graag bij naam genoemd wilt worden.

### **Algemeen**

- Korte kennismaking
- Familie
- Huis
- Thuis

### **Thuis in Marokko**

- Herinneringen
- Foto's, voorwerpen
- Huis
- Vakantie
- Verschillen met Nederland

### **Thuis in Nederland**

- Migratie



- Eerste paar jaar
- Heimwee
- Komst familie
- Belangrijk
- Foto's, voorwerpen

### **Algemene relaties met landen**

Als u nu aan Marokko denkt, waar denkt u dan aan?

Als u nu aan Nederland denkt, waar denkt u dan aan?

Waar voelt u zich het meeste thuis?

Hoe komt dat?

Wat zou er in een voor u totaal nieuwe/vreemde omgeving voor zorgen dat u zich toch thuis zou voelen?

### **Toekomst**

Waar ziet u zichzelf als u aan thuis denkt?

Wat is belangrijk?

Wie zijn daar nog meer?

Als u de mogelijkheid had, zou u dan terugkeren naar Marokko? Waarom?

### **Afsluiting**

Zijn er nog dingen die u zelf graag kwijt wilt en die nog niet aan bod zijn gekomen?

## Appendix 4: Detailed description of key-informants

- *Ad* works as a gerontologist at the gerontology diagnostic centre at the Slotervaart hospital in Amsterdam. One of his main interests is dementia among elderly members of ethnic minorities and as such he supports my research.
- *Bd* finished her master's thesis in psychology in 2007, on the subject: Screening for dementia with elderly from ethnic minorities: validation of a neuropsychological test with Turkish elderly. She conducted her research at the Slotervaart hospital and after her graduation she started to work there as a neuropsychologist. Subsequently she has guided other students on the same topic and until now she is working on the validation of the neuropsychological tests for dementia.
- *Cd* is staff-member of Vilans, a centre of knowledge for long term care and support. Vilans is the subcontractor of the Expertisenetwerk Levensvragen en Ouderen (Network of Excellence Life questions and Elderly). They support projects and research linked to this topic, and as such they support my research.
- *Dd* is a PhD student from the University of Groningen (the Netherlands). Her research focuses on home and belonging of the second generation of Moroccan immigrants in the Netherlands.
- *Em* works at day-care centre Darkom, as groupleader. She works four days a week, Monday's and Wednesday's with Moroccan elderly men and Tuesday's and Thursday's with Moroccan elderly women. Two women who visit the centre suffer from Alzheimer's disease.
- *Fm* is director of multicultural home care association Avicen, as well as nurse practitioner diabetic care at the Slotervaart hospital. Avicen provides home-care for many Moroccan elderly in Amsterdam, and she knows many of them.
- *Gm* is the first occupational therapist with a Moroccan background in the Netherlands. She works for Cordaan and focuses mainly on occupational therapy for elderly Moroccans.
- *Hd* is a gerontologist working for Alzheimer Nederland, team 'Belangenbehartiging en zorgvernieuwing'. She is furthermore conducting a PhD research on the prevalence of dementia with elderly members of ethnic minorities.
- *Ym* works voluntary as chairman of the board for Moroccan elderly in Amsterdam East; COMAZ. COMAZ organizes activities and informational meetings to elderly men and women with a Moroccan background.
- *Jd* is the coordinator of the day-care centre at the Flevohuis in Amsterdam East. The day-care centre at the Flevohuis provides day-care for over fifty elderly in four different groups. Together with COMAZ and CIVIC, Jd tends to organize cultural specific day-care for Turkish and Moroccan elderly.

- *Km* is the chairman of home-care association *Leven & Zorg*, settled in Amsterdam Slotervaart. They started in January 2010 and focus on providing patient specific care. *Leven & Zorg* employs professionals from all different backgrounds, to meet the specific needs of their patients.
- *Ld* works as a visiting nurse migrant care for home-care association *Thebe* in Tilburg (the Netherlands). Over several years she has been involved in the interculturalisation of Dutch health care, among other things organizing courses about interculturalisation.
- *Mm* is staff member of *Stichting Marokkaanse Nederlanders* (Foundation of Moroccans in the Netherlands) Two years ago, SMN initiated the start of *MOBiN* (Association for Moroccan Elderly in the Netherlands) and in 2010 *MOBiN* was officially started to support elderly Moroccans in the Netherlands with for example income, health and well-being.
- *Nm* is the founder of the voluntary organizations *Assadaaka* and *Onze Hoop* in Amsterdam. *Assadaaka* is an organization which promotes participation, integration and social cohesion. *Onze Hoop* advocates for disabled migrants in the Netherlands.
- *Om* works at the *Amsterdams Steunpunt wonen* and is project coordinator of *Andalus*. *Andalus* is a commune in Amsterdam West for Moroccan elderly above the age of 50. The commune is opened in January 2010 and in the meantime all nineteen apartments are hired. A total of twenty-nine Moroccan elderly now resides in *Andalus*.
- *Pm* works as a project coordinator at *Sefkat*, a home which provides intramural care on physical or psychogerontology areas, which cannot be offered in the home environment of Turkish and Moroccan elderly in the Netherlands. *Sefkat* is situated in Boxtel (Noord-Brabant) and at this moment consists only of a day-care facility. In 2010, the first Alzheimer Tearoom will be organised in cooperation with *Alzheimer Nederland*. In 2011, it hopes to open the cultural specific nursing home.
- *Qd* works as a social cultural worker at *Dynamo* and is the chairman of the *Alzheimer Café* in Amsterdam East. In the last year, she has organized and performed informative meetings about dementia for members of ethnic minorities.