Dementia care in families with a migration background

Dealing with gendered and cultural obstacles to shared care

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Dementia care in families with a migration background:

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Dementie zorg in families met een migratieachtergrond:

Omgaan met gender-gerelateerde en culturele barrières bij het delen van de zorg
(met een samenvatting in het Nederlands)

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Chapter 1

Introduction

1.1 Dementia care in families with a migration background: setting the context

> [You] simply have to keep on going, without making excuses… Even when you're really ill, you just keep on going. It doesn't matter to you when you're ill because all you're thinking is: "Can I take care of her?" … I have to tell you honestly though; you forget about yourself... You do set your own needs aside, you do.

In the above, Karima[1], a Moroccan-Dutch family caregiver in her early forties, explains how she copes with her care-role. At the time of her interview, her mother had late-stage dementia that required 24h care. Despite coming from a family with nine siblings, she received little care-support from them. Neither did she receive any formal care-support.

This short example illustrates the impact of providing exclusive care for a family member with dementia. Although care-experiences can also be positive, caring for a person with dementia is generally experienced as emotionally and physically demanding due to the behaviors often associated with dementia (such as mental confusion and distress, wandering, aggression, repetitive questions, and body maintenance) (Brodaty & Donkin, 2009; Zwaanswijk et al., 2013). As exemplified through Karima's quote, family caregivers' emotionally and physically demanding work can lead to adverse physical and mental health consequences, and reduced attention to their own health (Brodaty & Donkin, 2009; Zwaanswijk et al., 2013). That is why family caregivers of people with dementia are often called the "invisible second patients" (Brodaty & Donkin, 2009).

Compared to family caregivers[2] from white majority populations, the impact of these concerns may be magnified in the case of family caregivers with a migration background. For instance, in the Netherlands, persons with a migration background[3] (PwM) make less use of formal care services (de Boer et al., 2021; Denktaş et al., 2009; Hazeleger et al., 2016; Suurmond et al., 2016). Also, a population study among family caregivers in the Netherlands (de Boer et al., 2021) suggests that older PwM rely on family caregivers more often and more intensively than older individuals with a white-Dutch background. The study estimates that family caregivers with a migration background on average provide 7,5h of parental care per week, whereas white-Dutch family caregivers provide 5,1h of parental care per week. The study also reveals that family caregivers with a migration background more often wish they would receive care-support from relatives, friends or volunteers (47%), as compared to white-Dutch family caregivers (22%). This suggests that PwM more often experience a lack of care-support due to a lower utilization of formal services and thus a higher intensity of caregiving.

Studies suggest that this lower utilization of formal services relates to access barriers to formal care-support. These barriers include: negative experiences with services (e.g., discrimination and feeling misunderstood), language barriers, lack of clarity about where or how to access help, lack of knowledge about dementia, the belief that nothing could be done to help, shame and stigma within the community (Botsford et al., 2011; Greenwood et al., 2015; Mukadam et al., 2011), and the perception that it is the family and not professional outsiders who should provide care for aging parents (Monsees et al., 2020; Tonkens et al., 2011).

Additionally, the perception of family care as “women’s work” (Tonkens et al., 2011), as well as the perception that care-work is an extension of already existing gendered responsibilities (Johl et al., 2016), complicates and delays formal and informal help-seeking. This means that the lower utilization of formal services by PwM particularly impacts women. More specifically, it impacts one female family member who often shoulders the care-tasks with little or no support (Sagbakken et al., 2018; Tonkens et al., 2011; van Wezel et al., 2014) – which may explain the higher percentages of exhaustion in family caregivers with a migration background as compared to white-Dutch family caregivers (de Boer et al., 2021; van Wieringen & Grondelle, 2014).

This is not to say that being a family caregiver with a migration background automatically translates to having a more complicated caregiving-experience and higher caregiver-exhaustion. Rather, it means that higher levels of disadvantage, social exclusion, and inequalities may create additional access barriers for PwM, which may increase the risk of exhaustion in women who most often shoulder the care-tasks.

The abovementioned access barriers and gendered care norms suggest a lack of formal care-sharing throughout the caregiving process, as well as a lack of informal care-sharing within families with a migration background. Nonetheless, the experiences of family caregivers with a migration background who are proving care for a family member with dementia have not been studied enough to provide the empirical evidence to address their needs for care-sharing. As illustrated in the above, prior studies have been mainly concerned with the lower utilization of formal services by PwM caring for a family member with dementia (see, e.g., Botsford et al., 2011; Greenwood et al., 2015; Mukadam et al., 2011). While such studies offer valuable insights about access barriers to formal services, they do not provide insights into family caregivers' care-experiences and needs for (formal and informal) care-sharing. That is, within this dissertation, care-sharing does not imply a mere utilization of formal services. Rather, care-sharing is understood as a relational process within families, and between families and practitioners, in which family caregivers are guided and supported throughout the care for their family member with dementia. There is a gap in knowledge about these concerns, as little is known about possible obstacles and facilitators to care-sharing in families with a migration background caring for individuals with dementia.

Also, many scholars have critiqued studies on aging and dementia care in families with a migration background for essentializing and overemphasizing the effects of culture (see, e.g., Iliffe & Manthorpe, 2004; Koehn et al., 2013; Torres, 2015; Zubair & Norris, 2015). Here, the meanings attached to culture are often presented as static rather than dynamic[4] (Hoffer, 2016). This may be why relational aspects of caregiving, as well as the many other relevant social categories besides cultural norms and practices, are often neglected in research on PwM caring for a family member with dementia.

This dissertation responds to this knowledge gap through the experiences of PwM, as well as practitioners' (health and social care workers) experiences of dementia care-sharing with PwM. In doing so, I sought to offer a better understanding of family caregivers' different needs and wishes for dementia care-sharing. At the same time, this dissertation responds to growing concerns about dementia among PwM (Alzheimer Europe, 2020). The aging population in European societies is increasingly ethnically diverse and this will continue in the coming decades (Lanzieri, 2011). In the Netherlands, it is estimated that PwM above the age of 65 will make up 21 percent of the aging population by 2060, compared to 11 percent in 2015 (van Duin & Stoeldraijer, 2014). This raises concerns for dementia care and support services, as dementia prevalence increases with age (World Health Organization, 2012). The magnitude of these concerns reinforce the need for knowledge about dementia care-sharing in families with a migration background.

Thus, in this dissertation, I aim to answer the main research question:

- What are obstacles and facilitators to shared care in families with a migration background caring for individuals with dementia?

The three following empirical sub-questions answer the main research question:

- What are challenges to shared dementia care in families with a migration background, and between these families and formal care services?
- Which intersecting social categories impact on practices of care-sharing in families with a migration background caring for individuals with dementia?
- How do practitioners perceive and experience dementia care-sharing with PwM, and how does this relate to the care-experiences of PwM caring for a family member with dementia?

The above sub-questions are answered subsequently in the three empirical chapters of this dissertation. To offer a better methodological understanding of the conducted empirical study, this dissertation also answers the following methodological question:

- How do different aspects of the positionality of a researcher with a migration background intersect and affect research in a cross-cultural setting?

In what follows, I will highlight the study's research design and methods that were used to answer the empirical sub-questions, after which I will briefly present the analytical frameworks that guided the analyses of the conducted study. I will end this chapter with an outline of the dissertation.

1.2 Research design and methods

In this dissertation, I predominantly focused on the views and experiences of family caregivers. To offer a better understanding of obstacles and facilitators to dementia care-sharing, I also highlighted practitioners' views and experiences. In total, forty-one participants were included: 31 family caregivers and 10 practitioners. All participants were Dutch residents.

Data on family caregivers' experiences were gathered between February 2018 and February 2021. As part of the inclusion criteria, these were PwM who provide care, or have until recently provided care, for a family member diagnosed with dementia. All of them were a primary caregiver (i.e., they had a leading role in providing care for their relative or spouse). I recruited them purposively through community centers, social workers, organizers of peer groups for family caregivers, and through partner organizations (Pharos, MantelzorgNL, and NOOM[5]). Additionally, two of the included family caregivers were recruited through my personal network. Even though I did not purposively recruit women, the majority of the potential participants I encountered, or who were referred to me, were women (a wife, daughter, daughter-in-law, or sister of the care-recipient). That is why only two of the included family caregivers were men, both of whom were a son of the care-recipient. This is unsurprising, as it reflects the gendered dimension of caregiving (i.e., family care as “women’s work”).

The included family caregivers have a Chinese, Indian-Surinamese, Moluccan, Moroccan, and Turkish migration background. Thus, instead of focusing on a single ethnic-specific sample, I purposively recruited family caregivers from a variety of migration backgrounds. I did so because it was not my aim to generalize the findings of the conducted study to a specific ethnic group. Nor was it my aim to make generalized comparisons between several ethnic groups in order to describe the differences and breadth of experienced problems between groups. Rather, I aimed to offer an in-depth understanding of obstacles and facilitators to care-sharing within the context of families with a migration background. To achieve this aim, I strategically selected a research sample on the basis of expectations about their information content. I purposively recruited participants with a Moroccan, Surinamese, and Turkish background because they belong to the largest ethnic minority groups with a migration background in the Netherlands (Statistics Netherlands, 2022a), and because a previous study suggests that care-tasks are usually not shared in these groups (Tonkens et al., 2008). I also purposively recruited participants with a Chinese and Moluccan background because, within the Dutch context, their views are often neglected in socio-scientific research on dementia care. So, since studies concerning (dementia) care in Dutch families with a migration background have mostly focused on the largest ethnic minority groups (see, e.g., de Graaff & Francke, 2010; de Graaff & Francke, 2003; Suurmond et al., 2016; van Wezel et al., 2014; van Wezel et al., 2016; Yerden, 2013) the inclusion of family caregivers of Chinese and Moluccan descent was expected to provide new insights.

The experiences of family caregivers were gathered through five different qualitative methods. In a subsequent order, these were: semi-structured interviews ($n = 13$), photo-voice interviews ($n = 5$), life-story interviews combined with “shadowing” observations ($n = 6$), and focus group discussions ($n = 7$). The first four methods were conducted in person. Due to COVID-19 regulations, the focus group discussions were conducted through online video-calls in Microsoft Teams.

Data on practitioners’ experiences ($n = 10$) were gathered between July 2020 and January 2021. These included health and social care workers who have an important role in processes of dementia care-sharing. As part of the inclusion criteria, all participants have worked with clients with a migration background. I recruited them through partner organizations (Pharos and MantelzorgNL) and my professional network. Eight of the referrals had a white-Dutch background, and two of the referrals had a migration background (Chinese and Turkish). Here, too, the majority of the referrals were women. Out of the ten included practitioners, there was one male participant. The experiences of the included practitioners were collected through semi-structured interviews. Due to COVID-19 regulations, these interviews were conducted through online video-calls in Microsoft Teams.

1.3 Analytical frameworks

Two analytical frameworks were applied throughout the conducted study: the concept of "framing and feeling rules" (Hochschild, 1983, 2003), and an intersectionality approach (Crenshaw, 1989, 1991). These frameworks were chosen to avoid the mistake of constructing PwM as Others whose ethnic identity and assumed "cultural differences" are overemphasized (Iliffe & Manthorpe, 2004; Koehn et al., 2013; Torres, 2015; Zubair & Norris, 2015). Instead, both frameworks allowed for an understanding of relational, multilayered, and context-dependent aspects of care-sharing.

The interpretive framework of "framing and feeling rules" (Hochschild, 1983, 2003) guided the analyses presented in chapter two and chapter four. Framing rules are "rules governing how it is we see situations" (2003, p. 82). Based on these framing rules, feeling rules "define what we imagine we should and shouldn't feel and would like to feel over a range of circumstances; they show how we judge feeling" (2003, p. 82). This means that framing rules and feeling rules mutually inform each other, as framing rules "point to the cognitive, meaningful, and interpretive frame within which feeling rules are situated" (Tonkens, 2012, p. 199). Thus, in essence, this framework is premised on the notion that people's views and experienced feelings are not caused by situations or events, but they are mediated through social norms and how individuals reflect on these norms (Hochschild, 1983, 2003; Tonkens, 2012).

The framework of "framing and feeling rules" was used to study how the included participants understand and make sense of social situations. In chapter two, it was applied to highlight the complexity of care decisions within families with a migration background, and how these decisions are intertwined with feelings and behaviors that are deemed "appropriate" according to social norms. By analyzing how family caregivers cope with their care-role and reflect on their care-context, the gendered and moral experiences of family caregiving were elucidated. In chapter four, this framework was applied to understand how practitioners view and experience care-sharing with PwM caring for a family member with dementia, and how their expressed framing rules may stand in the way of successful care-sharing. Thereafter, practitioners' expressed framing rules were related to the care-experiences of the included family caregivers. Applying this framework to practitioners' expressed views and experiences helped shedding light on possible causes for friction between practitioners and family caregivers with a migration background.

Intersectionality guided the analysis presented in chapter three, and my reflexive account presented in chapter five. While the term "intersectionality" was coined in 1989 by American legal scholar Kimberlé Crenshaw (1989, 1991), women of color had been long advocating the ideas that are at the core of intersectionality. They critiqued white feminists for rendering women of color invisible through their lack of attention to issues of race and racism, and therefore argued for the need to deconstruct the category "woman" by recognizing that social categories (such as ethnicity, social class, and religion) produce both commonalities and differences between women (Phoenix, 2006, 2011). This means that "inequities are never the result of single, distinct factors. Rather, they are the outcome of intersections of different social locations, power relations, and experiences" (Hankivsky, 2014, p. 2).

I chose to apply an intersectionality-based approach because of its attention to how individual, lived realities exist through the intersections of different social categories that operate together. In chapter three, I highlighted the intersectionality of family caregivers' experiences in order to offer an understanding of how relationships between social categories affect care-sharing and the type of care-support that is (or is not) organized. Instead of reducing the experiences of PwM to single categories of difference (ethnicity or culture), an intersectionality-based approach helped to elucidate the context-dependent and multilayered experiences of care-sharing in families with a migration background. In chapter five, an intersectional understanding of my positionality was highlighted as a critique of "ethnic matching" (i.e., matching the ethnicity of the researcher with research participants because of the researcher's assumed "insider" status). Rather than assuming an essentialized identity of the researcher and researched, an intersectional understanding of my positionality allowed me to highlight the ways in which several aspects of a researcher's identity may intersect and affect the research process.

1.4 Dissertation outline

In chapter two, I highlight how the gendered and moral dimensions of family care can impede dementia care-sharing. Chapter three illustrates how intersections of various social categories affect care-sharing and the type of support that is (or is not) organized. Chapter four elucidates how practitioners' views can impede dementia care-sharing with families with a migration background. Here, practitioners' expressed views are related to family caregivers' experiences of care-sharing. Thus, while chapter two and three focus on family caregivers' views and experiences, chapter four mostly brings practitioners views and experiences to the fore. In chapter five, I follow critiques of "ethnic matching" by illustrating the intersectional nature of my positionality within the conducted research. Finally, in chapter six, I provide a brief recap of the most significant findings that are discussed in the preceding chapters, after which I present an outlook for practice, policy, and future research.

In addition, several photos and their accompanying descriptions are found before each of the following chapters. These photos relate to family caregivers' care-role and care-experiences, and were taken by the five family caregivers who were included for the photo-voice method.

1.5 Notes

1. The names of all mentioned participants in this dissertation are fictitious.
2. Within the context of this dissertation, family caregiving is understood as "the process of helping another person who is unable to do for themselves in a 'holistic' (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain character traits, emotions, skills, knowledge, time, and an emotional connection with the care recipient" (Hermanns & Mastel-Smith, 2012, p. 15).
3. The term person with a migration background was introduced in 2016 in the Netherlands as a replacement for the term allochthonous (originating elsewhere) – the opposite of autochthonous (original inhabitant) – because it was found to be a problematic term (de Ree, 2016). PwM is not an ideal term either because it demarcates people on what they are not (i.e., a person with a white-Dutch background), and it highlights differences from the majority. Furthermore, although the term PwM is divided into Western and non-Western, in Dutch discourse it commonly refers to persons who are not white. Nonetheless, this term is applied throughout this dissertation because I have yet to come across a term that is more inclusive and suitable to the Dutch context. (NB: the term PwM has recently been reconsidered in the Netherlands, see: Statistics Netherlands, 2022b).

4. Rather than an understanding of culture as a homogenous entity with a static set of norms and practices that members of a social group adhere to, I understand culture as dynamic and context-dependent, as described by Kleinman and Benson (2006): “Culture is not a single variable, but rather comprises multiple variables, affecting all aspects of experience … Culture is a process through which ordinary activities and conditions take on an emotional tone and a moral meaning for participants … Cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, religion, ethnicity, and even personality” (p. 1673-1674).

5. Pharos is a national center of expertise on health disparities. MantelzorgNL is a national association for family caregivers. The Network of Organizations for Older Migrants (NOOM) is committed to the health and well-being of older individuals with a migration background.

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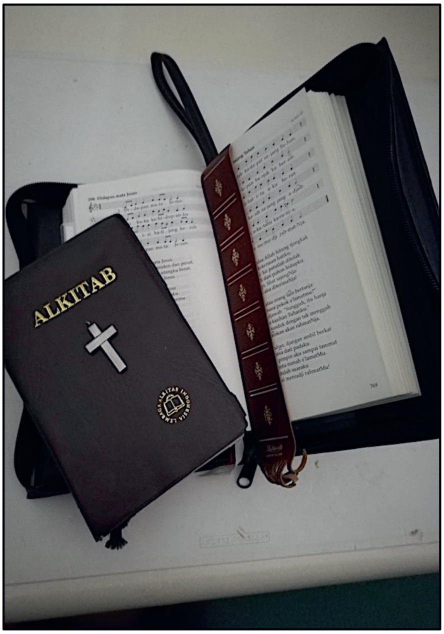
Self-preservation



My faith [is] my anchor, but I haven't gone to church in the past year; just for my self-preservation… Because if I would go to church, then of course I would drag [my sister] along too. I've actually withdrawn myself, and now my brother and sister-in-law are the ones taking her to church… Because otherwise, if I would go to church, then it would just be, "yes, Anneke will handle it" and "oh, Anneke will do it," and so on… I'd like to get rid of those assumed expectations, and not always having to ask [for support].
So I won that bit, so to speak, for myself.

◆ Anneke, primary caregiver of her sister

Chapter 2

The gendered and moral experience of family care

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Abstract

Background and objectives

By shedding light on the reasons why persons with a migration background (PwM) may take up the role of family caregiver of a person with dementia, and how this relates to gender norms, we aim to elucidate cultural and social dynamics that impede care-sharing.

Research design and methods

A qualitative study of 12 PwM who provide care, or have until recently provided care, for a family member with dementia was conducted through semi-structured interviews. Identified themes and patterns were analyzed with the help of Hochschild's interpretive framework of framing and feeling rules.

Findings

Our findings illuminate how motivations to provide care are framed through two moral framing rules, reciprocal love and filial responsibility, and how these framing rules are accompanied by the feeling rule of moral superiority over non-caregiving family members. We show how shared dementia care is impeded through these moral framing and feeling rules, and how gender norms impact on an unequal distribution of care-tasks.

Implications

Health and social care workers should identify the gendered and moral dialectics of caregiving. This means that, on the one hand, they should be aware that moral framing rules may pressure women into exclusive caregiving and that this can lead to health problems in the long term. On the other, healthcare practitioners should recognize that providing care can create a deep sense of pride and moral superiority. Therefore, showing acknowledgement of the caregiver contribution is a crucial step in creating trust between the caregiver and practitioner. Furthermore, asking for support should be normalized. Governmental advertisements on care–support can achieve this.

2.1 Introduction

Providing care exclusively, with little or no formal or informal support, is intensive. In particular, caring for a person with dementia is emotionally and physically demanding (Zwaanswijk et al., 2013). Dementia encompasses a set of progressive diseases in which cognitive functions (including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment) are impaired. This is commonly accompanied by deterioration in emotional control, social behavior, or motivation (World Health Organization [WHO], 2012). Zwaanswijk and coworkers (2013) found that behaviors often associated with dementia (such as mental confusion and distress, wandering, aggression, repetitive questions, and body maintenance) are related to greater caregiver stress and exhaustion.

Although dementia is not a normal aspect of aging, dementia has a higher prevalence rate among individuals aged 60 and older. Because of the ongoing aging of the world population, the incidence of dementia is therefore expected to increase (WHO, 2012). In the Netherlands, there are higher prevalence rates of dementia among persons with a migration background (PwM) than among white-Dutch. For instance, Parlevliet and coworkers (2016) found that dementia and mild cognitive impairment are three to four times more prevalent in the three largest non-Western groups with a migration background (Turkish, Moroccan, and Surinamese) compared with the white-Dutch population.

Despite the higher incidence of dementia among PwM, studies show that PwM make less use of formal support services (Denktaş et al., 2009; van Wezel et al., 2014), and that older PwM rely on family caregivers more often and more intensively than older white-Dutch persons (de Graaff & Francke, 2003; de Graaff et al., 2010). One of the reasons for this difference is that the current standardized models of care are often not attuned to the needs of PwM (de Graaff & Francke, 2003; de Graaff et al., 2010). Another reason for a limited use of formal support services by PwM is the belief that it is the family and not professional outsiders who should provide care for aging parents. Failure to do so (and the decision to invoke the help of professional care) may be considered dishonorable, which results in feelings of shame (Tonkens et al., 2008; Tonkens et al., 2011). Thus, social control, and feelings of honor and shame, may impede the use of home-care services and other forms of professional care (de Graaff & Francke, 2003; Denktaş et al., 2009).

There is an important gender dimension to all this, too. Although usually phrased in gender-neutral terms, it is not any family member who is expected to provide care for relatives with care-needs; it is the task of female family members due to gender norms (de Graaff & Francke, 2003; Tonkens et al., 2008; Tonkens et al., 2011). With gender norms we are referring to "the socially constructed roles, behaviors, activities, and attributes that a given society considers appropriate for boys and men or girls and women" (American Psychological Association, 2014). Although "caregiving as women's work" is a gender norm that cuts across all cultural groups (Calasanti & Slevin, 2001), for PwM residing in the Netherlands this norm may be stronger than among white-Dutch families (van den Berg, 2014), and it is often accompanied by a practice in which one female family member is expected to provide most of the care exclusively (van Wezel et al., 2014). This may explain why family caregivers with a migration background show higher percentages of exhaustion (van Wieringen & Grondelle, 2014).

The higher incidence of dementia among PwM, the underuse of formal support services, as well as the increase of migrant populations in Western societies, has implications for the provision of support services for family caregivers of older PwM. Indeed, social and demographic changes lead to more diverse family contexts and care needs (Roberto & Blieszner, 2015). Yet, PwM are underrepresented within research on dementia care and aging care in general (Zubair & Norris, 2015). Furthermore, empirical research on (the improvement of) shared dementia care within the context of PwM has been notably absent.

Studies that do focus on PwM caring for a person with dementia emphasize practical interventions, such as the employment of an intermediary for families with a migration background (Goeman et al., 2016), or better access to dementia support services (Shanley et al., 2012). Such interventions may in some cases help to ease the burden of family caregivers of persons with dementia. However, they do not address how individual and/or collective identity issues and concomitant emotions inform the division of care-tasks. What is neglected in this focus is the complexity of care decisions, and how these decisions are intertwined with feelings and behaviors that are deemed "appropriate" according to social norms (Hochschild, 1983, 2003).

This article remedies this neglect by shedding light on the ways in which the division of care-tasks is informed by the perceptions and experiences of PwM caring for a family member with dementia. In doing so, we aim to enrich our understandings of: (a) why PwM caring for a family member with dementia take up the role of family caregiver; (b) what may impede care-sharing within the family and with formal support services; and (c) how gender norms relate to an unequal distribution of care-tasks. Identifying these concerns, as well as suggesting appropriate ways to respond to these concerns, can help progress counseling and support for PwM caring for a family member with dementia – and open up ways for more gender equality.

2.2 Theoretical perspective

To better understand the social structure and moral complexity of emotions, Hochschild (1983, 2003) developed an interpretive framework to study how people make sense of their emotions and how this relates to their social context. This framework is described in terms of "framing rules" and "feeling rules." Our analysis is rooted in this framework.

Framing rules are "rules governing how it is we see situations" (2003, p. 82). They can be discerned as moral (compared with what is considered morally right), but also pragmatic (compared with what is currently available), or historical (compared with what was right, common or possible before) (2003, p. 116). People use feeling rules, Hochschild argues, to relate to these frames. Feeling rules "define what we imagine we should and shouldn't feel and would like to feel over a range of circumstances; they show how we judge feeling" (2003, p. 82). When we experience feelings, we judge them as appropriate or inappropriate by applying one of the three measures: clinical, moral, and social-situational appropriateness. "Clinical appropriateness refers to what is expectable for 'normal,' 'healthy' persons. Moral appropriateness refers to what is morally legitimate. Social-situational appropriateness refers to what is called for by the norms specific to the situation" (2003, p. 82). Framing rules and feeling rules mutually inform each other, as framing rules "point to the cognitive, meaningful, and interpretive frame within which feeling rules are situated" (Tonkens, 2012, p. 199).

Not surprisingly, framing and feeling rules are gendered because feelings are managed according to the socially constructed framing rules that apply to women and men. For example, women are more likely to be expected to suppress feelings of anger and aggression in the service of "being nice" because of how gender expectations are framed in society (Hochschild, 1983, p. 163). Gender norms that frame certain tasks and behaviors as feminine may be present as an implicit gender subtext (Smith, 1987). Applying Hochschild's concept of framing and feeling rules to the context of our study will offer insights into broader aspects of the caregiving experiences of PwM, and how these experiences are (implicitly) gendered.

2.3 Research design and methods

Design

The data for this research were collected through in-depth, semi-structured, face-to-face interviews focusing on the perceptions and experiences of PwM who provide care, or have until recently provided care, for a family member with dementia.

Data collection

Twelve family caregivers were interviewed in the Netherlands between February 2018 and September 2018. Participants were Dutch citizens with a migration background who identified as: Chinese ($n = 2$), Indian-Surinamese ($n = 2$), Moluccan ($n = 2$), Moroccan-Berber ($n = 2$), and Turkish ($n = 4$). Participants from these migration backgrounds were selected purposively. We recruited participants with a Turkish, Moroccan, and Surinamese background because a previous study has shown that care-tasks are usually not shared in these three largest non-Western groups with a migration background (Tonkens et al., 2008). We also focused on Chinese and Moluccan family caregivers because, within the Dutch context, these two groups are usually not included in socio-scientific research on dementia care.

Participants were recruited through gatekeepers. These included persons working with family caregivers with a migration background, such as social care workers and organizers of group-meetings for family caregivers. All the referrals who were recruited by these gatekeepers were female. Interviews were conducted by the lead author, with the support of a topic list focusing on six central topics: life history, dementia, caregiving process and experiences, talking about the care with family/friends, formal care-support, and receiving practical support from family/friends. Participants were informed about the study and gave verbal informed consent before the interview took place. All interviews were audio-recorded with the interviewees' permission and lasted between 45 and 120 min. One participant did not speak Dutch. For this participant, we made use of a Cantonese-Dutch interpreter – the other interviews were conducted in Dutch. An overview of the sample is given in Table 1.

Table 1. Overview of the research sample

Name[a] and age	Cultural background[b]	Relationship with care-recipient
Mrs. Chan (67)	Chinese	Wife
Dina (54)	Chinese	Daughter
Anna (55)	Indian-Surinamese	Daughter
Shivani (60)	Indian-Surinamese	Daughter
Nancy (44)	Moluccan	Daughter
Marjan (52)	Moluccan	Sister
Karima (42)	Moroccan-Berber	Daughter
Naïma (45)	Moroccan-Berber	Daughter
Meryem (45)	Turkish	Daughter
Bahar (48)	Turkish	Daughter
Betül (54)	Turkish	Daughter
Emine (51)	Turkish	Daughter-in-law

[a] Pseudonym.

[b] Indian-Surinamese (or Hindustani) are a group that migrated in the 19th century from India to Suriname, then a Dutch colony, and from there some migrated to the Netherlands. Moluccans are a group that migrated from Indonesia in the 1950s when Indonesia gained independence from the Netherlands. Chinese, Moroccan, and Turkish communities migrated to the Netherlands in the past decades, mostly for economic reasons.

Analysis

All data were transcribed verbatim and anonymized. Within the analysis we made use of a directed approach to qualitative content analysis (Hsieh & Shannon, 2005). We were guided by Hochschild's interpretive framework of framing and feeling rules as an analytical lens to understand how participants frame their perceptions and experiences of caregiving (framing rules), and how this relates to their feeling rules. This included two stages: (a) an initial identification of how perceptions and experiences of care were framed by participants, and (b) further analysis of how these frames can be interpreted in terms of Hochschild's framework.

We followed these stages through the following steps.

First, all authors read the interview transcripts individually, in which repetitive patterns and initial codes were identified. To maximize credibility, the findings of these individual analyses were compared and discussed together in several extensive meetings. An initial coding scheme was created after a consensus between the authors was achieved. Next, all transcripts were transferred to Atlas-Ti, in which they were further analyzed and coded by the lead author. Here, too, the identified patterns and themes were discussed together with all authors. Additionally, to check the reliability of the coding process in Atlas-Ti, two coded interviews were discussed together with all authors.

Second, we determined the coding categories by further analyzing the codes. While analyzing the codes, we asked: "How do participants frame their care-role, and how do their expressed feelings (such as pride, anger, and disappointment) relate to this frame?" And: "How do participants perceive their care-role in relation to family members, and to formal care?" Applying Hochschild's framework was useful to identify how care decisions are informed by identity issues and accompanying emotions, including gender norms.

More than 90 codes were identified. The identified codes were clustered into eight categories (see Table 2) that we organized in a coding scheme. The two stages of the analysis have led to the identification of two overarching themes: (1) the moral experience of caregiving, and (2) challenges to shared dementia care. These themes will be presented in the following sections.

Table 2. Categories of the coded data with exemplar codes per category

Category	**Exemplar codes**
Diagnosis	- after incident - unfamiliarity with dementia - informing care-recipient and relatives
Coping with the symptoms of dementia	- acquired knowledge - home modifications - (not) talking about the symptoms
Assuming the care-role	- love - unmarried - avoiding conflicts
Exhaustion	- anger - disappointment - giving up ambitions/interests
Division of care-tasks	- (not) asking for help - hands-on support - changing care situation
Formal care/support	- negative experience - different expectations - no love/attention
Socio-cultural norms	- taboo - differences in care-systems - caring for the other more important than caring for oneself
Family relations	- conflicts - being blamed - relationship with care-recipient

2.4 Findings

Theme 1: The moral experience of caregiving

Analysis revealed that moral framing rules of reciprocal love (*n* = 4) or filial responsibility (*n* = 3) or a combination of both framing rules (*n* = 5) were used to account for the role of family caregiver. For example, Anna framed her care-role in terms of reciprocal love: "I love my father… I thought: 'when I was little, you were there for me.'" Whereas Shivani framed this in terms of filial responsibility: "She's my mother… I feel obliged [to care]." In almost all cases (*n* = 11) these framing rules were used as a motivation to take up the care exclusively – with little or no support from others.

We argue that participants frame their motivation to provide care in direct contrast with family members who do not provide (an equal amount of) care. In doing so, both framing rules make space for the feeling rule of moral superiority over non-caregiving family members, as well as a sense of pride to be able to provide care.

In the following two sections, we elaborate on this by elucidating the framing rules and accompanying feeling rules that participants invoked to explain their motivations to provide care. We will do so by drawing upon two representative case examples that illustrate the two types of reasoning that our participants used to explain how and why they took up the role of family caregiver: through a framing rule of reciprocal love and a framing rule of filial responsibility. We choose to focus on two cases only, because this offers more detailed and contextualized insights into the caregiving experiences of PwM caring for individuals with dementia.

"You either care about your parents or you don't" – Karima

In this section we draw upon Karima's narrative, as an example of the framing rule of reciprocal love. Karima migrated with her family to the Netherlands in the early 1980s. She comes from a family with nine siblings – two sisters and seven brothers – who identify as Moroccan-Berber. Their mother got diagnosed with Alzheimer's disease when Karima was in her early 30s. Her family perceives her marital status (unmarried) and the fact that she does not have children, as a reason why she should provide most of the care alone – which she has been doing for the past 10 years after the diagnosis.

As the dementia progressed, providing care became more intense. Karima receives help from her younger sister who provides hands-on support twice every week. Her brothers do not provide any form of support, neither does her father who spends most of his time in Morocco. She feels disappointed by her brothers:

> We were quite a close family. There were never any real problems… And then at some point my mom became ill, and you realize that some of them become distant, to avoid helping… I really never expected this. I thought that we would always help each other if something… But I got disappointed.

Karima relates her feelings of disappointment not so much to her brothers' distance toward her, but mostly to them neglecting their mother: "It's not about me, but about her… I expected them to do the same as I'm doing."

Nevertheless, Karima continues to provide most of the care alone, and she does not wish to ask for formal or informal support. When asked to elaborate on her motivations to provide care, she explains:

> I think it has to do with love… There's always one person who would do anything for their parents, while the others would think: "Oh well, I have a sister or brother [who can provide the care]. Why would I help?" … See, you either care about your parents or you don't. I found out that they care a lot less than I do. I care a lot about my parents.

Providing care for her parents is what Karima considers to be morally appropriate. Reciprocal love is her moral framing rule because: "They took care of me, and they had a difficult time as well… They experienced poverty, and who knows what else. Despite that they came to the Netherlands and didn't know the language, they did a good job."

Karima explains that, when she does not feel exhausted, it makes her feel proud of her abilities to take care of her mother. In other words, Karima's role as family caregiver creates an empowering feeling of pride in her abilities to show gratitude and to reciprocate her love towards her mother. In doing so, she cultivates her moral identity as "more loving and caring" than her non-caregiving brothers. This gives rise to the feeling rule that she is allowed to feel proud and morally superior, because she is the one who is taking the lion's share of care whereas the others fail to respond to the framing rule of reciprocal love.

Our findings suggest that the feeling rule of moral superiority is stronger in participants who feel neglected and misunderstood by non-caregiving family members – especially when these family members live nearby but fail to respond to the framing rule. For instance, Anna, who has seven sisters and one brother (four of them living in the same city), contrasts her care-role with non-caregiving siblings: “Despite of my full-time job and voluntary work, I was always there for my father… I kept going, I wanted to do everything for my father… The others [non-caregiving siblings] wouldn’t do that.”

“If it’s not for Allah, then you wouldn’t do it” – Emine

The following describes Emine’s narrative, as an example of the framing rule of filial responsibility. Emine is a 49-year-old Turkish-Dutch woman who has provided care for her father-in-law until he passed away about a year ago. Unlike Karima, Emine does not frame her care-role as motivated by reciprocal love, because the relationship with her father-in-law was never experienced as loving. Instead, she frames her motivations in terms of filial responsibility.

Together with her parents, sister, and two brothers, Emine migrated to the Netherlands in the early 1980s. At age 21 she got married to her husband. After their marriage, Emine and her husband lived with Emine’s in-laws for two years until she and her husband found a home for themselves nearby. Far before her father-in-law got diagnosed with vascular dementia, Emine would provide care; for example by accompanying him to doctors’ appointments, translating letters and conversations, and reminding him to take his cardiac and thyroid medication. The care became more intense when behavioral changes (due to dementia) occurred. Although her father-in-law has two sons and a daughter living in the Netherlands, Emine did not receive any form of support from them. She provided most of the care alone, with some hands-on support from her mother-in-law, even though she did not experience a loving relationship with her father-in-law:

> My father-in-law was not a kind person, he made things difficult for me. Prior to his disease. He had a very difficult personality and he was very old-fashioned… When I came here [to live with her in-laws]… A woman did not count. You don’t have anything to say. You should just do what you’re asked to do, that’s it.

Emine did not feel appreciated by her father-in-law, and he would not treat her in an equal way. This made her experience hardship, especially in the first years of her marriage. Why, then, did she continue to provide care – even when it became unbearable and her health was at stake?

Contrary to prior research focusing on family caregivers with a migration background (Tonkens et al., 2011), Emine does not perceive her care-role as "a woman's duty." Rather, she relates it to her religious duty of filial responsibility:

> I did it for Allah. It's for my religion. I don't expect anything [in return]… I could've said: "You figure it out, I don't care." But I didn't do it for them. No, I really only did it for Allah. Even if you'd get paid, you wouldn't want to do this work. If it's not for Allah, and you don't believe, then you wouldn't do it.

Emine relates her motivation and acceptance of caregiving to Islamic norms of filial responsibility. PwM who consider themselves as belonging to a religious denomination emphasize the importance of filial responsibility more strongly than PwM without a religious denomination (Merz et al., 2009). However, filial responsibilities are not always related to religion. Some of our participants ($n = 4$) relate filial responsibility to culturally defined norms and duties instead. For instance, Marjan, a Moluccan-Dutch caregiver of her older sister, frames her care-role as a culturally defined duty of filial responsibility: "Even if you haven't slept for 24 hours, you have to provide the care because it's your sister."

Framing caregiving as a religious duty of filial responsibility gave Emine the strength to continue to provide care, to take pride in it, and to accept the unequal division of care-tasks. Like Karima, Emine perceives her behavior as morally superior to that of non-caregiving family members. While Karima derives her moral superiority from her response to reciprocal love, Emine considers herself "a better believer" than non-caregiving family members. In both cases, the moral framing rule of reciprocal love or filial responsibility gives rise to the feeling rule of pride and moral superiority. However, these framing and feeling rules impede shared dementia care, and pressure women into exclusive caregiving – as we will argue below.

Theme 2: Challenges to shared dementia care

All 12 participants reported feelings of emotional and physical exhaustion. Disappointment in non-caregiving family members, and feelings of isolation and of being misunderstood by other family members, often exacerbated the exhaustion. All this led to tensions, and sometimes conflicts, which were usually left unspoken. In the next two sections, we elaborate on the challenges to shared dementia care in two subthemes: *challenges to discussing shared care within the family* and *challenges to considering formal support services*. We will do so by illustrating how the framing rules of reciprocal love and filial responsibility impede care-sharing, and how both framing rules are implicitly gendered. Here, too, we draw upon Karima and Emine's narratives.

Challenges to discussing shared care within the family

Our findings reveal that the framing rule of reciprocal love and filial responsibility are both implicitly gendered, as gender norms influence the ways in which framing and feeling rules are applied (Hochschild, 1983, p. 163). The following example from Karima's narrative elucidates the gendered dimension of the framing rule of reciprocal love, as well as the gendered hierarchy of care obligations, as explained by Hooyman & Gonyea (1999): "The role of gender in the hierarchy of obligations to older family members is reflected in the fact that after spouses and daughters, it is daughters-in-law and not sons, and sisters versus brothers, who are likely to provide the care" (p. 150).

Even though Karima appreciates her sister's support, her care-role still has immense implications for her life. Ever since it started, she has no time for educational development or friends. She would not have had to set her needs aside if the care was equally shared with her siblings. That is why, at the start of her mother's disease, Karima expressed her worries to her father. She perceives him as "the head of the household" – his authority within the family could thus make him a strong ally to support her case: "I told him at the beginning: 'We should take care of her together.' Then he said, no. He said that it's not the mother of my sisters-in-law. But I'm thinking: 'What about your sons then?'"

When Karima expressed her concerns to her father, she did not refer to her sisters-in-law, but to her brothers who do not provide care. Yet, Karima's father instantly referred to the women in the family (i.e., his daughters-in-law). Karima's brothers, too, have told her that caring is "women's work." She does not agree with this, which is why Karima told her father that they should take care of her mother together.

Nonetheless, when we asked Karima about the unequal division of care-tasks, she insisted that it is an issue of reciprocal love, not of gender norms. Only when we asked her about a hypothetical situation in which, instead of her mother, her father would be the one in need of care, did she acknowledge the gendered division of care-tasks:

Karima:	You know how [white-]Dutch people are. They sometimes ask me: "What about your father?" … But my father's old. I can't expect him to take care of my mother.
MA:	But if the situation would be reversed, wouldn't your mother provide care for your father?
Karima:	Yes, yes… then it would've definitely been different… Yes, then maybe we [Karima and her sister] would help her, for example by taking father out of bed… Men are always taken care of by the wife.

Although Karima disagrees with the gendered hierarchy of care obligations in her family, she has tacitly accepted that she has to provide most of the care alone. Gender ideologies are left unquestioned, and the anger she feels toward her brothers is left unspoken. Her father and brothers, and probably her social environment more generally, perceive caregiving as "women's work." She is disappointed in her brothers, but by expressing her frustration at her brothers Karima would go against the frame. She is unable to do this. Instead, she has directed her anger toward her mother:

> There were times that I screamed [at her]: "You ruined my life!" But it's my mother, and later when I look at her and see a person who's half dead… I think: "Why do I say those things?" But it happens when I'm tired.

Her anger is a "misfitting feeling" (Hochschild 1983, p. 63) – an "inappropriate" feeling within the framing rule of reciprocal love. This implicitly gendered framing rule does not allow her to talk about the care-tasks with her siblings. Instead, Karima manages her emotions by reminding herself of her moral superiority: she loves and cares about her mother – more so than her brothers do. Thus, the impact of gender norms is suppressed through the feeling rule of moral superiority.

Some of our participants ($n = 5$) did talk about their exhaustion with family members who are not involved in the care. We will illustrate this with Emine's narrative. At the first stages of her father-in-law's disease, Emine did not wish to discuss the care-tasks with non-caregiving family members. Most of them were hardly ever present, and therefore unaware of the severity of the disease and the intensity of the care:

> They understood he was sick, but they didn't understand how serious it was because they were not involved… They'd come over once every few months. I can't call them each time to tell them: "This and that happened to him today." So, they just didn't know. But I [was] with him 24/7.

To be able to continue providing care, alongside running a household, Emine was forced to quit her position as chair at the women's association of her mosque. Giving up ambitions and interests further isolates women who are primary caregivers, which – as was the case with Emine – in the long term may lead to exhaustion. In order to continue providing care, Emine had to manage her emotions by suppressing feelings of isolation and exhaustion, and instead rely on her religious duty of filial responsibility. Nonetheless, like other rules, framing and feeling rules can be broken "by refusing to perform the emotion management necessary to feel what, according to the official frame, it would seem fitting to feel" (Hochschild, 2003, p. 99). Emine eventually chose to break the mentioned framing and feeling rules by voicing her concerns to her family:

> One day, when we were at my sister-in-law's house… My husband, brother-in-law, and sister-in-law were there. I told them: "Look, I can't do this any longer. You have to figure something out" … But in the end it all came down to me again, you know. We sat and talked about it, but we didn't reach a conclusion. None of them ever thought: "Alright, you expressed your worries, how are we going to continue?" or "How are you coping?"

Emine expressed her worries as a means of last resort – after two years of providing intensive care – but she was met with rebuff.

In conclusion, both Karima's and Emine's narrative seem to hint that, despite their identified framing and feeling rules, they disagree with the unequal distribution of care-tasks. In exceptional cases, family caregivers may decide to "break" with these framing and feeling rules, as was the case with Emine. However, our findings suggest that family caregivers are generally reluctant to press discussions about the care-tasks because of the mentioned framing and feeling rules – which includes the gendered nature of family caregiving – as well as feelings of being neglected and therefore misunderstood by family members who are not involved in the care.

Challenges to considering formal support services

The word “care” in caregiving implies: “A sense of emotional attachment which is usually identified with women, home, and family” (Calasanti & Slevin, 2001, p. 149). According to Calasanti & Slevin (2001), that is why family members often prefer informal care over formal care, because formal care lacks the commitment and affection that defines caregiving by women in the family. Indeed, most of our participants do not wish to share the care with formal support services. Sometimes this is because of negative experiences with healthcare professionals, as Dina states: “We didn’t have a lot of healthcare professionals because, yes, well, I think: ‘If you’re being unkind then I don’t want to have anything to do with you anymore.’” Karima, on the other hand, has never called in formal support services, because she considers these services as the most “distant” form of caregiving – in contrast with the framing rule of reciprocal love. It is, therefore, also frowned upon in the Moroccan community: “Imagine your mother or father becomes ill and goes to a nursing home. Then they [people in the Moroccan community] would say: ‘They have so many children, but the children threw her away.’” So, only if she would be physically unable to provide the care herself, she would consider calling in formal support.

The framing rules of reciprocal love and filial responsibility make the idea of formal services inappropriate. As Karima explains, the institutionalization of a parent is perceived as a sign of children failing in reciprocal love and/or filial responsibility (hence the notion of: “The children threw her away”). More specifically, a woman in the family who fails to (continue to) provide care is blamed, as was the case with Emine.

In the two years after the diagnosis, the care for Emine’s father-in-law became more intensive due to his behavioral changes. His aggressive behavior made it more difficult to continue to provide care at home, that is why Emine started looking for a suitable nursing home. Because the nursing homes nearby had long waiting lists, her father-in-law was admitted to a general hospital. The family was unhappy about his hospitalization. Especially her brothers-in-law (one of them living in Turkey) expressed anger, and blamed her after they heard about the hospitalization:

> Their eldest son got angry when he heard about the hospitalization. They were not happy about it at all. They blamed my mother-in-law and they blamed me… They said it wasn’t necessary. I told them: “Look, you only see him for two hours; you don’t know what happens the other hours.”

Hence, seeking formal support is generally not preferred because of negative experiences with healthcare professionals and because formal care is considered to be a sign of failure in responding to the framing rule of reciprocal love or filial responsibility. That is why women may be blamed when they fail to continue to manage the needs of the care-recipient, which again illustrates the gendered nature of caregiving.

2.5 Discussion

By examining the framing and feeling rules identified by our participants, we have aimed to elucidate the complexity of the perceptions and experiences of care. In doing so, we have shown why PwM caring for a family member with dementia take up the role of family caregiver, how this can impede care-sharing within the family and with formal services, and how implicit gender norms impact on an unequal distribution of care-tasks.

When the care-recipient was initially in need of care, our participants accepted their role as family caregiver through the implicitly gendered framing rule of reciprocal love or filial responsibility (or a combination of both framing rules) – a finding that resonates with O'Neill's study (2018) on the care motivations of Chinese daughters caring for their aging parents. Both framing rules made space for the feeling rule of moral superiority over non-caregiving family members, as well as a sense of pride to be able to provide care. As the dementia progressed, and the provided care became more intense, our participants felt more and more exhausted and isolated. Protesting and breaking with these framing and feeling rules is usually not an option, the exceptional efforts to do so resulted in further isolation.

Although there are differences in cultural background that may play a role, in our study the effects of gender norms on the division of care-tasks is dominant. Gender norms hinder women from asking for attention for their problems because they feel socially pressured to provide care, and thus avoid seeking support (see also, Del Río-Lozano et al., 2013). In addition, a gendered hierarchy of who is expected to provide care was clear in nearly all the narratives of this study. Our participants were female, but most of them had both male and female siblings who provided little or no support throughout the caregiving process. Unmarried women, women with previous care experiences, and women who live close to the care-recipient were more likely to become a primary caregiver.

In research focusing on PwM caring for a family member with dementia, the importance of this gender dimension in the division of care-tasks is often obscured due to an ethnocentric point of view on PwM. In this “othering” view, ethnicity and assumed cultural characteristics are overemphasized (Zubair & Norris, 2015). Emphasizing assumed cultural characteristics neglects the complexity of perceptions and experiences of care, and how these perceptions and experiences are gendered. This gender dimension deserves more attention, both in research and policy.

Limitations

First, our small sample limits generalizations about PwM caring for a family member with dementia. However, since we used a purposive sampling strategy, we did not aim to offer a representative sample of all PwM caring for a family member with dementia. Rather, our study highlights the gendered and moral complexity of caregiving and the possible challenges to shared care within the context of PwM caring for a family member with dementia. To some extent, our findings might also apply to white-Dutch family caregivers of persons with dementia. In a similar manner, family caregivers without a migration history may frame their care-role in terms of being “a good person” who prioritizes the person with dementia because of implicit feeling rules (Herron et al., 2019). However, an important difference is that PwM more often place a high responsibility on the informal care-network, whereas white-Dutch families more often perceive invoking support of formal care and the welfare-state as a more responsible way to provide appropriate care (van den Berg, 2014). This may in part be related to the ways in which care is organized in the country of origin. For example, in a well-developed welfare-state people develop and apply different framing rules than in a society in which care is regarded as a private matter. Different logics, originating from different contexts, affect thinking about healthcare, and may be related to why PwM often regard care as a private matter (Tonkens et al., 2008, p. 14). Similarities and differences in the ways in which different families frame their care-experiences deserves further research.

Second, our research sample does not include male participants. The ways in which male caregivers with a migration background assume and deal with caregiving responsibilities may be different from our female participants, because of their gender socialization (i.e., masculine gender norms and expectations). For example, in their study on the different ways in which women and men experience caregiving, Del Río-Lozano and coworkers (2013) found that, compared with women, men seek more help and show a greater willingness to accept support from people offering to help. Future research should also study the ways in which male caregivers with a migration background frame their caregiving experience.

2.6 Conclusions and implications

The identified themes of our findings show how the moral framing of care-tasks takes an enormous toll on one or two women in the family. We have shown that – although our participants often disagreed with the unequal division of care-task – in the end they acquiesced into a gendered division of care-tasks, and justified this for themselves through moral framing rules. At the same time, these moral framing rules made it more difficult to consider sharing the care with formal support services. This has important implications for practice and policy.

If one wants PwM caring for a family member with dementia to share the care with formal support services, it will not be enough to improve access of care through ethno-specific interventions. Rather, there should be an awareness among healthcare practitioners that moral framing rules may pressure women into exclusive caregiving, and that this can lead to health problems in the long term. Despite the heavy load of exclusive caregiving, providing care can create a deep sense of pride and moral superiority. Therefore, showing acknowledgement of the caregiver contribution is a crucial step in creating trust between the caregiver and healthcare practitioner. Furthermore, asking for support should be normalized. Governmental advertisements on care–support can achieve this.

In conclusion, to improve care-sharing between formal and informal care, healthcare practitioners should identify the moral dialectics of caregiving through a context-related approach, and attend to these concerns in a way that can lead family caregivers to "break" their framing and feeling rules. Now that we have revealed how these rules work, this means showing family caregivers possibilities and examples of how the care can be shared in a way that complements their care-role. Attending to these concerns can lead PwM caring for a family member with dementia to develop different framing and feeling rules on what is perceived as "good care" – for example by considering arranging support services as "good care" instead of having to provide the care exclusively themselves.

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Patience

In every corner of the room you find a bag full of her things… Today she woke up at five o'clock [in the morning]… And then she says, "my clothes are all gone!" … And then [I notice] she packed everything. Then I try to unpack her [clothes] with her, and look for her headscarves in her room where she hid them all…

And sometimes, I'm going to say it honestly, I'm angry. I want to snap at her… But we have something beautiful to hinder that: Islam. Islam says: you have to be patient with your mother and with your parents. And I repeat that every day.
That sustains me in taking care of my mother.

◆ Mabrouka, primary caregiver of her mother

Chapter 3

An intersectional exploration of family caregivers' experiences

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Abstract

Background and objectives

Previous studies show that persons with a migration background (PwM) caring for a family member with dementia often experience access barriers to formal care services, and that family caregivers often perform the lion's share of care. Yet research offering a detailed account on their experiences of dementia care-sharing is sparse. In this paper, we respond to this knowledge gap by exploring how different social categories impact practices of care-sharing among our participants and their families.

Research design and methods

A qualitative study of six PwM who provide care for a family member with dementia was conducted through two methods: semi-structured, life-story interviews followed by "shadowing" our participants in their daily lives. We were guided by intersectionality as an analytical lens in exploring the multifaceted experiences of care-sharing.

Findings

Throughout our analysis, intersections of migration history and social class stood out the most. We elucidate how they influence the attainment of necessary skills to organize and share care-tasks as well as perceptions of "good care." Additionally, our findings illustrate how one's position within the family, the presence or absence of supportive social networks, religion, gendered care norms, and relationship to the care-recipient are relevant to experiences of care-sharing.

Implications

Rather than overemphasizing ethnicity and culture, practice and policy should take into account that intersections of various social categories affect care-sharing and the type of support that is (or is not) organized.

3.1 Introduction

The aging population in European societies is increasingly ethnically diverse and this will continue in the coming decades (Lanzieri, 2011). This raises concerns for dementia care and support services, as dementia prevalence increases with age (World Health Organization, 2012). In the Netherlands, the magnitude of this concern is illustrated by Parlevliet and co-workers (2016), who found that dementia and mild cognitive impairment have a higher prevalence in the three largest minority groups with a migration background (Turkish, Moroccan, and Surinamese) compared with the majority population.

Due to the intensity and complexity of the care, family caregivers of individuals with dementia often experience psychosocial problems and support needs throughout the process (Zwaanswijk et al., 2013). Yet, within the Dutch context, knowledge about dementia care-sharing in families with a migration background is scant. This knowledge gap has also been pointed out in a recent policy report on informal care in the Netherlands (de Boer et al., 2020). This gap does not only apply to the Dutch context, as persons with a migration background (PwM) are underrepresented within research on dementia care and aging care in general (Zubair & Norris, 2015).

Most of the available knowledge on PwM caring for a family member with dementia relates to access barriers to service use. For instance, previous studies show that PwM who are providing care for a family member with dementia make less use of formal care and support services (see, e.g., Denktaş et al., 2009; Shanley et al., 2012; van Wezel et al., 2014). Possible barriers to formal services may include: negative experiences with services (such as discrimination), language barriers, lack of clarity about where or how to access help, lack of knowledge about dementia, the belief that nothing could be done to help, shame and stigma within the community (Mukadam et al., 2011), and the perception that it is the family and not professional outsiders who should provide care for aging parents (Tonkens et al., 2011).

Despite the perception that providing care for aging parents is a family obligation, a lack of care-sharing with formal services often means that one female family member ends up providing most of the care exclusively (Sagbakken et al., 2018; van Wezel et al., 2014). This may relate to an implicit, gendered hierarchy of care-obligations in which unmarried women, women with previous care experiences, and women who live close to the care-recipient are more likely to become a primary caregiver (Hooyman & Gonyea, 1999). Such a gendered hierarchy, as well as feelings of being misunderstood by non-caregiving family members, makes it difficult for PwM to press discussions about dementia care-sharing (Ahmad et al., 2020). This may explain the higher percentages of exhaustion in family caregivers with a migration background as compared to white-Dutch family caregivers (de Boer et al., 2021; van Wieringen & Grondelle, 2014).

Even though these studies offer valuable insights, to date, no studies have provided a detailed account on which intersecting social categories (e.g., gender, social class, and migration history) relate to practices of formal and informal dementia care-sharing in families with a migration background. So, little is known about why some PwM share the care within their families and/or with formal care-support, while others do not. Moreover, research on PwM caring for an aging family member (with dementia) is often informed by limited and static understandings of ethnicity and culture (Iliffe & Manthorpe, 2004; Koehn et al., 2013; Torres, 2015; Zubair & Norris, 2015). A scoping review on the health and health care of aging people with an ethnocultural minority background (Koehn et al., 2013) revealed that studies often reduce the experiences of entire groups to single categories of difference (ethnicity or culture) that obscure the heterogeneity of PwM. Many scholars emphasize the need to move toward an intersectional exploration of the influence of a number of social categories when studying the health and care-experiences of PwM (see, e.g., Iliffe & Manthorpe, 2004; Koehn et al., 2013; Torres, 2015; Zubair & Norris, 2015).

Therefore, in order to understand which social categories impact practices of care-sharing among PwM caring for a family member with dementia, we will incorporate an intersectionality approach (Crenshaw, 1989, 1991). In doing so, we will also illustrate why some family caregivers with a migration background organize and share the care-tasks more than others. Thus, we aim to answer the question: Which intersecting social categories impact on practices of care-sharing in families with a migration background caring for individuals with dementia? Additionally, our study may offer insights for researchers interested in incorporating an intersectionality approach into their research on care for older individuals.

3.2 Theoretical perspective

Intersectionality, a term coined by Crenshaw (1989, 1991), aims to analyze different social categories as interwoven. It emerged out of a critique of white feminists who neglected the intersecting realities and experiences of women of color. They argued for the need to deconstruct the category “woman” by recognizing that social categories (e.g., ethnicity, gender, class, and religion) produce both commonalities and differences between women (Phoenix, 2006, 2011). Intersectionality can be defined as a lens through which we can identify how multiple social categories intersect at the level of individual experience, that are contextualized within broader systems of power (Crenshaw, 1989, 1991). To do so, social categories are analyzed as categories that mutually constitute each other. Even when focusing on one social category, we cannot understand this category in isolation since there is no essence to any of these categories (Crenshaw, 1989, 1991; Phoenix, 2006, 2011). That does not mean that intersectionality can be equated with the analysis of diversity or difference. It moves beyond attention to difference, as it seeks to clarify instead relations of inequality and privilege (Calasanti & King, 2015).

Even though there is a general agreement about the above description of intersectionality, there are significant differences in how intersectionality is employed (Davis, 2011; Prins, 2006). Prins (2006) distinguishes between what she calls a "systemic approach" (foregrounding structure) and a "constructionist approach" (foregrounding agency). Accordingly, a systemic approach might neglect some of the ways in which people identify themselves because in this approach power is treated as unilateral and a matter of categorization. In contrast, a constructionist approach treats power as relational and dynamic. Here, identity is not treated as a matter of categorization, but one of storytelling. Foregrounding agency thus highlights that individuals are not merely "being subjected to," but that individuals are "both actor in and co-author of their life-story" (Prins, 2006, p. 280–281). That does not mean that structure is disregarded in a constructionist approach, nor that agency is disregarded in a systemic approach. Rather, it means that while foregrounding agency, a constructionist approach keeps structure into view – instead of the other way around (Prins, 2006). In our study, we highlight our participants' agency to elucidate how social categories are experienced and handled individually. While foregrounding our participants' agency, we keep structure in view through an analysis of their individual experiences.

Also, throughout our analysis, we take an inductive approach to the intersecting social categories that we analyze. Traditionally, intersections of race, class, and gender are most frequently analyzed (Davis, 2011). However, several studies show that an intersectional analysis that goes beyond intersections of race, class, and gender might expose inequalities that are relevant to the research aim. For example, in a narrative analysis of adults who grew up in visibly ethnically different households, age, nation, locality, historical period, and household cultural practices emerge as relevant social categories (Phoenix, 2011). In their intersectional analysis on the wellbeing of caregivers of individuals with dementia, Chappell and co-workers

(2015) analyzed the intersections of gender and relationship to the care-recipient. This underpins the need for an approach in which researchers make their inductive judgements and decisions about which intersections are relevant to analyze within the given context (Phoenix, 2006, 2011). Instead of pre-establishing a number of social categories to guide our analysis, we took an inductive approach in understanding our participants' intersectional realities based on our research aim and question.

3.3 Research design and methods

Design

The data for this research were collected through two methods: semi-structured, face-to-face life-story interviews followed by "shadowing" our participants in their daily lives. Life-story interviews allow for insights into intersecting identity markers, and the role of social structures in a person's life – which is why it is an important methodological approach to intersectional analysis (Christensen & Jensen, 2012; Prins, 2006). Atkinson (1998) defines the life-story interview as: "The story a person chooses to tell about the life he or she has lived, told as completely and honestly as possible, what is remembered of it, and what the teller wants others to know of it, usually as a result of a guided interview by another" (p. 8).

The shadowing method is ethnographic fieldwork in which the focus is placed on the experiences of a single individual. Quinlan (2008) defines shadowing as: "A researcher closely following a subject over a period of time to investigate what people actually do in the course of their everyday lives, not what their roles dictate of them. Behaviors, opinions, actions, and explanations for those actions are reflected in the resulting thick, descriptive data" (p. 1480).

We opted for these methods because our participants' life-stories contain information about intersecting constructions of identities and the role that social structures play in their care-experiences, whereas "shadowing" allows us to observe more closely how this manifests itself and is dealt with in practice – resulting in deeper insights of their care-experiences.

Data collection

Six family caregivers were interviewed and shadowed in the Netherlands between November 2019 and February 2020. Participants are Dutch residents who identify as: Chinese ($n = 1$), Moluccan ($n = 1$), Moroccan-Berber ($n = 2$), Turkish ($n = 1$), and Turkish-Kurdish ($n = 1$). They were recruited purposively through social workers who work with PwM. As part of our inclusion criteria, we recruited primary caregivers who were currently providing care for a family member diagnosed with dementia. We recruited participants with a Turkish and Moroccan background because they belong to the largest minority groups with a migration background in the Netherlands (Statistics Netherlands, 2021). We also purposively recruited participants with Chinese and Moluccan backgrounds because, within the Dutch context, their views are often neglected in socio-scientific research on dementia care. Furthermore, to highlight different perspectives in our study, we ensured that our group of participants was diverse in terms of class background. A succinct overview of our sample is given in Table 1.

Table 1. Overview of the research sample.

Name[a] and age	Brief migration history	Education	Relationship to care-recipient	Care shared within the family	Care shared with formal care
Atifa (59)	Morocco-Spain-Netherlands	Primary education	Daughter	Partly	No
Faiza (52)	Morocco-Netherlands	None	Daughter	Partly	No
Jun (39)	China-Austria-Netherlands	Higher education	Daughter	No	Daycare
Mrs. Aydin (70)	Turkey-Netherlands	None	Wife	No	Daycare and homecare
Lilian (60)	Raised in the Netherlands by parents who migrated from the Moluccas, Indonesia	Secondary vocational education	Daughter	Partly	Daycare and homecare
Meliha (52)	Turkey-Netherlands	Secondary vocational education	Daughter	Partly	Nursing home

[a] Pseudonym.

Both types of data collection were conducted by the lead author. Participants were informed about the study and given informed consent before the life-story interview and shadowing observations took place. First, to help elicit our participants' life-stories, open-ended, reflective questions were asked to encourage participants to tell their stories according to their subjective identity and views (Atkinson, 1998). We did this with the help of an interview guide that included the following themes: childhood; family life; education; partner/marriage; migration-process; work/career; dementia; caregiving process and experiences; care-sharing with family/friends; formal care-support. These themes served as a way to guide the interview chronologically by starting with questions about one's childhood and sequentially processing to the present. In doing so, the life-story interviews allowed for insights into intersecting social categories relevant to our research aim. The interviews were audio-recorded with the interviewees' permission, and lasted between 80 and 120 min.

Second, we scheduled an appointment to conduct shadowing observations. Participants were shadowed on one or two occasions. Shadowing mostly took place at the participant's home, and around their home environment. In one case, shadowing started at the participant's home and continued at the nursing home. While shadowing, we made use of a topic list focusing on the participant's expressed emotions and interactions (verbal and non-verbal) with the care-recipient, family members, and formal care-providers (when applicable). We made field notes and asked questions related to the care-practices we observed, as well as our participants' care-experiences more generally. When applicable, we related these questions to relevant issues that came up during the life-story interview. The shadowing process lasted between 3.5 and 4.5 hours per participant.

Interviews and shadowing observations with Jun, Lilian, Faiza, Meliha, and Mrs. Aydin were conducted in Dutch. Since Atifa does not speak Dutch, her daughter Amira[1] was present during the interview and shadowing observations. That way, her daughter could translate (from Dutch to Moroccan-Berber and vice versa). Also, Amira's presence was valuable in understanding the perspectives of a family member who is involved in care-sharing. In a similar manner, Mrs. Aydin's daughter Zeynep[1] was present during the shadowing observations to translate when necessary, as Mrs. Aydin's Dutch language proficiency was limited. Zeynep's presence was valuable in understanding the perspectives of a family member who is not involved in care-sharing. Among all six participants, the care-recipient was present while we were shadowing.

Analysis

All data were transcribed verbatim and anonymized. This included interview transcripts and observation reports. In total, the transcript data consisted of 241 pages. Within the analysis we made use of a directed approach to qualitative content analysis (Hsieh & Shannon, 2005). In this approach, existing theory or prior research is used to guide the analysis by first identifying key concepts or variables as initial categories. Next, operational definitions for each category are determined using the theory (p. 1281). In our study, this meant that we were guided by intersectionality as an analytical lens in exploring practices of care-sharing. Following Hsieh and Shannon (2005), our analysis included the following two stages.

Within the first stage, the interview and shadowing data were inductively coded. All authors read the interview transcripts and observation reports individually, and common patterns were identified. We compared and discussed our initial analyses together in several in-depth discussions, after which an initial coding scheme was created. In the second stage, the interview transcripts and observation reports were transferred to Atlas-Ti, where they were further analyzed and coded by the lead author. This process, too, was discussed together with all authors. We asked ourselves: "Which social categories are expressed by our participants?" And: "How do these social categories relate to our participants' experiences of care-sharing?" By answering these questions in our analysis, we identified patterns that illuminate both commonalities and differences in our participants' experiences of care-sharing.

We identified around 150 codes clustered into 14 categories that we organized into a coding scheme. The analysis led to the identification of three overarching themes: (1) sharing with family, (2) sharing with formal services, and (3) sharing with family and formal services. Within these themes, migration history, social class,[2] gendered care norms,[3] relationship to the care-recipient, supportive social networks, religion, and position within the family, emerged as social categories relevant to our participants' experiences of care-sharing. These were not simultaneously visible in all six of our participants' narratives. Rather, our analysis revealed how different intersections of the aforementioned social categories are strongly connected to practices of care-sharing in our study. In the following three themes, we will elaborate on this, while concomitantly making visible why some family caregivers organize and share the care more than others.

3.4 Findings

Theme 1: Sharing with family

Two of our participants, Atifa and Faiza, share the care-tasks with some of their family members. In both cases these tasks are not distributed equally, as they perform the lion's share, nor is the care shared with formal services. However, both participants are able to share and discuss the care-tasks with a few family members, and they both experience supportive social ties with a large circle of friends and acquaintances. Because of that, Atifa and Faiza did not feel isolated or exhausted in their care-role. Through Atifa's narrative, we illustrate how migration history, social class, gendered care norms, and supportive social networks intersect and impact on experiences of care-sharing.

Atifa

Atifa was born and raised in a rural area in Morocco, together with two sisters and three brothers. Atifa's father and sisters migrated to the Netherlands in the late 60s, when Atifa was about eight years old, to financially support his family through his job at a Dutch factory. She got married in her late teen years. Atifa's mother and brothers migrated to the Netherlands around that same time, where they were reunited with Atifa's father. Atifa, however, did not join them because of her married life in Morocco.

Some years later, Atifa migrated to Spain with her husband and children. This is when she started working as a cleaner, and later on as a cleaning coordinator, at a hotel. But when her mother's care-needs increased due to dementia, Atifa decided to quit her job and migrate to the Netherlands to become her mother's primary caregiver. Before Atifa came to this decision, her sisters were managing their mother's daily care for about two years. When the dementia progressed and the provided care became more intense, Atifa's sisters could no longer combine the care-tasks with their work and family life: "We discussed it together and then… my brothers and sisters all agreed that I'm the one who's going to take care of her. We thought: 'We won't take our mother to a nursing home.'" Atifa and her siblings came to the joint agreement that one of the children must take full responsibility for providing 24h care in the home-environment. Both Atifa and her siblings considered family care superior to formal care. Formal care-support, and especially a nursing home, is thus not compatible with their perceptions of "good care."

Atifa's narrative shows how migration history, social class, and gendered care norms intersect and are relevant for assuming the role of primary caregiver. Furthermore, it shows how supportive social networks help to cope with this role, as we will argue in the following.

Atifa migrated later in life, and her educational and career opportunities were limited in the Moroccan village that she grew up in. In contrast, Atifa's sisters migrated to the Netherlands at a young age, which allowed for educational and career opportunities. Atifa, however, attended school until the age of 13, and got married a few years after. She expresses a strong awareness of her (under-resourced) social class as compared to her sisters:

> My sister [manages] her own organization and [my other sister] used to work as a cop; now she has a ministry job… But my work was not that important. They all worked and still work, but I actually… I wasn't doing much.

Atifa's perceived and experienced social class thus reveals disparities between educated and uneducated, and how this has affected care-decisions in her family. Interestingly, in the above quote Atifa is only referring to her sisters who work in higher positions than herself. Her brothers' jobs are very similar to Atifa's previous job as a cleaner/cleaning coordinator, but she does not take her brothers into account due to gendered care norms. In addition, even though Atifa's brothers visit their mother on a regular basis, they do not provide hands-on care – unlike Atifa's sisters and daughter – which, again, reveals implicit gendered care norms. Moreover, when Atifa's father and sisters migrated to the Netherlands in the late 60s, Atifa supported her mother in the care of her three younger brothers. Caring for her younger brothers early on in her life may have shaped her siblings' gendered perception (as well as Atifa's own perception) of Atifa as a "caring person."

Nonetheless, even though Atifa sometimes feels exhausted in her care-role, she tells us that she would not want to change anything about the current situation:

> I love my mother… I made this decision, I'm responsible [for her]… Even though it's difficult, I don't need [formal care-support]… And whenever it's necessary, I get help from [my sisters and daughter].

One of Atifa's sisters and her 20-year-old daughter, Amira, provide care-assistance every day or every second day. Her sister also takes care of her mother's financial and administrative affairs related to housing and health. The other sister provides care-support over the weekends. While shadowing, we observed how Amira supports her mother in the care-tasks by lifting her grandmother out of bed and by providing dressing assistance. Even though Atifa's brothers do not provide care-support, they frequently visit – as Amira explains: "One of my uncles visits every evening, after work, except on Friday night. [My other uncles] visit on Saturday, Sunday… They come to talk and cuddle with [my grandmother]."

Additionally, relatives, friends, and neighbors visit Atifa frequently. This was also the case while we were shadowing, when several family members and a friend were paying Atifa a visit. A supportive relationship with her siblings and relatives, as well as close ties with her friends and neighbors, is an important reason why Atifa does not feel isolated in her care-role. Furthermore, despite the distance between the Netherlands and the countries she was living in before (Morocco and Spain), Atifa said she always experienced supportive ties with her siblings. Because of their supportive ties, she can openly discuss care-related issues with them: "We discuss things [together], and we have a good relationship." For instance, Atifa explains that, whenever she goes on a holiday, her sisters take up the care-responsibilities: "When we go to Spain, for example, my two sisters just take care of [my mother]… So, whenever [I want to] go somewhere, it can be arranged." There is no need to negotiate this with them because: "They'll just do it because they know I won't be available." The presence of social networks help Atifa cope with her care-role and avoid formal care-support. For Atifa, supportive social networks thus mitigate the impact of becoming a primary caregiver and barriers that hamper care-sharing with formal services.

Theme 2: Sharing with formal services

In this section we will draw upon Jun and Mrs. Aydin's narratives. Both participants share the care with formal services, but not with family members. Jun provides care for her mother; Mrs. Aydin provides care for her husband. Jun sought formal care-support because of her perceptions of "good care," and because she has no siblings or other relatives to support her in her care-role. Mrs. Aydin receives formal care-support because of a lack of support from her family, as they perceive her care-role as self-evident due to gendered care norms. In what follows, we will contrast both narratives in order to illustrate how social class, migration history, gendered care norms, relationship to the care-recipient, and religion may impact on care-experiences and care-sharing with formal services.

Jun

Jun was born in a large city in China, as an only child. When she was 15 years old she migrated with her parents to Austria,[4] where her mother continued her work as a Mandarin-German translator. Jun met her husband during her studies; together they had a daughter and a son. Long before Jun's mother was diagnosed with dementia, Jun migrated to the Netherlands with her husband and children for work-related reasons. In the Netherlands, Jun worked as a researcher and consultant but her life took a different turn when her mother was diagnosed. She quit her job and decided to take her mother to the Netherlands in order to become her mother's primary caregiver.

The reason why Jun assumed the role of primary caregiver is simply because there are no other family members around. Jun's father passed away due to cancer many years ago, and her only direct relatives are two uncles living in China. However, the ways in which Jun copes with her assumed care-role is importantly intertwined with her social class and migration history.

Jun comes from an educated, middle-class family that had the means to travel to Europe during Jun's childhood. Because of that, Jun was given the opportunity to become acquainted with different cultures and ways of living. Both her parents valued education, and they migrated to Europe for a more prosperous future for their daughter. These opportunities have equipped Jun with resources that were relevant to her development. Besides successfully obtaining her bachelor's and master's degree in Austria, Jun speaks Mandarin, German, English, and Dutch. Her family's social class aided her in obtaining a career in high, decision-making positions. Because of this, she is equipped with the necessary skills to seek formal care-support. For instance, after taking her mother into her home, Jun soon felt that she was not fully equipped to provide full-time care, which was why she contacted her general practitioner for help:

> At that time my mother was really not doing well because I didn't know what to do with her. She was just sleeping all day and I'd just let her do whatever she wanted… I thought: "I'm doing the best I can, but I don't know what's best [for her]."

Jun now takes her mother to an adult daycare five times a week (six hours per day):

> They have [activities] with her there. At home, I don't do that much with her. They are professional. And I, yes, I have my children, my family, myself. And I don't know how to… Because it can be quite exhausting when people in the final phase [of their lives]

> need care. Then you [need a] professional who has learned how to guide people [in the final phase of their lives].

Arranging formal care-support according to her mother's needs is something Jun considers to be "good care," as the above quotes imply ("I don't know what's best for her", "They are professional"). At the time of our interview and observations, Jun was visiting nursing homes to consider in the future. She tells us that she would prefer to continue providing care in the home-environment, but, at the same time, she understands that it might not be possible in the long run.

Jun's migration history also matters in terms of identity. Previous studies on PwM show that social control and feelings of honor and shame, may form barriers to invoking formal care services (Mukadam et al., 2011). However, Jun has no connections with a wider ethnocultural community in the Netherlands. Her double migration route at a young age (at age 15 and 24), multilingual and culturally diverse background, and marriage with her Austrian husband, have blurred her different cultural identities. In Jun's case, this barrier in invoking formal care therefore does not exist, which makes care-sharing with formal care services more likely when compared to PwM who *do* experience social control in their ethnocultural community. We will illustrate this through Mrs. Aydin's narrative.

Mrs. Aydin

Mrs. Aydin was born and raised in a small, rural village in Turkey. She comes from a large, lower-class family; Mrs. Aydin is the third of seven children. She got married to her husband at age sixteen, together they had three daughters and two sons. When Mrs. Aydin was in her late 20s, her husband migrated to the Netherlands to financially support his family through his work at a Dutch factory. The family was reunited a few years later, when Mrs. Aydin and her children joined him in the Netherlands.

In the years after their migration, Mrs. Aydin continued managing her household while Mr. Aydin continued his work at the factory. This changed about ten years ago, when Mr. Aydin had to undergo surgery to remove a brain tumor. Mrs. Aydin's care-tasks started around that time, and these care-tasks became more intense when her husband's behavior started changing due to dementia.

During our conversations and observations, Mrs. Aydin repeatedly expressed that she experienced the care-tasks as exhausting due to her asthma and chronic physical pain. Through her general practitioner, Mrs. Aydin was therefore matched with a Turkish-Dutch care-counselor. This care-counselor registered Mr. Aydin at a Turkish-Dutch adult daycare, where he goes to twice a week (six hours per day). In addition, a Turkish-Dutch home-care worker cleans their house twice every week. Despite sharing the care with formal services, Mrs. Aydin feels highly exhausted: "I'm ill too. Pain in my back, asthma... Pain in my legs." Showering and cleaning her husband are especially difficult. Mrs. Aydin's daughters and sons live nearby, but they provide little care-support.

Mrs. Aydin's narrative illustrates how social class, migration history, relationship to the care-recipient, gendered care norms, and religion intersect and affect care-sharing within the family and with formal care-support. First, Mrs. Aydin grew up in a lower-class household. While growing up, there was no school in her village and women were expected to marry at a young age – which is why Mrs. Aydin did not receive any form of education. She speaks some Dutch, but she was not given the opportunity to read and write in her native tongue, nor in Dutch. Since Mrs. Aydin migrated later on in life, her educational opportunities were also hampered in the Netherlands. Because of her class-background and migration history, Mrs. Aydin neither had the opportunities nor the means for self-development. This makes her less equipped with the necessary skills and assertiveness to allocate care-tasks within her family, and to seek more formal care-support. Fortunately, Mrs. Aydin's general practitioner was attentive to her family's care-situation. However, considering Mrs. Aydin's precarious health and lack of family support, the current formal care-support is insufficient.

In Mrs. Aydin's narrative, care-sharing is not solely affected by her social class and migration history, but these factors intersect with her relationship to the care-recipient (her husband), and thus also with other family members (her children). Mrs. Aydin has been taking care of her husband and household ever since her marriage. Mrs. Aydin's daughters, too, married and became housewives at a relatively young age. It thus appears that Mrs. Aydin's care-role is perceived as a usual practice – a "woman's duty" as a wife and mother – and thus a continuation of the spousal relationship. Care-tasks were therefore not discussed within the family, and discussions about more formal care-support in the future were avoided. When we ask Mrs. Aydin why she provides care for her husband she explains:

> What to do [what else can I do]? … I need to care, I must… because he is my husband… I want somebody to come and help, that's better for me, too. [But my husband] says: "No, why don't [you] want to do it, [why should] other people help me?" So, [what else can I do]? I must do it.

Even though Mrs. Aydin repeatedly told us she wants to share the care more, this is hampered because of her relationship to the care-recipient and because her voice is considered to be less legitimate than her husband's – who does not allow for other people besides his wife to provide care. As a result, Mrs. Aydin's children are unaware of the intensity of the care, as Mrs. Aydin explains when we ask her if she would ever consider a nursing home for her husband:

> Mrs. Aydin: I [said] maybe he [should] be [in a nursing home]. Then my youngest son said "no."
> MA: So, you've told your son, and your other children, that you want to consider a nursing home?
> Mrs. Aydin: Yes, then [they] say: "My father is [doing] well, [he] can't stay there." I say: "You [think] he's well, but you don't know... You come here for an hour [and] return back home. You don't know what I do here."
> MA: They don't understand how hard it is?
> Mrs. Aydin: Yes, that's why I say [to myself]: "It doesn't matter, I do it myself, do it myself."

Discussions about care-sharing are thus avoided, as our conversations with Zeynep – one of Mrs. Aydin's daughters who was present during our observations – confirms. When we ask Zeynep if she and her siblings would consider discussing and organizing the care-tasks together, she explains: "No, no, because when it gets too much for my mother she goes outside. Just for a walk or towards the city, sometimes she comes to [me or my sisters]." Zeynep emphasizes that she and her siblings do not feel ashamed of talking about their father's illness, as everybody within their community is already aware, but that they do not feel the need to discuss the care-tasks.

This relates to gendered care norms within their ethnocultural community, in which social control and feelings of honor and shame are attached to invoking (more) formal care outside of the home-environment, as Zeynep explains:

> Then they'll start gossiping in our family. [They'll say] that we can't take care of our father, that we left him in an old age home. We can't accept that. No, no, we can't… I haven't even thought about it, and I don't want to.

Even though Zeynep is referring to the care-tasks as a shared family responsibility (hence the use of "we"), in practice, Mrs. Aydin is the one who fulfills this responsibility – which illustrates implicit gendered care norms.

In Mrs. Aydin's narrative, religion is used as a way to cope with a lack of care-sharing within the family, as Zeynep explains:

> I tell [my mother]: "Patience. Allah gives patience, you have to be patient." She says: "Yes, I have patience, but it's too much. I can't take it anymore." So I tell her: "Well, you have to do it… We should be thankful for what God gives us… We have to be patient with this illness."

Avoiding discussions about care-sharing within the family intensifies feelings of isolation and of being misunderstood, as Mrs. Aydin explains: "[It's] really so difficult, [caring for] ill people at home…. Nobody understands, [they] don't see everything, but [there's] nothing to do [about it]… Only Allah [can] help me."

In sum, Mrs. Aydin's narrative illustrates that coming from an under-resourced background and migrating later on in life can hamper opportunities for self-development. This may lead to a lack of necessary skills to negotiate care-tasks – which, in turn, exacerbates existing gendered care norms. Simultaneously, her narrative illustrates that caring for a spouse further impedes care-sharing, as the care-tasks are perceived as a continuation of the spousal relationship. Also, it illustrates that caring for a spouse with dementia may further complicate the care-role because the caregiver, too, may be older and frail. Here, religion is used as a way to cope with a lack of care-sharing, but, at the same time, it shuts down discussions about the care. But, most importantly, Mrs. Aydin's narrative illustrates that, even when PwM share the care with culturally appropriate formal care-support, family caregivers may still experience exhaustion due to a lack of necessary skills to allocate care-tasks, as well as a lack of support from their families.

Theme 3: Sharing with family and formal services

Two of our participants, Lilian and Meliha, share the care-tasks within their family as well as with formal services. Like our other participants, Lilian and Meliha are primary caregivers. However, one of the main aspects that differentiates Lilian and Meliha's experiences from our other participants is that they both have acquired the necessary skills to organize and allocate care-tasks within their families and with formal services. Through Lilian's narrative, we illustrate how the intersection of her position within the family and social class impact on experiences of care-sharing within the family and with formal care.

Lilian

Lilian was born and raised in the Netherlands, together with three sisters and two brothers. Lilian's grandparents and parents migrated from Indonesia to the Netherlands in the 1950s when Indonesia gained independence from the Netherlands. For the past 30 years, Lilian worked as a social worker. She left this job a few years ago, around the same time that her mother was diagnosed with dementia, and decided to move into her mother's home in order to become her mother's primary caregiver:

> [My siblings and I] started discussing this with each other and we said, yes, actually it's better if someone moves in with her. And I became that person. It was a practical decision, [since] I lived alone.

Unlike her siblings, Lilian is unmarried and she has no children – which she perceives as the main reason for taking up the role of primary caregiver. However, even though Lilian perceives this decision as a practical one, more factors underpin this decision – as well as the ways in which she has organized the care-tasks.

In the first place, this can be related to her position within the family. Lilian is the eldest child in her family. Because of this, Lilian is (both implicitly and explicitly) expected to take responsibility over family matters and to make final decisions with regards to these matters, as she explains:

> When there's no useful discussions together, when we can't [work things out], then I take my role as the eldest… If no decision can be made, or if there's always bickering about this and that, then eventually I'd say: "Come on, enough. We're going to do it this

> way.” … In other situations I also notice that my sister, for example, says: “But aren’t you the eldest?”

So, Lilian felt responsible for taking the role of primary caregiver not only because of practical reasons but also because, as the eldest sibling, it was expected of her. While taking the lead, Lilian shows decision-making skills that are necessary in organizing and allocating care-tasks – which relates to her social class, as will be explained below.

Lilian tells us that, despite not experiencing her family ties as good, she asks for care-support when needed and frequently informs her siblings about their mother’s care-situation. Through her educational background and extensive experience as a social worker, Lilian has developed skills (assertiveness and strong organizational and communication skills) that are needed to allocate care-tasks within her family:

> I’d rather do it all by myself, but I can’t… So I ask my little brother or sister [for care-support]… I have to ask. But also, when it comes to professional care. And also, with my uncle who lives two doors away… I hate to ask him… but I have to do it, for my mother’s sake.

Lilian would prefer to provide exclusive care, but she realizes that this could lead to exhaustion – which, in turn, will prevent her from providing any care for her mother. Furthermore, Lilian’s obtained skills help her to also seek care-support outside of the family and to organize this in a structured way:

> My mother goes to [an adult daycare for Indonesian and Moluccan elders] three times a week, but I recently made a request for an additional day… And she goes to [a gathering] for the elderly in our local community center every Tuesday afternoon… And I found an organization where you can hire someone to take her for a coffee, to the mall, to walk a bit outside, for at least two hours… So she’s actually busy almost all five days of the week. Now I’m [figuring out if] I can find someone to do something like this with her during the weekends.

Apart from the above weekly planning, Lilian’s mother receives homecare services (showering and dressing assistance) three times a week. By organizing and managing her mother’s care, Lilian is ensuring that her mother is properly cared for. Sharing care-tasks is thus something

Lilian perceives as “good care” – as her earlier quote (“I have to do it, for my mother’s sake”) implies. This leaves us with the question of why Lilian does not experience a barrier in invoking formal care-support, as we saw in Atifa and Mrs. Aydin’s narratives. We argue that this, too, relates to her social class. That is, it relates to Lilian’s perception of her family’s social class compared to other Moluccan-Dutch families.

During our interview and observations, Lilian repeatedly mentioned that, because of her upbringing, she perceives herself and her family as “different from other Moluccans.” Her mother worked as a kindergarten teacher, although it was uncommon for women in their surrounding ethnocultural community to work – which is why Lilian’s family would be perceived as “different.” Furthermore, Lilian grew up in a close-knit Moluccan neighborhood. Most of its residents would not participate in social activities outside of their community, but Lilian and her family would:

> My parents were busy with social life in the neighborhood, but they also had a social life outside of the neighborhood… So, in that sense we were different too… It’s an advantage that my parents raised us both within the Moluccan neighborhood and outside the Moluccan neighborhood.

Lilian explains that, because of her upbringing, it was easier for her and her siblings to accept formal services. She does so by contrasting her family with another Moluccan-Dutch family:

> [One of our Moluccan-Dutch neighbors] is in her nineties. My mother asks every time: “Why don’t those children take her to the daycare?” But one of the volunteers there said: “She’s going to perish here. She’s not accustomed. She’s still of that generation, staying at home, taking care of the children. They haven’t had a social life outside the Moluccan neighborhood.” … But for us, as children, it wasn’t difficult to take that step.

Lilian’s perception of her family as “different from other Moluccan-Dutch families” thus relates to the ways in which she perceives and experiences her social class relative to other families with a Moluccan background. Those who provide parental care at home are perceived as “not accustomed” to contemporary norms of caregiving, in contrast with Lilian’s family.

3.5 Discussion and conclusions

Instead of isolating the impact of ethnicity and culture from other social categories that are relevant to care-experiences, we have sought to identify the complexity of dementia care-sharing in families with a migration background. In other words, we have sought to look beyond "ethnicity labels" that oversimplify practices of care (Botsford et al., 2011). Throughout our analysis, the intersection of migration history and social class stood out the most – as this was visible in all our participants' narratives. However, other social categories also affect care-sharing. Our findings illustrate how one's position within the family, supportive social networks, religion, gendered care norms, and relationship to the care-recipient are relevant to experiences of care-sharing.

Migration history and social class can either help or hinder educational opportunities, and thus impede or support care-sharing. Those who grew up in a lower or working-class family and migrated later on in life from an environment where educational opportunities were limited, were less likely to be equipped with the necessary management skills to organize and share care-tasks. In contrast, those who grew up in a middle-class family, migrated at a young age, and grew up in an environment with educational opportunities, were more likely to share the care (both with family and formal care).

In addition, migration history and social class influence perceptions of "good care" and therefore one's willingness to share the care with formal services. More specifically, level of education (or a lack thereof, depending on one's migration history and class background) impacts on how family caregivers conceptualize and describe the care-context, where they choose to (or have the opportunity to) seek help, and whether and how preventive measures are considered (Morhardt et al., 2010; Sagbakken, 2017). Jun and Lilian considered organizing and arranging formal care-support to be compatible with their perceptions of "good care," for example, whereas negotiating (more) formal care-support was incompatible with Atifa and Mrs. Aydin's perceptions of "good care." These findings resonate with a study conducted by Jutlla (2015), which also points to the importance of migration history and social class in seeking dementia care-support outside of the family, and to demand support when necessary. In a similar manner, Conkova and Lindenberg (2020) show how differences in migration history and social class influence how PwM perceive ideas of "aging well."

In addition to the above, our findings suggest that one's position within the family may play an important role in caregivers' ability and confidence to organize and allocate care-tasks within the family and with formal care. This factor played a role in Lilian's narrative, which illustrates how – as the eldest child in the family – her siblings trusted her and felt that she was more competent in making important decisions within the family.

Furthermore, our study suggests that, to avoid exhaustion, supportive social networks are especially crucial to under-resourced family caregivers who are less equipped to organize care-tasks. Someone like Atifa can discuss her concerns with her family members when she experiences feelings of exhaustion. Also, she has a large circle of friends for emotional support. In contrast, Mrs. Aydin's lack of a supportive social networks further hampers care-sharing. Supportive social networks thus may mitigate the impact of social categories that curtail care-sharing. Indeed, previous research has suggested a strong link between social networks and caregiver wellbeing (Roth, 2020). This may be why caregivers with supportive family and friends can generally cope better with their role than those who are isolated in their care-role or who have an uncooperative social network (Francis et al., 2010).

When supportive social networks are absent, PwM who identify as religious may use religion as a way to cope with isolation and a lack of care-sharing. This was visible in Mrs. Aydin's narrative, in which both her daughter and herself emphasized religion as a way to accept the care-situation as it is. Previous research (Merz et al., 2009) also suggests that PwM may use religion as a way to compensate for a lack of supportive social networks. However, even though family caregivers may derive a sense of strength and support from religion (van Wezel et al., 2014), it may further hamper discussions about care-sharing (see also, Ahmad et al., 2020), as Mrs. Aydin's narrative suggests.

By examining our participants' experiences at the individual level, our study also illuminates wider discourses of structural inequalities. First, our study confirms prior findings that report gendered care norms in families with a migration background (see, e.g., Ahmad et al., 2020; Sagbakken et al., 2018; van Wezel et al., 2014). In the context of our study, this implies that families must care for their older relatives, rather than professional outsiders. In practice, this often means that the care-tasks rest on the shoulders of one female family member, but to the outside world (i.e., the social community as well as healthcare professionals) other family members may express it as a joint effort. In Atifa's narrative this means that care-responsibilities are assigned to women rather than men in the family. When reflecting on the care-situation, the possible role of men is not considered. Allocating care-tasks outside of the home-environment is considered to be a form of neglect, and a source of shame for the family, as it may lead outsiders to think that the family does not care about the older relative. This was illustrated by Zeynep, a family member who was not involved in the care but expressed a fear of gossip within her extended family and wider ethnocultural community. To conform with this gendered care norm, providing care in the home-environment is thus vital in presenting and maintaining an image of a family who takes care of its older members – even when, in practice, the care is not equally distributed within the family.

How strongly our participants adhere to gendered care norms depends mostly on migration history and social class. We have shown how migration history and social class matter in terms of identity and feeling connected to, or "different" from, a wider ethnocultural community in the country of residence – and thus whether or not family caregivers can invoke formal care without having to give in to oppressive, gendered care norms. Jun, Lilian, and Meliha do not experience social pressure to (continue to) provide intensive care in the home-environment, whereas this community norm is present in Atifa, Faiza, and Mrs. Aydin's narratives. A major difference between Atifa, Faiza, and Mrs. Aydin on this matter is that Atifa and Faiza experience supportive social networks that sustain them in their care-role, whereas Mrs. Aydin does not. Furthermore, in Mrs. Aydin's narrative, gendered care norms intersect with her relationship to the care-recipient, which further complicates the care-situation. In other words, her care-role is perceived as an extension of her role as a wife and mother who had already dedicated her life to her household.

Second, in the Netherlands, as in many other Western countries, reform of long-term care has been accompanied by cutbacks and a larger amount of citizens' self-responsibility in providing care (Verbakel, 2014). Within the context of our study, this means that family caregivers have to rely on their management skills and surrounding network to organize the care-tasks – both within the family and with formal care. However, as our study suggests, this is not feasible for all PwM caring for a family member with dementia. PwM who come from an under-resourced background are less likely to negotiate and share care-tasks compared to PwM with the opportunities and financial means for self-development. Our findings thus reveal the dichotomy between educated and uneducated, and how this affects people's abilities and possibilities for care-sharing that is expected by the current institutional organization of care.

Our small sample is the first study using an intersectionality lens to offer a better understanding of practices of care-sharing among PwM caring for a family member with dementia. It was not our aim to present a representative sample. Instead, we aimed to present a diversified view of experiences of care-sharing as to better understand how social categories intersect, manifest themselves, and are dealt with in social practice. We explicitly did not classify our participants in ethnocultural groups in order to make a comparison between these groups. Such a comparison would not only be reductive and othering, but it would also fail to understand our participants' experiences.

The applied methods for our data collection are an important strength of this study. Each participant was interviewed and observed for a total of five to six hours – which allowed us to build trust and to have in-depth conversations. That is why, throughout the life-story interviews and while shadowing, the discussed topics came up in a natural and connecting way. This would not have been possible in an interview following a structured list of direct questions. For instance, we did not directly ask our participants about the ethnicity they identify with. In our experience, such questions objectify the interviewee and create distance between researcher and researched. Instead, our participants' self-identifications were revealed through their life-stories and while we were shadowing them.

The life-story interviews allowed us to explore how participants' life-stories relate to their current lives and decisions as family caregivers. Additionally, these interviews served as a preliminary conversation that was necessary to gain trust to conduct shadowing observations in a setting that generally does not welcome outsiders. Because of this gained sense of trust, we noticed that our participants felt more comfortable elaborating on their care-experiences while we were shadowing them (hence, a significant part of our presented data were collected through informal conversations).

In sum, our combined methods allowed us to better understand our participants' multilayered experiences in an analysis that does more justice to the experiences of care-sharing. To this end, a combination of the employed methods is suitable for an intersectional analysis. But, even more important, employing these methods made it possible to also include participants with low literacy, limited Dutch language skills, and/or participants from under-resourced backgrounds, who are often excluded in research (Bonevski et al., 2014; Redwood & Gill, 2013).

3.6 Implications for practice and policy

Dementia in PwM poses a relevant concern for European health and social care (Alzheimer Europe, 2020). It is thus important to find suitable interventions to support families with a migration background. The findings presented in this paper may help offer a better understanding of how to improve care-sharing in a way that corresponds to the different needs and wishes of PwM caring for a family member with dementia.

To optimally support family caregivers, it is essential that health and social care workers seek to understand the care-context and individual perspectives of every family caregiver. Both practice and policy should take into account that intersections of various social categories impact the type of support that is (or is not) organized in families with a migration background. Here, the availability of culturally appropriate services is important, but it is not always sufficient to relieve caregivers in their care-role. One should recognize that, even when the care is shared, family caregivers may still experience exhaustion. Thus, health and social care workers should be wary of making assumptions about caregivers' needs and wishes for care-support.

To be able to provide care-support that is attuned to caregivers' individual needs and care-context, the adoption of a biographical approach to needs assessment and care-planning may be useful. Such an approach has been used within the context of care-needs of individuals in long-term residential aged care (Clarke et al., 2003; Menn et al., 2020) and palliative care (Hesse et al., 2019). Listening to the life stories of PwM caring for a family member with dementia (including their current lives and care-experiences), and being aware of the circumstances and social structures that have shaped and affected them, may help practitioners to meet caregivers' individual needs. Here, it is particularly important to be attentive to gendered care norms, religion, migration history, social class, relationship to the care-recipient, and position within the family – and how different intersections of these social categories affect practices of care-sharing. Furthermore, health and social care workers should be aware of the presence or absence of supportive social networks, and how this may mitigate or exacerbate social categories that curtail care-sharing.

In other words, conversations with PwM caring for a family member with dementia should be carried out in a way that makes family caregivers feel safe and understood. This is only possible when assumptions are left aside, and each caregiver is approached as a unique individual whose experiences and care-context are influenced by distinct combinations of intersecting social categories.

3.7 Notes

1. Pseudonym.
2. In this paper social class is understood as: a marker of one's positioning within society related to one's socioeconomic status (SES) and subjective social status (SSS). Here, SES is defined as a combination of one's financial income, level of education and occupation. SSS is defined as one's subjective perception of their social class relative to others, including one's human, social and cultural capital (American Psychological Association, 2015).
3. With gender norms we are referring to: "social norms defining acceptable and appropriate actions for women and men in a given group or society. They are embedded in formal and informal institutions, nested in the mind, and produced and reproduced through social interaction" (Cislaghi & Heise, 2020, p. 9–10). With gendered care norms we are thus referring to social norms that (implicitly or explicitly) perceive caregiving as women's work.
4. Country altered to protect anonymity.

3.8 References

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Loneliness

I took this picture [at the nursing home] because it looks very lonely… Often when I arrive, this lady… she's either sleeping or sitting like this. So I can understand that it's really boring to stay in a living room like that and that you're just frustrated that you can't go outside.

How does it make you feel when you relate this to your mother?

It makes me feel sorry for her… It motivates me to think: "What can we do?"
It's going better now… But you have to take action the moment you see that, again, nothing has been done. You see, this lady more or less chooses to sit there… But, then again, nobody ever asked her: "Would you like to go outside for a bit?" … So, yes, to me, this picture sort of symbolizes that loneliness.

◆ Nick, primary caregiver of his mother

Chapter 4

Practitioners' perceptions and experiences of shared care

This chapter has been submitted ('revisions under review') to an international peer-reviewed journal as:

Ahmad, M., Saharso, S., & Tonkens, E. Caring for individuals with dementia: How do practitioners perceive and experience care-sharing with families with a migration background?

Abstract

Background and objectives

Previous studies focusing on persons with a migration background (PwM) caring for a family member with dementia have been mainly concerned with access barriers to service use. Based on these studies, we suspect that practitioners' views and experiences of care-sharing can have a major impact on care-sharing with PwM. In this study we aim to offer a better understanding of these views and experiences.

Research design and methods

A qualitative study of 10 practitioners (health and social care workers) was conducted through semi-structured interviews. The analysis of these interviews was inspired by Hochschild's interpretive framework of "framing and feeling rules." In addition, we highlighted how practitioners' identified frames can be understood in light of the care-experiences of PwM caring for a family member with dementia ($n = 31$).

Findings

Practitioners frame successful care-sharing through the framing rule of "proximity within the practitioner-client relationship" and the framing rule of "a demand-oriented approach." Obstacles to successful care-sharing may be perceived through the framing rule of "the migrant Other" and the framing rule "they look after their own." All four framing rules can lead to a feeling of caution and inadequacy to perform professional duties.

Conclusions and implications

When care-sharing is hampered, this is detrimental to both practitioners and family caregivers. Thus, there is a need to rethink the outcomes of professional approaches to care-sharing. Instead of perceiving PwM as a divergence from the majority population, there is a need to move towards a perception in which diversity is recognized within all professional approaches to dementia care-sharing. This requires an adaptive approach that creates space for difference, rather than an approach that fits a majority.

4.1 Introduction

The demographic landscape of Europe is changing due to its aging populations and changing ethnic composition (England & Azzopardi-Muscat, 2017). For instance, in the Netherlands, older individuals with a migration background are expected to make up 21% of the aging population by 2060 compared with 11% in 2015 (van Duin & Stoeldraijer, 2014). This means that the incidence of dementia among persons with a migration background (PwM) will increase, since dementia has a higher prevalence rate among individuals aged 60 and older (World Health Organization, 2012). Consequently, dementia care among PwM poses a pressing concern for European health and social care (Alzheimer Europe, 2020; Canevelli, 2019).

Nevertheless, this concern does not seem to have been accompanied by research focusing on (the improvement of) care-sharing between formal care and PwM who are providing care for a family member with dementia. Previous studies have mostly focused on experienced access barriers to service use. These access barriers may include: negative experiences with services (such as discrimination and feeling misunderstood), language barriers, lack of clarity about where or how to access help, lack of knowledge about dementia, the belief that nothing could be done to help, and shame and stigma within the community (Botsford et al., 2011; Greenwood et al., 2015; Mukadam et al., 2011).

Although these barriers are commonly perceived as internal barriers (i.e., obstacles related to PwM themselves or to ethnocultural community norms that hinder formal care-sharing), studies suggest that external barriers may also hinder service use among PwM. For example, in their research briefing, Moriarty and co-workers (2011) point out that when practitioners lack the confidence and competence to cope with language and cultural differences, ethnic minority populations may refrain from using dementia care-support. Also, a lack of culturally sensitive approaches (Hossain & Khan, 2020), and social exclusion (Juttla, 2015) may lead PwM to withdraw from provided care-services. Stereotypical assumptions about care-support in families with a migration background may also hinder service use. For instance, a qualitative study on homecare for Turkish and Moroccan families in the Netherlands (de Graaff & Francke, 2003) suggests that general practitioners (GPs) may sometimes not refer these families to homecare because of the assumption that there are enough family members who will together provide care. However, in reality, one female family member often provides most of the care exclusively – which can lead to feelings of exhaustion and isolation in the long term (Ahmad et al., 2020; van Wezel et al., 2014).

Such barriers, both at the internal and external level, suggest a lack of dementia care-sharing between practitioners and PwM caring for a family member with dementia. However, these identified barriers do not provide an understanding of how experienced social situations may hamper or facilitate care-sharing between practitioners and PwM. That is, our understanding of care-sharing does not imply a mere utilization of formal services. Rather, we understand care-sharing as a relational process within families, and between families and practitioners, in which family caregivers are guided and supported throughout the care for their family member with dementia. We suspect that practitioners' views can have a major impact on care-sharing with PwM.

Thus, in this paper we aim to understand how practitioners' views may impede or facilitate dementia care-sharing with families with a migration background. To offer a fuller picture, we will relate practitioners' expressed views to the care-experiences of PwM who provide care for a family member with dementia. After all, a possible reason for suboptimal care-sharing could also be a mismatch in expectations or misunderstood intentions or behaviors between practitioners and PwM. To achieve our study's aim, we will answer the question: How do practitioners perceive and experience dementia care-sharing with PwM, and how does this relate to the care-experiences of PwM caring for a family member with dementia? Identifying these concerns can open up discussions about the improvement of dementia care-sharing with PwM.

4.2 Theoretical perspective

As mentioned in the above, most of the available knowledge about dementia care in families with a migration background relates to internal and external access barriers to formal services. Based on this knowledge, as well as our already collected data in our larger research project, we suspect that dementia care-sharing does not only relate to access barriers to formal care; it also relates to differences in views and feelings – which may be a cause for friction within the practitioner-client relationship. However, there is a gap in knowledge about such relational aspects of care-sharing. This paper responds to this knowledge gap with the help of Hochschild's interpretative framework of "framing and feeling rules" (1983, 2003), which will guide our analysis of practitioners' perceptions and experiences of care-sharing. Thereafter, we will add another layer to the analysis by relating practitioners' expressed "framing and feeling rules" to the experiences of PwM caring for a family member with dementia.

Framing rules are "rules governing how it is we see situations" (2003, p. 82). According to these frames, people ascribe definitions or meanings to situations. People use feeling rules, Hochschild argues, to relate to these frames. Feeling rules "define what we imagine we should and shouldn't feel and would like to feel over a range of circumstances; they show how we judge feeling" (2003, p. 82). Thus, framing rules and feeling rules mutually inform each other, as framing rules "point to the cognitive, meaningful, and interpretive frame within which feeling rules are situated" (Tonkens, 2012, p. 199). For instance, someone who just got fired may perceive this through a frame of personal failure or heartless capitalism (2003, p. 99). A frame of personal failure will lead to a feeling of disappointment in oneself, whereas a frame of heartless capitalism will lead to a feeling of indignation. So, framing and feeling rules together determine how we grasp social situations (Hochschild, 1983, 2003).

We chose this framework because it helps to bring dilemmas, tensions, and conflicts of human interactions to the fore (Tonkens, 2012). Rather than placing a focus on access barriers to service use, we aim to offer an in-depth understanding of relational aspects of care-sharing with PwM. By highlighting how practitioners frame dementia care-sharing, and how these frames determine their perceptions of and experiences with PwM, this paper highlights new insights for discussions about dementia care in families with a migration background.

4.3 Research design and methods

Design

Our study was conducted in the Netherlands, and is part of a larger, qualitative research project on care-sharing in families with a migration background caring for individuals with dementia.

Our data on practitioners' perceptions and experiences were collected through semi-structured interviews. These include health and social care workers who are in contact with PwM who are providing care for a family member with dementia. Our interviews with practitioners are taken as this paper's primary focus. Due to COVID-19 regulations, they were conducted through online video-calls in Microsoft Teams.

Our data on the care-experiences of PwM were gathered through PwM who provide care, or have until recently provided care, for a family member with dementia. In the present study, we use this set of data to better understand our findings from the practitioners' interviews. As part of our larger research project, this dataset was gathered through five different qualitative methods, namely: semi-structured interviews, photo-voice interviews, life-story interviews combined with "shadowing" observations, and a focus group discussion. The focus group discussion was conducted through an online video-call in Microsoft Teams, the remaining four methods were conducted in person.

In the Netherlands, when a study is subject to the Medical Research Involving Human Subjects Act (WMO), it must undergo a review by an accredited Medical Research Ethics Committee (MREC). The MREC of the University Medical Center Utrecht has assessed that our research project is not subject to the WMO (decision date: 17/08/2017). Therefore, ethical approval was not required. For more information on this matter, see: Central Committee on Research Involving Human Subjects (2022). All included participants were given informed consent.

Data collection

Both datasets were conducted by the lead author. For the first dataset, practitioners ($n = 10$) were interviewed between July 2020 and January 2021. We recruited them through partner organizations and the lead author's professional network. Eight of the referrals have a white-Dutch background, two of the referrals have a migration background (Chinese and Turkish). Interviews were conducted with the support of a topic list focusing on five central topics, namely: professional background; caring for a person with dementia; communication with family caregivers and their relatives; care-sharing within families; care-sharing with formal services. All interviews lasted between 60 and 80 min. An overview of the sample is given in table 1.

The second set of data was gathered between February 2018 and February 2021. We spoke with family caregivers ($n = 31$) who have a Chinese, Indian-Surinamese, Moluccan, Moroccan, and Turkish migration background. They were recruited through community centers, social care workers, organizers of peer groups for family caregivers, and through partner organizations. Within the five conducted methods, the following themes were included: dementia; caregiving process and experiences; discussing care-tasks with family/friends; receiving emotional/practical support from family/friends; discussing and sharing the care-tasks with practitioners. The semi-structured interviews ($n = 13$) lasted between 45 and 120 min. The photo-voice interviews ($n = 5$) lasted between 60 and 100 min. The life-story interviews were followed by "shadowing" observations of our participants' ($n = 6$) daily lives as caregivers. Here, each participant was interviewed and observed for a total of five to six hours. The focus group discussion ($n = 7$) lasted 100 min.

Table 1. Overview of the research sample - Practitioners (P)

	Age	Gender	Cultural background	Profession
P1	42	F	Dutch	District nurse
P2	61	F	Dutch	Caregiver support-manager
P3	57	F	Dutch	Dementia case-manager
P4	47	F	Dutch	Caregiver support-manager
P5	54	F	Dutch	Dementia case-manager
P6	52	F	Turkish	Social care worker
P7	55	M	Chinese	Care consultant for Chinese-Dutch elders
P8	58	F	Dutch	Geriatric nurse
P9	44	F	Dutch	Geriatric internal medicine specialist
P10	58	F	Dutch	Practice nurse

Analysis

All data were transcribed verbatim and anonymized. Within the analysis of our first dataset, we made use of a directed approach to qualitative content analysis (Hsieh & Shannon, 2005). In this approach, existing theory or prior research is used to guide the analysis by first identifying key concepts or patterns as initial categories. Next, operational definitions for each category are determined using the theory (p. 1281). This meant that we were guided by Hochschild's (1983, 2003) interpretive framework of "framing and feeling rules" as an analytical lens to understand how practitioners frame their perceptions and experiences of dementia care-sharing with PwM. Following Hsieh & Shannon (2005), the analysis of our first dataset included the following steps.

First, the interviews were inductively coded. We identified repetitive patterns and initial codes while reading all transcripts, after which an initial coding scheme was created. After that, all transcripts were transferred to Atlas-Ti where they were further analyzed and coded by the lead author. Identified patterns and themes were discussed with all authors in several extensive meetings. Second, we established the coding categories by further analyzing the codes. Here, we asked: "How do practitioners frame successful care-sharing?" "How do practitioners frame their perceptions and experiences of care-sharing with PwM?" And: "How do practitioners' expressed emotions (such as a feeling of inadequacy, victory, and hesitation) relate to these frames?" Around 90 codes were identified. The identified codes were clustered into eight categories that we organized in a coding scheme.

Next, we used our second dataset to better understand the research findings from the practitioners we spoke with. We already analyzed and reported the second dataset in two previous papers (Ahmad et al., 2020; Ahmad et al., 2022). Our comparison with the first dataset was based on the data that were already coded for these papers, as well as the complete raw dataset of all family caregivers included in our larger research project. In other words, we made use of data source triangulation. Here, we revisited codes that relate to family caregivers' perceptions and experiences of formal and informal care-sharing. After that, we compared this to the analysis of the first set of data. The findings from both datasets were thus not expected to match, but were meant to create a fuller picture of experiences of dementia care-sharing between practitioners and PwM.

The combined stages of the analyses have led to the identification of four overarching themes in which we discuss practitioners' expressed framing rules, namely: (1) proximity within the practitioner-client relationship, (2) a demand-oriented approach, (3) the migrant Other, and (4) "they look after their own."

4.4 Findings

Analysis revealed that practitioners perceive successful care-sharing through two framing rules: a framing rule of proximity within the practitioner-client relationship, and a framing rule that calls for a demand-oriented approach. In their attempts to stimulate care-sharing with PwM, meeting with these framing rules is often hindered. This may result in a feeling of inadequacy to perform professional duties, and a feeling of caution in offering care-guidance. Our analysis also revealed two framing rules of cultural explanations for obstacles to care-sharing with PwM: a framing rule in which PwM are perceived as the migrant Other, and a framing rule that assumes "they look after their own." Due to a perceived lack of cultural knowledge about PwM, these framing rules, too, may lead to a feeling of caution and inadequacy to perform professional duties. In the following four sections, we elaborate on each framing rule through the perspectives of practitioners, while we highlight how these framing rules can be understood in light of family caregivers' experiences.

Proximity within the practitioner-client relationship

Practitioners experience proximity with their clients as essential to successful care-sharing. This is framed as the ability to build a relationship of trust in which the needs and wishes of both caregiver and care-recipient are communicated. Such a process ideally starts at an early stage of dementia, usually after a family member has noticed early symptoms in their relative or spouse. In their contacts with PwM, practitioners express a number of obstacles within the process of achieving proximity.

First, practitioners express that, more often than in white-Dutch families, the early stage of dementia is overlooked or denied in families with a migration background. Some practitioners (P2 and P5) indicate that, despite working in an ethnically diverse neighborhood, they have a small number of PwM in their client database – as a dementia case-manager explains: "I work in several neighborhoods where quite a lot of [PwM] live, but the group of people with dementia is a small group in my file… People are not open to talk about such matters" (P5). By the time family caregivers seek formal help, the dementia has often progressed so far that hospitalization is needed. Since this leaves little space to guide families through the care-process, the process of building trust with their clients is inhibited. A caregiver support-manager expresses this as follows:

> You should be able to get close earlier [in order to give care-guidance], but that's a really tricky thing with this group… Especially in the early stages of dementia, there's a lot of shame and it's often brushed aside as if it's not there. So, by the time they [acknowledge] it's there, [their relative] is already in a very advanced stage. Then it has already come so far that there are very few solutions (P4).

When PwM *do* seek help at an early stage, practitioners often experience a language barrier with the care-recipient. This is experienced as an obstacle to proximity because: "You often have to speak with children of the patients, who then interpret. And because of this, you don't have direct contact with the patient; it always goes through another person" (P10). Indeed, this obstacle is further complicated when both the care-recipient and family caregiver do not speak Dutch well.

Other expressed obstacles include a general feeling of distance between practitioners and clients, and families' lack of trust in formal care-support. This may be the result of an experienced language barrier. A dementia case-manager explains how this creates distance and prevents her from performing her job well:

> This morning I visited a [client who has dementia]; he's from Azerbaijan… His wife takes care of him. Through her daughter, I asked her: "How are you doing?" So she [started] crying, without being able to explain why… And of course I know why. You can see the worries drawn on someone's face… And you want to [help them] so much, I really enjoy walking that path together, so that she can share [the care] a bit… And this lady was very nice, very friendly, very sweet people, but there's a distance (P3).

Thus, when the framing rule of proximity is inhibited, practitioners may experience a feeling of inadequacy to perform professional duties (hence, "You want to [help them] so much… but there's a distance").

In addition, a lack of trust due to a fear to be "sent away" to a nursing home may exacerbate a feeling of distance:

> I also [have contact with] a Vietnamese caregiver. Her daughter has settled well here, speaks Dutch well. But this lady, well… They look at me very much during conversations… A certain look of well, who's that? What is she saying? Because, of course, [the caregiver and care-recipient] don't understand me. So, I always explain to [their daughter]: "I'm not here to put people away. Do you want to translate that? Tell them that I'm here to see what I can do for them and if I can help them" (P3).

Even though an experienced distance and lack of trust in formal care-support (sometimes due to the effects of an experienced language barrier) have been expressed by nearly all practitioners ($n = 8$), our data suggest that practitioners who have more professional experience with PwM are more equipped to overcome obstacles to proximity. For instance, the above example (P3) is from a case-manager who expressed to have little to no experience working with PwM, as she was recently relocated from a white majority neighborhood to an ethnically diverse neighborhood. Practitioners who have more experience working with PwM expressed several approaches to overcome obstacles to proximity. One such approach involves the support of a social worker with a migration background, as a caregiver support-manager explains:

> We don't have employees with a migration background in our team… So, when we know there are barriers [in our interaction with PwM], we call in a social worker who is familiar with the culture. Then we try to go in pairs… If you do that at least once or twice then eventually they'll embrace you, too… It's often better to initially go with [a social worker who has the same migration background as the clients]. And even though I'll be just sitting there drinking tea – thinking, "jeez, this is a waste of my time" – it's actually very important to make that connection (P4).

Practitioners also expressed other approaches to overcome obstacles to proximity. These include: making use of a professional interpreter; calling in a religious (e.g., Islamic) counselor in family meetings; showing acknowledgement of caregivers' contribution; scheduling informal meetings with the caregiver and/or care-recipient.

Family caregivers, too, often experience distance with practitioners. One such example is when practitioners do not show acknowledgement of caregivers' contribution by (sometimes implicitly) suggesting a need to move away from family care. A Moroccan-Dutch family caregiver explains how she felt when a district nurse repeatedly insinuated a need to move away from family care to a nursing home:

> She keeps saying: "Are you able to care?" "Can you handle it?" … It's as if she's [saying]: "You can't handle it." … She also [said]: "Are you considering a nursing home?" I was so angry… Why does she ask that every time? (FC8)

Data from the caregivers we spoke with suggest that the care-role gradually becomes an important part of one's moral identity (Ahmad et al., 2020). When practitioners do not express acknowledgement of caregivers' work, and instead give the impression that caregivers should distance themselves from their care-role, this can inhibit proximity within the practitioner-client relationship – as illustrated in the above example.

Family caregivers may also experience distance when practitioners express their concerns, or the course of the disease, in a straightforward manner. A Chinese-Dutch family caregiver of her mother explains this as follows:

> [The nurse] was very unkind because she said to me: "This lady, with such an old age, she will never get well." Because she's old and didn't speak Dutch and had dementia…

> But how can she say such a thing? Who is she to write off an old lady like that? … That is why we thought: "We don't want mom to be stressed and we just want to give her a nice old day" (FC2).

The above experience, as well as other similar negative experiences with practitioners, have created a sense of distance with formal care – which is the main reason why this family caregiver decided to refrain from formal care services. A Turkish-Dutch social care worker is aware of this, and thus avoids speaking in straightforward terms:

> Dutch people are used to speaking in straightforward terms. In fact, I say the same thing [that my white-Dutch co-workers say], only with many indirect turns, you know? And people appreciate that more… Yes, then you notice that [clients with a migration background] trust me more (P6).

As illustrated in the above, our data suggest there may be a feeling of distance on both ends, but practitioners can take away obstacles to proximity. Hence, some practitioners find ways to overcome these obstacles. When this happens, it is experienced as rewarding, as a dementia case-manager illustrates:

> I now have [clients] who are from Suriname… Recently [the care-recipient] started going to a day-care, which he had been evading for a year… He has a great time there, which I had already told him many times, but before taking that step, yes, that takes a lot of work… And, you know, that sometimes feels like a victory (P5).

In this example, the practitioner managed to gradually build trust with the care-recipient by scheduling separate, informal appointments in which she would lend an ear. Eventually, this led to the care-recipient accepting formal care. By being able to respond to the framing rule of proximity, both the practitioner and her clients were able to move forward.

A demand-oriented approach

The second expressed framing rule to successful care-sharing entails a demand-oriented approach within the practitioner-client relationship. This is framed as an approach in which clients have to express their demands for care-sharing, after which practitioners align their professional support to these demands. Implicitly or explicitly, practitioners expressed this approach in their views about care-sharing. A district nurse expresses this as follows: "You have to sort of make sure that the initiative is left with [the clients] themselves… but offer them what's possible" (P1).

As mentioned earlier, practitioners indicated that, compared to white-Dutch families, PwM seek less formal care-support – which also stands in the way of a demand-oriented approach. When PwM *do* seek help through referral, practitioners notice that PwM often decline a follow-up appointment for further counseling:

> We get referrals from the dementia network and after that you want to start [the process] with a client; you start arranging home visits. And what you notice [with PwM] is that they don't want to make a follow-up appointment. [They'll say]: "I'll call sometime" (P3).

In this example, a family caregiver has declined support and a follow-up meeting with the dementia case-manager s/he had been referred to. Within the framing rule of a demand-oriented approach this means that the case-manager should respect this decision, since the family caregiver did not express a need for care-support after their initial consultation. Thus, practitioners generally experience a feeling of caution to further get in touch with PwM who decline help or who do not express their needs for care-support. A caregiver support-manager describes this as follows:

> I know [a family caregiver with a migration background], her father-in-law has dementia. I told her about the work we do and sent her [our monthly] Family Caregiver Newsletter and an [online dementia information tool]… She said: "We're handling it ourselves." I said: "Fine, but know that we're here." … If you can do it yourself then you should do it yourself, right? But I am convinced that 99 out of 100 people have to deal with rules and regulations… Anyway, they handle it themselves and I haven't heard anything from her. So, I find it difficult to impose myself and email her: "How are things going now?" – because she's not asking for my help. That wouldn't be demand-oriented, you know (P2).

In other words, due to a complicated healthcare system and the progressive nature of dementia, practitioners know that family caregivers will benefit from formal care-sharing throughout the care-process. But when a demand-oriented approach is inhibited, practitioners generally experience a feeling of caution to follow up with family caregivers.

Eventually, PwM may seek help when the dementia in their relative has further progressed. Practitioners are aware of this issue, but may not press discussions with their clients because it does not fit within the framing rule of a demand-oriented approach:

> And then when it's no longer possible [to provide care at home] they'll come to us, but then it's already on the late side… [But] I'm not going to tell them: "Hey, don't come [to us] too late," because I don't want to impose myself on people (P1).

So, when PwM do not express their needs and wishes for support, practitioners will refrain from offering possibilities for support.

However, when there is an experienced distance within the previously discussed framing rule of proximity within the practitioner-client relationship, it is unlikely that PwM will express their demands within an early stage of dementia. Moreover, when there is unclarity about dementia and the possibilities for care-support, PwM may not express their demands. This is illustrated through the following example from a Moroccan-Dutch family caregiver who contacted her GP for care-guidance:

> We literally told [our GP] what's [going on] with our mother, and then he didn't say: "Your mother needs this." So they should've diagnosed her and [we could've] hired [homecare services] to take care of her at home; he never informed us about this… He did mention: "We can do a lot for you" and "We are prepared to help you." … But explaining to us that things can be arranged in the Netherlands… We didn't know that there's [caregiver-]compensation and that you can hire people. [I had] never expressed: "My mother needs help and I have to arrange something." So maybe that's the reason, [but] the GP never said: "There's something wrong, you need to go there" (FC18).

Instead of being referred to a geriatric specialist, and being provided with the information and tools that would support her in her care-role, this family caregiver was left with further unclarity about her mother's behavioral changes due to dementia. As an alternative, she sought help within her community:

> We [later] found out about it ourselves, through other people. We asked people: "How did you take care of your mother?" Then we saw other examples… And then we said [to our GP]: "We also want to do that assessment to determine whether our mother has

> [dementia]." So we really had to address it this way, and we didn't know that. I felt so bad about it because my mother couldn't take care of herself anymore, and I had to take her into my home… She left the tap on, and the stove, it was dangerous. And, really, it took two years until that diagnosis was made.

The above example illustrates that, even when family caregivers seek formal help at an early stage of dementia, they may not be provided with care-guidance due to practitioners' framing rule of a demand-oriented approach. In a similar manner, a care consultant for Chinese-Dutch elders expresses this concern as follows:

> In the Chinese situation, dementia is complicated… There's no cure for it, so there's no ready-made solution. That's a barrier for the family to seek help. It's not like diabetes or a stroke, in which the possibilities for help are clear… You have dementia, so why ask for help? They need to know what they are entitled to, and whether it's covered free of charge. Not all Chinese people are familiar with the basics of the Dutch healthcare system… let alone formal help, such as homecare services (P7).

In other words, a lack of knowledge about dementia and possibilities for care-support will logically discourage people from expressing their demands for support. Thus, this framing rule is harmful to families who do not express their demands accordingly.

Furthermore, data from the caregivers who participated in this study suggest that, especially in a later stage of dementia, it may be difficult for family caregivers to accept formal care-sharing – as the care-role often gradually becomes a significant part of their identity. It is crucial that practitioners discuss this emotional barrier with family caregivers as early as possible, instead of waiting for family caregivers to express their demands. Simply providing family caregivers with, for example, an online dementia information tool (P2) is thus insufficient to achieve care-sharing.

The migrant Other

Half of the practitioners we spoke with ($n = 5$) perceive culture or cultural differences as an obstacle to care-sharing with PwM. These are cultural explanations attributed to specific ethnic groups or PwM in general. When this happens, PwM are framed as the migrant Other. A dementia case-manager illustrates this in the following example:

> They’re very nice, very friendly, but still there’s this line that seems to entail: “I am Afghan, you are Dutch.” You know? … I don't know exactly [how to explain it], but I do sense this [feeling] with all of them (P3).

Thus, when making contact is experienced as difficult, practitioners may attribute this feeling to cultural differences. The experience of these differences is informed by comparisons with clients from the majority Dutch population, as the same case-manager explains: “And there was a couple before them, a Dutch couple, and you notice the difference. We were able to make contact right away” (P3). A district nurse makes this comparison in a similar manner:

MA:	What do you think is the reason that [PwM] seek help in a late stage?
P1:	I think that’s culturally determined… Because, in the Dutch culture, I think we’re more used to signing people up for homecare services, and that parents [make use of] homecare. And, of course, in a lot migrant cultures it’s more common that they want to handle it themselves.

In other words, when practitioners experience obstacles to care-sharing, this may be perceived as “a culture thing”:

> We have a Turkish daycare and a Moroccan daycare … But what’s difficult about that, and I think that’s also a culture thing… is that they very easily [cancel and] say: “Oh, but I’m not coming tomorrow” (P4).

While such experiences are legitimate, cultural explanations are unproductive within the context of dementia care-sharing with PwM – as will be illustrated in the following.

First, when obstacles to care-sharing are attributed to cultural differences, the complexity of the situation is left unexplored. This prevents the emergence of possible solutions, as the following example from a dementia case-manager illustrates:

> The other day I heard from someone that they see dementia as a kind of curse. That you get it because you did something wrong. And then I thought to myself: “Oh help! Now I have to do something about that” (P5).

The case-manager elaborates on the above, by telling us that she wonders what this ("dementia as a curse") means within other cultures. Focusing solely on the meaning of culture leaves her feeling stumped, as it blocks her from exploring (and thus offering solutions to) the root of the problem she is facing. For instance, data from the caregivers we spoke with suggest that the problem she describes may be related to a lack of knowledge about dementia, more so than it relates to culture. We will illustrate this through the following example from a Moroccan-Dutch family caregiver who describes how, during the early stages of her mother's dementia, she believed her mother was possessed by a *djinn* (demon):

> Suddenly she was seeing things that weren't there, hearing things that weren't there… She couldn't sleep, was afraid, anxious… And then I thought maybe she's [possessed by a *djinn*]… Two or three times [imams] came here, for *ruqya* [exorcism]. They said: "That woman has no *djinn*." … And then I thought: "I'll go to the doctor." When I [understood] she has dementia, I thought: "I have to learn how to deal with this." I told the GP that I need to learn this… She [referred me] to someone specialized in teaching how to deal with [dementia]… I learned it there, *alhamdullilah* [thank God] (FC22).

When her mother's behavioral changes became visible, this family caregiver was unfamiliar with dementia. That is why she initially searched for non-medical answers. But the moment she was informed that these behavioral changes relate to dementia, she sought information about dementia(-care). With this gained knowledge, she now also informs people within her community:

> My cousin and her daughters don't know how to deal with [my aunt who has dementia]… Then I explained to them a little bit, what it means, and, yes, only then [they] started treating her properly. [It's] hard though, some people don't know and then they don't look for information. [It's] really difficult. Because I also experienced it myself, at the beginning [I thought]: "What should I do?" … [That's why] I tell many people about my mother, [about] the disease.

So, when family caregivers lack knowledge about dementia – or when finding information is an obstacle – this gap may be filled with other (non-medical) explanations. This was also emphasized by a care-consultant for Chinese-Dutch elders (P7). Fixating on culture (through the frame of the migrant Other) when facing obstacles to care-sharing therefore exacerbates a lack of care-sharing with PwM.

Second, a fixation on cultural differences creates a feeling of caution while interacting with PwM, as a district nurse explains:

> [Then] I think: “Okay how [am I] going to communicate this well?” … Then I have a goal in mind which I have to move towards in order to [have them] accept more care, but how do you achieve that without offending people? [How do] you take their culture into account? These are quite tricky matters (P1).

Besides a feeling of caution, a focus on cultural differences can lead practitioners to feel they are unable to perform their jobs well due to a perceived lack of cultural knowledge about the migrant Other. A dementia case-manager expresses this as follows: “It feels as if I need to read a book on how to deal with foreign people. Do you understand what I mean? That’s where [the problem] seems to be situated” (P3). Consequently, this dementia case-manager is left feeling stumped – as she is unable to adequately perform her profession. When this happens, practitioners may seek “diversity trainings” or professional tools about culturally appropriate care, while neglecting families’ knowledge about the care-recipient’s individual needs – as a Turkish-Dutch family caregiver explains:

> [An employee at the nursing home] said to me: “I'm going to find out what culture[-sensitive] care means.” I said to her: “But we’re right here [for questions about my mother’s care], we live with these people and we know how they’ve lived.” But, no, they wanted to go to a conference, to figure this out independently from our family… And that's really upsetting (FC30).

The above illustrates an implicit hierarchy of knowledge, in which this caregiver’s knowledge of her family’s culture and care-needs is considered to be inferior to professional knowledge about culturally-sensitive care. Indeed, our data suggest that PwM are willing to make use of formal care when it meets their needs. However, as illustrated in the above, family caregivers’ knowledge is not always utilized to determine these needs.

Thus, an overemphasis on culture does not only interfere with practitioners’ professional performance; it also prevents PwM from receiving adequate formal care-support. This is further illustrated through the following example from a Turkish-Dutch family caregiver:

> When I brought my mother [to the nursing home], [a care-worker] said to me: "Why are you bringing your mother here? There are also Muslim residential homes, right?" … I said: "What are you saying? What difference does it make if she's Muslim or non-Muslim? My mother is not [even] Muslim. My mother is Alevi!" … [They said] they had never dealt with this before because my mother's the first [PwM] in that nursing ward… [But] that doesn't matter because [residents] of that [ward] can't talk, can't share anything with each other. My mother doesn't talk anymore either… People in this [ward] are similar to my mother. They have the same disease as my mother (FC24).

Due to the perceived otherness of PwM, including the perception of PwM as a homogenous group (in the above case, Muslims) and preconceptions about cultural differences in care-needs, this family caregiver was met with rebuff and social exclusion when she sought formal care for her mother. When this happens, practitioners are unable to adequately perform their profession (by guiding PwM in their care-process), while PwM are prevented from receiving support that matches their needs and wishes.

"They look after their own"

A frequently expressed framing rule from some of the practitioners we spoke with ($n = 5$) is that PwM refrain from formal care-sharing because they prefer to "look after their own." This framing rule can be shaped in several ways. First, practitioners may base it on an actual observation of the family's preference to provide care in the home-environment, as a geriatric specialist explains:

> I don't experience at all that children don't [share] their parents' care. I have a lot of migrant elderly [patients], and I see quite a lot of children who are all incredibly involved; children who move into their parents' home or children who take their parents into their homes (P9).

Second, practitioners may also base this framing rule on their observations of children's involvement in different care-tasks:

> In my experience: when there's a number of children, then these children are generally involved and they distribute the [care-]tasks among themselves. I have a Moroccan [patient], her daughter is the one who provides physical care, the other daughter is the one whom I talk with about medical concerns, one son takes care of the finances, the

> other son does the groceries, and so on and so forth. So, the care is usually adequately distributed… I mostly encounter families who are very much together involved in the care-tasks (P10).

Third, besides the above expressed perceptions of care-sharing within families with a migration background, this framing rule may be shaped through a perceived presence of an extensive and supportive ethnocultural community, as pointed out by a district nurse:

> They are willing to do a lot and that's part of their culture, that migrants are surrounded by a large social network… So you notice that people around them, like neighbors, are quite willing to help a lot… I'm sure that Turkish migrants and the like always have enough people who can arrange this sort of thing (P1).

So, moving into the care-recipient's home, the presence of several family members, as well as the (assumed) presence of members from the same ethnocultural community, might create the perception that PwM share the care within an extensive social network. Such perceptions may be based on practitioners' observations of the distribution of care-tasks within families with a migration background. As a result, these observations are generalized to all PwM – creating the framing rule "they look after their own."

However, our data reveal that, in practice, the majority of the care-tasks typically rests on the shoulders of one or two family caregivers. Due to gendered care norms, this is usually a daughter(-in-law) or wife of the care-recipient. This is evident both from the experiences of the remaining five practitioners we spoke with (P3, P5, P6, P7, P8), and from the experiences of the included family caregivers ($n = 31$). On the surface, it may seem as if families are managing the care-tasks together; for example due to the presence of several family members during a hospitalization or during consultations with practitioners. But, in practice, this is often not the case. Therefore, when practitioners perceive informal care-sharing by PwM through the frame "they look after their own," family caregivers' needs for care-support will be neglected. This is illustrated by a Moroccan-Dutch family caregiver:

> Two of my brothers always accompanied [my mother] for an examination or when she was sick, they always went together. So, [the GP] saw that we were taking good care of my mother, and [maybe] he thought: "It's not necessary to [support them]." But he didn't know that we also had problems (FC18).

In other words, practitioners may refrain from providing care-guidance when they have the impression that PwM are managing the care-tasks together. As a result, an unequal distribution of care-tasks within families is not detected.

Even when practitioners *do* detect an unequal distribution of care-tasks within families, practitioners may explain the lack of formal care-sharing with the stereotypical assumption that PwM "are very much inclined to resolve matters within their own circle and do not quickly ask for [formal] help" (P4), and that they "look after their own" (P2). A caregiver support-manager explains this as follows:

> We Dutch people, we like to think that we have to provide [families] with [formal] support. But they [i.e., PwM], they just look after their own, in their own way, and they probably also get their information in all kinds of ways (P2).

Whether practitioners do or do not detect an unequal distribution of care-tasks within families, the framing rule that assumes PwM "look after their own" is harmful. Instead of exploring the care-context and barriers that PwM may experience, this framing rule hinders possibilities for (the improvement of) care-sharing.

Only a few (*n* = 6) of the family caregivers we spoke with experience their social network (including family members, and sometimes also neighbors/friends) as supportive. One such example is a Moluccan-Dutch family caregiver who has managed to share her mother's care within her social network and with formal care. This is not due to the idea that people within her community "look after their own," but it is due to her assertiveness and management skills. She tells us that a dementia case-manager did not acknowledge these efforts, and instead expressed an assumption about care-sharing within her ethnocultural community:

> [A dementia case-manager] came to see me once, but after that I didn't want to meet with her anymore. She kept saying that it's so nice that I have so many family members and Moluccans around me in this neighborhood, so that I don't have to feel alone [in my care-role]. I found that so irritating. Being a family caregiver is hard, even when you have people around you (FC20).

As illustrated in the above, not only does the assumption that PwM “look after their own” obscures family caregivers’ contribution; it also leaves no room for discussions about (the improvement of) formal and informal care-sharing.

4.5 Discussion and conclusions

The changing social and demographic landscape of Europe leads to more diverse family contexts and care-needs (Roberto & Blieszner, 2015). At the same time, within families with a migration background, care-experiences and needs for care-sharing are multilayered (Ahmad et al., 2022). This calls for an approach that fosters dementia care-sharing in a way that is sensitive to these different needs and experiences. However, as highlighted in this paper, it is not always possible to achieve this within current professional approaches. By examining how practitioners frame and experience care-sharing with PwM caring for a family member with dementia, we have highlighted obstacles and tensions within the process of care-sharing. In the following we reflect upon these findings.

Due to an experienced feeling of distance, practitioners are often unable to respond to the framing rule of proximity within the practitioner-client relationship. A language barrier and reaching out to formal care in a late stage of dementia are experienced as major obstacles to achieving proximity with PwM – a finding that is also highlighted in previous studies (e.g., Gulestø et al., 2020; Sagbakken et al., 2020). Even when communicating with family members was possible, practitioners often experienced a sense of distance. This could be due to an overlap of language and culture. For example, ways of speaking, or implicit references to religious and culturally shared knowledge, are suggested to impact communication between one another (Gora & Conner, 2013; Sagbakken et al., 2020). PwM, too, often experienced a lack of proximity with practitioners. Other studies report that this may be due to a general feeling of anxiety to accept professional outsiders which could be related to shame and stigma within the community (Tonkens et al., 2011), as well as experiences of social exclusion and institutionalized racism experienced by PwM (Jutlla, 2015). Also, PwM may experience a lack of proximity when practitioners fail to recognize the moral dimensions of caregiving or when concerns are expressed in a straightforward manner.

Within the framing rule of a demand-oriented approach, practitioners will generally experience a feeling of caution to offer care-guidance when PwM do not express their needs for care-support, or when PwM express a desire to perform the care-tasks themselves. As suggested in other studies (Sagbakken & Kumar, 2017; Mukadam et al. 2011), our study shows that knowledge about dementia and formal care-support is essential to help-seeking behavior. Also, studies show that when PwM experience language barriers, it is difficult to advocate for themselves, ask questions, and navigate healthcare systems (Espinoza & Derrington, 2021; Gengler, 2014). This may explain why families with a migration background often do not seek formal support in an early stage of dementia (Mukadam et al., 2011), and why PwM often receive delayed diagnosis or inadequate treatment for dementia (Chin et al., 2011). Nonetheless, the framing rule of a demand-oriented approach expects family caregivers' responsibility and assertiveness to express their care-needs. In doing so, this framing rule excludes families who have not yet been fully informed about dementia and possibilities for care-guidance. Previous studies (Ahmad et al., 2022; Jutlla, 2015) illustrate that (formal and informal) care-sharing is less likely for PwM who come from an under-resourced background, as compared to PwM who had the opportunities and financial means for self-development. Our findings thus suggests that the framing rule of a demand-oriented approach particularly excludes under-resourced family caregivers.

The framing rule of proximity within the practitioner-client relationship and the framing rule of a demand-oriented approach should be understood as interrelated, as they correspond with each other. This means that an experienced lack of proximity within the practitioner-client relationship will logically prevent PwM from expressing their needs and wishes within a demand-oriented approach. This may lead PwM to (further) distance themselves from formal care. Subsequently, obstacles to responding to these framing rules may be perceived through the framing rule the migrant Other and the framing rule "they look after their own."

Within the framing rule the migrant Other, care-sharing with PwM is contrasted with clients from the white majority population. Differences in PwM are attributed to their culture. Due to its essentialist and othering effects, the framing rule of the migrant Other hinders a full understanding of the care-context (see also, Botsford et al., 2011). As a result, practitioners experience a feeling of hesitation and inadequacy to perform their profession due to a perceived lack of cultural knowledge about the migrant Other. To resolve this matter, practitioners may seek knowledge about culturally sensitive care while neglecting family caregivers' knowledge about their family's culture and care-needs.

Within the framing rule "they look after their own," PwM are assumed to share the care-tasks within an extensive social network of family members and members within their wider ethnocultural community, or that PwM simply prefer to handle the care-tasks themselves. This frame is based on practitioners' observations of informal care-sharing within families with a migration background or on stereotypical assumptions about PwM. In either case, the frame "they look after their own" hinders practitioners from a complete understanding of the care-situation and family caregivers' individual needs for care-sharing – which can reinforce social inequalities and exclusion faced by PwM (Jutlla, 2015).

Thus, when obstacles to the framing rules of proximity and a demand-oriented approach are perceived through the framing rule of the migrant Other and "they look after their own", practitioners are blocked from finding solutions to these experienced obstacles. As our study suggests, not only does this prevent practitioners from adequately performing their profession; it also risks PwM from being excluded from formal care-sharing. In accordance with previous studies on dementia care in families with a migration background (Berdai-Chaouni et al., 2020; Gulestø et al., 2020), our findings suggest that practitioners are often unaware of the complexities of care-needs within these families. This could be why obstacles to successful care-sharing are framed through cultural explanations.

Strengths and limitations

There are some limitations in our study that deserve mention. First, our small sample of included practitioners limits generalizations about practitioners' expressed perceptions and experiences. However, it was not our aim to offer a representative sample. Rather, by highlighting practitioners' expressed frames, we aimed to offer an in-depth understanding of views and approaches that may impede or facilitate dementia care-sharing with PwM. Attaining this aim was in part possible because we related practitioners' expressed framing rules to family caregivers' experiences of care-sharing.

Second, rather than bringing family caregivers' framing rules to the fore, we only elucidated practitioners' expressed framing rules. We made this decision based on our research aim and question. Family caregivers' framing and feeling rules have been highlighted in a previous study on care-sharing among PwM caring for a family member with dementia (Ahmad et al., 2020). It shows that PwM may take up the role of family caregiver through the moral framing rules reciprocal love and/or filial responsibility. To cope with a lack of informal care-sharing, these framing rules gradually become a part of caregivers' moral identity (e.g., being a "more loving and caring daughter" or a "better believer" than non-caregiving family members). The moral component and implicitly gendered nature of both framing rules make it difficult to seek formal care-guidance – especially in a later stage of dementia when providing care has become a significant part of one's identity.

Within the context of our current study this implies that adaptive and more inclusive approaches to building trust are needed within the framing rule of proximity, and that it is crucial to discuss family caregivers' emotional barriers to care-sharing as early as possible instead of taking the framing rule of a demand-oriented approach as a focus. That way, practitioners can reduce emotional barriers to expressing care-needs. At the same time, an awareness of the harmful effects of the framing rule the migrant Other and "they look after their own" is needed, as these frames may exclude PwM from formal care-sharing while they also neglect the moral and gender dimensions of care in families with a migration background.

4.6 Implications

Our study suggests a need to rethink the outcomes of professional approaches to dementia care-sharing, and to give more attention to the relational dimension of communication with PwM. This entails a need to find alternative approaches to building a trusting relationship in which PwM feel safe to express their demands and concerns with practitioners. Even when there are language difficulties, a relationship of trust can overcome language barriers to a large extent (Degrie et al., 2017). When interacting with PwM with dementia and their family caregiver(s), we thus suggest a flexible approach in which practitioners adapt to the specific situation by paying more attention to relationship building.

While taking such an approach, it is crucial to move away from the current discourse in which the care-needs of PwM are perceived as a divergence from the majority population. These perceptions need to be shifted to a perception in which the diversity and uniqueness of individuals is recognized within all professional approaches to dementia care-sharing. In other words, rather than operating within an approach that fits a majority, professional approaches to care-sharing should create space for difference. Given the ongoing diversification of societies, this focus appears to be more sustainable (Phillimore et al., 2016). Here, we do not believe that "diversity trainings" or "cultural awareness workshops" are a solution. Such trainings run the risks of treating ethnic minority cultures as static and problematic (Shepherd, 2019), while ignoring professional cultures and neglecting caregivers' knowledge of their family's culture and care-situation. Rather, there needs to be an ongoing discussion about the tenability of practitioners' views and approaches to dementia care-sharing in an increasingly globalized and diverse society. In this paper, we have made an attempt to open up this discussion.

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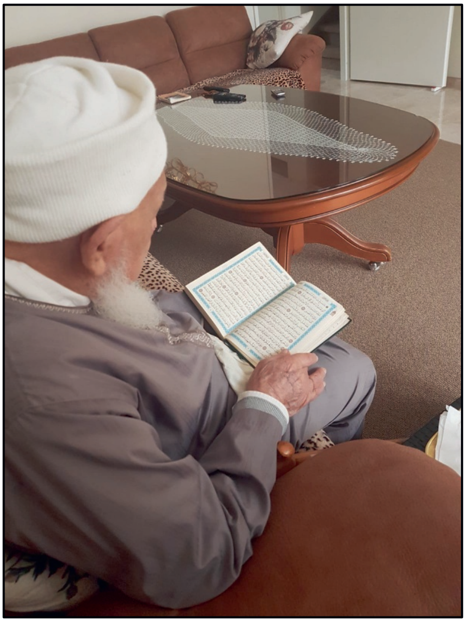
Religion

Twelve years ago my father moved [into my house]… Then I made a schedule, I said every month my father [should] go to someone. None of [my siblings] wanted that. None of them.

Is that why you accepted to provide all the care?

I accepted it because… I'm [a] truly believing woman. So I say Allah has given me this task and I have to do this task, even when [I'm] ill and can't do it; I have to do it because he is my father.



My father used to be an imam. He used to give Koran classes, he was also respected in the family... [Sometimes] I hear him say, "I hope Allah supports my daughter." You know, he does *du'a* for me… That's *kenz*. Yes, *kenz*, when your father says, *"Allah yakhaleek"* or "I hope you'll enter paradise." When [I] hear that… it doesn't matter if I'm having a tough time [providing care].*

* *Du'a* – supplication prayer
Kenz – a treasure
Allah yakhaleek – may Allah preserve you

◆ Khadija, primary caregiver of her father

Chapter 5

A reflexive account of a researcher with a migration background

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Abstract

The importance of a researcher's positionality has been well documented in prior studies. Yet, reflections on cross-cultural research from the positionality of a researcher with a migration background are rare. In this paper, I respond to this knowledge gap through a reflexive account of my positionality as a researcher with a migration background who has conducted cross-cultural research concerning dementia care. Following critiques of "ethnic matching," I apply a reflexive approach in which researcher positionality is understood as intersectional. I illustrate how both commonalities and differences within the researcher-researched relationship impact rapport-building and power dynamics. Also, I highlight how a researcher's experienced emotions can impact the content and analysis of the collected data. The insights from my reflexive account may help improve research strategies in culturally diverse settings. Moreover, I argue for a reflexive approach – rather than a deployment of "ethnic matching" – throughout future research in this field.

5.1 Introduction

Research claims are always negotiated through the voice of the researcher. This relates to the idea of "researcher as instrument" in qualitative research (Clift et al., 2018) and that "researchers are part of the social world they are researching" (Holmes, 2020, p. 3) – the implication being that research is never neutral, unbiased, or objective. That is why the researcher's personal accounts of conducting research should not be ignored or eradicated, but rather included as part of the research process (England, 1994; Holmes, 2020). Hence, especially in qualitative research, researchers have increasingly scrutinized their positionality and the complex interactions with participants.

However, reflections on cross-cultural research from the positionality of a researcher with a migration background are rare. Especially in cross-cultural dementia research, such reflexive accounts are absent. This is unsurprising, as persons with a migration background (PwM) are underrepresented within research on dementia care and aging care in general (Zubair & Norris, 2015), which makes studies discussing researcher positionality within this context even more unlikely.

When the positionality of researchers with a migration background is discussed at all in cross-cultural (dementia) research, it is limited to brief categorizations of the researcher's ethnically and linguistically matched background. For instance, Shanley and co-workers (2013) mention the use of an Arabic, Italian, and Spanish fieldworker as a research strategy within their study on dementia care in ethnically diverse communities. However, a reflexive account of these fieldworkers' backgrounds is not provided. This research strategy is often referred to as "ethnic matching." According to Papadopoulous and Lees (2002), "ethnic matching" entails that the ethnicity of the interviewer is matched to the participant's ethnicity to produce more cultural understanding, accurate details, and sensitivity throughout the research process. Thus, especially in research on topics that are sensitive, it can be seen as a strategy for overcoming distrust (Bhopal, 2009). For example, in her study on Asian women's views on arranged marriages and dowries, Bhopal (2009) incorporated her own experiences as an Asian woman in British society into the collection of data. Bhopal revealed personal details about her life throughout the interviews to minimize power differences and enable participants to share their stories – without fearing they will be othered. In doing so, she argues that "othered researchers who sit outside the confines of the privileged, white, middle-class academy are able to understand the experiences of women who continue to be othered" (p. 37).

While I acknowledge the value of such studies, the rationale for “ethnic matching” is problematic. First, it reveals an unjustified expectation that, simply by not being white, ethnic minority researchers have the natural ability to conduct cross-cultural research (Sin, 2004). Second, the idea that ethnically matched researchers can produce more trustful and accurate data is questionable, since this implies a static notion of identity that can be accessed through a shared ethnicity (Adu-Ampong & Adams, 2020; Rhodes, 1994; Ryan et al., 2011). In doing so, matching for difference neglects the fact that researcher positionality is complex, multiple, fluid, and context-dependent (Adu-Ampong & Adams, 2020; Holmes, 2020; Phoenix, 1994; Ryan et al., 2011; Soedirgo & Glas, 2020). Hence, “ethnic matching” does not necessarily produce “better” data (Phoenix, 1994; Ryan et al., 2011). That is why critics of “ethnic matching” emphasize that researchers should continuously be aware that their positionality is never fixed. In other words, as argued by Crenshaw (1989, 1991) and other intersectionality scholars (e.g., Davis, 2011; Hankivsky, 2014; Phoenix, 2006), all individuals are shaped by the intersections of different social categories (e.g., ethnicity, gender, class, age, and religion). So, rather than focusing on a single social category, researcher positionality should be understood as intersectional (Soedirgo & Glas, 2020).

The reflexive account captured in this paper will therefore illustrate how different aspects of a researcher’s identity intersect and permeate the entire research process. This is done from my positionality as a researcher with a migration background who has conducted cross-cultural research concerning dementia care (see, Ahmad et al., 2020; Ahmad et al., 2022, Ahmad et al., n.d.). Despite sharing the social category “migration background” with most of the included participants, other intersecting aspects of my identity played a role in the recruitment of participants, and the quality and content of the research data. In this paper, I aim to illustrate what this meant in practice. In doing so, I respond to the gap in knowledge on the positionality of researchers with a migration background who conduct cross-cultural research. Also, my reflexive account of the conducted research may offer insights for future research in cross-cultural settings.

5.2 Researcher positionality

There is an extensive body of literature discussing researcher positionality and its influence on the research process (e.g., Adu-Ampong & Adams, 2020; Bourke, 2014; Carter et al., 2014; Clift et al., 2018; Davis, 2018; Holmes, 2020; Kapinga et al., 2020; Merriam et al., 2001). Researcher positionality can be described as a disclosure about the researcher’s individual worldview and position about how the research is conducted (Holmes, 2020), and where the researcher stands in relation to the researched (Merriam et al., 2001). This means that, in the same way that the experiences of research participants are placed within a socio-cultural context, the experiences of the researcher, too, should be analyzed as such (Bourke, 2014). Therefore, it is necessary that researchers make explicit how their positionality has influenced the production of knowledge.

To make this explicit, reflexivity is used to identify and articulate positionality. Reflexivity can be defined as a process of thoughtful, conscious self-awareness in which a researcher seeks to understand intersections between self, other, and the research (Carter et al., 2014; Finlay, 2002b). Thus, through a reflexive analysis, the implicit becomes explicit. This entails that "rather than trying to eliminate their effects, researchers should acknowledge and disclose their selves in their work, aiming to understand their influence on and in the research process" (Holmes, 2020, p. 3). This makes reflexivity essential in increasing the integrity, transparency, and trustworthiness of a research (Carter et al., 2014; Finlay, 2002b; Guillemin & Heggen, 2009; Holmes, 2020).

The notion of reflexivity is not new; in the past few decades it has been highlighted across ethnographic and sociological work. The debate has moved from a positivist ideal of value neutrality in which the researcher's presence is eradicated to minimize subjectivity, to a recognition that research is "a joint product of the participants, researcher, and their relationship" (Finlay, 2002a, p. 212). For instance, in the field of anthropology, ethnographies such as *Reflections on Fieldwork in Morocco* (Rabinow, 1977) challenged the division between subjective and objective writing styles through reflections on decisions and dilemmas in their fieldwork experience. Almost a decade later, the influential book *Writing Culture: The Poetics and Politics of Ethnography* (Clifford & Marcus, 1986) gave rise to more debates about reflexivity in ethnographic methods and qualitative research in general, which further pushed qualitative researchers towards a growing "methodological self-consciousness" (Finlay, 2002a, p. 210).

In a similar vein, feminist philosopher Donna Haraway (1988) critiqued the myth of objective or value-free research. She refers to this as a "god trick" – the myth of a researcher who speaks from a position of authoritative knowledge outside and above social reality – and instead calls for the notion of situated knowledge. That is, within the process of acquiring knowledge, neutrality is not possible since every person comes from somewhere and perceives the world from a partial perspective. This means that "the researcher is always more than her theories, methodological perspectives, and normative commitments. S/he is also situated in a particular social, cultural, and geopolitical location, and this 'situatedness' has consequences for the kind of knowledge that can be produced" (Davis, 2018, p. 640). Reflexivity is, therefore, tied to the notion of situated knowledge. In this paper, I will use the discussed notion of reflexivity to make my intersectional positionality within the conducted research project explicit.

5.3 Outline of the research project

Research context and methods

The present paper is based on four-year doctoral research that explored how PwM perceive and experience dementia care-sharing within their families and with formal care. The need for this research stems from the increasingly aging populations and changing ethnic composition in European societies (England & Azzopardi-Muscat, 2017), making dementia care in families with a migration background a pressing concern for European health and social care (Alzheimer Europe, 2020; Canevelli, 2019).

In total, forty-one participants were included in the study. Purposive sampling was used to select PwM who provide care, or have until recently provided care, for a family member with dementia ($n = 31$). Included family caregivers were Dutch citizens with a Chinese, Indian-Surinamese, Moluccan, Moroccan, and Turkish migration background. In addition, practitioners ($n = 10$) were included to highlight their professional experiences with PwM caring for a family member with dementia. These were health and social care workers (such as caregiver support managers, nurses, and dementia case managers). Eight of the practitioners had a white-Dutch background, two had a migration background.

I recruited family caregivers through gatekeepers who were contacted through different channels, namely: community centers, social workers, organizers of peer groups for family caregivers, and partner organizations. Additionally, two of the included family caregivers were recruited through my personal network. I recruited practitioners through partner organizations and my professional network. In the case of family caregivers, obtaining the support of gatekeepers was vital to opening doors to potential participants. These gatekeepers often had the same ethnic identity as potential participants and had local influence within their ethnocultural community. That is why, especially in minority populations, gatekeepers are known to add credibility to a research project by their acceptance of it (Dempsey et al., 2016).

I met with these gatekeepers in person, in which I explained the research project and its objectives. This allowed for relationship building and clarification of the research project.

I collected data between February 2018 and January 2021, in the Netherlands. The dataset on the care experiences of family caregivers was gathered through five different qualitative methods: semi-structured interviews, photo-voice interviews, life-story interviews combined with “shadowing” observations, and focus group discussions. The first four methods were conducted in person. Due to COVID-19 regulations, the focus group was conducted through an online video-call in Microsoft Teams. Data on practitioners’ experiences were collected through semi-structured interviews with the help of online video-calls in Microsoft Teams (due to COVID-19 regulations). The names of all mentioned participants in this paper are pseudonyms.

The researcher

My reflexive journey will start with a succinct disclosure of my background. I was born in the Netherlands shortly after my parents fled the Iran-Iraq war that ended in the late 80s. Both of my parents are Iranians who were born and raised in working-class families in Iraq, but, as Iranian nationals, they were compelled to return to Iran when the war started. From there, they fled to the Netherlands. Like many PwM, my parents’ complex migration history reflects on my identity as a second-generation PwM. For instance, it is why I grew up with both the Iranian and Iraqi culture and language while simultaneously growing up in a white majority society. These aspects of my identity have made me increasingly aware of the diversity within groups and how this complicates static terms relating to one’s ethnic or cultural background. It has also fueled my academic interests in topics related to social exclusion and the process of “othering” within Western societies. Moreover, I am a woman who was raised in a religious, lower-middle class, Shi’ite family that places an emphasis on traditional gender roles. Also, from a very young age, I have been frequently visiting my extended family in Iran. These experiences have led to my interest in understanding gender inequalities, and how these inequalities are often justified through religious beliefs. In sum, my background may explain why I identify as a feminist researcher (with a background in cultural anthropology), and why I perceive my sense of self as intersectional.

My background is relevant to my positionality within the conducted research, as it is intertwined with the entire research process. In what follows, I will illustrate its intersectional relevance through the three following themes: rapport-building, power dynamics, and the role of emotions.

5.4 Rapport-building

Rapport-building can be described as the ability to connect with others to create understanding and trust within the researcher-researched relationship (Dickson-Swift et al., 2007; Guillemin & Heggen, 2009). In doing so, rapport-building contributes to the depth and quality of the data, while it also ensures that respect is maintained between researcher and participant (Guillemin & Heggen, 2009). Qualitative research is thus largely based on the researcher's efforts to build rapport with participants. This especially applies to research on sensitive, taboo topics that may evoke emotions from those participating in it (Dempsey et al., 2016). Within the context of PwM, shame and stigma are often attached to discussing dementia, and dementia care is often experienced as emotionally and physically demanding (Mukadam et al., 2011). Thus, the sensitivity of the research topic, as well as the emotions attached to it, made rapport-building essential to the recruitment of family caregivers and the collection of data. In what follows, I will reflect on intersecting aspects of my identity that were relevant to rapport-building with PwM caring for a family member with dementia.

Recruitment of family caregivers

The process of data collection started with the recruitment of family caregivers of individuals with dementia. The gatekeepers I was in contact with would either give me the telephone number of a family caregiver they asked to participate in the study, or they would refer me to gatherings or peer group sessions at community centers where I could find potential participants. This entails that my initial interaction with participants either happened over the phone or in person. When initiating the contact over the phone, I would often receive the question "where are you from?" – which referred to my non-Dutch name. After explaining my migration background, this would usually follow with an informal conversation about the participant's migration background. Although none of the participants I spoke with had an Iranian or Iraqi migration background, these informal conversations may have enhanced rapport through a sense of shared "otherness." Even before meeting the participant in person, this facilitated a sense of trust, as none of the potential participants rejected participation in the study. Here, it needs to be said that the gatekeepers have also played a role in creating this sense of trust, as participants generally know and trust them. Nevertheless, when I would initiate the contact in person, and gatekeepers did not play a role in facilitating contact and trust, the initial conversations with participants would still proceed in a similar manner.

Particularly when recruiting participants in person, it became clear that my migration background intersects with gender, religion, and age. Not surprisingly, the gender norm "caregiving as women's work" cuts across all cultural groups (Calasanti & Slevin, 2001), including families with a migration background (Tonkens et al., 2011). Thus, as expected, many of the family caregivers I encountered were women. Being a woman with a migration background was therefore an important commonality in accessing gatherings and caregiver peer groups that consisted of female caregivers. These groups were considered safe spaces in which women shared their thoughts and experiences with each other. In one group, Moroccan-Dutch women gathered once per week to chat about their daily lives and to read qur'anic verses together. Instead of directly recruiting participants from this group, I engaged in two qur'anic reading sessions. This was possible because of my gender (as this group was organized for women), as well as my religious upbringing in which I was taught to memorize the most commonly known qur'anic verses. Afterwards, I would chat with some of the women in this group, which led to the inclusion of two new participants. Thus, my migration background, gender, and religious background facilitated participation in these gatherings. Through my participation, these aspects of my identity enhanced rapport, which worked as a strategy of access. That does not mean that I always deployed my religious background to recruit participants. Instead, my religious upbringing particularly helped recruit participants who identify as Muslim. Rather than religious background, shared gender, and a shared "otherness" (due to migration background) supported rapport-building in the recruitment of non-Muslim participants.

In addition to these intersecting aspects of my positionality, age may have also been relevant to the recruitment of family caregivers. My presence as a young woman (between the age of 29 and 32 at the time of conducting fieldwork), who sometimes belonged to the same age range as my participants' children, could be a reason why participation in the study did not feel threatening. For instance, many family caregivers asked me "what I'm studying." After describing my previous studies and explaining that I now work as a researcher, they often described their children's studies. This hints that my age made some family caregivers more inclined to help me carry out the research project through their participation.

Data collection

While collecting data, my migration background was often the basis for both commonality and difference within the researcher-researched relationship. Here, one of the first aspects that comes to mind is the fact that, while I shared the social category "migration background" with all included family caregivers, I did not share the same ethnic identity. While recalling the process of data collection, I realized that this difference facilitated trust rather than distance, as it avoided a frequently expressed fear of gossip and judgment by members of their ethnocultural community. Zeynep, a daughter of a family caregiver, expressed this fear as follows: “Then they’ll start gossiping in our family. [They’ll say] that we can’t take care of our father, that we left him in an old age home. We can’t accept that. No, no, we can’t…”

Many of the family caregivers I spoke with expressed similar concerns. For instance, a Turkish-Dutch family caregiver of her mother, explains how she frequently needs to defend why she admitted her mother to a nursing home:

> MA: What do your relatives and people in your surrounding community think of your mother being in a nursing home?
>
> Meryem: …When I see people at the market or in a store, they ask about [my] mother. I say [to them] that she’s in a nursing home. [Then] they say: “why don’t you take care of her yourself?” If I [could’ve] done it myself, then I wouldn’t have sent her there. If [my] mother had been at home, then two people really had to be with [her] twenty-four hours a day… “The children don’t [care], they ditch their mom, dad there” – that’s how people think, right. But [there’s no other option] when the situation at home doesn’t allow for it.

Due to gendered care norms, social control and feelings of honor and shame may be attached to invoking formal care outside of the home environment (Ahmad et al., 2020; Ahmad et al., 2022). As suggested in the above examples, social control often leads family caregivers to fear gossip and judgments within the ethnocultural community that they identify with. Hence, the fact that I had a different ethnic identity from the included family caregivers most likely worked in favor of the research project. Considering the sensitivity of the research topic, this difference may have given more room for openness and trust. However, this difference cannot be understood as separate from the social category “migration background,” which I shared with all included family caregivers.

That is, even though I did not share the same ethnic identity as my participants, my migration background helped to build trust and rapport with them. This was apparent in several ways. For instance, it meant that I often deliberately incorporated my background in the interview in order to find a common ground with participants, as shown in the following example of a photo-voice interview:

Anneke: Let me show you a picture of the bible…

MA: [The cover of the bible says] "al kitab"; that's Arabic for "the book." Is that the same in the Malay language?

Anneke: Yes, the Malay language. [And] *hawa, nafas*, means "breath" [in the Arabic and Malay language].

MA: Breath, yes.

Anneke: I know that because… I had a Turkish intern whom I had to supervise and [when] I said something about *hawa,* she said: "Hey, that means 'breath,' right?" … Well, there you go, there are so many similarities.

When I first contacted Anneke, a Moluccan-Dutch caregiver of her sister, she went to great lengths to explain that she experienced the relationship with her dementia case manager as difficult. One of the reasons she expressed related to an experienced lack of interest in her cultural background, as well as the migration history of the Moluccan community in the Netherlands. This exacerbated a feeling of being misunderstood by her dementia case manager. Throughout the interview, I deliberately avoided this from happening through examples such as the above, combined with questions about her migration history. In other interviews, too, I tried to level myself with participants' narratives by revealing aspects of my migration background. This is illustrated in the following example:

Jun: Chinese people have a custom… We all eat together, each person has their own plate and together you have a [dish/dishes]… [It's a custom for a person to] put food on other people's plates… My mother does that [at the adult daycare], [but] the daycare worker doesn't get it. They say my mother's aggressive, and that other patients can't handle her.

MA: Ah, yes, we do that as well [in Middle Eastern cultures]… You mean she ladles food onto people's plates, and they don't understand that she means well?

Jun: You get it because that's what is done in your culture, too. But for other cultures… they say: "What are you doing! I don't want that!"

The above interview excerpts from Anneke and Jun are examples of how I would use my migration background to put myself on a "level playing field" with participants (Dickson-Swift et al., 2007, p. 332). Even though my comments about my background were brief and subtle, revealing such personal details validated participants' stories and it created a common ground, which enhanced rapport. In addition to such aspects of my migration background, I would sometimes also incorporate aspects of my religious background into interviews with participants who identify as Muslim. This is illustrated through the following example.

Faiza is a Moroccan-Dutch family caregiver of her mother. When I spoke with her over the phone, she explicitly told me that I am allowed to interview her, but that I am not allowed to conduct "shadowing" observations of her care-role. Upon meeting with her, we first had an informal, brief conversation about our migration backgrounds. Since I am not visibly Muslim, most practicing Muslim participants, including Faiza, asked me whether I identify as Muslim. When I affirmed my religious background, this followed with "alhamdullilah" (thank God). Despite this common ground, Faiza appeared cautious about sharing her narrative throughout the interview. Interestingly, through rapport-building, she became more comfortable in sharing her experiences with me. This gradually happened using Islamic/Arabic words, as they helped Faiza to feel understood. The following is an example of how this went:

> Faiza: Suddenly she was seeing things that weren't there, hearing things that weren't there... She couldn't sleep, was afraid, anxious… And then I thought maybe she's… how should I say it… We [call them] spirits.
>
> MA: Do you mean, *djinn* [demons]?
>
> Faiza: Yes, *djinn,* yes, that's what I thought… Two or three times [imams] came here, for *ruqya* [exorcism]. They said: "That woman has no *djinn*." … And then I thought: "I'll go to the doctor."
>
> MA: So, you didn't think she was seeing *djinn*, but you thought it was [possessing] her?
>
> Faiza: Yes, that's what I thought, at the beginning [of my mother's dementia].

As shown in the above, at first, Faiza was hesitant to use the word *djinn.* Complementing her sentence with this word helped to make her feel understood. The effect of building rapport during the interview was confirmed when, after the interview, she let me know that I can conduct "shadowing" observations at her home – something she rejected before, when I spoke with her over the phone. This illustrates the importance of developing a relationship of trust through rapport-building prior to conducting fieldwork in a private space (see also Dempsey et al., 2016).

Hence, the above examples from Anneke, Jun, and Faiza, illustrate that, while a shared "otherness" (through migration background) and shared religious background were helpful in the recruitment of participants, it was not enough to gain participants' trust to share their narratives with me. Rather, deploying my migration background and/or shared religious background facilitated rapport-building, and therefore more openness and trust during the collection of data.

Even when I would not deliberately incorporate my migration or religious background into the interviews and observations, I was often positioned by participants through a hinted shared "otherness." This was particularly visible through a perceived dichotomy on care-views between "us" (PwM) and "them" (white-Dutch people) – as expressed by Karima, a Moroccan-Dutch caregiver of her mother:

> You know how [white-]Dutch people are. They sometimes ask me: "What about your father?" … They easily think: "Dad will take care of mom or mom will take care of dad." They think very easily about it. But that doesn't apply to us.

Although the perception of a shared "otherness" (which sometimes intersected with a shared religious background) facilitated rapport-building throughout the interviews, it also risked misinterpretations or unwarranted shared cultural or religious understandings about expressed concerns. To avoid this from happening, I would respond to participants' expressed concerns with follow-up questions; even when a shared understanding about the expressed matter appeared to be assumed. The following example illustrates this:

> Mabrouka: When my mother was [doing] better… she used to go to [my sister] for a few days. But now [my sister] says: "I really don't want to have anything to do with it anymore."
> MA: And what do you think of that?
> Mabrouka: … I feel sorry for her, more for her than for my mother. Because my mother is taken care of.
> MA: Why do you feel sorry for her?
> Mabrouka: She's missing out on a lot, *hasanat* [religious "credits" for doing good deeds].
> MA: *Hasanat*. So you mean because she's not fulfilling her religious duties?
> Mabrouka: Yes, and… she's ill now, but she's still your mother. She still does nice things… And she does a lot of *du'a* [supplication prayer] for my kids.

And then you think to yourself, she's still there, even though she's [ill]… Those are very beautiful moments.
MA: And those are moments that [your sister] will no longer experience because she distanced herself.
Mabrouka: Exactly.

As most of the participants who identified as Muslim, Mabrouka used Islamic/Arabic words she knew I would be familiar with (e.g., *alhamdullilah, du'a, hasanat*). In the above, Mabrouka mentions the importance of *hasanat* in Islam. Because of my upbringing, I am familiar with this term and how its message is applied to daily life. Nonetheless, to make sure I understood Mabrouka correctly, I asked her to confirm how I had interpreted her answer to my question. Her additional explanation appeared to be essential, as it shows that, besides missing out on *hasanat,* Mabrouka meant that her sister is also missing out on experiencing beautiful moments with her mother. Thus, throughout the interviews with family caregivers, I tried to beware of making assumptions based on an assumed shared understanding. However, there were still instances in which I unintentionally failed to pose follow-up questions during the collection of data, which is a notable risk of rapport-building through shared "otherness" and/or shared religion.

In sum, different intersections of my migration background, religious background, gender, and age, have supported rapport-building in the recruitment of family caregivers and the collection of data. This is not to say that these intersections of my positionality have made the recruitment and data collection effortless, or that it guaranteed access to family caregivers and in-depth data. It rather means that, whether deliberately or unknowingly, these intersecting social categories were deployed to enhance rapport with family caregivers.

5.5 Power dynamics

Power is an important feature of the research process and the researcher-researched relationship (Bashir, 2019; England, 1994; Karnieli-Miller et al., 2009; Kvale, 2006; Sin, 2007). For instance, qualitative research has focused on minimizing power relations between the researcher and participant (Karnieli-Miller et al., 2009), and how the shifting nature of power can also render researchers vulnerable (Bashir, 2019; Sin, 2007). Following England (1994), who argues that researchers should approach power relations in the research encounter by exposing the partiality of their perspectives, I will reflect upon the power dynamics in my encounters with family caregivers and practitioners.

Family caregivers

In the prior section, I have illustrated how intersections of my background contributed to rapport-building. Deploying these aspects of my identity made space for a “friendly” and low-threshold conversation which enabled family caregivers to open to me. These forms of rapport-building are thought to minimize power dynamics between researcher and participant (Bhopal, 2009). Deploying different, intersecting aspects of my identity may indeed have heightened empathy and encouraged family caregivers to share their experiences with me. This was visible when some of the family caregivers I spoke with expressed that, before talking with me, they had never disclosed their concerns to anyone in detail.

Nonetheless, it would be naïve to claim that deploying my background minimized or even lifted power dynamics between myself and family caregivers. No matter how much I would level myself with participants to create a low-threshold research setting, in the end, there would remain a difference in that I would do this with the aim of collecting data. That is why Kvale (2006) argues that it is problematic to view interviews through the popular conception of a warm, caring, and empowering dialogue because it gives a false image of a joint and equal endeavor. Even though rapport-building led to an atmosphere in which participants felt comfortable to share their stories with me, the purpose of building rapport makes our positions inherently unequal: “The research interview is not a dominance-free dialogue between equal partners. The interviewer’s research project and knowledge interest set the agenda and rule the conversation” (Kvale, 2006, p. 484).

Especially during my interactions with participants who expressed shocking circumstances about their care-role, I felt uneasy about deploying my background for the use of data collection while being unable to provide them with practical support. Furthermore, while creating trust through rapport-building served to obtain data, in some cases, it may have been interpreted as friendship. For instance, some family caregivers sent me text messages (long after the interview or observation took place) to ask me “how I’m doing.” This raises ethical concerns, especially when considering the sensitivity of the research topic. In other words, I levelled myself with participants for the sake of data collection without realizing this may be interpreted as friendship, and that participants may have opened up to me due to an image of a “friendly” dialogue. Hence, although rapport-building through intersecting aspects of my background allowed for openness and trust, this only gives the impression of minimized power dynamics. Asymmetrical power dynamics within the relationship were not erased nor minimized.

Practitioners

Unlike my interactions with family caregivers, the interviews with most of the practitioners I spoke with were carried out without a direct disclosure or deployment of my migration and religious background. I was generally positioned as a student or a researcher, which was exemplified through practitioners' questions about my studies and research. However, in an interview with a dementia case-manager, a white-Dutch woman in her fifties, I found myself positioned as a migrant Other:

MA: You told me earlier that your co-worker heard a client [with a migration background] say that they perceive dementia as a curse.
Case-manager: Yes.
MA: Could you tell me more about that?
Case-manager: No, I was thinking [about it] this very week, when I got in touch with you. Then I thought: "Well, maybe I should ask if that's indeed how you perceive it." So, what's your [ethnic] background?
MA: [silence] I have an Iranian background.
Case-manager: Iranian...

Before interviewing this case-manager, I had only contacted her through e-mail. As with my initial phone-contacts with family caregivers, my non-Dutch name shaped an image of who I might be. However, while in the case of family caregivers my name generally engendered a sense of familiarity and shared "otherness," for this case-manager it created a perception of migrant Other. To understand how this affected the power dynamics and content of the interview, it is necessary to understand how her posed question impacted me.

Like many PwM, I am all too familiar with the question "where are you from?" or different versions of it, such as the one posed in the above. White-Dutch people have asked me this question for as long as I can remember; often out of curiosity and sometimes out of visible hostility towards PwM. In either case, throughout the years, this question has constructed me as an Other whose Dutch legitimacy is questioned, and who can thus never truly be considered Dutch. As argued by Sara Ahmed (2017), such questions are posed to assert that a person does not belong: "'Where are you from?' is a way of being told you are not from here. The questioning, the interrogation, can stop only when you have explained yourself… These questions only appear to be questioned; they often work as assertions” (pp. 116-117). Hence, in my experience, negative feelings are attached to this seemingly simple question, which explains my rather acquiescent response to the case-manager who posed the question.

I started the interview with the expectation to be perceived as a researcher/student who will interview this case-manager’s professional experiences with regards to dementia care in families with a migration background. Through her question, I was suddenly positioned as a migrant Other who belongs to the same group of people who a part of my study’s focus is (i.e., PwM caring for a family member with dementia). During the interview, this affected my perceived and experienced positionality, as the dynamics of power shifted from “researcher” to “Other.” Even though I was familiar with this case-manager’s question, as well as the reasons why it is problematic when posed by a white-Dutch person, I did not know what to say. To break the silence, I simply answered her question and continued with the interview. Afterwards, I realized that, due to feeling stumped because of the implications and feelings attached to the case-manager’s question, I failed to use her question as an opportunity to inquire about her underlying assumptions about PwM caring for a family member with dementia.

Thus, the above example illustrates how intersecting aspects of my identity (being an ethnic and religious minority) affect the interviewing process and therefore the content of the collected data. Moreover, there is a presumption that researchers are always the ones in power, but, as illustrated in the above example, “the power relations between researcher and researched can often be reversed even in the course of a single interview and this is complicated by racial/ethnic axes of differentiation and their associated sets of power differentials that are never constant” (Sin, 2007, p. 479). The subjective experience of power is thus often ambivalent for both researcher and participant (Bashir, 2019; Sin, 2007).

5.6 The role of emotions

So far, I have reflected upon intersecting aspects of my identity that were relevant to my interactions with participants. Indirectly, this also affected the content of the collected data. In this section, I will reflect upon aspects of my identity and accompanying emotions that have directly impacted on the content and analysis of the data. As argued by feminist scholars, a reflexive account of a researcher’s experienced emotions offers a deeper understanding of the issues being studied (Blakely, 2007; Reger, 2001). By doing so, researchers acknowledge that (intersecting) aspects of their identity influence their perceptions and thus their analyses

(Reger, 2001). In what follows, I will illustrate this by highlighting how my experienced emotions – that are specific to my gender, religious background, and migration background – have affected the content and analysis of the data.

First, albeit under different circumstances, my experiences as a woman who was raised in a religious, patriarchal environment have made me sensitive to detecting the effects of gender inequalities within the context of dementia care-sharing in families with a migration background. These experiences include the gender-related restrictions (i.e., restrictions that only apply to women) I experienced within familial and communal contexts, as well as the gender-related restrictions and regulations I experienced and observed during my frequent stays in Iran. Consequently, my familiarity with the harm and complexity of gendered contexts in the family sphere and broader social communities makes me experience a feeling of indignation when detecting gender inequalities. This has prompted me to bring the theme of gender to the fore throughout the data collection and research papers. Within the analyses, this meant that I was particularly interested in understanding the gendered mechanisms underlying an unequal distribution of care-tasks (see, Ahmad et al., 2020; Ahmad et al., 2022). Within the conducted interviews, observations, and focus group, this meant that my inquiries generally included (indirect) questions relating to participants' perceptions and experiences with regards to gendered care norms. This is visible in the following excerpt from an interview with a Moroccan-Dutch family caregiver of her mother:

> Karima: They [i.e., white-Dutch people] sometimes ask me: "What about your father?" … But my father's old. I can't expect him to take care of my mother.
> MA: But if the situation would be reversed, wouldn't your mother provide care for your father?
> Karima: Yes, then it would've been different, yes…
> MA: Because women are often viewed as caregivers.
> Karima: Yes, yes… then it would've definitely been different… Yes, then maybe we [Karima and her sister] would help her, for example by taking father out of bed… Men are always taken care of by the wife.

By asking Karima about a hypothetical situation in which, instead of her mother, her father would be the one in need of care, the interview was directed towards an inward reflection on gender norms. I posed such questions not only because I believed they would provide relevant data, but also through my detection of implicit gender inequalities that made me experience a feeling of indignation. This feeling was incited by my own experiences relating to gender inequalities, which directed me to pose follow-up questions to elucidate the gendered dimension of family caregivers' narratives.

Second, growing up as a minority woman in the Netherlands, I have experienced first-hand the harmful effects of cultural stereotypes and racist attitudes about Muslim women and people of Middle Eastern descent (and PwM in general). Whether directly or indirectly, this has often led me to feel like an Other within Dutch society. This became worse after the 9/11 terror attacks, after which anti-immigration and anti-Islam sentiments increased. These experiences have undeniably affected the lens through which I analyzed and wrote about the collected data, as I deliberately aimed to avoid reproducing stereotypes and ethnocentric views about PwM. For instance, in my analyses of family caregivers' experiences, I aimed to avoid cultural stereotypes about families with a migration background by using an analytical framework that studied how participants make sense of their emotions (and how this relates to their social contexts) rather than their "cultural differences" (Ahmad et al., 2020), and through an intersectional exploration of the influence of a number of social categories rather than a single category of difference such as ethnicity or culture (Ahmad et al., 2022). In my analysis of practitioners' views, my experiences as an Other within Dutch society have led me to capture the harmful effects of stereotypical assumptions and othering views about PwM, that practitioners expressed through a frame of "the migrant Other" and the frame "they look after their own" (Ahmad et al., n.d.).

So, a felt sensitivity to detecting gender inequalities, as well as a feeling of being made into an Other within Dutch society, was ingrained in my gaze as a researcher and co-determined the content and analysis of the research data. This helped opening doors within the collection and analyses of the data, and it helped to avoid reproducing cultural stereotypes about PwM. This should not be taken to imply that another researcher would have been unable to arrive at findings like my research. Instead, it means that my lived experiences regarding gender inequalities and othering, that are specific to my religious and migration background, have provoked emotions that cannot be detached from the content and analysis of the data – including the final text.

5.7 Concluding thoughts

In cross-cultural research, “ethnic matching” is often assumed to provide “insider status,” and that this allows for richer data that is collected in a more sensitive way (see e.g., Bhopal, 2009; Papadopoulous & Lees 2002). That is why the practice of “ethnic matching” has also been deployed and promoted as a research strategy in research on dementia care in ethnic minority populations (see, e.g., Berdai-Chaouni et al., 2018; Richardson et al., 2017; Shanley et al., 2013). Following critiques of “ethnic matching,” I have illustrated the intersectional nature of my positionality within the conducted research project. In doing so, this paper draws attention to the need for a reflexive approach – rather than a deployment of “ethnic matching” – throughout future research in culturally diverse settings.

That is not to say that the importance of a researcher’s ethnic identity should be disregarded in cross-cultural research. As illustrated in this paper, both my ethnic identity and migration background were relevant to the research process. Considering the sensitivity of the research topic and family caregivers’ expressed fear of gossip within their ethnic communities, not sharing the same ethnic identity with the included family caregivers may have worked in favor of the research project. This is in line with Ryan and co-workers (2011), who argue that “being interviewed by someone from your locality, who is likely to be known to you, may lead participants to have concerns about being judged by a peer, and despite assurances of confidentiality, may worry about breaches of privacy and local gossip” (p. 51). Also, despite not sharing the same ethnic identity, having a migration background (which sometimes intersected with a shared religious background) often led to a felt shared “otherness” and common ground, which facilitated rapport-building with family caregivers. On the other hand, my ethnic identity and migration background also affected the power dynamics in an interview with a white-Dutch dementia case-manager. The shifting power dynamics rendered me vulnerable, and they affected the collection of data during this interview.

Hence, my ethnic identity and migration background were indeed relevant to the research project, but not as understood through the logic of “ethnic matching.” More importantly, my ethnic identity and migration background were not the only aspects of my background that were relevant to the research. Intersections of my migration background, religious background, gender, and age, have enhanced rapport-building in the recruitment of family caregivers and the collection of data. These aspects of my identity benefitted rapport-building with family caregivers, but they also risked unwarranted shared understandings about expressed concerns. Another risk of rapport-building through (intended or unintended) deployment of my background, is that it may have been interpreted as friendship. This raises ethical concerns. Namely, family caregivers' openness and trust may have been a result of an unintentionally created image of friendship, even though the researcher-researched relationship is not a dialogue between equal partners. The claim that rapport-building through "ethnic matching" minimizes power dynamics (Bhopal, 2009) is therefore not completely justified. Thus, as researchers we should be mindful of the power dynamics inherent to the research relationship, especially within the context of a sensitive topic such as dementia care. Indeed, these dynamics shape how knowledge is produced (see also, Bashir, 2019).

As illustrated in this paper, knowledge production is not only shaped through relational aspects of the research, but also through emotions experienced by the researcher. Within the context of my research, this meant that my lived experiences with regards to gender inequalities and othering – that are specific to my religious and migration background – have provoked emotions that impacted the questions I posed during the collection of data, as well as the analysis and final text.

In conclusion, by highlighting the intersectionality of my background through my reflections on and responses to my positionality, this paper responds to growing calls that caution against an application of positionality that is essentialist and static (Adu-Ampong & Adams, 2020; Ryan et al., 2011; Soedirgo & Glas, 2020). To the best of my knowledge, this is the first paper to offer a reflexive analysis of researcher positionality within the context of cross-cultural dementia care. Considering the increasingly ethnically diverse populations in European societies (England & Azzopardi-Muscat, 2017), the insights from my reflexive account may help improve research strategies in culturally diverse settings in the field of dementia care and beyond. That does not mean that this paper does not have its limitations. Indeed, any reflexive account is subjective, and there are always aspects of ourselves that we are unaware of (Holmes, 2020). Nonetheless, it is essential in striving for honest, transparent, and ethical research.

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The meaning of ‘home’

When he was still living at home, we had a key to enter. Now we need to enter a code… This picture shows that a big part of his independence has been taken away from him, but for his own safety… At the beginning it was confronting… and now we don’t know any better. [We] know he’s doing well; that he’s well looked after and that he’s comfortable. He refers to it as his home, too. A few months ago when I brought him back [to the ward] he said, “I’m home.” That says a lot. That’s really not a given.

- Rita, primary caregiver of her father

Chapter 6

Discussion and conclusions

6.1 Introduction

In this dissertation, I focused on practices of dementia care-sharing in families with a migration background. I set out to answer the main research question: What are obstacles and facilitators to shared care in families with a migration background caring for individuals with dementia? For the most part, this research question is answered through analyses of family caregivers' views and experiences of their care-role and of (formal and informal) care-sharing. An important part of the research question is also answered through an analysis of practitioners' views and experiences. The findings presented in this dissertation discussed three interconnected aspects of dementia care-sharing, namely: the gendered and moral experience of family care (chapter two), the impact of intersecting social categories on practices of care-sharing (chapter three), and practitioners' views to care-sharing with PwM (chapter four). The findings and arguments of these chapters answer the main research question. Together, they point towards the importance of understanding dementia care in families with a migration background as a gendered, moral, and multifaceted experience that requires context-dependent formal care-guidance. In addition to the presented research findings, I also offered a reflexive account of my positionality within the conducted research (chapter five). Not only does this offer a better methodological understanding of the presented findings in chapter two, three, and four; it may also offer insights for future research in cross-cultural settings.

In this concluding chapter, I will briefly recap the most significant findings and present an outlook for practice, policy, and future research in the field of dementia care and migration.

6.2 Main findings

In chapter two I highlighted how the included family caregivers make sense of and cope with their role of primary caregiver. In doing so, I aimed to shed light on cultural and social dynamics that impede care-sharing within families and with formal services. With the support of Hochschild's interpretive framework of "framing and feeling rules" (1983, 2003), I identified how family caregivers frame their perceptions and experiences of caregiving, and how this relates to their expressed feelings. Simultaneously, the analysis of family caregivers' framing and feeling rules revealed implicit gender norms that are inherent to the context of the study.

Two moral framing rules were identified: reciprocal love and filial responsibility. Family caregivers expressed either one of these framing rules, or a combination of both framing rules, as a motivation to take up the role of primary caregiver. Through the framing rule of reciprocal love, the care was expressed as a means to reciprocate the parental love and support that caregivers experienced earlier in their lives. The framing rule of filial responsibility was expressed as a culturally or religiously defined duty to provide care for a relative with care-needs – even when caregivers did not experience their relationship with the care-recipient as loving. Responding to these framing rules created a sense of strength and pride, but it also (further) hampered care-sharing. That is, the role of primary caregiver was assigned based on an implicit gendered hierarchy of care-obligations – making both framing rules inherently gendered. This meant that one female family member was assigned the role of primary caregiver, with no (or little) support from others. Due to the gendered nature of these framing rules, discussing the care-tasks was not an option and the exceptional efforts to do so resulted in further isolation. Thus, to cope with an unequal distribution of care-tasks, the framing rule of reciprocal love and/or filial responsibility gradually became a part of caregivers' moral identity (e.g., being a "more loving or caring daughter" or a "better believer" than non-caregiving family members). As such, feelings of exhaustion, anger, and disappointment were suppressed through the feeling rule of "moral superiority" over family members who were not involved in the care.

In sum, the findings presented in chapter two illustrate how the moral component and implicitly gendered nature of both expressed framing rules make it difficult to discuss and share the care within the family and with formal services; especially in a later stage of dementia when providing care has become a significant part of caregivers' moral identity.

While in chapter two gender emerged as a relevant social category to experiences of dementia care-sharing, in chapter three I aimed to offer a detailed account of several, intersecting social categories that are relevant to dementia care-sharing. Therefore, in chapter three, an intersectionality lens (Crenshaw, 1989, 1991) was applied to the life-stories and care-experiences of family caregivers. Here, migration history and class background stood out the most, as the impact of these social categories were visible in all participants' narratives. This implies that those who grew up in a lower/working-class family and migrated later on in life from an environment where educational opportunities were limited, were less likely to be equipped with the necessary management skills to organize and share care-tasks. Whereas those who grew up in a middle-class family, migrated at a young age, and grew up in an environment with educational opportunities, were more likely to share the care (both with family and formal care). Migration history and class background were also found to influence whether or not formal care-support was compatible with participants' perceptions of "good care."

Other social categories intersected with caregivers' migration history and class background. For instance, the presence of supportive social networks played an important role in preventing caregiver exhaustion. This was found to be especially crucial to under-resourced family caregivers who were less equipped to organize and share care-tasks. The findings also suggest that, when there is a lack of care-sharing and supportive social networks, family caregivers who identify as religious may use religion as a way to cope with feelings of exhaustion and isolation. This means that religion may motivate family caregivers to be patient about the care-situation, and to endure the negative aspects of providing care exclusively. Even though this might offer caregivers strength and support throughout the care-process, the findings suggest that it shuts down discussions about care-sharing.

The presented findings in chapter three also illuminated discourses of wider structural inequalities related to gendered care norms. How strongly the included family caregivers adhered to gendered care norms depended mostly on feeling connected to, or "different" from, a wider ethnocultural community in the country of residence (which relates to migration history and social class) – and thus whether or not caregivers could invoke formal care without having to give in to oppressive, gendered care norms. Moreover, the findings suggest that the impact of gendered care norms may be further complicated within spousal relationships. This means that the care-role of a woman who provides care for her husband with dementia could be perceived as her duty as a wife and mother – which further hampers discussions about care-sharing.

In conclusion, the findings presented in chapter three draw attention to the differences in needs and wishes for care-sharing in families with a migration background. Also, they draw attention to the fact that citizens' self-responsibility for (formal and informal) care-sharing, that is expected by the current institutional organization of care, is not feasible for all PwM caring for a family member with dementia. Considering the small research sample, however, this should be further investigated in future studies.

In chapter four, I focused on relational aspects of formal and informal care-sharing, as experienced by practitioners. Here, Hochschild's concept of "framing and feeling rules" (1983, 2003) was used to shed light on the ways in which practitioners frame and experience dementia care-sharing with PwM. To offer a more complete picture, I related practitioners' expressed framing rules to the care-experiences of the included family caregivers.

The analysis revealed four framing rules. Two of these expressed practitioners' views to successful care-sharing through a framing rule of proximity within the practitioner-client relationship, and a framing rule that calls for a demand-oriented approach. Within the framing rule of proximity within the practitioner-client relationship, practitioners expressed the importance of building a relationship of trust in which the needs and wishes of both caregiver and care-recipient are communicated. Due to an experienced feeling of distance with their clients with a migration background, practitioners were often unable to respond to this framing rule. I argued that, when this happens, a feeling of inadequacy to perform professional duties may arise. Data from the included family caregivers suggested that family caregivers, too, often experience distance with practitioners. Nonetheless, in a few cases, practitioners found alternative ways to gradually build trust in order to overcome obstacles to proximity. Their efforts did not involve tools or complicated approaches. Rather, they adapted to the specific situation by paying more attention to relationship building through ways that are different from their usual approach. Overcoming obstacles to the framing rule of proximity may result in a feeling of victory.

The framing rule of a demand-oriented approach was expressed as an approach in which clients need to express their demands for care-sharing, after which practitioners align their professional support to these demands. Within this framing rule, practitioners will generally experience a feeling of caution to offer care-guidance when PwM do not express their needs for care-support, or when PwM express a desire to perform the care-tasks themselves. However, a lack of knowledge about dementia and care-support, as well as a lack of proximity within the practitioner-client relationship, will logically discourage family caregivers from expressing their demands for support. The framing rule of a demand-oriented approach can thus hamper care-sharing.

The remaining two framing rules expressed cultural explanations to experienced obstacles to care-sharing with PwM: a framing rule in which PwM are perceived as the migrant Other, and a framing rule that assumes that "they look after their own." Through the framing rule *the migrant Other*, care-sharing with PwM was contrasted with clients from the white majority population. Differences in PwM were attributed to their culture. As a result, practitioners experienced a feeling of hesitation and inadequacy to perform their profession due to a perceived lack of cultural knowledge about the migrant Other. Through the framing rule "they look after their own," PwM were assumed to share the care-tasks within an extensive supportive social network, or that PwM simply prefer to handle the care-tasks themselves. Data from the included family caregivers, however, revealed that the care-context is a multifaceted rather than a static cultural experience, and that the care-tasks typically rest on the shoulders of one caregiver rather than an extensive social network. Hence, the findings suggest that both framing rules are harmful, as they prevent practitioners from exploring the care-context in order to understand and support families according to their individual backgrounds and needs.

The findings in chapter four draw attention to the need for adaptive approaches to building a trusting relationship in which PwM feel safe to express their demands and concerns with practitioners. At the same time, an awareness of the harmful effects of the framing rules the migrant Other and "they look after their own" is needed. This also means that, assumptions about family caregivers' needs and wishes for care-support should be replaced with an open attitude to how caregivers themselves perceive and experience their care-context.

Finally, in chapter five, I illustrated the intersectional nature of my positionality within the conducted research. This was done through three themes that have impacted my positionality in the research process, namely: rapport-building, power dynamics, and the role of emotions. By elucidating my positionality through these themes, I followed scholars who have critiqued the practice of "ethnic matching" within cross-cultural research (e.g., Rhodes, 1994; Ryan et al., 2010; Sin, 2004).

In my discussion of the first theme, rapport-building, I highlighted how different intersections of my migration background, religious background, gender, and age, enhanced rapport-building in the recruitment of family caregivers and the collection of data. While these aspects of my identity benefitted rapport-building, they also risked unwarranted shared understandings about expressed concerns. Also, I argued that, due to the sensitivity of the research topic, my ethnic identity may have worked in favor of the research. That is, while I shared the social category "migration background" with all included family caregivers, I did not share the same ethnic identity. I argued that this difference may have facilitated trust rather than distance, as it avoided a frequently expressed fear of gossip and judgment by people within the ethnocultural community that family caregivers identify with.

In the second theme, power dynamics, I highlighted power dynamics within the researcher-researched relationship. I argued that, even though rapport-building through a deployment of my background may have created an image of a "friendly" dialogue, asymmetrical power dynamics within the relationship were not erased nor minimized. Furthermore, I illustrated how, when an interviewed practitioner positioned me as a migrant Other rather than a researcher, I failed to inquire about her underlying assumptions about PwM caring for a family member with dementia. Thus, I argued that, for ethnic minority researchers, the power dynamics can be affected negatively in interviews with white interviewees – which can influence the content of the collected data.

In the third theme, the role of emotions, I argued that the process and outcomes of the conducted research were not only shaped through relational aspects, but also through my experienced emotions with regards to gender inequalities and othering that are specific to my religious and migration background. I argued that a felt sensitivity to detecting gender inequalities, as well as a feeling of being made into an Other within Dutch society, was ingrained in my gaze as a researcher and co-determined the content and analysis of the research data. This helped opening doors within the collection and analyses of the data, and it helped to avoid reproducing cultural stereotypes about PwM.

Hence, through a reflexive account of my positionality, I have argued that the practice of "ethnic matching" should not be promoted as a research strategy. Also, I illustrated that "ethnic matching" is not necessarily a prerequisite for conducting research in cross-cultural settings. Chapter five thus draws attention to the need for a reflexive approach – rather than a deployment of "ethnic matching" – throughout future research in this field.

6.3 Implications for practice and policy

So far, I have offered a recap of the main findings that are presented in this dissertation. Based on these findings, below I discuss some implications for practice and policy. These implications suggest ways to overcome obstacles to dementia care-sharing with PwM caring for a family member with dementia, in order to facilitate shared care in a way that corresponds to family caregivers' different needs and wishes for care-support.

First, the moral component and implicitly gendered nature of the care-context should be taken into account. This means that, in both practice and policy, there should be an awareness that moral and gendered care-norms can pressure women into exclusive caregiving. Despite the heavy load of exclusive caregiving, providing care may gradually become a significant part of family caregivers' moral identity and thus a source of (silent) moral superiority over non-caregiving family members. Later on in the care-process, and especially when family caregivers feel neglected and misunderstood, this moral and gendered component can make it difficult to discuss the care-tasks within the family and/or to seek formal care-support. This calls for an approach in which practitioners discuss family caregivers' feelings, and how these feelings can function as emotional barriers to (formal and informal) care-sharing. To open up possibilities for care-sharing, this should be done as early as possible. Here, family caregivers should be acknowledged for their care-work, and shown possibilities and examples of how the care can be shared in a way that complements (rather than supplants) their care-role.

This also means that, when developing policies with regards to long-term and dementia care, there must be an awareness that welfare policies can amplify gender inequality within families. In the past few years, changes in Dutch (as well as in other European countries) long-term care policies have increasingly shifted care-responsibilities towards informal care-networks (Verbeek-Oudijk et al., 2014). This is problematic because welfare policies that shift care responsibilities to the family often de facto shift these responsibilities to women, since gendered care norms make women more responsive to these policies than men (Schmid et al., 2012). Future policymaking should take these concerns into account.

Second, besides taking into account the moral and gendered component of the care-context, an approach that takes into account how various social categories intersect and impact care-sharing is essential. The intersectionality of family caregiver's background can be identified through their life-stories. By listening to their life-stories, practitioners can identify and be aware of the circumstances and social structures that have shaped and affected them. Here, it is particularly important to be attentive to the impact of migration history, social class, gendered care norms, religion, relationship to the care-recipient, position within the family, and the presence or absence of supportive social networks. Identifying these concerns can facilitate dementia care-sharing in two important ways: 1) Rather than making assumptions (based on an assumed cultural background) about family caregivers' needs for care-support, it gives insights into the family's background, care-context, and the type of support that is (or is not) organized. 2) Based on these gained insights, practitioners can offer support that aligns with the specific context and needs for care-sharing.

Third, in order for the above suggestions to work, a relationship of trust between practitioners and family caregivers is crucial. When experienced distance or friction stands in the way of proximity within the practitioner-client relationship, it is essential that practitioners seek adaptive approaches to overcome this. This also implies that practice and policy should reconsider the potential harm of a demand-oriented approach to dementia care-sharing, as this approach cannot work when proximity within the practitioner-client relationship has not yet been established. Furthermore, a demand-oriented approach assumes family caregivers' responsibility and assertiveness to express their care-needs – which ultimately excludes families who have not yet been fully informed about dementia and possibilities for care-sharing. Thus, there is a need to give more attention to relational aspects of dementia care-sharing in families with a migration background.

If the above suggestions would be translated into practice and policy, this could also benefit white-Dutch family caregivers. Even though this dissertation focused on PwM, it is plausible that practitioners' approaches to dementia care-sharing do not always match the needs of white-Dutch family caregivers either. Through an approach that takes into account family caregivers' life-stories and possible emotional barriers to care-sharing, and seeks adaptive ways to achieve a trusting relationship in which caregivers feel safe to express their demands for support, the needs of every family caregiver (irrespective of their ethnic background) can be identified and met.

Finally, it is imperative to move away from the current discourse in which the care-needs of PwM are assumed to be a divergence from the majority population. Practitioners should be wary of making assumptions about "the migrant Other" and stop presuming that "they look after their own." Such essentialist perceptions should be shifted to a perception in which the diversity and uniqueness of every individual is recognized within all professional approaches to dementia care-sharing. Both practice and policy should keep in mind that there is no tailor-made solution to overcoming obstacles to dementia care-sharing with PwM, as different care-situations may require different approaches.

Also, while I acknowledge that the availability of ethno-specific services (i.e., formal services that align with caregivers' ethnic background and language) may reduce some access barriers to service use, this is not sufficient to achieve care-sharing. That is, the utilization of ethno-specific services does not guarantee that family caregivers will experience (formal and informal) care-sharing as positive, as they may still experience exhaustion due to issues that are specific to their care-context. Additionally, ethno-specific services are not sustainable in responding to future diversity. Ongoing migration and diversification of societies will continuously lead to a larger number of languages and different cultures within Western societies. This makes it impossible to adjust services according to all differences, and to provide staff that can represent all languages and cultures. So, a gradual change in which mainstream services become more sensitive to family caregivers' individual backgrounds and needs would be more effective (see also, Sagbakken et al., 2018). Thus, instead of further developing ethno-specific services, or following standardized models of care, it would be more effective to increase the accessibility and flexibility of all formal care services. Policymakers should therefore keep in mind that formal services should be sensitive and adaptive to different needs and care-contexts.

This also implies that "diversity trainings" or "cultural awareness workshops" for practitioners are not a solution. Such trainings/workshops have the potential of treating PwM as static and problematic (see, e.g., Shepherd, 2019), while ignoring professional cultures and neglecting caregivers' knowledge of their family's culture and care-situation. Moreover, considering the ongoing diversity within societies, and thus also the ongoing diversity of healthcare professionals and family caregivers, "it is unclear who counts as the stranger" within healthcare encounters (Bradby et al., 2017, p. 6). Therefore, practitioners cannot assume common cultural knowledge when they encounter PwM because there is simply too much diversity to learn everything about any social group. Indeed, this does not only apply to the context of dementia care, but to all healthcare encounters within diverse societies. As a way of responding to ongoing diversity, policymakers should continuously involve minorities and new migrants in the development of formal care-support (see also, Phillimore, 2011).

6.4 Implications for future research

Besides implications for practice and policy, the conducted study also offers some directions for future research. In what follows, I will lay this out by reflecting upon the employed methods, after which I will highlight three themes to consider in future research. In doing so, this section also discusses the study's strengths and limitations.

Research methods

Throughout the course of the research I employed five different qualitative methods to study family caregivers' experiences of care-sharing. In a subsequent order, these were: semi-structured interviews, photo-voice interviews, life-story interviews combined with "shadowing" observations, and focus group discussions. I can now conclude that the semi-structured interviews, life-story interviews, and "shadowing" observations were significant strengths of the conducted research.

Initiating the collection of data with semi-structured interviews allowed me to first grasp the most pressing themes of dementia care-sharing in families with a migration background. Here, the interview questions were mostly open-ended and conducted in participants' place of choice (usually at their home), which allowed for an informal setting in which participants could feel comfortable and safe to express themselves freely.

Later on in the research process, caregivers' experiences were further investigated through life-story interviews and shadowing observations. Combining these methods allowed me to build trust and to have in-depth conversations, which resulted in thick data about family caregivers' experiences. The life-story interviews allowed me to explore how participants' life-stories relate to their current lives and decisions as family caregivers, but they also served as a preliminary conversation that was necessary to gain trust in order to conduct shadowing observations in a setting that generally does not welcome outsiders. Because of this gained sense of trust, participants felt more comfortable elaborating on their care-experiences while I was conducting shadowing observations. All this would not have been possible in an interview following a structured list of direct questions.

Another strength of these combined methods was that, while shadowing the family caregiver, I also had the opportunity to ask questions to family members who were sometimes present during the observations. This allowed for broader insights about the care-context. But, even more important, employing these methods made it possible to also include participants with low literacy, limited Dutch language skills, and/or participants from under-resourced backgrounds, who are often excluded in research (Bonevski et al., 2014; Redwood & Gill, 2013). A combination of the life-story interview with shadowing observations is thus highly recommended for future research in this field.

However, not all employed methods were as appropriate. The photo-voice method turned out to be unsuitable for the research population and thus counter-productive to the research process. This method was developed by health promotion researchers Wang and Burris (1997) as a means to give research participants the space to raise their knowledge and concerns through photos taken by themselves. Including this approach in qualitative research may indeed be fitting and empowering to some research participants, but it did not fit with most of the family caregivers that I encountered – which suggests that this method is not inclusive to all research participants.

For this method, (potential) participants were asked to take photos of situations relating to their daily care-tasks (i.e., situations in which their care-tasks were going well or were experienced as difficult). Based on these photos, they would be interviewed about their care-role. To find participants for this method, I contacted several gatekeepers who work with PwM caring for a family member with dementia. Also, I presented the research objectives and the photo-voice assignment at a gathering for family caregivers (at a community center), and, together with a partner organization, I organized a photo-voice workshop for potential participants. These efforts turned out to be in vain. Both gatekeepers and caregivers expressed concerns about sharing these photos, despite assurances of confidentiality. For instance, one of the participants at the photo-voice workshop expressed that it would not be respectful to her mother (who has dementia) to share photos of her home-environment. Additionally, gatekeepers and caregivers expressed to find the assignment pointless or too complicated. Thus, contrary to the process of conducting interviews and "shadowing" observations, bringing up the photo-voice assignment led to distrust and misunderstanding. In retrospect, this is understandable as the photo-voice method stood in the way of rapport-building.

After an extensive recruitment, five participants were included for the photo-voice method – two of whom misunderstood the assignment, as they did not deliver photos at the time of the interview. That is why I asked these participants to send me some photos after I had already interviewed them. Nonetheless, the five included participants delivered interesting photos relating to their care-role. While these photos did not add new information to the already collected research data, they did visualize relevant themes in a unique and personal way.

In conclusion, the other methods (semi-structured interviews, life-story interviews, and shadowing observations) were more suitable for the research population and they also offered more in-depth data than the photo-voice method.

At the final stage of the collection of data, I conducted online focus group discussions among family caregivers. This provided useful data, which mostly confirmed prior findings collected through the preceding methods, but a major downside of the focus group was that it excluded some family caregivers. Due to COVID-19 regulations, it was conducted through an online video-call in Microsoft Teams. This automatically excluded family caregivers with low literacy, limited Dutch language skills, and/or family caregivers from under-resourced backgrounds.

The interviews with the ten included practitioners, too, were conducted through online video-calls in Microsoft Teams. Even though conducting face-to-face interviews would have been more ideal (especially for relationship building), I did not experience difficulties recruiting and interviewing practitioners through an online medium. The partner organizations of the research project, as well as the contacts from my professional network, have greatly supported the process of recruiting practitioners.

Themes for future studies

A number of recurring themes run through all chapters of this dissertation. Considering the small research sample of the conducted study, these themes need to be further studied. In the following, I highlight and reflect upon their relevance for future studies in the field of dementia care and migration.

First, the impact of gendered care norms should always be included in future research in this field. It has long been known that “caregiving as women’s work” is a gender norm that cuts across all cultural groups, and that, because of a gendered hierarchy of care obligations, most of the care-tasks typically rest on the shoulders of one woman in the family (Calasanti & Slevin, 2001; Hooyman & Gonyea, 1999). Consequently, women may suffer more from the negative outcomes of providing care than men do (see, e.g., Del Río-Lozano, et al., 2013; Egdell, 2013; Rodríguez-Madrid et al., 2019). The findings presented in this dissertation suggest that this could also be the case for PwM caring for a family member with dementia. Throughout the chapters, I illustrated how gendered care norms can make it difficult for family caregivers to share (more) care-tasks, and to press discussions about experienced exhaustion and the care-situation in general. As a result, family caregivers may acquiesce into their gendered care-role. These findings show that the study of care-experiences in families with a migration background cannot be separated from the study of gendered care norms.

Nevertheless, even though the impact of gendered care norms within the context of (dementia) care and migration has been reported in some studies (Sagbakken et al., 2018; Tonkens, Verplanke et al., 2011; van Wezel et al., 2014), it is generally understudied in research focusing on the care-experiences of PwM. Thus, this gender dimension should continuously be addressed in research in the field of dementia care and migration.

Here, it is also important to study the care-perceptions of men who are primary caregivers. Within the conducted study, the majority of the included family caregivers are female; of the

31 included family caregivers, 29 are women, while only 2 are men. The ways in which men assume and deal with caregiving responsibilities may be very different from the included female participants, because of their gender socialization (i.e., masculine gender norms and expectations). This could be why both included male participants were able to admit the care-recipient to a nursing home before experiencing severe exhaustion, while gendered care norms can lead female caregivers to experience pressure to persist until there is no other option. However, within the conducted study I did not examine such gender differences. This is an important limitation, which requires attention in future research.

Second, besides taking into account the impact of gendered care norms, the impact of other relevant social categories (and their intersections) should also be studied in future research. This means that, rather than overemphasizing cultural aspects of care, intersections of a number of social categories should be investigated in research on dementia care in families with a migration background. While there is a recognition in the literature for the need of an intersectionality lens when studying the health and care-experiences of PwM, “this seems to be honored more in principle than in how research is undertaken, or at least how the results are written up” (Koehn et al., 2013, p. 457). In other words, an overemphasis of “cultural influences” on care still dominates the field of dementia care in families with a migration background (see, e.g., Nielsen et al., 2020; Richardson et al., 2017).

Studies focusing on the impact of culture may offer insights about care-experiences in families with a migration background (since some aspects of dementia care may indeed take different forms in different ethnic minority groups), but these insights are one-sided and incomplete. Hence, when the care-experiences of PwM are described as being located in their specific cultural norms and differences, the complexity of these experiences, including the impact of social inequalities, are neglected (Iliffe & Manthorpe, 2004; Zubair & Norris, 2015). Moreover, an emphasis on culture as an explanation for differences in care-experiences is in and of itself problematic. Not only does it assume that PwM adhere to a static set of cultural norms and practices, it also constructs PwM as an Other whose needs for care-support are assumed to be problematic and difficult as opposed to the white majority population. As the findings of the conducted study suggest, the ways in which PwM experience dementia care-sharing, and the options that are available to them, will vary as a consequence of an interplay between multiple social categories. This illustrates that it is not meaningful nor productive to isolate culture from other social categories relevant to dementia care.

Hence, an overemphasis of culture should be avoided throughout future research in this field. That does not mean that the impact of cultural norms and practices should be completely avoided, but that they cannot be understood in isolation from other social categories that are relevant to care-experiences. In essence, this means that family caregivers' experiences should be understood as dynamic and multilayered rather than fixed. This is ultimately necessary to acknowledge and understand the complexity of dementia care-sharing in families with a migration background.

This also means that, within future research in this field, matching the ethnicity of the researcher with the research participants should not be deployed as a research strategy. The rationale for "ethnic matching" has been critiqued for being problematic and counter-productive as it assumes an essentialized identity of the researcher and researched, as well as a fixed "insider" status (see, e.g., Rhodes, 1994; Ryan et al., 2010; Sin, 2004). Yet, it is still promoted and deployed as a research strategy in research concerning dementia care and migration (see, e.g., Berdai-Chaouni et al., 2018; Richardson et al., 2017; Shanley et al., 2013). Through my positionality, I have argued against "ethnic matching" by illustrating how more factors than the researcher's ethnic identity affect the research process. Also, due to fear of gossip and judgements within ethnocultural communities, "ethnic matching" could hinder research on topics (including dementia care) that are considered to be sensitive. Thus, researchers should move away from the practice of "ethnic matching." Instead, regardless of their ethnic background, they should continuously be aware of the ways in which different, intersecting aspects of their positionality affect the research process.

Third, there is a need for further inquiries about the viability of practitioners' views and approaches to dementia care-sharing in an increasingly globalized and diverse society. A professional approach that fits with some families, can be harmful to others. This problem becomes particularly urgent when we consider that globalization and migration will further the ongoing "diversification of diversity" in Western societies (Vertovec, 2007, p. 1025). Hence, a superdiverse context requires adaptive approaches that can cope with the ongoing changing populations that practitioners encounter within the process of dementia care-sharing. In the conducted study I have made an attempt to open up discussions about care-sharing between practitioners and family caregivers with a migration background, but, considering the small sample of included practitioners, more research is needed on this matter. Here, it is crucial to study how professional services and approaches can be shaped in an inclusive and sustainable way, so that they can benefit all family caregivers of individuals with dementia.

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Addendum

Nederlandse samenvatting

Dit proefschrift is gebaseerd op een vierjarig onderzoek gericht op de ervaringen en behoeften van mantelzorgers met een migratieachtergrond die zorgen voor een familielid met dementie. Voorgaand onderzoek laat zien dat mantelzorgers met een migratieachtergrond minder gebruik maken van formele zorg- en ondersteuning en dat zij vaker overbelast raken. Dit kan te maken hebben met drempels die de toegang tot het gebruik van formele diensten belemmeren (bijv., discriminatie, een taalbarrière en een gebrek aan kennis over dementie). Een ongelijke verdeling van de zorgtaken binnen families leidt er daarnaast toe dat mantelzorgers met een migratieachtergrond vaker intensieve zorg geven. Door gendernormen betekent dit dat de zorg veelal bij een vrouw (vaak een dochter of schoondochter) terecht komt.

Echter, er is een gebrek aan kennis over het (verbeteren van het) delen van de zorg binnen families met een migratieachtergrond die zorgen voor iemand met dementie. Dat wil zeggen, er is nog weinig bekend over hoe relationele processen binnen families, en tussen families en zorg- en hulpverleners, het delen van de zorg kunnen bevorderen of verhinderen. Aan de hand van de ervaringen en perspectieven van mantelzorgers en zorg- en hulpverleners draagt dit proefschrift bij aan het dichten van deze kenniskloof. Dit proefschrift beantwoordt daarmee de volgende hoofdvraag: Wat zijn belemmerende en bevorderende factoren voor het delen van zorg in families met een migratieachtergrond die zorgen voor personen met dementie? Deze vraag wordt beantwoordt aan de hand van drie empirische hoofdstukken. Daarnaast wordt in dit proefschrift ook een methodologisch hoofdstuk behandeld, waarin ik reflecteer op mijn positionaliteit binnen het onderzoek. Middels drie verschillende perspectieven (het perspectief van mantelzorgers, zorg- en hulpverleners, en mijn perspectief als onderzoeker), biedt dit proefschrift unieke inzichten voor praktijk, beleid en onderzoek.

Hoofdstuk twee gaat in op de gender-gerelateerde en morele dimensies van het geven van zorg aan een familielid met dementie. Aan de hand van Hochschild's "framing and feeling rules" wordt uitgelicht hoe mantelzorgers de zorg ervaren en hoe dit samenhangt met hun gevoelswereld en sociale context. Hiermee wordt getracht inzicht te geven in de culturele en sociale dynamieken die het delen van de zorg binnen families, en tussen families en formele zorg, belemmeren. De bevindingen laten zien dat het geven van zorg gezien wordt als iets wat gedaan wordt vanuit de frame "reciprocal love" en/of vanuit de frame "filial responsibility." Door impliciete gendernormen geeft vaak een vrouw in de familie gehoor aan deze frames. Om het hoofd te bieden aan een ongelijke verdeling van de zorgtaken, wordt het geven van zorg via deze frames een deel van haar morele identiteit. Hoewel dit een gevoel van kracht en trots geeft, staat het ook gedeelde zorg in de weg – waardoor de kans op overbelasting bij mantelzorgers verder toeneemt.

In hoofdstuk drie wordt aan de hand van de levensverhalen en zorgervaringen van mantelzorgers, en met behulp van een intersectionele lens, getracht inzicht te geven in hoe verschillende, met elkaar verweven sociale categorieën (zoals migratiegeschiedenis, religie en sociale klasse) relevant zijn voor ervaringen rondom het delen van de zorg in families met een migratieachtergrond. Migratiegeschiedenis en sociale klasse kwamen hierbij het sterkst naar voren. De bevindingen illustreren hoe beide sociale categorieën van invloed zijn op het verkrijgen van vaardigheden die nodig zijn om zorgtaken te kunnen delen. Daarnaast laten de bevindingen zien dat (intersecties van) de volgende sociale categorieën ook van belang zijn bij ervaringen rondom het delen van de zorg: iemands positie binnen het gezin; de aan- of afwezigheid van sociale netwerken; religie; genderspecifieke normen over het geven van zorg; de relatie die men heeft met de zorgontvanger.

Hoofdstuk vier gaat in op relationele processen rondom het delen van de zorg, zoals ervaren door zorg- en hulpverleners. Hier wordt Hochschild's concept van "framing and feeling rules" gebruikt om licht te werpen op de manieren waarop zorg- en hulpverleners het delen van de zorg met families met een migratieachtergrond ervaren. Om een vollediger beeld te schetsen, worden deze ervaringen en perspectieven gerelateerd aan de zorgervaringen van de geïncludeerde mantelzorgers. Uit de bevindingen komt naar voren dat zorg- en hulpverleners het delen van de zorg begrijpen vanuit de frame "proximity within the practitioner-client relationship" en de frame "a demand-oriented approach." In hun contacten met families met een migratieachtergrond is het vaak niet mogelijk om aan deze frames te voldoen. Dit heeft te maken met een gevoel van afstand, wat bij zowel zorg- en hulpverleners als bij mantelzorgers aanwezig is. Belemmeringen bij het delen van de zorg met families met een migratieachtergrond worden mogelijk ervaren vanuit de frames "the migrant Other" en "they look after their own." De bevindingen in dit hoofdstuk laten zien dat wanneer het delen van de zorg belemmerd wordt, dit nadelig is voor zowel mantelzorgers als zorg- en hulpverleners.

In hoofdstuk vijf wordt een methodologische beschouwing gegeven van mijn positionaliteit als onderzoeker met een migratieachtergrond die onderzoek heeft verricht in een cultureel diverse setting. Als een kritiek op "ethnic matching" (d.w.z., het matchen van de etniciteit van een onderzoeker met die van de participanten vanwege een veronderstelde "insider"–status van de onderzoeker) wordt in dit hoofdstuk positionaliteit begrepen vanuit het gedachtegoed van intersectionaliteit. Hiermee wordt geïllustreerd dat zowel overeenkomsten als verschillen met participanten van invloed zijn bij het opbouwen van een vertrouwensband en op machtsdynamieken binnen de relatie. Daarnaast wordt in dit hoofdstuk beargumenteerd dat de ervaren emoties van een onderzoeker de inhoud en analyse van de data kunnen beïnvloeden. Door uit te lichten hoe verschillende aspecten van de identiteit van een onderzoeker elkaar overlappen en het onderzoeksproces kunnen beïnvloeden, wordt in dit hoofdstuk gepleit voor een reflexieve aanpak – in plaats van "ethnic matching" – in toekomstig onderzoek op dit terrein.

Tot slot wordt in hoofdstuk zes een overzicht gegeven van de belangrijkste bevindingen van dit proefschrift en de daaruit voortkomende inzichten voor beleid, praktijk en toekomstig onderzoek. Deze bevindingen en inzichten wijzen erop dat het belangrijk is om dementie-zorg binnen families met een migratieachtergrond te begrijpen als een morele en veelzijdige ervaring waarvoor situatie-afhankelijke, formele begeleiding nodig is. Hierbij is het noodzakelijk dat het huidige discours, waarin verondersteld wordt dat families met een migratieachtergrond afwijken van de meerderheidspopulatie, doorbroken wordt. In plaats daarvan is het belangrijk dat in beleid, praktijk en toekomstig onderzoek rekening wordt gehouden met de diversiteit en uniciteit van families en mantelzorgers met een migratieachtergrond.

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Curriculum vitae

Menal Ahmad was born in Borger, the Netherlands, to Iranian parents who were born and raised in Iraq. Her multilingual (fluent in Dutch, English, Persian, and Iraqi-Arabic) and mixed cultural background has fueled her academic interest in topics related to migration, gender norms, and cultural diversity. Menal also has a mixed educational background, as her education and career started off on a path different from the social sciences. In 2008, she completed a secondary vocational training (MBO) of pharmacy technician at ROC Aventus Deventer. After a year of working at several pharmacies, she continued her pharmaceutical studies (Farmakunde) at the University of Applied Sciences Utrecht (Hogeschool Utrecht). Her internships at patient-centered organizations sparked her interest in research that takes into account the perspectives and circumstances of individuals. Upon completing her studies in 2013 with a Bachelor of Health, she moved to Iran in order to connect with her cultural roots and to further study the Persian language. During her year in Iran, her interest in cultural anthropology and the role of gender norms grew. Therefore, from 2014 until 2016, she studied the pre-master and master of Cultural Anthropology at Utrecht University. Her ethnographic study on the relationship between gender norms, martial arts, and Iranian women's citizenship was awarded a prize of best master thesis in the field of gender studies and feminist anthropology in the Netherlands (LOVA/Marjan Rens MA Thesis Award). Between December 2017 and December 2021, she pursued a Ph.D. at the department of Citizenship and Humanization of the Public Sector at the University of Humanistic Studies in Utrecht.

What are obstacles and facilitators to shared care in families with a migration background caring for individuals with dementia?

This dissertation aims to answer this question through analyses of family caregivers' views and experiences of their care-role and of (formal and informal) care-sharing. An important part of this question is also answered through an analysis of practitioners' views and experiences. In doing so, this dissertation points towards the importance of understanding dementia care in families with a migration background as a gendered, moral, and multifaceted experience that requires context-dependent formal care-guidance. Through a reflexive analysis of the author's positionality within the conducted research, this dissertation also provides insights for future research in cross-cultural settings. Thus, by shedding light on three very different but interrelated points of view (i.e., family caregivers, practitioners, and the researcher), the presented findings offer a unique outlook for practice, policy, and research.