



UvA-DARE (Digital Academic Repository)

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

van Wezel, N.; Francke, A.L.; Kayan-Acun, E.; Devillé, W.L.J.M.; van Grondelle, N.J.; Blom, M.M.

DOI

[10.1177/1471301213517703](https://doi.org/10.1177/1471301213517703)

Publication date

2016

Document Version

Final published version

Published in

Dementia

[Link to publication](#)

Citation for published version (APA):

van Wezel, N., Francke, A. L., Kayan-Acun, E., Devillé, W. L. J. M., van Grondelle, N. J., & Blom, M. M. (2016). Family care for immigrants with dementia: The perspectives of female family carers living in the Netherlands. *Dementia*, 15(1), 69-84.
<https://doi.org/10.1177/1471301213517703>

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (<https://dare.uva.nl>)

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

Dementia
2016, Vol. 15(1) 69–84
© The Author(s) 2014
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1471301213517703
dem.sagepub.com



Nienke van Wezel

Alzheimer Nederland, Amersfoort, the Netherlands

Anneke L Francke

Netherlands Institute for Health Services Research (NIVEL), Utrecht, the Netherlands;
Department of Public and Occupational Health, EMGO+/VUmc Amsterdam, the Netherlands

Emine Kayan-Acun

Alzheimer Nederland, Amersfoort, the Netherlands

Walter LJM Devillé

Netherlands Institute for Health Services Research (NIVEL), Utrecht, the Netherlands; Faculty of Social and Behavioural Sciences, University of Amsterdam, Amsterdam, the Netherlands; Pharos Knowledge and advisory center, Utrecht, the Netherlands

Nies J van Grondelle

Pharos Knowledge and advisory center, Utrecht, the Netherlands

Marco M Blom

Alzheimer Nederland, Amersfoort, the Netherlands

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

Corresponding author:

Nienke van Wezel, Dutch Alzheimer Association, Stationsplein 121, Postbus 2077, 3800 CB Amersfoort, the Netherlands.
Email: n.wezel@alzheimer-nederland.nl

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. 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, &

Table 1. Features of the backgrounds of the family carers interviewed

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

Johnson, 2006). Table 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 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? 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 1 h 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 (1× Turkish, 1× 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

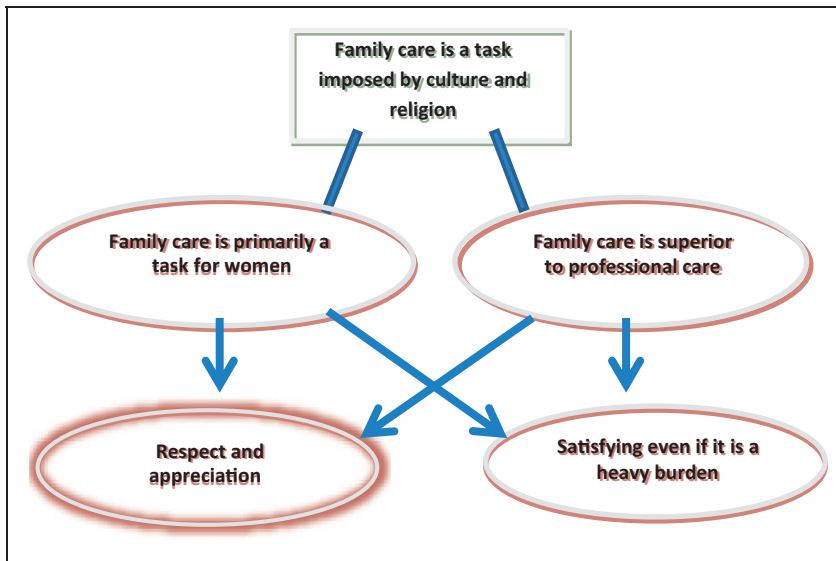


Figure 1. Perceptions of carers with Turkish, Moroccan and Surinamese Creole backgrounds regarding family care for a close relative with dementia

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 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 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 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).

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

- Alzheimer's Disease International. (2012). *World Alzheimer report 2012: Overcoming the stigma of dementia*. London, UK: ADI.
- Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as mud': Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods*, 2(2), 1–24.
- De Boer, A., Broese van Groenou, M., & Timmermans, J. (2009). *Mantelzorg. Een overzicht van de steun van en aan mantelzorgers in 2007 [Family care. An overview of support for carers in 2007]*. The Hague: Social and Cultural Planning Agency.
- De Graaff, F. M., & Francke, A. L. (2002). Zorg voor Turkse en Marokkaanse ouderen in Nederland, een literatuurstudie naar zorgbehoeften en zorggebruik [*Care for Turkish and Moroccan elderly in the Netherlands, a literature study on their care needs and use of care*]. *Verpleegkunde*, 17(3), 131–139.
- De Graaff, F. M., & Francke, A. L. (2003). Home care for terminally ill Turks and Moroccans and their families in the Netherlands: Carers' experiences and factors influencing ease of access and use of services. *International Journal of Nursing Studies*, 40, 797–805.
- De Graaff, F. M., Francke, A. L., van den Muijsenbergh, M. E. T. C., & van der Geest, S. (2010). Palliative care: A contradiction in terms? A qualitative study of cancer patients with a Turkish or Moroccan background, their relatives and care providers. *BMC Palliative Care* 9(19).
- Demirovic, J., Prineas, R., Loewenstein, D., Bean, J., Duara, R., Sevush, S., . . . Szapocznik, J. (2003). Prevalence of dementia in three ethnic groups: The South Florida program on aging and health. *Annals of Epidemiology*, 13, 472–478.
- Denktas, S., Koopmans, G., Birnie, E., Foets, M., & Bonsel, G. (2009). Ethnic background and differences in health care use: A national cross-sectional study of native Dutch and immigrant elderly in the Netherlands. *International Journal for Equity in Health*, 8, 35–43.

- Dilworth-Anderson, P., & Gibson, B. E. (2002). The cultural influence of values, norms, meanings and perceptions in understanding dementia in ethnic minorities. *Alzheimer's Disease and Associated Disorders*, 16(Suppl): 56–63.
- Downs, M., Turner, S., Bryans, M., Wilcock, J., Keady, J., Levin, E., . . . Iliffe, S. (2006). Effectiveness of educational interventions in improving detection and management of dementia in primary care: Cluster randomised controlled study. *British Medical Journal*, 332(7543), 692–696.
- Fitzpatrick, A. L., Kuller, L. H., Ives, D. G., Lopez, O. L., Jagust, W., Breitner, J. C. S., . . . Dulberg, C. (2004). Incidence and prevalence of dementia in the cardiovascular health study. *Journal of the American Geriatrics Society*, 52, 195–204.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59–82.
- Herrera, A. P., Lee, J. W., Nanyonjo, R. D., Laufman, L. E., & Torres-Vigil, I. (2009). Religious coping and caregiver well-being in Mexican-American families. *Aging and Mental Health*, 13(1), 84–91.
- Neary, S., & Mahoney, D. F. (2005). Dementia caregiving: The experiences of Hispanic/Latino caregivers. *Journal of Transcultural Nursing*, 16, 163–170.
- Peeters, J., Werkman, W., & Francke, A. L. (2012). *Dementiemonitor Mantelzorg: Problemen, zorgbehoeften, zorggebruik en oordelen van mantelzorgers [Dementia monitor for family care: Problems, care needs, use of care and opinions of the carers]*. Utrecht: NIVEL.
- Pierret, C. R. (2006). The 'sandwich generation': Women caring for parents and children. *Monthly Labor Review*, 9, 3–9.
- Rijkers, C. (2010). *Dementia among elderly Moroccan immigrants in the Netherlands* (Master's social & cultural anthropology thesis). Department of Social Sciences, VU University Amsterdam, the Netherlands.
- Schellingerhout. (2004). *Gezondheid en welzijn van allochtone ouderen [Health and welfare of the elderly in the ethnic minorities]*. The Hague: Social and Cultural Planning Agency.
- Statistics Netherlands. (2012). StatLine 20/12/2012. Retrieved from statline.cbs.nl.
- Uiters, E., Deville, W. L. J. M., Foets, M., & Groenewegen, P. P. (2006). Use of health care services by ethnic minorities in the Netherlands: Do patterns differ? *The European Journal of Public Health*, 16, 388–393.
- Uiters, E., Deville, W. L. J. M., Foets, M., Spreeuwenberg, P., & Groenewegen, P. P. (2007). The use of primary medical care by migrant groups: A systematic review. PhD Thesis, Erasmus University, Rotterdam.
- Van Campen, C., de Boer, A. H., & Iedema, J. (2013). Are informal caregivers less happy than non-caregivers? Happiness and the intensity of caregiving in combination with paid and voluntary work. *Scandinavian Journal of Caring Science*, 27(1), 44–50.
- Zwaanswijk, M., Peeters, J. M., van Beek, A. P., Meerveld, J. H., & Francke, A. L. (2013). Informal caregivers of people with dementia: Problems, needs and support in the initial stage and in subsequent stages of dementia: A questionnaire survey. *Open Nursing Journal*, 7, 6–13.

Author Biographies

Nienke van Wezel is psychogerontologist, senior project leader migrants and dementia at the Alzheimer Society in the Netherlands. Currently, her research focusses on the perspectives of female family carers with a migrant background who care for a relative with dementia.

Anneke L Francke (RN and PhD) is nurse and sociologist, programme coordinator at NIVEL – Netherlands institute for Health Services Research (Utrecht) and professor at VU University medical center/EMGO+, department Public and Occupational Health (Amsterdam).

Emine Kayan-Acun (MSc) is junior researcher at VU University medical center (Amsterdam) – Department of Medical Psychology.

Walter LJM Devillé (MD, DTMH, PhD) is an epidemiologist and senior researcher at NIVEL (Netherlands Institute for Health Services Research), and Professor Migrants, Refugees and Health at University of Amsterdam, Faculty of Social and Behavioural Sciences.

Nies J van Grondelle (MSc, social pedagogical science) is senior project leader research and development at Pharos – the national knowledge centre regarding the health and healthcare for migrants and refugees. Her focus is on the healthcare for the older migrants and refugees.

Marco M Blom (MSc) is psychogerontologist, scientific director of the Alzheimer Society in the Netherlands and board member of the Dutch Delta Plan on Dementia. Currently his research focusses on the (cost) effectiveness of an Internet intervention for family caregivers of people with dementia.