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Informal caregiver and nurse perceptions of access to culturally appropriate health care for ethnic minority persons with dementia: A qualitative study

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Abstract

Aims: This study explored what informal caregivers of ethnic minority (EM) persons with dementia in the Netherlands perceive as culturally accessible health care and nurses' perceptions of how cultural competence can be improved to facilitate access to health care for EM persons with dementia and their informal caregivers.

Design: Qualitative description research with semi-structured individual interviews and focus group discussions (FGDs).

Methods: Semi-structured interviews with 15 nurses and 6 informal caregivers provided input for two FGDs with nurses about the need to strengthen their cultural competence to improve access to health care for EM persons with dementia and their informal caregivers. Interview data were collected between September 2020 and April 2021 in the Netherlands. Focus group discussion data were collected between June and September 2021 in the Netherlands.

Results: Nurses and informal caregivers experienced difficulty building and maintaining a relationship. Contrary to informal caregivers' experiences, nurses felt a shared cultural background with the persons with dementia and informal caregiver is necessary. Although nurses acknowledged the importance of cultural knowledge, cultural skills, in particular, were mentioned as needing improvement. Examples are mapping involved family members and their roles, asking the right questions and letting go of personal judgements. Nurses frequently mentioned stereotypical thinking and seeing 'the other' as different, and collaboration with(in) family proved difficult for informal caregivers and nurses.

Conclusion: Strengthening cultural skills will contribute to facilitating better access to cultural appropriate health care for EM persons with dementia and their informal caregivers.

Patient or Public Contribution: No patient or public contribution.

Impact: This study explores what is perceived as culturally accessible health care and what nurses need to improve their cultural competence. We show that strengthening nurses' cultural competence by addressing which skills should be improved can improve access to health care for EM persons with dementia and their informal caregivers.

1 | INTRODUCTION

In 2018, the estimated number of ethnic minority (EM) people with dementia living in Europe was 476,500. The ratio between the EM people with dementia and the overall population ranged from 0.9% to 51.2%, depending on the country (Canevelli et al., 2019). Despite their higher vulnerability to developing dementia (Parlevliet et al., 2016), related to risk factors such as diabetes, cardiovascular diseases and low literacy (Bindraban et al., 2008; Parlevliet et al., 2016), EM persons living in Europe utilize health care services less frequently than the native population (Schmachtenberg et al., 2020b). EM persons with dementia use less long-term health care, such as nursing homes (Alzheimer Nederland, 2014; Stevnsborg et al., 2016). A Danish study concluded that dementia coordinators have less contact with EM persons with dementia for post-diagnostic care and support than with native Danish persons with dementia (Nielsen et al., 2020). These inequalities in service utilization can lead to poorer health-related dementia-specific outcomes for EM persons with dementia (Schmachtenberg et al., 2020b). Results of an EU-Atlas project show a lack of appropriate health care services (culturally sensitive diagnosis, assessment and treatments) for EM persons with dementia in EU and European Free Trade Associate countries (Iceland, Liechtenstein, Norway and Switzerland) and in the UK (Schmachtenberg et al., 2020a). Even after locating public care services, family care is sometimes continued because of barriers such as poor collaboration between family caregivers and health care professionals and professionals' limited knowledge about and familiarity with the person with dementia (Blix & Munkejord, 2022).

2 | BACKGROUND

Cultural competence can be seen as an ongoing process in which the health care professional strives to achieve the ability to work within the cultural context. This process contains developing and integrating cultural awareness, cultural knowledge, cultural skills, cultural encounters and the desire to want to be cultural competent (Campinha-Bacote, 2002). However, access to health care is complex and does not only depend on factors from the professionals' or organizations' viewpoint. To address difficulties in access to care, Levesque et al. (2013) developed a framework that describes the dimensions and determinants that integrate the demand and supply

side of care. Each step in this framework relates to the abilities required to navigate the care landscape (demand side) and determinants of accessibility from an organizational viewpoint (supply side). According to Levesque et al. (2013), culture is one of the dimensions and determinants that can influence access to health care on the supply and demand side. The framework describes how people perceive the need for professional care and what is acceptable in their cultural context on the demand side. On the supply side, the framework describes how cultural factors determine the possibility for people to accept (aspects of) the service. A recent study reported on the barriers EM persons with dementia and (in)formal caregivers experience regarding perceiving a need for health care, seeking health care and utilizing health care (Duran-Kiraç et al., 2022). Another study also found corresponding barriers in perceiving a need for health care and seeking health care. A lack of knowledge about services is experienced as a barrier to accessing public health care services (Blix & Munkejord, 2022).

Duran-Kiraç et al. (2022) found barriers from an organizational viewpoint, the supply side of access to health care. A language barrier makes it difficult to develop a relationship and to connect with the person with dementia. In addition, the professionals' attitude towards EM persons with dementia may reflect stereotypical thinking, and there may be differences in beliefs about dementia between professionals and EM persons with dementia. Professionals also experience difficulties in collaboration with families.

It has been theorized that strengthening health care professionals' cultural competence will contribute to better patient and family care experiences, therefore, addressing the mismatch between the demand and supply side of access to health care for EM persons with dementia and their informal caregivers (Duran-Kiraç et al., 2022). Several studies also showed barriers professionals experience related to their lack of cultural competencies. These studies focus on providing high-quality health care (Chaouni et al., 2020; Nielsen et al., 2021) and improving access to health care services for EM persons with dementia (Nielsen et al., 2021). The lack of cultural competencies can make professionals feel paralysed when working with EM persons with dementia and their informal caregivers (Bowes & Wilkinson, 2003). Cultural competence is achieved when health care professionals strive to work effectively within the cultural context of an individual, family and community and is the explicit use of culturally based care and health knowledge in a sensitive, creative and meaningful way to fit the general lifestyle and needs of individuals or

groups regarding their health care needs (Darnell & Hickson, 2015). It is recommended that cultural competencies of staff (Clark et al., 2018; Sagbakken, Spilker, & Nielsen, 2018) are strengthened, as health care professionals' behaviours, biases and attitudes contribute to health care disparities (Darnell & Hickson, 2015).

Cultural competence is relevant for all health care professionals but gets limited attention in the education of health care professionals in the Netherlands. Two groups of nurses encounter EM persons with dementia during the care trajectory in the Netherlands: practice nurses (PN) and dementia case managers (DCM). Most Dutch General Practices have a Practice Nurse (PN), who may specialize in mental health, care for older adults, or chronic conditions. The PN specialized in care for older adults plays a role in screening for dementia, referrals to dementia specialists or guiding and supporting persons with dementia. Additionally, every person with dementia is entitled to support from a DCM. The DCM, often a nurse or social worker specialized in dementia care, offers support and guidance for persons with dementia and their informal caregiver(s) and helps them navigate the Dutch health care system. The PN and DCM thus have an important role in improving access to health care for EM persons with dementia and their informal caregivers.

3 | THE STUDY

Behaviour, attitudes and biases of health care professionals are known to contribute to health care disparities (Darnell & Hickson, 2015), and professionals' cultural competencies are essential in increasing access to health care for EM persons with dementia and their informal caregivers (Duran-Kiraç et al., 2022). To date, research has mainly focused on concluding that health care for EM persons with dementia and their informal caregivers needs to be more accessible, and education and training of nurses are needed on working with EM persons with dementia. However, which attitudes, skills and knowledge among nurses that should be strengthened to improve access to health care is not clear.

3.1 | Aims

This study explores what informal caregivers of EM persons with dementia in the Netherlands perceive as culturally accessible health care and nurses' perceptions of how cultural competence can be improved to facilitate access to health care for EM persons with dementia and their informal caregivers.

3.2 | Design

Our qualitative approach, that is, qualitative description research, helped us discover and understand the perspectives of the people involved (Caelli et al., 2003) and lies within the naturalistic approach, which creates an understanding of a phenomenon by accessing the

meanings participants ascribe to them (Bradshaw et al., 2017). We used two data collection methods. Semi-structured interviews enabled us to understand the difficulties in access to health care nurses and informal caregivers experience. Focus group discussions (FGDs) helped us understand what nurses need to overcome these obstacles and increase access to health care. Themes of the framework of Levesque et al. (2013) served as input for our interview questions and discussions in the FGDs. Qualitative description research facilitated the process in which the interview data served as input for the FGDs as it provided general direction about topics addressed in interviews and FGDs (Sullivan-Bolyai et al., 2005). Qualitative description research allowed the descriptions obtained from participants to be analysed and synthesized from the perspective of the framework of Levesque et al. (2013) (Bradshaw et al., 2017). We used the COREQ checklist to assess our study's quality (Appendix C and D).

3.3 | Data collection

We conducted individual semi-structured interviews with EM informal caregivers and nurses to explore how access to health care is experienced and what EM persons with dementia and their informal caregivers need from nurses to improve their access to health care. We then organized two FGDs with nurses to unravel what nurses need, to strengthen their competencies and thus increase access to health care.

Three health care organizations were contacted and consented to participate in this study. Located in the Dutch cities of Amsterdam, Almere and Zwolle, the organizations provided nurses who work with EM persons with dementia. A selected group of nurses were asked to participate in this study after presenting the study content. After consenting, they were asked to contact informal caregivers they work with to request their participation in interviews. Inclusion criteria for nurses were being a PN in primary care or DCM.

Informal caregivers were recruited by asking participating nurses if there were informal caregivers who wanted to participate in this study. There were no exclusion criteria. Inclusion criteria for informal caregivers were having Turkish or Moroccan roots and being involved in caregiving tasks for a person with dementia. All subtypes of dementia were included. Participants for the FGDs were recruited via the three participating health care organizations.

3.3.1 | Interviews

The individual semi-structured interviews were conducted between September 2020 and April 2021 to collect information on experienced barriers to and facilitators of access to health care. Following the conceptual framework of Levesque et al. (2013) (see Appendix A), the topic list of the semi-structured interviews with nurses was based on dimensions of accessibility of services, and for the informal caregivers on corresponding abilities of persons. Levesque et al. (2013) conceptualized five dimensions of access to health care

for health care providers and receivers. These dimensions served as the main topics in the topic list that guided us through our interviews. We also looked for themes beyond the conceptual framework of Levesque et al. (2013).

The first author conducted the interviews, lasting 36–137 min, at a location chosen by the participants. Due to COVID-19, some participants preferred an online interview. Dutch was the primary language during data collection. One participant sometimes expressed herself better in Turkish. The first author speaks and writes Dutch and Turkish fluently.

Our goal was to include people with dementia in our study; however, due to their advanced stages of dementia this was impossible. Therefore, we chose to interview their informal caregivers and collected data which includes the needs of the person with dementia as perceived by proxies.

3.3.2 | Focus group discussions

To understand what nurses need to strengthen their cultural competencies, two FGDs were organized with nurses. We used the preliminary results of the interviews with informal caregivers and nurses as input for these FGD. The interviews revealed seven themes that informal caregivers and nurses indicated as barriers to accessing health care for EM persons with dementia and their informal caregivers (Table 1). As such, FGDs also served as a member check, in which results from the individual interviews were presented and participants in the FGDs were asked whether the results were recognizable.

One FGD consisted of PNs, and the other FGD consisted of DCMs. FGDs lasting 90–120 min were led by the first and third author at a location chosen by the health care organization. Data were collected between June 2021 and September 2021 from FGDs

consisting of 11 participants in the first group (see Table 2) and 12 participants in the second group (see Table 3).

3.4 | Ethical considerations

All participants provided written informed consent after receiving verbal and written information about participating in this study. Participation was voluntary and without any financial incentive. To maintain confidentiality, participants were coded and audio recordings were destroyed after completion of this study. We adhered to guidance from VU University's ethical committee. This guidance implied that the objectives and non-invasive nature of the study were not considered to fall under the Medical Research legislation, so-called non-WMO. As such, a full independent assessment was not required, and informed consent sufficed (Research Ethics Review FSS, 2022).

3.5 | Data analysis

The use of framework analysis allowed us to perform data analysis during the data collection process. We followed the five steps of framework analysis: (1) familiarization with data; (2) identifying our thematic framework; (3) indexing data where we identified portions of sections of data that correspond to a particular theme; (4) charting data and (5) mapping and interpretation of data (Goldsmith, 2021). Although we had a set of a priori themes, based on the framework of Levesque et al. (2013), as our topic list, framework analysis allowed us to maintain an open mind. We followed these five steps separately for data of interviews and FGDs. To order and code the interviews and FGDs, we used MaxQda, a software program for computer-assisted qualitative data analysis.

TABLE 1 Themes from the individual interviews and corresponding dilemmas nurses experience.

Themes	Dilemmas
1. Building and maintaining a relationship	It is difficult to build and maintain contact with EM persons. I would like to (continue to) support them, but everyone also has their own responsibility
2. Shared cultural background	Every professional should have skills to support EM persons with dementia and their informal caregivers, but it is more appropriate if EM persons are in contact with professionals who share the same cultural background
3. Cultural knowledge and skills	I need knowledge about the cultural background of EM persons with dementia, but it is impossible to have knowledge of all cultures that are present in the Netherlands
4. Stereotypical thinking	The biggest pitfall of starting from the knowledge and experiences I have about EM groups is that it can lead to assumptions and stereotypes that can hinder me
5. Collaboration with(in) family	Family is very involved in caring for the person with dementia, but the size of the people involved makes it difficult for me to work with the family through different contacts and different beliefs about (caring for the person with) dementia
6. Language barrier	Language barrier between me and the person with dementia prevents me from making contact and a third person is always needed for the translation. But the presence of that third person can cause noise and I cannot check the translation
7. Education/training	We work with all kind of patient groups and different diseases that are present in our training, but there is too little attention paid to EM persons with dementia

TABLE 2 Characteristics of participants of the first focus group discussion.

Professional	Gender	Profession
R1	f	Practice nurse in primary care
R2	f	Practice nurse in primary care
R3	f	Practice nurse in primary care
R4	f	Practice nurse in primary care
R5	f	Practice nurse in primary care
R6	f	Practice nurse in primary care
R7	f	Practice nurse in primary care
R8	m	Practice nurse in primary care
R9	f	Practice nurse in primary care
R10	F	Practice nurse in primary care
R11	f	Practice nurse in primary care

TABLE 3 Characteristics of participants of the second focus group discussion.

Professional	Gender	Profession
R1	f	Dementia case manager
R2	f	Dementia case manager
R3	f	Dementia case manager
R4	f	Dementia case manager
R5	f	Dementia case manager
R6	f	Dementia case manager
R7	f	Dementia case manager
R8	f	Dementia case manager
R9	f	Dementia case manager
R10	f	Dementia case manager
R11	f	Dementia case manager
R12	f	Dementia case manager

Data saturation was reached when data obtained from the interviews and FGDs no longer provided new codes, in our opinion. Once data saturation was reached, we stopped registering new codes in MaxQDA.

3.6 | Rigour

The interviews and FGDs were based on open questions and open discussions which enabled the participants to express their experiences and opinions freely (Bowling, 2002).

The first author primarily analysed the interviews and FGDs. In order to prevent biased interpretations of the data, the second author then analysed the assigned codes for the interviews and FGDs. Disparities regarding the analysis and coding between the first and second author were resolved through consensus or a group discussion with all the authors. To eliminate the risk of premature analytic closure by committing to some a priori view

(Sandelowski, 1995), we decided to look beyond the themes from the conceptual framework, which resulted in additional codes (Appendix B).

4 | FINDINGS

The interviews with EM informal caregivers and nurses led to seven themes (Table 1) reflecting dilemmas experienced by nurses in providing access to health care for EM persons with dementia and their informal caregivers. These were discussed in the FGDs. Table 1 lists the overall results of the interviews and the FGDs.

4.1 | Participants

Fifteen semi-structured interviews with nurses (Table 4) and six semi-structured interviews with EM informal caregivers (Table 5) were conducted. The first FGD consisted of 11 participants, all PNs (see Table 2), and the second FGD consisted of 12 participants, all DCMs (see Table 3). Some of the nurses who were interviewed, also contributed to the FGDs.

4.2 | Building and maintaining a relationship

All informal caregivers indicated they needed more support from nurses. One informal caregiver mentioned that although the dementia diagnosis was received 6 years ago, there still was a need for knowledge regarding formal care, such as the option to receive care and support from a DCM. This lack of knowledge about health care options can cause delays in receiving support and building the relationship:

I: Do you think knowing about the existence of a case manager from the start would have helped you?
R: Maybe. I don't know what a dementia case manager does.
I: You don't know how they could support your mother?
R: No. I don't know, we haven't been assigned one either. Maybe that's a doctor's mistake or ours. So that's why I don't know about the pros or the cons either. (Interview, IC5)

When talking about maintaining the relationship, one informal caregiver explicitly mentioned the importance of nurses being interested in the cultural background of persons with dementia. For example, nurses can build better relationships by observing and considering cultural norms that matter to the persons with dementia.

On the other hand, interviews with nurses revealed that they struggled to get through to the persons with dementia and their informal caregiver(s) and that their outreach activities generally did not result in positive outcomes. These outreach activities can consist of contacting people by telephone or home visits and can help build and maintain a relationship. However, nurses felt that undertaking

these activities when working with EM persons with dementia and their informal caregivers often does not result in building and maintaining a relationship. Some nurses mentioned the need for one designated contact person to maintain the relationship with the family because this may aid the continuity of the appointments. However, during the FGDs, it emerged that the appointed contact person is not always the decision-maker within the family:

> 'But sometimes the eldest son calls you back, when something has been agreed with the daughter. Then it is changed again because the eldest son wants something different' (FGD1, R1).

Nurses, therefore, mentioned the importance of having insight into all the relatives involved and being able to distinguish between the different roles and tasks they have. Although PNs and DCMs experienced difficulties in maintaining contact, PNs explicitly mentioned shared responsibility as a solution.

> 'I always say that we are doing this together. I cannot do it alone. We need each other' (FGD1, R7).

TABLE 4 Characteristics of participants among professionals (P).

Professional	Gender	Profession
P1	m	Practice nurse in primary care
P2	f	Practice nurse in primary care
P3	f	Practice nurse in primary care
P4	f	Practice nurse in primary care
P5	f	Practice nurse in primary care
P6	f	Practice nurse in primary care
P7	f	Practice nurse in primary care
P8	f	Practice nurse in primary care
P9	f	Dementia case manager
P10	f	Dementia case manager
P11	f	Practice nurse in primary care
P12	f	Practice nurse in primary care
P13	f	Dementia case manager
P14	m	Practice nurse in primary care
P15	f	Practice nurse in primary care

4.3 | Shared cultural background

All informal caregivers explained that nurses should consider the cultural, linguistic and religious needs of the EM persons with dementia. However, these cultural or religious aspects in care do not necessarily have to be offered by nurses with the same cultural background. Moreover, informal caregivers think cultural and religious needs may change as the disease progresses and that nurses need to move along and respond in a timely fashion to those changing needs:

> The prayer times, the structure, that was their basis but as the disease progresses, that also fades. Then you no longer have the structure of the prayer times, they do not pray anymore. They are no longer performing their ablution or praying five times a day. So, the daily schedule no longer has to be as strict as it was at first. (Interview, IC4)

Furthermore, the needs of EM persons with dementia are not that different from those of native Dutch persons with dementia:

> In the end, being culturally sensitive is simply being people-oriented or being person-oriented. Person-centred care must match the patient's wishes. My parents' trajectory and the contact with Dutch informal caregivers also taught me that the differences are not that big. A Dutch man does not want to be washed by a young nurse, either. Also, a Dutch woman does not like to be washed by a complete stranger. People have to cross a threshold of shame. (Interview, IC4)

Although most informal caregivers indicated that a shared cultural or religious background between the persons with dementia and the nurse is not necessary, nurses asked themselves whether they were able to offer the best possible care because of their different cultural backgrounds:

> 'Because the connection between me and the people from another culture is not always equal. It usually

TABLE 5 Characteristics of participating informal caregivers (IC).

Informal caregiver	Gender	Person with dementia	Ethnic background	Diagnosis
IC1	f	Father	Moroccan	Lewy body dementia and vascular dementia
IC2	f	Father	Moroccan	Vascular dementia
IC3	f	Mother	Turkish	Frontotemporal dementia
IC4	f	Father and mother	Turkish	Vascular dementia and Alzheimer's disease
IC5	f	Mother	Turkish	Alzheimer's disease
IC6	f	Father	Turkish	Vascular dementia

isn't. And I will always remain an outsider' (Interview, P5).

As such, some nurses (PNs) refer EM persons with dementia and their informal caregiver to their colleague (PN) with the same EM background:

> Well, they know each other's culture. My colleague would understand better why Mrs A is under so much stress, for example, due to her youngest son. She has seven kids and the youngest always causes trouble. In Dutch culture you would think 'well, he'll figure it out for himself', but apparently this is different in Moroccan culture. And those are things I don't quite understand because I'm not from that culture. So, I thought, maybe my colleague will understand and then maybe they can talk about it more easily. That did not quite work out in her case, which is a pity. (Interview, P15)

Nurses with a shared EM background stated that they sometimes apply different strategies when working with EM persons with dementia and their informal caregivers and use their specific cultural knowledge. For example, nurses seem to have a certain status within some EM groups and some nurses with an EM background use this status to do what they think is needed:

> *R:* We were able to put her in professional health care for her diabetes and that is simply because I said to her: you are getting home care. I did not ask her if she wanted professional care as I would according to Dutch rules. I, the health care professional, decided what needs doing and she accepted that.
>
> *I:* Why did you do it that way with her?
>
> *R:* I saw that the daughter was suffering because she had to go there twice a day and the daughter was clearly overworked. Besides, I know the culture, I know she won't accept it from her daughter but she will accept it from me. (Interview, P14)

Another strategy nurses with an EM background use is involving family members (besides the informal caregiver) in shared decision-making. The reason is the pressure the persons with dementia and/or informal caregiver can feel from family and social circles when important decisions are made in the care trajectory. Nurses with an EM background use their cultural knowledge that the informal caregiver is not always the decision-maker within the family:

> I say: next time bring someone with you, maybe one of the children and then I can also explain the necessity to the children. But I also know that in our culture, the Moroccan culture also is a collective culture, social pressure is high. (Interview, P14)

However, matching persons with dementia and nurses with the same EM background is not always practicable or desirable. FGDs show that nurses think linking nurses to persons with dementia with the same EM background is unrealistic, and FGDs reveal that nurses and persons with dementia sharing the same EM background is not always what the person with dementia wants.

4.4 | Cultural knowledge and skills

Informal caregivers mentioned the importance of nurses having knowledge about the cultural background of the person with dementia. It can be helpful if nurses have this knowledge and understand the cultural context of the person with dementia and informal caregiver and considers this in the care and support they provide:

> *I:* What should a dementia case manager be able to do, in your opinion, to support ethnic minorities with dementia?
>
> *R:* They need more knowledge about cultural differences. For example, to know how to start a conversation with them. They should be able to ask questions instead of directly communicating that the person has dementia.
>
> *I:* Do you think the dementia case managers are too straightforward in their communication?
>
> *R:* Yes exactly. Look, when you say to a person with dementia with an EM background that they have dementia, they would reply: 'I don't have dementia at all'. And my dad said to the dementia case manager: 'you're crazy, I'm not crazy'. You should be less straightforward in your communication. (Interview, IC3)

Sharing the same background with the person with dementia is not always important, but understanding the cultural background is:

> 'It is important to understand the culture. The nurses must understand the cultural background and apply this knowledge in the care they provide' (Interview, IC6).

Although nurses with an EM background may feel they understand the cultural background of the EM person with dementia and their informal caregiver, and they are aware of the influence of the cultural background on decisions that are (or are not) made within health care, they also experienced a lack of knowledge and skills to ask the right questions in screening for dementia symptoms:

> But the people in our, in Turkish and Moroccan circles, are ashamed of it. When I ask, do you sometimes forget, people usually say no. I would actually like to have more skills and tools to ask EM persons, the older adult, more specific questions, to be able break through that. (Interview, P14)

Nurses with a native-Dutch background also felt this same need for knowledge and skills to ask the right questions:

> Exactly, how can you adopt this open attitude that allows you to ask the right questions. Questions like, is this disease known in your culture? What kind of family do you come from? How did you get along with your parents, how did you do that? Who made decisions? I think we should put those questions in there. (Interview, P10)

However, FGDs revealed that some nurses with a native-Dutch background felt insecure asking questions about (what they see as) sensitive topics in working with EM persons with dementia and their informal caregivers. Because of this insecurity, nurses do not always dare to ask questions they would like to ask:

> 'I would not dare do that'. (FGD1, R12).

Nurses felt they needed more skills to overcome their insecurity and more insight and information about how cultural groups see certain sensitive subjects. Nurses mention the importance of these skills in working with persons with dementia:

> 'Mostly when working with other cultures, to strengthen your confidence'. (FGD2, R8).

Reasons for insecurity were fear of being accused of discrimination and the feeling that nurses should know everything. The feeling of lacking competencies can lead to insecurity and sometimes to referring persons with dementia and their informal caregivers to a colleague with an EM background:

> 'And those are things I don't quite understand, because I'm not from that culture'. (Interview, P15).

When asked what the nurse needs to provide the same care and support as a colleague with an EM background, nurses answered they need more cultural knowledge and skills:

> I think more insight into the culture. We still have plans, for example, to visit the mosque here, to better understand how that works. I think the social map is also important. I have colleagues who can help. Like 'this is what they, do for that reason' or 'this is not the case at all, you don't have to worry about that'. That sort of thing helps, of course. It helps me understand them better. (Interview, P12)

FGDs revealed that when talking about cultural knowledge, it is not about needing the knowledge itself but more about using skills to acquire knowledge. An open attitude and the ability to ask the right questions are skills nurses need to improve their cultural knowledge.

4.5 | Stereotypical thinking

Stereotypical thinking and assumptions were mentioned frequently in the interviews and FGDs with nurses and are related to a shared cultural background with the person with dementia and their informal caregiver. Assumptions about EM persons with dementia and their informal caregivers and seeing them as 'the other' or referring to them as 'different', combined with the insecurity nurses can feel regarding appropriate responses, can influence the choices nurses make in the health care process. One assumption some nurses make is that EM persons benefit more from nurses who speak the same language. One nurse reflected on the consequence of this assumption and appeared to realize afterwards that this assumption was wrong:

> **R:** We have a colleague with a Moroccan background and I thought that's great, that's possible then. It would be nice if he could guide her, because then they can also speak in their own language. There was a feeling of shame.
> **I:** A feeling of shame of the informal caregiver?
> **R:** No of the woman herself and the informal caregivers. Of both. And they said: No, we don't want this, because in the Moroccan culture, we know that there is a lot of gossip. And then I explained that we have a duty of confidentiality, I explained that whole story. And they said: No, we don't want that, we want you to keep coming. (Interview, P12)

Another nurse assumed that people with dementia would not benefit from a nurse with a different cultural background because they do not speak each other's language:

> **I:** For example, do you know if a dementia case manager is involved?
> **R:** No. Then I should have known that, because that is requested through the GP. And often these are also Dutch-speaking people.
> **I:** The dementia case managers?
> **R:** Yes, the dementia case managers, so yes, they don't have much use for that either. (Interview, P8)

These stereotypes and assumptions of nurses were also discussed in the FGDs. Asked what nurses should avoid or adjust their stereotypes and assumptions, they indicated that they should ask the right questions to get the right answers and to their judgement 'about the other' go, and they should not presume to know what 'the other' should do.

4.6 | Collaboration with(in) family

One of the themes most informal caregivers mentioned is the need for more caregiver support from nurses. Informal caregivers' main task is to mediate between the nurse and other involved family members. This mediating role of the informal caregiver is experienced as lonely and difficult. Caregiver support can help them explain the

consequences and seriousness of dementia to involved family members and also try to explain to family members the value of involving (more) formal care:

> 'I think it is very important that at first, the family receives the same information about dementia as the informal caregiver. That can be done through a dementia case manager or by experts by experience' (Interview, IC3).

> Yes, with my brother and with the whole family. Explain what's going on. That we could discuss it in a group. And I missed that very much and because of that I distanced myself from the whole thing a little bit. Because I don't know how to handle it. (Interview, IC5)

Both PNs and DCMs experienced difficulties in collaborating with the family of the EM persons with dementia. Difficulties arise when beliefs and knowledge about dementia differ within one family, or when there are tensions between family members. FGDs with DCMs show that DCMs think that all involved family members should agree with each other. Without this agreement, the DCM feels they cannot help:

> Because I can't help. I want to help, but if I get different input from everyone, I don't know what to do or what the family wants. There must be a somewhat clear request for help, they must agree with each other. (FGD2, R7)

According to the DCMs, the DCM can have a mediating role to get everyone within the family thinking along the same lines, for example, by guiding the group dynamics within the family.

PNs and DCMs highlighted the importance of family conversations directed by the nurse. These family conversations can help improve knowledge about dementia and discuss decisions the family should make. However, it is unclear which nurses should direct this family conversation. Some PNs see possibilities to direct these family conversations themselves, and some PNs see it as part of the DCM's task:

> It is part of your job as a dementia case manager. You explain and you speak to everyone involved about what everyone knows about dementia. You also give everyone attention. People easily feel excluded. For example, 'I don't agree with my brother and sisters, so I don't count'. No, your voice certainly counts. But it also takes time. You often need to have multiple conversations. (FGD1, R7)

DCMs seem to see family conversations as their task. However, data also reveals all informal caregivers experience or have experienced a lack of knowledge about the existence of the DCM, and in some cases only a PN is involved.

4.7 | Language barrier

All informal caregivers mentioned a language barrier between the person with dementia and the nurse. This language barrier can make building and maintaining a relationship between the person with dementia, involved family members and the nurse difficult. Even if the person with dementia or involved family members spoke Dutch, informal caregivers still preferred information about dementia in their mother language (verbally or in writing). One informal caregiver mentioned the difficulties nurses experience when a language barrier between the nurse and the person with dementia is present:

> I noticed that some health care professionals find it difficult to deal with EM persons with dementia because they don't know the language. These professionals think that they can't communicate with each other, that's why they don't make jokes. This changes the communication. (Interview, IC6)

All nurses experienced difficulties because of the language barrier. This language barrier caused difficulties in building and maintaining a relationship between them and the person with dementia. However, communication between the nurse and informal caregivers is possible as the younger generation usually speaks Dutch. Nurses want to communicate with the person with dementia without the children having to interpret because some topics are sensitive to discuss in the presence of children. Additionally, several nurses mentioned they had doubts about the correctness of the translation, but they cannot check the translation. This doubt can be caused by the complexity of some Dutch words, but nurses also doubt the honesty of the translator:

> 'If I have to ask those questions with a son or daughter translating. I don't know to what extent you get an honest answer' (Interview, P6).

5 | DISCUSSION

In this study, we explored the perceptions of access to culturally appropriate care among informal caregivers of EM persons with dementia and nurses' recommendations for strengthening their cultural competence to facilitate access to health care for EM persons with dementia and their informal caregivers. The framework of Levesque et al. (2013) helped us understand the complexity of access to health care by organizing access in several dimensions and gaining a complete overview. In addition, we found five new (sub)themes that enriched the framework and our findings. On the supply side of access to health care: language barriers, knowledge about the population,

strategies used by professionals, stereotypes and collaboration with family. Two new themes have been found on the demand side of access to health care: language barriers and family issues.

First, findings show that informal caregivers need more support in their mediating role between nurses and other involved family members. Although caregiver support related to the caregiver role and education about dementia has been recommended in several studies (Johl et al., 2016; Nielsen et al., 2021) into difficulties due to the impact of their caregiver role and education about dementia, our study highlights the importance of the need for support in the mediating role of informal caregivers between involved family members and nurses. This mediating role between nurses and involved family members is experienced as a lonely and difficult task. It appears to overshadow their task of providing care for the person with dementia, but nurses do not seem to be aware of this mediating role and the difficulties that accompany it.

Second, our findings reveal a paradox: informal caregivers all indicate that a shared cultural background is not necessary for good care, whereas nurses think this shared cultural background is needed to provide good care. Earlier research showed that professionals should be culturally and linguistically competent (Szczepura, 2005). However, our findings indicate that a shared cultural and linguistic background is not always necessary to receive appropriate care. One consequence of nurses' belief that a shared cultural background is needed, is that they refer EM persons with dementia to colleagues with an EM background, without asking whether this is what the EM persons with dementia and their informal caregivers need. Due to this different cultural background, nurses sometimes struggle with 'othering' (Torres, 2006) EM persons with dementia and their informal caregivers. This finding is in line with studies showing that nurses feel insecure about how to respond when the demands of EM persons with dementia are different from their frame of reference, or what they consider normal from their western perspective, norms and values (Chaouni et al., 2020; Sagbakken, Spilker, & Ingebretsen, 2018). Health care professionals find care for EM persons with dementia difficult because they believe that patients expect them to do something different. Since they perceive the other as different, health care professionals expect such patients to have other needs (Claeys et al., 2021).

Third, nurses with an EM background appear to apply different strategies when working with EM persons with dementia and their informal caregivers than nurses with a native-Dutch background. They understand how culture can influence the health care choices EM persons with dementia and their informal caregivers make. Nurses with an EM background appear to have the skills to understand the frame of reference of EM persons with dementia and their informal caregivers. Thus, to improve the nurses' acceptability (Levesque et al., 2013), and thereby improve access to health care for EM persons with dementia and their informal caregivers, nurses' competencies in applying different strategies, being able to let go their own frame of reference and reducing 'othering' need strengthening.

Finally, our results show that nurses need more insight into which family members are involved and what the involved family members' roles and tasks are. Mapping all involved family members can improve the continuity of the (care) relationship. We found that nurses need to know which family members have which roles and tasks. Hierarchical and gendered family roles can mean that the decision-maker within the family is not always the person who provides care (Nielsen et al., 2021). Thus, knowing who is involved in caring for the EM person with dementia and better collaboration between families and nurses can contribute to an improved relationship and improve continuity of health care. This finding is in line with a previous study in which informal caregivers emphasized the importance of collaboration between family caregivers and health care nurses; Blix and Munkejord (2022) recommend a better collaboration for authentic partnerships. Therefore, strengthening nurses' competencies in the appropriateness (Levesque et al., 2013) of their caregiver support is required, and mapping involved family members should ultimately contribute to better access to health care for EM persons with dementia and their informal caregivers.

5.1 | Strengths and limitations

This study had several strengths and limitations. A first strength is the use of a theoretical framework which helped us understand the complexity of access to health care. A second strength is the inclusion of formal and informal caregivers, which enabled us to approach accessibility from two perspectives. Third, qualitative description research helped us to use input from individual interviews in our FGDs.

The first limitation was that our design did not allow for comparison or distinction between Moroccan and Turkish informal caregivers. This may be important because of the diversity between and within EM groups. Second, all participating informal caregivers had already been in contact with nurses when they participated. We remain uncertain as to what EM persons with dementia and their informal caregivers who are not yet utilizing health care need to access health care. Third, our study lacked input from persons with dementia because they were too far along in the disease process, making it difficult to participate. Fourth, our study included very few informal caregivers, all women. Our study showed that it is common for different family members (all with individual tasks) to be involved in caring for a person with dementia. Parveen et al. (2018) also found this issue. Therefore, further research should include all involved family members. And fifth, our research included only Moroccan and Turkish informal caregivers. We are aware that EM groups consist of more than these ethnic groups. Therefore, further research should include more ethnicities.

6 | CONCLUSION

Although nurses want to learn more about different ethnic groups in terms of more cultural knowledge (Claeys et al., 2021), our study shows that not only is cultural knowledge needed, but strengthening

cultural skills is perhaps even more essential. We are convinced that nurses' education should pay structural attention to strengthening these cultural skills. Further research needs to focus on existing methods or tools within education and how these can be used to strengthen nurses' cultural skills in supporting informal caregivers in their mediating role, learning to cope with 'othering', being able to apply different strategies appropriate to persons with an EM background and mapping all involved family members.

CONFLICT OF INTEREST STATEMENT

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

PEER REVIEW

The peer review history for this article is available at https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.15687.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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