



SPECIAL ISSUE ARTICLE

'The desire for a harmonious interaction': A qualitative study of how healthcare professionals in community-based dementia teams perceive their role in reaching and supporting family caregivers from minority ethnic backgrounds

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Abstract

Aims and objectives: To explore how healthcare professionals in community-based dementia teams perceive their role in reaching and supporting family caregivers from minority ethnic backgrounds when caring for a family member suffering from dementia or cognitive impairment.

Background: Despite increased focus on barriers to accessing the dementia healthcare service for family caregivers from minority ethnic backgrounds, the lack of knowledge on how to address these barriers in order to reach and support this group is evident.

Design: The study has a qualitative, explorative design. The principles of consolidated criteria for reporting qualitative research (COREQ) were applied for reporting methods and findings.

Methods: Based on data from semi-structured interviews ($n = 9$) conducted in two large Norwegian municipalities, a thematic analysis influenced by Braun and Clarke was used. The analytical findings draw on Pierre Bourdieu's theoretical concepts of *field*, *habitus* and *capital*.

Findings: 'The desire for a harmonious interaction' was identified as an overarching theme. However, while desirable, the analysis shows that healthcare professionals in community-based dementia teams do not always succeed in reaching and supporting family caregivers from minority ethnic backgrounds. The study reveals that the dementia healthcare service is a complex, normative and sometimes rigid system that requires a number of distinct attributes to navigate.

Conclusions: The different social structures within the dementia healthcare service can both create and retain barriers that prevent family caregivers from minority ethnic backgrounds from receiving support on their own terms.

Relevance to clinical practice: A practical implication of allowing critical reflection on the dementia healthcare service is that it provides opportunities for discussion. Healthcare professionals in community-based dementia teams need to reflect on how normative ideals and 'taken-for-granted' mindsets can affect their ability to reach and support family caregivers from minority ethnic backgrounds.

KEYWORDS

Bourdieu, cognitive impairment, community-based dementia teams, dementia, dementia healthcare service, family caregivers, minority ethnic background, qualitative research

1 | INTRODUCTION

Dementia is one of the most common reasons for needing healthcare services and represents a global issue that creates significant public health concerns (World Health Organization, 2017). Worldwide, around 50 million people have dementia, and with nearly 10 million new cases every year, the number of people living with dementia globally is predicted to increase to 132 million by 2050 (Alzheimer's Disease International, 2015; World Health Organization, 2017). The Norwegian health authorities estimate that there are currently between 80,000 and 100,000 people living with dementia, and as in the rest of the world, that number is expected to increase in the years to come (Norwegian Institute of Public Health, 2019).

Although immigrants and Norwegian-born to immigrants in Norway are still of young age, representing just five per cent of the total population over 70 years of age or older, Statistics Norway (2018) estimates that by 2060 this proportion will increase to 24%, meaning that a quarter of people over the age of 70 in Norway will then be immigrants. Ageing increases the prevalence of dementia and cognitive impairment, and older people from minority ethnic backgrounds are therefore as likely to develop this disease as older people from the majority ethnic Norwegian population (Nordic Welfare Center, 2020). A rights-based approach that emphasises autonomy, participation, equity and choice is beginning to saturate dementia policies in some countries, such as Norway, Scotland, Belgium, the United States and Australia (Cahill, 2019). Additionally, the engagement of communities in addressing challenges accompanied by dementia is also seen as critical to successful social adoption (Whitehouse et al., 2018). However, in Norway as well as in other Western countries, the prevalence of dementia in minority ethnic populations and the challenges they may face are poorly documented (Dilworth-Anderson et al., 2020; Razum & Tezcan-Güntekin, 2019), and more research about this topic is therefore needed.

1.1 | Background

According to the Global Action Plan on the Public Health Response to Dementia 2017–2025 (WHO, 2017), supporting people from minority ethnic backgrounds suffering from dementia and their families is an ethical and important principle. However, to reach this goal,

What does this paper contribute to the wider global clinical community?

- Demonstrates that the dementia healthcare service is a complex system that involves specific expectations of social actions and behaviours.
- Raises awareness about how 'taken-for-granted' mindsets can have an impact on opportunities and limitations when healthcare professionals in community-based dementia teams attempt to reach and support families from minority ethnic backgrounds.
- Identifies the need for reflection on how ideal and normative assumptions can create barriers to accessing the dementia healthcare service for family caregivers from minority ethnic backgrounds.

there is a need to adequately organise healthcare services to meet the future demands for dementia care for everyone (WHO, 2017). In addition to a top-down approach, there is a need for coordinated actions from different stakeholders to create a society that is inclusive of all people living with dementia and their family members (Cahill, 2019).

To meet the WHO's goals (2017), research exploring the fields of dementia, family caregiving and ethnic minorities and their access to healthcare services has emerged (Dilworth-Anderson et al., 2020; Kenning et al., 2017; Nielsen et al., 2019; Sagbakken et al., 2018). Overall, these studies indicate that existing practices and support for people from ethnic minority groups suffering from dementia or cognitive impairment and their families are still below optimal. Reasons for this may be the scarce, almost non-existent, number of people from minority ethnic groups receiving healthcare services in their communities (Kenning et al., 2017; La Fontaine et al., 2007; Mukadam et al., 2011; Nielsen et al., 2015, 2019; Parveen et al., 2017; Sagbakken et al., 2018) and difficulties in recruiting these groups in healthcare research (Fryer et al., 2015; Sahdia Parveen et al., 2018). As a consequence, older people from minority ethnic backgrounds and their families are at risk of social exclusion (Razum & Tezcan-Güntekin, 2019).

Language barriers, including a lack of available comprehensible information and difficulties in communicating with families and those suffering from dementia or cognitive impairment, are seen as major concerns (Kenning et al., 2017; Mukadam et al., 2011; Nielsen et al., 2019; Parveen et al., 2017; Sagbakken et al., 2018). Studies also point out that, due to cultural aspects, family caregivers from minority ethnic backgrounds may have different needs from and expectations of dementia healthcare service, suggesting a need to develop more culturally sensitive and appropriate pathways of care (Baghirathan et al., 2018; Chaoui & De Donder, 2018; Flakerud, 2009; Mukadam et al., 2011; Nielsen et al., 2015, 2019, 2020; Sagbakken et al., 2018).

In 2015, the Norwegian health authorities published Dementia Plan 2020 describing strategies and initiatives for further developing a dementia healthcare service suitable for everyone. By putting dementia challenges on the local municipalities' agenda, the plan sought to ensure high quality in the development of services for an increasing number of people with dementia and their families (Norwegian Directorate of Health, 2015). This plan and various studies (Bjørge et al., 2019; Todorova et al., 2016; White et al., 2018) highlight that family caregivers of those suffering from dementia or cognitive impairment are particularly affected because of the emotional impact of their role. Research indicates that family caregivers from minority ethnic groups may even be more affected because they may play a more significant role in managing dementia at home (Boughtwood et al., 2011; Chaoui & De Donder, 2018; Razum & Tezcan-Güntekin, 2019; Xiao et al., 2016).

In Norway, dementia diagnostics is usually performed by general practitioners in collaboration with dementia teams in the municipalities. These teams, often referred to as community-based dementia teams, are interdisciplinary, consisting of healthcare professionals with different backgrounds such as registered nurses, physiotherapists, occupational therapists and qualified nursing assistants (Norwegian Directorate of Health, 2019). The dementia teams play an important role in guiding and helping home-dwelling older people with dementia and their families in receiving help that is adapted to their needs (Ingebretsen et al., 2015). However, as stated in Dementia Plan 2020, older immigrants and their families often come in contact with the dementia healthcare service at a late stage of the disease. Moreover, the burden on the family may increase if they do not receive help adapted to their language, customs and traditions (Norwegian Directorate of Health, 2015). Although both national and international recommendations on improving cultural care exist, the health care provided to patients from minority ethnic backgrounds and their families varies considerably (Diaz & Kumar, 2019). A Norwegian survey conducted in 2018 revealed that only 3.5 per cent of 403 municipalities had provided training for employees in facilitating services for people with dementia from minority ethnic backgrounds. Moreover, of the 357 municipalities that had training programmes where services to people suffering from dementia were mentioned, only 7.3 per cent mentioned assessment, treatment and care facilitated for people

with dementia from minority ethnic backgrounds (Norwegian Directorate of Health, 2019).

As the literature demonstrates, concerns about reaching and supporting family caregivers from minority ethnic backgrounds have been the subject of several studies that have shown various barriers to accessing the healthcare services. However, to the best of our knowledge, no studies have critically examined these issues within the Norwegian context. The aim of this study is therefore to explore the perceptions of healthcare professionals in community-based dementia teams of their role in reaching and supporting family caregivers from minority ethnic backgrounds caring for a family member suffering from dementia or cognitive impairment.

1.2 | Theoretical framework

By using a more structural approach based on Pierre Bourdieu's theory, this study provides a critical and reflective lens through which to explore how healthcare professionals' perceptions and understandings are constructed, shaped and developed within the dementia healthcare service (Nairn & Pinnock, 2017). Among the key concepts in Bourdieu's (1990) theory, we find *field*, *habitus* and *capital* suitable for the present study.

According to Bourdieu (1990, p. 67), the concept of *field* is understood as a social space with specific norms and rules that define both limitations on and opportunities for actions (Nairn & Pinnock, 2017). In this study, the dementia healthcare system is understood as the field, a social space where interaction between healthcare professionals in community-based dementia teams and family caregivers from minority ethnic backgrounds take place. The norms and rules are defined by what Bourdieu (1990) calls the concepts of *habitus* and *capital*. *Habitus* is understood as a set of individuals' characters (Bourdieu, 1990, p. 56), where some are seen as more desirable than others (Franklin et al., 2019; Lynam et al., 2007). This may be understood as healthcare professionals' specific mindsets, perceptions and attitudes regarding older people from minority ethnic backgrounds suffering from dementia and their families. *Capital* denotes a set of advantages for some individuals in the field (Segre, 2014, pp. 22–23). It includes apparent economic capital, but also attaches significance to different categories of symbolic capital such as knowledge (Bourdieu, 1990, pp. 16–17). Possession of a specific type of knowledge can be used as a tool of dominance in that some views are considered to be less or more valuable than others (Nairn & Pinnock, 2017). This can be understood as healthcare professionals possessing a specific type of knowledge about how older people with minority backgrounds and their families get help from dementia care service.

The concepts of field, habitus and capital represent different aspects of processes that influence how social relations are constituted and experienced (Lynam et al., 2007; Lynam & Cowley, 2007; Nairn & Pinnock, 2017). Analysing the concept of field, habitus and capital reveals the tension that exists both within the dementia

healthcare service and between the dementia healthcare service and its users. This is a useful contribution to nursing knowledge about dementia and family care among minority ethnic groups living in Norway because it challenges existing, but often invisible, power structures in society. To address the aim of the study, the following research question was formulated: How do healthcare professionals in community-based dementia teams perceive their role in reaching and supporting family caregivers from minority ethnic backgrounds caring for a home-dwelling family member suffering from dementia or cognitive impairment?

2 | METHODS

2.1 | Study design

To explore how healthcare professionals in community-based dementia teams perceive their role in reaching and supporting family caregivers from minority ethnic backgrounds, a qualitative study using semi-structured interviews was employed. The consolidated

criteria for reporting qualitative studies (COREQ) (Appendix S1), a 32-item checklist for interviews and focus groups, were applied (Tong et al., 2007).

2.2 | Recruitment of participants

The recruitment of participants took place in two large municipalities in Norway and was carried out through a contact person at a regional research centre. Some participants were recruited through the 'snowball sampling method', which means that participants recruited other participants (Noy, 2008). The recruitment period lasted for four months, from December 2019 to February 2020, and during this period, a total of 13 healthcare professionals from nine different dementia teams consented to participate in the study. No participants chose to withdraw from the study.

The inclusion criteria for participating were as follows: (a) working as a healthcare professional in a community-based dementia team and (b) having experience with family caregivers from a minority ethnic background. All the participants were women with

No. interview	Age of participants	Sex	Professional background	Work experience in dementia team
Interview 1				
HP1	63 years	Female	Occupational therapist	10 years
Interview 2				
HP2	40 years	Female	Registered nurse	6 months
Interview 3				
HP3	53 years	Female	Registered nurse	9 years
Interview 4				
HP4a	49 years	Female	Qualified nursing assistant	4 years
HP4b	38 years	Female	Occupational therapist	3 weeks
Interview 5				
HP5	40 years	Female	Registered nurse	4 years
Interview 6				
HP6a	58 years	Female	Occupational therapist	9 years
HP6b	52 years	Female	Registered nurse	5 years
Interview 7				
HP7	60 years	Female	Registered nurse	7 months
Interview 8				
HP8	56 years	Female	Registered nurse	3 years
Interview 9				
HP9a	39 years	Female	Registered nurse	4 years
HP9b	36 years	Female	Occupational therapist	2.5 years
HP9c	25 years	Female	Occupational therapist	1 month

TABLE 1 Interview information and characteristics of the participants

TABLE 2 Braun and Clarke (2006) phases of thematic analysis

Phase	Description of the process
1. Familiarising with the data	Transcribing data, reading and re-reading the dataset, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data systematic across the entire data set, organising data relevant to each code.
3. Searching for themes	Organising codes into potential themes, gather all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic 'map' of the analysis.
5. Defining and naming themes	Refining the specifics of each theme, generating clear definitions and names for each theme.
6. Producing the report	Selection of vivid, compelling extract examples, producing a report of the analysis.

various professional backgrounds and work experience. The participants' characteristics are shown in Table 1.

2.3 | Data collection

The data were collected through nine interviews with a total of 13 participants using a semi-structured interview guide and follow-up questions. Most of the interviews were performed individually with one participant from the team. However, some wanted to participate as a team, which resulted in two to three participants taking part in three of the nine interviews conducted. The interviews were conducted at the participants' workplaces. The first author conducted all the interviews, and the last author attended one of the interviews.

The interviews lasted from 42 to 75 min and were guided by a semi-structured interview guide. The participants were first invited to describe their general role and how they worked, and thereafter to describe their experience with family caregivers from minority ethnic backgrounds. The questions in the semi-structured interview guide included the following: 'What are your experiences with family caregivers from minority ethnic backgrounds, and what do you think is important when interacting with them?' and 'How do you ensure that family caregivers from minority backgrounds who provide care to an older family member suffering from dementia get access to adequate professional health care?'. The participants were also asked to describe in their own words specific situations, cases, challenges and positive experiences where they had worked with families from minority ethnic backgrounds. The interviews were digitally recorded and transcribed verbatim by the first author.

2.4 | Data analysis

Because three of the interviews were conducted with more than one participant, it is important to note that the differences in the number of participants in the various interviews may have had an impact on the outcome due to group dynamics. The transcribed data generated

from all nine interviews resulted in approximately 200 pages of text comprising 80 700 words. As shown in Table 2, a thematic analysis inspired by Braun and Clarke (2006) was employed to analyse the data. Analysis of the interviews was undertaken using both an inductive and deductive approach. In the following, the process is described as a linear process, although in fact it involved a constant moving back and forth between the entire dataset, the coded extracts and the analysis of the data produced (Braun & Clarke, 2006).

2.5 | Inductive phase of the analysis

As part of the first phase of the thematic analysis, the first author familiarised herself with the dataset by transcribing all the interviews, reading the transcripts repeatedly, and listening to the audio recordings (Braun & Clarke, 2006). In the second phase, taking an inductive approach to the dataset, the coding was performed without trying to fit the dataset into a pre-existing coding frame or the authors' analytic preconceptions. To achieve this, the codes consisted of semantic codes referring solely to verbal statements (Braun & Clarke, 2006). However, even without much theoretical awareness, pre-understandings and past experiences will always affect the analysis to some extent (Malterud, 2016). Since all the authors are female nurses with different experiences from the fields of research and dementia and with different ethnic backgrounds, it is inevitable that past experiences will influence how they interpreted the participants' statements. Exactly how these have influenced the analysis is difficult to know, although reflexivity as a fundamental part of qualitative health research was discussed between the authors (Doyle, 2013).

2.5.1 | Deductive phase of the analysis

The remaining phases of the thematic analysis formed the deductive phase. In phase three, the first author began looking for potential themes across the semantic codes and discussed these with the co-authors to

determine how to combine them to form different themes (Braun & Clarke, 2006). As the first author began engaging with the literature, subthemes, main themes and the overarching theme were defined, inspired by the theoretical ideas of Pierre Bourdieu (1990).

The concepts of *field*, *habitus* and *capital* were applied to the empirical data, enabling the researchers to understand the participants' statements from a critical point of view. At the end of phase four of the thematic analysis, the authors had gained an idea of how the different themes were interrelated and how they fitted with the overall story obtained by the data material (Braun & Clarke, 2006). The concept of field (Bourdieu, 1990) was used to analyse the dementia healthcare service as the social context in which interactions between the healthcare professionals and the family caregivers took place. The concepts of habitus and capital (Bourdieu, 1990) were used to explore how the participants described normative assumptions, regarding both their own role as healthcare professionals and that of the family caregiver, of how to successfully 'navigate' the dementia healthcare service. By seeing the concepts of field, habitus and capital in conjunction with one another, the overarching theme – 'the desire for a harmonious interaction' – was created during phase five. Phase six consisted of writing the report.

The themes presented in Table 3 are analytical constructions of how the participants perceived and described their role in reaching and supporting family caregivers from minority ethnic backgrounds.

2.6 | Rigour

The adequacy of the final sample size was continuously evaluated during the research process (Malterud et al., 2016). Saturation was reached when 'new codes' in the dataset did not necessarily add anything new to the overall story (Saunders et al., 2018). In terms of reflexivity, the authors acknowledge that the phenomena explored can be perceived and interpreted in many ways. However, by describing the analytical process and theoretical assumptions, transparency and credibility are sought to be maintained (Malterud, 2016). The participants were not offered an opportunity to provide feedback on the findings; however, confirmability is retained by providing quotes from participants' statements when presenting the findings. To ensure the trustworthiness of the findings, the themes will be presented along with the participants' statements that were

made during the interviews. Each statement ends with a number representing the code that was assigned to each healthcare professional (HP) during the interviews. In statements involving more than one participant, the codes are given as HPXa, and HPXb.

2.7 | Ethical considerations

The study was approved by the Norwegian Centre for Research Data (NSD, project number 153884). Prior to the interviews, participants received both oral and written information about the study, and informed written consent was obtained from all participants. Participants were informed that they could withdraw from participation at any time, for any reason, without this entailing negative consequences for their employment. Confidentiality was ensured by not mentioning the participants' names or other identifying information such as workplace in transcripts and analyses. In addition, some of the participants shared very descriptive experiences with family caregivers they had met, for example by mentioning that 'this family was from...'. To ensure anonymity, the names of any countries that were mentioned during the interviews were omitted from the transcripts and replaced by the continent.

3 | FINDINGS

Despite the different ways in which the participants articulated their role in supporting family caregivers from minority ethnic backgrounds, the analysis revealed one overarching theme – 'the desire for a harmonious interaction' – that specifically highlights the study's research question. The overarching theme is supported by two main themes: 'challenges in reaching the families and meeting their needs' and 'flexibility with some boundaries'. Within each main theme, three subthemes were constructed.

3.1 | Challenges in reaching the families and meeting their needs

Although the participants expressed concerns regarding having little experience with families from minority ethnic groups, they also

TABLE 3 Subthemes, main themes and overarching theme.

Subthemes	Main themes	Overarching theme
Lack of knowledge about the dementia healthcare service	Challenges in reaching the families and meeting their needs	The desire for a harmonious interaction
The importance of collaboration		
Language as a barrier to communication		
The act of soft persuasion	Flexibility with some boundaries	
Knowledge about the system versus knowledge about the culture		
Managing a diversity of choice		

emphasised that the dementia teams had no outreach function, meaning that to identify the families' needs, someone had to contact the dementia team first. During the interviews, the families' lack of knowledge of the dementia healthcare service was particularly highlighted by the participants.

3.1.1 | Lack of knowledge about the dementia healthcare service

Although the dementia teams did not offer outreach, they assessed all the requests they received. This was done in many ways, and there were no specific procedures or guidelines for how to get in touch with the dementia teams, as one of the participants stated:

We are a kind of low threshold service, so we get requests from all over. Relatives, sometimes the patients themselves, GPs, hospitals, yes, and not least, the home care service.

(HP8, lines 9–11)

Furthermore, neighbours, occupational therapists, physiotherapists and staff employed at the day centres could also contact them. Some of the participants had posted information in local newspapers and on the municipality's own website. Despite the information available, few families from minority ethnic backgrounds had contacted them. Most of the participants stated that one reason for this was a lack of knowledge among the families about the dementia healthcare service the municipality offered.

No, I don't think they have knowledge about the possibilities they have, but they don't seek out any of the available healthcare service from the municipality either.

(HP6b, lines 537–538)

The participants expressed different opinions on how much effort healthcare professionals should invest in getting in touch with the families. Some talked about visiting mosques or other places where they could meet them and provide information, although none of these actions had actually taken place. Others were slightly more passive in their attitudes, concluding that the responsibility lay with the families themselves. It was also expressed that minority ethnic cultures will change as society demands more from them, thus becoming almost similar to the majority ethnic Norwegian population. In these cases, participants wondered whether there was anything else they could do, arguing that in order to get help, people need to know how to find it.

Once you have moved to another country, to a different culture, and a different [healthcare] system, then you must get to know the system. It is your duty. By

that I mean that when you are Norwegian and born in Norway, you must know your country because you must know your rights, know where to turn and where not to turn, know when you can expect help and when you cannot expect help.

(HP3, lines 170–175)

However, despite their different opinions about their duties, many participants raised concerns about the system being very difficult to navigate and perhaps even harder to understand for those from minority ethnic backgrounds.

3.1.2 | The importance of collaboration

The participants emphasised the importance of a solid network that provided good collaboration across the healthcare system in order to establish and maintain consistent care provision. However, statements regarding collaboration were mostly about families and users from the majority ethnic Norwegian population. When asked about collaboration with a view to reaching families from minority ethnic backgrounds, general practitioners (GPs) were considered particularly important because they often had first-hand knowledge about such situations. They also felt that the collaboration with hospitals over the past few years had significantly improved.

I'm talking about GPs, this is very important because they [families from minority backgrounds] go to GPs. They [GPs] have an 'eye' for it and they can see that something is wrong here and they inform us. And the specialist healthcare service, they are also good at informing us now.

(HP9a, lines 560–562)

However, good collaboration to reach families from minority ethnic backgrounds who need help did not only depend on professionals in the community-based service. Reaching these families also greatly depended on who the patient suffering from dementia or cognitive impairment was living with. Many stated that the patients' adult children were more active in contacting them, although they admitted to having too few families from minority ethnic backgrounds on their list compared to families from the majority ethnic Norwegian population.

There are more than we have on our lists, so I think it's important that the GPs know about us and our work, because they [GPs] can send them [patients and their family] to us. However, it all depends on which generation the next of kin belongs to. If they are relatively young, then they probably use the internet and keep up with the information.

(HP4a, lines 295–298)

3.1.3 | Language as a barrier to communication

All the participants agreed that a lack of language skills was a major challenge in reaching, communicating with and providing necessary information to caregivers from minority ethnic groups. Although they had some information leaflets in other languages, the health-care professionals were often unsure of what language the families spoke, which led to ambiguity over what kind of brochures to bring with them. Another challenge was that they did not know exactly what was written in the brochures.

I don't know what's in them [brochures], and I don't want to distribute something that I have no idea about. (...) It would be very awkward.

(HP7, lines 291–292)

All the participants had positive experiences with schools/courses where family members and friends could learn about dementia, learn about the system and talk to other families who were in the same situation. However, the courses were held in Norwegian and were not suitable for those who had difficulties understanding Norwegian. The participants had almost no experience of meeting families other than those who could speak Norwegian at these courses. The few who attended the courses from minority ethnic backgrounds were usually adult children of the family member who had dementia or cognitive impairment.

There were many attendants. (...) We had 38 participants. (...) at least 10 of them had minority backgrounds, but those were adult children, born and raised here in Norway.

(HP2, lines 384–393)

Although language was often a barrier to communication, professional interpreters were almost never used. Most of the participants were satisfied with using family members as interpreters; however, some described situations in which some members 'took on' the role of interpreters, even though they had hired a professional. Some of the participants considered this to be ineffective and even uncomfortable at times.

(...) this family had many family members and neighbours who also wanted to interpret. So, everyone interpreted, and (I) sat there and did not understand anything. (...) and the person who was there to interpret did not get the opportunity to say a word. (...) Neighbours and families and everybody, they all talked at the same time.

(HP6b, lines 367–374)

3.2 | Flexibility with some boundaries

The importance of flexibility when meeting the families was stressed by all the participants. This particularly applied when

dealing with families from minority ethnic backgrounds because they might have other understandings or requirements when caring for a family member suffering from dementia or cognitive impairment.

3.2.1 | The act of soft persuasion

Although it was difficult to reach the families, the participants had some experience with providing practical help and equipment to families. The families often turned down offers from the community-based healthcare service, such as help with personal care or information meetings with the dementia team, but different types of practical help were usually accepted. Providing practical devices gave an opportunity to observe and to build a relationship with the families. Persuading them to accept dementia as a disease, and thus helping them to accept the need for help, was therefore considered an important task. The participants frequently mentioned that family caregivers from minority ethnic backgrounds found it difficult to 'let go'. The main explanation for this was that their culture required the families to take care of their own without help from the healthcare services. In these cases, the participants saw it as their responsibility to make the families accept that it was normal to receive help and that it did not mean that they had failed or betrayed their family or family member. The solution was trying to get in touch with them early on and to build a good and safe relationship so that the families would trust the healthcare professionals and their decisions later on.

HP9a: We call them, we talk to them, try to make them understand, and it tends to really work if we meet them early on. Usually then they accept help little by little. HP9b: It's a lot about relationship building so that they can gain trust in the system. HP9a: Yes, very important, relationship building is very, very important in our job.

(HP9a / HP9b, lines 609–616)

Different understandings, such as seeing dementia not as a disease but as a curse, posed potential barriers to receiving help. They often referred to the spouses of those suffering from dementia or cognitive impairment as being more difficult to collaborate with than their adult children, who usually had more adequate understandings of dementia as a disease. One participant stated the following:

(...) having this disease is seen as God's punishment – it's a shame brought on your family, and your children will not marry. You have a lot of that kind of mindset. Luckily, they have children who are Norwegian or who were raised and born in Norway.

(HP7, lines 141–147)

3.2.2 | Knowledge about the system versus knowledge about the culture

Although the participants did not experience any differences in the needs of families from the minority ethnic population for knowledge, differences often emerged in the ways in which the families received information provided by healthcare professionals. The participants perceived the adult children in the family to be more open-minded than the spouses, and even more willing to receive help.

(...) usually it's not the spouse who says that things are not going well, it's the children who say that 'dad is struggling' or 'mum is struggling'. Yes, that's our experience.

(HP9a, lines 131–133)

The need for knowledge was twofold. The participants felt they needed knowledge about the families' different cultures and habits. At the same time, they felt that the families needed knowledge about dementia as a disease and about the dementia healthcare service. Having knowledge about different cultures was a way of showing respect and interest, which made them better at interacting with the families. However, because of the scarce number of users they visited from minority ethnic groups, many lacked such knowledge. In addition, different kinds of knowledge needs were expressed; for example, one participant stated the following:

What sort of traditions, what is common? Because I understand that a loose handshake is common, you know, that's the first impression you react to in almost all meetings with immigrants, when you greet people and get such a loose handshake. But then I heard somewhere that that was how they greeted people. It's always annoying, because you have been raised to give a proper handshake and look people in the eye when greeting them.

(HP4a, lines 345–353)

Having some knowledge of the culture was an advantage, but knowing everything about all cultures was impossible and, as some stated, could even create prejudices that were not appropriate to the family they met. Approaching the families 'where they were' and being open-minded was important to creating a relationship built on trust and respect. However, just as important was informing them of how things were done in Norway.

It is also about being able to inform them well about our culture in Norway, so that people can understand what is happening around them. When you meet a person or a family, you need to try to understand their mindset. But at the same time, if there are big differences, I guess you need to inform them about how we

do things in Norway, but at the same time respect how they think.

(HP1, lines 827–835)

3.2.3 | Managing diversity of choice

The participants emphasised the need to respect the families' choices, even though the families might turn down the offer of support and help. In these cases, it was important to ensure that the family caregivers understand what they would miss out on by providing all the necessary information and knowledge. Reflecting on their own preconceptions when meeting the families was also of great importance. The fact that the families might have different ways of providing care did not mean that the care was unsatisfactory. However, it was deemed necessary to consider the care they provided, as exemplified in the following statement:

Given the fact that they often choose to take a greater share of the care themselves, we should also show respect for these choices. In these cases, we look at the care provided – is it good enough, even though it may not be exactly how we usually see it being done?

(HP5, lines 185–187)

The participants expressed that, due to traditions, the family members often wanted to take care of their parents or spouses themselves, a wish that they had to respect. However, this could also be perceived as an obstacle to supporting the families. The participants found that some families did not talk much about how they felt about being caregivers to a family member with dementia or cognitive impairment. They perceived this as a challenge because they never knew what the families were thinking or feeling. This marked a clear difference between families from minority ethnic backgrounds and families from ethnic Norwegian backgrounds. Although ethnic Norwegian families sought help for almost everything, the introvert nature of some of the families from ethnic minority backgrounds made it challenging to reach them or gain access to their homes. The participants talked about families 'hiding' or not showing what the situation was really like.

They don't say as much as the Norwegians, they don't unfold their life to such an extent. (...) I mean, they give some hints, but they don't say as much as Norwegians, who talk about everything. (...) This woman never mentioned anything like that. She just mentioned that she had to stay up at night, make sure the door was locked, that sort of thing.

(HP7, lines 624–634)

Another obstacle was when the families accepted help from the healthcare service but failed to 'let go', so when healthcare personnel from homecare came to offer help, the families had often already done the work (i.e. giving medication, making breakfast or helping with

showering) or disturbed the healthcare professionals when doing their job.

HP4b: (...) You often see that the family interferes a lot with what we [community-based dementia teams] and those from the home care service are doing. It kind of doubles up, and that is problematic. (...) HP4a: And what happens then is that the service provision is stopped because the home care service does not see any need because the medicine is given anyway.

(HP4a / HP4b, lines 136–148)

When asked about expectations, the participants' opinions varied. Some felt that families from minority ethnic backgrounds were very grateful and did not expect anything. Some participants described the opposite, saying that some families had too many expectations, demanding tasks which the community-based healthcare services did not have the resources to perform, such as cleaning the floor every day or delivering practical aids on the same day as they were ordered. Many stated that expectations varied widely, but others expressed their views more directly.

There are those who cry and make a lot of noise and are terribly verbal and loud because they want help right here, right now. Others understand the system and manage to operate within it in a slightly smarter way and understand how they should or how they must behave to get the right help at any time. So we all deal with diseases a little differently.

(HP3, lines 157–162)

4 | DISCUSSION

The aim of the present study was to explore how healthcare professionals in community-based dementia teams perceive their role in reaching and supporting family caregivers from minority ethnic backgrounds. The main finding reveals a complex and comprehensive dementia healthcare system which healthcare professionals in dementia teams, as well as families from minority ethnic backgrounds, must 'navigate', a descriptive term used by several of the participants. By analysing the participants' statements, it became apparent that in order to navigate the system successfully, a set of distinct attributes was needed. In the following, these attributes will be discussed in light of Pierre Bourdieu's key concepts: *field*, *habitus* and *capital* (Bourdieu, 1990).

To understand interactions between people or to explain a social phenomenon, it is, according to Bourdieu, necessary to examine the social space, which he called *the field*, where these interactions take place (Thomson, 2008). In the current study, the dementia healthcare service provided by the community-based dementia teams is understood to be what Bourdieu (1990) defined as the field in which

both the healthcare professionals and the family caregivers from minority ethnic backgrounds find themselves. It is in this field that different social actions are valued and responded to according to specific normative assumptions.

The participants revealed their perceptions of how to reach and support families from minority ethnic backgrounds. They also revealed their perceptions of how families from minority ethnic backgrounds should act in order to be reached and to receive necessary and adequate support. The interaction between family caregivers and the dementia healthcare system can be understood as what Bourdieu (1990) called 'a game', where each player has to play their assigned role; one played by the healthcare professionals and the other played by the family caregivers from minority ethnic backgrounds. However, it is important to note that, in contrast to an actual game (such as a ball game), where specific rules are clearly set, the individuals in the social game have no awareness about the rules because they are taken for granted (Bourdieu, 1990).

Although the dementia team is a low threshold healthcare service, very few families from minority ethnic backgrounds had sought out the service. In accordance with previous research (Chaoui & De Donder, 2018; Kenning et al., 2017; R. T. Nielsen et al., 2015; R. T. Nielsen et al., 2019; T. R. Nielsen et al., 2020), the participants stated that it was difficult to find the families who needed help. The analysis revealed that in order to accomplish 'a harmonious interaction' and thereby reach and provide adequate support to families from minority ethnic backgrounds, the roles needed to be well played. This, however, was not always the case, as the participants described the system as too complex and not always suitable for these families, hence hindering both the family caregivers and the healthcare professionals from playing their 'assigned' roles. The lack of experience seemed often to apply to the families, with the participants stating that the families lacked sufficient knowledge about the system to 'navigate' it. Efforts to find different arenas where information about the system could be distributed were mentioned, but these ideas had not been put into practice. This suggests that the ability to navigate the dementia healthcare system requires certain attributes which some families from minority ethnic backgrounds lack but which, according to the participants, they have a responsibility to acquire on their own.

Besides knowledge, the ability to collaborate was an important attribute for 'navigating' the system. The participants asserted that it was easier to collaborate with the patients' adult children than with their spouses because the children were often more open to receiving and accepting help. They also had the advantage of being able to speak Norwegian. Similar findings have also been presented in a study conducted by van Wezel et al. (2016), where younger family caregivers showed a more modern and 'normal' view of providing care by ensuring that professional care was provided rather than performing the caregiving tasks themselves. Importantly, as noted by Chaoui and De Donder (2018), a normative approach practised by healthcare professionals, such as relying on the presence of adult children in order to achieve good collaboration, creates structural barriers because in reality not

everyone has adult children born or raised in Norway (Chaouni & De Donder, 2018).

The present study reveals that good collaboration was highly valued by those who had experience of supporting families from minority ethnic backgrounds. In these cases, language was often brought up as a key feature, where adult children who were born or raised in Norway were considered easier to interact with. Bourdieu referred to language as symbolic capital (Bourdieu, 1990), where power and dominance are not only derived from material resources but also from cultural and social resources (Crossley, 2008). Families with adult children who were either born or had lived in Norway long enough to speak Norwegian were described as 'lucky' because they then had the possibility of using the internet to find information and could also be used as interpreters. However, language was not always considered the main prerequisite for good interaction since, as some of the participants explained, family members sometimes took on the role of interpreters even when they were not supposed to do so. Such experiences were found to be uncomfortable and inappropriate. As Bourdieu (1990) asserted, the concepts of both habitus and capital are essential to 'play the game'. Although capital is something an individual possesses, such as language skills, habitus is described as reasonable and 'common-sense' perceptions and behaviours produced within the field (Bourdieu, 1990). It was apparent that there were behaviours which healthcare professionals accepted more easily than others, creating a distinction between desirable and undesirable behaviours. As exemplified, it was not enough to be able to interpret; the families needed to know when it was appropriate to act as interpreters and when it was not. When the different roles were played well, for example when the families knew their position in 'the game' by not interfering or disrupting the work of the healthcare professionals, 'a harmonious interaction' was easier to achieve.

The participants shared a belief in showing respect to the families even if they did not want to receive the help offered. In a normative matter, this is usually understood as a way of seeing the family caregivers as autonomous individuals with the ability to make their own choices. This respect did have some limitations, however, given that they first needed to evaluate the care that was provided by the family caregiver. By doing this, the participants played their role in controlling the situation and thereby acted responsibly in order to accomplish their tasks as good healthcare professionals. However, the participants felt that there were some problematic situations where the need for help was observed but not recognised or admitted by the family caregiver. This kind of behaviour, such as not being open about their situation and needs, was characterised as an issue. Similar findings are revealed in other studies, where stigma and the lack of openness are understood as barriers to accessing the healthcare system (Kenning et al., 2017; Mukadam et al., 2011). Drawing on Bourdieu's (1990) concept of habitus, these are mindsets that relate to 'common-sense' behaviour. Some of the participants compared the ethnic minority families with families from the majority ethnic Norwegian population, who were usually open and talked about

'everything'. The participants felt that the need to control the situation and be able to respond to the family caregivers in a proper way was hindered when the family caregivers were silent and did not talk about their emotions.

When the healthcare professionals eventually came into contact with the families and the family caregivers, it was apparent that some behaviours were more desirable than others, especially in terms of accepting dementia as a disease, receiving the help offered and collaborating with the healthcare professionals. It was considered problematic if the family caregivers did not let the healthcare professionals do the job they were assigned to do, and if this was the case, the service offered was sometimes taken away from them. These examples show ways in which social structures contribute to social positioning, thereby influencing access to a variety of resources (Lynam et al., 2007). In order to receive help and support, it is therefore necessary to behave in a certain way.

Bourdieu (1990) looked at how knowledge can be taken for granted within the field. The concept of *doxa* relates to the practices that pass as unquestionable because of a correspondence between the social structures and mental structures (Deer, 2008). Although not explicitly expressed, the findings reveal how knowledge and possession of it were important to all the participants. As exemplified, they were very direct in their statements about the families' need for knowledge about the Norwegian healthcare system and about Norwegian society in general. Furthermore, the need to provide knowledge to the family caregivers so that they can acknowledge and accept dementia as a disease is supported by R. T. Nielsen et al. (2019). These practices can be understood as unquestionable because medical understandings within the healthcare system are needed to provide good and adequate health care. Although knowledge of culture, traditions and religion was considered central when working with families from minority backgrounds, when the participants were asked whether there was any knowledge they lacked, they responded that it was impossible to possess knowledge about the cultures of all minorities. An open and respectful approach was deemed more important than having substantial cultural knowledge. When knowledge is understood through the concept of *capital*, this illustrates a 'taken-for-granted' mindset whereby value is assigned to different forms of knowledge (Lynam et al., 2007). These findings suggest the existence of a subconscious hierarchical understanding of knowledge, where the families' knowledge of their own culture may be deemed less significant than the knowledge possessed by healthcare professionals.

The findings of this study suggest there may exist normative and 'hidden' perceptions of how to position oneself in the context of the dementia healthcare system, both as a healthcare professional and as a family caregiver. As the findings reveal, although the participants were concerned about not having enough experience with family caregivers from minority ethnic backgrounds, there are certain normative assumptions about how family caregivers must change in order to manage the navigation required to achieve the help and support needed from the community-based dementia teams.

4.1 | Strengths and limitations

The use of Bourdieu's key concepts of field, habitus and capital enables a theoretical framework for the analysis that allows a deeper understanding of encounters between healthcare professionals in community-based dementia teams and family caregivers from minority ethnic backgrounds. However, there are some limitations that need to be declared. First, this study focuses only on the healthcare professionals' perceptions, not on the family caregivers' own perceptions of been reached or receiving help. This is a limitation because, as Bourdieu (1990) emphasised, the field is the whole social context, including all individuals in 'the game'. Second, this study focuses only on how the healthcare professionals described their interactions with families from minority ethnic backgrounds, which means that these findings do not provide insights into how the interactions actually took place, but rather into how they were perceived by the participants. Therefore, a sample consisting of family caregivers from minority ethnic backgrounds and their perceptions of their role might reveal important differences in the findings and provide a starting point for a future study. Third, the findings represent only 13 healthcare professionals from nine dementia teams, which may impact the generalisability of the findings. However, despite the small sample, the richness in the participants' descriptions was a strength. A more diverse sample consisting of healthcare professionals in the home-based healthcare service could provide a more comprehensive insight.

5 | CONCLUSION

The present study has explored how healthcare professionals in community-based dementia teams perceive their role in reaching and supporting family caregivers from minority ethnic backgrounds. The existing literature on barriers to reaching and supporting family caregivers from minority ethnic backgrounds offers few studies featuring critical perspectives on how social structures impact our understandings. The present study demonstrates that the dementia healthcare service is a complex system of specific, normative expectations of our social actions and behaviours. Bourdieu's (1990) concepts of field, habitus and capital provide useful and important insights into how these expectations can have an impact on opportunities for and limitations on the work of healthcare professionals in community-based dementia teams in reaching and supporting families from minority ethnic backgrounds. In contrast to many other studies, the present study does not offer any solutions to the concerns about how to reach and support this group. The participants' statements were similar to what other studies have shown previously. However, the study does identify a need for reflection on ideal and normative assumptions, and especially on how these assumptions can create distinctions and power relations where some families are more suitable for the dementia healthcare system than others.

6 | RELEVANCE TO CLINICAL PRACTICE

With regard to the wide range of nursing research, arguing that a problem exists that needs to be solved is not enough to make a difference. One must, in addition to proposing a solution to the problem, explore and reflect more critically on why the problem exists. Implicit attitudes often exist outside of conscious awareness, making them difficult to acknowledge and control. The findings of this study suggest the need for more research that explores the dementia healthcare system in a more critical way, as this approach can expand understandings of the wide range of social structures that organise individuals' everyday experiences.

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CONFLICTS OF INTEREST

The authors have no conflict of interests to declare.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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