Knowing about forgetting

Perspectives and outcomes regarding dementia in family caregivers with a Turkish, Moroccan or Surinamese migration background

Nienke van Wezel

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Colofon

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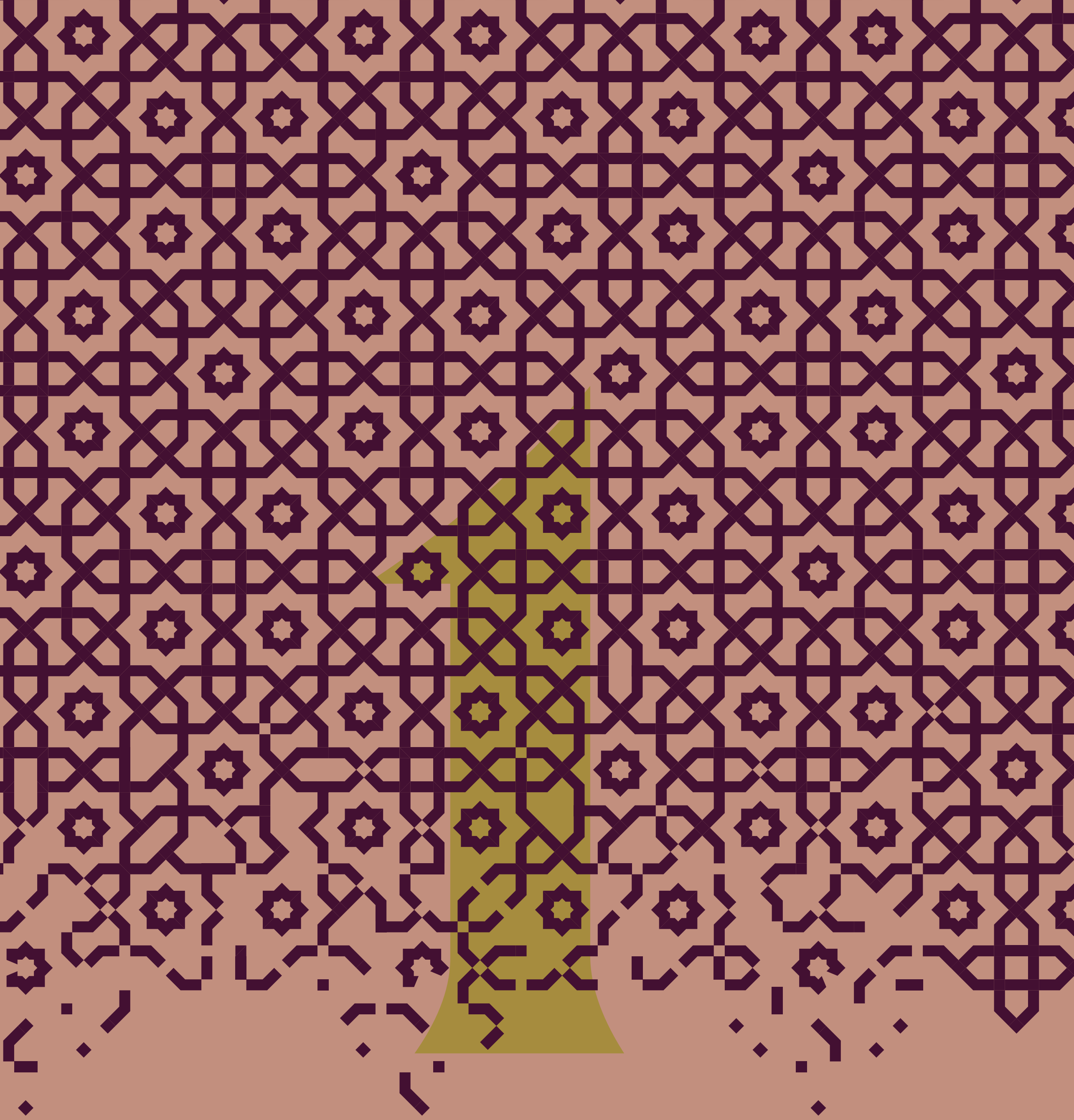
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Chapter 1

General introduction

General Introduction

Background

The number of people worldwide suffering from dementia is increasing (Alzheimer Disease International, 2021), including those with migration backgrounds. Research indicates that people with non-Western immigrant backgrounds make less use of professional dementia care and support options than people without migration backgrounds (Phillipson *et al.*, 2014). This might be due partly to them lacking information and knowledge about the available care and support options, and partly to culturally based perspectives on dementia and on care for family members (Shinan-Altman and Werner, 2019; Quinn *et al.*, 2017).

To assure equal access to dementia care and support, it is important to get a better understanding of how people with non-Western migrant backgrounds living in the Netherlands perceive these issues. So far, little is known about the perceptions, experiences and knowledge of non-Western migrant groups with respect to dementia, family care, dementia care and support options. We also did not know whether culture-specific educational programmes for family carers from these communities would result in positive effects on knowledge, use of support and care options, care pressure and quality of life. The research described in this thesis addresses these knowledge gaps.

First, this general introduction gives descriptions of dementia in general and with regard to people with non-Western migrant backgrounds. After that, information is given about family care and perceived care burden, quality of life, knowledge about dementia and explanations for dementia in non-Western migrant groups. Interventions for enhancing dementia-related knowledge are then shared, including an educational peer-group intervention for family carers with Turkish or Moroccan backgrounds. Finally, the main research questions and the structure of the thesis are presented.

Dementia

Dementia is a broad term covering various brain disorders that affect memory, thinking, behaviour and emotions. Symptoms of dementia can include memory loss, difficultly performing familiar tasks, problems with language and changes in behaviour. There are currently estimated to be 50 million people worldwide with dementia. The number of people affected is set to rise to over 152 million by 2050 (Alzheimer Disease International, 2020).

An estimated 280,000 people in the Netherlands suffer from dementia (Alzheimer Nederland, 2021). The number of people with a formal diagnosis of dementia is lower; that was estimated at 180,000 in 2017. More than half (62%) of them live at home and seven per cent of the total number of people with dementia are younger than 65 (Döpp *et al.*, 2020). Alzheimer's disease is the most common form of dementia. Alzheimer's disease is a progressive condition for which no single cause has yet been identified. However, several risk factors are linked to it, of which age is the most relevant, in addition to heredity.

Vascular dementia is the second most prevalent type of dementia (Liao *et al.*, 2016; Haaksma *et al.*, 2017). It is caused by a decreased supply of blood to the brain (Ueno *et al.* 2016). A significant proportion of people with vascular dementia (around 15%) have combined types of dementia, mostly a combination with Alzheimer's disease. About 13% of people with dementia have another form of dementia, such as dementia with Lewy bodies or frontotemporal dementia.

The course of the decline in functions can vary between one functional domain and another in the same person with dementia. For example, cognitive functioning may deteriorate rapidly while general daily functioning or neuropsychiatric symptoms remain stable for a long time (Haaksma *et al.*, 2018). Dementia often has a large impact on people who suffer from it. When looking at the individual consequences, the person's perspectives on their identity changes, and the feeling of dignity and the feeling that they matter often decrease during early to advanced dementia. A sense of loss of autonomy and uncertainty about the future are also common (Bunn *et al.*, 2012; The, 2017; Van Gennip *et al.*, 2016). People with dementia often have trouble retaining their former autonomy, especially when the symptoms multiply and become more serious. This might also produce feelings and expressions of loss, anger, insecurity and frustration.

In addition, having dementia also has consequences for social participation. Fear of disorientation, not being taken seriously or condemnation of their behaviour can make people with dementia withdraw from public life, which has consequences for their participation in society (Van Gennip *et al.*, 2016). It is often difficult for them to maintain social contacts, participate in club life and participate in group conversations (The, 2017).

Dementia in people with non-Western migrant backgrounds

In epidemiological research on dementia, non-western migrant groups are underrepresented. Nevertheless, there are indications that the prevalence of dementia is relatively high among these groups. A study conducted by Parlevliet and colleagues (2016, 2018) showed that mild cognitive impairment (MCI) and dementia were three to four times more prevalent in the majority of non-western immigrant groups compared to the native Dutch population. This higher prevalence is related to a higher prevalence of risk factors for developing dementia, such as diabetes, cardiovascular disease and depression, as well as socioeconomic position (Parlevliet *et al.*, 2016).

The largest non-western groups in the Netherlands are people with a Turkish, Moroccan or Surinamese background, which is defined in this thesis as people who themselves or at least one of their parents were born in Turkey, Morocco or Suriname. In the next section, their migration histories and cultural backgrounds are described, since this thesis focusses on these groups.

Migration histories and cultural backgrounds

The number of Dutch residents with non-Western backgrounds who have dementia is expected to increase in the coming years. This is because many of them immigrated to the Netherlands about half a century ago and are aging now.

In the 1960s and ’70s, thousands of Turkish and Moroccan men came to the Netherlands at the invitation of companies, or later on their own initiative (Akgündüz, 1993). They usually did arduous, unskilled and poorly paid work. Many of them wanted to save money to start their own business in their home country. However, life in the Netherlands turned out to be expensive and the salaries often lower than hoped, so they stayed in the country.

A new wave of migration started as a result of family reunification (Esveldt, 1995). The Turkish and Moroccan ‘guest workers’ often had a low level of education (CBS, 2020). The mother tongue of the Turkish guest workers was Turkish; Moroccan guest workers spoke either Moroccan Arabic or Berber dialects. The latter can only be written phonetically.

Although ethnic roots varied between and within the Turkish and Moroccan migrant groups, they had some cultural characteristics in common, not only regarding their migration histories but also in terms of religion (mainly Muslim). Furthermore, in both Turkish and Moroccan migrant communities, respect for older family members and the responsibility of younger family members to support ageing parents are key values. There are also similarities in the division of male and female tasks within the family. A study by Yerden (2013) described the first generation of Turkish migrants as coming from a predominantly agricultural society with a patrilineal family structure. Within the family, the men are considered responsible for the organization of family care while the female family caregivers actually give the care for care-dependent family members. Although Yerden’s research focused on people with Turkish migrant backgrounds, there seem to be similarities in the first generation of Moroccan migrants living in the Netherlands.

Tthe first generation of Surinamese Creole migrants is also aging now, although their migration history and cultural backgrounds are different from those of people with Turkish or Moroccan origins. In the middle of thetwentieth century, young Surinamese (primarily boys from the Creole and Jewish elites) came to study in the Netherlands. After graduating, many of them continued to live in the Netherlands because there wer better career prospects than in Suriname. A new migration wave appeared around the independence of Suriname in 1975, when large groups of Surinamese Creole or Hindustani origins came to the Netherlands (CBS, 2020). Social security in the Netherlands was the primary reason for this second group to come to the Netherlands. In terms of education, they were on average less educated than the first group of Surinamese migrants (Bovenkerk, 1983).

Language barriers to participating in Dutch society did and do not exist in the Surinamese Creole migrant group, which is the Surinamese subgroup addressed in this thesis. The vast majority speak Dutch. The Christian religion of many migrants of Surinamese Creole origin also corresponds to the religious background of many native Dutch people. However, there are also some cultural specifics: especially in the Surinamese Creole group, there are relatively many single-parent families, in which strong and independent women have a pivotal role in caring for both their children, parents and other elderly people in their community (Distelbrink, 2000).

Family caregivers' knowledge and explanations regarding dementia

Family might be the first to pick up on early signs and symptoms of dementia. However, in general, the family do not always understand the symptoms they are observing and do not always relate them to dementia, even after the relative has been diagnosed (Quinn *et al.*, 2017). This might be extra difficult for people in non-Western groups (Nielsen *et al.*, 2016; Parveen *et al.*, 2017) because of language problems and the – often relatively low – levels of education. Difficulties recognizing symptoms of dementia may result in later diagnosis of dementia or no diagnosis at all (Goudsmit *et al.*, 2021; Berdai Chaouni and De Donder, 2018).

People with non-Western backgrounds may also have other explanations and perceptions of illness than the general population. An international scoping review of a total of 25 studies revealed that, in general, people often explain dementia as a chronic condition, caused by age, heredity and abnormal brain changes (Shinan-Altman and Werner, 2019). However, the scoping review did not describe what knowledge and explanations family caregivers with non-Western migrant backgrounds have for dementia. In the Netherlands, some studies focused on this issue. The qualitative study by Hootzen *et al.* (2012) showed that family caregivers with a Turkish, Moroccan or Surinamese Creole immigration background described dementia as severe forgetfulness and as a result of old age or life events like immigration or divorce. The study by De Vries (2007) among people with Turkish immigrant backgrounds living in Amsterdam showed similar results.

This thesis, focusing particularly on Dutch nationals with Turkish, Moroccan or Surinamese Creole backgrounds, gives more insight into the knowledge about dementia and explanations of it in these groups.

Preferences for family care rather than professional care in non-Western migrant groups

In non-Western cultures, family care for people with dementia is often preferred to professional care (Berdai-Chaouni and De Donder, 2019; Hootzen *et al.*, 2012). Various interacting factors could explain this preference, e.g. lack of knowledge of and unfamiliarity with facilities such as professional home care, language barriers, a sense of responsibility to care for your parents, the perception of being stigmatized by the community for reliance on professional care, lack of culturally sensitive professional care for older people, and financial barriers affecting the accessibility of services (Berdai-Chaouni and De Donder, 2019; Denktas *et al.*, 2009; Denier and Gastmans, 2013; McClearly and Blain, 2013; Mukadam *et al.*, 2011 and 2013; Monsees *et al.*, 2020; Sagbakken *et al.*, 2018). These interacting factors might reinforce hesitancy and wariness against turning to professional care services.

The burden of care on family caregivers

The preferences for family care mentioned above and barriers to the use of professional support options have an impact on family caregivers. By ‘family caregivers’ we mean people who provide unpaid care on a voluntary basis to people from their family or broader social network, e.g. a partner, father, mother, brother, sister, friend or neighbour. Due to the significant personal relationship between the caregiver and care receiver, we have deemed the term ‘family caregiver’ more appropriate than ‘informal caregiver’, although friends and neighbours are not literally ‘family’.

In general, family caregivers often provide direct care and support and/or arrange professional care for their relative with dementia. In addition, family caregivers of people with dementia often offer emotional support, administrative assistance, personal care and arrange transport (Vernooij-Dassen *et al.*, 2017; Peeters *et al.*, 2012).

Various studies have shown that caring for a relative with dementia is demanding and that the self-perceived pressure of family caregivers is often high (Van der Heide *et al.*, 2020; Connors *et al.*, 2020; Hootzen *et al.*, 2012). As the disease progresses, the burden of family care often increases (Connors *et al.*, 2020); the demands arising from caring for the person with dementia are often not proportionate anymore to the space family carers also need for other roles, activities and thoughts (De Boer *et al.*, 2012). A survey in 2020 among more than 3,500 Dutch family caregivers of people with dementia showed that family carers on average provide 40 hours of family care per week and that fourteen per cent feel overburdened. Family caregivers who live with the person with dementia often feel most pressured. A large percentage provide care day and night (36%) for the person with dementia. The actual hours differ depending on the domestic situation: for family caregivers caring for people with dementia who live together, the actual average hours are the highest, namely 65 hours (Van der Heide *et al.*, 2020).

To alleviate the pressure in family caregivers, the availability of care and support from professionals and from other people in the community is important. However, related to the preferences mentioned above for family care, people from non-Western migrant communities often make limited use of the available support options and services (Phillipson *et al.*, 2014; Cooper *et al.*, 2010; Kenning *et al.*, 2017, Hootzen *et al.*, 2012; Van Wieringen and Van Grondelle; 2014). They initially often do not feel that support is needed (Carpentier *et al.*, 2008) and also fear stigma, losing independence (Clement *et al.*, 2015), and negative attitudes towards accepting support can hamper the use of professional support (Dam *et al.*, 2017). Another reason for limited use of professional support concerns difficult and time-consuming access procedures (Peel and Harding, 2014: Phillipson, 2014; O'Donnell *et al.*, 2016), and late detection and diagnosis of dementia (Vissenberg *et al.*, 2018). In a study performed in the UK, family carers expressed the need for better advice and support in this process of accessing professional care (Peel and Harding, 2014). A lack of information after the dementia diagnosis about dementia and about available resources can be another reason for limited uptake of professional support (Goudsmit *et al.*, 2011). The systematic review carried out by Greenwood and Smith (2015) established that providing such information post-diagnosis is a facilitator in help-seeking.

Effects of family care on quality of life of family caregivers

Family care affects aspects of quality of life of the caregivers. A systematic review carried out by Yu *et al.* (2018) showed positive feelings from giving family care; family caregivers can perceive personal accomplishment and gratification, feelings of mutuality in a two-way relationship, increased family cohesion and functionality, and personal growth and a purpose in life (Yu *et al.*, 2018).

Because of these positive factors, family caregivers may not have a great need to share care with others. However, limited use of professional support can result in a high burden of care for family caregivers and can therefore also negatively affect their quality of life (Bleijlevens *et al.*, 2015; Alltag *et al.*, 2019; Conrad *et al.*, 2018; Stall *et al.*, 2019). A decrease in the quality of life is often associated with the physical and emotional burden of caring for a relative with dementia (Farina *et al.*, 2020; Sittironnarit *et al.*, 2020.) In addition, not sharing the care with others might have consequences for social aspects of quality of life. The Dutch survey study by Van der Heide *et al.* (2020) mentioned previously showed that 38% of the family caregivers reported a decline in social contacts.

Although the afore-mentioned studies mainly focus on general populations, negative consequences of caring for a relative with dementia might also be seen among family caregivers of people with dementia in non-Western migrant communities. Maybe even more so, given the great demands that are often made of them. The report by Alzheimer Europe about intercultural dementia care states that people from non-Western migrant groups provide relatively many hours of family care (Gove *et al.*, 2020), which might have an impact on their quality of life. This thesis therefore also provides a picture of the quality of life of family caregivers with Turkish or Moroccan migrant backgrounds who care for a person with dementia.

Interventions to enhance dementia-related knowledge and to realize access to care and support

Appropriate knowledge about dementia and about support options is important for giving people access to professional support as well as for support from other people in the community. Until now, there was only limited evidence about the effects of educational interventions on dementia-related knowledge. In the systematic review by Moore and colleagues (2020) on educational interventions about dementia, only two of the total of eleven studies reviewed had knowledge as an outcome variable. The two studies provided inconsistent results: one showed no effects on knowledge (Paun *et al.*, 2015), while the other showed a short-term positive effect on knowledge (Christancho-Lacroix *et al.*, 2015).

In the Netherlands, various organizations (e.g. Alzheimer Netherlands, Pharos, Vilans) and programmes and campaigns (e.g. 'Care for better'; 'Dementiezorg voor Elkaar' and 'Samen Dementievriendelijk') provide information about dementia and support options. Most of the initiatives are aimed at the general population, although some of the organizations involved pay attention specifically to migrants (Pharos and Vilans). Information about the characteristics of the disease and about options for care and support for people with dementia and their family is often offered in Dutch, requiring Dutch reading and comprehension skills. Such information and educational programmes might therefore not be automatically accessible and culturally sensitive enough to reach family caregivers with migrant backgrounds. This might be problematic, particularly for those with knowledge gaps about dementia and support options.

This prompted a decision by the author of this thesis plus other staff of Alzheimer Netherlands to develop the culturally sensitive educational peer group intervention "Knowing about forgetting", which targeted groups of family caregivers with Moroccan or Turkish migrant backgrounds. The main aim of the educational intervention was to enhance knowledge about dementia and the care and support options. The intervention was limited to Turkish and Moroccan groups and was not carried out among Surinamese Creole groups, as it was not feasible within the scope of this thesis to recruit enough participants with Surinamese Creole backgrounds.

Background and elements of the peer group educational intervention

The "Knowing about forgetting" intervention was offered to groups who then participated in two educational sessions. The first session focused on learning about dementia and the symptoms and course of the disease. In the second, participants were actively invited to discuss dementia with each other on the basis of predefined cases about providing family care for a person with dementia. The groups were homogenous in the sense that only educators and people with the same migrant background participated (either Turkish or Moroccan).

The intervention was a form of 'peer education', which is defined as an approach for delivering information to peers, for improving social learning and providing psychosocial support. Peers are people who have the same background, e.g. culture, social status and interests (Abdi *et al.*, 2013). Peer education is often used among adolescents but can be effective in adults as well. Previous studies of the effects of peer education in adults are relatively often done among cancer patients, showing that peer education can lead to increased levels of knowledge and comprehension, and knowledge about treatment and complications (Gozum *et al.*, 2010; Heydarzadeh *et al.*, 2019). Peer education is considered especially useful in target groups who are hard to reach (Turner and Shepherd, 1999), of which people with non-Western migrant backgrounds are a good example.

The group sessions in the "Knowing about forgetting" intervention were led by one or two peer educators. As is usual in peer education, each peer educator received special training and information about the topics discussed in the intervention and about how to create positive behaviour changes among the peer group (Mason-Jones *et al.*, 2011), how to act as role models (Merakou *et al.*, 2006), and how to create levels of trust and comfort within the peer group (Medley *et al.*, 2011). The principles of our peer education approach are based on te social learning theory, which was proposed by Bandura (1977) and emphasizes the importance of observing, modelling and imitating the behaviours, attitudes and emotional reactions of others. This theory asserts that individuals can function as role models due to their aptitude for encouraging behavioural changes in other individuals (Bandura, 1977; Burke *et al.*, 2012). Education by peer educators who can function as role models and who have the same culture and language/dialect was expected to be beneficial for enhancing knowledge and openness about dementia in the "Knowing about forgetting" intervention.

Our peer education approach also met the principles of VETC (*Voorlichting in Eigen Taal en Cultuur*/ Information in your own language and culture; Enting, 2006). Particularly in the late 1990s and early 2000s, a lot of local and regional organizations organized health care campaigns and interventions in which VETC consultants were involved. These consultants were trained and certified health educators who gave health education to migrant groups in their own language and culture (Helberg-Proctor *et al.*, 2017). Over the last decade, VETC consultants were less involved in campaigns, which might be due to the emphasis in politics and healthcare policy on integration rather than on culture-specific issues of migrants. Nevertheless, we expected that a culturally specific peer approach, in which participants and trainers could identify with each other, would promote the transfer of knowledge and strengthen interactions in the "Knowing about Forgetting" intervention.

We selected 23 peer educators with Turkish or Moroccan backgrounds. Together they offered role modelling in the relevant cultural groups with their own language or dialects. The peer educators selected received appropriate training from dementia experts and the researcher, which enabled them to understand the purpose of the intervention, be good listeners and motivators, be open when speaking about dementia, provide motivation and improve knowledge about dementia and support options. They were trained in transferring knowledge about dementia and the options for local support and knew other relevant information sources to refer to when participants asked for appropriate help during or after the intervention. In the meantime, there was an intensive intervision process between peer educators and the author of this thesis/researcher to share and stimulate interim learning effects.

The evaluation of the intervention

To date, there is only very limited knowledge about the effectiveness of educational interventions about dementia in migrant communities and there were no studies with a strong methodological design (i.e. RCTs). However, some relevant studies have been done among people with migration backgrounds into the effects of educational programmes about cancer. These studies show promising results. For example, in a pre- and post-test study by Cullerton *et al.* (2016) in Australia, a culturally tailored cancer screening education programme was evaluated. It showed positive effects on knowledge, attitudes and intentions to participate in cancer screening among migrant and ethnic minority groups. Comparable results were found in a study by Kwok *et al.* (2016). This study evaluated the impact of a culturally sensitive education programme among Australian-Chinese women about breast and cervical cancer. The programme was effective in improving awareness and knowledge about cancer. Although these studies concern people faced with cancer rather than dementia, they point towards offering culturally sensitive educational interventions being able to enhance awareness and knowledge about a disease. This thesis therefore also describes the effects of the “Knowing about forgetting” intervention on knowledge and other outcomes of family carers of people with dementia with a Dutch-Moroccan or Dutch-Turkish background.

Aim, outline and research questions of the thesis

The aim of this thesis is:

“to gain an understanding of the experiences with family care, the explanations given of the causes of dementia and the communication about dementia among family caregivers from Turkish, Moroccan and Surinamese Creole migrant groups in the Netherlands. An additional aim is to get a picture of the effects of the “Knowing about forgetting” educational programme on the knowledge, ability to talk about dementia, use of informal and professional care, perceived pressure of care and quality of life of Turkish-Dutch and Moroccan-Dutch family caregivers of someone with dementia”.

The first part of the thesis – chapters 2 and 3 – is based on qualitative interviews and focus group interviews with women from Turkish, Moroccan and Surinamese Creole migrant groups about their explanations of the causes of dementia and about their experiences with family care for a relative with dementia.
The main research questions addressed in **Chapter 2** are:

How do female family carers with a Turkish, Moroccan or Surinamese Creole background and who are living in The Netherlands explain and describe the dementia of their close relatives'?
Do they perceive that their close relatives' dementia can be discussed openly within the family or in the wider community?

The main research question of **Chapter 3** is:

What are the perspectives of female family carers with a Turkish, Moroccan or Surinamese Creole background, and living in the Netherlands, about family care to a close relative with dementia?

The second part of this thesis – chapters 4 and 5 – presents psychometric properties of two questionnaires that were used to describe the effects of the "Knowing about forgetting" educational intervention. ***Chapter 4*** *reports on the psychometric properties of the Dementia Knowledge Scale (DKS). The main research question in this chapter is:*

What are the internal consistency and validity of the DKS as completed by family caregivers with a Turkish or Moroccan background?

Chapter 5 reports the psychometric properties of the Turkish version of the original Dutch questionnaire SSPIC (in Dutch EDIZ). The questionnaire measures self-perceived pressure from family care. The research question answered in this chapter is:

What is the internal consistency and the known group validity of the Turkish version of the SSPIC, as completed by family caregivers of people with dementia in Turkish migrant communities in the Netherlands?

The third part of this thesis - chapters 6 and 7 – describes the effects of the "Knowing about forgetting" intervention. The following main research questions were addressed in **Chapter 6:**

Does participation in the educational peer-group intervention "Knowing about forgetting" lead in family caregivers with a Turkish or Moroccan background to:
- *improved knowledge about dementia?*
- *improved perceived ability to talk about dementia or severe memory problems?*
- *increased use of informal or professional support?*
- *decreased self-perceived pressure from informal care?*

Chapter 7 describes the quality of life of family caregivers with Turkish or Moroccan migrant backgrounds, as well as the effects of the "Knowing about forgetting" intervention on the quality of life of these caregivers. The main research questions are:

What is the health-related quality of life of family caregivers of people with dementia with a Turkish or Moroccan background living in the Netherlands?

Can the health-related quality of life in these groups be enhanced by the educational peer group intervention "Knowing about forgetting"?

Chapter 8 concerns the summary and general discussion of the results as described in the previous chapters and also contains a reflection on the research process. This chapter ends with conclusions and recommendations for research and practice.

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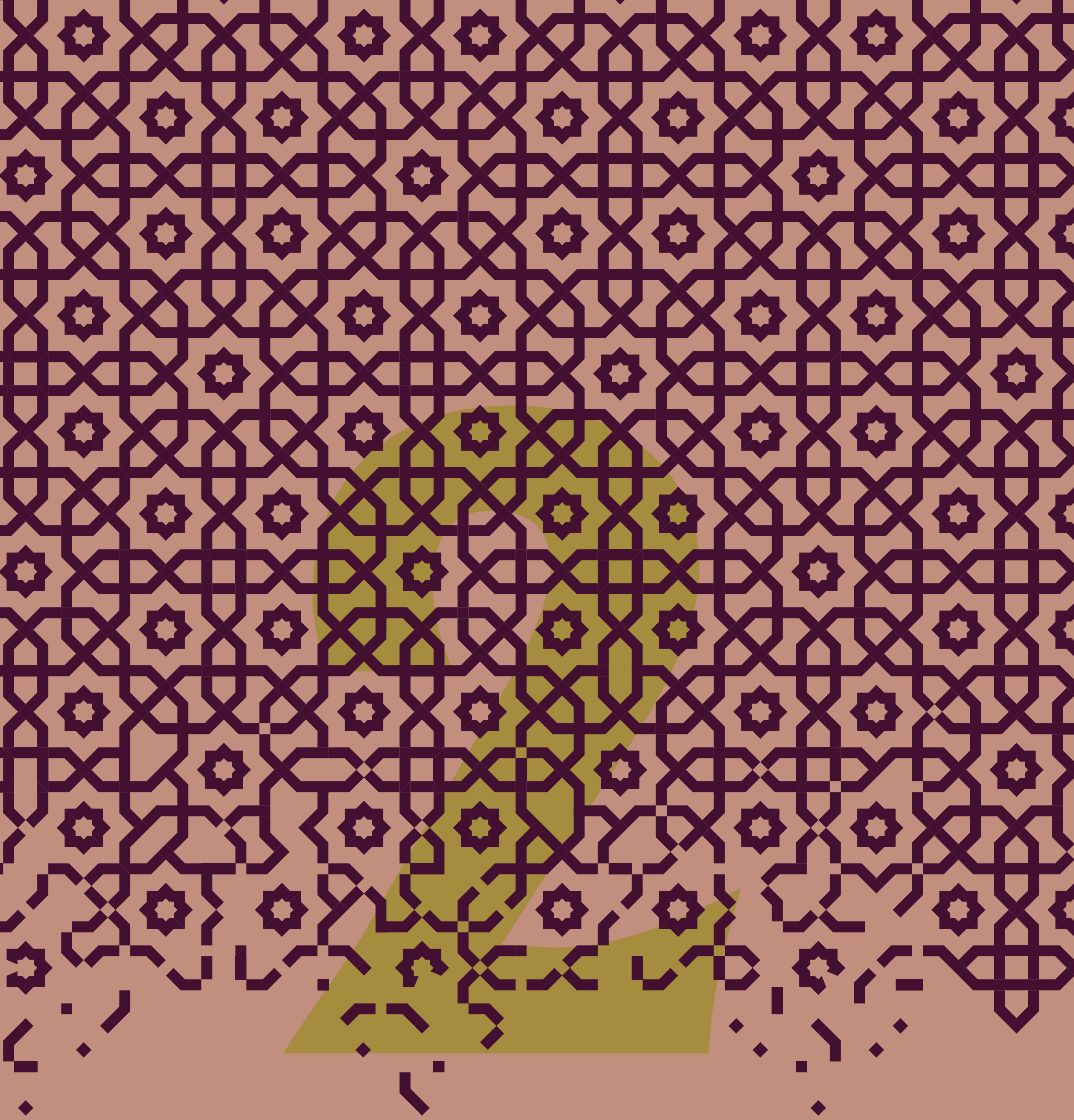
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Chapter 2

Explanatory models and openness about dementia in migrant communities: A qualitative study among female family carers

van Wezel N, Francke AL, Kayan Acun E, Devillé WL, van Grondelle NJ, Blom MM. Explanatory models and openness about dementia in migrant communities: A qualitative study among female family carers. Dementia (London). 2018 Oct;17(7):840-857.

Abstract

Background: The prevalence of dementia is increasing among people with a Turkish, Moroccan and Surinamese-Creole background. Because informal care is very important in these communities, it is pertinent to see what explanations female family carers have for dementia and whether they can discuss dementia openly within the community and the family.

Method: Forty-one individual interviews and six focus group interviews (*n*= 28) were held with female Turkish, Moroccan and Surinamese Creole family carers who are looking after a close relative with dementia, and who live in The Netherlands. Qualitative analysis has been carried out, supported by the software MaxQda.

Results: The dominant explanations of dementia given by the female family carers interviewed are in line with what Downs *et al.* describe as the explanatory models 'dementia as a normal ageing process' and 'dementia as a spiritual experience'. In addition, some female family carers gave explanations that were about an interplay between various factors. Turkish and Moroccan informal caregivers ascribe the causes of dementia relatively often to life events or personality traits, whereas Surinamese Creole caregivers frequently mention physical aspects, such as past dehydration. However, the explanatory model 'dementia as a neuropsychiatric condition', which is dominant in Western cultures, was rarely expressed by the informal caregivers. The female family carers generally talked openly about the dementia with their close family, whereas particularly in the Turkish and Moroccan communities open communication within the broader communities was often hampered, e.g. by feelings of shame.

Conclusions: Female family carers of Turkish, Moroccan or Surinamese Creole backgrounds often consider dementia as a natural consequence of ageing, as a spiritual experience, and/or as an interplay between various factors. They feel they can talk openly about dementia within their close family, while outside the close family this is often more difficult.

Keywords:
dementia, family care, explanatory models, openness, communication, immigrants

Introduction

Dementia among populations with a non-western background is a topical issue. The ageing population and increasing life expectancy are leading to significant increases in the number of people with dementia in industrialized countries (Alzheimer's Disease International (ADI), 2012). This also applies to non-Western communities in those countries (Demirovic *et al.*, 2003; Fitzpatrick *et al.*, 2004). In the Netherlands, for instance, it is estimated that about 28,000 people with a non-western background have dementia, which is 10% of the total number of patients. It is expected that this figure will have risen to about 38,000 (+34%) by 2020, after which the increase will continue further due to the increased life expectancy and ageing of non-western minority groups (Alzheimer Nederland, 2013). The increase in dementia will in fact be relatively greater among these groups than in the indigenous population, because illnesses such as diabetes and cardiovascular disease (which increase the risk of dementia) are more prevalent among people from non-western origin (Adelman, Blanchard, & Livingstone, 2009; Dijkstra, Berghout, & Sauerwein, 2003; Forouhi *et al.*, 2006; Denktas *et al.*, 2009).

The rise of dementia will place heavy demands on informal caregivers. Family-based care given by women is relatively common in non-western communities in The Netherlands, e.g. communities of people with a Turkish, Moroccan or Surinamese background. This is related to the importance placed there on care by close female family members, as well as barriers in the access to professional care (De Graaff, Francke, van den Muijsenbergh, & Van der Geest, 2010; Denktas, 2011; van Wezel *et al.*, 2014). Because of the increasing number of people with dementia and the fact that female family carers have an important role, it is relevant to explore what explanations those family carers have for dementia and the extent to which it is possible for them to discuss dementia openly within the community and the family.

Medical, gerontological and anthropological literature describes a variety of explanatory models regarding the cause of illness (e.g. Botsford, Clarke, & Gibb, 2011; Cohen, 1992; Downs, Clare, & Mackenzie, 2006; Kleinman, 1976; Sun, Ong, & Burnette, 2012). Explanatory models of illness in contemporary Western societies are largely framed within a medical model, where the causes of illness are sought in biological alterations in individuals (Crossley, 2000). However, the medical model is challenged by the biopsychosocial model (Engel, 1997). This model allows for an integration of the psychological and social aspects of illness alongside the purely biological aspects (Marks, Murray, Evans, & Estacio, 2005).

Downs *et al.* (2006) described explanatory models of dementia in particular. They determine four explanatory models: dementia as a neuropsychiatric condition (which fits with the aforementioned medical model), dementia as a form of interplay between biological, psychological and social factors (which fits with the biopsychosocial model), dementia as a spiritual experience, and dementia as a normal ageing process.

People who explain dementia as a normal ageing process, see the memory and behavioural problems of people with dementia as inherent of ageing. This way of looking at dementia is, according to Byetheway (1994), to be found above all in non-western groups in which being old is respected and the elderly are treated with respect. Other studies also indicate that non- western dementia caregivers often incorporate non-medical terms into their explanations of dementia (Botsford *et al.*, 2011; Hinton, Franz, Yeo, & Levkoff, 2005; Zhan, 2004).

Within the model of dementia as a spiritual experience, dementia is seen as a consequence of the effects of good spiritual influences, or often also of evil ones (the 'evil eye' or 'witchcraft', for instance). Spiritual forces are also thought to underpin the changes in behaviour or 'madness' of the person with dementia. Ascribing dementia to spiritual forces is seen primarily in non-Western cultures (Downs *et al.*, 2006; Hussain, 2001).

The explanatory model that considers dementia as a neuropsychiatric condition sees dementia as a progressive brain disorder, generally Alzheimer's disease or vascular dementia, or both. Cognitive and behavioural changes that are associated with dementia are described in this model – which is dominant in Western cultures (Ayalon & Arean, 2004; Hinton *et al.*, 2005; Roberts *et al.*, 2003) – as 'symptoms'.

Seeing dementia as an interplay of factors is an explanatory model that is also quite common in Western cultures. People who work from this model (e.g. Kitwood, 1990) see dementia as an interaction between brain disorders (such as Alzheimer's disease) and psychosocial environmental factors. Downs *et al.* (2006) do point out here that the four explanatory models are not entirely mutually exclusive: different explanatory models can coexist within a single person, let alone any given community.

Next to describing the explanatory models that Turkish, Moroccan and Surinamese- Creole female family carers use for dementia, we look at how openly the subject of dementia can be discussed in the communities concerned; this can also depend in part on the explanatory models that people have adopted for the illness. Studies among non-Western minorities in the US (Gary, 2005), Great Britain (Wolff, Pathare, Craig, & Leff, 1996), Greece (Papadopulos, Leavey, & Vincent, 2002) and the Netherlands (De Vries, 2009; Rijkers, 2010) show taboos against speaking openly about dementia. For instance, in Moroccan-Dutch communities, denial, shame and the emotions that come hand in hand with dementia keep the subject taboo (Rijkers, 2010). Dementia would also hardly discussed at all in Turkish-Dutch non-western communities; this is thought to be associated with fear of the condition as well as feelings of shame (De Vries, 2009). Finally, 'public stigma' (social groups endorsing stereotypes against a stigmatised group, in this case people with dementia) would hamper open discussions on dementia (Corrigan & Watson, 2002; Graham *et al.*, 2003; Werner & Heinik, 2008).

The majority of the studies mentioned above (De Vries, 2009; Rijkers, 2010) only examine the perspectives of a single group. Comparisons are however interesting, because it seems likely that explanations chosen for dementia and how freely it can be discussed, varies between different non-western groups. Therefore this qualitative study gives insights into the differences and similarities in the explanations for dementia and how freely this illness can be discussed, from the perspectives of female family carers from the three largest non- Western communities in the Netherlands (Turkish, Moroccan and Surinamese Creole). These insights can be used to tailor information and support for these non-western groups that are increasingly faced with dementia.

The following research questions are central to this study:

1. How do female family carers with a Turkish, Moroccan or Surinamese Creole background and who are living in The Netherlands explain and describe the dementia of their close relatives'?
2. a. Do they perceive that their close relatives' dementia can be discussed openly within the family or in the wider community?
   b. Do they think that it is important to be able to discuss dementia openly?
3. What similarities and differences are there between female family carers with Turkish, Moroccan and Surinamese Creole backgrounds in terms of how openly dementia can be discussed and regarding the explanations of dementia?

We use the term 'family carers' for people who voluntarily provide unpaid care for people in their family or social network. Family carers are for example partners, children or other close relatives who look after someone from their family or wider network.

The description as having a 'Turkish, Moroccan or Surinamese Creole background' refers in this case to people who are resident in the Netherlands but were themselves born in Turkey, Morocco or Suriname, or who have at least one parent who was born in one of those countries. The indicator 'Creole' appended to 'Surinamese' is used to refer to people who are at least partly of African descent. The Creole culture is a melting pot of various African cultures plus Indian and European influences; the religion is predominantly Christian and the mother tongue is Dutch. The first generation of Surinamese Creoles came to the Netherlands in the sixties or seventies to study, or as a consequence of decolonialization (Suriname used to be a Dutch colony).

The migration history of Turkish and Moroccans is different: the first migrants arrived in the Netherlands between 1965 and 1980 to work, or as family members of these so-called 'guest workers'. Although Turkish and Moroccans living in The Netherlands have differing ethnic backgrounds, there are overlaps, not only in their migration history, but also in terms of socio-economic status (generally low), religion (mostly Muslim) and mastery of Dutch (often poor among the first generation).

Method

Choosing to do a qualitative study from the emic perspective of family caregivers

We opted for qualitative research (individual interviews and focus group interviews) because we wanted to gain insights into individuals' own experiences and opinions. In our research, we focused on describing the 'emic perspective' (Headland, Pike, & Harris, 1990; Reis, van der Geest, & Gerrits, 2008), which in this case implies that we obtained a picture of how the Turkish, Moroccan and Surinamese-Creole female family carers themselves explain dementia and how openly it can be discussed within their own cultural and social context. We focused on this emic view of family carers because of our special interest in this target group. Our research strategy can be characterized as a 'generic qualitative approach'. Generic qualitative research does not have a guiding set of philosophic assumptions or methodological strategies from one specific qualitative methodology, but exhibits some characteristics of various methodologies (such as grounded theory methodology or ethnography). Basic requirements of a generic qualitative approach are noting the researchers' position, congruence between methods and methodology, making explicit the approach to rigour, and identifying the researchers "analytic lens" (Caelli, Ray, & Mill, 2003).

Recruitment and sampling for the individual interviews

During the period from April 2010 to March 2011, semi-structured interviews were held with female family carers who were looking after a close relative with dementia or – where there was no official diagnosis (yet) – severe memory problems.

A total of 16 Turkish, 14 Moroccan and 11 Surinamese Creole female informal caregivers were interviewed. These women were recruited indirectly through nursing staff, dementia case managers, key figures from the ethnic communities or dementia educators. The recruitment process attempted to achieve some degree of spread in age and between the three groups involved. No minimum or maximum number of interviews was defined beforehand. A total of 41 individual interviews turned out to be sufficient to achieve data saturation in each of the three groupings, i.e. the point at which no more new or relevant information was being found when additional data was collected (Guest, Bunce, & Johnson, 2006). Table 2.1 shows the backgrounds of the female family carers interviewed.

Recruitment and sampling for the focus group interviews

Focus group interviews were held in the period from May 2012 to July 2012, so that we could further refine the insights obtained from the preceding individual interviews. Six focus group interviews were held: two with Turkish female family carers, two with Surinamese Creole and two with Moroccan. Two to seven caregivers took

Table 2.1 *Features of the backgrounds of the female family carers interviewed.*

Group	Age (distribution)	Lives with a close relative with dementia?	Family relationship
Family carers from the individual interviews (n = 41)			
Turkish (*n* = 16)	Distribution = 31–74	Yes: 6 No: 10	Daughter: 14 Daughter-in-law: 1 Spouse: 1
Moroccan (*n* = 14)	Distribution = 20–48	Yes: 5 No: 9	Daughter: 12 Daughter-in-law: 2 Spouse: 0
Surinamese (*n* = 11)	Distribution = 50–84	Yes: 1 No: 10	Daughter: 8 Daughter-in-law: 2 Spouse: 1
Female family carers from the focus group interviews (n = 28)			
Turkish (*n* = 10)	Distribution = 30–50	Yes: 4 No: 6	Daughter: 10 Daughter-in-law: 0 Spouse: 0-
Moroccan (*n* = 12)	Distribution = 30–60	Yes: 5 No: 7	Daughter: 5 Daughter-in-law: 4 Spouse: 1 Other: 2
Surinamese (n = 6)	Distribution = 30–70	Yes: 0 No: 6	Daughter: 6 Daughter-in-law: 0 Spouse: 0

part in each of the focus groups. A total of ten Turkish, six Surinamese Creole and twelve Moroccan carers participated in the focus group interviews (see Table 2.1). The recruitment of the participants for the focus groups was also done via care providers (nursing staff, case managers), key figures from the community and dementia educators with the same ethnic origins. Carers were only allowed to take part in a focus group interview if they had not yet been interviewed individually.

Organization and content of the individual and focus group interviews

Both the individual interviews and the focus group interviews worked with a list of topics and open questions, such as "Why are you able or not able to talk openly about the illness of your close relative within your family?", "Are you able to talk about it openly within your community or not?" and "How would you explain how the illness arose in your relative?"

These topic list questions were drawn up after discussions with experts of Dutch, Turkish, Moroccan and Surinamese origins and after studying the relevant literature (De Graaff & Francke, 2003, 2010; Downs *et al.*, 2006; Rijkers, 2010; Uiters, Deville, Foets, & Groenewegen, 2006).

The individual interviews were held by the first author (NvW, a female native Dutch researcher and gerontologist, employed by Alzheimer Nederland), the third author (EK, a female Turkish/Dutch health scientist employed by Alzheimer Nederland) or by trained female interviewers with the same non-western backgrounds as the interviewees. The individual interviews were all held at the participants' homes. The interviews were held in Dutch, except for six of the Turkish family carers, whose mastery of Dutch was insufficient. These six interviews in Turkish were then translated literally into Dutch by the third author (EK), whose mother tongue is Turkish but also speaks fluent Dutch. The interviews took between one and two hours.

The six focus group interviews were held by the third author (EK), the fifth author (NvG, a female native Dutch health scientist who works as a project leader at Pharos, a knowledge and advice centre for healthcare for immigrants and refugees) or by trained interviewers with the same non-western background as those taking part. The focus group interviews were held in social centres, community centres and nursing and care homes. One focus group interview was held in Turkish and one in Arabic; the other four focus group interviews were in Dutch. The focus group interviews lasted between two and three hours.

Analysis of the data from the individual interviews and focus group interviews

In the initial phases of the analyses of the individual and focus group interviews open, inductive qualitative analyses were performed, within a cyclic process of data collection, analysis, additional data collection, et cetera. After each interview, the audio recording was typed out and the interview transcripts were read a number of times. Based on the interviews' content and sticking closely to the statements made by the interviewees, codes were assigned to interview fragments. Examples of these codes are 'shame', 'fear' 'life experience', 'normal aging' and 'openness'. In the final analyses stages, we also analysed deductively, using the concepts of explanatory models. The process of ordering and coding was assisted by MaxQda, a software program designed for computer-assisted qualitative data analysis (www.maxqda.com).

The first author analysed all the individual and focus group interviews. To improve the quality of the analyses and to prevent biased interpretation of the data, a main part of the interviews (all six focus group interviews and ten individual interviews) were independently analysed by at least one of the co-authors. The selected ten interviews were chosen because they contained much information. After the independent analysis, the results were compared and discussed with each other.

Codes that are related to one another in terms of content were categorised in the final phase of the analyses, which led to the final themes presented in the Results section. The results of the analyses were checked by the trained interviewers with the same non-western background as the participants. They considered the representations of the carer's perspectives accurate.

The qualitative analyses revealed several themes, which are partially described in this paper. In another paper we described the informal carers' perspectives on caring for a loved one with dementia (van Wezel *et al.*, 2014).

Ethics statement

All participants gave both written and verbal consent at the beginning of the individual or focus group interview. Verbal consent was also noted, partly because particularly the Moroccan and Turkish participants are more likely to have difficulty reading and writing in the Dutch language, which may possibly have meant they would just put a random scribble on the written declaration of consent. After the study was completed, the audio recordings were destroyed.

Since in this interview study only competent subjects were involved and the interviews did not involve any actions or interventions imposed to the participants, no approval by an ethics committee was required (according to the Dutch Medical Research Involving Human Subjects Act, see ccmo-online.nl).

Results

Explanatory models

In this study, the female family carers gave various explanations for how dementia had arisen in their close relative. The majority gave explanations that were in line with the explanatory model of '*dementia as a normal ageing process*'. These caregivers saw the appearance of dementia in their relatives as something that they had no influence over and which was a logical consequence of natural ageing. When caregivers were asked about the 'first signs' or when they were asked if they knew the term 'dementia', they mostly referred to forgetfulness and mental deterioration. The terms 'dementia' and 'Alzheimer' were generally not used, despite the fact that most of the relatives concerned had already been formally diagnosed with dementia. The caregivers interviewed often referred to dementia as 'the forgetfulness disease' or just 'forgetfulness' for short. Other terms used were 'bunamak' or 'demans' (by Turkish informal caregivers) and 'kindsie' or 'kindsheid' (literally *childishness*, by Surinamese caregivers). These latter terms were explained by saying "when you get really old, it's like you're becoming a child again".

> *What I understand by 'dementia' is that you forget things, that you forget the structure – you lose the structure of your daily life. That you keep repeating things. Your purpose in life, what people expect of you, what you will be doing tomorrow – you don't know these things any more. Losing track of things in your head – that's dementia." (Turkish focus group interview) Another word that's often used is 'kindsie'. You go back to being a kid. They say that in Suriname too: you can be a child twice, but you only grow up once. You're born a child, you grow up, and then you become a child again. (Surinamese focus group interview)*

In addition, other family carers gave explanations that were about an *interplay between life events, personality traits, and social and psychological factors*. In this context, caregivers stated for example that their relative with dementia had had a very tough life, with depression or divorce, a great deal of reflection and worry and 'awkward' personality traits.

Prior physical problems or medication use were also given as explanations of dementia, often combined with life events and personality traits. Dehydration, sexually transmitted diseases or incorrect use of medication were often listed in this context, for example.

> *Yes, my father was always ... he fretted about things a lot, thinks about things a lot, so maybe he does simply have problems with his brain. He also has trouble sleeping, for instance, he suffers from insomnia and he's always had lots of sleeping pills for that. So yes, maybe that did play a part, him having to take so many sleeping pills because he was always staying awake and thinking about things. (Moroccan, individual interview)*
> *Why do you think that your mother-in-law has memory problems?*
> *Like I said earlier, she was always busy, she worshipped money – still does, even now that she's sick, but she's got no idea when to put her purse to one side. Her bank card, her handbag – all that money robbed her of her common sense. All I know is that she worships money. She didn't like anybody much, not even her own kids; she loved money. That's what caused it. (Turkish, individual interview)*
> *Um, the way I explain it – and it's what the doctor thought too, and I read about it as well then – is that dementia can occur suddenly in old people if they get dehydrated. And I think, because we saw it then, is that my mother really ... it was as if she suddenly went blank, and then when they've gone blank like that you really see that something has happened in the brain. It's all down to the dehydration. (Surinamese Creole, individual interview)*

It is noticeable here that Turkish and Moroccan family carers ascribe the causes of dementia relatively often to non-physical aspects, such as having had a difficult life or personality traits, whereas Surinamese Creole caregivers mention physical aspects, such as dehydration and sexually transmitted diseases relatively often. When physical aspects were mentioned as explanations for dementia, these were often not sought in brain disorders such as Alzheimer's disease or vascular dementia.

Furthermore, the family carers interviewed also included a number – all of whom were relatively old Moroccan caregivers – who gave *spiritual explanations* for their relative's dementia: they saw their family member's dementia as a kind of 'possession' or 'magic' that God could cure. Various caregivers from the Moroccan and Turkish communities also stated that ascribing dementia to punishment by God or seeing it as a form of 'possession' was generally commonplace among more elderly first-generation Turks and Moroccans.

> *Somebody from the home care services comes and reads to him from the Koran about black magic. It's by no means certain that the cause of dementia isn't medical. There could still be hope. Hope that God will bestow his blessing after all and cast out the evil from him. (Moroccan, individual interview)*
> *A lot of older people don't know what Alzheimer's or dementia are – they just don't know. They can't name it, or they confuse it with getting old or being possessed or black magic. They go looking for it in the alternative spiritual side of things, as it were. (Moroccan, individual interview)*

Openness about dementia within the close family

The Turkish, Moroccan and Surinamese Creole family carers who were interviewed stated that the illness of their family member (usually a parent or parent-in-law) could in principle be discussed openly with sisters, sisters-in-law, brothers or other very close family.

> *I can talk easily enough about dementia. It isn't something that you have to hide. We talk about it within the family too, particularly because we want to help each other. (Turkish focus group interview)*

When talking about the subject with close family sometimes did become difficult was when it involved the problem of accepting the diagnosis and the grief that this engendered. The immediate family would sometimes refuse to believe it during the initial stages of the disease; they did not yet accept that their family member had dementia and thought that it was just fatigue or ordinary symptoms of ageing. Problems discussing the matter openly with close family members were mostly restricted to the initial stages of the condition.

Whether or not it could be discussed with the person who had dementia depended largely on how they themselves viewed it. Informal caregivers sometimes found it awkward or impossible to talk to the person with dementia about their state of health. This was particularly true when that person did not recognize or acknowledge the disease themselves. In order to protect the close relative with dementia and avoid creating additional unrest, the subject was sometimes not discussed with that relative. In other cases, the relatives with dementia were themselves open about it and the family could therefore talk freely about it.

> *We are not at all ashamed about it, but that's more because of the attitude of my parents themselves. They acknowledge it is happening. If my mother were to adopt an attitude showing she was ashamed, then I might have responded*

> *differently too. But she says it easily enough, and she makes talking about it possible. And then so do I. (Turkish focus group interview)*

Denial, shame and uneasiness within the broader community

Among Moroccan and Turkish family carers, it often seemed less easy to discuss the disease within the wider family and/or the community than it was within the immediate family.Turkish and Moroccan family carers sometimes experienced disbelief and denial from e.g. uncles, aunts or others from their community ("she's just old"), which caused distress among the caregivers and made them feel they were not being understood.

> *Well, my other family members don't believe that my mother is forgetful or that she's got a condition – they simply don't believe it. And if they do notice her repeating what she says or notice things in her behaviour, then ... well, they laugh about it and forget it, because they don't want to acknowledge it. They're more likely to think, well she's old, she's just old, she's a bit nutty .. . literally 'crazy'... they say she's old and crazy. And well, they ignore her in fact too. (Moroccan, individual interview)*

The reasons given for this were unfamiliarity with the disease and the associated fear and discomfort (particularly among older members of the community). The physical deterioration could be discussed, but talking about mental deterioration in particular went hand in hand with unease and reticence. People from the community did not inquire any further if the informal caregiver talked about their family member's condition, which left the caregivers feeling that there was no real interaction or depth in the conversation.

> *But my mother does say it, if they ask how she is doing. She say, well, it's not only physical – my head doesn't work like it should any more either. And then I think, oh, it's very good that she says it – she's aware of what's happening. Because that's the worst thing about it: your memory. And then you see that it's very straightforward if you say I've got headaches or a pain in my stomach, but very awkward if you say that your mother is getting very forgetful. Then they really don't know what to say – oh, isn't that awful, yes, but they don't really dare to talk about it properly. It's new for them, it really is new. (Moroccan, individual interview)*
>
> *I can talk about it freely with the second generation, and with my mother-in-law as well, and with her family, with her brothers. But I do notice for instance if I talk*

> *about it with my own parents, my father gets very ... he's very quick to empathize with others and he finds its very difficult ... I think my father finds it extremely uncomfortable to see my father-in-law like that. Maybe he associates it with the thought that he might end up like that too; he has a great deal of difficulty with it, he forces himself to come round and visit, in fact... but it keeps him awake at night after he's been round. (Turkish, individual interview)*

Some informal caregivers point out that in Turkish and Moroccan communities a 'culture of shame' and a 'culture of silence' exist, which affect the limited openness for such discussions within the wider community. Shame about dementia was 'shame about the disease', as well as 'shame about the behaviour of the person with dementia'. Within the Turkish and Moroccan communities, shame was also associated with the fact that the person with dementia was also sometimes seen within the community as being 'crazy'.

> *I don't feel ashamed about it personally, but I can understand why other Turks might. In our culture, it is important what other people say and think about you. We feel for other people a lot, actually. People do get bothered about gossip and rumours, or that they might say weird things about your parents or family. Maybe it has something to do with that. (Turkish focus group interview)*
> *In the Moroccan community, people don't talk about dementia. There are people who think that somebody with dementia has gone mad. That they're round the bend. Gone a bit nutty. They don't think that the person is sick and has become forgetful; the label they put on them is 'mad', as if they did the same things but didn't have dementia. They're ashamed of it. (Moroccan, focus group interview)*

There was also shame amongst the immediate family about the changed behaviour that their family member sometimes showed, which the community might start gossiping about. It was not possible to see that anything was wrong from the outward appearance of their family member with dementia. That meant that the family carers felt there was not much empathy from the community for the behavioural changes of the person with dementia. In those situations, the family carers got a feeling that they had to justify the patient's behaviour to the surrounding community. However, the person suffering from dementia often did not want the community at large to know that they had this disease. Family carers were therefore unable to offer an explanation for the behaviour of their family member and felt ashamed or at lease 'uncomfortable', also because of the fact that people in the community thought that their relative had 'gone mad'.

Within the Surinamese Creole community, the family carers who were interviewed came up against little or no denial, shame or unease when talking about their relative's dementia with others from their community.

> *I don't come across people who don't want to talk about dementia, or who – shall we say – don't want to be open about it and want to keep it hidden. We are ... I think that our people are open and honest about it. And when I say 'our people', I mean the Surinamese community. (Surinamese focus group interview)*

Compared with the Turkish and Moroccan communities, it was also possible to speak relatively openly about the mental deterioration within the Surinamese Creole community. Nevertheless, some family carers did feel uncomfortable about being seen with their family member who had dementia. This shame in public was primarily related to the behaviour of the person with dementia (aggressive behaviour, for example).

> *A feeling of shame isn't something that comes only from you. I think that what the person with dementia does ... well ... that makes you ashamed of some of the behaviour. You have people who hit out or kick. Or person with dementias who'll pinch you. Some people can't handle that, and then you do feel ashamed. (Surinamese Creole, focus group interview)*

The importance of talking about dementia

Despite the shame, feelings of unease and the 'culture of silence' mentioned in some cases, the family carers who were interviewed stated that it was important to be able to talk about the illness openly. One reason was that they thought their wider community should know more about dementia. The family carers of Moroccan or Turkish descent in particular said that little was known about the condition in their communities. They therefore wanted to tell other people about the illness of their parent, parent-in-law or other relative with dementia. Communication with other Turkish and Moroccan family carers about dementia was also important for them, allowing them to provide emotional support for one another. Some Turkish and Moroccan caregivers also said that the dementia of their relative would be better accepted and that there would be more understanding and less prejudice if other people knew that it was a common illness.

> *But I do think it's important to be able to talk about it easily. The more I talk about it with people and the more you give them information, then you start*

> *noticing them saying 'Oh, that's in my family too, I've got a grandmother like that too, or an uncle ... so she's not going mad.' So that makes it easier for me to keep talking about it. The people .. . it's an open subject .. . yes, making it something you can talk about freely, so that people can learn something from you. And vice versa. Because it's good when you hear another Moroccan saying that their mother has got the same problem. You've then got feelings that you can share. (Turkish, individual interview)*

> *We have to talk about dementia and provide information. The imam in the mosque should provide information. Make the community aware of it. So that others get to know about it. So that people will talk about it and overcome the shame. And they won't stick the 'mad' label on people any more then either. (Moroccan, focus group interview)*

The family carers of Surinamese Creole descent also thought it important to speak openly about dementia. However, since they were able to talk openly about the disease within their community, they were less explicit compared to the Moroccan and Turkish caregivers about stating the importance of open communication about dementia.

Discussion

Female family carers from the Turkish, Moroccan or Surinamese Creole communities generally talk openly with their close family about dementia (which the caregivers often called "forgetfulness") and they also think this is very important. The taboo around the subject of dementia, as has been described in other studies among non-western populations (*inter alia* Papadopulos *et al.*, 2002; Rijkers, 2010; Wolff *et al.*, 1996) was less pronounced in our study. It was not so much a question of a taboo as feelings of unease and shame – primarily perceived by informal caregivers from the Turkish and Moroccan communities. It is possible that this reflects progress over the course of time: most of the studies referring to 'taboos' were carried out years ago and family carers nowadays (largely second generation immigrants) are possibly more integrated into Dutch society. Therefore, they might have adopted aspects of the 'host culture' (Botsford *et al.*, 2011), and 'cultural exchange' might have taken place (Kottak, 2005), resulting in taking over aspects of the open communication style of the general Dutch population. Another explanation could be that the ageing population means that people within their own communities are increasingly being faced with dementia. There is also a great deal of attention from the media and many informational programmes about dementia, which will also have increased openness in discussing the subject. It is noteworthy here that, despite their own openness about discussing the dementia of their close relatives, the family carers interviewed generally used other names for the condition than those employed in the Western healthcare sector, 'dementia' or 'Alzheimer's disease'. Studies carried out by Hinton *et al.* (2005) have shown comparable results.

However, talking about dementia outside the immediate family circle is still often difficult for family carers with Turkish or Moroccan backgrounds. They point out that the mental deterioration of the person with dementia is something that more elderly members of their communities in particular do not like facing up to. Communication issues are exacerbated by fear, shame, lack of awareness and uncertainty, not so much among the family carers interviewed themselves but rather among other members of the Turkish and Moroccan communities. The study by De Vries (2009) also clearly highlights that shame and fear within the community. Also 'public stigma' (Benbow & Reynolds, 2000; Corrigan & Watson, 2002; Graham *et al.*, 2003; Werner & Heinik, 2008), still appear to be a problem, since some family carers indicated that they see it as their task to refute in their communities beliefs such as dementia is a form of 'madness' or 'possession'. Stigma, anxiety and shame associated with dementia have a negative impact on how freely it can be discussed when dementia is seen as a 'spiritual experience', in the sense of possession or magic. If a person with dementia is seen as someone who is possessed or under the influence of black magic, this might go hand in hand with gossip in the community and shame within the family, which will also inhibit communication about dementia.

Themes such as shame, fear and a bar against discussion of dementia within the community play less of a role in the experiences of Surinamese Creole family carers than in those with Turkish or Moroccan backgrounds. Possible explanations for this can be found in the cultural 'proximity' to Dutch society, education and the degree of integration. First- generation immigrants from Suriname are on average better educated, speak Dutch better and are more familiar with the Dutch healthcare system than Turkish or Moroccans living in The Netherlands (Denktas, 2011). Another explanation is that they are more familiar with dementia because their average age is greater than in the Turkish and Moroccan groups, so they have been confronted with dementia more. Based on those differences, it is possible to explain why informal caregivers from the Surinamese Creole community are able to talk more freely about dementia with other people from that community.

Downs *et al.* (2006) also listed the explanatory model of 'dementia as an interplay of factors. However, the explanations given by the family carers in our study do not fit this entirely, because the physical factors mentioned in our study are not the progressive brain disorder (where Downs *et al.*, 2006), but other physical factors (such as dehydration or certain medicines) that have nothing to do with dementia when seen from the perspective of Western medicine.

Regarding the explanation of dementia as a 'a normal ageing process', the most frequent variant in this study, Downs *et al.* (2006) state that this explanation does not have a negative impact on the status of the person with dementia. The honour and respect owed to the close relative who has dementia then remain intact; after all, it is only due to their advanced age and nobody can do anything about that. The explanation that '*dementia is an interplay between life events, personality traits and social and psychological factors*' also does not seem to have a direct negative impact on the relative with dementia. After all, this does treat the individual person with dementia as a unique person for whom the support and supervision has a chance of succeeding if it focuses on the psychological and social factors and life events that underpin the dementia, rather than the general medical explanation. This was also found in a study carried out by Bagley, Angel, Dilworth-Anderson, Liu, and Schinke (1995).

Strengths, limitations and recommendation for future research

One of the strong points of this study is that it used both individual interviews and focus groups. Individual interviews have the advantage of allowing in-depth questions about personal and individual experiences, which generates rich and detailed information. Focus group discussions have the advantage of allowing scope for discussion and exchange of ideas amongst those taking part. The individual interviews and the focus groups have reinforced and complemented each other. One finding that was highlighted strongly in the focus groups and provided further backing for the findings from the individual interviews, for instance, was that the often uncomfortable openness to discussion of dementia within the wider community is primarily founded on fear of the condition and lack of awareness of it among other members of that community, as well as fear of gossip about the immediate family members of the person with dementia.

One limitation of this study is that it only involved family carers from non-western communities in the Netherlands and no native Dutch caregivers. When interpreting the study's results and conclusions, allowances should also be made for the fact that there is diversity within communities too and that the Surinamese family carers we interviewed were all ethnically Creoles. It is possible that some aspects of the results obtained might not apply to family carers from other Surinamese communities, such as the Surinamese-Hindustani- or Surinamese Chinese-communities in The Netherlands.

We must also take account of the fact that this study did not involve native Dutch family carers, although not only the cultural or ethnic background but also aspects like education, social networks, income or duration of contacts with health systems might be related to explanatory models and openness to discuss dementia within others. Therefore, we recommend future comparative research also involving native family carers.

Another (obvious) limitation is that this study only included informal caregivers who themselves were willing and able to talk openly about their close relative's dementia. Family carers who have difficulty talking about dementia or found discussing the subject inappropriate for other reasons will of course not have wanted to be interviewed. The observation that the informal caregivers interviewed wanted to talk openly and also see it as their task to make dementia a topic that can be discussed more freely in their community can therefore not automatically be generalized to other caregivers from the community in question. Furthermore, previous research has shown that ethnic background appears to account for differences in experiences of dementia and caregiving, but that other compounding variables, including socio-economic factors and education, also need to be taken into account when considering the experiences of specific ethnic communities (Botsford *et al.*, 2011).

Finally, an explanatory model reveals how people make sense of their illness and their experiences of it. They perceive are used to explain how people view their illness in terms of how it happens, what causes it, how it affects them, and what will make them feel better (Kleinman, 1976). We did not focus on the explanatory models of people with dementia themselves, but we only focused on how family carers explain the origin of the disease and how it affects them in the sense of communicating about dementia. Further research is recommended on how people with (early) dementia in non-western communities make sense of their disease and how they experience it as illness.

Recommendations

Special interest groups for dementia – such as the national Alzheimer Associations – are currently making major efforts to provide culture-specific information about dementia.

There is an assumption here that it is important not only to pay attention to increasing people's knowledge about dementia, but also to make the disease a subject that can be more freely discussed. Among the family carers interviewed for this study, it was very clear that they themselves also value open communication about dementia very highly, both within their families and in the community at large. Nevertheless, these family carers do also point out that there are still barriers within the Turkish and Moroccan communities against talking openly about dementia. These barriers seem partly to be associated with explanations of dementia such as 'this condition is due to them being possessed' or that they 'have a difficult personality'. These barriers can however also be due to the way people look at communicating about sensitive subjects. People producing information about dementia should allow for the fact that not everyone will necessarily subscribe to the idea that talking freely about dementia is a good idea or that perceiving dementia within the dominant western 'normalizing' explanatory model automatically means that there is enough capacity and agency to cope with the disease or that family carers are better off. In light of the growing number of people with dementia and family carers it may therefore be worthwhile to make use of trained information providers from the same non-western origins as the target groups, who know about the causes and symptoms of dementia and who themselves have experience as family carers. Information providers with the same language and culture, may be able to build bridges between these partially culturally determined explanations of dementia, at the same time paying attention to filling in the gaps in people's knowledge about dementia. These information providers can also function as role models in communication about dementia in Turkish, Moroccan and Surinamese-Creole communities. This might also increase the openness on dementia.

Informational programmes have now been developed for dementia that focus specifically on the groups of informal caregivers with a Turkish, Moroccan or Surinamese background (Blom & Willemsen, 2011; Willemsen & van Wezel, 2011). It is therefore important to investigate whether these specific informational programmes do improve knowledge about dementia and openness to discussion.

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Authors' contributions

NvW conceived and designed the study. AFr and MB adjusted the study design and MB obtained funding. NvW drafted the manuscript and coordinated the data collection. The individual interviews were held by NvW and EK. The six focus group interviews were held by EK and NvG. All authors have been involved in revising the manuscript. All authors read and approved the final manuscript.

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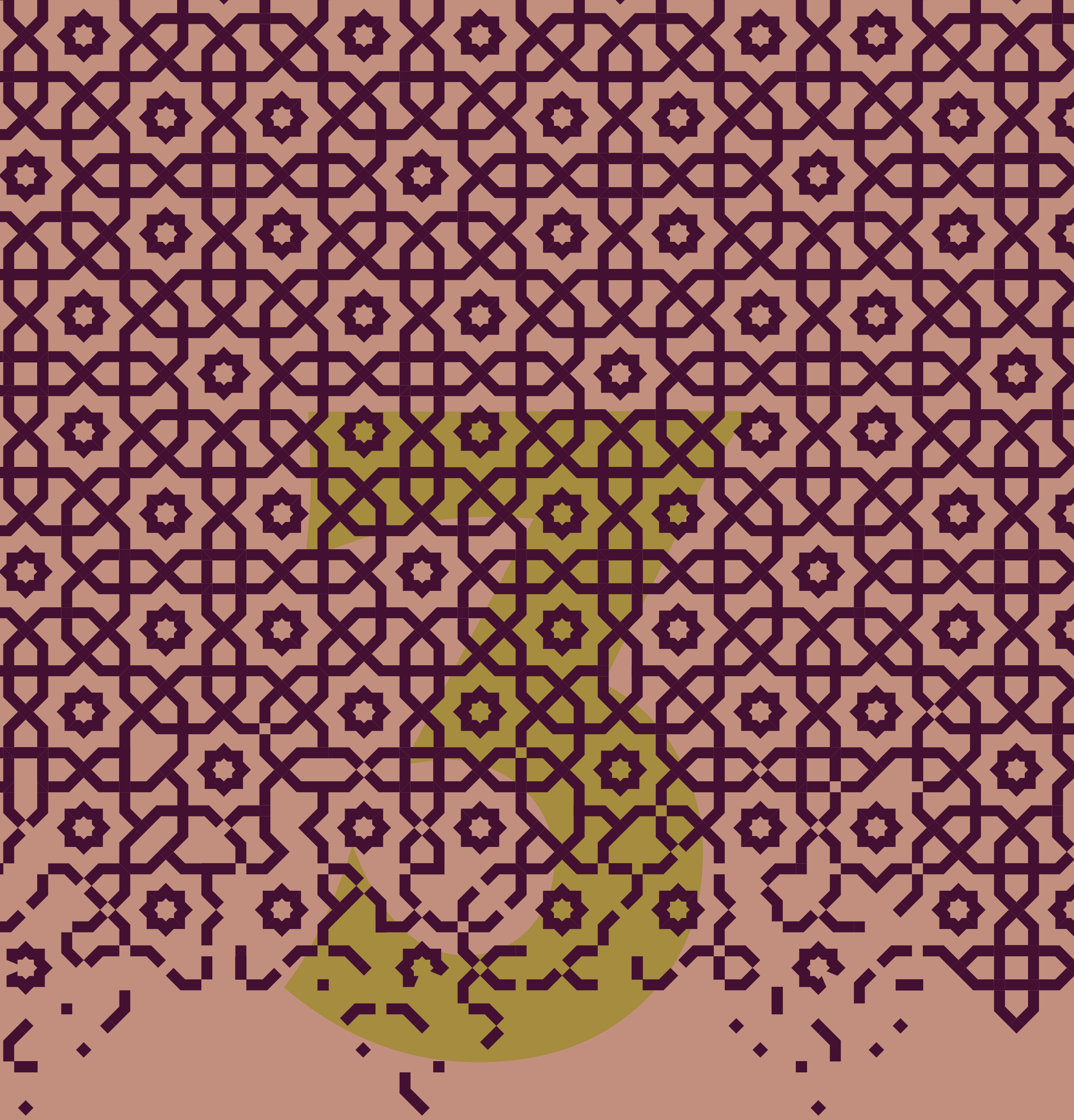
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Chapter 3

Family care for immigrants with dementia: The perspectives of female family carers living in the Netherlands

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Abstract

Background: The prevalence of dementia is increasing among non-western immigrants. It is known that family care is provided relatively often among immigrant groups. Until now, however, relatively little was known about how relatives of people with dementia in the immigrant communities perceive family care. This study therefore focuses on describing the perspectives of female Turkish, Moroccan and Surinamese Creole family carers in the Netherlands about providing family care to a close relative with dementia.

Methods: Forty-one individual interviews and six focus group interviews (*n*=28) were held with female Turkish, Moroccan and Surinamese Creole family carers who are looking after a close relative with dementia. A qualitative analysis of the interviews has been carried out, supported by the software MaxQda.

Results: Related to their cultural and religious backgrounds, female family carers with Turkish, Moroccan or Surinamese Creole origins see family care as a task that they should carry out with respect and love. They feel that family care is superior to professional care and that it is principally a task for women. If men do have a role in family care, then it generally covers non-physical aspects. Despite the fact that the family carers interviewed listed aspects that make caring for a close relative with dementia difficult, they do say that they get a great deal of satisfaction from providing this care. In Turkish and Moroccan families in particular this type of care leads to more recognition and appreciation of the daughter or daughter-in-law who is giving it.

Conclusion: Family carers of Turkish, Moroccan or Surinamese Creole origin derive a great deal of satisfaction from giving family care to a relative with dementia. This fulfilment largely outweighs the burden of care. Professional support or information for these family carers can be improved by also focusing on the positive aspects of providing family care instead of an exclusive focus on reducing the burden.

Keywords:

dementia, family care, informal care, immigrants, caregiver perspectives

Introduction

Dementia is reaching epidemic proportions. According to the World Alzheimer Report (2012), 36 million people worldwide are living with dementia. These figures are doubling every 20 years, which means that we could get an expected figure of 66 million people in 2030 and 115 million by 2050 (ADI, 2012). Dementia is also increasing among non-western immigrants in industrialised countries (Demirovic *et al.*, 2003; Fitzpatrick *et al.*, 2004).

Research has shown that elderly migrants use family care more often and more intensively compared to native Dutch elderly (Denktas, Koopmans, Birnie, Foets, & Bonsel, 2009; Uiters, Deville, Foets, & Groenewegen, 2006). However, care for a family member with dementia can be a heavy burden, both physically and emotionally. Recent research among 2400 Dutch family carers of persons with dementia showed that 10% feel the burden of care to be heavy and 36% feel it to be quite heavy (Peeters, Werkman, & Francke, 2012). These percentages may be higher among non-western migrants because the expectation that they will look after sick family members themselves is often higher in immigrant communities (De Graaff & Francke, 2003, 2010; Neary & Mahoney, 2005).

In the Netherlands, 13% of the population is of non-western origin (Statistics Netherlands, 2012). At the moment, the largest groups of non-western migrants in the country are Turks, Moroccans and Surinamese. Together they represent 65% of all non- western immigrants. The immigrants who came to the Netherlands in the 1960s and 1970s are ageing now. This will also have consequences for their need for family care. There are no specific records or figures about the degree to which people with dementia are getting family care within the Turkish, Moroccan and Surinamese communities. It is known, though, that the percentages of older immigrants (55+) with one or more chronic conditions who are receiving family care are 60% for Moroccans, 30% for Turks and 23% for Surinamese. These percentages are much higher than for elderly native Dutch people with chronic conditions, of whom only 10% make use of family care (Denktas *et al.*, 2009). Most family care in the Turkish, Moroccan and Surinamese immigrant groups is provided by women (Schellingerhout, 2004). Family carers from immigrant groups provide a relatively large amount of care, namely 30 h a week. This is considerably more than the 21 h a week provided by Dutch family carers (De Boer, Broese van Groenou, & Timmermans, 2009).

Earlier research has given various explanations for the high frequency and intensity of family care in immigrant groups: limited knowledge about the range of professional care available; a negative image of professional care; difficulty paying their own contributions to professional care; and poor alignment of the range of professional care available with the care needs (De Graaff & Francke, 2002; De Graaff *et al.*, 2010). Lower levels of education and other socio-economic factors may also influence the greater utilisation of family care in migrant groups (Denktas *et al.*, 2009; Uiters, Deville, Foets, Spreeuwenberg, & Groenewegen, 2007). The studies mentioned above do however focus either on the general elderly migrant population or on terminally ill elderly migrants, rather than on migrants who are affected by dementia. Until now, relatively little was known about how family carers of people with dementia in the immigrant communities perceive family care. Such insights are desirable to create a culture-specific range of information and support for family carers.

The following research questions are therefore central to this study:

1. What are the perspectives of female Turkish, Moroccan and Surinamese Creole family carers in the Netherlands about providing family care at home to a close relative with dementia?
2. What similarities are there between family carers from various immigrant communities, in terms of the way they perceive family care for a close family member with dementia?

Method

Composition, recruitment and sampling of the individual interviews

First of all, semi-structured interviews were held with female family carers who look after a close relative with dementia or – in cases where no official diagnosis could be made – with severe memory problems. These women were recruited from three of the largest non-western migrant groups in the Netherlands, namely the Turkish, Moroccan and Surinamese Creole groups. Although Turkish and Moroccan groups have different ethnic and cultural backgrounds, there are similarities in terms of religion (primarily Muslim) and migration history as 'guest workers' or their families. The Surinamese Creole population in the Netherlands had a different immigration pattern: most representatives of the first generation came to the Netherlands in the 1960s or 1970s to study or because they wanted to move at the end of the colonial period. Their religion is predominantly Christian.

A total of 16 Turkish, 14 Moroccan and 11 Surinamese female family carers were interviewed. These women were recruited indirectly via care providers (nursing staff, case managers), key figures from the ethnic communities or dementia educators.

Table 3.1 *Features of the backgrounds of the family carers*

Group	Age (distribution)	Lives with a close relative with dementia?	Family relationship
Family carers from the individual interviews (n=41)			
Turkish (*n*=16)	Distribution= 31 to 74	Yes: 6 No: 10	Daughter: 14 Daughter-in-law: 1 Spouse: 1
Morocco (*n*=14)	Distribution = 20 to 48	Yes: 5 No: 9	Daughter: 12 Daughter-in-law: 2 Spouse: 0
Surinamese (*n*=11)	Distribution = 50 to 84	Yes: 1 No: 10	Daughter: 8 Daughter-in-law: 2 Spouse: 1
Family carers from the focus group interviews (n=28)			
Turkish (*n*=10)	Distribution = 30 to 50	Yes: 4 No: 6	Daughter: 10 Daughter-in-law: 0 Spouse: 0
Morocco (*n*=12)	Distribution = 30 to 60	Yes: 5 No: 7	Daughter: 5 Daughter-in-law: 4 Spouse: 1 Other: 2
Surinamese (n=6)	Distribution = 30 to 70	Yes: 0 No: 6	Daughter: 6 Daughter-in-law: 0 Spouse: 0

The recruitment process attempted to achieve some degree of spread in age and between immigrant groups. A total of 41 individual interviews (in addition to the six focus group interviews: see below) turned out to be sufficient to reach the data saturation point at which no new and relevant information was being found when additional data were collected (Guest, Bunce, & Johnson, 2006). Table 3.1 shows the most important features of the backgrounds of the family carers interviewed.

Recruitment and composition of the focus group interviews

Focus group interviews were held after the individual ones because we wanted to test and refine interim findings by discussing them with groups of family carers from the immigrant communities concerned. A total of six focus group interviews were held: two with Turkish family carers, two with Surinamese Creole and two with Moroccan. Two to seven family carers took part in each of the focus groups.

A total of 10 Turkish, six Surinamese Creole and 12 Moroccan family carers participated in the focus group interviews (see Table 3.1). The recruitment of the participants for the focus groups was also done via care providers (nursing staff, case managers), key figures from the immigrant communities and dementia educators with the same ethnic origins. Carers were only allowed to take part in a focus group interview if they had not yet been interviewed individually.

Organisation and content of the individual and focus group interviews

Both the individual interviews and the focus groups started with broadly phrased, open questions. Examples of the interview questions included in the list of topics were ‘What has looking after your relative with dementia been like for you?’, ‘Are there things that you find difficult about looking after your relative with dementia?’ and ‘Some people say that family care is part of their culture. Do you agree or not?

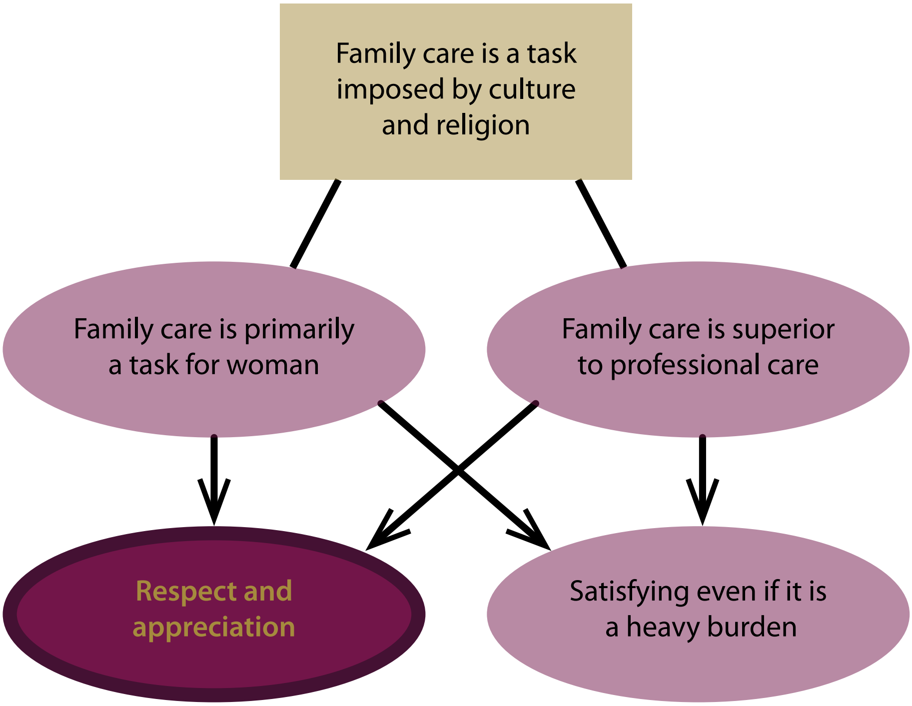

Figure 3.1 *Perceptions of carers with Turkish, Moroccan and Surinamese Creole backgrounds regarding family care for a close relative with dementia*

Why?' The interview questions for the list of topics were drawn up after discussions with Dutch, Moroccan, Turkish and Surinamese experts after studying relevant literature (e.g. De Graaff & Francke, 2003, 2010; Downs *et al.*, 2006; Rijkers, 2010; Uiters *et al.*, 2006).

The individual interviews were held by the first author (NvW; a native female Dutch researcher and gerontologist employed by Alzheimer Nederland, the Dutch Alzheimer Association), the third author (EK; a female Dutch-Turkish health scientist also working at Alzheimer Nederland) or by trained freelance female interviewers with the same cultural background as the person being interviewed. The individual interviews were all held at the participants' homes. The interviews were held in Dutch, except for six of the Turkish family carers whose mastery of Dutch was insufficient. The six Turkish interviews were literally translated into Dutch by the third author (EK) who is a native Turkish speaker and also speaks Dutch fluently. No back translation was done. The interviews took between 1h and 2 h.

The six focus group interviews were held by the third author (EK), the fifth author (NvG; a native Dutch female social scientist working as a project leader at Pharos, an institute in the field of research and health development of migrants and refugees) or by trained freelance female interviewers with the same cultural background as those taking part. The focus group interviews were held in social centres, community centres and nursing and care homes. Two focus groups were held in other languages (1x Turkish, 1x Arabic) and the remaining focus group interviews were held in Dutch. The focus group interviews lasted between 2 h and 3 h.

Analysis of the data from the individual and focus group interviews

The generic qualitative approach was used for this study. Generic qualitative research does not have a guiding set of philosophic assumptions or methodological strategies from one specific qualitative methodology, but exhibits some characteristics of various methodologies (such as grounded theory methodology or ethnography). Basic requirements of a generic qualitative approach are: noting the researchers' position, congruence between methods and methodology, making explicit the approach to rigor and identifying the researchers 'analytic lens' (Caelli, Ray, & Mill, 2003).

A cyclic process of data collection, analysis, more data collection, etc. was carried out. After conducting an interview the audio recording was typed out and then analysed qualitatively. The first author read all the interview transcripts a number of times. Based on the interviews' content and sticking closely to the statements made by the interviewees, she assigned codes to fragments and themes. Examples of these codes are 'superior', 'women's job' and 'lonely'. The process of ordering and coding was assisted by MaxQda, a software program designed for computer-assisted qualitative data analysis (www.maxqda.com).

All six focus group interviews were analysed by both the first and fifth authors. In addition, a selection of individual interviews (*n* = 10) was independently analysed by at least one of the co-authors in order to improve the quality of the analyses and to prevent biased interpretation of the data. These 10 interviews were chosen because they contained much information. After the independent analysis, the results were compared and discussed with each other.

Codes that are related to one another in terms of content were categorised in the final phase of the analyses, which led to the final themes and sub-themes that can be seen in Figure 3.1. The results of the analyses were checked by the trained interviewers with the same cultural background as the participants. They considered the representations of the carer's perspectives accurate.

Ethical aspects

All participants gave both written and verbal consent at the beginning of the individual or focus group interview. Verbal consent was also noted, partly because immigrants are relatively more likely to have difficulty in reading and writing, which may possibly have meant that they would just put a random scribble on the written declaration of consent. After the study was completed, the audio recordings were destroyed. Since in this interview study competent subjects were involved and the interviews did not involve any form of invasion of the participant's integrity, no approval by an ethics committee was required (according to the Dutch Medical Research Involving Human Subjects Act, see ccmo- online.nl).

Results

Central themes and the similarities and differences between the groups

In the interviews with Turkish, Moroccan and Surinamese Creole family carers, certain central themes appear that represent their opinions about family care (see Figure 3.1(a)). These perceptions are: family care is a task imposed by culture and religion, family care is primarily a task for women, family care is superior to professional care and satisfying even if it is a heavy burden. Particularly in the Moroccan and Turkish groups, giving family care is respected and appreciated within the community and family. In the case of the Surinamese family carers, the appreciation that is experienced comes less often from the broader community. This difference is shown in Figure 3.1 by the red outline that has been given to the 'respect and appreciation' element. The various items from the figure will be explained in this section.

Family care is a task imposed by culture and religion

All the family carers interviewed see providing care for their family member as a task that their religion (Islam for the Turkish and Moroccan participants, Christianity for the Surinamese) and/or their broader cultural context would expect of them. Caring for those who need help is a value that they have been brought up with: good Christians and good Muslims look after their parents or other family members who need care, and do so with honour and respect. When caring for parents or parents-in-law, there is also a kind of reciprocity: family carers are repaying the sick parent or parent-in-law for the care that they or their spouse received as a child, as it were.

> *From an Islamic point of view, the respect you have for your parents would mean you look after them - that's just what a good Muslim should do. And when someone gets sick, it's important that this is more available than ever, that the care is clearly there. (A Turkish woman who looks after her mother, in an individual interview)*

> *Look, where Surinamese people come from, the elderly are part of the family and stay part of it until they die. And whatever happens to them, whatever mental or physical condition they end up in later, the family should deal with it. Because they did the same for you when they were fit and strong. It's a kind of repayment. (A Surinamese Creole woman who looks after her mother, in an individual interview)*

Relatively young family carers – whether or not from the second generation – also see giving care as an obligation. However, there are some ways in which differences can be seen between the perceptions of the younger and older female family carers. The older ones assume that you yourself must also provide the actual care, whereas some of the younger carers indicate that they also interpret the term 'caring' as meaning 'ensuring that good care is provided'.

> *Care for your elderly is what the Islam says. And sometimes I think that they interpret that wrongly: providing care doesn't mean actually doing it all yourself, but making sure that you arrange for proper care. That's the way I look at it. (A Turkish woman who looks after her father, in an individual interview)*

Family carers with Turkish or Moroccan backgrounds also say that they see providing care as God/Allah testing them. The trials of this life are an important way of atoning for your own sins and being rewarded by being admitted to paradise. In addition, tests such as these are a way for a believer to grow and to learn.

> *As Muslims, we believe that the road to paradise - which is something I also want of course, as a believer – is under your mother's feet. And as a believer, I also believe that there are obstacles on your path through life that help shape you, that you can learn from. (A Moroccan woman who looks after her mother, in an individual interview)*

Family care is primarily a task for women

Family care is seen as a duty, but then above all one that is primarily a task for women. In both the Turkish and Moroccan communities, family care is primarily handled by the eldest daughter or the wife of the eldest son. In the Surinamese Creole community, it is also often a daughter who is involved in the care of a parent with dementia, but it does not necessarily have to be the eldest daughter. Male family members are less often involved in giving family care.

> *My brothers don't generally do anything. If Mother wants something, they fetch it. But the wives do most of it, for example my eldest brother's wife washes her once a week, my other sister she does the cooking when she's not at work. Everything is done by the daughters. (A Turkish woman who looks after her mother, in an individual interview)*

The physical, personal care (showering, washing and dressing) is in most cases done entirely by women. When Moroccan or Turkish immigrant men do provide physical care, it is generally for male family members of their own 'family line' (their own father or uncle). Men do sometimes play a part in care tasks such as doing the shopping, arranging care and social support.

Family care is superior to professional care

Family carers with Turkish, Moroccan and Surinamese Creole backgrounds see that care as superior to professional care; this is linked to the way they see care in the family as an obligation. According to them, family care has major benefits over professional care, because they see family care as being more loving and as offering more security and recognition for the person who has dementia.

> *I think it's very important, particularly in the case of my mother, who has dementia, that she should be cared for by family, by people she already knows. Above all, she needs recognised family members around her, somebody who makes her feel calm, somebody trusted, so I do think that's important (A Moroccan woman who looks after her mother, in an individual interview)*

Interviewees also think family care is superior because the carers have the same cultural background as the patient. This is important for recognition and for feeling secure, as well as for the social contacts and how the family member with dementia functions.

> *If my mother were to end up in a home with only Dutch women, then there would be no communication. She wouldn't be able to have her say; she'd just sit there not talking. Then they get even more isolated and even more closed off from the world and there's no interaction. And I think that the dementia would then progress rapidly to a stage where she no longer recognises anybody. (A Turkish woman who looks after her mother, in an individual interview)*

Family care is also seen as superior because the carers and/or the people with dementia often have a negative image of residential care for the elderly. That negative image is particularly expressed in the interviews with Turkish and Moroccan family carers and to a lesser extent in the interviews with the Surinamese Creole carers.

> *They leave people there, suffering. They have no contact at all with the patients. It's just their job and that's it - just waiting for them to kick the bucket. Yup, that was an extremely good reason as far as I was concerned for looking after my mother myself. (A Moroccan woman who looks after her mother, in an individual interview)*

Despite the fact that residential care for the elderly has a poor image in the Turkish and Moroccan communities in particular, family carers do understand that admission can sometimes be inevitable – for example, if looking after somebody with dementia at home creates extremely unsafe situations, or if the carers become mentally or physically severely overburdened. But these concern extreme situations.

> *Look, if I end up walking along the street talking to myself without any idea where I am, then it'll be time for my family member to move into a home. But not before that. (A Moroccan woman who looks after her father, in a focus group interview)*

> *This culture of ours tells us that we do not put our parents in old peoples' homes. If the life of the ill person is in danger or if their illness means that they are harming others and if we cannot resolve the situation ourselves and if it really cannot go on like that anymore, then a care home could be an option. Because my beliefs do allow this under such circumstances. (A Turkish woman who looks after her father, in a focus group interview)*

Family carers with Turkish or Moroccan backgrounds indicate that admission to a nursing home or care home is simply 'not done' in their community. If a decision is made to put them in a home, even though there are children, others from the community will condemn it.

> *It's part of the culture, isn't it? A kind of taboo... I mean, putting your father in a care home is a big no-no for us. (A Turkish woman who looks after her father, in an individual interview)*

Surinamese Creole family carers also see that care as being superior to professional care, although at the same time there is greater acceptance among them of professional care. Unlike the situation with the Turkish and Moroccan family carers, fear of negative responses from the family or community weighs much less (if at all) in their decision making about using professional care. It is not generally expected that the carer will provide all the care alone, which is again different to the Turkish and Moroccan families and immigrant communities. Family carers with a Surinamese Creole background are also less likely to say that they have a negative image of residential care. Nevertheless, they also feel barriers having a relative with dementia admitted to care homes, with the fact that the relative often prefers to stay at home and be looked after by the family.

> *Touch wood, but if her condition gets worse then, yes, it will become too much and we will then have to look at how, we're going to do it or what we're going to do. I mean, my mother refuses to go to a care home or a nursing home. So*

> *one way or another, we'll have to find help or something so that she can stay at home. (A Surinamese Creole daughter who looks after her mother, in an individual interview)*

Respect and appreciation

Providing family care is also a way for Turkish and Moroccan carers to acquire more respect within the family and community – to be seen as a good daughter or daughter-in-law. This respect can come not only from a parent or parent-in-law, even if the relationship with them was previously difficult, but also from brothers and sisters or other people from the (broader) community. The aspect of 'respect and appreciation' is less clearly expressed in the interviews with Surinamese family carers. Surinamese Creole carers do get individual appreciation based on the personal relationship that the family carer has with the person with dementia or from other close family members. Unlike the situation in the Turkish and Moroccan immigrant groups, it is not about appreciation from the broader community.

> *I get a lot of satisfaction from it because I think that there's nothing better in the whole world... At the time, they did a great deal for me, as all parents would, but my father is - well - he's always been a great source of strength. I'm thirty-four and I really did pick up all sorts of good, lovely, educational things from my father. I hope I'm doing it right and well, when I hear him talking about me and about the care I'm giving, that is very fulfilling. I know that my efforts have been more like 200% than 100% - everything I possibly can. I do my very best, and I guess you can't do more than that. (A Turkish daughter who looks after her father, in an individual interview)*

Satisfying even if it is a heavy burden

When family carers are asked whether they feel that giving that care is a major effort, they mention physical and mental fatigue, the feeling that it is impacting on their own immediate families and the feeling that the care is something they can never mentally put aside and that they 'take it home with them'. Being faced with the mental and physical deterioration of a close relative with dementia is also something that family carers find difficult to cope with.

> *There are moments when the care does weigh heavily on me. The moments when I see she is suffering, in particular. Those are tough. Not tough in the sense of physically tiring or whatever, not at all. It's her suffering that weighs most*

> *heavily. (A Surinamese Creole woman who looks after her mother, in an individual interview)*

There are also family carers of Moroccan or Turkish origin who say that they find the care a burden because they miss the freedom of choice: freedom to provide care in the way they feel is right, or the freedom to share the burden of care with professionals. The freedom of choice is limited because deviating from the expectations prevalent in the family or the broader community has consequences: disrupted relationships and less respect within the family or the broader community.

> *My culture doesn't accept changes. They expect you to do what is traditional. I can't decide how I want to care for my mother because they consider it a bad choice. If I share the care for my mother with a professional they'll tell me I'm a bad daughter for not caring for my mother after all she has done for me' (A Moroccan woman who looks after her mother, in an individual interview).*

Some family carers point out that they feel lonely because they have less time for their own social contacts and activities. These are principally family carers who handle the care for a family member with dementia alone and are not supported by other family members.

> *My circle of friends is getting smaller and smaller. I can't make any time for myself to go outside for a bit. That's why they asked for one of those general helpers, to make sure I can get out more often. The care assessment people agreed to that, and I'll be getting it shortly. (A Turkish woman who looks after her mother, in an individual interview)*

It is however striking that despite family carers saying that caring for a close relative with dementia is a heavy burden, they always contrast that with their positive experiences with giving that care. Family care is satisfying for them, because they are fulfilling their religious and cultural obligations to look after family members who need help, as well as the fact that it in some cases strengthens the bond with the ill family member. Feelings of fulfilment seem to be strongest among family carers who emphasise these religious and cultural obligations more strongly. They say that they derive a great deal of strength and support from their religion and it makes them able to keep going independently for longer. Particularly among Turkish and Moroccan family carers, caring gets them more respect and appreciation within the family and from the community. The satisfaction derived from family care goes a long way towards compensating for its burdensome aspects.

> *It is very fulfilling for me - I'm pleased to be with her and pleased that I've got her, and so I'm fully committed to it. It's fulfilling for me, and yes it's very tough. You see her deteriorating. But I do it because I love her. Every morning when I wake up, I pray and I hope that she's still there. I get a lot out of it. (A Surinamese Creole woman who looks after her mother, in an individual interview).*
>
> *Caring for my mother means very much to me. I see it as something special that only I as her daughter can give her. I feel thankful to do this (A Turkish woman who looks after her mother, in an individual interview).*
>
> *To see my mother disappear makes me sad. But the moment she laughs of tells me something about her past, it makes it all worthwhile. More than when she was not sick I feel that I have a second chance of connecting with my mother. I'm so thankful for this chance.. . this way to get to know her better. (A Moroccan woman who looks after her mother, in an individual interview).*

Discussion

Related to their cultural and religious backgrounds women with Turkish, Moroccan or Surinamese Creole origins consider family care as a task that they should carry out with respect and love for a family member who has dementia. Despite the largely positive associations made with family care, the family carers do also point out the negative sides: it is sometimes hard going and lonely, and it makes them have to face the suffering and deterioration of those close to them. Negative sides are expressed by all family carers, both by family carers who live in the same house as the person with dementia and family carers who live separately. Those who live together with the relative with dementia experience an always continuing care situation and care burden, while family carers who live separately often feel burdened because of the worry about the safety and situation of their relative in moments when they aren't there. It is however striking that negative aspects of care in the family are perceived by the women to weigh less heavily than the positive aspects. From other research, it is known that also native Dutch family carers have both positive and negative associations with family care (De Boer *et al.*, 2009; Van Campen, de Boer, & Iedema, 2013).The 'respect and appreciation' aspect – in the sense of showing that you are a 'good' daughter or daughter-in-law – is however less clearly present in publications about family care in the Dutch population at large. In addition, acceptance of professional care is greater among Dutch caregivers than among those with Turkish or Moroccan backgrounds (Denktas *et al.*, 2009).

If family care tasks of Turkish and Moroccan immigrants were to be alleviated by making use of professional care, there is a risk of the respect and appreciation from the family or the broader community being diminished. However, in this study a number of the younger family carers show a more modern view of providing care in the family, in that they see themselves as 'directing' that care. The respect and appreciation can also be gained in these cases by arranging the professional care for your parents properly, without necessarily having to provide that physical care personally.

The family carers interviewed also see that care as being superior to professional care. The superior status accorded to care in the family is another reason why family carers, particularly those from Turkish or Moroccan backgrounds, only want to make use of professional care to support them looking after their relative with dementia in extreme situations. This is in line with the research by Denktas *et al.* (2009) mentioned above, which showed that Moroccan and Turkish people aged 55 and over are cared for in the home more often and use professional care less often than their counterparts from the indigenous population.

The Surinamese Creole family carers interviewed also see family care as being superior to professional care. Nevertheless, there is greater acceptance of professional care such as home care and day centres among them in comparison to Turkish and Moroccan family carers. It is less generally expected (by the family or the community) that the carer will provide all the care alone, which is again different to the Turkish and Moroccan immigrant communities. One possible explanation for this effect may be found in the migration history and the degree of integration. Suriname used to be a colony of the Netherlands and immigrants from Suriname, including the first-generation immigrants, mostly speak good Dutch. This may be related to a more westernised view of family care and the uptake of professional care.

Caring in the family is seen by both Turkish and Moroccan and by Surinamese Creole family carers as the act of a good religious person (Muslim or Christian). Being religious may also be important in keeping up family care. In studies among ethnic minorities and immigrants in the United States, Dilworth-Anderson and Gibson (2002) and Herrera, Lee, Nanyonjo, Laufman and Torres-Vigil (2009) observed that religion helped family carers handle the care burden better.

Strengths and weaknesses

One of the strong points of this study is that it used both individual interviews and focus groups. Individual interviews have the advantage of allowing in-depth questions about personal and individual experiences, which generates rich and detailed information. Focus group discussions, however, have the benefit of allowing scope for discussion and exchange of ideas among those taking part. The individual interviews and focus groups have therefore reinforced and complemented one another. One finding that was strongly expressed in the focus groups and thereby reinforcing the findings from the individual interviews concerned the fulfilment and gratitude family carers get from providing care for their relative with dementia.

The family carers taking part in our study were mostly the daughters or daughters-in-law. Very few wives who were giving family care to their husband were prepared to be interviewed. It is known that the Turkish and Moroccan communities tend to use family members with a relatively good mastery of the language as a ‘spokesperson’; that effect will have been playing a role here too. However, we have no indications that the perspectives of the daughters and daughters-in-law are essentially any different from those of the spouses of people with dementia. In five cases, the interview was held with the daughter or daughter-in- law in the presence of the wife who was also involved in the care for the relative with dementia. During these interviews, the wife of the patient confirmed the answers of the daughter or daughter-in-law by nodding or making brief remarks. When the interviewer invited the wife of the person with dementia to take part in the interview more directly, the answer was always that the daughter or daughter-in-law was more capable of expressing the way they looked at family care.

Although we did aim to obtain a certain degree of age spread when recruiting the family carers, the Turkish and Moroccan carers interviewed were mostly relatively young (aged 20 to 48). People are mostly physically capable of doing more when they are younger, which could be associated with the largely positive perceptions of family care. At the same time, it can be particularly hard because younger carers belong to the so-called sandwich generation who are caring for parents as well as for children and therefore have a dual burden (Pierret, 2006). The remarks made by some family carers stating that they had a feeling that they were not doing all they should for their own families because of the time put into caring is another pointer in that direction.

The age distribution among the Surinamese Creole interviewees was broader (aged 30 to 84). These carers did however describe themselves a lot more often than their counterparts of Turkish or Moroccan origins as being the care ‘director’ for the family member with dementia, rather than a person who necessarily had to give all the care themselves. In general, there were also fewer barriers for them against making use of additional professional care.

Another limitation of this study is that it only involved family carers from three immigrant groups in the Netherlands. The findings can therefore not be generalised to other immigrant groups. When interpreting the study’s results and conclusions, allowances should also be made for the fact that there is diversity within cultures too and that the Surinamese family carers we interviewed were all ethnically Creole. It is possible that some aspects of the results obtained might not apply to family carers from other Surinamese immigrant communities, such as the Hindustani or Chinese communities from Suriname.

Recommendations

Further research is needed to investigate the extent to which family carers from other immigrant groups (e.g. originating from China or Indonesia) have different or similar views on care in the family for people with dementia. Future research is also recommended to examine how people's views about family care evolve over the coming years, zooming in on differences and similarities between the current and subsequent (third and fourth) immigrant generations.

Insights into diversity – both between immigrant groups and between immigrant generations – are a help when providing information and support to immigrant people with dementia and their family carers. Special interest groups for dementia – such as the national Alzheimer Associations – are currently making major efforts to provide professional support for family carers, for example in information programmes and case management for dementia. It appears to be important to pay attention to more than merely reducing the burden of care. One thing that was strongly highlighted in the interviews with carers was actually that they get a lot of satisfaction from providing family care, and (particularly among Turkish and Moroccan women) the caregiver role creates respect and appreciation for them from the family and the community. Paying also attention to the positive aspects of care in the family may improve the carers' resilience. Both in the media and in scientific research, providing care within the family is often primarily associated with the weight of the burden of caring for an ill family member (e.g. Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013).

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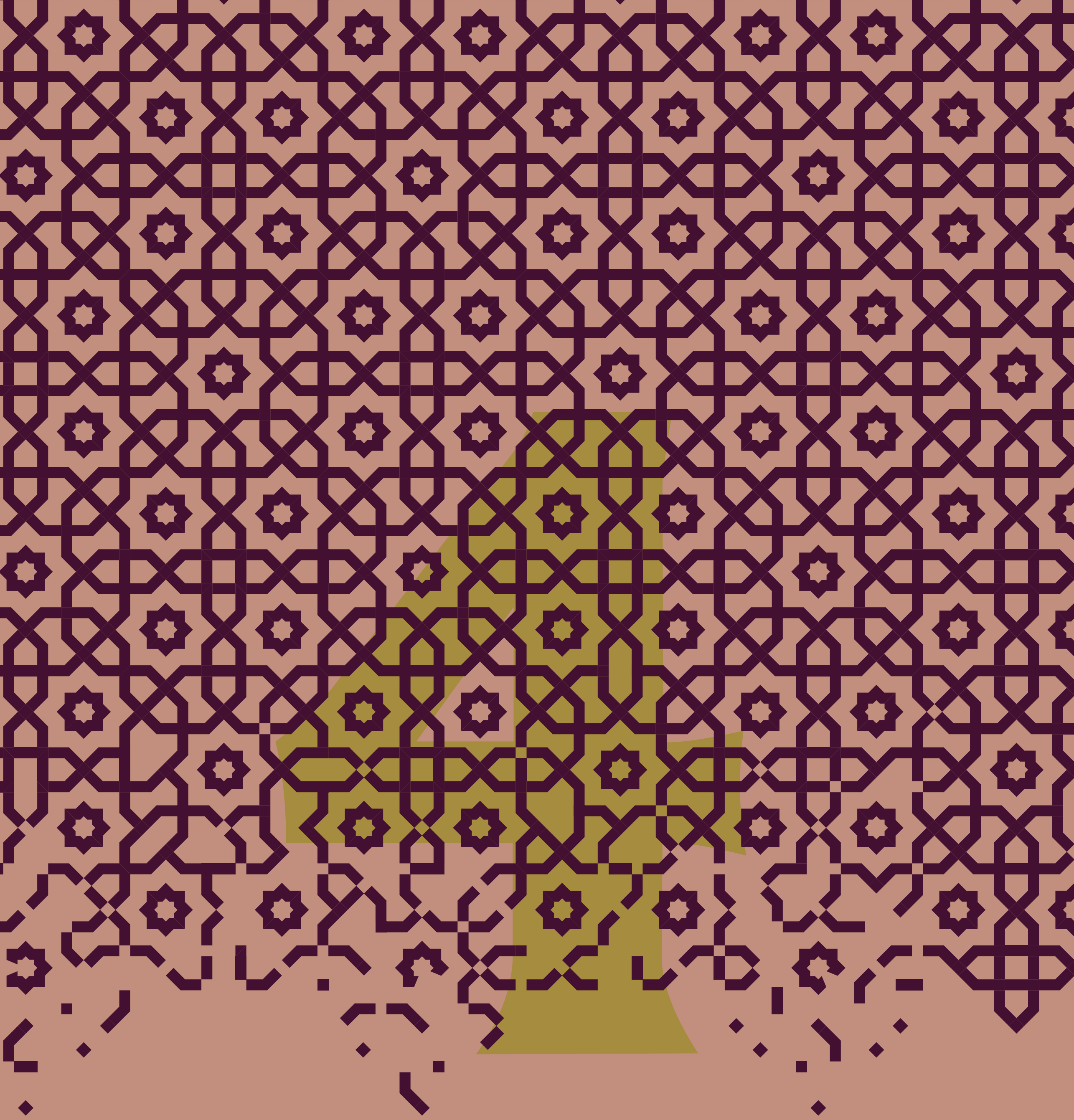

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Chapter 4

Knowledge about dementia among family caregivers with a Turkish or Moroccan immigrant background: development and validation of a dementia knowledge scale

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Abstract

Objective: To describe the development and validation of the Dementia Knowledge Scale (DKS) among family caregivers with a Turkish or Moroccan immigrant background.

Methods: The 11 items of the DKS, selected by professionals and people with a Turkish or Moroccan background, were translated and adapted in Turkish and Dutch. The feasibility, comprehensibility and appropriateness of the two language versions were examined. Subsequently, both languages were assessed among caregivers from these groups. The internal consistency of both language versions was determined by calculating Cronbach's α. The known group validity was determined by comparing mean scores between subgroups.

Results: Both language versions of the DKS were considered feasible, comprehensible and appropriate. A total of 117 caregivers with a Turkish background completed the Turkish version of the DKS and 110 with a Moroccan background the Dutch version. The Turkish version showed adequate internal consistency but the Dutch version did not. No differences were found in mean scores between those with a low level of education versus those with a higher level; those who frequently provided care versus those who did so less frequently; and those who lived together with a person with dementia versus those who did not.

Conclusions: The DKS is feasible, comprehensible and reliable and can be used among groups with an immigrant background.

Practice implications: The DKS provides insight into various aspects of dementia knowledge, including knowledge about risk factors and symptoms, among caregivers with a Turkish or Moroccan background, and thereby supports the development of tailored education for these groups.

Keywords:
dementia; dementia knowledge; family caregivers; migration background; minorities

Introduction

According to the World Alzheimer Report (1), 55 million people worldwide are living with dementia. Given the ageing population, this figure is expected to double every 20 years, increasing to 78 million by 2030 (1).

Some groups are more at risk for developing dementia, including people with a non-western immigrant background (2). This might in part be related to a relatively high prevalence of diseases such as diabetes and cardiovascular conditions among these groups, that increase the risk of dementia (3,4).

In the Netherlands, 12.6% of the population has a non-western migrant background, of which people with a Turkish or Moroccan background are the largest two groups (5). The first generation of people with a Turkish or Moroccan background that came to the Netherlands in the 1960s and 1970s are now at an age in which dementia becomes more prevalent.

A few studies show that knowledge about dementia among people with a non-western immigrant background tends to be poor, such as knowledge about symptoms and progression of the disease (6,7). However, this type of knowledge could help recognize the disease and thereby provide access to timely care and support. Furthermore, it could help (family caregivers of) people with dementia in communicating with care professionals and with their social network about dementia and about future needs (8).

However, in-depth insights into knowledge about dementia and associated factors among people with a non-western migrant background is currently lacking. A commonly used instrument to measure knowledge about dementia, such as the Alzheimer Disease Knowledge Scale (ADKS), that measures knowledge among healthcare professionals or among the general population is not suitable for groups with migrant backgrounds (9, 10). Furthermore, translation and cross-cultural adaptation of these scales to be used among groups with an immigrant background is also lacking (11).

To increase knowledge about dementia among family caregivers with a Turkish or Moroccan background, the educational peer-group intervention 'Knowing about Forgetting' was developed. In order to be able to test the effect this culturally sensitive intervention on knowledge about dementia, an instrument was developed to assess knowledge regarding the topics that were covered in this intervention: risk factors of dementia, disease symptoms, progression of the disease and dealing with dementia.

This paper aims to describe the development and validation of the 'Dementia Knowledge Scale' for its use among individuals with a Turkish or Moroccan background. This paper thereby provides insights that are relevant for other researchers who aim to assess dementia knowledge or who aim to develop other disease-specific knowledge scales to be used among these groups. It thereby helps resolve the existing lack of culturally sensitive health measurement scales and our understanding of them.

The research question addressed is 'What is the internal consistency and validity of the DKS as completed by family caregivers with Turkish or Moroccan backgrounds?'

Methods

Selection of the Dementia Knowledge Scale items

For the development of the Dementia Knowledge Scale (DKS), the ADKS was used as a basis. The ADKS is a validated instrument to assess knowledge regarding Alzheimer's Disease. It contains 30 items and is suitable for use in the general population (9). Eight professionals and nine people with a Turkish or Moroccan background screened the 30 ADKS items in Dutch and selected the ones that they thought represented the most essential knowledge about dementia and fitted best with the content of the intervention 'Knowing about Forgetting'. Based on those individual selections, the 11 most frequently selected items, were included in the final tool (see Appendix 1).

These items were then translated from English into Dutch and (if the eight professionals deemed it necessary), reformulated into more plain language when needed. An example of such a reformulation is: 'Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease'. This item was reformulated in Dutch as '*Symptomen van een ernstige depressie kunnen lijken op dementie*' (in English: 'Symptoms of severe depression can look like dementia').

The Dutch statements were then translated by native speakers into Turkish and Moroccan Arabic. The statements in Turkish and Moroccan Arabic were compared by other native speakers with the Dutch statements to identify and eliminate any nuance differences in the wording.

Pilot testing

To determine the feasibility, comprehensibility and appropriateness of the 11 statements of the DKS, a pilot test was conducted among sixty people with a Turkish or Moroccan background: 30 filled out the Dutch version of the DKS, 15 filled out the Turkish version and 15 filled out the Moroccan Arabic version. The respondents were recruited in community centres in a large city in the south of the Netherlands

(Tilburg). This region was not part of the overall study. Respondents were between 25 and 72 years old and their level of education ranged from no education to a university degree. A researcher evaluated whether the 11 statements were comprehensible (correctly understood), feasible (easy or difficult to answer), and appropriate (seen as relevant for assessing dementia knowledge). These evaluations showed that only minor adaptations were needed. For example, changes to the sequence of the statements and starting with a relatively straightforward statement. These amendments resulted in the final versions of the DKS.

Assessing the internal consistency and known group validity of the Dementia Knowledge Scale

Participants and setting

The final version of the DKS was part of a larger questionnaire that was used to evaluate the educational peer-group intervention 'Knowing about Forgetting', intended for family caregivers with a Turkish or Moroccan background of a person with dementia. The participants were recruited in parts of the Netherlands with relatively many inhabitants with a Turkish or Moroccan background and where no educational intervention on dementia was offered before.

Participants were recruited through key figures in the communities in question (such as community workers, imams, ethnic-minority senior citizen advisers, ethnic minority care organizations and regional branches of the Dutch Alzheimer Association). These key figures asked people in their network who had a relative with severe forgetfulness or dementia whether they would be willing to take part in the educational programme. The key figures gave a verbal explanation and provided written information about the educational programme and associated study. The following inclusion criteria were applied to select participants:

- must have a relative with dementia or – if there has not yet been a formal diagnosis of dementia – with severe forgetfulness;
- must have been born in Turkey or Morocco or have at least one parent born in one of those countries;
- must live in the Netherlands;
- must be able to complete a written questionnaire independently or to complete the questionnaire with the aid of a trained research assistant;
- must not be suffering from severe forgetfulness or dementia themselves.

Procedure

The peer-group educational intervention was evaluated in a Cluster Randomized-Controlled Trial including three measurement points: T0 which was directly before the intervention (baseline), T1 which was directly after the intervention (two weeks after T0) and T2 which was three months after the intervention. Only data from the baseline measurements, i.e. the measurements before the start of the peer-group based educational intervention, were used for the psychometric analyses described in this article.

Participants who could write were asked to fill out a questionnaire themselves. Participants could choose whether they wanted to complete the questionnaire in Dutch or in Turkish/Moroccan Arabic. The questionnaires were filled out in a room at a mosque or a cultural community centre under the supervision of a research assistant with a Turkish or Moroccan background. The research assistants helped participants who were low literate. For those participants, the research assistants read out the questions and scored the items according to the answers given by the participant.

Since merely three respondents filled out the Moroccan Arabic version of the DKS, it was not possible to perform any psychometric analyses for this version.

Prior to participation, the research coordinator gave the participants an information letter about the study together with a consent form, which were in Turkish and in Dutch. In the case of illiterate participants, a research assistant who spoke their mother tongue read out the information letter and consent form. All participants gave their informed consent in writing.

Ethics

Under Dutch law, approval from a medical ethics committee or social/societal ethical committee was not required for this study as the participants were mentally competent, they were not subject to the imposition of a certain kind of behaviour and they were not subjected to burdensome interventions or measurements (https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not).

Assessments

In addition to knowledge about dementia, the following sociodemographic variables were assessed: gender, age, level of education (no schooling or primary school, secondary school, secondary vocational education, higher pre-university education or university, or other) and country of birth. In addition to that, it was assessed whether the respondent lived together with a person with dementia and how often the respondent provided help (daily, 3-6 times a week, up to twice a week, less than once a week, less than once a month).

Statistical analyses

For this paper, a sub-selection was made of individuals who had stated that they were caring for a person with dementia at T0.

Firstly, the 11 items of both the Turkish and the Dutch version of the DKS were analysed descriptively. Secondly, the internal consistency was determined for both versions by calculating Cronbach's alpha (with an α of at least 0.7 indicating adequate internal consistency). Thirdly, the known group validity scores of both versions were determined by comparing the DKS sum scores between subgroups using an independent t-test. It was hypothesized that:

a. Participants who had attended upper secondary or tertiary education would score higher in the knowledge questionnaire than participants who had no education or had only attended primary school (12)
b. Participants who provide informal care for a relative with dementia or severe forgetfulness on a weekly basis would score higher in the knowledge questionnaire than participants who provide informal care less than once a week. This hypothesis was based on an expectation that a person who is intensively involved in informal care will see more of the condition and its symptoms and therefore know more about dementia (12).
c. Participants who live in the same home as the relative with dementia or severe forgetfulness would score higher in the knowledge questionnaire than participants who do not live with the relative in question. This hypothesis is also based on the expectation that a person who lives with a relative with dementia will see more of the condition and its symptoms and therefore know more about it (12)

All statistical analyses were conducted separately for the Turkish and the Dutch version of the DKS using Stata version 15.0.

Results

Sample

For this paper, a sub-selection was made of individuals who had declared that they cared for a person with dementia at T0 (N=244). Of this subselection, 117 participants with a Turkish background completed the Turkish version of DKS and 110 participants with a Moroccan background the Dutch version. These participants were included in the analyses. A total of 16 participants with a Turkish background completed the Dutch version of the DKS and 1 participant with a Moroccan background the Moroccan Arabic version. Given these small group sizes, the Dutch version of the DKS was not validated among participants with a Turkish background and the Moroccan Arabic version not among participants with a Moroccan background.

Sample characteristics

Most of the respondents were female (83% and 92% respectively), aged between 36 and 55 (56% and 54%), and not born in the Netherlands (85% and 76%) in both the respondents with a Turkish background and the respondents with a Moroccan background (see Table 4.1).

Half of the respondents with a Turkish background had no education or had only attended primary school, among respondents with a Moroccan background this was 35%. At the same time, 19% of the participants with a Moroccan background had attended higher professional education or university, compared to 8% among participants with a Turkish background.

Most respondents in both groups did not live in the same home as the person with dementia (61% and 77%). Yet many respondents stated that they cared for a person with dementia on a daily basis: 36% among respondents with a Turkish background and 31% among respondents with a Moroccan background.

Table 4.1 *Sample characteristics*

	Turkish version of DKS filled out by respondents with a Turkish background (N=117)		Dutch version of DKS filled out by respondents with a Moroccan background (N=110)	
	N	*%*	*N*	*%*
Gender				
Female	97	83%	101	92%
Male	17	15%	9	8%
Missing	3	3%	0	0%
Age				
15 – 35	23	20%	34	31%
36 – 55	65	56%	59	54%
56 – 75	22	19%	14	13%
76 – 85	2	2%	0	0%
Missing	5	4%	3	3%

Table 4.1 *Continued*

	Turkish version of DKS filled out by respondents with a Turkish background (N=117)		Dutch version of DKS filled out by respondents with a Moroccan background (N=110)	
	N	*%*	*N*	*%*
Country of birth				
Netherlands	15	13%	26	24%
Other country	100	85%	84	76%
Missing	2	2%	0	0%
Highest level of education				
None or primary school	59	50%	39	35%
Secondary school	24	21%	21	19%
Secondary Vocational Education	20	17%	28	25%
Higher professional education or University	9	8%	21	19%
Other additional courses	2	2%	1	1%
Missing	3	3%	0	0%
Do you live together with the person with dementia?				
Yes	45	38%	24	22%
No	71	61%	85	77%
Missing	1	1%	1	1%
How often do you provide help?				
Daily	42	36%	34	31%
3-6 times a week	15	13%	23	21%
Up to twice a week	26	22%	25	23%
Less than once a week	12	10%	11	10%
Less than once a month	15	13%	16	15%
Missing	7	6%	1	1%

Scores on the items of the Dementia Knowledge Scale

The overall mean score on the DKS was 7.4 (SD:2.1; range 2 – 11). Table 4.2 shows that there is large variation between items in the percentage of respondents that answers the item correctly. This applies for both the respondents with a Turkish background who filled out the Turkish version of the DKS and the respondents with a Moroccan background who filled out the Dutch version.

In addition, Table 4.2 shows that both language versions of the DKS differ with respect to the percentages that answer the items correctly e.g. the items that are the most and least often answered correctly based on the Turkish version are different items that the items that are the most and least often answered correctly based on the Dutch version.

Based on the Turkish version of the DKS, item D9 ('Difficulty handling money or paying bills is a common symptom of dementia') was most often answered correctly (by 88.8% of the respondents) and item D2 ('If somebody starts suffering from sudden confusion and memory problems, that is dementia') the least often (by 35.3%).

Based on the Dutch version, item D6 ('Someone with dementia will eventually need 24-hour supervision') was most often answered correctly (by 86.0% of the respondents) and item D7 ('A high cholesterol level increases the risk of getting dementia') the least often (31.4%).

A striking difference between the two language versions is that questions about risk factors are answered incorrectly relatively often by respondents with Moroccan backgrounds filling out the Dutch version.

Table 4.2 *Number of missing answers per item, % answering correctly and Cronbach's alpha if item dropped*

	Turkish version of the DKS (N=117)			Dutch version of the DKS (N=110)		
	Missing answers per item	% of respondents answering correctly	Cronbach's α if item dropped[a]	Missing answers per item	% of respondents answering correctly	Cronbach's α if item dropped[a]
D1. Hiding memory problems is a behavioural characteristic that is often seen in the early stages of dementia	0	84.6	0.696	0	85.5	0.613

Table 4.2 *Continued*

	Turkish version of the DKS (N=117)			Dutch version of the DKS (N=110)		
	Missing answers per item	% of respondents answering correctly	Cronbach's α if item dropped[a]	Missing answers per item	% of respondents answering correctly	Cronbach's α if item dropped[a]
D2. If somebody starts suffering from sudden confusion and memory problems, that is dementia	1	35.3	0.675	3	54.2	0.603
D3. A poor diet (insufficiently varied diet, few vitamins, a lot of fats and carbohydrates) increases the risk of dementia	1	72.4	0.675	2	38.9	0.549
D4. Dementia can occur in someone aged 35	1	50.0	0.676	2	49.1	0.585
D5. Someone with dementia runs an increasing risk of falling as the disease gets worse	0	87.2	0.657	3	80.4	0.575
D6. Someone with dementia will eventually need 24-hour supervision	0	82.9	0.718	3	86.0	0.609
D7. A high cholesterol level increases the risk of getting dementia	3	63.2	0.651	5	31.4	0.535
D8. Symptoms of severe depression can look like symptoms of dementia	2	85.2	0.673	1	70.6	0.551
D9. Difficulty handling money or paying bills is a common symptom of dementia	1	88.8	0.683	1	64.2	0.588
D10. One possible symptom of dementia is being convinced other people are stealing your things	1	83.6	0.700	3	82.2	0.566
D11. High blood pressure increases the risk of getting dementia	1	64.7	0.636	5	36.2	0.520

[a] *Cronbach's alpha based on 11 items for the Turkish version of the DKS= 0.698*

[b] *Cronbach's alpha based on 11 items for the Dutch version of the DKS= 0.597*

Internal consistency

Cronbach's alpha for the Turkish version of the DKS was 0.698, which can be considered borderline adequate. This could be increased to a maximum of 0.718 by dropping item D6 ('Someone with dementia will eventually need 24-hour supervision'). Cronbach's alpha for the Dutch version of the DKS, which was filled out by respondents with a Moroccan background, was lower at 0.597. This alpha could be increased to a maximum of 0.613 by dropping item D1 ('Hiding memory problems is a behavioural characteristic that is often seen in the early stages of dementia').

Known group validity

For both the Turkish and the Dutch versions of the DKS, no significant differences were found in mean DKS scores between those who had received no education or primary education and those who had received mid-level or higher education (see Table 4.3). Furthermore, no significant differences were found in mean DKS scores between those who cared for a person with dementia at least once a week and those who cared for a person less than once a week. Finally, no significant differences were found in mean DKS scores between those who lived with a person with dementia and those who did not live together.

Table 4.3 *Known-group validity*

		Turkish version of the DKS		Dutch version of the DKS	
Hypotheses	Subgroups	N	Mean (SE) DKS score	N	Mean (SE) DKS score
1*	None or primary school	55	7.9 (0.3)	35	6.9 (0.3)
	Middle or higher education	50	8.0 (0.3)	60	6.8 (0.3)
2**	Caring for a person with dementia minimal once a week	78	8.1 (0.2)	72	6.9 (0.3)
	Caring for a person less than once a week	26	7.5 (0.4)	23	6.5 (0.4)
3***	Living together	42	8.2 (0.3)	21	6.7 (0.5)
	Not living together	67	7.9 (0.2)	75	6.8 (0.2)

* *The level of education influences knowledge of dementia*

** *The intensity of caring for the person with severe memory loss or dementia influences knowledge of dementia*

*** *Living together with the person with severe memory loss or dementia influences knowledge of dementia*

Discussion

This paper describes the development, internal consistency and known group validity of the Dementia Knowledge Scale in Dutch and the Turkish among family caregivers with a Moroccan or Turkish backgrounds.

The internal consistency of the Turkish version of the DKS filled out by respondents with a Turkish background was adequate. On the other hand, the internal consistency of the Dutch version of the DKS, filled out by respondents with a Moroccan background, was poor. This implies that there is more variation among the respondents who filled out the Dutch version in the extent to which items are answered correctly or not answered, compared to respondents who filled out the Turkish version.

A lot of variation was found in the scoring on the individual DKS items, indicating especially that respondents with a Moroccan background filling out the Dutch version of the DKS have relatively good knowledge of aspects related to symptoms of dementia but know less about the risk factors for dementia. This is in line with the study by Jorge *et al.*(13), who found that the risk factors for dementia are often unknown.

Strikingly, our three hypotheses with respect to the known group validity were not confirmed. Respondents with a higher level of education did not score higher on the DKS than respondents with a lower educational level. Furthermore, respondents who took care for a person with dementia more often did not get higher scores than those who took care for a person with dementia infrequently. Thirdly, those who lived with a person with dementia did not get higher scores than those who did not live with a person with dementia.

We do however see variation between respondents in mean scores on the DKS. This indicates that there may be other background characteristics than those we included that are associated with right or wrong answers on the DKS. To validate the DKS further, people who have nothing to do with dementia in their family could also be included, to compare their scores against the family caregivers of people with dementia. This will provide another opportunity to assess known group validity. As this is one of the first studies that addresses dementia knowledge among persons with a Turkish or Moroccan migration background, additional (qualitative) research is needed to examine if this could indeed be the case and to obtain a better understanding of factors that do relate to dementia knowledge among these groups. More research, explaining differences in dementia-related knowledge between subgroups of people with non-western migrant backgrounds is therefore recommended.

Because we expected that written language skills would be limited in some participants, the decision was made to have a maximum of 11 items in the questionnaire. It would be interesting to explore whether extending the questionnaire, using different wording of the items or a combination of the two could increase the internal consistency and the known-group validity.

The number of missing answers was low, which indicates that the participants understood the questions and had the motivation to fill them in. The fact that participants could choose between different language versions and the fact that participants who could not read and write could be helped by a trained research assistant who spoke their language might also have contributed to the low rate of missing answers.

Participants with a Turkish background stated that they had greater reading and writing competence in Turkish than in Dutch. Consequently, these participants more often opted to fill out the Turkish version of the DKS instead of the Dutch version. This was different for the participants with a Moroccan background, who were more likely to choose the Dutch version than the Arabic version. Most of these participants had stated that they had greater competence in Dutch (reading and writing) than in Moroccan Arabic. This underlines the importance of verifying with the target population what preferred languages are in which an instrument such as the DKS is offered, especially since some mother tongues or dialects are rarely written down.

A recommendation for future research is to assess the psychometric properties of the DKS among family caregivers without migrant backgrounds. It would specifically be interesting to verify whether different patterns of answers can be found among family caregivers without migration backgrounds compared to those with Turkish or Moroccan backgrounds.

Conclusion

This study shows that the internal consistency of measurement scales can differ according to the population to which it is applied. This underlines the importance of cross-cultural adaptation of measurement scales that are used among groups with immigrant backgrounds. The Dutch and the Turkish versions of the Dementia Knowledge Scale can be used to obtain a picture of the level of knowledge among family caregivers with a Turkish or Moroccan background about the risk factors, symptoms and characteristics of dementia. These understandings could assist in the development of tailored information and education for these groups.

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Appendix 4.1 Alzheimer Knowledge Scale

You will find eleven statements about dementia below. After reading each statement, you can circle the answer that you think is correct.

D1. Hiding memory problems is a behavioural characteristic that is often seen in the early stages of dementia.
Agree/disagree

D2. If somebody starts suffering from sudden confusion and memory problems, that's dementia.
Agree/disagree

D3. A poor diet (insufficiently varied diet, few vitamins, a lot of fats and carbohydrates) increases the risk of dementia.
Agree/disagree

D4. Dementia can occur in someone aged 35.
Agree/disagree

D5. Someone with dementia runs an increasing risk of falling as the disease gets worse.
Agree/disagree

D6. Someone with dementia will eventually need 24-hour supervision.
Agree/disagree

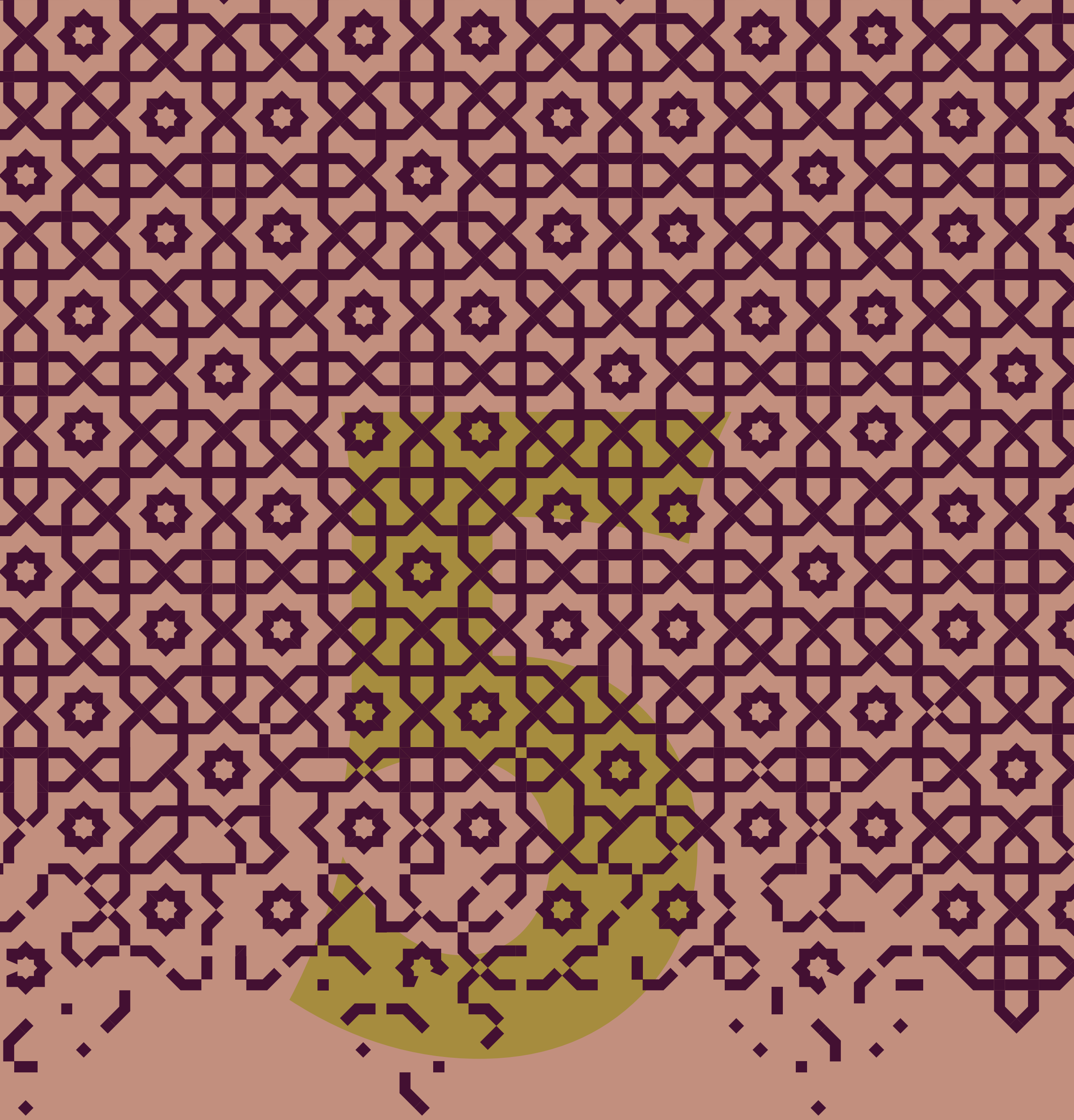
D7. A high cholesterol level increases the risk of getting dementia.
Agree/disagree

D8. Symptoms of severe depression can look like symptoms of dementia.
Agree/disagree

D9. Difficulty handling money or paying bills is a common symptom of dementia.
Agree/disagree

D10. One possible symptom of dementia is being convinced other people are stealing your things.
Agree/disagree

D11. High blood pressure increases the risk of getting dementia.
Agree/disagree


5

Chapter 5

The Turkish version of the SPPIC validated among informal caregivers with a Turkish immigrant background

van Wezel N, van der Heide I, Devillé WLJM, Duran G, Hoopman R, Blom MM, Pot AM, Spreeuwenberg P, Francke AL. The Turkish version of the SPPIC validated among informal caregivers with a Turkish immigrant background. BMC Geriatr. 2021 Apr 29;21(1):284.

Abstract

Background: This study assesses the internal consistency and known group validity of the Turkish version of the SPPIC, a measurement instrument to assess the self perceived pressure from informal care in family caregivers of people with dementia that was originally in Dutch.

Methods: The feasibility, comprehensibility and appropriateness of the Turkish SPPIC were assessed during a pilot test. Internal consistency was examined based on data from 117 family caregivers with a Turkish immigrant background by calculating Cronbach's alpha and by conducting a single-factor Confirmatory Factor Analysis (CFA). Known group validity was determined to obtain an understanding of the validity of the translated instrument, testing differences in the self-perceived pressure from informal care, depending on frequency of caregiving, living with a person with dementia and level of education.

Results: The pilot test showed that the translated SPPIC was considered to be feasible, comprehensible and appropriate. The internal consistency appeared to be strong (Cronbach's alpha: 0.94). The CFA indicated that the factor 'Self-perceived Pressure from Informal Care' explained varying levels of variance in the items of the SPPIC (ranging from .52 to .87). Family caregivers who provided care at least once a week and who shared a home with a person with dementia perceived a greater pressure from informal care ($p=0.007$, $p=0.001$).

Conclusions: The Turkish translation of the SPPIC can be used in future research and practice to obtain insight into self-perceived pressure from informal care of family caregivers with Turkish immigrant backgrounds. At the same time it is recommended to conduct more research on how the measurement of self-perceived pressure from informal care in this group can be further improved.

Keywords:

dementia; family caregivers; Self-perceived Pressure from Informal Care; questionnaire validation; migrants

Background

Studies show that family caregivers often perceive caregiving as stressful or burdensome, especially those who take care of a person with dementia (1,2,3). Compared to other family caregivers, family caregivers taking care of a person with dementia are more often overburdened (4,5,6,7). Many studies show that the stress and pressure as a consequence of caring for a person with dementia can lead to poor health outcomes in family caregivers, including depression (8,9). In order to offer timely support and thereby prevent overburdening in family caregivers, it is important to have insight into their self-perceived care pressure. The model of carer stress and burden, as published by Sörensen and colleagues (10), combines several theoretical models of carer burden and stress, and is a commonly used theoretical framework for guiding caregiving research (10). It entails well-documented primary and secondary stressors as well as background and contextual factors that relate to care burdens in family caregivers of people with dementia. A primary stressor in this model is the severity of the disease. As dementia progresses, problem behaviour as well as cognitive and functional impairment tend to worsen, increasing the pressure on family caregivers. Furthermore, the care situation, including the hours of care and the duration of care, is also one of the primary stressors. Spousal caregivers, sharing a home with a person with dementia, often provide long-term care on a day-to-day basis and are therefore more likely to experience a high self-perceived pressure from informal care than caregivers who live separately from the person with dementia (11). Background and contextual factors that account for a higher self-perceived pressure from informal care in family caregivers, according to the model of carer stress and burden, include having a lower socioeconomic status (and therefore fewer resources) (12,13,14,10), being older, being a female caregiver and having a specific ethnic or cultural background compared to other ethnic groups (15).

Assessing the self- perceived pressure from informal care can help recognize those family caregivers who are especially in need of support. Various measurement instruments have been developed to assess self- perceived pressure from informal care among family caregivers (16,17,18). A validated and frequently used Dutch questionnaire for measuring the self- perceived pressure from informal care of family caregivers of people with dementia is the SPPIC (Self-perceived Pressure from Informal Care) (17). The SPPIC was originally developed and validated in Dutch in 1995. The SPPIC measures the demands of the care situation as perceived by the family caregiver and in relation to the caregiver's needs, such as time for other activities (19). However, this version of the SPPIC is only available in Dutch. A Turkish version of the SPPIC is highly desirable as 12.7% of the Dutch population has non-Western immigrant backgrounds (19) and people with a Turkish background are the largest group within that category (20). The first generation of immigrants with Turkish background have now reached the age at which dementia becomes increasingly prevalent. We assume that the self- perceived pressure from informal care in family caregivers with a Turkish background might be relatively high because (a) the care for a family member with dementia is preferred to be provided within the family circle, (b) beliefs regarding severe memory loss and ageing might make people refrain from seeking professional support, and (c) because the options for professional care and support are often not known (21).

For these reasons, we developed a supportive peer-group-based educational intervention to enhance knowledge about the disease dementia and about care and support options for family caregivers with an immigrant background (30). We aimed to study the effects of this intervention on self- perceived pressure from informal care in family caregivers with a Turkish background. The translation and validation of the SPPIC in Turkish were part of this larger study, which included a pilot phase before the main study in order to test the feasibility, comprehensibility and appropriateness of the translated measurement instruments, including the SPPIC.

The aim of the current study is to examine the internal consistency and the known group validity of the Turkish version of the SPPIC.

Method

Translation of SPPIC

The SPPIC consists of nine statements about the care provided by the family caregiver (see Appendix 5.2). Each statement can be answered with 'No!', 'No', 'More or less', 'Yes' or 'Yes!' To give an example, one of the statements is "I must always be available for my …" To translate the Dutch SPPIC we used the principles of forward and back-translation (22). The nine statements were first translated from Dutch into Turkish by a professional Turkish native-speaking translator. After that, the Turkish version of the SPPIC was translated back into Dutch. The original Dutch version was then compared against the back-translated Turkish version by one of the research group members who is a native Turkish speaker. The research group members discussed some minor differences in the nuances of the translations and the wording was amended accordingly.

Pilot test: feasibility, comprehensibility and appropriateness

To determine the feasibility, comprehensibility and appropriateness of the translated items of the SPPIC, a pilot test was conducted among 30 Turkish first or second-generation family caregivers aged 25-72 whose level of education ranged from none to a university degree. The participants in the pilot test were recruited in community centres in a large city in the south of the Netherlands (Tilburg). This region was not part of the overall study. Participants were offered the choice of filling in the Dutch or the Turkish version of the questionnaire. All thirty participants completed the Turkish version of the SPPIC. The research staff then made a verbal inventory of whether the participants correctly understood the items (comprehensibility), whether the items were difficult to answer (feasibility) and whether the items were seen as relevant for assessing the self-perceived pressure from informal care (appropriateness). This inventory showed that no adaptations of the items of the SPPIC were needed. The Dutch version as well as the English translation are included in Appendix 5.2.

Main study: internal consistency and validity

Participants:

The internal consistency and validity of the Turkish version of the SPPIC were assessed in the context of an intervention study that was set up to evaluate the effects of a peer-group-based educational intervention for family caregivers with an immigrant background. The participants for this intervention study were recruited in two provinces of the Netherlands, in which no peer-group-based educational intervention was offered before and where relatively many people live with a Turkish immigrant background (20). Participants were recruited through key figures in the communities (such as community workers, imams, ethnic minority senior citizen advisers, ethnic minority care organizations and regional branches of the Dutch Alzheimer Association). These key figures asked people in their network who had a relative with dementia or severe forgetfulness whether they would be willing to take part in the peer-group based educational intervention. The key figures gave a verbal explanation and provided written information about the intervention and the associated study and inclusion criteria. If family caregivers wanted to take part, the key figures then passed on their contact details to the research coordinator. The coordinator assessed (by means of a short oral intake interview with each participant) whether the family caregivers who had expressed an interest met the inclusion criteria. The following inclusion criteria were applied to select participants with a Turkish background:

- must have a relative or loved one with dementia or – if there has not yet been a formal diagnosis – with severe forgetfulness;
- must have been born in Turkey or have at least one parent born in that country;
- must live in the Netherlands;
- must be able to complete a written questionnaire independently or to complete the questionnaire with the aid of a trained research assistant;
- must not be suffering from severe forgetfulness or dementia themselves.

Procedure

Only data from the baseline measurements, i.e. the measurements before the start of the peer-group based educational intervention, among participants who filled in the Turkish version of the SPPIC were used for the psychometric analyses described in this article. Participants who were literate were asked to fill in the questionnaire themselves. Participants could choose whether they wanted to complete the questionnaire in Dutch or in Turkish. Research assistants with a Turkish background were available to help participants who were not literate. For those participants, the research assistants read out the questions and scored the statements according to the answers given by the participant. Prior to participation, the research coordinator gave the participants an information letter about the study together with a consent form. These were available in Turkish and in Dutch. All participants gave their informed consent in writing. In the case of illiterate participants, a research assistant who spoke their mother tongue read out the information letter and consent form.

Ethical approval

Under Dutch law, approval from a medical ethics committee or social/societal ethical committee was not required for this study as the participants were mentally competent, they were not subject to the imposition of a certain kind of behaviour and they were not subjected to burdensome interventions or measurements (https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not)

Assessments

The following sociodemographic variables were assessed by a questionnaire: sex, age, highest completed level of education (none or primary school, secondary school, secondary vocational education, higher professional education or university, or other) and country of birth. In addition to that, characteristics related to familiarity with dementia were assessed: whether dementia is present in the family, whether the respondent lived together with a person with dementia, whether the respondent provided care (personal care, domestic help, practical help, providing a listening ear, watching over, nursing care and companionship), how often the respondent provided help (daily, 3-6 times a week, up to twice a week, less than once a week, less than once a month). The language proficiency in both the mother tongue and Dutch were also assessed for reading, writing, understanding and speaking (none, little or good). Answers to the nine items of the SPPIC were recoded to a numeric score, ranging from 1 to 5 per item. Sum scores were subsequently calculated ranging from 9 (the lowest self-perceived pressure of informal care) to 45 (the highest self-perceived pressure of informal care).

Statistical analyses

Descriptive statistics were used to describe the scores on the items of the SPPIC. The internal consistency of SPPIC was examined by calculating correlation coefficients between the items of the SPPIC and the Cronbach's α across the items (with an α of ≥ 0.7 indicating adequate internal consistency) (22). Subsequently, confirmatory factor analysis (CFA) was conducted using structural equation modelling to determine whether all nine items of the SPPIC reflected a single homogeneous dimension of 'self- perceived pressure from informal care', as suggested in the original validation study of the SPPIC (17). The extent was therefore tested to which the nine items loaded on a single factor and to what extent this single factor model fitted the data. The goodness of fit was used to evaluate how well the proposed single-factor model fitted the data. χ^2 is a statistic for evaluating the overall model fit (22, 23). A non-significant χ^2 value suggests that the hypothesized model fits the data. Furthermore, Comparative Fit Index (CFI), and Tucker-Lewis index (TLI) were used to assess the model fit. Values of < 0.90 indicate no fit; values between 0.90 and 0.95 indicate acceptable fit; values of > 0.95 suggest an excellent fit (22, 23). Values of the root mean square error of approximation (RMSEA) between 0.05 and 0.08 indicate an acceptable fit, below 0.05 indicates an excellent fit (24). In addition to the internal consistency, the known group validity of the Turkish version of the SPPIC was determined by comparing the mean sum scores for subgroups of participants by using an independent t-test. A significance level of 0.05 was adopted, see below. As there were few missing data items, listwise deletion was adopted in the case of missing values and sum scores were only calculated for those who completed all items of the scale. The following hypotheses were tested.

- Participants who provide family care at least once a week are expected to have a higher self- perceived pressure from informal care as measured by SPPIC than participants who provide family care less than once a week (10).
- Participants who live in the same home as the relative with severe forgetfulness or dementia are expected to have a higher self- perceived pressure from infor-

mal care as measured by SPPIC than participants who do not live in the same home as the relative with severe forgetfulness or dementia family (24, 26).

- Participants with no education or only primary education are expected to have a higher self- perceived pressure from informal care as measured by SPPIC than participants who completed secondary or tertiary education (14, 10). Education is here considered to be an indicator of socioeconomic position.

All analyses were conducted using Stata version 15.0.

Results

Pilot test: feasibility, appropriateness and comprehensibility

The content of the questions was considered appropriate by the 30 participants of the pilot test. In addition, the nine questions of the Turkish version of the SPPIC were considered comprehensible by the participants. Furthermore, the length of the questionnaire was evaluated positively and therefore considered feasible for application in research and practice. The pilot test therefore did not reveal any need for further amendments to the Turkish version of the SPPIC.

Main study: internal consistency and validity

Background characteristics

A total of 133 participants with Turkish backgrounds provided family care to loved ones with dementia of whom 117 (89%) completed the Turkish version of SPPIC and could therefore be included in the current analyses. Most of the participants were aged between 36 and 55, were female and had been born in Turkey (see Table 5.1). A substantial proportion of the participants had no education or had only attended primary school (50.4%). The participants had a greater competence in reading, writing, comprehending and speaking in Turkish than in Dutch (see Appendix 5.3). Most of the participants (91%) cared for a relative with dementia and few for a friend, neighbour or other person with dementia (9%). More than a third of the participants (38.5%) were living in the same home as the relative with dementia or severe forgetfulness. Domestic help, offering a listening ear and assistance are the most common forms of family care. Around a third of the participants provided family care on a daily basis (see Table 5.2).

Table 5.1 *Sociodemographic sample characteristics (N=117)*

Characteristics	Mean (SD)	*n* (%)
Sex		
Female		97 (82.9)
Missing		3 (2.6)
Age	45.7 (13.2)	
15-35		23 (19.6)
36-55		65 (55.6)
56-75		22 (18.8)
76-85		2 (1.7)
Missing		5 (4.3)
Education*		
None or primary school		59 (50.4)
Secondary school		24 (20.5)
SVE**		20 (17.1)
HPE or university***		9 (7.7)
Other****		2 (1.7)
Missing		3 (2.6)
Brought up in the Netherlands?		
Yes		15 (12.8)
Missing		2 (1.7)

* *Education* = *Highest level of education*
** *SVE* = *Secondary Vocational Education*
*** *HPE or University* = *Higher professional education or University*
**** *Other* = *Other additional courses*

Table 5.2 *Features of the relationship between the respondents (N=117) and their relative with dementia*

Characteristics	*n* (%)
Dementia in the family?	
Yes	99 (84.6)
No, but in immediate environment	17 (14.5)
*Who is the person with dementia? **	
Partner	22 (18.8)
Child	4 (3.4)
Father (father-in-law)	40 (34.2)
Mother (mother-in-law)	55 (47.0)
Brother or sister	4 (3.5)
Neighbour	13 (11.2)
Different	20 (17.1)
Do you live together with the person with dementia?	
Yes	45 (38.5)
Missing	1 (0.9)
Do you provide help?	
Yes	117 (100)
Missing	0 (0.0)
*If yes, what kind of help? **	
Personal care	25 (21.2)
Domestic help	58 (49.6)
Practical help	51 (43.6)
Listening ear	63 (53.8)
Watching over	41 (35.0)
Nursing care	15 (12.8)
Accompaniment	53 (45.3)
How often do you provide help?	
Daily	42 (35.9)
3-6 times a week	15 (12.8)
Up to twice a week	26 (22.2)
<1 once a week	12 (10.3)
<1 once a month	15 (12.8)
Missing	7 (5.9)

* *multiple answers possible*

Internal consistency of the SPPIC

The mean sum score on the SPPIC was 25.8 (SD=7.9). More detailed information on the scores on the individual items can be found in Appendix 5.1. The nine items were highly correlated (see Table 5.3) and showed high internal consistency with a Cronbach's alpha of 0.94. χ^2=71.26, p=.000. The Confirmatory Factor Analysis indicated that the single factor self- perceived pressure from informal care explained varying levels of variance in the items of the SPPIC (ranging from .52 to .87) (see Figure 5.1). Most variance was explained in the first three items and the fifth item of the SPPIC. Less variance was explained in the last four items of the SPPIC and the least variance was explained in the fourth item of the SPPIC (see Figure 5.1). This implies that factors other than self- perceived pressure from informal care caused variance in the scoring on these items. The comparative fit index (CFI) showed an acceptable model fit (.916), yet the RMSEA (.123) and the Tucker-Lewis fit index (TLI) indicated a lack of fit (.888), as well as the χ^2 which turned out to be significant (p=.000).

Table 5.3 Correlation matrix including the nine items of the Turkish version of the SPPIC

	1	2	3	4	5	6	7	8	9
C1. Owning to the situation of my… I have too little time for myself.	1.00								
C2. Combining the responsibility for my… and for my job and/or family is not easy.	0.70	1.00							
C3. Because of my involvement with my…I don't pay enough attention to others.	0.71	0.71	1.00						
C4. I must always be available for my…	0.38	0.39	0.40	1.00					
C5. My independence is suffering	0.64	0.64	0.69	0.44	1.00				
C6. The situation of my … constantly demands my attention	0.49	0.50	0.55	0.58	0.59	1.00			
C7. Because of my involvement with my…I am getting into conflict at home or at work.	0.49	0.52	0.60	0.36	0.59	0.43	1.00		
C8. The situation of my…is a constant preoccupation	0.46	0.45	0.56	0.37	0.36	0.54	0.51	1.00	
C9. Generally speaking I feel very pressured by the situation of my…	0.52	0.49	0.58	0.30	0.51	0.45	0.54	0.64	1.00

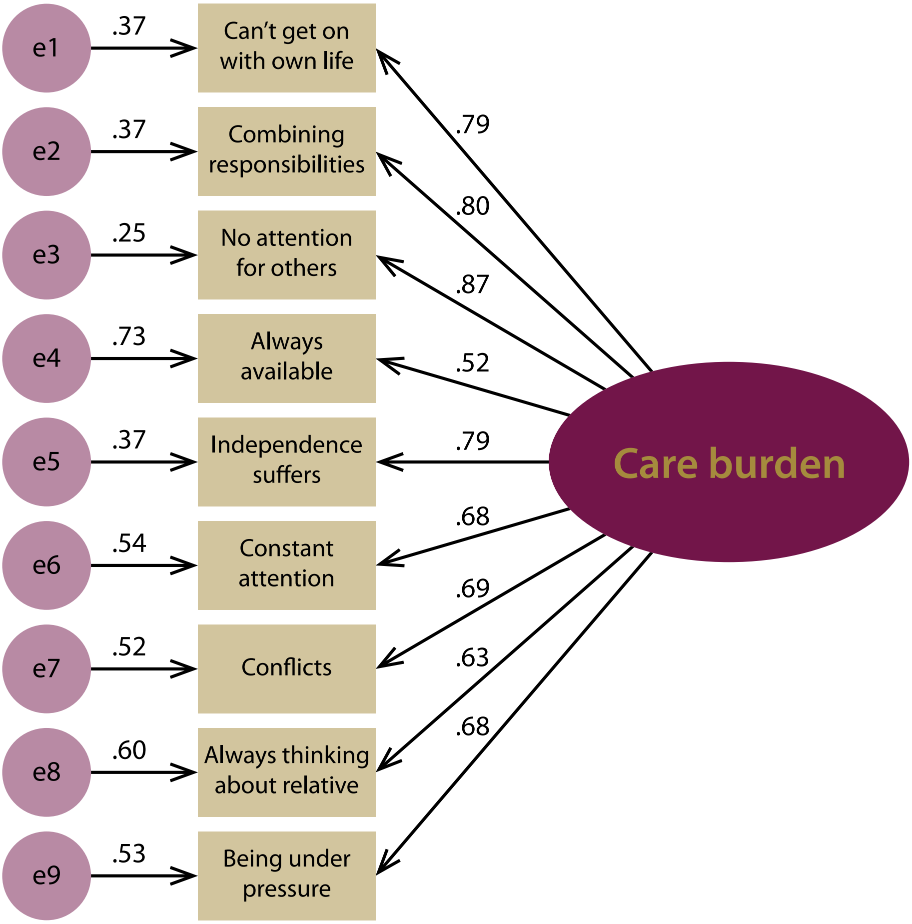


Figure 5.1 *Results of the Confirmatory Factor Analysis for SPPIC including a single factor.* χ^2*=71.26, p=.000; comparative fit index (CFI)=.916; Tucker-Lewis fit index (TLI)=.888; RMSEA=.123.*

Known group validity

In line with the expectations, there was an association between the frequency of caregiving and self- perceived pressure from informal care: family caregivers who provided care at least once a week to a relative with severe forgetfulness or dementia perceived a greater pressure from informal care (M=26.6, SD=7.7) than those who offered care less than once a week (M=21.9, SD=7.1; t(100)=2.76, p=0.007). Also in line with the expectations, family caregivers who shared a home with the relative with severe forgetfulness or dementia experienced a greater pressure from informal care (M=28.9, SD=7.3) than those who did not (M=23.8, SD=7.7; t(105)=3.37, p=0.001). However, contrary to what we expected, people who had completed no education or had only been through primary school did not have a higher self- perceived pressure from informal care (M=26.5, SD=7.3) than those who completed secondary or tertiary education (M=25.1, SD=8.6; t(103)=0.89 , p=0.378).

Discussion

The aim of the current study was to evaluate the internal consistency and validity of the Turkish translation of the SPPIC. The SPPIC is a measurement instrument, originally developed and validated in Dutch, to assess the self- perceived pressure form informal care among family caregivers (31). A pilot test was conducted to obtain insights into the feasibility, comprehensibility and appropriateness of the translated items of the Turkish SPPIC. All participants of the pilot test found the translated items of the SPPIC comprehensible, appropriate and feasible.

After the pilot test, a validation study was conducted to evaluate the internal consistency and validity of the Turkish translation of the SPPIC. The number of missing answers was low, which indicates that the participants understood the questions and were motivated to fill in the whole questionnaire. Research among ethnic minority populations is characterised by relatively high attrition rates (27). In order to prevent both attrition and missing values, we applied various strategies: involving people with the same cultural background in the design of the research, pre-testing the questions and explaining in detail how the questionnaire should be completed.

Where study participants had the option of choosing between the Dutch and the Turkish versions of the SPPIC, a vast majority of participants chose the Turkish version, even though most of the participants were aged 55 or younger, and had often lived most of their life in the Netherlands. This finding is all the more relevant in the context of offering educational interventions to people with a Turkish immigration background. It is sometimes assumed that the second generation have a good command of Dutch but that when, as in this study, a choice is offered between completing a written questionnaire in Turkish or Dutch, the majority of the participants opt for the Turkish questionnaire. It is therefore recommended that the language preferences of the target group should be taken into account.

The internal consistency of the nine items of the SPPIC could be considered good based on the Cronbach's alpha. However, the outcomes of the Confirmatory Factor Analysis, testing a single factor solution, indicated an overall moderate model fit, which could imply that a multiple factor solution might better fit the data. Although all items seemed to measure an aspect of self-perceived pressure from informal care, not all variance in the item scores could be explained by the underlying factor 'self-perceived pressure from informal care'. This especially applied for the item "I must always be available for my […]", which suggests that factors other than 'self-perceived pressure from informal care' might better explain variation in the scoring on these items. The strongest indicators of 'self-perceived pressure from informal care' seem to be the items that assess perceptions with respect to getting on with life (item 1); combining responsibilities (item 2); giving enough attention to others (item 3); personal independence (item 5). Most variance in these items can be explained by 'self-perceived pressure from informal care'.

A possible explanation for the moderate fit of the single factor solution, is that self-perceived pressure from informal care aspects as addressed in the nine items of the EDIZ, are better indicators of self-perceived pressure from informal care in family caregivers with a Dutch background than in family caregivers with a Turkish migration background. When comparing the outcomes of our validation study with the outcomes of the validation study of the original (Dutch) version of the EDIZ, there are some notable differences in how participants responded to the nine items. Pot and colleagues (17) listed the nine items, with at top of the list the item that most participants agreed with (and that are therefore assumed to require the least pressure in order to make them agree) and at the bottom of the list the item that fewest participants agreed with (and therefore required the most pressure in order to make them agree). When listing the items based on the outcomes of our study according to the proportion that agreed with an item, we see a slightly different order (see Appendix 5.4). The main notable difference between our list and the list as presented by Pot and colleagues (17), is that relatively many participants in their study agreed with the item "Owning to the situation of my….I have too little time for myself", whereas in our study we found that few people agreed with this item. This suggests that family caregivers with a Dutch background feel that their care duties start interfering with their life at an earlier stage than caregivers with a Turkish background.

In addition, our findings imply that agreement with the item "I must always be available for my […]" cannot be explained well by the latent variable 'self-perceived pressure from informal care'. It could be that family caregivers with Turkish background might strongly agree with the statement that they always have to be available for their relative with dementia, regardless of the self-perceived pressure from informal care. This assumption is supported by the finding that the largest proportion of participants agreed with this item, perhaps including those who perceived little pressure. Among caregivers with a Dutch background, agreeing with this statement might be more strongly associated with a higher self-perceived pressure from informal care.

Based on these findings, more research is recommended on aspects that should be measured in order to obtain a more comprehensive insight into self-perceived pressure from informal care in family caregivers with a Turkish immigrant background.

In line with other studies (1, 2, 3, 11, 28, 29), the current study showed that the intensity of providing family care is associated with the self-perceived pressure from informal care: frequently providing care is associated with a higher self-perceived pressure from informal care and this is even more so for spouses of a person with dementia. This is a relevant finding because providing family care is seen in Turkish immigrant communities as a task provided primarily by women (21).To prevent psychological and physical health problems in family caregivers (1, 2, 3, 11, 12, 13), it is important to signal a high self-perceived pressure from informal care in family caregivers.

Little is known about the self-perceived pressure from informal care and possible health effects in ethnic minorities. The SPPIC could be used to obtain more insights in this respect. However, a limitation of this study is that it only focuses on the validation of a Turkish translation of the SPPIC. For future research regarding family caregiving in ethnic minorities, it is recommended that there should be an evaluation of whether the SPPIC should be translated and validated in the mother tongues of other ethnic minority groups. As some languages are largely phonetic (Moroccan Berber), the main language of the country of residence might be more applicable for some ethnic minority groups.

Another limitation of this study is that the majority of the participants were female and it was not known if family caregivers were assisted in caring for the person with dementia by healthcare professionals (for instance home care) or other family caregivers. More research is recommended into the validation of the (Turkish) SPPIC among larger groups of male caregivers and to get a better understanding of the level of professional or family support received.

Furthermore we would recommend that additional studies be carried out using larger samples of participants in order to further document the validity and responsiveness of the Turkish SPPIC. Finally, it is also important to test Turkish version of SPPIC in other western European countries that are home to large communities of Turkish migrants (for example Flanders in Belgium, and France and Germany). Turkish migrants living in these countries have similar background characteristics, migration history and socioeconomic conditions to the migrants in the present study.

Conclusion

The Turkish translation of the SPPIC can be considered a feasible and valid measurement instrument to assess self-perceived pressure from informal care among family caregivers with a Turkish immigrant background, caring for a person with dementia living in the Netherlands. Four out of the nine items of the SPPIC seem specifically to be strong indicators of self-perceived pressure from informal care. The Turkish translation of the SPPIC can be used in future research and practice, to obtain insight into the (more intensive) support needs in the care for a loved one with dementia. At the same time it is recommended to conduct more research on how the measurement of self-perceived pressure from informal care among family caregivers with a Turkish immigrant background can be further improved.

Abbreviations

SPPIC (Self-perceived Pressure from Informal Care)
CFA (confirmatory factor analysis)
CFI Comparative Fit Index,
TLI (Tucker-Lewis index)
RMSEA (Values of the root mean square error of approximation)

Declarations

Ethics approval and consent to participate

Under Dutch law, approval from a medical ethics committee or social/societal ethical committee was not required for this study as the participants were mentally competent, they were not subject to the imposition of a certain kind of behaviour and they were not subjected to burdensome interventions or measurements (https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not)

All participants gave their informed consent in writing. In the case of illiterate participants, a research assistant who spoke their mother tongue read out the information letter and consent form.

Consent to publish

Not Applicable

Availability of data and materials

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

Competing Interests

The authors declare that they have no competing interests.

Funding

Not applicable

Authors' contributions

All: the conception and the design of the study, analysis and interpretation of the data. Drafting and/or revising it critically for intellectual content. Final approval of the version to be submitted. All authors have read and approved the manuscript N.v.W.: conceptualization; data curation; investigation, original draft; writing; project administration. I.v.d.H.: conceptualization; data curation; writing; methodology; writing. W.L.J.M.D.: supervision; review and editing. G.D.: Investigation, writing, review and editing. A.M.P.: supervision; review and editing. R.H.: supervision; review and editing. P.S.: conceptualization; data curation; writing; methodology; validation; supervision, analysis. M.M.B.: funding acquisition; resources; Supervision; review and editing. A.L.F.: conceptualization; supervision; review and editing.

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Additional files

Appendix 5.1 Missing values, mean, skewness and kurtosis for the Turkish translation of the EDIZ per item

Items of the EDIZ	Scoring on the items						
	Missing	Mean	SD	Min	Max	Skewness	Kurtosis
C1. Owning to the situation of my….I have too little time for myself.	3	2.52	1.11	1	5	0.329	2.37
C2. Combining the responsibility for my…. and for my job and/or family is not easy.	4	2.79	1.23	1	5	0.120	1.92
C3. Because of my involvement with my….I don't pay enough attention to others.	2	2.57	1.16	1	5	0.299	2.19
C4. I must always be available for my…..	4	3.50	1.20	1	5	-0.777	2.69
C5. My independence is suffering	3	2.82	1.21	1	5	0.041	1.98
C6. The situation of my …. constantly demands my attention	3	3.36	1.20	1	5	-0.534	2.42
C7. Because of my involvement with my….I am getting into conflict at home or at work.	3	2.42	1.14	1	5	0.542	2.39
C8. The situation of my…..is a constant preoccupation	3	3.17	1.11	1	5	-0.371	2.67
C9. Generally speaking I feel very pressured by the situation of my…..	2	2.74	1.12	1	5	0.188	-0.715

Appendix 5.2 EDIZ questionnaire (Dutch and English)

Ervaren Druk door Informele Zorg

(Ontwikkeld door prof. dr. Anne Margriet Pot, 1995)

Instructie:

Overhandig dit formulier aan de mantelzorger en laat deze zelf invullen.

Er volgt nu een aantal uitspraken over de zorg die u aan uw naaste geeft. De bedoeling is dat u bij elk van deze uitspraken aangeeft, in hoeverre die op u van toepassing is. U heeft hierbij de volgende antwoordmogelijkheden:

Nee! **Nee** **Min-of-meer** **Ja** **Ja!**

Als een uitspraak helemaal op u van toepassing is, zet u een kruisje bij 'ja!'. Wanneer een uitspraak helemaal niet op u van toepassing is, zet u een kruisje bij 'nee!'. Of iets er tussenin.

Vragen	**Nee!**	**Nee**	**Min-of-meer**	**Ja**	**Ja!**
1. Door de situatie van mijn … kom ik te weinig aan mijn eigen leven toe	☐	☐	☐	☐	☐
2. Het combineren van de verantwoordelijkheid voor mijn … en de verantwoordelijkheid voor mijn werk en/of gezin valt niet mee	☐	☐	☐	☐	☐
3. Door mijn betrokkenheid bij mijn … doe ik anderen te kort	☐	☐	☐	☐	☐
4. Ik moet altijd maar klaarstaan voor mijn …	☐	☐	☐	☐	☐
5. Mijn zelfstandigheid komt in de knel	☐	☐	☐	☐	☐
6. De situatie van mijn … eist voortdurend mijn aandacht	☐	☐	☐	☐	☐
7. Door mijn betrokkkenheid bij mijn … krijg ik conflicten thuis en/of op mijn werk	☐	☐	☐	☐	☐
8. De situatie van mijn … laat mij nooit los	☐	☐	☐	☐	☐
9. Ik voel me over het gehaal genomen erg onder druk staan door de situatie van mijn …	☐	☐	☐	☐	☐

Perceived Burden of Family Care (Developed by Prof. Anne Margriet Pot. 1995)

Instructions:
Hand this form to the family-based carer and get them to fill it in themselves.

You will see a number of statements below about the care that you provide for your relative. The idea is that should indicate how much each of these statements applies in your case. You have the following possible answers for this:
no!
no
more or less
yes
yes!

If a statement applies very much to you, put a cross in the "yes!" column. If a statement does not apply to you at all, put a cross in the "no!" column, or somewhere in between.

	no!	no	more or less	yes	yes!
C1. Owning to the situation of my….I have too little time for myself.					
C2. Combining the responsibility for my…. and for my job and/or family is not easy.					
C3. Because of my involvement with my….I don't pay enough attention to others.					
C4. I must always be available for my…..					
C5. My independence is suffering					
C6. The situation of my …. constantly demands my attention					
C7. Because of my involvement with my….I am getting into conflict at home or at work.					
C8. The situation of my…..is a constant preoccupation					
C9. Generally speaking I feel very pressured by the situation of my…..					

Appendix 5.3 Characteristics relating to language skills

	Turkish (N=117)			
	None	Little	Good	Missing
DU Understanding	4 (3.4)	73 (57.4)	39 (33.3)	1 (0.9)
DU Speaking	5 (4.3)	71 (60.7)	39 (33.3)	2 (1.7)
DU Reading	14 (12.0)	60 (51.2)	43 (36.8)	0 (0)
DU Writing	23 (19.7)	55 (47.0)	39 (33.3)	0 (0)
MT Understanding	3 (2.6)	29 (24.7)	81 (69.2)	4 (3.4)
MT Speaking	2 (1.7)	33 (28.2)	81 (69.2)	1 (0.9)
MT Reading	7 (6.0)	32 (27.4)	78 (66.7)	0 (0)
MT Writing	9 (7.7)	37 (31.6)	71 (60.7)	0 (0)

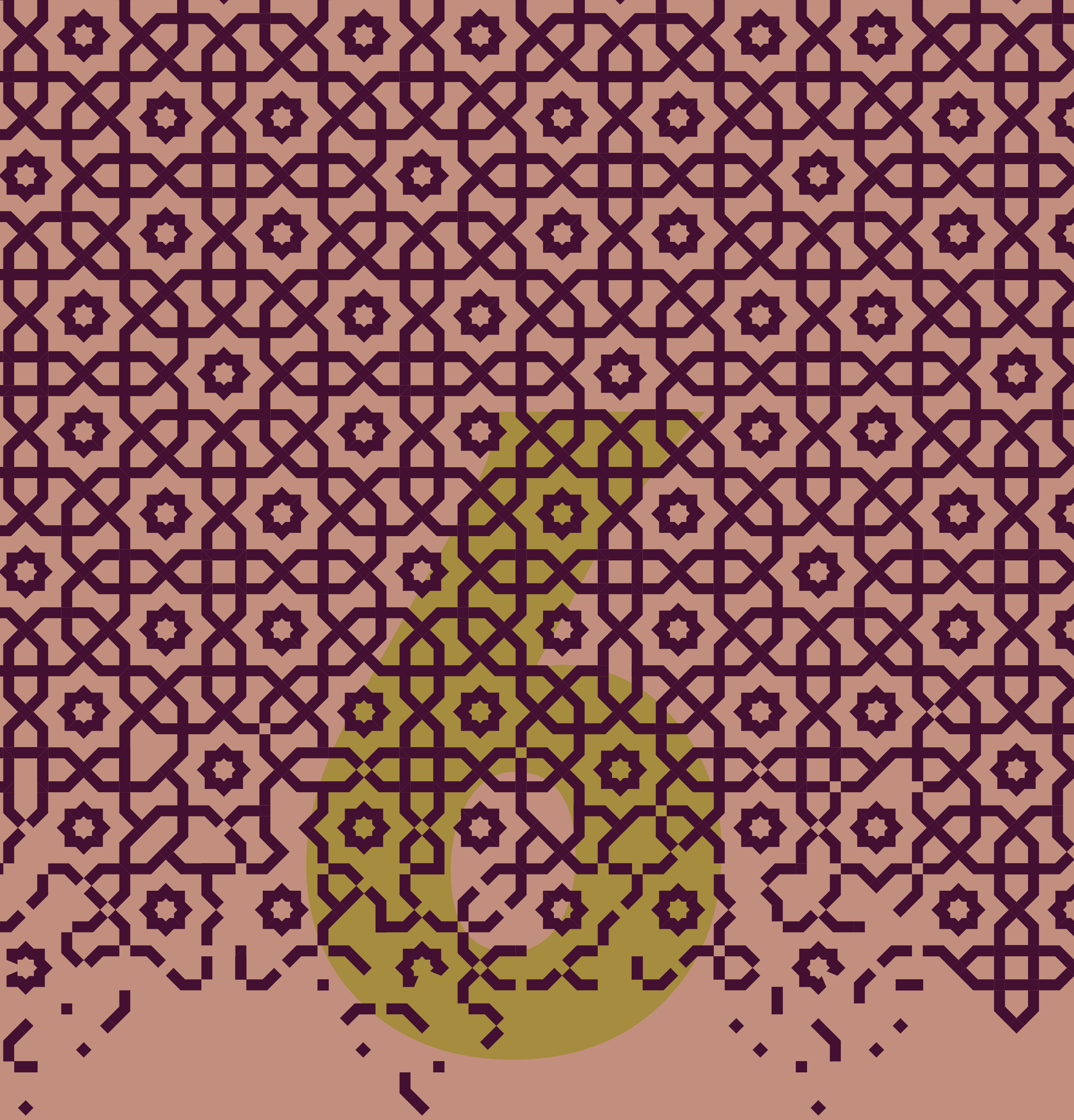
DU=Dutch; MT=mother tongue

Appendix 5.4 Items of the EDIZ in order of proportion that agreed

Items of the EDIZ in order of proportion that agreed with the items ranging from the highest to the lowest proportion

Item	*Based on the outcomes of the validation study of the Dutch EDIZ (see Pot e.a., 1998*[a]*)*	*Based on the outcomes of this validation study of the Turkish version of the EDIZ*
1	The situation of my … constantly demands my attention	I must always be available for my…
2	The situation of my…is a constant preoccupation	The situation of my … constantly demands my attention
3	I must always be available for my…	The situation of my…is a constant preoccupation
4	Owning to the situation of my…I have too little time for myself.	Combining the responsibility for my… and for my job and/or family is not easy.
5	Generally speaking I feel very pressured by the situation of my…	My independence is suffering
6	Combining the responsibility for my… and for my job and/or family is not easy.	Generally speaking I feel very pressured by the situation of my…
7	My independence is suffering	Because of my involvement with my…I don't pay enough attention to others.
8	Because of my involvement with my…I don't pay enough attention to others.	Because of my involvement with my…I am getting into conflict at home or at work.
9	Because of my involvement with my…I am getting into conflict at home or at work.	Owning to the situation of my…I have too little time for myself.

a *Pot, A.M., van Dyck, R., Deeg, D.J.H. (1995). Ervaren druk door informele zorg; constructie van een schaal. Tijdschrift voor Gerontologie en Geriatrie 26, p 214 – 219.*



Chapter 6

Effects of an educational peer-group intervention on knowledge about dementia among family caregivers with a Turkish or Moroccan immigrant background: a cluster randomised controlled trial

van Wezel N, van der Heide I, Devillé WL, Kayan Acun E, Meerveld JHCM, Spreeuwenberg P, Blom MM, Francke AL. Effects of an educational peer-group intervention on knowledge about dementia among family caregivers with a Turkish or Moroccan immigrant background: A cluster randomised controlled trial. Patient Educ Couns. 2021 Jul;104(7):1726-1735.

Abstract

Objective: The aim of this paper is to examine the effects of an educational peer-group intervention on knowledge about dementia, perceived ability to talk about it, received support and self-perceived pressure from informal care among family caregivers with a Turkish or Moroccan immigrant background who cared for a person with dementia.

Methods: This paper is based on a cluster randomised controlled trial with three measures, including participants who knew or cared for a person with dementia. For the purpose of this study, a selection was made of participants who cared for a person with dementia. Knowledge about dementia, perceived ability to talk about dementia, support received and self-perceived pressure from informal care were assessed inthe intervention and the control condition. Multi-level analyses were conducted to examine the effects.

Results: Data for 386 participants was analysed. Improvement in knowledge about dementia over time was significantly greater in the intervention condition than in the control condition. In the intervention condition, there was also a significant increase over time in the support received from home-care staff, which was not found in the control condition. No effects were found on other types of support received, the ability to talk about dementia or the self-perceived pressure from informal care.

Conclusion: Offering a culturally sensitive educational peer-group education intervention enhances knowledge about dementia and has a small but positive effect on the support received from home-care staff in these groups.

Practice Implications: Offering peer-group-based education about dementia to family caregivers with Turkish or Moroccan immigrant backgrounds is important for multicultural dementia care.

Keywords

immigrants, Turkish, Moroccan, dementia, knowledge, self-perceived pressure, informal care, family care, cluster randomised controlled trial

Introduction

Dementia has been declared to be one of the major health challenges of the 21st century [1]. According to the WHO, there were 35.6 million people with dementia worldwide in 2010 and this number is expected to rise by 71% by 2050 [2].

The number of people with dementia is also increasing in non-Western migrant groups [3]. They often do not receive care and support in time [4,5,6,7,8]. One of the major barriers to access to care and support services is a lack of targeted information [9,10]. In addition, beliefs and perceptions with respect to dementia and professional care can play an important role in determining whether they receive timely care and support [11,12,13,14].

In the Netherlands, 22.6% of the population is of non-Western origin; most of these first- and second-generation migrants have a Turkish or Moroccan background [15]. The first generation of Turkish and Moroccan immigrants who moved to the Netherlands in the 1960s and 1970s is now ageing and they increasingly face age-related diseases, including dementia [16].

An interview study among family caregivers with a Turkish or Moroccan immigrant background indicated that they and their families often perceive the onset and symptoms of dementia as inherent to ageing or as a spiritual experience rather than the characteristics of a neuro-psychiatric disorder [14]. This might inhibit people from visiting a doctor in time and thereby receiving a formal dementia diagnosis, which is important for access to professional care and support [11,17].

Furthermore, interviews with family carers with a Turkish or Moroccan background also indicated that they often refrain from talking about the mental deterioration of an older family member outside the immediate family circle because of respect for older relatives, who often do not want the wider community to know about their dementia [14]. This makes it more difficult to obtain additional informal or professional support for persons with dementia and their family caregivers.

With respect to the care for a person with dementia, migrant families with a Turkish or Moroccan background tend to prefer care that is provided by female family members, which might also inhibit the use of additional informal or professional support [13,18]. Family caregivers are therefore likely to perceive a high pressure from informal care , since support from others, including healthcare professionals, is called upon infrequently or only in a late stage of the disease [18].

A better understanding of the disease and awareness of support options might reduce the barriers preventing family carers and their relatives with dementia from arranging additional care and support, and reduce the self-perceived pressure from informal care. There are ongoing local and national campaigns and educational programmes on dementia in the Netherlands, as in other countries, that are aimed at increasing knowledge about dementia. However, very few specifically target migrant groups or are easily accessible to migrant groups, and these are often not been properly evaluated [19,10].

To address the lack of educational programmes specifically targeting people with a Turkish or Moroccan migrant background, the Dutch Alzheimer Association developed the peer-group educational intervention 'Knowing about forgetting' (Weten over vergeten). In this intervention, information on dementia and support options is provided to family carers in a culturally and linguistically sensitive manner in two two-hour interactive sessions.

The aim of the current study is to examine the effects of this educational peer-group intervention.

The specific primary research question addressed in this paper is:

1. Does participation in an educational peer-group intervention improve knowledge about dementia among family caregivers with a Turkish or Moroccan background?

The secondary research questions are:

2. Does participation in an educational peer-group intervention result in:
    - an improvement in the perceived ability to talk about dementia?
    - an increase in the use of informal or professional support?
    - a decrease in the self-perceived pressure from informal care?
3. Are the outcome measures associated with background characteristics?

As the intervention included education about dementia and discussions on how and where additional support could be arranged, as well as discussions about the importance of talking about dementia with other people in the family and broader community, we expected the intervention to have a positive effect on the perceived ability to talk about dementia with others, on the amount of support received (informal or professional) and on the self-perceived pressure from informal care. This expectation was based on previous studies by Keyes *et al.* [20] and Smith *et al.* [21,22] who found that peer support had a positive emotional and social impact that was rooted in identification with others, a commonality of experience and reciprocity of support.

Some small positive changes in the outcomes of participants in the control condition were also expected since these participants also filled in questionnaires on three separate occasions at a meeting place along with other participants in the control condition in the specific region. This might result in learning effects and also in positive effects related to unstructured and spontaneous interactions with peers.

Methods

Design

This study is based on a cluster randomised controlled trial with repeated measures. The unit of randomisation was the region in which family caregivers lived. We applied a commonly used regional classification system (for instance used by the Dutch Alzheimer Organisation), which divides the Netherlands into 47 regions. The eligibility criteria for the regions (clusters) included (a) no educational programmes on dementia were already being offered to the target groups; (b) a relatively large numbers of people with Turkish or Moroccan backgrounds living in the region.

A total of 16 regions in the Netherlands (clusters) were included, which were then randomly assigned to either the intervention or the control condition, following simple randomisation procedures (computer-generated random numbers). The allocation sequence was concealed from the researcher (NW) who enrolled the regions. Regions were anonymised using numbers before the randomisation procedure, which was conducted by a researcher who was kept blinded with respect to the region names.

Within the regions, participants were subdivided into different groups: 15 regions included one group of participants with Turkish backgrounds and one of participants with Moroccan backgrounds and one region included three groups of participants with Turkish backgrounds and one of participants with Moroccan backgrounds. A total of 34 groups were included in the study, 16 comprising participants with Moroccan backgrounds and 18 comprising participants with Turkish backgrounds. The groups had a minimum of 4 participants and a maximum of 40. All groups within a region were assigned either to the control condition or to the intervention condition.

The study comprised a measurement directly before the first educational session (i.e. the first session in the intervention condition = T0, baseline), a measurement one to two weeks later (namely directly after the second educational session = T1) and a measurement (T2) three months after T0. Participants in a cluster (region) that was randomly assigned to the control condition completed the same questionnaires as participants in the intervention condition at T0, T1 (one to two weeks after T0) and T2 (three months after T0).

Sample size

We calculated the minimum sample size taking into account the intracluster correlation coefficient, the expected effect and the power of the study. In order to detect a difference of 35% with a power of .80 and an α of .05, the control condition and intervention condition should each include 129 participants. In order to account for clustering, the sample size should be enlarged by 10%, leading to a total sample size of 284. Taking into account a 20% loss to follow-up, a total of 340 participants should initially be included. In fact, the actual group of participants was somewhat larger as we did not want to disappoint and exclude family carers who were willing to participate in the study.

The study participants had to know someone with dementia or severe memory problems (see 2.3). However, for the purpose of the current paper, only data were analysed of the 386 participants who themselves cared for a person with dementia or in case of absence of a formal diagnosis, with severe memory problems.

Participants and recruitment

The eligibility criteria for the study participants were:

a. knowing someone with a dementia diagnosis or severe memory problems;
b. being born in Turkey or Morocco or having at least one parent who was born in one of these countries;
c. not having dementia or memory problems themselves.

Potential participants were invited for participation by key figures (i.e. imams, older immigrant consultants, immigrant care organisations and regional departments of the Dutch Alzheimer Association. If potential participants were interested in participating, the key figures provided their contact details to the study coordinator (NW) after obtaining the consent of the potential participant. The study coordinator assessed whether the candidate participant fulfilled all the inclusion criteria.

This article is part of a larger study that, in addition to the outcomes described in this article also measures aspects of quality of life. It also includes questions that specifically ask about (a) the living situation of the family caregiver (with or without the person with dementia or serious forgetfulness), (b) whether they offer help to their loved one with dementia or severe forgetfulness and if so, what kind of help and (c) how often this help/care was finally provided).

Intervention

Participants in the intervention condition received two educational sessions on dementia of two hours each, together with other participants (peers) with the same cultural background (Turkish or Moroccan). In all the regions this was the first time ever that family carers came together in a group to get about a clearer understanding of dementia and to take part in a group conversation about dementia.

The two sessions were different in nature: the first was purely informational, the second was a group discussion.

In the first session, a trained educator with the same background (Turkish or Moroccan) gave information about the differences between dementia and 'normal' forgetfulness (symptoms) and explained that dementia is a brain disease. In the second session, which took place one to two weeks after the first, the trained educator facilitated a group discussion about whether or not it is important to talk openly about dementia and to talk about local options for care and support and the extent to which participants are willing to accept local options for care and support. To get the conversation started hypothetical scenarios were used to provide a safe way for participants to talk with each other about these topics during the session. The groups had a minimum of 4 and a maximum of 40 participants each. The two sessions for each group were held in the afternoon in a meeting place, for instance in a room at a mosque or in a cultural community centre.

Participants in the control condition came together in similar meeting places to complete the questionnaires on three occasions, whereby the second occasion was one to two weeks after the first and the third three months after the first. Since participants in the control condition also met peer caregivers when coming to the meeting place to fill in the questionnaire, they had the opportunity to talk to others about their situation. Yet only participants in the intervention condition received the educational peer-group intervention during the study period; this intervention was offered to the control condition participants only after completion of the study.

Outcome measures and measurements

Knowledge about dementia was measured using a scale largely based on items in the Alzheimer Disease Knowledge Scale (ADKS) [23]. Eleven items from the ADKS that corresponded with the content of the educational peer-group intervention were translated from English into Dutch, Turkish and Moroccan Arabic and validated (Van Wezel *et al.*, submitted). The 11 items addressed characteristics of dementia, determinants of dementia and the course of the disease. All items had 'true' and 'false' as the answer options. Correct answers were scored as 1. Sum scores were calculated with a range from 0 to 11, with higher scores indicating more knowledge about dementia.

The perceived ability to talk about dementia was measured by three self-developed items asking how well participants felt able to (a) talk to the general practitioner (GP) or another healthcare provider about dementia; (b) talk to friends about dementia; (c) talk to family about dementia. Answers could be given on a five-point Likert scale ranging from feeling not at all able to talk about dementia (score 1) to feeling very able to talk about dementia (score 5).

The support received was measured with four self-developed questions asking whether respondents received (a) advice from their GP or another doctor, (b) support from their family, (c) support from friends or neighbours, or; (d) support from home-care staff in the care for a person with dementia. Answers could be given on a five-point Likert scale including the following range: 1 (No!) 2 (No) 3 (More or less) 4 (Yes) 5 (Yes!).

The perceived pressure from informal care was measured by the SPPIC-Self Perceived Pressure from Informal Care- (in Dutch: EDIZ) [24], a scale that was originally developed in Dutch and validated in Dutch and was translated for this study into Turkish and Moroccan Arabic as well [25]. The scale was based on nine items and answers could be given on a five-point Likert scale ranging from 1 (no self-perceived pressure from informal care) to 5 (high self-perceived pressure from informal care). Sum scores were calculated with a range from 9 to 45, with higher scores indicating a higher perceived pressure from informal care.

In addition the following background characteristics were assessed: age (included as a continuous variable), sex (1. male; 2. female), level of education (1. no education; 2. primary education; 3. secondary education; 4. secondary vocational education; 5. higher vocational education; 6. university), ethnicity (1. Turkish; 2. Moroccan), frequency of caregiving (1. on a daily basis; 2. three to six times per week; 3. once or twice a week; 4. less than once a week; 5. less than once a month; 6.living situation of the family caregiver (with or without the person with dementia or serious forgetfulness).

All participants had the option of filling in the questionnaires in Dutch, Moroccan Arabic or Turkish. None of the participants chose to fill in the Moroccan Arabic version of the questionnaire, which might be related to the fact that female caregivers of Moroccan descent often cannot read or write Arabic. On all three measurement occasions, a majority of the participants with Turkish backgrounds filled in the Turkish version of the questionnaire (87% at T0, 88% at T1 and 96% T2). For those who had poor literacy, a research assistant read the questionnaire out loud and wrote down the participant's answers to the questions on their behalf.

Ethical procedures

Before participation, participants were informed firstly face-to-face about the study by the key figure who recruited them, then a second time by the study coordinator over the phone and thirdly in an information letter that they received at home before the first measurement occasion. On the first measurement occasion (T0) all participants received another copy of the information letter and an informed consent form in their language of preference (Dutch, Turkish or Moroccan Arabic). The information letters and informed consent forms were read out loud by a research assistant in case some participants had poor literacy, to ensure that all participants understood the information letter and the informed consent form. The informed consent forms were provided by the research assistant during the first measurement occasion to ensure that the participants themselves provided consent and not another person (e.g. a spokesman in the family). Written consent was obtained from each participant.

No formal permission from a medical ethics committee was required for this study according to the relevant Dutch law, as the research did not concern medical research and participants were not required to follow rules of behaviour (https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not).

Statistical analyses

Descriptive statistics, a two-sample t-test, Chi-squared tests and a Kruskal-Wallis test were used to provide insight into participants' background characteristics and into differences in background characteristics between the intervention and the control condition. Subsequently, nine repeated-measures (RM) multi-level analyses were conducted, taking into account the effects of clustering at the region level [35]. At the participant level an unstructured covariance structure between the three measurement occasions was modelled to control for the correlation between measurements within participants. This was done separately for the control and intervention conditions. The model was used to estimate the corrected mean scores for the conditions for: the dementia knowledge scale; the three items about the perceived ability to talk about dementia; the four items about received support; and the items on the self-perceived pressure from informal care. These mean scores were calculated for the intervention condition and the control condition at T0, T1 and T2 and adjusted for age, sex, level of education, migration background and frequency of caregiving. The analyses estimating the effect of the intervention on the perceived ability to talk about dementia, on the support received and on the self-perceived pressure from informal care were also adjusted for dementia knowledge. All the co-variables were included in the multi-level analyses at the same time. RM multilevel regression analysis takes into account differences in baseline scores. Chi-squared tests were performed to test for significant trends in both the intervention and the control condition and to test whether trends in the intervention condition differed from trends in the control condition. In repeated measure RM multilevel analyses, participants are included when having at least one completed outcome measure (at T0, T1 and/or T2) as well as no missing data on any of the co-variables [36]. The analyses were conducted in MLwiN.

Results

Participants and background characteristics

Initially, a total of 288 participants were assigned to the intervention condition and 262 to the control condition, see Appendix, Figure 6.1. For this paper, a sub-selection was made of individuals who had declared that they cared for a person with dementia (n=202 in the intervention condition and n=184 in the control condition), see Appendix, Figure 6.1. Of this sub-selection 319 participants completed the questionnaire at T0, 313 at T1 and 290 at T2.

Equivalence between participants in the intervention condition versus those in the control condition was examined based on age, sex, ethnicity and level of education. There were more women, slightly more respondents of Turkish origin (although this difference was not statistically significant) and more respondents with no or only primary education in the intervention condition compared to those in the control condition, see Table 6.1. Furthermore, participants in the intervention condition were generally slightly older than participants in the control condition (mean age 45.5 versus 42.5; $p=0.04$).

Effects on knowledge about dementia

In both the intervention condition and the control condition there was a significant trend of increased knowledge about dementia over time, see Table 6.2. This increase was significantly stronger in the intervention condition than in the control condition (Chi-squared (2) = 22.21; $p < 0.001$). The increase in knowledge shows a different pattern over time for the two conditions: whereas the participants in the intervention condition show the largest knowledge gain between T0 and T1, the participants in the control condition showed the largest gain between T1 and T2. A higher level of education and a Turkish migration background were associated with higher scores in the dementia knowledge test ($p < .05$), see Table 6.5.

Table 6.1 *Participants' background characteristics*

	Intervention condition (*n*=202)	Control condition (*n*=184)	p-value
Age, mean (SD)	45.5 (13.7)	41.4 (13.9)	0.004*
Sex, %			0.02**
Male	9.5	17.4	
Female	90.0	81.5	
Missing	0.5	1.1	
Migrant background, %			0.22
Turkish	60.0	53.8	
Moroccan	40.0	46.2	
Country of birth, %			0.000**
The Netherlands	10.0	29.3	
Other	88.5	69.6	
Missing	1.5	1.1	
Level of education, %			0.0001***
No education	23.5	8.2	
Primary education	28.0	22.2	
Secondary education	14.5	15.8	
Secondary vocational education	18.0	31.0	
Higher vocational education	12.5	14.7	
University	1.5	6.5	
Other or missing	2.0	1.6	

* *Based on two-sample t-test*
** *Based on Chi-squared test*
*** *Based on Kruskal-Wallis equality-of-populations rank test*

Table 6.2 *Mean scores in dementia knowledge scale at T0, T1 and T2 for the intervention and control conditions (N=340)*

	Intervention condition	Control condition
T0, mean (95% CI)*	7.6 (7.1 to 8.1)	6.7 (6.2 to 7.2)
T1, mean (95% CI)*	9.0 (8.6 to 9.5)	6.9 (6.5 to 7.4)
T2, mean (95% CI)*	8.9 (8.4 to 9.4)	7.4 (6.9 to 7.8)
Does T1 differ significantly from T0? Chi-squared (df); p-value	47.15 (1); p < 0.001	1.54 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared (df); p-value	37.48 (1); p < 0.001	10.27 (1); p < 0.01
Trend over time, Chi-squared (df); p-value	51.03 (2); p < 0.001	10.50 (2); p < 0.01
Do the trends differ significantly? Chi-squared (df); p-value	22.21 (2); p < 0.001	

* *Corrected for region, sex, age, level of education, ethnicity and frequency of caregiving*

Effects on talking about dementia, support received and self-perceived pressure from informal care

In the intervention condition there was a small but significant increase over time in the support received from home-care staff (Chi-squared (2)=7.91; $p < 0.05$), which was not found in the control condition (Chi-squared (2)=8.44; $p < 0.05$) (see Table 6.3). No significant differences were found at T1 and T2 compared to T0 in either the intervention condition or the control condition for advice received from a doctor, support received from family and support received from friends or neighbours. Furthermore, no significant differences were found over time in the perceived ability to talk about dementia (see Table 6.4) and the self-perceived pressure from informal care (see Table 6.5) in either the intervention condition or the control condition.

Table 6.3 *Mean scores for support received at T0, T1 and T2 for the intervention condition and the control condition (N=340; 338; 340; 340)*

	Intervention condition	Control condition
	Received advice from a doctor	
T0, mean (95% CI)*	2.7 (2.3 to 3.1)	2.7 (2.3 to 3.1)
T1, mean (95% CI)*	2.8 (2.4 to 3.2)	2.8 (2.4 to 3.1)
T2, mean (95% CI)*	2.6 (2.3 to 3.0)	2.8 (2.5 to 3.2)
Does T1 differ significantly from T0? Chi-squared; p-value	0.36 (1); p > 0.1	0.14 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	0.22 (1); p > 0.1	0.38 (1); p > 0.1
Trend over time, Chi-squared; p-value	1.11 (2); p > 0.1	0.38 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	1.11 (2); p > 0.1	

Table 6.3 *Continued*

	Intervention condition	Control condition
	Received support from family	
T0, mean (95% CI)*	3.3 (2.9 to 3.6)	3.4 (3.0 to 3.7)
T1, mean (95% CI)*	3.3 (3.0 to 3.6)	3.4 (3.1 to 3.6)
T2, mean (95% CI)*	3.5 (3.2 to 3.8)	3.5 (3.2 to 3.7)
Does T1 differ significantly from T0? Chi-squared; p-value	0.06 (1); p > 0.1	0.00 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	3.79 (1); p > 0.05	0.48 (1); p > 0.1
Trend over time, Chi-squared; p-value	4.26 (2); p > 0.1	1.59 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	0.87 (2); p > 0.1	
	Received support from friends or neighbours	
T0, mean (95% CI)*	2.2 (1.7 to 2.6)	2.4 (1.9 to 2.8)
T1, mean (95% CI)*	2.1 (1.6 to 2.6)	2.2 (1.8 to 2.6)
T2, mean (95% CI)*	2.4 (1.9 to 2.9)	2.4 (1.9 to 2.8)
Does T1 differ significantly from T0? Chi-squared; p-value	0.27 (1); p > 0.1	2.11 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	3.53 (1); p > 0.05	0.00 (1); p > 0.1
Trend over time, Chi-squared; p-value	7.16 (2); p < 0.05	3.04 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	2.33 (2); p > 0.1	
	Received support from home care or nurses	
T0, mean (95% CI)*	2.0 (1.6 to 2.5)	2.5 (2.1 to 2.9)
T1, mean (95% CI)*	2.2 (1.7 to 2.6)	2.4 (2.0 to 2.8)
T2, mean (95% CI)*	2.4 (1.9 to 2.9)	2.4 (2.0 to 2.8)
Does T1 differ significantly from T0? Chi-squared; p-value	1.14 (1); p > 0.1	0.78 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	7.87 (1); p < 0.05	1.21 (1); p > 0.1
Trend over time, Chi-squared; p-value	7.91 (2); p < 0.05	1.41 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	8.44 (2); p < 0.05	

* *Corrected for region, sex, age, level of education, ethnicity, frequency of caregiving and dementia knowledge*

Table 6.4 *Mean scores for ability to talk about dementia at T0, T1 and T2 for the intervention condition and the control condition (N=339; 340; 339)*

	Intervention condition	Control condition
	Talking to a GP	
T0, mean (95% CI)*	3.8 (3.5 to 4.1)	3.8 (3.6 to 4.1)
T1, mean (95% CI)*	3.9 (3.6 to 4.2)	4.0 (3.7 to 4.2)
T2, mean (95% CI)*	3.8 (3.5 to 4.2)	3.9 (3.6 to 4.2)
Does T1 differ significantly from T0? Chi-squared; p-value	0.75 (1); p > 0.1	3.65 (1); p > 0.05
Does T2 differ significantly from T0? Chi-squared; p-value	0.11 (1); p > 0.1	0.28 (1); p > 0.1
Trend over time, Chi-squared; p-value	0.81 (2); p > 0.1	3.81 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	0.36 (2); p > 0.1	
	Talking to family	
T0, mean (95% CI)*	3.9 (3.6 to 4.2)	3.8 (3.5 to 4.1)
T1, mean (95% CI)*	4.0 (3.7 to 4.3)	3.9 (3.6 to 4.2)
T2, mean (95% CI)*	3.9 (3.6 to 4.3)	3.9 (3.6 to 4.2)
Does T1 differ significantly from T0? Chi-squared; p-value	3.67 (1); p > 0.05	0.19 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	0.70 (1); p > 0.1	1.58 (1); p > 0.1
Trend over time, Chi-squared; p-value	3.77 (2); p > 0.1	1.59 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	1.52 (2); p > 0.1	
	Talking to friends	
T0, mean (95% CI)*	3.7 (3.4 to 4.0)	3.5 (3.2 to 3.8)
T1, mean (95% CI)*	3.6 (3.3 to 4.0)	3.4 (3.1 to 3.7)
T2, mean (95% CI)*	3.6 (3.3 to 4.0)	3.4 (3.1 to 3.7)
Does T1 differ significantly from T0? Chi-squared; p-value	1.41 (1); p > 0.1	0.71 (1); p > 0.1
Does T2 differ significantly from T0? Chi-squared; p-value	1.60 (1); p > 0.1	0.21 (1); p > 0.1
Trend over time, Chi-squared; p-value	2.04 (2); p > 0.1	0.72 (2); p > 0.1
Do the trends differ significantly? Chi-squared; p-value	0.18 (2); p > 0.1	

* *Corrected for region, sex, age, level of education, ethnicity, frequency of caregiving and dementia knowledge*

Table 6.5 *Mean scores for perceived pressure from informal care at T0, T1 and T2 for the intervention condition and the control condition (N=333)*

	Intervention condition	Control condition
T0, mean (95% CI)*	26.0 (23.8 to 28.2)	24.6 (22.5 to 26.6)
T1, mean (95% CI)*	25.6 (23.4 to 27.9)	24.1 (22.0 to 26.2)
T2, mean (95% CI)*	25.2 (23.0 to 27.4)	24.8 (22.7 to 27.0)
Does T1 differ significantly from T0? Chi-squared; p-value	0.27 (1); $p > 0.1$	0.77 (1); $p > 0.1$
Does T2 differ significantly from T0? Chi-squared; p-value	1.17 (1); $p > 0.1$	0.15 (1); $p > 0.1$
Trend over time, Chi-squared; p-value	1.07 (2); $p > 0.1$	1.23 (2); $p > 0.1$
Do the trends differ significantly? Chi-squared; p-value	1.68 (2); $p > 0.1$	

* *Corrected for region, sex, age, level of education, ethnicity, frequency of caregiving and dementia knowledge*

Associations between background characteristics and outcome measures

Table 6.6 shows that a higher level of education, a higher frequency of caregiving and having a Turkish background were significantly ($p < 0.05$) associated with a higher perceived ability to talk about dementia with a GP, with family member and with friends. In addition, being younger was associated with a higher perceived ability to talk about dementia with a GP ($p < 0.05$) and being a woman with a higher perceived ability to talk about dementia with friends ($p < 0.05$).

With respect to the support received, a higher level of education, a higher frequency of caregiving and more knowledge about dementia were associated with receiving more advice from a doctor ($p < 0.05$). Furthermore, being a male caregiver, having a higher level of education and a higher frequency of caregiving were associated with receiving more support from family ($p < 0.05$). A higher level of education was also associated with receiving more support from friends or neighbours and with receiving more support from home-care staff ($p < 0.05$). In addition, being older, having a higher level of education, a higher frequency of caregiving and more knowledge about dementia were associated with receiving more support from home-care staff ($p < 0.05$).

A higher self-perceived pressure from informal care was associated significantly with being older, a higher frequency of caregiving, a Turkish background and more knowledge about dementia ($p < 0.05$), see Table 6.6.

Table 6.6 Associations between background characteristics and outcome measures

Background characteristics	Outcome measures								
	Dementia knowledge B (SE)	Self-Perceived pressure from informal care B (SE)	Talking with a GP B (SE)	Talking with family B (SE)	Talking with friends B (SE)	Advice from doctor /b18 B (SE)	Support from family /b19 B (SE)	Support from friends/ neighbours /b20 B (SE)	Support from home-care staff /b21 B (SE)
Age	0.006 (0.01)	0.07 (0.03)*	-0.01 (0.003)*	-0.001 (0.003)	-0.003 (0.004)	-0.001 (0.005)	-0.003 (0.005)	0.005 (0.005)	0.012 (0.005)*
Sex (reference group: male)	0.42 (0.28)	1.43 (1.11)	0.05 (0.10)	0.02 (0.11)	0.28 (0.13)*	-0.16 (0.17)	-0.43 (0.18)*	0.24 (0.15)	0.14 (0.18)
Level of education	0.18 (0.07)*	0.002 (0.30)	0.10 (0.03)*	0.06 (0.03)*	0.10 (0.03)*	0.13 (0.05)*	0.11 (0.05)*	0.10 (0.04)*	0.16 (0.05)*
Frequency of caregiving	0.002 (0.05)	-1.50 (0.20)*	-0.06 (0.02)*	-0.06 (0.02)*	-0.11 (0.02)*	-0.20 (0.03)*	-0.06 (0.03)*	0.02 (0.03)	-0.06 (0.03)*
Migrant background (reference group: Turkish)	-0.49 (0.21)*	-3.10 (0.84)*	-0.44 (0.07)*	-0.38 (0.08)*	-0.25 (0.09)*	0.03 (0.13)	0.18 (0.13)	-0.16 (0.12)	0.09 (0.14)
Dementia knowledge	-	0.31 (0.13)*	0.02 (0.01)*	0.01 (0.02)	0.03 (0.02)	0.07 (0.02)*	-0.01 (0.02)	0.00 (0.02)	0.04 (0.02)*

* *Significant association ($p < .05$)*

Discussion and conclusion

Discussion

This study aimed to examine the effects of the educational peer-group intervention 'Knowing about forgetting' for caregivers with a Turkish or Moroccan background.

The intervention, consisting of two interactive group sessions, improved knowledge about dementia among the family caregivers. Knowledge about dementia also improved in the control condition, which might be explained by the unguided and unstructured social interactions between the control participants who came together in a meeting place to complete the questionnaires. Besides, there might have been some learning effects from repeatedly completing the same knowledge questions. However, as the increase in knowledge about dementia was significantly greater in the intervention condition than in the control condition, the educational element of the intervention seems to have had an additional positive effect on knowledge about dementia on top of the social interactions and the learning effect.

Our findings regarding the improvement of knowledge about dementia as a result of an educational peer-group intervention fills a gap in scientific research. So far there has been limited evidence on the effects of educational group interventions on family carers' knowledge about dementia, as indicated by the systematic review by Moore and colleagues [26]. The two studies described in this review that included knowledge about dementia as an outcome measure showed either no effect on knowledge [27] or a short-term effect after three months [28]. As far as we know, no study so far has evaluated the effects of educational interventions specifically targeting family caregivers with a migration background.

This paper also shows that the educational peer-group intervention did not affect family carers' perceived ability to talk about dementia. This might in part be explained by high baseline scores, indicating that most participants already found it fairly easy to talk about dementia. A possible explanation for these high baseline scores is that participation in this study in itself required a willingness to talk about dementia with others. Besides, a different type of intervention specifically focusing on communication, such as communication training, might be more effective in improving the ability to talk about dementia than our intervention, which was directed primarily at improving knowledge about dementia and options for care and support [29].

Our findings also indicate that offering the educational peer-group intervention might result in family caregivers receiving more formal support (i.e. support from home-care staff) but not informal support (i.e. from other relatives, friends or neighbours). This finding indicates that the intervention raises awareness on options for formal support and on how to organise formal support.

It could be that the intervention condition included more participants caring for a person with more advanced dementia than the control condition. Participants who cared for a person with advanced dementia seem more likely to receive formal support during the study period. In part we controlled for this, since the analyses were adjusted for frequency of caregiving, which can be regarded as an indication of dementia severity.

The finding could also imply that those who know more about the nature of dementia and available care and support options might be more likely to call on professional support, as suggested in the literature [10]. The fact that the educational intervention had a small but significant effect on the support received from home-care staff supports this latter assumption.

One healthcare system implication, following this finding, is that efforts should be put into reaching out to and informing family caregivers of people with dementia with Moroccan or Turkish immigrant backgrounds, to ensure they are familiar with available care and support options, in case they are needed. In addition, it seems important at the healthcare system level to develop and keep refining culturally and linguistically competent dementia home care, which is currently not generally offered in the Netherlands.

No significant intervention effects were found on the self-perceived pressure from informal care experienced by family carers. This suggests that the self-perceived pressure from informal care depends on factors other than the support received from home-care staff. The self-perceived pressure from informal care might for instance be more dependent on the stage of the disease, on personal circumstances, on a person's resilience, and possibly on cultural beliefs regarding family care [30,31,32,33].

Another finding is that the participating family caregivers with a Moroccan background generally knew less about dementia and had a lower perceived ability to talk about dementia with the GP, family and friends than the participants with a Turkish background. On the other hand, the participating family caregivers with Turkish backgrounds perceived a higher pressure from informal care than caregivers with Moroccan backgrounds. These findings are not easy to explain, and further research is needed comparing variations in outcomes and experiences of family caregivers from different migrant groups.

Strengths and limitations

A major strength is that this study evaluated an intervention that was developed specifically for family caregivers with a Turkish or Moroccan background. This means that the information was shared, presented and discussed in a culturally and linguistically sensitive manner, which is shown to be essential for effective education for family caregivers with a migration background [34].

Another strength is that the educational programme was provided exclusively by trainers with a Turkish or Moroccan background, who spoke the participants' language and understood their culture. This might have been attractive for participants and might explain why we were able to recruit large groups of family caregivers with Turkish or Moroccan backgrounds.

However, a limitation of this study is that no long-term effects were measured, e.g. with regard to knowledge about dementia. It would be relevant to know if family caregivers experience any benefits in the long term from their increased knowledge about dementia, for instance in terms of coping with dementia.

Conclusion

Offering peer-group-based education enhances knowledge about dementia among family caregivers with a Turkish or Moroccan immigrant background. In addition, this intervention seems to lead to more support from home-care staff. No evidence was found for the effectiveness of the peer-group educational intervention on the perceived ability to talk about dementia, the self-perceived pressure from informal care or additional support from family, friends or neighbours and advice from doctors.

Practice Implications

We found that older family carers had a lower perceived ability to talk about the dementia of their relative with a GP than younger family carers. A recommendation for GPs is therefore that they should be aware that older people with Turkish or Moroccan backgrounds might not inform them about problems such as memory loss and that dementia might therefore be diagnosed at a relatively late stage in these groups.

As we found no effect of the educational intervention on the self-perceived pressure from informal care , it is recommended on the one hand that more information should be included in the intervention about coping with the pressure from informal care. On the other hand, this finding suggests that education alone might not be sufficient to decrease the perceived pressure of informal care. It is therefore recommended that more research should be conducted into the determinants of the perceived pressure from informal care in family caregivers with Turkish or Moroccan backgrounds and into additional ways or interventions for supporting these family caregivers.

Furthermore, as the effects of the educational intervention on the support received were limited, another recommendation is to intensify the intervention slightly, for instance by offering a third session that focuses primarily on how to arrange additional informal and formal support.

Competing interests

The authors declare that they have no competing interests.

Submission declaration

This article has not been published previously, is not under consideration for publication elsewhere, has been approved by the responsible authorities where the work was carried out and (if accepted) will not be published elsewhere in the same form, in English or in another language, including electronically, without the written consent of the copyright holder.

Informed consent and patient details statement

We confirm that all patient/personal identifiers have been removed or disguised so the patients/people described are not identifiable and cannot be identified through the details of the narrative.

Author contributions and authorship:

All:

- The conception and the design of the study, analysis and interpretation of the data.
- Drafting and/or revising it critically for intellectual content
- Final approval of the version to be submitted

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Walter LJM Devillé	Supervision; review and editing
Emine Kayan Acun	Data collection; review and editing
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Peter Spreeuwenberg	Conceptualization; data analysis; writing; methodological advise
Marco M Blom	Funding acquisition; resources; supervision; review and editing
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Appendix 6.1 Flow diagram for participants

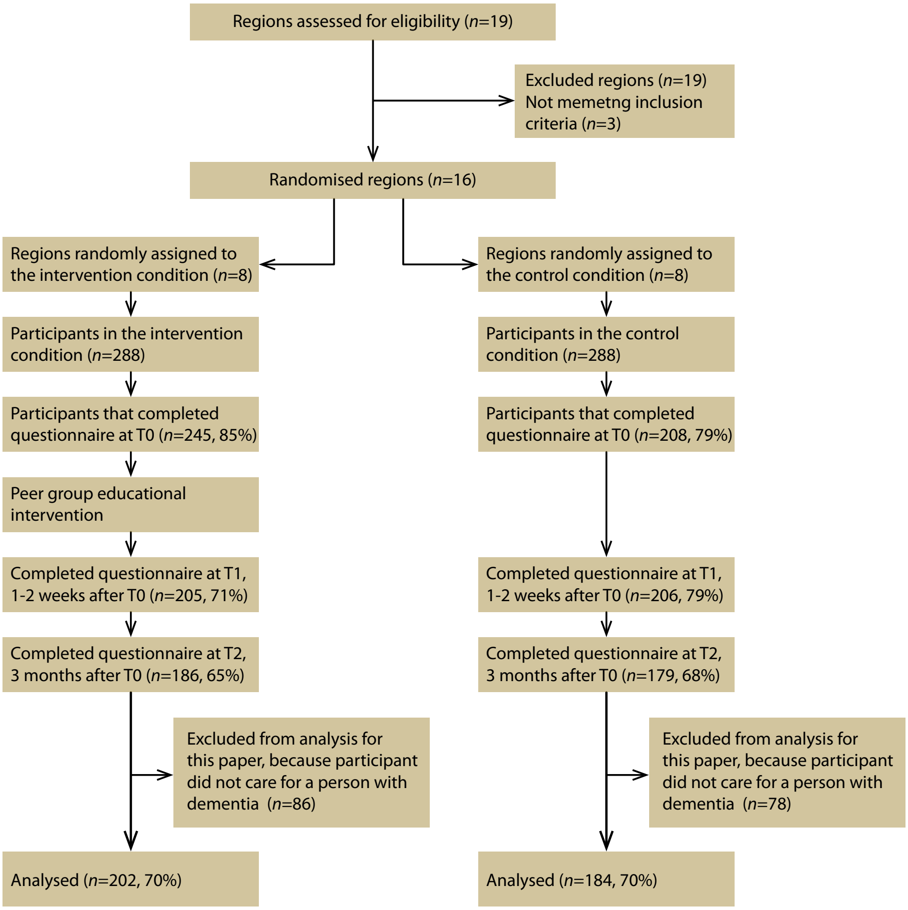
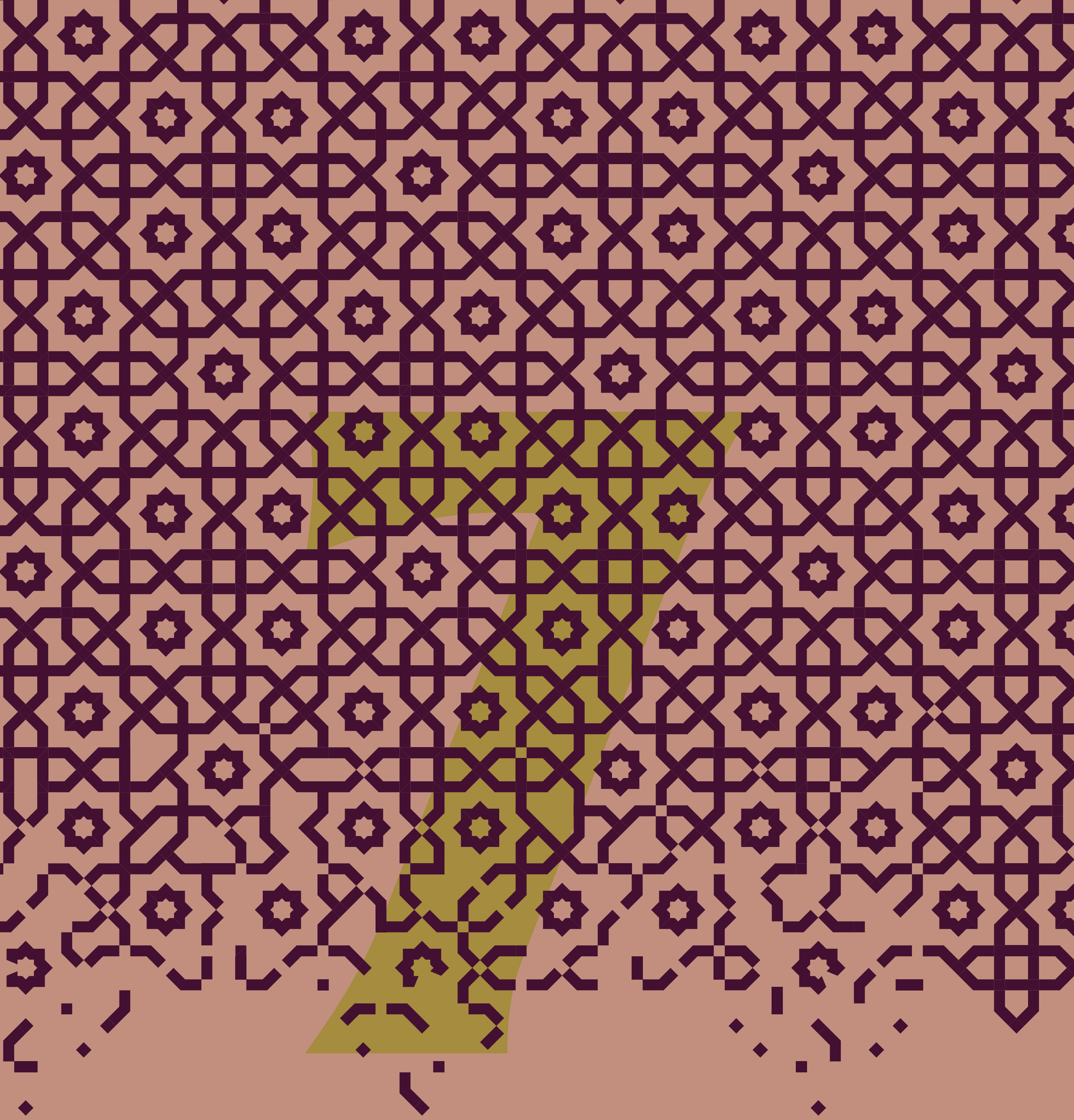


Figure 6.1 *Flow diagram for participants*


7

Chapter 7

Effects of an educational intervention on health-related quality of life among family caregivers of people with dementia with a Turkish or Moroccan immigrant background: insights from a cluster randomised controlled trial

van der Heide I, van Wezel N, Blom M, Spreeuwenberg P, Devillé WLJM, Francke AL. Effects of an educational intervention on health-related quality of life among family caregivers of people with dementia with a Turkish or Moroccan immigrant background: Insights from a cluster randomised controlled trial. Patient Educ Couns. 2021 May;104(5):1168-1175.

Abstract

Objective: Gaining understanding of the health-related quality of life (HRQL) of family caregivers of people with dementia with Turkish or Moroccan immigrant backgrounds and to examine whether an educational peer group intervention can improve HRQL.

Methods: Understanding of HRQL and associated variables was obtained by multiple linear regression analyses. The effects of the intervention on HRQL were assessed in multilevel analyses using data collected before the start (baseline), directly after the intervention (one to two weeks after baseline) and three months after the start of the intervention. The intervention (two interactive group sessions) entailed providing information about dementia and care/support options.

Results: At baseline (n=319), HRQL was moderately and significantly associated with migration background, gender, self-perceived pressure from informal care and the formal and informal support received ($p<.05$). The intervention had a small effect on emotional wellbeing directly after the intervention ($p<.05$) and on perceived general health status three months after ($p<.05$).

Conclusion: Culturally sensitive peer group education on dementia and care/support options can to some extent enhance HRQL among family caregivers in the short term.

Practice implications: The intervention as described in this study is recommended for supporting family caregivers of people with dementia with Turkish or Moroccan backgrounds.

Keywords:

Educational intervention; family care; Turkish immigrants; Moroccan immigrants; dementia; health-related quality of life; cluster randomised control trial

Introduction

Taking care of someone with dementia can be burdensome, both mentally and physically [1-4]. Several studies show that the mental and physical consequences of caring for a person with dementia can result in reduced health-related quality of life (HRQL) in family caregivers of people with dementia [4-7]. Yet little is known specifically about the HRQL of caregivers from minority populations or about strategies that could enhance the HRQL in these groups.

In several European countries, including the Netherlands, people with Turkish or Moroccan immigrant backgrounds are among the largest non-Western minority groups. In the Netherlands, a total of 791,000 people were of Turkish or Moroccan origin in 2017, which was 4.6% of the Dutch population in that year [8]. The first generation of Turkish and Moroccan immigrants, who moved to the Netherlands as labour migrants in the late 1960s and 1970s, have now reached an age in which dementia is becoming increasingly prevalent.

A better picture of the HRQL of family caregivers with a Turkish or Moroccan background who care for a person with dementia is important, given indications that there is a great reliance within these groups on care provided by (female) family members [9,10].

The primary aim of the current study is therefore to provide this insight in relation to sociodemographic and care-related characteristics. We are using the term 'family caregivers' to refer not only to relatives but also to friends, neighbours or others who provide unpaid care for a person with dementia [11].

The secondary aim of this study is to evaluate whether the HRQL of family caregivers with Turkish or Moroccan backgrounds could be enhanced by an educational peer group intervention developed specifically for these groups.

The goal of this intervention was to enhance knowledge about dementia and about care and support options among family caregivers and to facilitate the exchange of experiences between caregivers. The effects of this intervention on knowledge about dementia and on the self-perceived pressure from informal care have been described elsewhere [12]. In the context of the current study, we were interested in the effect of the intervention on HRQL.

The specific research questions that guide the current study are:

1. What is the health-related quality of life of family caregivers of people with dementia with a Turkish or Moroccan background living in the Netherlands?
2. To what extent are sociodemographic characteristics associated with the health-related quality of life in these groups?
3. To what extent are the frequency of caregiving, the self-perceived pressure from informal care and the support received from others in the care for the relative with dementia related to the health-related quality of life in these groups?

4. Can the health-related quality of life in these groups be enhanced by the implementation of an educational peer group intervention?

We expect the HRQL to be lower in older caregivers, in those who have a lower socioeconomic position and in women [13,14]. Secondly, we expect that a poorer HRQL will be associated with a higher frequency of caregiving, a higher self-perceived pressure from informal care and less support from professionals, friends or family members [14-20]. Thirdly, we expect that the social element of the intervention will enhance emotional wellbeing in family caregivers and their engagement in social activities, which are two dimensions of HRQL as measured in this study [21-24].

Methods

Design

This study is part of a cluster RCT that aims to evaluate the effect of an educational peer group intervention on knowledge about dementia (primary outcome), self-perceived pressure from informal care(secondary outcome) and HRQL (secondary outcome) among family caregivers of people with dementia. The current study includes two components:

a. assessing the HRQL of family caregivers of people with dementia with a Turkish or Moroccan background using baseline data from a cluster randomised controlled trial (cluster RCT) with repeated measurements;
b. evaluating the effect of an educational peer group intervention on the HRQL based on this cluster RCT.

The cluster RCT included a measurement directly before the first educational session (T0, baseline), directly after the second educational session, which was one to two weeks after T0 (T1), and three months after T0 (T2). The unit of randomisation was the region in which the family caregivers lived. The study included a total of 16 'clusters', namely regions in the Netherlands that were randomly and blindly assigned to either the intervention or the control condition by an independent researcher.

The cluster RCT design was chosen over an RCT design in which individuals are allocated to the intervention or control conditions for two reasons. Firstly, a cluster RCT did not require participants to travel long distances participate in the intervention, thereby encouraging participation. Secondly, participants under the control conditions could not be influenced by participants living in the same region and receiving the intervention. The CONSORT extension for Cluster Trials was considered for reporting our findings.

Participants who were in a cluster (i.e. region) that was randomly assigned to the control condition completed the same questionnaires as participants in the intervention condition at T0, T1 (one to two weeks after T0) and T2 (three months after T0).

Sample Size

We calculated the sample size taking into account the intra-cluster correlation coefficient, the expected effect and the power of the study. In order to detect a difference of 35% in the primary outcome measure of the cluster RCT (dementia knowledge) with a power of .80 and an α of .05, the control and intervention condition should each include 129 participants. In order to account for clustering, the sample size should be enlarged by 10%, leading to a total sample size of 284. To allow for a 20% loss during follow-up, a total of 340 participants needed to be included.

Participants and Recruitment

The study was performed in regions in the Netherlands where no educational programmes on dementia were already being offered to the target groups and where a relatively large number of people with a Turkish or Moroccan background lived. The eligibility criteria for study participants were:

a. knowing someone with a dementia diagnosis or severe memory problems;
b. being born in Turkey or Morocco or having at least one parent who was born in one of these countries;
c. not having dementia or memory problems themselves.

Potential participants were invited to participate by key contacts (e.g. imams, immigrant care organizations or regional departments of Alzheimer Netherlands). If the potential participant was interested in participating, the key contact passed on their contact details to the study coordinator (NvW), after obtaining the consent of the potential participant. The study coordinator assessed whether the potential participant fulfilled all the inclusion criteria. For the purpose of the current paper, a selection was made of participants who stated that they cared for a person with dementia or severe memory problems.

Intervention

Participants in the intervention condition received two educational sessions of two hours each, together with other participants with the same background (Turkish or Moroccan), in a meeting place such as a room in a mosque or in a cultural community centre. In the first session, a trained educator with the same migrant background as the participants explained what the difference was between dementia and 'normal' forgetfulness and that dementia is a brain disease. In the second session, which took place one to two weeks after the first session, the educator facilitated a discussion about the importance of open communication about dementia and about local options for care and support. The educational sessions were provided in the native language of the participants, which was either Turkish or Moroccan Arabic.

Participants in the control condition did not receive the educational peer support sessions. They met three times in similar meeting places with other participants with the same migrant background, but only to complete the questionnaires. The second meet-up for completing the questionnaire took place one to two weeks after the first and the third took place three months after the first. As participants in the control condition also met peer caregivers when filling in the questionnaire, they might have talked to others about their situation. The peer support sessions were also offered to the participants in the control condition, but only after the study ended.

In 15 of the 16 regions, one group consisted of participants with a Turkish background and one consisted of participants with a Moroccan background. In one region, three groups were made up of participants with a Turkish background and one of participants with a Moroccan background. A total of 34 groups were included in the study: 16 of participants with a Moroccan background and 18 of participants with a Turkish background. The groups had a maximum of 30 participants each.

Outcomes and Measurements

The HRQL – a secondary outcome measure of the cluster RCT pertaining to the individual participant level – was measured by three dimensions in the COOP/WONCA charts: 1) emotional problems during the past two weeks; 2) being hampered in social activities by emotional or physical problems during the past two weeks; and 3) perceived general health status during the past two weeks. Each dimension was assessed by one item. Answers could be given on a 5-point Likert scale that was illustrated by simple drawings of smiling and sad faces, with higher scores indicating a poorer quality of life. The COOP/WONCA charts have been validated for use in Turkish and Moroccan populations [25] and were therefore applied in this study.

To answer the second research question, the sociodemographic characteristics included were age (in years), sex (1=male; 2=female), level of education (1=no education; 2=primary education; 3=secondary education; 4=secondary vocational education; 5=higher vocational education; 6=university), country of birth (1=the Netherlands; 2=other) and migrant background (1=Turkish; 2=Moroccan). The level of education was included as a proxy for the socioeconomic position [26].

To answer the third research question, the frequency of caregiving, the self-perceived pressure from informal care and support received from other people were included. Frequency of caregiving was assessed by asking how often people care for their loved one with dementia, with the following answer options: 1) on a daily basis; 2) three to six times a week; 3) maximum of twice a week; 4) less than once a week; 5) less than once a month.

The self-perceived pressure from informal care was assessed by the 'Self Perceived Pressure from Informal Care' (SPPIC) scale (in Dutch called the EDIZ) [27,28]. The SPPIC was originally developed and validated in Dutch, but has also been validated in Turkish [29]. The SPPIC scale involves nine items and answers can be given on a 5-point Likert scale ranging from 1 (no burden of care) to 5 (high burden of care). Sum scores were calculated ranging from 9 to 45, with higher scores indicating a higher perceived care burden.

Support received from other people in the care for the relative with dementia was measured using four questions developed by the research team, asking whether participants received 1) advice from their GP or another doctor; 2) support from family; 3) support from friends or neighbours; 4) support from home care staff in the care for a person with dementia. Answers could be given on a five-point Likert scale including the following range: 1 (No!) 2 (No) 3 (More or less) 4 (Yes) 5 (Yes!).

All participants had the option of filling in the questionnaires in Dutch, Moroccan Arabic or Turkish. None of the participants chose to fill in the Moroccan Arabic version of the questionnaire. On all three measurement dates, a majority of the participants with a Turkish background filled in the Turkish version of the questionnaire (87% at T0, 88% at T1 and 96% at T2). For those who had poor literacy skills, a research assistant read the questionnaire out loud and wrote down the participant's answers to the questions on their behalf.

Ethical Procedures

Before participation, participants were informed face-to-face about the study by the key contact who recruited them, then a second time by the study coordinator over the phone and thirdly in an information letter that they received at home before the first meeting.

In the first meeting (T0), all participants received another copy of the information letter and an informed consent form in their language of preference (Dutch, Turkish or Moroccan Arabic). The information letters and informed consent forms were read out loud by a research assistant in cases where a participant had poor literacy skills to ensure that all participants understood the information letter and the informed consent form. The informed consent forms were provided during the first meeting (not sent by post) to ensure that participants themselves provided consent and not a family member. For this study, permission from a medical ethics committee was not required according to Dutch law as the study did not concern medical research and participants were not required to follow rules of behaviour (https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not).

Statistical Analyses

Descriptive statistics were calculated to describe the sociodemographic characteristics and the HRQL of family caregivers using the baseline data. Three multiple linear regression analyses were then conducted using the baseline data to estimate the association between the three dimensions of HRQL as the dependent variables (emotional problems, being hampered in social activities, and perceived general health status) and age, sex, level of education, migrant background, country of birth, frequency of caregiving, self-perceived pressure from informal care and support received as the independent variables. All independent variables were included simultaneously in the regression models. To examine the effect of the intervention on the HRQL, three repeated measures multi-level analyses were conducted, taking into account the effects of clustering at the region level. Each analysis used a different dimension of the HRQL as the outcome variable. At the participant level, an unstructured covariance structure between the three measurement points was modelled to control for the correlation between measurements within participants. This was done separately for the control and intervention conditions. Differences in the mean HRQL scores in the intervention and the control condition at T1 and T2 compared with T0 were estimated, adjusted for age, sex, level of education, migrant background, country of birth, frequency of caregiving and self-perceived pressure from informal care. Analyses were based on a treatment allocation framework: all participants were analysed as part of the condition (intervention or control) to which they had been allocated. The descriptive statistics and linear regression analyses were conducted in STATA version 14 and the multi-level analyses in MlwiN. In multi-level analyses, participants are only included if they have at least one completed outcome measure (at T0, T1 and/or T2) and no missing data on any of the background characteristics that were included in the analysis (such as gender and age).

Results

Participants

A total of 288 eligible participants were from regions assigned to the intervention condition and 262 from regions assigned to the control condition; see Figure 7.1. A total of 386 participants provided family care. Of this group, 319 participants filled in the questionnaire at T0, 313 at T1 and 290 at T2.

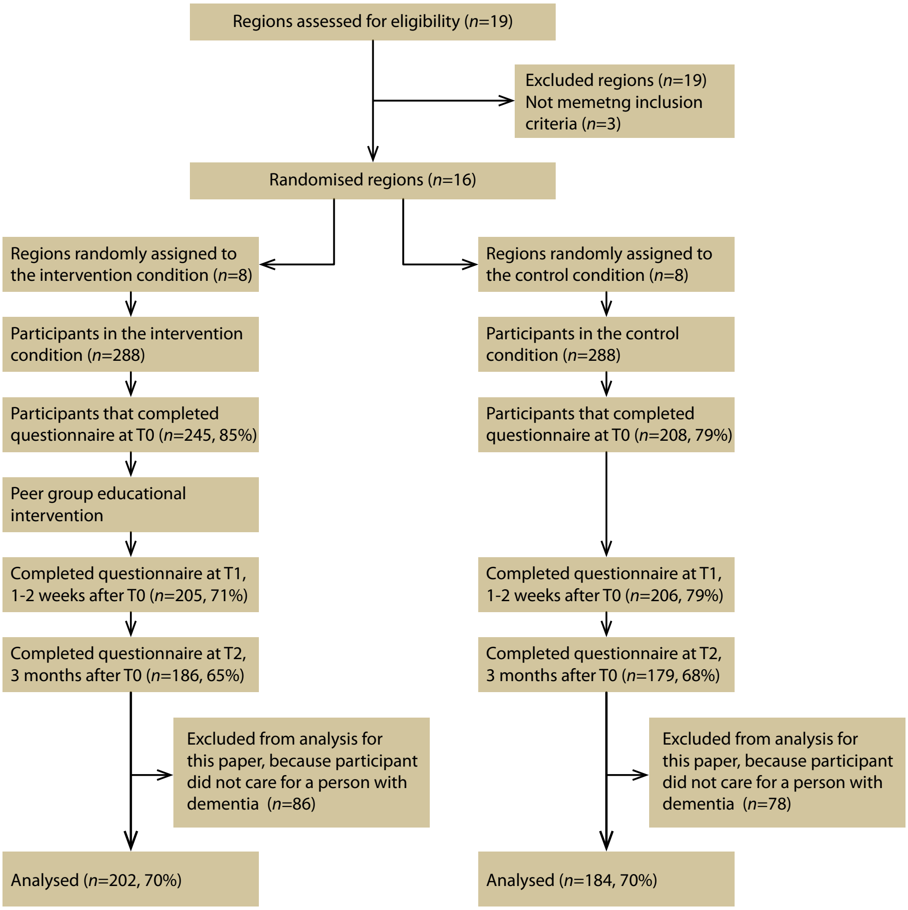


Figure 7.1 *Flow diagram for participants*

Background Characteristics

Table 7.1 shows the background characteristics of the participants of Turkish or Moroccan origin who were included in the analyses. The proportion who were female, born in the Netherlands and had no education was higher for participants with Moroccan backgrounds than for Turkish backgrounds.

Table 7.1 *Participants' background characteristics*

	Participants with a Turkish background (*n*=180)	Participants with a Moroccan background (*n*=139)
Age, mean (SD)	45.4 (13.8)	41.0 (12.7)
Sex, %		
Male	18.9	7.9
Female	81.1	91.4
Missing	0	0.7
Country of birth, %		
Netherlands	12.8	23.7
Other	86.7	75.5
Missing	0.6	0.7
Level of education, %		
No education	8.3	22.3
Primary education	35.6	14.4
Secondary education	18.9	13.0
Secondary vocational education	21.1	26.6
Higher vocational education	11.1	18.0
University	3.9	5.7
Missing	1.1	0

Health-Related Quality of Life

A total of 180 caregivers with a Turkish background and 139 caregivers with a Moroccan background filled in a questionnaire at the baseline. The mean HRQL scores per dimension for each of these groups are presented in Table 7.2 on a scale from1 (good HRQL) to 5 (poor HRQL) as well as the percentages for each category.

Especially with respect to emotional problems, participants with a Turkish background show poorer outcomes than participants with a Moroccan background: 41.6% of the participants with a Turkish background gave a '4' or a '5' (the worst two categories) where this only applied to 16.6% in the participants with a Moroccan background.

Of participants with a Turkish background, 19.5% were hampered quite a bit or very often in their social activities by emotional or physical problems, compared with 15.9% of participants with a Moroccan background.

Table 7.2 *Health-related quality of life (HRQL) scores as measured at baseline ranging from 1 (good HRQL) to 5 (poor HRQL)*

Quality of life dimensions	Participants with a Turkish background (*n*=180)	Participants with a Moroccan background (*n*=139)
Emotional problems, mean (SD)	3.0 (1.3)	2.3 (1.3)
1. Not at all, %	14.6	32.4
2. Slightly, %	23.0	32.4
3. Moderately, %	20.8	18.7
4. Quite a bit, %	27.0	7.2
5. Extremely, %	14.6	9.4
Being hampered in social activities by emotional or physical problems, mean (SD)	2.4 (1.2)	2.1 (1.2)
1. Not at all, %	28.5	41.3
2. Slightly, %	29.1	29.7
3. Moderately, %	22.9	13.0
4. Quite a bit, %	15.6	10.1
5. Extremely, %	3.9	5.8
Perceived general health status, mean (SD)	3.6 (0.9)	3.0 (1.1)
1. Excellent, %	1.7	13.0
2. Very good, %	9.6	16.7
3. Good, %	26.0	31.9
4. Fair, %	48.0	30.4
5. Poor, %	14.7	8.0

The majority of the participants with a Turkish background, namely 62.7%, perceived their general health status to be fair to poor, compared with 38.4% of the participants with a Moroccan background.

The overall mean score is 3.0 for participants with a Turkish background and 2.5 for participants with a Moroccan background, implying moderate overall HRQL for both groups.

Associations between Health-Related Quality of Life, Sociodemographic and Care-related Characteristics

The results of the multiple linear regression analyses as presented in Table 7.3 show that at the baseline, family caregivers with a Turkish background have had significantly more emotional problems during the last two weeks (B=-0.74 (SE=0.16) p<.01), are more often hampered in social activities (B=-0.32 (SE=0.14); p<.05);

Table 7.3 *Associations between health-related quality of life, sociodemographic characteristics, frequency of caregiving, self-perceived pressure from informal care and received support as measured at baseline*

Explanatory variables	Health-related quality of life dimension[a]		
	Emotional problems B (SE)	Being hampered in social activities by emotional or physical problems B (SE)	Perceived general health status B (SE)
Age	0.004 (0.008)	0.009 (0.007)	0.010 (0.006)
Migrant background (reference group: Turkish)	-0.735 (0.156)**	-0.322 (0.143)*	-0.576 (0.126)**
Sex (reference group: male)	0.586 (0.249)*	0.482 (0.229)*	0.347 (0.202)
Country of birth (reference group: the Netherlands)	-0.390 (0.233)	-0.316 (0.214)	0.053 (0.192)
Level of education	-0.080 (0.063)	0.013 (0.058)	-0.069 (0.051)
Frequency of caregiving[b]	-0.012 (0.060)	0.047 (0.055)	-0.044 (0.049)
Self-perceived pressure from informal care[a]	0.049 (0.100)**	0.055 (0.010)**	0.036 (0.008)**
Received advice from doctor[c]	0.032 (0.068)	0.026 (0.063)	-0.031 (0.055)
Received support from family[c]	-0.179 (0.064)**	-0.066 (0.059)	-0.130 (0.052)*
Received support from friends/neighbours[c]	0.149 (0.072)*	0.074 (0.066)	0.038 (0.058)
Received support from home-care staff[c]	-0.132 (0.065)*	-0.073 (0.061)	-0.043 (0.053)

a Higher scores refer to a poorer quality of life/higher pressure from informal care
b Higher scores refer to a lower frequency of caregiving
c Higher scores refer to more advice/support
*** Significant association (p < .01)*
** Significant association (p < .05)*

p<.01) and report poorer perceived general health status (B=-0.58 (SE=0.13; p<.01) than caregivers with a Moroccan background.

Furthermore, female caregivers were more likely to report emotional problems (B=0.59 (SE=0.25); p<.05) and being hampered in social activities because of emotional or physical problems (B=0.48 (SE=0.23); p<.05) than male caregivers.

In addition, a higher self-perceived pressure from informal care was significantly associated with more emotional problems during the last two weeks (B=0.05 (SE=0.10); p<.01), being hampered in social activities more often (B=0.06 (SE=0.01); p<.01) and poorer perceived general health status (B=0.04 (SE=0.01); p<.01).

With respect to support received from other people in caring for the relative with dementia, more support from family was associated with fewer emotional problems (B=-0.18 (SE=0.06); p<.01) and with a better perceived general health status (B=-0.13 (SE=0.05); p<.05). In addition, more support from home care staff was associated with fewer emotional problems (B=-0.13 (SE=0.07); p<.05). In contrast, more support from friends or neighbours was associated with more emotional problems (B=0.15 (SE=0.07); p<.05).

Country of birth, level of education, frequency of caregiving and advice from a doctor were not associated with the HRQL, according to on the outcomes of these multiple regression models.

Effect of the Educational Peer Group Intervention

The effects of the educational peer group intervention on the HRQL in family caregivers are presented in Table 7.4. In the intervention condition, the mean score for perceived emotional problems during the last two weeks was significantly lower at T1 compared with T0 (mean: 2.47 versus 2.86; chi^2(1)=16.20; p<.001). However, this was not a lasting decrease, as the mean score at T2 was higher than the mean score at T0. No significant differences over time were found in the control condition with respect to perceived emotional problems.

With respect to being hampered in social activities, there seemed to be an increase over time in mean scores in both the intervention and the control condition, implying that participants were increasingly hampered in their social activities, yet these trends are not significant in either group.

On the other hand, Table 7.4 shows a small but significant trend towards improved perceived general health status in the intervention condition. Although the decrease in the mean score at T1 (mean: 3.33) compared with T0 (mean: 3.45) is not significant, the decrease in the mean score at T2 (mean: 3.22) compared with T0 *is* significant (chi^2(1)=6.15; p <.05). No such decrease is found in the control condition, where scores seem to increase over time, although not significantly, implying poorer HRQL.

Table 7.4 *Mean health-related quality of life at T0, T1 and T2 for the intervention condition and the control condition*

	Intervention condition (n=202)	Control condition (n=184)
Perceived emotional problems		
T0, mean (95% CI)*	2.86 (2.60 to 3.12)	2.60 (2.37 to 2.83)
T1, mean (95% CI)*	2.47 (2.23 to 2.71)	2.72 (2.50 to 2.94)
T2, mean (95% CI)*	2.89 (2.62 to 3.16)	2.67 (2.45 to 2.88)
Does T1 differ significantly from T0? Chi^2(*df*); p-value	16.20 (1); p <.001	1.23 (1); p >.1
Does T2 significantly differ from T0? Chi^2(*df*); p-value	0.05 (1); p >.1	0.44 (1); p >.1
Trend over time, Chi^2; p-value	19.33 (2); p <.001	1.26 (2); p >.1
Do the trends differ significantly? Chi^2(*df*); p-value	14.20 (2); p <.001	
Being hampered in social activities		
T0, mean (95% CI)*	2.29 (2.05 to 2.54)	2.27 (2.04 to 2.49)
T1, mean (95% CI)*	2.34 (2.09 to 2.60)	2.31 (2.11 to 2.51)
T2, mean (95% CI)*	2.50 (2.25 to 2.75)	2.43 (2.24 to 2.62)
Does T1 differ significantly from T0? Chi^2(*df*); p-value	0.20 (1); p >.1	0.20 (1); p >.1
Does T2 differ significantly from T0? Chi^2(*df*); p-value	2.87 (1); p >.05	2.22 (1); p >.1
Trend over time, Chi^2(*df*); p-value	2.90 (2); p >.1	2.54 (2); p >.1
Do the trends differ significantly? Chi^2(*df*); p-value	0.09 (2); p >.1	
Perceived general health status		
T0, mean (95% CI)*	3.45 (3.26 to 3.64)	3.17 (3.00 to 3.34)
T1, mean (95% CI)*	3.33 (3.13 to 3.53)	3.12 (2.95 to 3.28)
T2, mean (95% CI)*	3.22 (3.04 to 3.41)	3.28 (3.12 to 3.44)
Does T1 differ significantly from T0? Chi^2(*df*); p-value	1.59 (1); p >.1	0.35 (1); p >.1
Does T2 differ significantly from T0? Chi^2(*df*); p-value	6.15 (1); p <.05	1.41 (1); p >.1
Trend over time, Chi^2(*df*); p-value	6.15 (2); p < .05	3.11 (2); p >.1
Do the trends differ significantly? Chi^2(*df*); p-value	7.56 (2); p < .05	

* *Corrected for region, sex, age, level of education, country of birth, migrant background, frequency of caregiving and self-perceived pressure from informal care*

Discussion and Conclusion

Discussion

Generally, the HRQL of family caregivers with a Turkish or Moroccan immigrant background is moderate. To assess whether the HRQL scores that we found in our study differ from the HRQL in non-caregivers, we looked at a study using Dutch census data. This study reported on the perceived health status, which is one dimension of the HRQL. It showed that 68% of Dutch inhabitants with a Turkish background and 64% of Dutch inhabitants with a Moroccan background perceive their health to be good or very good, compared with 37% and 62% respectively of the participants in our study [30]. This implies that family caregivers with a Turkish background have a much poorer perceived health status than Dutch inhabitants with a Turkish background in general. In comparison, 83% of the Dutch inhabitants without a migration background perceive their health as good or very good [30].

A recent study found that 19% of all Dutch adult inhabitants with non-Western migration backgrounds perceived their psychological wellbeing as poor [31]. In comparison, we found 42% and 17% of the family caregivers with a Turkish or Moroccan immigrant backgrounds respectively to have experienced emotional problems quite a bit or extremely often. This implies that family caregivers with a Turkish background have more emotional problems than people with a non-Western migration background in the general population. Further research is needed to explain the relatively poor quality-of-life scores in family caregivers with a Turkish background.

With respect to country of birth (either The Netherlands, Turkey or Morocco), we did find an initial association with perceived general health status, which is one aspect of HRQL, based on univariate regression analysis (data not shown). However, in the multivariate regression model this association was no longer significant, implying that other variables (including age and gender) account for this association. It therefore appears that country of birth does not explain any unique variance in the HRQL of family caregivers with a Turkish or Moroccan immigrant background.

In addition, we found that the quality of life of female caregivers was lower than the quality of life of male caregivers; this was also reported in previous research [13]. This can probably be explained by the fact that women are more likely to provide the domestic and physical care for a relative with dementia [32,33], while male caregivers often provide other types of help, such as administrative or transport tasks [34], which might involve less of a care burden.

Moreover, we found that the HRQL was strongly associated with the self-perceived pressure from informal care. Such an association was not found between the HRQL and the frequency of caregiving. Although various studies suggest that perceived pressure from informal care is one of the strongest predictors of quality of life in family caregivers [15,17], there is also evidence that the frequency of caregiving is related to quality of life when controlling for the care pressure [17]. However, our findings suggest that among family caregivers with a Turkish or Moroccan immigrant background, the self-perceived pressure from informal care is more strongly related to the HRQL than the frequency of caregiving.

There are few comparable studies on the effects of support from others on HRQL in family caregivers of people with dementia [20,35]. However, our finding that receiving support from home care staff is associated with better emotional wellbeing is in line with the findings of Rosness and colleagues, who found a reduction in depression symptoms in family caregivers of people who received nursing care [20]. Remarkably, we found that more support from family and from home-care staff was associated with better emotional wellbeing, whereas more support from friends or neighbours was associated with worse emotional wellbeing. Further research is recommended to explore the roles of different types of support in the emotional wellbeing of family caregivers with a Turkish or Moroccan background.

We expected that contact with peers would have a positive effect on emotional and social wellbeing, as found in four other educational intervention studies among caregivers of people with dementia [21-24]. We found an initial improvement in emotional wellbeing, although this positive effect was no longer present three months after the start of the intervention. To achieve a more long-lasting effect on emotional wellbeing, it might be necessary to increase the number of sessions and to prolong the intervention period.

Furthermore, no effect of the intervention was found for the dimension regarding social activities in relation to emotional and physical problems. Two sessions might not be enough to achieve effects on this dimension either.

We did find a small effect of the intervention on perceived general health status, three months after the start of the intervention. A possible explanation for the small improvement in the general health status could lie in the assumption that the intervention led to more awareness about support options and consequently more actual support, which might have had an alleviating effect on family caregivers, thereby positively affecting their wellbeing.

A limitation of the current study is that we did not measure any long-term effects of the intervention, because of limited resources. It would be valuable to examine in the long term whether interventions, like the intervention evaluated in the current study, actually encourage people to make use of informal or professional care and support options and whether this has a beneficial effect on the quality of life and coping with dementia. The initial findings of our study, indicating effects (albeit small) of the HRQL intervention among family caregivers with immigrant backgrounds, therefore serve as grounds for conducting further research into the long-term effects of the intervention.

Another limitation is that we were unable to allow for the severity of dementia in the analyses. However, earlier research indicates that subjective experiences of family caregivers, such as feelings of being overburdened, are better predictors of the quality of life in family caregivers than the level of cognitive impairment of the person with dementia [15,36]. This implies that the main results of the current study would probably not have been different if the severity of dementia had been included in the regression models. Ideally, information about the severity of dementia would have been obtained from an healthcare professional involved, for instance a GP.

Conclusion

Overall, the HRQL of family caregivers with Turkish or Moroccan immigrant backgrounds tends to be moderate. A greater self-perceived pressure from informal care is related to a poorer HRQL in these groups. The HRQL was found to be lower in female than in male caregivers and in caregivers with a Turkish background compared with caregivers with a Moroccan background. Culturally sensitive peer group education on dementia and on local care and support options has a small but positive effect on two dimensions of the HRQL in family caregivers shortly after it is provided.

Practice Implications

In order to support family caregivers of people with dementia with a Turkish or Moroccan background, it is recommended that culturally sensitive peer group education on dementia and on local care and support options should be offered. Sufficient time for reaching and informing the target population is crucial for successful implementation of the intervention in other settings.

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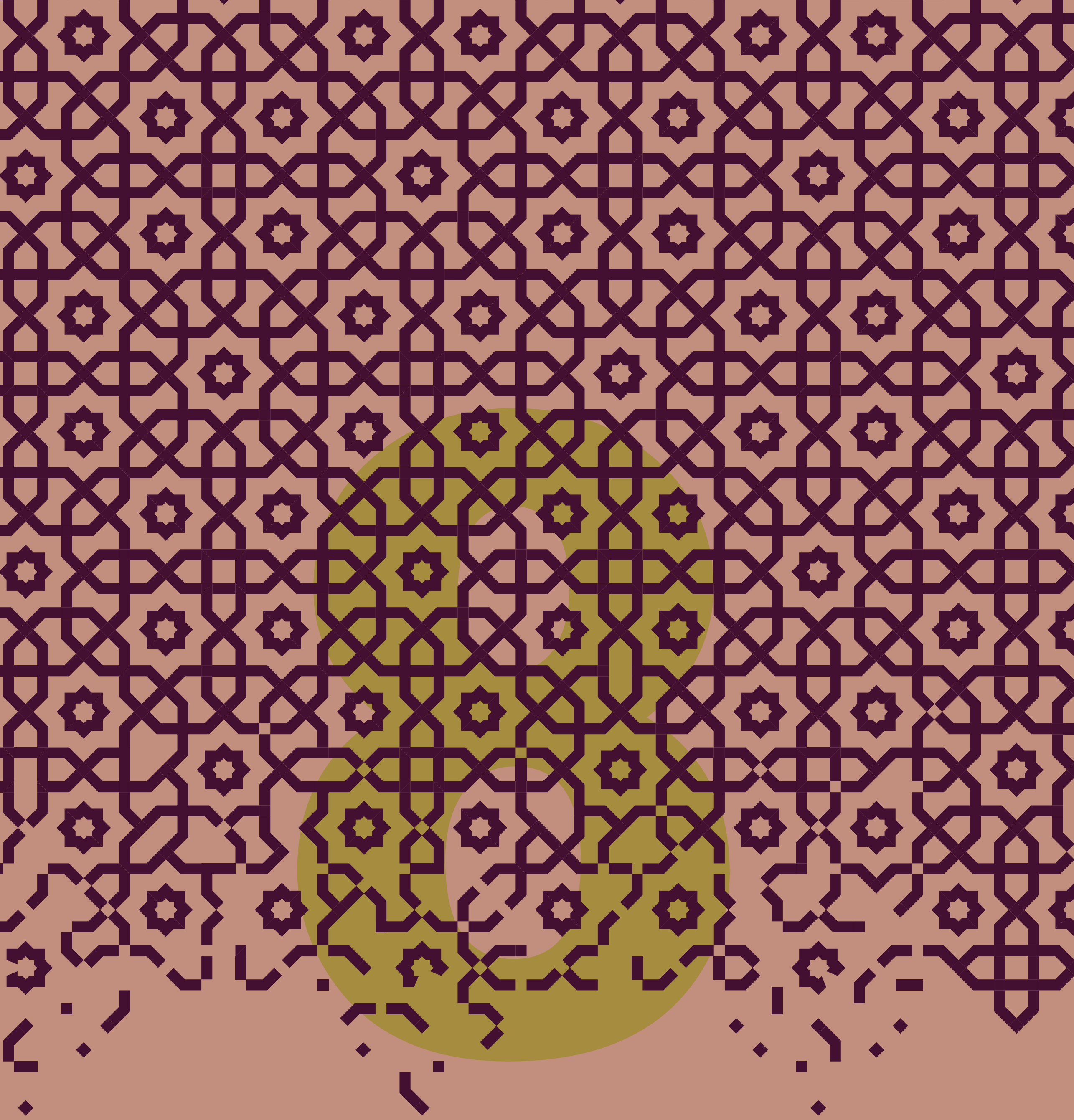
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Chapter 8

Summary and General Discussion

This final chapter starts by giving a summary of the main study findings. Then the main findings are discussed. Subsequently, methodological considerations and research recommendations are addressed, as well as implications for practice, education and policy.

Summary of the main findings

The research presented in this thesis aimed to gain an understanding of experiences with family care, explanations given for the causes of dementia and the communication about dementia among family caregivers from Turkish, Moroccan and Surinamese Creole migrant groups in the Netherlands. An additional aim is to provide a picture of the effects of the "Knowing about forgetting" educational programme on the knowledge, ability to talk about dementia, use of informal and professional care, perceived pressure of care and quality of life of Turkish-Dutch and Moroccan-Dutch family caregivers of people with dementia.

Based on the results of forty-one individual qualitative interviews and six focus groups, Chapter 2 looked at the perspectives of female caregivers with a Turkish, Moroccan or Surinamese Creole background on dementia and on communication about dementia.The following main research questions were addressed in that chapter:

- How do female family carers with a Turkish, Moroccan or Surinamese Creole background and who are living in The Netherlands explain and describe the dementia of their close relatives?
- Do they perceive that their close relatives' dementia can be discussed openly within the family or in the wider community?

The family carers interviewed often considered dementia as a natural consequence of ageing, as a spiritual experience and/or as interplay between various biological, psychological and social factors. Family caregivers with Turkish or Moroccan backgrounds saw life events or personality traits relatively often as causes of dementia, whereas caregivers with a Surinamese Creole background frequently mentioned physical aspects, such as past dehydration, as a cause of dementia. The explanatory model 'dementia as a neuropsychiatric condition', which is dominant in Western cultures, was rarely expressed by the family caregivers.

The family caregivers generally communicated openly about the dementia with their close family. However, family carers with Turkish or Moroccan backgrounds in particular stated that open communication within their broader community was often hampered, e.g. by feelings of shame or out of respect for the relative with dementia. The family carers with a Surinamese Creole background experienced little or no denial, shame or unease when talking about their relative's dementia with others from their community.

Chapter 3 gives us an understanding of the perspectives of female caregivers with Turkish, Moroccan or Surinamese Creole backgrounds on family care. The results were based on the interviews and focus groups that were also used for Chapter 2. The following main research question was addressed:

- What are the perspectives of female family carers with Turkish, Moroccan or Surinamese Creole backgrounds in the Netherlands about providing family care to a close relative with dementia

The family carers interviewed derived a great deal of fulfilment from giving family care to their relative with dementia. The caregivers saw family care as a task that they should carry out with respect and love. Even though the family carers found that caring for a close relative with dementia was sometimes burdensome, they did say that they get a great deal of satisfaction from providing this care. Family carers with a Turkish or Moroccan background in particular said that providing family care led to recognition and appreciation from family and community members. This fulfilment they experienced in providing family care seemed to outweigh their care pressure.

Especially family carers of Turkish or Moroccan origin felt that family care is superior to professional care and that it is principally a task for women. If men do have a role in family care, then it generally covered practical, non-physical support, e.g. regarding administrative and transport tasks and doing groceries. Interviewees with a Surinamese Creole background attached a great deal of value on family care, although at the same time they seemed to be more open to professional care. Unlike family caregivers with Turkish or Moroccan backgrounds, the interviewees with a Surinamese Creole background were not afraid of negative responses from the family or community when using professional care.

The insights from Chapter 2 and Chapter 3 were used in a culturally sensitive peer group educational intervention called "Knowing about forgetting", for family caregivers with a Turkish or Moroccan migrant background living in the Netherlands. To be able to measure the effects of the educational intervention on dementia-related knowledge, we developed the Dementia Knowledge Scale (DKS), a questionnaire that was largely based on items translated from the English Alzheimer Disease Knowledge Scale. **Chapter 4** describes the development and validation of the DKS and the following main research question was addressed:

- What are the internal consistency and validity of the DKS as completed by family caregivers with a Turkish or Moroccan background?

Eleven items from the original 30-item Alzheimer Disease Knowledge Scale were selected by nine people with Turkish or Moroccan backgrounds and eight professionals. The items selected were translated and adapted from English into Dutch, Turkish and Moroccan Arabic, using plain language. A pilot test among the target groups showed that these language-specific versions of the Dementia Knowledge Scale were considered feasible, comprehensible and appropriate for assessing dementia-related knowledge.

Subsequently, the internal consistency and known group validity of the DKS was determined based on the baseline data of the cluster randomized controlled trial described in chapters 6 and 7 of this thesis. This was only done for the Dutch and Turkish versions, as almost all participants with a Moroccan background chose the Dutch version rather than the Moroccan Arabic version.

Baseline data of 117 Dutch-Turkish family carers who completed the Turkish version of the DKS and 110 Dutch-Moroccan family caregivers who filled out the Dutch version was used.

The internal consistency of the DKS was adequate for the Turkish version but not for the Dutch version. Furthermore, no differences in mean knowledge scores were found when testing the known group validity between those with a low level of education versus those who were more highly educated. Neither were there differences in knowledge scores between those who frequently cared for a person with dementia versus those who did so less frequently. Also, no differences were found between those who lived with a person with dementia versus those who did not.

In **Chapter 5,** we present the psychometric analyses of the Turkish version of the SSPIC (abbreviation in Dutch: EDIZ), an instrument that we later used in the cluster RCT to measure effects on the self-perceived care pressure. The original Dutch SSPIC was translated into Moroccan Arabic and Turkish and then back-translated as a check. As very few respondents filled out the Moroccan Arabic version, and because the psychometric qualities of the original Dutch version were already known, psychometric analyses were only done for the Turkish version of the SSPIC. **Chapter 5** addresses the following main research question:

- What is the internal consistency and the known group validity of the Turkish version of the SSPIC as completed by family caregivers of people with dementia in Turkish migrant communities in the Netherlands?

A pilot test showed that the Turkish version of the SSPIC was comprehensible and appropriate. The internal consistency of the Turkish version was examined by using baseline data from the cluster RCT of 117 family caregivers who completed this version. A single-factor Confirmatory Factor Analysis was conducted, and the internal consistency of the SSPIC was considered good, as Cronbach's alpha was 0.94.

Furthermore, the known group validity of the Turkish version of the SSPIC was assessed and appeared to be good, as family caregivers who provided care at least once a week or who shared a home with a person with dementia perceived a greater care pressure than those who offered care less than once a week or who did not live with the person with dementia.

Chapter 6 and Chapter 7 describe the effects of the educational peer group intervention "Knowing about forgetting". The intervention consisted of two interactive peer group sessions for relatives of people with dementia or severe memory problems from non-western migrant groups. In these sessions, the participants received information about dementia and about care and support options. In addition, communication between participants was encouraged during the sessions, lettign them swap experiences about relatives with dementia. Each group consisted of participants and trained educators with the same migrant background.

The effects of the intervention were investigated in the cluster RCT mentioned earlier. The RCT only concerned participants with Turkish or Moroccan migrant backgrounds, as it was not feasible within the scope of this thesis to recruit enough participants with Surinamese Creole backgrounds.

The clusters in the RCT consisted of groups of participants from 16 regions in the Netherlands. The regions were randomly assigned to either the intervention condition (educational intervention) or the control condition (no educational intervention during the study period).

Participants in the intervention condition as well as in the control condition had to complete the same set of questionnaires at the same moments, namely at T0 (before the intervention started in the intervention condition), T1 (directly after the intervention which was one to two weeks after T0) and T2 (three months after T0).

The set of questionnaires included the Dementia Knowledge Scale, the SSPIC measuring self-perceived care pressure, COOP/WONCA charts measuring health-related quality of life, and questions developed in-house about the perceived ability to talk about dementia and receiving informal or professional support in the care for the person with dementia.

Chapter 6 addresses the following main research questions:

- Does participation in the educational peer-group intervention "Knowing about forgetting" in family caregivers with a Turkish or Moroccan background result in
  - improved knowledge about dementia?
  - improved perceived ability to talk about dementia or severe memory problems?
  - increased use of informal or professional support?
  - decreased self-perceived pressure from family care?

Multilevel analyses of data of 386 participants with a Turkish or Moroccan background (intervention condition n=202, control condition n=184) showed that knowledge about dementia and about care and support options improved significantly more in participants who received the educational intervention than in those in the control condition.

Furthermore, in the participants who received the educational intervention, there was a significant increase of support from home care staff, which was not found in the control condition. However, no effects of the intervention were found on other types of support, i.e. from doctors, other family members, friends or neighbours. Neither were there effects on the perceived ability to talk about dementia or severe memory problems and on self-perceived care pressure.

Chapter 7 provides a picture of the quality of life of family caregivers with Turkish or Moroccan backgrounds and of the effects of the educational peer group intervention on the quality of life. The following main research questions were addressed:

- What is the health-related quality of life of family caregivers of people with dementia with a Turkish or Moroccan background living in the Netherlands?
- Can the health-related quality of life in these groups be enhanced by the implementation of the educational peer group intervention "Knowing about forgetting"?

The quality of life at baseline (T0) was generally moderate, although significantly lower in family caregivers with a Turkish background and in females than in caregivers with a Moroccan background and in males. A low quality of life was associated significantly with a relatively high self-perceived care pressure. Furthermore, receiving support from other family or from home care staff was associated with a high level of emotional wellbeing and a high general health status (two dimensions of quality of life).

The educational peer group intervention had short-term positive effects on some dimensions of the quality of life, namely emotional wellbeing directly after the intervention, and on perceived general health status three months after. However, no effects of the intervention were found on the social wellbeing dimension.

Reflections on the main findings

Perspectives on dementia

The interview study showed that caregivers with a Moroccan, Turkish or Surinamese Creole migrant background often deem dementia to bea normal consequence of old age or a spiritual experience, which is not in line with the dominant view in Western cultures where dementia is seen as a neuropsychiatric condition (Downs *et al.*, 2006; Quinn *et al.*, 2017).

Our finding that other explanations and illness representations are often given in the groups investigated for the causes and essence of dementia is in line with other studies among minority groups (Berdai *et al.*, 2019; De Vries, 2007; Hootzen *et al.*, 2013; Nielsen and Waldemar, 2020, 2016; Parveen *et al.*, 2017; Sagbakken *et al.*, 2018; Kenning *et al.*, 2017; Mukadam *et al.*, 2011 and 2015). The study by Berdai *et al.* (2019), for instance, concerned caregivers with a Belgian-Moroccan background. Berdai *et al.*, 2018 found that dementia is often labelled differently as the older person is assumed to be forgetful, crazy, possessed, spoiled 'fsoesh' and being confused in the head. The label of 'forgetfulness 'was also found in the studies by Hootzen *et al.* (2013) and De Vries (2007), where Dutch-Turkish and/or Dutch-Moroccan people explained dementia as a severe form of forgetfulness.

Contrary to the illness representations of the family caregivers interviewed ,dementia is mainly considered in western cultures as a neuropsychiatric condition, which is mostly described in medical and diagnostic terms (Quinn *et al.*, 2017). However, it is also known that explaining and framing dementia in medical terms might not necessarily be beneficial for patients and relatives (Clare *et al.*, 2016; Quinn *et al.*, 2019). Quinn and colleagues (2019) indicated that it is important, first and foremost, that people recognize that the person with dementia has a condition that has a major impact on memory and functioning. Regardless of the specific diagnostic label, information about the causes, symptoms and course of dementia lets people anticipate the further development of the disease and possible future support needs. Providing this kind of information might be more helpful than emphasizing that everyone must adopt the dominant Western view of dementia as a neuropsychiatric condition.

Reflections on communication about dementia

The family carers interviewed talked openly with their close family about dementia or severe memory problems of their relative. However, those from the Turkish or Moroccan migrant groups in particular stated that this open communication was done less outside the immediate family circle. Some of them related this to a 'culture of shame and silence', feelings of unease, shame and fears about gossip. This suggests that there might still be a taboo on dementia within the Turkish and Moroccan migrant communities. This is in line with what has been described in other studies among non-Western populations (Kontos *et al.*, 2020; Nguyen and Li, 2020; Vissenberg *et al.*, 2018).

The barriers to open communication about dementia or severe memory problems in the wider community were not mentioned by the family caregivers interviewed with a Surinamese Creole background. A possible explanation might be that this group has much in common in terms of language and culture with the native Dutch population, which is reflected in an open communication style about severe illnesses.

Reflections on perspectives on family care

Previous research indicated that people from non-Western migrant populations are relatively often unfamiliar with the available supply of professional care and support services and that there are often strong norms and preferences for keeping care within the family (Sagbakken *et al.*, 2018; Shanely *et al.*, 2012; Berdai Chaouni *et al.*, 2019; Hootzen *et al.*, 2013; De Graaff & Francke., 2003; Yerden, 2013). This picture also emerges from the interview study, where we found that family caregivers with a Turkish or Moroccan background in particular generally prefer family care to professional care. This preference is prompted by the perceived importance and value of reciprocity within families, as well as the belief that family care is superior to professional care, although this belief might be less present among second and third-generation immigrants compared to the first generation.

Furthermore, our interviews also showed that family carers of Dutch-Turkish or Dutch-Moroccan origin especially feel that domestic and emotional care above all – the lion's share of daily care – are better given by women in the family. This is in line with findings of various other studies (Kim *et al.*, 2012; Del Rio Lozano *et al.*, 2017; Yerden, 2013; Rodríguez-Madrid *et al.*, 2018). Jutlla (2013) emphasizes that even though identity roles can open new possibilities because of migration, culturally determined traditions and gender roles in general often seem to be strengthened in migrant groups. Decisions about who should care for older adults are often made in non-Western communities within a hierarchy of obligation, running from the female spouse as the first choice and the daughter and daughter in-law as the second or third choice (Jutlla, 2013).

Although family caregivers in our study mentioned that giving family care was sometimes hard, they also mentioned a great deal of satisfaction and fulfilment from providing family care. This finding is in line with the review by Yu *et al.* (2018) describing how family caregivers might perceive personal accomplishment and gratification, feelings of mutuality in the relationship with the person with dementia, an increase of family cohesion and functionality, personal growth and a purpose in life (Yu *et al.*, 2018). These factors are all relevant for the quality of life as experienced.

Reflections on effects of the educational peer group intervention on knowledge

The cluster RCT study showed positive effects of the educational intervention on the level of knowledge about dementia, support from home care and on the perceived general health status. These positive effects underline the relevance of an educational intervention for family caregivers with a Dutch-Moroccan or Dutch-Turkish background and possibly also for other non-Western migrant groups.

The effects on knowledge in particular imply that family carers are more aware of dementia symptoms, which is relevant for a diagnosing dementia in good time and subsequently getting access to professional care and support. Various studies have shown that the diagnostic rate in people with dementia with a non-Western background is lower than in the general population (Vissenberg *et al.*, 2018; Diaz *et al.*, 2015; Nielsen *et al.*, 2011). In addition, previous research established that non-Western groups have a lower uptake of post-diagnostic support and care (Nielsen *et al.*, 2020). Eeducational interventions about dementia and about support options could therefore improve dementia-related knowledge and can therefore also have positive effects on access to and use of professional support.

Our study of the effects of the educational intervention “Knowing about Forgetting” helps eliminate one of the gaps in research. To date,there was limited evidence on the effects of educational interventions on dementia-related knowledge. In the systematic review by Moore and colleagues (2020), only two of the total of eleven studies included had knowledge as an outcome variable and they did not provide unanimous results. Moreover, none of the studies in the review by Moore *et al.* (2020) specifically targeted family caregivers with non-Western migration backgrounds. Nevertheless, it is interesting to reflect on why our study did show an effect on knowledge. Our educational intervention was based on principles of the social learning theory (Bandura, 1977; Burke *et al.*, 2012). This implied that participants had the same cultural background and language and that the intervention was delivered by specially trained peer educators with the same background, and who spoke Dutch as well as the mother tongue of the participants. The social learning theory and the peer education approach fit with the assumption that trained peers can function as role models and are appropriate for encouraging behavioural changes in their peers (Burke *et al.*, 2012). In addition to the social learning theory, our educational intervention was based on the VETC method (Voorlichting Eigen Taal en Cultuur/ Information in own Language and Culture; Enting, 2006). It was expected that this culturally specific approach, in which participant and trainer could identify with each other, would promote the transfer of knowledge and strengthen interactions in the group sessions.

The elements of peer education using role models with the same culture and language or dialect have probably helped the positive effects of the intervention in terms of increased knowledge. This assumption is supported by a systematic review by Henderson *et al.* (2011) on the effectiveness of interventions for managing or preventing chronic diseases in culturally diverse communities. The review showed that using well-educated bilingual trainers was important in enhancing knowledge of chronic diseases, such as diabetes or heart conditions. Studies of peer education about cancer also showed that peer education can lead to increased knowledge, e.g. about the disease and chemotherapy complications (Gozum *et al.*, 2010; Heydarzadeh *et al.*, 2019).

Reflections on the educational intervention's effects on uptake of support options and care pressure

Another finding was that family caregivers of Turkish or Moroccan origin made more use of support from home care staff after participating in the educational intervention "Knowing about Forgetting". This finding is in line with a study in a general population of family caregivers of people with dementia, showing that after a psychological educational intervention, family members made more use of professional home care facilities (Dovi *et al.*, 2020).

Beforehand, we expected that an increased use of home care would not only be the result of increased knowledge about support options, but also a result of an increased ability to talk with professionals and others about the dementia or severe memory problems of the relative. However, we could not find significant effects on this ability of participants. The latter finding might be explained by the fact that the participants probably were already able to talk with others about dementia or the severe memory problems of their relative, as participation in the intervention implicitly required a willingness to talk about the subject with others.

In addition, our study did not establish a decrease in the self-perceived care pressure after the educational intervention. This is in line with the systematic review of educational interventions by Moore and colleagues (2020) mentioned earlier, who did not find effects on care pressure either. Like our study, all the studies that were included in the review by Moore *et al.* (2020) had short-term measurements within just a few weeks or months after the intervention. Positive effects on care pressure might possibly be a long-term result, because arranging and using additional professional support may need longer than the duration of the study to show any effect.

Reflections on health-related quality of life

This thesis also shows that the quality of life of family carers with Turkish or Moroccan migrant backgrounds was moderate, although those with a Turkish background reported a poorer quality of life on average than those with Moroccan backgrounds in terms of emotional wellbeing, social activities and general health status. We are unable to offer a clear explanation for this finding.

In addition, we found that the quality of life of female caregivers was on average lower than the quality of life of male caregivers. This might be related to the fact that women are more likely to provide domestic and physical care for a relative with dementia, while male caregivers often provide practical types of help, such as administrative or transport tasks. Such practical support might involve lower care burdens and therefore also does not have much effect on the quality of life.

Furthermore, we found that the health-related quality of life was associated with the self-perceived care pressure. Previous studies have also indicated that perceived care pressure is associated with quality of life in family caregivers (Abdollahpour *et al.*, 2015; Chapell *et al.*, 2002). There is also evidence that the frequency of caregiving is related to th equality of life (Chapell *et al.*, 2002). However, our findings suggest that among family caregivers with Turkish or Moroccan migrant background, the self-perceived care pressure is more strongly related to the quality of life than to the frequency of caregiving.

Our finding that support from home care staff is associated with better emotional wellbeing is in line with the findings of Rosness and colleagues (2011), who found a reduction in depression symptoms among family caregivers of people who received home care (Rosness *et al.*, 2011).

Methodological reflections and recommendations for future research

Reflections and recommendations on recruitment of participants with non- Western migrant backgrounds

A major challenge in studies that focus on people with non-Western migrant backgrounds is recruiting enough study participants (Waheed *et al.*, 2015). An important strength of the current study is that we did succeed in including relatively large samples, in both the qualitative and the quantitative study parts. Our approach to recruiting participants with Turkish, Moroccan or Surinamese Creole backgrounds therefore gives grounds for the following recommendations for future research.

A first recommendation is to include people in the project team who have the same cultural background as the target population. Our team included two researchers of Dutch-Turkish descent as well as peer educators of Dutch-Moroccan and Dutch-Turkish descent to implement the educational intervention. These people helped with specific insights about recruitments strategies and how to approach people through key figures in the specific communities, such as imams and keypeople in migrant organizations.

A second recommendation is to recruit participants in close collaboration with locally organized welfare organizations and migrant organizations or local elderly organizations of migrants. Especially the close cooperation with local migrant organizations helped to get access in migrant communities and get in touch with key figures from these communities. With the knowledge, experience and contacts of the key figures, specific recruitment strategies were chosen for recruiting participants. In some organizations, we were invited to organize meetings for informing potential participants about the study.This created the mutual trust that was essential for effective actual recruitment.

A third recommendation is to schedule sufficient time for recruiting the participants from non-Western migrant groups. In both our qualitative and quantitative studies (see chapters 2, 3, 6 and 7) 6-15 months were spent on recruitment. Sufficient time is needed in the first place to come in contact with and to get trusted by key figures in the communities, such as imams and their wives, who in turn are trusted by the people from the migrant communities. These key people should be familiarized with the study aim and topic, see the importance of it and they have to be willing to inform community members about the study. We found that key people who are actively involved in the recruitment play a crucial role in the recruitment process.

The researchers or research assistants who do the recruiting also need enough time to gain the trust of potential participants, after they have shown initial interest in study participation. This trust was gained by taking the time to explain (sometimes several times) to the potential participants the purpose and importance of the intervention and the study, and what it means to participate in the study.

Reflections and recommendations about group and individual interviews with participants from migrant groups

The qualitative research (see chapters 2 and 3) was based on a combination of individual interviews and focus groups. We opted for this combination because individual interviews are appropriate for getting to understand individuals' personal experiences and opinions, while focus groups can give additional insights through the interactive discussions between peers with the same cultural background. For future research about perspectives on and experiences with family care, we therefore recommend using the combination of individual and focus group interviews and organizing focus groups for people with the same cultural background.

For sharing experiences and opinion,s it is important that participants can use a language they feel familiar with. Some interviews were therefore conducted in Turkish by a member of the research team with a Dutch-Turkish background. However, some of the participants with Moroccan backgrounds could not speak Dutch and we did not have a team member who spoke Moroccan Arabic or Berber. In these cases, a family member (often an adult daughter) joined the interview to translate the questions and answers from Moroccan Arabic or Berber to Dutch and vice versa. We are aware that using family as translators comes with certain risks, for instance the risk of distorting a question or answer, because of feelings of shame or respect. However, we have no indication that there have been such distortions, as no differences in perspectives emerged that could be attributed to whether or not a family member translated questions and answers.

Reflections and recommendations regarding instruments to measure dementia knowledge and self-perceived pressure from informal care

For evaluating the educational peer-group intervention (see chapters 4 and 5), we needed appropriate questionnaires. A lot of effort was put into developing the Dementia Knowledge Scale (DKS; see Chapter 4), by involving healthcare professionals and lay people with Turkish-Dutch or Moroccan-Dutch backgrounds in the selection, formulation and pre-testing of the items. The Dementia Knowledge Scale will therefore be an instrument that is aligned with the languages and considerations of the target groups. A limitation is that the internal consistency of the DKS was good for the Turkish version but not for the Dutch one. In addition, the known group validity appeared to be poor, although we did see some variation between respondents in mean scores on the DKS. This indicates that there may be other background characteristics, other than those we have included, that are associated with right or wrong answers on the DKS. To validate the DKS further, also people who have nothing to do with dementia in their family could be included, to compare their scores with family caregivers of people with dementia. This will provide another opportunity to assess known group validity.

Because we expected that written language skills would be limited in some participants, the decision was made to have a maximum of 11 items in the questionnaire. It would be interesting to explore whether extending the questionnaire, different wording of the items or a combination of the two could increase the internal consistency and the known-group validity.

We also made a Moroccan Arabic version of the Dementia Knowledge Scale. Strikingly, this version was not chosen by participants with Moroccan migrant backgrounds. This might be partially explained by the fact that there were participants who spoke Berber dialects, which are “spoken” rather than written dialects. For future research, it is therefore advisable to have prior insight into the possible dialects of migrant target groups, and what this must mean for the development and use of questionnaires.

As said earlier, for the measurement of perceived pressure from informal care, we translated the Dutch language SPPIC in Turkish and Moroccan-Arabic. Participants could therefore choose between the original Dutch version, the Turkish or the Moroccan-Arabic version. The outcomes of the psychometric analyses suggested that the Turkish version of the SPPIC might less accurately reflect perceived care pressure in family caregivers compared with the Dutch SPPIC. This seems to be related to the indicators of perceived care pressure that are reflected by the items of the SPPIC. For instance, one item of the SPPIC questions to what extent the family caregivers have time for themselves. Having less time for yourself might lead to increased perceived care pressure in most family caregivers with Dutch backgrounds. However, this might not be different for family caregivers with Turkish backgrounds because of different (general lymore positive) perspectives on caregiving. It is therefore recommended thatindicators of care pressure in family caregivers with Turkish or Moroccan backgrounds should be explored further and, in line with that, that the efforts should be made to adapt culturally sensitive items for measuring perceived care pressure from informal care.

As already said, one limitation of the cluster RCT is that only short-term effects of the educational intervention were measured, respectively two weeks and three months after the start of the intervention. It would be valuable to follow up during a longer term whether this type of intervention actually encourages people to use informal or professional care and support options and whether this has a beneficial effect on their quality of life. Our study, indicating effects (albeit small) of the intervention on quality of life of family caregivers with Turkish or Moroccan backgrounds provides reasons for conducting further research into specifically the long-term effects of the intervention.

Implications for practice, education and policy

Implications for practice

The participants in the interview study (chapters 2 and 3) did not feel it was taboo to discuss dementia in the inner family circle. However, in the wider community, particularly among Dutch-Turkish and Dutch-Moroccan participants, there were sometimes feelings of shame and discomfort when talking about their relative's dementia. In addition, the interview study showed that the participants had other explanations for the causes of dementia than the dominant Western view on dementia. It is recommended that GPs, case managers or other care professionals in first-line contact with people with dementia and family carers from migrant communities try to get an understanding oftheir perceptions and explanations of dementia. These insights may improve the quality of the communication and care relationship with the patient and the family caregivers, and probably also help diagnose dementia in good time. The new national Dementia Care Standard 2020, which is currently implemented nationwide in the Netherlands, states: "To start a diagnosis process, migrants still often depend on general practitioners or other professionals. That is why it is important for them to be alert to signs of dementia, for example in the event of unexplained complaints, changes in behaviour (including restlessness or agitation), problems with organizing their actions and with therapy compliance for medication use, and increasing relationship problems. Information about the environment is often particularly important for people with migrant backgrounds, because they often have no reference examples of people with dementia in their country of origin".

The interview findings also show that, in addition to the sometimes heavy burden of care, family caregivers with a Turkish, Moroccan or Surinamese Creole background might also derive joy and satisfaction from providing family care. These positive feelings can partly compensate or alleviate the perceived pressure from providing family care. It is therefore advisable for care professionals, to explore the positive aspects that family members may experience and to discuss the possibilities for strengthening these positive aspects. This may result in greater resilience among family carers and, if desired and necessary, family care during a longer period.

Nevertheless, the risk of high care pressure among family carers is a negative side of providing family-based care. Because there is a strong cultural preference for providing family care and it is also seen as mainly a task for women, female family caregivers derive recognition and positive appreciation from their status as a family caregiver within the family and wider community.

Due to the preference for family-based care, families are sometimes keen to be highly involved in care, also in cases even where professionals are providing care or support. This can be mutually beneficial for both family and professional carers. It might however require a clear definition of mutual responsibilities and roles.

Finally, among participants in the cluster RCT, we saw that the knowledge about dementia had increased, which might be related to the increased use of home care facilities.

Implications for future education and information for family caregivers

The cultural and linguistic sensitivity and peer group-based character of the "Knowing about forgetting" intervention might have played a key role in the low level of drop-out of participants. The intervention was culturally sensitive, also taking account of the fact that dementia is a sensitive topic to discuss for many people with Moroccan and Turkish backgrounds. The first session therefore only aimed to inform the participants about dementia; during the second session, the trainer cautiously encouraged the participants to swap experiences. The peer educators were able to explain things in the mother tongue of the participants when needed.

Furthermore, the peer educators took the cultural background into consideration when introducing dementia-related casuistry. The combination of cultural sensitivity and the intervention being peer-group based proved to be strong.

During the two two-hour sessions, family caregivers from the same region met up andshared their experiences and knowledge of dementia. Such an intervention on dementia had never previously been offered in these regions to peer groups. Exchanging experiences may have added to the mutual understanding and continued willingness to participate in this intervention and the planned measurements. For future educational interventions in migrant populations, we therefore advise investing in a culturally sensitive peer group approach.

Providing culturally specific information and education about dementia and local options for professional care has to be largely available. Besides online information on relevant websites and social media, other helpful sources might include video images, written material, flyers and leaflets, verbal information, information meetings and discussion groups. We recommend making information available both in Dutch and in the mother tongues, and making it culturally sensitive by for instance using culturally diverse photography and images or using culturally appropriate examples when explaining dementia-related behaviour.

Among Dutch-Moroccan and Dutch-Turkish family carers, we found that it often seemed less easy to discuss the disease within the wider family and community than it was within the immediate family. Family carers with a Turkish or Moroccan background sometimes experienced disbelief and denial from e.g. uncles, aunts or others from their community ("she's just old"). This caused distress among the family caregivers and made them feel they were not understood. It is therefore important not to limit education and information about dementia only to immediate family members of people with dementia, but also to focus on the wider family and community.

This study also showed positive aspects of providing family care, which indicates that it is time for a shift from an exclusive focus on 'reducing the care burden' to 'optimizing positive experiences and improving resilience'. It is recommended that educational interventions should help family caregivers on the one hand to reduce the risk of overburdening, but on the other hand to focus on positive aspects of providing family care and thus to increase resilience, satisfaction, support, appreciation and competence among family caregivers.

Implications for policy

There was a large response and many positive reactions from people from the Turkish, Moroccan and Surinamese Creole communities for participating in the interview study. Recruitment for the educational intervention was also successful, which indicated that it met the needs and demands of the participants from Turkish and Moroccan migrant groups. Considering the increase in the number of older people with dementia in non-Western migrant groups, the relatively high prevalence of dementia and the knowledge gaps about dementia within these groups, specific attention must be given to these groups in national, regional and local dementia care policy. The care for people with non-western migrant backgrounds requires specific attention from national stakeholder parties. Currently, the national strategy of the Dutch government described in the 'National Dementia Strategy for 2021-2030' is being implemented in the Netherlands. This policy document states that "improving care is a continuous process, in which attention must also be paid to demographic developments. This also relates to the cultural diversity of the care recipients". However, people with dementia with a migration background and their family carers are not mentioned as specific target groups in the National Dementia Strategy. Nevertheless, the National Dementia Strategy document states that by no later than2025, all professionals involved in dementia care will have to work according to the 2020 national Dementia Care Standard. As said earlier, this care standard recommends specific attention for the needs of migrant groups. In line with the Dementia Care Standard , we also recommend paying explicit attention in future policy programmes and national strategies to culturally sensitive dementia care.

Conclusion

Family carers of Turkish, Moroccan or Surinamese Creole origins often see dementia as a natural consequence of ageing, as a spiritual experience and/or as interplay between various biological, psychological and social factors. The dominant Western view of dementia as a neuropsychiatric condition was rarely expressed by these family caregivers.

The family caregivers generally reported that they communicated openly about the dementia with their close family. However, family carers with Turkish or Moroccan backgrounds in particular stated that open communication within the broader communities was often hampered, e.g. by feelings of shame or out of respect for the relative with dementia.

Family carers of Turkish, Moroccan or Surinamese Creole origins derived a great deal of fulfilment from giving family care to their relative with dementia. This fulfilment seemed to outweigh their burden of care.Family carers with Turkish or Moroccan backgrounds in particular said that providing family care led to recognition and appreciation from family and community members and that family care is superior to professional care.

The culturally sensitive educational peer-group intervention “Knowing about forgetting” enhanced knowledge about dementia in family caregivers with Turkish or Moroccan migrant backgrounds in the Netherlands. The intervention also increased the use of support from home care staff. Additionally, the educational intervention enhanced one aspect of health-related quality of life, namely the perceived general health status.

Given the increase in the number of people with dementia, including among non-Western migrant groups, it is important to invest in culturally sensitive education about dementia and options for care and support. This could help reduce inequalities in accessing and usingf care and support options among these groups.

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A

Addendum

Nederlandse samenvatting
Dankwoord
About the author

Nederlandse samenvatting

Het doel van dit proefschrift was inzicht geven in de ervaringen met mantelzorg, de verklaringen voor de oorzaken van dementie en de communicatie over dementie onder mantelzorgers met een Turkse, Marokkaanse of Surinaams-Creoolse migratieachtergrond in Nederland. Een bijkomende doelstelling was inzicht geven in de effecten van het voorlichtingsprogramma "Weten over vergeten" op de kennis over dementie, de bespreekbaarheid van dementie, het gebruik van professionele zorg, de ervaren zorgbelasting en de kwaliteit van leven onder mantelzorgers met een Turkse, Marokkaanse of Surinaams-Creoolse migratieachtergrond.

Op basis van de resultaten van 41 individuele kwalitatieve interviews en zes focusgroepen, wordt in **Hoofdstuk 2** inzicht gegeven in de visie op dementie en op communicatie over dementie onder vrouwelijke mantelzorgers met een Turkse, Marokkaanse of Surinaams-Creoolse achtergrond. In dit hoofdstuk kwamen de volgende centrale onderzoeksvragen aan de orde:

- Hoe verklaren en beschrijven vrouwelijke mantelzorgers met een Turkse, Marokkaanse of Surinaams-Creoolse achtergrond die in Nederland wonen de dementie van hun naaste?
- Ervaren zij dat de dementie van hun naaste openlijk besproken kan worden binnen de familie of in hun bredere kring?

Vaak beschouwden de ondervraagde mantelzorgers dementie als een natuurlijk ouderdomsverschijnsel, als een spirituele ervaring en/of als een samenspel van verschillende biologische, psychologische en sociale factoren. Mantelzorgers met een Turkse of Marokkaanse achtergrond vermeldden ook relatief vaak levensgebeurtenissen of persoonlijkheidskenmerken als oorzaken van dementie, terwijl mantelzorgers met een Surinaams-Creoolse achtergrond vaker lichamelijke aspecten, zoals dehydratatie (in het verleden), als een oorzaak van dementie noemden. Het verklaringsmodel 'dementie als een neuropsychiatrische aandoening', dat in westerse culturen overheerst, werd maar zelden door de mantelzorgers naar voren gebracht.

Over het algemeen communiceerden de mantelzorgers in alle openheid over dementie met hun naaste familie. Vooral mantelzorgers met een Turkse of Marokkaanse achtergrond vermeldden echter dat open communicatie met mensen uit de bredere gemeenschap vaak belemmerd of vermeden werd door bijvoorbeeld schaamte gevoel of uit respect voor de naaste met dementie. Mantelzorgers met een Surinaams-Creoolse achtergrond ervoeren weinig of geen schaamte of ongemakken wanneer zij met anderen in hun omgeving over de dementie van hun naaste spraken.

In **Hoofdstuk 3** wordt ingegaan op de opvattingen over mantelzorg onder vrouwelijke mantelzorgers met een Turkse, Marokkaanse of Surinaams-Creoolse migratieachtergrond. De resultaten zijn gebaseerd op de interviews en focusgroepen die ook voor hoofdstuk 2 gebruikt werden.
Daarbij kwam de volgende hoofdonderzoeksvraag aan de orde:

- Wat zijn de opvattingen over het verlenen van mantelzorg aan een naaste met dementie onder vrouwelijke mantelzorgers met een Turkse, Marokkaanse of Surinaams-Creoolse achtergrond in Nederland?

De ondervraagde mantelzorgers haalden veel voldoening uit het geven van mantelzorg aan hun naaste met dementie. Zij beschouwden mantelzorg als een taak die ze met eerbied en liefde behoorden uit te voeren. Hoewel de mantelzorgers de zorg voor een naaste met dementie soms zwaar vonden, gaven ze aan ook veel voldoening te halen uit het verlenen van deze zorg. Vooral mantelzorgers met een Turkse of Marokkaanse achtergrond zeiden dat het verlenen van mantelzorg leidde tot erkenning en waardering onder de familie en mensen uit hun omgeving. Hun voldoening bij het verlenen van mantelzorg leek op te wegen tegen de belasting die ze ook ondervonden van de mantelzorg.

Vooral mantelzorgers van Turkse of Marokkaanse afkomst waren van mening dat mantelzorg superieur is aan professionele zorg en dat het voornamelijk een taak voor vrouwen is. Waar mannen toch een rol speelden bij mantelzorg, betrof het doorgaans praktische, niet-fysieke hulp, bijvoorbeeld administratieve hulp, vervoerstaken en boodschappen doen. Geïnterviewden met een Surinaams-Creoolse achtergrond hechtten ook veel waarde aan mantelzorg, hoewel zij meer open leken te staan voor professionele zorg. In tegenstelling tot de mantelzorgers met een Turkse of Marokkaanse achtergrond waren de geïnterviewden met een Surinaams-Creoolse achtergrond niet bang voor negatieve reacties van familie of sociale omgeving wanneer zij een beroep deden op professionele zorg.

De inzichten uit hoofdstuk 2 en 3 werden gebruikt en verwerkt tot een cultuursensitief voorlichtingsprogramma, genaamd “Weten over vergeten”, voor groepen mantelzorgers met een Turkse of Marokkaanse migratieachtergrond. Om de effecten van de educatieve interventie op de kennis over dementie te kunnen meten, is de Dementie Kennis Schaal *(Dementia Knowledge Scale,* DKS) ontwikkeld, een vragenlijst die grotendeels gebaseerd is op vertalingen van delen van de Engelstalige *Alzheimer Disease Knowledge Scale*. In **Hoofdstuk 4** staan de ontwikkeling en validatie van de DKS beschreven en is de volgende hoofdonderzoeksvraag behandeld:

- Wat zijn de interne consistentie en validiteit van de DKS zoals die werd ingevuld door mantelzorgers met een Turkse of Marokkaanse achtergrond?

Elf van de dertig items van de oorspronkelijke *Alzheimer Disease Knowledge Scale* werden geselecteerd door negen mensen met een Turkse of Marokkaanse achtergrond en acht zorgprofessionals. De geselecteerde items werden uit het Engels vertaald naar het Nederlands, Turks en Marokkaans-Arabisch. Uit een pilottest onder de doelgroepen bleek dat de versies van de Dementie Kennis Schaal in deze talen bruikbaar, begrijpelijk en geschikt bevonden werden voor het meten van de kennis over dementie.

Vervolgens werden de interne consistentie en de known group validiteit van de DKS bepaald op basis van de scores op T0 van de cluster gerandomiseerde studie met controlegroep die in hoofdstukken 6 en 7 van dit proefschrift beschreven wordt. Dit is alleen gedaan voor de Nederlandstalige en Turkstalige versie, omdat bijna alle deelnemers met een Marokkaanse achtergrond voor de Nederlandstalige versie hebben gekozen en niet voor de Marokkaans-Arabische versie.

Daarbij werd gebruikgemaakt van de scores op T0 van 117 Nederlands-Turkse mantelzorgers die de Turkstalige versie van de DKS invulden en van 110 Nederlands-Marokkaanse mantelzorgers die de Nederlandstalige versie invulden.

De interne consistentie van de DKS was voldoende voor de Turkstalige versie, maar niet voor de Nederlandstalige. Verder werden bij het testen van de known group validiteit geen verschillen gevonden in de gemiddelde kennisscores tussen laagopgeleiden en hoogopgeleiden. Evenmin waren er verschillen in kennisscore tussen degenen die vaak voor een persoon met dementie zorgden en degenen die dat minder vaak deden. Ook werden er geen verschillen gevonden tussen degenen die met de persoon met dementie samenwoonden en degenen die dat niet deden.

In **Hoofdstuk 5** beschrijven we de psychometrische analyses van de Turkstalige versie van de EDIZ, een instrument dat in de cluster-RCT gebruikt is om ervaren zorgbelasting te meten. De oorspronkelijke EDIZ werd vertaald in het Marokkaans Arabisch en Turks (en ter controle ook in het NL terugvertaald). Omdat ook de Marokkaans-Arabische versie door heel weinig respondenten ingevuld werd en de psychometrische eigenschappen van de oorspronkelijke Nederlandstalige versie al bekend waren, zijn psychometrische analyses alleen voor de Turkstalige versie van de EDIZ uitgevoerd. In **Hoofdstuk 5** komt de volgende hoofdvraag aan de orde:

- Wat is de interne consistentie en de known group validiteit van de Turkstalige versie van de EDIZ zoals die werd ingevuld door mantelzorgers met een Turkse migratieachtergrond die zorgen voor een naaste met dementie?

De pilottest toonde aan dat de Turkstalige versie van de EDIZ begrijpelijk en geschikt was. De interne consistentie van de Turkstalige versie werd gebaseerd op de gegevens op T0 uit de cluster-RCT van 117 mantelzorgers. Er werd een confirmatieve factorananalyse voor één factor uitgevoerd en de interne consistentie van de EDIZ werd goed bevonden (Cronbachs alfa: 0,94).

De known group validiteit van de Turkstalige versie van de EDIZ bleek ook goed: mantelzorgers die minstens één keer per week zorg verleenden of het huis deelden met een naaste met dementie ervoeren een grotere druk als gevolg van de zorg dan degenen die minder dan één keer per week zorg verleenden of niet samenwoonden met hun naaste met dementie.

In **Hoofdstuk 6** en **Hoofdstuk 7** staan de effecten van het voorlichtingsprogramma “Weten over vergeten” beschreven. Dit programma bestond uit twee interactieve groepsbijeenkomsten voor familieleden van mensen met dementie met een Turkse of Marokkaanse migratieachtergrond. Tijdens deze bijeenkomsten kregen de deelnemers informatie over dementie en over de mogelijkheden voor zorg- en hulpverlening. Daarnaast werden de deelnemers tijdens de bijeenkomsten gestimuleerd hun ervaringen met de dementie van hun naaste, onderling uit te wisselen. Elke groep bestond uit deelnemers en geschoolde voorlichters met een zelfde migratieachtergrond.

De effecten van de interventie werden onderzocht in de eerder genoemde cluster RCT. De RCT had alleen betrekking op deelnemers met een Turkse of Marokkaanse migratieachtergrond, omdat het binnen het kader van dit proefschrift niet haalbaar was om voldoende deelnemers met een Surinaams-Creoolse achtergrond te werven.

De clusters in de RCT werden gevormd door groepen deelnemers afkomstig uit 16 regio’s in Nederland. De regio’s werden at random toegewezen aan ofwel de interventieconditie (educatieve interventie), ofwel de controleconditie (geen educatieve interventie tijdens de onderzoeksperiode).

De deelnemers in de interventieconditie en controleconditie moesten dezelfde vragenlijsten invullen op dezelfde momenten, namelijk op T0 (voordat de interventie in de interventieconditie begon), T1 (direct na de interventie, één à twee weken na T0) en T2 (drie maanden na T0).

De vragenlijstset omvatte naast vragen over achtergrondkenmerken, de Dementie Kennis Schaal, de EDIZ (die ervaren zorgbelasting meet), COOP/WONCA-kaarten die de gezondheid gerelateerde kwaliteit van leven meten en ten slotte items om de bespreekbaarheid van dementie te meten en om inzicht te krijgen in het gebruik van informele of professionele hulp.

In **Hoofdstuk 6** staan de volgende onderzoeksvragen centraal:

- Leidt deelname aan het voorlichtingsprogramma "Weten over vergeten" bij mantelzorgers met een Turkse of Marokkaanse migratieachtergrond tot:
    - meer kennis over dementie?
    - een betere bespreekbaarheid van dementie?
    - een toename in het gebruik van mantelzorg of professionele zorg?
    - een afname van de ervaren zorgbelasting?

Multilevel-analyses van gegevens afkomstig van 386 deelnemers met een Turkse of Marokkaanse achtergrond (interventieconditie n=202, controleconditie n=184) toonden aan dat de kennis over dementie en de mogelijkheden voor zorg en ondersteuning significant meer toenam onder deelnemers in de interventieconditie dan onder de deelnemers in de controleconditie.

Bovendien was er bij de deelnemers in de interventieconditie sprake van een duidelijke toename in gebruik van thuiszorg, wat niet het geval was in de controleconditie. Er waren geen effecten van de interventie op het gebruik van andere vormen van informele of professionele zorg. Evenmin waren er effecten op de bespreekbaarheid van dementie en op de ervaren zorgbelasting van mantelzorgers.

Hoofdstuk 7 geeft inzicht in de kwaliteit van leven van mantelzorgers met een Turkse of Marokkaanse migratieachtergrond en in de effecten van de educatieve groepsinterventie op de kwaliteit van leven. Hierbij stonden de volgende onderzoeksvragen centraal:

- Wat is de gezondheid gerelateerde kwaliteit van leven van mantelzorgers met een Turkse of Marokkaanse migratieachtergrond die zorgen voor een naaste met dementie in Nederland?
- Kan de gezondheid gerelateerde kwaliteit van leven in deze groepen verbeterd worden door deelname aan het voorlichtingsprogramma "Weten over vergeten"?

De kwaliteit van leven bij aanvang (T0) was over het algemeen middelmatig, maar wel beduidend lager bij mantelzorgers met een Turkse achtergrond en bij vrouwen in vergelijking met mantelzorgers met een Marokkaanse achtergrond of mannen. Een lage kwaliteit van leven hing significant samen met de ervaren zorgbelasting die relatief hoog was. Verder was hulp van andere familieleden of thuiszorgpersoneel geassocieerd met een goed emotioneel welzijn en een goede algemene gezondheidstoestand (twee aspecten van de kwaliteit van leven).

Het voorlichtingsprogramma had op korte termijn positieve effecten op sommige aspecten van kwaliteit van leven, met name op het emotionele welzijn direct na de interventie en op de ervaren algemene gezondheidstoestand van mantelzorgers drie maanden na de interventie. Er werden geen effecten gevonden op sociaal welbevinden van mantelzorgers.

In het laatste hoofdstuk van het proefschrift, de *General Discussion*, staan onder meer conclusies en aanbevelingen voor beleid en praktijk.

Gezien de toename van het aantal mensen met dementie, ook onder ouderen met een niet westerse migratieachtergrond, is het van belang om te investeren in cultureel sensitieve voorlichting over dementie en over de mogelijkheden voor zorg en ondersteuning. Dit zou de ongelijkheid in de toegang naar zorg en ondersteuning onder deze groepen kunnen reduceren.

Ook verdient goede dementiezorg voor mensen met een niet westerse migratieachtergrond specifieke aandacht van de overheid en andere landelijke stakeholderpartijen. Op dit moment worden de 'Nationale Dementiestrategie 2021-2030' en de Zorgstandaard Dementie 2020 geïmplementeerd in Nederland. In de Dementiestrategie staat dat aandacht besteed moet worden aan culturele diversiteit van zorgvragers en de Zorgstandaard beveelt aan specifieke aandacht te hebben voor de behoeften van migrantengroepen. Deze aanbevelingen sluiten aan bij dit proefschrift waar ook uit blijkt dat een cultureel sensitieve benadering bij voorlichting over dementie en over ondersteuningsmogelijkheden van belang is. Daarbij is ook een aanbeveling voor professionals om bij mantelzorgers uit migrantengroepen niet alleen aandacht te hebben voor de soms zware zorglast, maar ook voor de voldoening die mantelzorgers vaak halen uit mantelzorg voor een naaste met dementie. Aandacht voor de positieve aspecten van mantelzorg kan helpen om de draagkracht van mantelzorgers te vergroten.

Dankwoord

Eindelijk, het is zover! Na jaren van voorstellen ontwerpen, data verzamelen, analyseren, artikelen schrijven, herschrijven en publiceren is dan eindelijk de tijd gekomen voor het laatste onderdeel van dit proefschrift, mijn dankwoord. Daar neem ik dan ook met veel plezier de ruimte voor.

Allereerst gaat mijn zeer grote dank uit naar alle mantelzorgers die aan dit proefschrift hebben bijgedragen. Jullie vertrouwen, eerlijkheid en moed om te praten over dementie heeft er toe geleid dat er meer inzicht is in de percepties en bespreekbaarheid van dementie in de Turkse, Marokkaanse en Surinaams-Creoolse cultuur. Hiermee kunnen we verder werken aan de verbetering van de multiculturele dementiezorg in Nederland.

Daarna gaat alle dank naar de betrokken vrijwilligers en trainers van Alzheimer Nederland die samen met mij in de regio's honderden mantelzorgers hebben geworven, geïnformeerd en geïncludeerd in dit onderzoek. In het bijzonder veel dank aan **Emine Kayan-Acun**. Je tips, kennis, geduld en medewerking hebben ervoor gezorgd dat het mogelijk werd voldoende mantelzorgers met een Turkse of Marokkaanse migratieachtergrond te includeren en effectonderzoek te doen. Een mijlpaal.

Ook alle dank aan **Alzheimer Nederland**. Niet alleen een fantastische werkgever maar voor mij de belichaming van 'A great place to work'. Vanaf de eerste dag dat ik werkzaam ben bij Alzheimer Nederland heb ik kansen gekregen, mocht ik uitdagingen aangaan en kon ik nieuwe initiatieven ontplooien. Hierdoor werden kleine projecten groot, groter en uiteindelijk zo groot dat het mogelijkheden bood voor promotieonderzoek. **Marco Blom**, een groot en welgemeend dankjewel voor het aanbieden van deze mooie kans, je steun, energie en meedenkkracht. Zonder jou zou dit proefschrift er überhaupt niet zijn. Ook **Julie Meerveld** wil ik bedanken, het managen van een fulltime baan naast het uitvoeren van promotieonderzoek was soms uitdagend. Bij jou kon ik af en toe de vele bordjes opnieuw sorteren en hoog houden. Dank, je humor en optimisme is geweldig! **Patricia Kerckhoff**, dank voor je aanmoediging en support in de laatste 3 jaar, sparren met jou gaf altijd nieuwe input voor mogelijkheden. Ook **Els Bokkers- Vos** en in een latere fase **Mariken Martens**, wat had ik zonder jullie hulp moeten beginnen. Het printen en versturen van honderden kilo's materiaal, afspraken plannen, lunches organiseren, telefoontjes aannemen, bestanden gereed maken voor de drukker.. zomaar een greep uit de dingen waar jullie me mee geholpen hebben en daarbij altijd een glimlach en de nodige gezelligheid. Ten slotte een dank aan **Ievonne van Limpt**, **Gerjoke Wilmink** en alle (voormalige) **collega's van Alzheimer Nederland** die me ergens in dit traject aangemoedigd, gespiegeld, geholpen of uitgedaagd hebben. Dat heeft altijd veel voor me betekend.

Dan zeer grote dank aan **Anneke Francke**, mijn promotor. Van jou heb ik de meeste steun mogen ontvangen. Mijn bewondering voor jou is groot. De manier waarop je denkt, schrijft en redeneert is ijzersterk. Ik heb veel van je mogen leren. Je commentaar is altijd straight, gegrond en sterk. Je liet me zien dat hard werken prachtige vruchten afwerpt en zo hebben we samen artikel voor artikel gewerkt naar dit uiteindelijke proefschrift. In die momenten heb ik je ook leren kennen als een warme vrouw met een groot hart. Anneke, dankjewel, voor alles. **Iris van der Heide**, mijn co-promotor, in de zomer van 2018 leerden wij elkaar kennen. Jij werkzaam bij het Nivel als onderzoeker in het team van Anneke. Wij waren beiden net bevallen: jij van een prachtige dochter en ik van een zoon. Je kennis en vriendelijkheid zijn een geweldige combinatie en je bent in deze fase van mijn promotieonderzoek een grote bron van inspiratie geweest! Dankjewel voor alles wat je gedaan en bijgedragen hebt. Ook **Walter Devillé**, dankjewel voor je betrokkenheid als promotor tijdens dit promotietraject. Je reflecties en suggesties bij de artikelen waren altijd verfrissend, verrijkend en gedegen. Je kennis is zeer gewaardeerd.

Alle leden van de beoordelingscommissie en/of opponenten, **Maria van den Muijsenbergh**, **Fatima el Fakiri**, **Marjolein Broese Van Groenou**, **Henk Nies**, **Semiha Denktas**, **Juliette Parlevliet** en **Bregje Onwuteaka – Philipsen**, dankjewel voor jullie tijd, energie en bijdragen in deze fase.

Dan mijn grootste steun in dit hele traject. Mijn maatje, oerman, en geweldige vent **Tabe de Boer**. Dankjewel voor je steun. Samen hebben we het zo fijn. Je bent een bijzondere man, je ervaring als ultra-renner, Boeddhist en officier hebben me geholpen de lat iedere keer een stukje hoger en verder te leggen. De finish in het oog te houden en tegelijkertijd te focussen op de stukken die op dat moment recht voor me lagen. Jouw motto 'als je denkt dat je niet verder kunt, kun je altijd nog een stukje verder' is de rode draad geweest voor dit proefschrift. Niet omdat het altijd zo zwaar was maar omdat de combinatie met een fulltime baan soms gewoon lastig was om te managen. Alle avonden, extra uren en vakantiedagen die erin gestoken werden, heb je me aangemoedigd. Kopjes thee gebracht of me gedwongen een noodzakelijke pauze te nemen. Je inspireert me. Met veel liefde draag ik dit proefschrift dan ook aan jou op. Aum Bhur Bhuvar Svah.

Mijn lieve kinderen, **Ima en Tara**. Man o man wat is het leven een verrijking met jullie erin. Jullie onschuldige en nieuwsgierige kijk op het leven is een prachtige metafoor. Allebei zo verschillend en toch zo jezelf. Overtuigd van je eigen kunnen en vol vertrouwen naar het leven. Dankjewel dat jullie in mijn leven zijn gekomen en dat ik jullie (bonus) mama mag zijn.

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En dan tot slot al mijn **Sisters**, en in het bijzonder, **Leanne**, **Kim**, **Jose**, **Astrid**, **Karin**, **Chantal**, **Geertje**, **Heleen** en **Larissa**. Wat een rijkdom is het om jullie te kennen en deze jaren van werk mee te delen. Te zien waar dit ten diepste over gaat en waar het zich naartoe mag ontwikkelen. Een zegen zijn jullie.

En met deze woorden rond ik mijn dankwoord met een glimlach af.

En zo zal het zijn.

En zo zal het zijn.

En zo zal het zijn.

Curriculum vitae

Nienke van Wezel is op 12 april 1984 geboren in Bemmel. In 2002 behaalde ze daar aan het Over Betuwe College haar Atheneum diploma. Hierna startte ze gelijk haar vervolgstudie Psychologie aan de Radboud Universiteit in Nijmegen. In haar Bachelor jaar (2005) specialiseerde ze zich in de psychogerontologie en schreef ze haar bachelor scriptie over gebruik van thuiszorg onder ouderen met een Turkse of Marokkaanse migratieachtergrond. Haar masterjaar (2006) voltooide ze in zes maanden. In die stagefase schreef ze in de avonduren haar master thesis 'Rijker Leven', over een interventie en voorlichtingsprogramma gericht op ouderen van Turkse of Marokkaanse afkomst in Nederland. Direct daarna startte ze haar loopbaan bij Alzheimer Nederland. In de daaropvolgende 16 jaren heeft ze haar brede en gedegen ervaring opgedaan als senior in het team 'Lobby en zorginnovatie' en daarmee aan de wieg gestaan van het landelijke dementieprogramma. Hierna is ze drie jaar projectleider geweest van het voorlichtingsprogramma 'Weten over Vergeten' om daarna drie jaar programmaleider te zijn van het programma 'Samen Dementievriendelijk' dat onderdeel was van het toenmalige Deltaplan Dementie (2015-2020). In haar laatste jaren heeft ze een waardevolle bijdrage geleverd als teamleider van het 'team Zakelijke Markt' binnen de marketing en fondsenwerving.

Tegelijkertijd heeft zij in haar loopbaan bij Alzheimer Nederland de master Hoger Management van de Gezondheidszorg en Welzijn afgerond en is zij in 2012 gestart met het schrijven van het onderzoeksvoorstel dat later resulteerde in het promotieonderzoek als buitenpromovenda aan de VU. In dit promotietraject heeft zij diverse opleidingen en bijscholingen gevolgd en ruime kennis en ervaring opgedaan met het presenteren van resultaten van deelonderzoeken als key-note speaker op vele (inter)nationale congressen.

Vanaf 1 april start Nienke in haar nieuwe functie als Practor waar zij leiding zal geven aan het practoraat 'Tech@doptie'. Dit is een practoraat gericht op technische innovatie en implementatie in de zorg aan het Rijn IJssel Arnhem en Nijmegen.

Nienke is samen met Luitenant-Kolonel Tabe de Boer woonachtig in Gendt en samen hebben zij de zorg voor twee prachtige kinderen, Tara en Ima.