Dementia care-sharing and migration: An intersectional exploration of family carers' experiences

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A B S T R A C T

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 carers 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 on practices of care-sharing in 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 multi-faceted 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.

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, Uysal-Bozkir, Goudsmit, et al. (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 carers of individuals with dementia often experience psychosocial problems and support needs throughout the process (Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 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, Plaisier, & de Klerk, 2020). This gap does not only apply to the Dutch context, as persons with a migration background (PwM[1]) are underrepresented within

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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 (i.e., a person with a native Dutch background), and it highlights differences from the majority. Furthermore, although the term PwM is still divided into Western and non-Western (Statistics Netherlands, 2021b), in Dutch discourse it commonly refers to persons who are not white. Nonetheless, this term is applied here because we have yet to come across a term that is more inclusive and suitable to the Dutch context.

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 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, Koopmans, Birnie, Foets, & Bonsel, 2009; Shanley et al., 2012; van Wezel et al., 2016). 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, Cooper, & Livingston, 2011), and the perception that it is the family and not professional outsiders who should provide care for aging parents (Tonkens, Verplanke, & de Vries, 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, Spilker, & Ingebretsen, 2018; van Wezel et al., 2016). 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 carer (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, van den Broeke, Saharso, & Tonkens, 2020). This may explain the higher percentages of exhaustion in family carers with a migration background as compared to native Dutch family carers (Oudijk, de Boer, Woittiez, Timmermans, & de Klerk, 2010).

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, whilst 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, Neysmith, Kobayashi, & Khamisa, 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 on practices of care-sharing for 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 carers 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.

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 story-telling. 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 carers of individuals with dementia, Chappell, Dujela, and Smith (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.

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 carers 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 carers 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, 2021a). 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.

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 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[2] 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[2] 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. In 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,[3] gendered care norms,[4] 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 carers organize and share the care more than others.

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[2] Pseudonym.

[3] 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).

[4] 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.

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.

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 carer. 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 carer. 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 carer 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,[5] 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 carer.

The reason why Jun assumed the role of primary carer 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 ethno-cultural 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 wider 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 day-care, where he goes 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

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[5] Country altered to protect anonymity.

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: Mrs. Aydin: I [said] maybe he [should] be [in a nursing home]. Then my youngest son said "no."
Interviewer: 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."
Interviewer: 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 the 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 carer, 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 sensitive formal care-support, family carers may still experience exhaustion due to a lack of necessary skills to negotiate more 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 carers. 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 carer:

> [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 carer. 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 carer not only because of practical reasons but also because, as the eldest sibling, it was expected of her. Whilst 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.

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, Clarke, & Gibb, 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 carers 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, Pereyra, & Iris, 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 carers' 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 carers 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 carer wellbeing (Roth, 2020). This may be why carers 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, Worthington, Kypriotakis, & Rose, 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, Ozeke-Kocabas, Oort, & Schuengel, 2009) also suggests that PwM may use religion as a way to compensate for a lack of supportive social networks. However, even though family carers may derive a sense of strength and support from religion (van Wezel et al., 2016), 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., 2016). 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 carers 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. That is, the 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 carers 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 in 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 carers. 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, Randell, Paul, et al., 2014; Redwood & Gill, 2013).

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 carers, it is essential that health and

social care workers seek to understand the care-context and individual perspectives of every family carer. 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 carers in their care-role. One should recognize that, even when the care is shared, family carers may still experience exhaustion. Thus, health and social care workers should be wary of making assumptions about carers' needs and wishes for care-support.

To be able to provide care-support that is attuned to carers' 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, Hanson, & Ross, 2003; Menn, Corsten, Lauer, & Wallace, 2020) and palliative care (Hesse, Forstmeier, Mochamat, & Radbruch, 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 carers' 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 carers feel safe and understood. This is only possible when assumptions are left aside, and each carer is approached as a unique individual whose experiences and care-context are influenced by distinct combinations of intersecting social categories.

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The authors declare no conflict of interest.

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