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Persons With a Migration Background Caring for a Family Member With Dementia: Challenges to Shared 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 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 though these moral framing and feeling rules, and how gender norms impact on an unequal distribution of care-tasks.
Implications: Healthcare practitioners should identify the 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 healthcare practitioner. Furthermore, asking for support should be normalized. Governmental advertisements on care–support can achieve this.

Key words: Family care, Framing and feeling rules, Gender norms

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, Peeters, van Beek, Meerveld, & Francke, 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 wandering, 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 in persons with a migration background (PwM[1]) than among native 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 native Dutch population.

Despite the higher incidence of dementia in PwM, studies show that PwM make less use of formal support services (Denktaş, Koopmans, Birnie, Foets, & Bonsel, 2009; Van Wezel et al., 2016), and that older PwM rely on family caregivers more often and more intensively than native older Dutch persons (De Graaff & Francke, 2003; de Graaff, Francke, van den Muijsenbergh, & van der Geest, 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 professionals care) is considered dishonorable, and results in feelings of shame (Tonkens, van den Broeke, & Hoijtink, 2008, Tonkens, Verplanke, & de Vries, 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, 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, 2019). Although "caregiving as women's work" is a gender norm that cuts across all cultural groups (Calasanti & Slevin,

2001), in PwM residing in the Netherlands this norm may be stronger than among native 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., 2016). This may explain why family caregivers with a migration background show higher percentages of exhaustion (Oudijk et al., 2010).

The higher incidence of dementia in 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, King, & Koch, 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 health or 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.

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

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[1]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 (Statistics Netherlands, 2016). PwM is not an ideal term either because it demarcates people on what they are not (e.g. a person with a native 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, we adapted this term in our paper because we have yet to come across a term that is more inclusive.

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.

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 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), Moroccan-Berber (n = 2), Moluccan (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 key figures. These included persons working with family caregivers with a migration background, such as social workers, and organizers of group-meetings for family caregivers. All the referrals who were recruited by these key figures 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

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
Karima (42)	Moroccan-Berber	Daughter
Naïma (45)	Moroccan-Berber	Daughter
Nancy (44)	Moluccan	Daughter
Marjan (52)	Moluccan	Sister
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.

interpreter—the other interviews were conducted in Dutch. An overview of the sample is given in Table 1.

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 caregiving role, and how do their expressed feelings (such as pride, anger, and disappointment) relate to this frame?" And: "How do participants perceive their caregiving 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: *the moral experience of caregiving* and *challenges to shared dementia care*. In the following sections these themes will be presented.

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 caregiving 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:

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 caregiving 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

"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, 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 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 reciprocate her love and gratitude toward 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 more 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 caregiving 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 caregiving 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 2 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 other research focusing on family caregivers with a migration background (Tonkens et al., 2011), Emine does not perceive her caregiving 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, Ozeke-Kocabas, Oort, & Schuengel, 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 caregiving 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 sees 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, their moral framing rules of reciprocal love and 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 health and 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's 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 caregiving 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 (e.g. his daughters-in-law). Karima's brothers, too, have told her that caring is "women's work." She does not agree with this, that 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 would insist 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 [native] 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.
> Interviewer: 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, see caring 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 worries 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 2 years of providing intensive care—but she was met with rebuff. In conclusion, both Karima's and Emine's narrative seems 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 misunderstanding by family members who are not involved in the care.

Challenges to Considering Formal Health and 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 care with professional health and 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 professional support.

The framing rules of reciprocal love and filial responsibility make the idea of professional health and support 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 2 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.

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 health or support 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 effect 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, del Mar García-Calvente, Marcos-Marcos, Entrena-Durán, & Maroto-Navarro, 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 presumed 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 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 native Dutch family caregivers of persons with dementia. In a similar matter, family caregivers without a migration history may frame their caregiving role in terms of being "a good person" who prioritizes the person with dementia because of implicit feeling rules (Herron, Funk, & Spencer, 2019). However, an important difference is that PwM place a high responsibility on the informal care-network, whereas native Dutch families perceive invoking support of professional 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 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 (e.g. 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. More research is needed on the ways in which male caregivers with a migration background frame their caregiving experience.

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 health or 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 caregiving 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 health and support services as "good care" instead of having to provide the care exclusively themselves.

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Conflict of Interest

The authors declare no conflict of interest.

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