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Ageing-in-place care preferences of persons living with dementia and informal care-givers with a migration background: a qualitative interview study

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Abstract

Ageing-in-place for persons with dementia and informal care-givers is encouraged by governments and society. However, individuals with non-Western migration backgrounds are at higher risk of dementia yet underrepresented in research and care. This study aims to identify ageing-in-place care preferences of persons with dementia and their informal care-givers in the Netherlands. Semi-structured interviews ($n = 8$ participants with dementia, $n = 20$ informal care-givers) were analyzed using reflexive thematic analysis. Findings reveal that informal care-givers feel a strong duty to care, assisting with various daily tasks. While they desire shared care with professionals, identifying concrete care needs is challenging, highlighting the need for proactive professional support. Participants also emphasized the importance of culturally sensitive in-home care, home adaptations, social care and accessible dementia information. Additionally, the emotional impact of dementia on care recipients and care-givers underscores the need for emotional support. These insights enhance understanding of the care preferences of persons with dementia and their informal care-givers, aiding more efficient and culturally responsive health service planning.

Keywords: ageing-in-place; care preferences; dementia; informal care-giver; migration background; person living with dementia

Background

Dementia is one of the leading causes of death, disability and dependency among older adults globally (World Health Organization 2017). In 2019, care for 55.2 million individuals with dementia resulted in an estimated global economic burden of 1.3 trillion US dollars (Wimo et al. 2023; World Health Organization 2017). To cope with these growing expenditures, there has been a global policy shift towards ageing-in-place by minimizing long-term care institutionalizations for older adults and increasing the responsibilities of informal care-givers (Ranci and Pavolini 2015; Spasova et al. 2018). Ageing-in-place is defined as 'the ability of older people to live in their own home and community safely, independently and comfortably, regardless of age, income or level of intrinsic capacity' (World Health Organization 2015, p. 36). Ageing-in-place with the help of community-based care is assumed to be less costly in comparison to institutionalized care (Spasova et al. 2018). However, the shift towards community-based care will only be successful if services are appropriate and accessible for everyone.

A systematic review found that dementia is 3.1 times more prevalent in persons with a non-Western migration background compared to reference populations using European population-based samples (Selten et al. 2021). In the Netherlands, about two-thirds of migrants have a non-European background, with the largest groups being Turkish (457,100), Moroccan (429,176), Surinamese (365,352) and Indonesian (356,566) (Statistics Netherlands 2024). Additionally, there is a sizeable, younger group of migrants from other Asian countries (848,065) (Statistics Netherlands 2022, 2024). In the Dutch context, the prevalence of dementia and mild cognitive impairment is three to four times higher for persons with a Turkish, Moroccan or Surinamese background in comparison with the native Dutch population (Parlevliet et al. 2016). The higher prevalence is associated with cardiovascular risk factors and depression, which are more common for persons with a Turkish, Moroccan or Surinamese migration background (Parlevliet et al. 2016). Despite the higher prevalence of dementia, persons with a migration background are underrepresented in research and care (Schmachtenberg et al. 2020).

Individuals with a migration background are known to encounter numerous challenges in accessing dementia care (Duran-Kıraç et al. 2022). Access to dementia care starts with a diagnosis; however, persons with a migration background generally receive this diagnosis at a later stage of the condition (Cooper et al. 2010; Vissenberg et al. 2018). Furthermore, a strong sense of obligation to personally care for ageing parents, embedded within cultural and religious values, potentially leads to the perception of failing and fear of community stigma if one were to rely on formal support (Ahmad et al. 2020; Chaouni et al. 2020; van Wezel et al. 2016). Health-care professionals need to be aware of these underlying constructs and strive to explore and understand care needs, while actively avoiding stereotyping and generalizing groups through 'othering' ideologies (Sagbakken et al. 2018). Finally, if care needs are successfully identified, the lack of culturally sensitive care options further complicates access to formal care and support (Mukadam et al. 2013; Sagbakken et al. 2020). Even though it is clear that persons with a migration background face several barriers to access dementia care, it remains unknown what the implications of these barriers are for ageing-in-place.

In the Dutch context, there are some existing studies that focus on ageing-in-place for persons with a migration background, revealing the importance of neighbourhoods with good housing, social cohesion and proximity to facilities (Hussein *et al.* 2024; Nieboer and Cramm 2024). However, these studies often do not include persons with dementia (Hussein *et al.* 2024), or are targeted at one specific aspect such as the importance of neighbourhood characteristics (Nieboer and Cramm 2024).

To successfully age-in-place, persons with dementia often need support with a variety of daily activities, from both formal and informal care-givers (Pani-Harreman *et al.* 2021). Therefore, this study aims to identify ageing-in-place care preferences for persons living with dementia with a migration background and their informal care-givers in the Netherlands by conducting semi-structured interviews. Decisions about care are often made by more than one person; it is therefore important to include both the person with dementia and the informal care-giver (Groen-van de Ven *et al.* 2018). To our knowledge, this is the first article to qualitatively report on the care preferences and needs of persons with dementia and informal care-givers with a migration background ageing-in-place in the Netherlands. The findings can be used to guide future research on building dementia care packages that are appropriate and accessible to avoid crisis situations such as unplanned hospitalizations and long-term care admissions (Vullings *et al.* 2023).

Methods

Study design

For this qualitative explorative study, semi-structured interviews were conducted between March and August 2023 with persons with dementia and informal care-givers living across the Netherlands. The consolidated criteria for reporting qualitative health research (COREQ) checklist (Tong *et al.* 2007) was followed for the reporting of the study (Supplementary material).

Study participants

We approached adults with dementia and informal care-givers with a migration background. Purposive sampling was used to include persons across the Netherlands, in both urban and rural places. We primarily recruited first-generation older adults with dementia and informal care-givers with an Indonesian, Turkish, Moroccan or Surinamese background, because these are the largest ethnic minority groups in the Netherlands (Parlevliet *et al.* 2016). Inclusion criteria were: (1) adults aged 65 years and older; (2) persons who were living at home; (3) informal care-givers who were providing care to the care recipient on a regular basis. Exclusion criteria consisted of: (1) persons with dementia who were not able to engage in a conversation; (2) persons who were unable to provide informed consent; (3) persons with dementia who were living in a long-term care facility.

We recruited participants through: Pharos (Dutch centre of expertise on health disparities), general practitioners, daycare facilities and (in)formal organizations that

serve persons living with dementia and informal care-givers with a migration background. These professionals and organizations provided potential participants with a bilingual invitation letter, which contained information about the study. With the participants' consent, the researchers received their contact information and contacted them by telephone to explain more about the study and schedule an appointment for the interview.

Setting

To ensure that participants felt comfortable, the interviews were conducted in a place they preferred, mostly the participant's home, community centre or daycare facility. Interviews were held in the preferred language of the participants, Turkish, Moroccan (Arabic dialect or Berber) or Dutch.

Data collection

The interviews were conducted by trained interviewers who were part of the research team (IV, SEJ, BAM); bilingual interviewers conducted the Moroccan (SEJ) and Turkish (BAM) interviews. We used an interview guide with a topic list (supplementary material) to provide a framework for the semi-structured interviews, while leaving room for new topics to be brought up by the participants. The interview guide was based on the results of a previous study on the care preferences of Dutch persons with dementia and informal care-givers ageing-in-place (Vullings et al. 2020), and existing knowledge about the experiences of dementia care in families with a migration background (Ahmad et al. 2020, 2022; Duran-Kıraç et al. 2022). To maximize cultural sensitivity, the interview guide was modified accordingly by discussing and reviewing the guide together with researchers specialized in inclusivity. All interviews were audio-recorded and transcribed verbatim in either Dutch or English by the researchers (BAM, SEJ and IV). The transcripts were anonymized, and field notes of the researchers were added. Transcripts were not returned to the participants; instead, researchers summarized and asked for clarifications during the interviews to ensure proper interpretation and understanding.

Analysis

We used reflexive thematic analysis to analyze the data and develop themes (Braun and Clarke 2019). Reflexive thematic analysis emphasizes the active role of researchers in creating themes, which are patterns of shared meaning (Braun and Clarke 2019). The analysis was a combination of a deductive and an inductive approach (Braun and Clarke 2006, 2019). The researchers were guided by the empirical and theoretical knowledge of previous studies (van Wezel et al. 2016; Vissenberg et al. 2018), while staying close to the data and keeping an open approach.

According to the six steps of thematic analysis by Braun and Clarke (Braun and Clarke 2006), the researchers (IV, SEJ and BAM) first familiarized themselves with the data by transcribing and reading the transcripts. Subsequently, the researchers generated initial codes using MAXQDA (Software 2019). The first three interviews were all coded independently by the researchers, who then discussed what codes they assigned,

where and why. These discussions led to the development of a coding tree, which was used for the coding of the remaining transcripts. The remaining transcripts were coded by one researcher (IV, SEJ or BAM); updates in the coding tree were shared with the group. For the next step, the researchers started generating themes by clustering the data and codes per potential theme (Braun and Clarke 2006). In the process of developing and analyzing the codes, an initial thematic map was constructed with the most prominent themes. After reviewing, renaming, refining the final thematic map and discussing it in the research group, main themes were created regarding the in-home care needs and preferences of people with dementia and informal care-givers with a migration background. Data saturation was reached since no new codes or themes emerged from the data (Hennink and Kaiser 2022). The results of the study were communicated to the participants, allowing them to provide feedback on the findings.

Ethical considerations

The Medical Ethics Research Committee of the Amsterdam University Medical Centre confirmed that the Medical Research Involving Human Subject Act did not apply to this research project (W23_122 #23.137), because participants were asked to be involved in semi-structured interviews that did not pose any threats to the psychological integrity of the participants. Prior to the interviews, the researchers went through the information letter and informed consent form together with the participants to provide the opportunity to ask questions and ensure a thorough understanding. Subsequently, participants were asked to provide written informed consent. Verbal continued informed consent was used throughout the study, reminding participants that they were participating in research to ensure that they remained informed and felt comfortable (McKeown *et al.* 2010). It was stressed that participation could be stopped at any given moment. Where possible we connected study participants with health-care professionals to help enable access to care.

Findings

Participants' characteristics

Eight participants with dementia and 20 informal care-givers were interviewed; no participants withdrew from the research. Interviews lasted between 40 and 90 minutes. Participants lived across the Netherlands, in both rural and urban areas. Most informal care-givers were female ($N = 17$), whereas most participants with dementia were male ($N = 6$). All persons with cognitive impairment had a diagnosis of dementia; further details about the participants' characteristics can be found in Table 1.

Main findings

Seven themes pertaining to care and support preferences were identified in the data: (1) socio-cultural sense of duty towards taking care of the person with dementia, (2) proactive involvement of professionals, (3) culturally sensitive in-home care, (4) adaptations in the home, (5) culturally sensitive social care, (6) accessible information about dementia and (7) creating opportunities for emotional support.

Table 1. Characteristics of the study population

Nr	Respondent	Gender	Age	Migration background	Duration of living in NL	Level of education	Relation to PwD	Living situation
1.	Person with dementia	Male	85	Turkish	50–60 years	Primary school		Alone
2.	Person with dementia	Male	82	Turkish	50–60 years	Primary school		With partner
3.	Person with dementia	Male	84	Surinamese	40–50 years	Secondary school		Alone
4.	Person with dementia	Female	85	Turkish	40–50 years	Primary school		Alone
5.	Person with dementia	Female	84	Turkish	50–60 years			With partner
6.	Person with dementia	Male	79	Turkish	50–60 years	Primary school		With partner
7.	Person with dementia	Male	86	Turkish	50–60 years	Higher education		Alone
8.	Person with dementia	Male	70	Turkish	20–30 years	Primary school		With partner
9.	Informal care-giver	Female	60	Moroccan	40–50 years	Secondary school	Daughter-in-law	Together with PwD
10.	Informal care-giver	Female	49	Moroccan	Born in the Netherlands	Higher education	Daughter	Separate from PwD
11.	Informal care-giver	Female	90	Surinamese	50–60 years	Secondary school	Partner	Together with PwD
12.	Informal care-giver	Male	59	Turkish	40–50 years	Higher education	Son	Together with PwD
13.	Informal care-giver	Female	45	Moroccan	40–50 years	Higher education	Daughter	Separate from PwD
14.	Informal care-giver	Female	54	Moroccan	20–30 years	Secondary school	Daughter	Together with PwD
15.	Informal care-giver	Female	72	Indonesian	40–50 years	Higher education	Partner	Separate from PwD
16.	Informal care-giver	Female	34	Moroccan	Born in the Netherlands	Higher education	Daughter	Separate from PwD
17.	Informal care-giver	Female	54	Moroccan	40–50 years	Primary school	Daughter	Together with PwD
18.	Informal care-giver	Female	48	Turkish	40–50 years	Secondary school	Daughter	Separate from PwD
19.	Informal care-giver	Male	62	Turkish	40–50 years	Secondary school	Son	Separate from PwD

(Continued)

Table 1. (Continued.)

Nr	Respondent	Gender	Age	Migration background	Duration of living in NL	Level of education	Relation to PwD	Living situation
20.	Informal care-giver	Female	49	Turkish	Born in the Netherlands	Higher education	Daughter	Together with PwD
21.	Informal care-giver	Female	89	Surinamese	50–60 years	Higher education	Partner	Separate from PwD
22.	Informal care-giver	Female	55	Surinamese	Born in the Netherlands	Higher education	Daughter	Separate from PwD
23.	Informal care-giver	Female	26	Moroccan	Born in the Netherlands	Higher education	Daughter	Together with PwD
24.	Informal care-giver	Female	53	Moroccan	20–30 years	Primary school	Partner	Together with PwD
25.	Informal care-giver	Male	23	Moroccan	20–30 years	Higher education	Son	Together with PwD
26.	Informal care-giver	Female	68	Indonesian	50–60 years	Primary school	Partner	Separate from PwD
27.	Informal care-giver	Female	74	Indonesian	40–50 years	Higher education	Partner	Together with PwD
28.	Informal care-giver	Female	48	Indonesian	Born in the Netherlands	Higher education	Daughter	Separate from PwD

Socio-cultural sense of duty towards taking care of the person with dementia

Informal care provided by the family of the person with dementia played an important role in enabling ageing-in-place. All informal care-givers described a strong feeling of responsibility and sense of duty when it came to providing care for their parents or partner, mainly embedded in socio-cultural and religious values. They helped the person with dementia with a wide variety of daily activities such as getting dressed, bathing, cooking and cleaning the house. Many informal care-givers mentioned that they had a long history of caring for their parents, since they helped their parents overcome language barriers by accompanying them to appointments, helping them read letters and fill in paperwork.

Your parents you know, they're simply your parents. You must do everything for them. And of course, considering our religion, your parents are second to God. After Allah, it's your parents. So that also plays a significant role. Therefore, as a care-giver you are constantly in dialogue with yourself, thinking, But if I don't do this, I am falling short. It is my duty to do it, I just must. No matter how, I must do it, or else I won't be a good daughter. (Participant 10, informal care-giver_

In addition, the participants with dementia expressed that they preferred to be taken care of by their family members instead of care professionals. The participants with dementia often expressed their gratitude for the care that they received from their children.

I am really satisfied with my children. I am so happy that I have my children. He [my son] said: 'We are happy that you are here, Dad. You took care of us, we have to take care of you'. (Participant 6, participant with dementia)

Participants with dementia who did not receive care from their children expressed their disappointment:

I: Would you like your children to live with you?

P: Yes, I would very much like that, but they only visit me and then leave. They don't take care of me, don't clean the house. Nothing. (Participant 5, participant with dementia)

While informal care-givers described taking care of their parents or partners with dementia as fulfilling, they also experienced a considerable care-giving burden. Informal care-givers were willing to share care with professionals with the prerequisite that they remain in charge of the details of the care trajectory. Since this was not feasible in most cases, it led to more usage of the personal budget (PGB), which enables informal care-givers to arrange their own care and support.

In the beginning I did everything by myself, I took care of him. However, it became too much for me, it was just too heavy. I needed some help and started using the personal budget, which helped me to arrange his care and save myself some time. I can coordinate the care to make sure that my father gets the support he needs in a way that he will also accept it. (Participant 23, informal care-giver)

While informal care is of great importance and highly valued by both the participants with dementia and the informal care-givers, there is also a considerable care-giving burden. To help minimize the care-giving burden, informal care-givers have the desire to share care with professionals.

Proactive role of professionals

Many informal care-givers experienced problems with accessing formal care and support options. Informal care-givers indicated that the Dutch health-care system is request-driven in the sense that without concrete questions regarding care, no support is offered. However, those who were not familiar with the health-care system and unaware of existing services found it harder to formulate their concrete needs. Some felt that their lack of explicit and specific requests for help resulted in health-care professionals assuming that they were comfortable in their situation and preferred to provide all the care themselves. These informal care-givers experienced a high care-giving burden and wanted to receive formal care or support.

If we are talking about people with low health literacy, these are often people with a low socio-economic status, people with a migration background, or older adults. For older people with a migration background, this often means that they tick three of these boxes. If you then expect them to be able to formulate their care needs and to know where they need to be with these specific questions. ... It is almost as if there is the idea that persons are comfortable in their situations, because they do not ask for anything. However, that is not the case; those conversations can be very awkward. (Participant 17, informal care-giver)

Informal care-givers emphasized that it would be helpful if general practitioners or case managers had a proactive attitude in asking patients about their needs. They emphasized that professionals need to take their time to understand the situation of the person with dementia while detecting possibilities for culturally sensitive formal care and support. This would enable the persons with dementia to access the care they need and support their informal care-givers. Nevertheless, there were positive examples of a general practitioner or case manager who helped family carers to explore their wishes when it came to formal care and support.

We come together as a team once every two/three months [general practitioner, case manager, person with dementia, and informal care-giver]. The professionals always start by asking questions. They ask if we have any wishes, because caring for someone can be tough. The involved health-care professionals always want to make it easier for me and think along if there is anything that I want or that could help us. (Participant 11, informal care-giver)

For those who are less familiar with the health-care system, it might be harder to formulate concrete care needs. Therefore, the proactive role of professionals is needed to help identify the care needs of both informal care-givers and persons with dementia.

Culturally sensitive in-home care

A potential way to relieve informal care-givers and maintain a sustainable living situation for the person with dementia is through formal in-home care, such as help with getting dressed and taking medicine. Unfortunately, participants had unpleasant experiences with formal in-home care. It was often mentioned that persons with dementia found it hard to accept home care, as they experienced having a 'stranger' in their home as an invasion of their autonomy and privacy. Language barriers and a lack of knowledge about cultural values made it harder to connect with home care providers and build trusting relationships.

At first, we had a nice agreement with the home care organization; they would come to pray with her and she would let them in. However, at some point it changed. She [mother with dementia] did not want it anymore, she saw it as an invasion of her freedom and time[.] These ladies also only spoke Dutch. We are planning to switch to an organization with people from the same culture, who speak Indonesian. Perhaps that would make it easier. (Participant 28, informal care-giver)

Many participants indicated that it would be helpful to have culturally sensitive in-home care. Having someone who speaks the same language and has a shared cultural history would help to build a trusting relationship with the person with dementia.

Our help is an Indonesian woman, I specifically requested it[.] I thought it would be easier, if my husband will start to speak more Indonesian, then it will just be easier. She also knows the habits of Indonesian people[.] If we talk about Indonesia, she understands what we are talking about. (Participant 27, informal care-giver)

However, not all participants were able to find appropriate, culturally sensitive in-home care. Limited availability of home care workers with a shared cultural history made it harder to find someone that could build a trusting relationship with the person with dementia. The organizations that did offer culturally sensitive in-home care services often had limited staff members and long waiting lists. Consequently, informal care-givers provide the in-home care themselves, even though they were overburdened.

We had in-home care from two different organization[s]; one of them no longer exists because they had a shortage of staff. We are of course also looking for people who speak Arabic, that makes it more difficult. I understand, but we really need the care. It would allow me to have a break as the informal care-giver. (Participant 10, informal care-giver)

Culturally sensitive in-home care is important to support the person with dementia and unburden the informal care-givers. Unfortunately, culturally sensitive in-home care is not always available for the persons who need it.

Adaptations in the home

Many participants talked about the importance of having a house that enables ageing-in-place. In some cases, children were taking care of their parents with dementia and moved in with them. This sometimes led to problems because the appartements were

not suitable for older adults or there was limited space. It was often challenging to find a new home that was more suitable for providing informal care.

We live in a social housing unit, but the apartment is too small for us. It is located on the second floor, but my mother has trouble getting up the stairs. It would really help me if I could find a bigger house that is more suitable for informal care-giving. I understand that this is something that is difficult, we have a housing shortage of course, but it would really help me. (Participant 20, informal care-giver)

In most cases the participant with dementia was living alone or with their partner. Adaptations were made to the house such as installing a stair lift, grips in the bathroom or a chair for in the shower. These adaptations helped the participants with dementia to remain at a level of independence, and increased their safety and wellbeing.

I have grips in the bathroom and the toilet to help me. Someone from the municipality came to my house and arranged this for me (Participant 6, participant with dementia)

Thus, having a home that supports persons with dementia in their daily activities and enables informal care-giving is a prerequisite for ageing-in-place.

Culturally sensitive social care

The importance of social activities that match the cultural background and language proficiency of persons with dementia was emphasized by both informal care-givers and participants with dementia. Many of them are first-generation migrants who learnt the language at a later stage in life and regressed to their native language because of their dementia. This led to them being unable to connect and feel at home in regular daycare facilities where the majority of the attendees only spoke Dutch and activities were tailored to the Dutch culture.

The other visitors are foreign to me; I cannot really communicate with them. I am on my own, I sit here, I eat, I drink. I do not make a friendly connection with them. (Participant 2, participant with dementia)

Some participants found culturally sensitive daycare facilities where the persons with dementia felt at home and were able to connect with the other visitors and staff members. This was mainly because the setting was equipped to connect to the persons with dementia by adjusting to their mother tongue and providing opportunities for religious practices such as prayer. This was experienced as a meaningful activity for persons with dementia, and an important form of respite care for the informal care-givers.

Daycare is important for persons with dementia, to make sure that they are stimulated and to lower the burden for the persons taking care of them[.] The facility is designed for migrants, so that is great. The Turkish language, Turkish food, halal, praying, everything is possible. They play games, listen to the news, or get music therapy. (Participant 12, informal care-giver)

However, not all participants had access to these culturally sensitive daycare facilities since these were primarily located in the bigger cities. Some participants found alternatives that worked for them, such as having a personal companion come to their home to interact with the person with dementia. It was important that these persons spoke the mother language of the persons with dementia and could relate to the activities that they liked to do.

Most of the time, I am at home. She comes and helps me. I ask her to read the Quran, she does that. She is a very nice person. (Participant 1, participant with dementia)

To summarize, the participants indicated that culturally sensitive social activities are important for the persons with dementia to connect with others, and offer a form of respite care for the informal care-givers. Unfortunately, the availability of culturally sensitive daycare facilities is limited.

Accessible information about dementia

It was evident that a lack of accessible and appropriate information was hindering participants with dementia and informal care-givers in receiving appropriate care. Many informal care-givers indicated that they had searched for information about (1) the condition, (2) how to recognize symptoms, (3) practical information on how to care for the person with dementia and (4) available care and support options. This quest for information and advice was often challenging. Participants had a hard time finding information in the right language, or on a level that was understandable to them.

We sent videos to our aunt about Alzheimer. I found it hard to find videos in Arabic or Berber who were meant to inform people[.] If there were a database for this, with the right information, that would be great for my parents. I use the website of Alzheimer Nederland because I speak Dutch. This is convenient for me, but for others it is more difficult. (Participant 14, informal care-giver)

Participants stated that places of worship, such as the mosque or the church, could be locations where accessible information and support is provided. Since these places are already part of the daily lives of many persons with dementia with a migration background, more persons would be reached when organizing informative meetings or social activities.

We started organizing senior groups in the mosque [.] Every municipality has community centres; however, when you look around there you do not see anyone with a migration background. Then the question arises: do they not have a desire to come together? To talk and have a cup of coffee? Well, of course they do, but it is about the setting in which it is happening. If it is organized in the mosque, many people would come. (Participant 23, informal care-giver)

Thus, informal care-givers indicated a need for accessible information about dementia and envisioned a role for religious organization in the delivery of this information.

Creating opportunities for emotional support

From the interviews, it was evident that the participants with dementia were worried about their situation. They stated that noticing their memory deteriorate made them anxious and fearful of the future. In the early stages, they were struggling with the idea that they would become more dependent on care and support from others.

It makes me sad when the forgetfulness occurs. I pray to God that my body will work well. I pray to God that He may take my life without making me beg people for help. (Participant 2, participant with dementia)

Informal care-givers often felt a significant emotional burden as well. They struggled with dilemmas in choosing between their own needs and the needs of their parent or partner with dementia. They stated that the general practitioner or case manager should understand this emotional burden and pay more attention to the needs of the informal care-givers. This could be achieved by explicitly enquiring about the wellbeing of informal care-givers and directing them to support options, such as informal care-giver support groups or a psychologist.

The case manager introduced me to the informal care-giver support groups. He was the one who really emphasized that I also must take care of myself because it was a tough situation. He saw that I did not get support from the Church or from my family. Then you are alone and you really have to take care of yourself. It was very helpful that he kept saying that; it gave me the feeling that I deserved to have a break and, for example, go on a vacation. (Participant 28, informal care-giver)

Participants emphasized the importance of initiating conversations about dementia and care within the community to raise awareness, address concerns and dispel misconceptions about formal care. This could reduce guilt among informal care-givers and ease their emotional burden.

My father was one of the first persons with a migration background to go to a day-care facility. I noticed people came to me with questions; they were curious or even a bit reproachful. I think that within the community the concept of respite care is not done; you are supposed to take care of your parents. However, when we started talking about it, I explained that it is also in the best interest of my father. I told them that it is the same as when the doctor tells your father to take antibiotics. This helped them to understand. (Participant 25, informal care-giver)

The informal care-givers described a similar negative connotation about nursing homes, stemming from the idea that it is a child's duty to care for their parents, making it difficult to consider alternative options. However, informal care-givers indicated that at a certain point caring for their parents with dementia was too overwhelming, leading them to consider a nursing home. These considerations were often accompanied by guilt and a sense of failure. Respondents suggested that open discussion on this issue could help to reduce feelings of guilt and isolation when such decisions become necessary.

I think that this should be discussed more often from a religious perspective. That it is discussed more in the mosque, that it is okay if it is time. That it is not a sin, if you must bring your father or mother to a care home[.] We always talk about putting someone away; you are putting them away and it is very traumatic. But if someone is no longer safe at home, you do not really have a choice. (Participant 10, informal care-giver)

It is evident that dementia has a considerable emotional impact on both the older adults who receive the diagnosis and their parents or partners who are taking care of them. Informal care-givers underscored the value of open discussion about dementia and care within the community to help increase awareness about care trajectories and provide emotional relief for informal care-givers.

Discussion

This study provides a first in-depth exploration of the care preferences of persons living with dementia and informal care-givers with a migration background ageing-in-place in the Netherlands. The findings highlight the socio-cultural sense of duty in caring for persons living with dementia, where participants with dementia prefer assistance from close family members, and informal care-givers find fulfilment in this role. However, owing to a considerable care-giving burden, the inclusion of formal care is desired. Unfortunately, linguistic barriers and a lack of culturally sensitive care hinder access for those with migration backgrounds. The proactive involvement of professionals is essential for building trust, identifying opportunities to integrate formal care and alleviating the burden on informal care-givers. Furthermore, the findings emphasize the need for culturally tailored in-home care, social activities, accessible information about dementia, and emotional support. While these insights align with previous research on Dutch individuals with dementia (Vullings et al. 2020), differences emerge owing to the socio-cultural contexts and challenges faced by minority groups, who often struggle to find appropriate care.

Consistent with international literature, the participants in our study feel a strong responsibility to provide informal care, motivated by moral considerations, filial and reciprocal love and strong care norms (Ahmad et al. 2020; Stenberg and Hjelm 2023). Previous research often describes a reluctance of informal care-givers to share care with professionals, stemming from the belief that the family should provide care for ageing parents, (Ahmad et al. 2020; Shrestha et al. 2023) and the fear that important religious or cultural values would be disregarded (Berdai Chaouni and De Donder 2019). However, the findings of this study suggest that involving formal care is actually desired by informal care-givers and in some cases perceived as necessary to enable ageing-in-place.

Unfortunately, involving formal care proves to be challenging for several reasons. Firstly, there are individual-level barriers, such as limited health literacy (Gove et al. 2021), a lack of knowledge about dementia (Taiebne et al. 2024) and unfamiliarity with the health-care system and available support options (Nielsen et al. 2021). Additionally, system-level factors play a role, such as a shortage of culturally sensitive care, which is an issue recognized in both the Netherlands, (Vissenberg et al. 2018) and other

European countries (Duran-Kıraç *et al.* 2022; Sagbakken *et al.* 2020). The findings of this study reveal that the structure of the health-care system itself poses an additional barrier. In the Netherlands, the current demand-drive system assumes that individuals will actively seek care when necessary, typically by reaching out to their general practitioner. However, persons with a migration background may struggle to recognize and express their care needs owing to cultural contexts and limited knowledge of available services. As a result, they may not seek formal help, even when this is needed. Health-care professionals should not assume that no request means no need; instead, they should actively enquire about potential needs and opportunities for formal support. This might be particularly relevant for other countries where the general practitioner acts as a gatekeeper to services and support, such as the UK (Sripa *et al.* 2019) and Norway (Czapka and Sagbakken 2020).

Additionally, the participants in this study envisioned a more prominent role for religious organizations in the dementia care trajectory. While existing research often highlights the involvement of key community figures in bridging the gap between individuals with a migration background and health-care institutions (Hurley *et al.* 2024; Steunenbergh *et al.* 2014), our findings suggest that religious organizations, rather than traditional health-care institutions, should play a central role in disseminating information about dementia. Echoing the results of a recent UK study, participants emphasized that mosques or churches are more familiar and accessible venues for individuals with a migration background, potentially reducing barriers to attending educational events on dementia (Hussain *et al.* 2024). In addition, participants suggested that religious organizations could play a vital role in opening up discussions about caring for parents with dementia. While caring for one's parents holds significant religious value, acknowledging the challenges of this responsibility and exploring different ways to provide care could reduce feelings of failure and stigma associated with seeking external support (Ahmad *et al.* 2020). Participants emphasized the importance of addressing this topic from a religious perspective, fostering dialogue within the community.

Finally, this study illustrated that receiving a dementia diagnosis has a considerable emotional impact on the older adults. While emotional impact and support for informal care-givers is often discussed, emotional support for the person with dementia is less commonly addressed (Queluz *et al.* 2020). However, especially for persons with a migration background, who have often experienced traumatic events in the past related to their migration journey, emotional support is of great importance (Sun *et al.* 2022).

Strengths and limitations

To the best of our knowledge, this is the first qualitative interview study on ageing-in-place preferences in the Netherlands to include persons living with dementia with a migration background. Previous studies included mainly the informal care-givers of persons living with dementia, or health-care professionals (Duran-Kıraç *et al.* 2022). Including persons living with dementia with a migration background in research is crucial as it provides insights into their own personal experiences and care preferences. We emphasize the importance of giving voice to all groups within the population and

enabling them to express their needs and preferences, rather than relying solely on informal care-giver proxies. The in-depth nature of the interviews and the composition of the team, which consisted of bilingual researchers, also enabled us to include participants who were not proficient in Dutch.

A limitation of this study is the restricted diversity in migration backgrounds. While participants represented major non-Western migration groups in the Netherlands (Moroccan, Turkish and Surinamese), they do not capture the full cultural diversity present in the country. In addition, all the participants had been living in the Netherlands for at least 20–30 years. People who migrated to the Netherlands in a later stage of their lives might have different situations or face different challenges; however, this was not the target population of our study. Future research should aim to include these groups to identify their care needs and preferences. Another limitation is the small sample size, which requires cautious interpretation of the results.

Implications

This study found that while the preferences of older persons living with dementia and informal care-givers with a migration background ageing-in-place are similar to the general Dutch population (Vullings et al. 2020), the care organization does not meet their personal needs. Beside the challenges that persons with a migration background experience regarding involving formal care, limited culturally appropriate dementia services and the predominantly one-size-fits-all approach in health care enhances inequity in accessibility and utilization of care. Instead of focusing solely on individual-level barriers in accessing care, current dementia services should be evaluated and adjusted to meet all the needs and preferences of persons living with dementia regarding ageing-in-place. For example, instead of focusing on the language proficiency of persons with a migration background, it should be emphasized that the current provision of services and information is not linguistically inclusive.

Moreover, this study is an important example of inclusive research in which persons living with dementia and a migration background were included. Persons living with dementia can express their experiences and preferences. Important strategies to ensure inclusive research are illustrated, such as building trusting relationships, collaborations with informal organizations within the communities, involvement of religious institutions that are part participants' daily lives, composition of diverse research teams and seeking advice from experts that specialize in health inequality and inclusiveness.

This study highlights the need to centre persons with dementia and a migration background in care discussions, promoting inclusivity. While this study provides a first in-depth exploration of the care preferences of persons with a migration background, further research is required to quantify care preferences in larger, more diverse samples.

Conclusion

This study identified care preferences and needs related to ageing-in-place for persons with dementia with a migration background and their informal care-giver. It became evident that informal care is of great value as it enables persons living with dementia to age-in-place and provides the informal care-givers with strong feelings of fulfilment.

However, providing informal care is also considered to be hard at times and the informal care-givers of this study were open to sharing care with professionals. Informal care-givers desire professionals, such as the general practitioner, to take a more proactive role in identifying appropriate options for care and support. Thematic analysis of participants' interviews identified that options for care and support should include: (1) culturally sensitive in-home care; (2) adaptations in the home; (3) culturally sensitive social care; (4) accessible information about dementia; and (5) emotional support. This study is relevant for professionals seeking to establish practice standards aimed at facilitating culturally sensitive and person-centred dementia care to persons living with dementia and informal care-givers with a migration background.

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Author contributions. For this study, JMV conceptualized the study and developed the study design together with the other researchers; IV and SEJ contributed to the development of the study design; and IV, SEJ and BAM were responsible for data collection and analysis. The authors provided input on the study design from their own area of expertise; inclusive research (CS and ÖUB), qualitative research (NL and JW), health economics (EBG). Then, IV and SEJ wrote the manuscript, and the co-authors read, edited and approved the final version.

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