Ageing & Society (2023), 1–22
doi:10.1017/S0144686X23000260

ARTICLE

Framing dementia care in families with a migration background: an analysis of practitioners' and family carers' views and experiences

Menal Ahmad[1], Sawitri Saharso[1,2] and Evelien Tonkens[2]

[1]Department of Sociology, VU Amsterdam, Amsterdam, The Netherlands and [2]Department of Citizenship and Humanization of the Public Sector, University of Humanistic Studies, Utrecht, The Netherlands
Corresponding author: Menal Ahmad; Email: m.ahmad@vu.nl

(Accepted 29 March 2023)

Abstract
Little is known regarding the ways in which practitioners' views and approaches impact support for persons with a migration background (PwM) caring for individuals with dementia. This paper responds to this knowledge gap by identifying how practitioners frame dementia care in families with a migration background, and how these frames can be understood in light of the experiences of PwM caring for a family member with dementia. A total of 41 participants were included: ten practitioners (*i.e.* health and social care workers) and 31 PwM caring for a family member with dementia. All participants were part of a qualitative research project on dementia care in Dutch families with a migration background. Practitioners' expressed frames were identified through Hochschild's interpretive framework of 'framing and feeling rules'. Thereafter, practitioners' identified frames were related to the care experiences of PwM caring for a family member with dementia. Findings indicate that practitioners operate within an approach that does not sufficiently take into account the uniqueness of each family carer. This leads to frictions within the practitioner–client relationship. We thus highlight the need for discussions about the tenability of practitioners' views and approaches in an increasingly globalised and diverse society.

Keywords: dementia care; migration; framing and feeling rules; formal care; family care; diversity; inclusion

Introduction

The demographic landscape of Europe is changing due to its ageing populations and changing ethnic composition (England and Azzopardi-Muscat, 2017). For instance, in the Netherlands, older individuals with a migration background are expected to make up 21 per cent of the ageing population by 2060 compared with 11 per cent in 2015 (van Duin and Stoeldraijer, 2014). This means that the incidence of dementia among persons with a migration background (PwM)[1] will increase, since dementia has a higher prevalence rate among individuals aged 60 and older (World Health Organization, 2012). Consequently, dementia care among PwM poses a pressing concern for European health and social care (Canevelli *et al.*, 2019; Alzheimer Europe, 2020).

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

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

Such barriers, both at the internal and external level, suggest a lack of care-sharing between practitioners and PwM caring for a family member with dementia. However, these identified barriers do not provide an understanding of how practitioners' views and approaches impact the ways in which the care is shared within the practitioner–client relationship. That is, our understanding of care-sharing does not imply a mere utilisation of formal services. Rather, we understand care-sharing as a relational process within families, and between families and practitioners, in which family carers are supported and guided throughout the care for their family member with dementia.

Thus, in this paper we aim to understand how practitioners' views and approaches impact the ways in which the care is shared with PwM caring for a family member with dementia. To offer a fuller picture, we will relate practitioners' expressed views to the care experiences of PwM. After all, a possible reason for sub-optimal care-sharing could also be a mismatch in expectations or misunderstood intentions or behaviours between practitioners and PwM. Our study was conducted in the Netherlands, and is part of a larger research project on dementia care in families with a migration background. To achieve our study's aim, we will answer the question:

- How do practitioners frame dementia care-sharing with PwM, and how can these frames be understood in light of the experiences of PwM caring for a family member with dementia?

Identifying these concerns can open up discussions about the improvement of care support for PwM caring for a family member with dementia.

Theoretical perspective

As mentioned in the above, most of the available knowledge about dementia care in families with a migration background relates to internal and external access barriers to formal services. However, little is known about how differences in views may be a cause for friction within the practitioner–client relationship. This paper responds to this knowledge gap with the help of Hochschild's interpretative framework of 'framing and feeling rules' (Hochschild, 1983, 2003), which will guide our analysis of practitioners' views and approaches to care-sharing with PwM. Thereafter, we will add another layer to the analysis by relating practitioners' expressed 'framing and feeling rules' to the experiences of PwM caring for a family member with dementia.

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

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

Methodology

Methods of data collection

For this paper, we made use of two sets of data (N = 41) that are part of our larger research project; one focusing on practitioners and the other focusing on family carers. Both datasets were based on a qualitative study design. Our data on practitioners' perceptions and experiences (N = 10) were collected through semi-structured interviews, and are taken as this paper's primary focus. Due to COVID-19 regulations, they were conducted through online video calls in Microsoft Teams. The interviews were conducted with the support of a topic list focusing on five central themes, namely professional background; caring for a person with dementia; communication with family carers and their relatives; care-sharing within families; and care-sharing with formal services. All interviews lasted between 60 and 80 minutes.

Our data on the care experiences of PwM (N = 31) were gathered through PwM who provide care, or have until recently provided care, for a family member with dementia. In this paper, we use this set of data to better understand our findings from the practitioners' interviews. As part of our larger research project, this dataset was gathered through five different qualitative methods, namely semi-structured interviews, photo-voice interviews, life-story interviews combined with 'shadowing' observations, and a focus group discussion. The focus group discussion was conducted through an online video call in Microsoft Teams, the remaining four methods were conducted in person. The semi-structured interviews (N = 13) lasted between 45 and 120 minutes. The photo-voice interviews (N = 5) lasted between 60 and 100 minutes. The life-story interviews were followed by 'shadowing' observations of our participants' (N = 6) daily lives as carers, and lasted five to six hours per participant. The focus group discussion (N = 7) lasted 100 minutes.

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

Throughout the research, all authors upheld the key ethical principles in conducting qualitative research, such as confidentiality, privacy, honesty and integrity. All participants gave informed consent, and all interviews were audio-recorded with the interviewees' permission.

Participant recruitment and characteristics

The data from both datasets were collected by the lead author. For the first dataset, practitioners were interviewed between July 2020 and January 2021. These include health and social care workers with professional experience relating to dementia care, and who have patients/clients with a migration background. We recruited them through partner organisations and the lead author's professional network. Eight of the participants have a white-Dutch background and two of the participants have a migration background (Chinese and Turkish). An overview of the sample is given in Table 1.

The second set of data was gathered between February 2018 and February 2021. We spoke with family carers who have a Chinese, Indian-Surinamese, Moluccan, Moroccan or Turkish migration background. We purposively recruited participants

Table 1. Overview of the research sample – practitioners (P)

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

with a Moroccan, Surinamese and Turkish background because they belong to the largest ethnic minority groups with a non-Western migration background in the Netherlands (Statistics Netherlands, 2022). We also purposively recruited participants with a Chinese and Moluccan background because, within the Dutch context, their views are often neglected in socio-scientific research on dementia care. Family carers were recruited through community centres, social care workers, organisers of peer groups for family carers and through partner organisations. An overview of the sample is given in Table 2.

Analysis

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

First, the interviews were inductively coded. We identified repetitive patterns and initial codes while reading all transcripts, after which an initial coding scheme was created. After that, all transcripts were transferred to ATLAS.ti where they were further analysed and coded by the lead author. Identified patterns and themes were discussed with all authors in several extensive meetings. Second, we established the coding categories by further analysing the codes. Here, we asked: 'How do practitioners frame successful care-sharing?', 'How do practitioners frame their perceptions and experiences of care-sharing with PwM?' and 'How do practitioners'

Table 2. Overview of the research sample – family carers (FC)

	Age	Cultural background	Relationship to care recipient
FC1	67	Chinese	Wife
FC2	54	Chinese	Daughter
FC3	55	Indian-Surinamese	Daughter
FC4	60	Indian-Surinamese	Daughter
FC5	44	Moluccan	Daughter
FC6	52	Moluccan	Sister
FC7	42	Moroccan-Berber	Daughter
FC8	45	Moroccan-Berber	Daughter
FC9	45	Turkish	Daughter
FC10	48	Turkish	Daughter
FC11	54	Turkish	Daughter
FC12	51	Turkish	Daughter-in-law
FC13	48	Turkish	Son
FC14	61	Indian-Surinamese	Daughter
FC15	35	Moluccan	Son
FC16	59	Moluccan	Sister
FC17	71	Moroccan-Berber	Daughter
FC18	55	Moroccan-Berber	Daughter
FC19	39	Chinese	Daughter
FC20	60	Moluccan	Daughter
FC21	59	Moroccan-Berber	Daughter
FC22	52	Moroccan-Berber	Daughter
FC23	70	Turkish	Wife
FC24	52	Turkish-Kurdish	Daughter
FC25	58	Moluccan	Daughter
FC26	58	Moluccan	Daughter
FC27	42	Moroccan-Arabic	Daughter
FC28	48	Moroccan-Berber	Daughter
FC29	49	Turkish	Daughter
FC30	61	Turkish	Daughter
FC31	52	Turkish	Daughter

expressed emotions (such as a feeling of inadequacy, victory and hesitation) relate to these frames?' Around 90 codes were identified. The identified codes were clustered into eight categories which we organised in a coding scheme.

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

The combined stages of the analyses have led to the identification of four overarching themes in which we discuss practitioners' expressed framing rules, and how family carers' experiences can be understood in light of these framing rules, namely *proximity within the practitioner–client relationship*, *a demand-oriented approach*, *the migrant Other* and *'they look after their own'*.

Findings

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

Proximity within the practitioner–client relationship

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

First, practitioners expressed that, more often than in white-Dutch families, the early stage of dementia is overlooked or denied in families with a migration background. Some practitioners (P2 and P5) indicated that, despite working in an ethnically diverse neighbourhood, they have a small number of PwM in their client database – as a dementia case manager explained:

> I work in several neighbourhoods where quite a lot of [PwM] live, but the group of people with dementia is a small group in my file … People are not open to talk about such matters. (P5)

By the time family carers seek formal help, the dementia has often progressed so far that hospitalisation is needed. Since this leaves little space to guide families through the care process, the process of building trust with their clients is inhibited. A carer support manager expressed this as follows:

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

When PwM *do* seek help at an early stage, practitioners often experience a language barrier with the care recipient. This is experienced as an obstacle to proximity because:

> You often have to speak with children of the patients, who then interpret. And because of this, you don't have direct contact with the patient; it always goes through another person. (P10)

Indeed, this obstacle is further complicated when both care recipient and family carer do not speak Dutch well.

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

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

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

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

> I also [have contact with] a Vietnamese carer. Her daughter has settled well here, speaks Dutch well. But this lady, well … They look at me very much during conversations … A certain look of well, who's that? What is she saying?

> Because, of course, [the carer and care recipient] don't understand me. So, I always explain to [their daughter]: 'I'm not here to put people away. Do you want to translate that? Tell them that I'm here to see what I can do for them and if I can help them.' (P3)

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

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

Practitioners also expressed other approaches for overcoming obstacles to proximity. These include: making use of a professional interpreter; calling in a religious (*e.g.* Islamic) counsellor in family meetings; showing acknowledgement of carers' contribution; and scheduling informal meetings with the carer and/or care recipient.

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

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

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

Family carers may also experience distance when practitioners express their concerns, or the course of the condition, in a straightforward manner. A Chinese-Dutch family carer of her mother explained this as follows:

> [The nurse] was very unkind because she said to me: 'This lady, with such an old age, she will never get well.' Because she's old and didn't speak Dutch and had dementia … But how can she say such a thing? Who is she to write off an old lady like that? … That is why we thought: 'We don't want mom to be stressed and we just want to give her a nice old day.' (FC2)

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

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

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

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

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

A demand-oriented approach

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

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

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

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

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

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

Eventually, family carers may seek help in a much later stage of dementia. Practitioners are aware of this issue, but may not press discussions with their clients because it does not fit within the framing rule of *a demand-oriented approach*:

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

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

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

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

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

> We [later] found out about it ourselves, through other people. We asked people: 'How did you take care of your mother?' Then we saw other examples … And then we said [to our GP]: 'We also want to do that assessment to determine whether our mother has [dementia].' So we really had to address it this way, and we didn't know that. I felt so bad about it because my mother couldn't take care of herself anymore, and I had to take her into my home … She left the tap on, and the stove, it was dangerous. And, really, it took two years until the diagnosis was made.

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

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

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

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

The migrant Other

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Besides a feeling of caution, a focus on cultural differences can lead practitioners to feel they are unable to perform their jobs well due to a perceived lack of cultural knowledge about the migrant Other. A dementia case manager expressed this as follows:

> It feels as if I need to read a book on how to deal with foreign people. Do you understand what I mean? That's where [the problem] seems to be situated. (P3)

Consequently, this dementia case manager is left feeling stumped – as she is unable to perform her profession adequately. When this happens, practitioners may seek 'diversity trainings' or professional tools about culturally appropriate care, while neglecting families' knowledge about the care recipient's individual needs – as a Turkish-Dutch family carer explained:

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

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

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

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

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

'They look after their own'

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

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

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

> In my experience, when there's a number of children, then these children are generally involved and they distribute the [care] tasks among themselves. I have a Moroccan [patient], her daughter is the one who provides physical care, the other daughter is the one whom I talk with about medical concerns, one son takes care of the finances, the other son does the groceries, and so on and so forth. So, the care is usually adequately distributed … I mostly encounter families who are very much together involved in the care tasks. (P10)

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

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

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

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

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

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

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

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

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

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

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

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

Discussion and conclusions

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

Due to an experienced feeling of distance, practitioners are often unable to respond to the framing rule of *proximity within the practitioner–client relationship*. A language barrier and reaching out to formal care in a late stage of dementia are experienced as major obstacles to achieving proximity with PwM – a finding that resonates with previous studies (*e.g.* Gulestø *et al.*, 2022; Sagbakken *et al.*, 2020). Even when communication with family carers was possible, practitioners often experienced a sense of distance. This could be due to an overlap of language and culture. For example, ways of speaking, or implicit references to religious and culturally shared knowledge, are suggested to impact communication between one another (Gora and Conner, 2013; Sagbakken *et al.*, 2020). PwM, too, often experienced a lack of proximity with practitioners. Other studies report that this may be due to a general feeling of anxiety to accept professional outsiders which could be related to shame and stigma within the community (Tonkens *et al.*, 2011), as well as experiences of social exclusion and institutionalised racism experienced by PwM (Jutlla, 2015). Our findings suggest that PwM may also experience a lack of proximity when practitioners fail to recognise the moral dimensions of caregiving or when concerns are expressed in a straightforward manner.

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

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

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

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

Thus, when obstacles to the framing rules of *proximity* and *a demand-oriented approach* are perceived through the framing rule of *the migrant Other* and *'they look after their own'*, practitioners are inhibited from finding solutions to these experienced obstacles. As our study suggests, not only does this prevent practitioners from adequately performing their profession, it also risks PwM being excluded from formal care. In accordance with previous studies on dementia care in families with a migration background (Berdai-Chaouni *et al.*, 2020; Gulestø *et al.*, 2022), our findings suggest that practitioners are often unaware of the complexities of care needs within these families. This could be why obstacles to successful care-sharing are framed through cultural explanations.

An important limitation of this paper is that our small sample of included practitioners limits generalisations about practitioners' identified framing rules. However, it was not our aim to offer a representative sample. Rather, by identifying practitioners' framing rules, we aimed to offer an in-depth understanding of views and approaches that impact formal support for PwM caring for a family member with dementia. Attaining this aim was in part possible because we highlighted how practitioners' framing rules can be understood in light of family carers' experiences.

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

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

Implications

Our study suggests a need to rethink the outcomes of professional approaches to dementia care-sharing, and to give more attention to the relational dimension of communication with PwM. This entails a need to find adaptive approaches to building a trusting relationship in which PwM feel safe to express their demands and concerns with practitioners. Even when there are language difficulties, a relationship of trust can overcome language barriers to a large extent (Degrie *et al.*, 2017). When interacting with PwM with dementia and their family carer(s), we thus suggest a flexible approach in which practitioners adapt to the specific situation by paying more attention to relationship building. At the same time, it is crucial to take into account the intersectional aspects of each family carer's background (Ahmad *et al.*, 2022).

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

Acknowledgements. We wish to thank all participants for sharing their experiences. Also, we are very grateful to Roshnie Kolste, Gülay Batman-Struik and Jennifer van den Broeke for their help with the recruitment of participants.

Financial support. This work was supported by the The Netherlands Organization for Health Research and Development (ZonMw).

Competing interests. The authors declare no competing interests.

Ethical standards. Ethical approval was not required for this study.

Note

[1] 'Race' is not an official social category in the Netherlands. Instead, 'migration background' or 'ethnicity' are commonly used terms within Dutch discourse. The term person with a migration background (PwM) was introduced in 2016 in the Netherlands as a replacement for the term allochthonous (originating elsewhere) – the opposite of autochthonous (original inhabitant) – because it was found to be a problematic term (de Ree, 2016). PwM is not an ideal term either because it demarcates people on what they are not (*i.e.* a person with a white-Dutch background), and it highlights differences from the majority. Furthermore, although the term PwM is divided into Western and non-Western, in Dutch discourse it commonly refers to persons who are not white. Nonetheless, this term is applied throughout this paper because we have yet to come across a term that is more inclusive and suitable to the Dutch context.

References

Ahmad M, van den Broeke J, Saharso S and Tonkens E (2020) Persons with a migration background caring for a family member with dementia: challenges to shared care. *The Gerontologist* **60**, 340–349.

Ahmad M, van den Broeke J, Saharso S and Tonkens E (2022) Dementia care-sharing and migration: an intersectional exploration of family carers' experiences. *Journal of Aging Studies* **60**, 1–10.

Alzheimer Europe (2020) *Intercultural Dementia Care: A Guide to Raise Awareness Amongst Health and Social Care Workers*. Luxembourg, Alzheimer Europe.

Berdai-Chaouni S, Smetcoren A and de Donder L (2020) Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: a qualitative study. *International Journal of Nursing Studies* **101**, 1–9.

Botsford J, Clarke CL and Gibb CE (2011) Research and dementia, caring and ethnicity: a review of the literature. *Journal of Research in Nursing* **16**, 437–449.

Canevelli M, Lacorte E, Cova I, Zaccaria V, Valletta M, Raganato R, Bruno G, Bargagli AM, Pomati S, Pantoni L and Vanacore N (2019) Estimating dementia cases among migrants living in Europe. *European Journal of Neurology* **26**, 119–199.

Central Committee on Research Involving Human Subjects (2022) Your research: Is it subject to the WMO or not? Available at https://english.ccmo.nl/investigators/legal-framework-for-medical-scientific-research/your-research-is-it-subject-to-the-wmo-or-not.

Chin AL, Negash S and Hamilton R (2011) Diversity and disparity in dementia: the impact of ethnoracial differences in Alzheimer disease. *Alzheimer Disease and Associated Disorders* **25**, 187–195.

de Graaff FM and Francke AL (2003) Home care for terminally ill Turks and Moroccans and their families in the Netherlands: carers' experiences and factors influencing ease of access and use of services. *International Journal of Nursing Studies* **40**, 797–805.

Degrie L, Gastmans C, Mahieu L, Dierckx de Casterlé B and Denier Y (2017) How do ethnic minority patients experience the intercultural care encounter in hospitals? A systematic review of qualitative research. *BMC Medical Ethics* **18**, 1–17.

de Ree M (2016) *Termen allochtoon en autochtoon herzien*. Statistics Netherlands. Available at https://www.cbs.nl/nl-nl/corporate/2016/43/termen-allochtoon-en-autochtoon-herzien.

England K and Azzopardi-Muscat N (2017) Demographic trends and public health in Europe. *European Journal of Public Health* **27**, 9–13.

Espinoza J and Derrington S (2021) How should clinicians respond to language barriers that exacerbate health inequity? *AMA Journal of Ethics* **23**, 109–116.

Gengler AM (2014) 'I want you to save my kid!': illness management strategies, access, and inequality at an elite university research hospital. *Journal of Health and Social Behavior* **55**, 342–359.

Gora M and Conner PS (2013) Language disorders in multilingual and multicultural populations. *Annual Review of Applied Linguistics* **33**, 128–161.

Greenwood N, Habibi R, Smith R and Manthorpe J (2015) Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature. *Health & Social Care in the Community* **23**, 64–78.

Gulestø R, Halvorsrud L, Bjørge H and Lillekroken D (2022) The desire for a harmonious interaction: a qualitative study of how healthcare professionals in community-based dementia teams perceive their role in reaching and supporting family carers from minority ethnic backgrounds. *Journal of Clinical Nursing* **31**, 1850–1863.

Hochschild AR (1983) *The Managed Heart*. Berkeley, CA: University of California Press.

Hochschild AR (2003) *The Commercialization of Intimate Life: Notes from Home and Work*. Berkeley, CA: University of California Press.

Hossain MZ and Khan HTA (2020) Barriers to access and ways to improve dementia services for a minority ethnic group in England. *Journal of Evaluation in Clinical Practice* **26**, 1629–1637.

Hsieh HF and Shannon SE (2005) Three approaches to qualitative content analysis. *Qualitative Health Research* **15**, 1277–1288.

Jutlla K (2015) The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton, UK. *Ageing & Society* **35**, 1032–1054.

Moriarty J, Sharif N and Robinson J (2011) Black and minority ethnic people with dementia and their access to support and services. London, UK: Social Care Institute for Excellence, Research Briefing 35.

Mukadam N, Cooper C and Livingston G (2011) A systematic review of ethnicity and pathways to care in dementia. *International Journal Geriatric Psychiatry* **26**, 12–20.

Phillimore J, Klaas F, Padilla B, Hernandez-Plaza S and Rodrigues V (2016) Adaptation of health services to diversity: an overview of approaches. Institute for Research into Superdiversity, University of Birmingham, Birmingham, UK, IRiS Working Paper Series 15.

Roberto KA and Blieszner R (2015) Diverse family structures and the care of older persons. *Canadian Journal on Aging* **34**, 305–320.

Sagbakken M and Kumar B (2017) *Dementia, Ethnic Minorities and Migrants: A Review of the Literature*. Oslo, Norway: Norwegian Centre for Migration and Minority Health (NAKMI).

Sagbakken M, Ingebretsen R and Spilker RS (2020) How to adapt caring services to migration-driven diversity? A qualitative study exploring challenges and possible adjustments in the care of people living with dementia. *PLOS ONE* **15**, e0243803.

Shepherd SM (2019) Cultural awareness workshops: limitations and practical consequences. *BMC Medical Education* **19**, 1–10.

Statistics Netherlands (2022) Hoeveel mensen met een migratieachtergrond wonen in Nederland? Available at https://www.cbs.nl/nl-nl/dossier/dossier-asiel-migratie-en-integratie/hoeveel-mensen-met-een-migratieachtergrond-wonen-in-nederland-.

Tonkens E (2012) Working with Arlie Hochschild: connecting feelings to social change. *Social Politics* **19**, 194–218.

Tonkens E, Verplanke L and de Vries L (2011) *Alleen slechte vrouwen klagen. Problemen en behoeften van geïsoleerde allochtone spilzorgers in Nederland*. Utrecht, the Netherlands: Movisie.

van Duin C and Stoeldraijer L (2014) *Bevolkingsprognose 2014–2060: groei door migratie*. The Hague: Statistics Netherlands.

van Wezel N, Francke AL, Kayan-Acun E, Ljm Devill W, van Grondelle NJ and Blom MM (2014) Family care for immigrants with dementia: the perspectives of female family carers living in The Netherlands. *Dementia* **15**, 69–84.

World Health Organization (2012) *Dementia: A Public Health Priority*. Geneva: World Health Organization.

Cite this article: Ahmad M, Saharso S, Tonkens E (2023). Framing dementia care in families with a migration background: an analysis of practitioners' and family carers' views and experiences. *Ageing & Society* 1–22. https://doi.org/10.1017/S0144686X23000260