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ARTICLE

Understanding dementia in ethnically diverse groups: a qualitative study from Norway

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Abstract

As the number of older immigrants in Europe rises, dementia within minority ethnic populations warrants attention as a significant public health problem. Equitable health and care services constitute a prioritised health policy aim on both supranational and national levels in Europe and is formulated in the Norwegian health legislation. Through interviews and focus groups with older immigrants, relatives of immigrants with dementia and health personnel, we explored the perceptions of dementia among ethnically diverse groups in Norway. The findings show that many interpret symptoms such as memory loss and disorientation as a natural part of ageing. Others consider dementia symptoms to have a psycho-social origin, deriving from social isolation. Some describe symptoms as an expression of a potentially transient sign of madness, while others point to destiny and God's will, representing basic and unalterable causes. However, another pattern of perception includes viewing dementia as a potentially transient physical illness, including a belief in a medical cure. By investigating how people with dementia and their families understand and manage the condition, one may facilitate access to relevant and adapted information. Furthermore, by exploring how people relate to their illness, health personnel may challenge explanatory models that create unrealistic expectations of cure, as well as models that, due to stigma or normalisation of symptoms, prevent the use of public care.

Keywords: dementia; cognitive impairment; perceptions; management; diversity; minority ethnic groups

Introduction

As the number of older immigrants in Europe rises, dementia within immigrant and minority ethnic populations warrants attention as a significant public health problem. Equitable health and care services constitute a prioritised health policy aim both on supranational and national levels in Europe (Mladovsky, 2011) and is also formulated in the health legislation of Norway (Ministry of Health and Care Services, 1999, 2008). If policy and practice are to be based on an

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understanding of diverse life situations, family structures and socio-economic conditions, adaptive and innovative thinking with regard to care of the older population will be necessary (Krilic, 2013). However, information on older immigrants, in particular their health and their use of health and care services, is scarce, as European public health research and policies focus largely on younger immigrants, workers and refugees (Krilic, 2013).

Dementia is described as the greatest global health challenge for health and social care in the 21st century (Livingston *et al.*, 2017). Globally, approximately 47 million people were living with dementia in 2015, and this number is projected to triple by 2050 (Prince *et al.*, 2013; Livingston *et al.*, 2017). As most cases occur in people older than 65 years old, the increase in numbers is driven mainly by increased longevity. In 2015, the global costs of dementia were estimated to be US $818 billion, an amount that will continue to rise along with the increase in people affected (Livingston *et al.*, 2017). Approximately 85 per cent of these costs are related to resources and efforts performed by the family and in the social sector, rather than medical care. In a recent review published in *The Lancet*, it is concluded that 'family carers are the most important resource available for people with dementia' (Livingston *et al.*, 2017: 37).

In Norway, a country with 5.2 million inhabitants, the health authorities estimate that approximately 80,000 people are living with dementia and that there are around 10,000 new cases per year (Norwegian Directorate of Health, 2015). As the number of inhabitants over 80 years old is expected to increase sharply in the coming years, the number of people affected by dementia may double by 2040–2050 (Norwegian Institute of Public Health, 2014). In 2018, immigrants and their children born in Norway made up more than 17 per cent of the total population. The immigrant population is on average much younger than the general population, but according to projections from Statistics Norway (SSB), the percentage of immigrants among persons over 70 years old will increase from 4 per cent today to 24 per cent in 2060 (Leknes *et al.*, 2018).

In Norway, knowledge of dementia in immigrant groups is lacking in most areas, partly because the country of origin has not been recorded in medical records until recently. However, research from Norway (Diaz *et al.*, 2015) and elsewhere (Daker-White *et al.*, 2002; Nielsen *et al.*, 2010) shows that disproportionately few patients with immigrant backgrounds are diagnosed with dementia, and that there is a general under-utilisation of relevant treatment and care services.

Given the increasing ethnocultural diversity among older populations in many countries, it seems important to understand how cultural values and traditions as well as migration processes and socio-economic status affect patterns of care and use of health services (Kleinman, 1980; Morhardt *et al.*, 2010). Different studies have found a variety of explanations and concepts used to explain and address symptoms of dementia. For example, one systematic review of religion and dementia care pathways in black and minority ethnic populations (Asians and African Americans) showed that symptoms of cognitive impairment can be seen as caused by God's will, a supernatural intervention or a curse (Regan *et al.*, 2013). In another systematic review of ethnicity and pathways to dementia care among minority ethnic groups, it was found that Chinese carers, in particular, tended to provide explanations such as 'fate' or karmic retribution. In the same review, some of the

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African-American respondents provided spiritual explanations, associating the symptoms of cognitive impairment with an act of God or some sort of supernatural curse. Among British carers of South Asian descent, causes such as the 'evil eye' were mentioned, while other respondents in the same groups associated physical decline or diseases such as diabetes, heart problems and high blood pressure with symptoms of dementia (Mukadam *et al.*, 2011*b*). Psychological causes are also commonly described as part of people's explanatory models; studies in a variety of countries on several continents have reported mental illness (often termed 'craziness') as a perceived cause of cognitive impairment in old age (Morhardt *et al.*, 2010; Mukadam *et al.*, 2011*a*; Uppal and Bonas, 2014). A systematic literature review on constructions of dementia found that people from South Asia tend to have significantly less biomedical knowledge of dementia (such as which part of the body is affected and whether there is a cure) and knowledge related to epidemiology (types, prevalence) than, *e.g.* Caucasians (Uppal and Bonas, 2014). In many countries, including some parts of South Asia (*e.g.* the Punjabi culture), there is no equivalent word for 'dementia', and in other parts of the continent, the concept is little known. Among those using the word 'dementia', it tends to be used as stigmatising rather than neutral; a usage relating to the perception of the condition as an act of God, karmic retribution, a mental illness or the result of a lack of family care and support (Uppal and Bonas, 2014).

A variety of perceptions may prevent people from seeking help for dementia, and one barrier relates to the recognition and attribution of early symptoms (Mukadam *et al.*, 2011*b*). Studies indicate that among some minority ethnic groups, for example, groups of people from Asian countries living in the United Kingdom (UK) or Hispanic Americans and African Americans in the United States of America (USA), people may categorise symptoms of memory loss, disorientation and loss of functional abilities as a part of normal ageing more often than the majority population. This interpretation may imply that such symptoms will not inspire help seeking within the frames of the biomedical health-care system (Botsford *et al.*, 2011; Mukadam *et al.*, 2011*b*; Johl *et al.*, 2014; Uppal and Bonas, 2014). Other barriers relate to the way people understand the aetiology of dementia. Systematic review studies show that groups adhering to explanatory models that attribute the condition to psychological factors (*e.g.* 'craziness'), social factors (*e.g.* isolation) or spiritual factors (*e.g.* God's will) may delay or prevent seeking help from people outside the family (Mukadam *et al.*, 2011*b*; Uppal and Bonas, 2014). It is, however, important to bear in mind that it can be challenging to separate the effects of 'cultural' differences (*e.g.* culturally based perceptions of cause) from the effects of structural barriers, such as not speaking the majority language, not having access to an interpreter or facing the costs of accessing relevant health services (Morhardt *et al.*, 2010).

This study is viewed through some of the concepts introduced by Kleinman (1980), who conceptualises illness and disease as socially constructed *explanatory models* – models representing patterns of thoughts that provide answers to questions regarding aetiology, symptoms, course and treatment. According to Kleinman's perspective, illness comprises all the ways that the sick person, the members of the family and the wider social network perceive, interpret, live with and respond to symptoms and disability (Kleinman, 1988: 3–4). On the other

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hand, disease is the way biomedical practitioners view the symptoms and does not include cultural implications. Thus, the health-care system or the 'clinical reality' (Kleinman, 1980: 42) is constructed partly by individual beliefs, values and behaviours, partly by cultural beliefs and values, and partly by the concepts and practices within the (biomedical) professional part of the health-care system (Kleinman, 1980: 26). In a time of transnational migration, however, immigrants are involved in transnational practices. Thus, the migration process may change or partly transform culturally defined explanatory models serving as the reference for treatment and care (Schiller *et al.*, 1995).

Aim and methods

This study is part of a comprehensive study on older immigrants and dementia in Norway, where the overall goal has been to assist the Norwegian Directorate of Health in designing appropriate strategies for the care of immigrants with dementia. The target groups for this project are immigrants above the age of 50 years, relatives of immigrants with dementia (family care-givers), health personnel and care workers, and decision and policy makers.

The aim of this particular study is to explore and describe the perception of dementia and dementia care among groups of older immigrants, relatives of immigrants living with dementia and professional care-givers working with immigrants with dementia or age-related cognitive impairment (not diagnosed). Understanding dementia from the perspective of older persons was addressed through focus group discussions with older immigrants (without dementia). Based on discussions in the research team and the resource group (groups of experts such as health personnel, researchers and representatives of relevant non-governmental organisations (NGOs), serving as resources throughout the research process), this seemed to be the best solution as it would be difficult to access and recruit people with dementia as verbal expression is often limited. Including the person with dementia was also discussed with several of the relatives, but none of potential participants could communicate (in any language) to such an extent that they were able to participate in an interview. As documented in research, a person with an immigrant background might face even stronger problems with communication due to insufficient knowledge or dementia-related loss of their second language, Norwegian (Goral and Conner, 2013).

Choice of concepts

Based on studies from the UK and the USA showing that there are few Asian participants associating the biomedical term 'dementia' with symptoms indicating cognitive impairment (Mukadam *et al.*, 2011*b*), *e.g.* neither in Punjabi nor Urdu are there words that directly translate to resemble the biomedical concept of dementia (Uppal and Bonas, 2014; Næss and Moen, 2015), we thus decided to use the concept 'cognitive impairment' alongside dementia throughout the research process.

In this paper, we use 'minority ethnic groups' when we refer to studies from outside Scandinavia. However, in the parts of the paper where we refer to Norwegian statistics, Norwegian/Scandinavian studies and the present project, we use the term

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'immigrant', which is the terminology used by Statistics Norway, and is the most commonly used term in academic and public discourse. Importantly, the use of 'immigrant' also indicates that we are not referring to our native population, such as the Saamis.

Further, in this paper, we use both the concepts of culture and ethnicity. Culture refers to the inherited ways of life in which a person is socialised, including a system of shared ideas, a system of concepts, and rules and meanings underlying and being expressed through the ways human beings live (Helman, 2007: 2). Ethnicity is seen as a broader concept that includes culture, an expression of group affinity and a collective sense of identity. Thus, ethnicity is meaningful to people only in contrast to that of other groups (Barth, 1969; Bell, 2015).

Design

Because research on the topic is scant in Norway, the research team considered qualitative methods to be the most adequate approach. Through qualitative individual in-depth interviews (IDIs), including dyad interviews (DYIs), as well as focus group discussions (FGDs), we sought to explore different participants' own descriptions of perceptions, understandings, experiences and management of dementia in people with different ethnic and cultural backgrounds. The questions in the interview guides were partly inspired by a literature review, partly by perspectives provided from the first FGDs with older adults with immigrant backgrounds and partly through exchanges of experiences with experts in the field (health personnel, researchers, representatives of NGOs) who served as a resource group throughout the research period. The approach was flexible in the sense that the interviews and discussions also were guided by answers and themes introduced by the participants and not only by predefined themes identified by the researchers.

Sampling strategy and respondents

To obtain experiences from a variety of relevant respondents, we applied an emergent purposeful sampling strategy aimed at maximum variation in relation to age, gender, country of origin and occupation (among the health personnel). Because most of the previous studies on ageing and migration seem to be based on small convenience and ethnic-specific samples, we sought to include a larger group of respondents representing a variety of countries and backgrounds. The aim was not to compare ethnic groups but to identify and obtain an overview of diverse and unique variations and to identify potential common patterns cutting across these variations (Patton, 2002: 243–244). By including both older immigrants, relatives of people with dementia as well as different health-care providers, we aimed to examine variations and contradictions as well as the consistency of different data sources; and through this sampling strategy reach theme saturation.

Older immigrants

Initially, open questions related to perceptions and understandings regarding aetiology, and accepted and common treatment and care practices were addressed in FGDs. The participants were all seniors (over 50 years old) and recruited from

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immigrant organisations (organising social or religious activities for different groups of immigrants), religious communities and senior centres. They consisted of 34 women and 17 men (51 persons) between 50 and 80 years (without cognitive impairment). We continued to recruit participants until we were confident that we had reached theme saturation; in total nine FGDs were held. The FGDs were conducted either at the place of recruitment or at the Norwegian Centre for Migration and Minority Health (NAKMI). The participants originated from Pakistan, India, Afghanistan, Iran, Turkey, Algeria, Mexico, Chile, Poland and Bosnia: countries representing large immigrant groups (*e.g.* Poland and Pakistan) and immigrant groups that have been in Norway for a long time (*e.g.* Chile, Iran, Pakistan and Turkey). The final composition was the result of a mixed purposeful sampling aiming for maximum variation among a variety of ethnic groups and included opportunistic sampling techniques to achieve such variation (Patton, 2002: 243–244). FGDs were chosen as a starting point to enable access to topics and ways of communicating about dementia that we considered less accessible in one-to-one interviews (Malterud, 2012). Thus, the information gathered from these groups was also meant to inspire topics for further exploration in the interviews with relatives as well as health personnel.

Relatives of immigrants with dementia

Twelve relatives, between 25 and 78 years old, who had family members affected by dementia were recruited for IDIs with the assistance of health personnel at hospital diagnostic clinics, nursing homes, day-care centres or community-based home care. Additionally, within this group of respondents, we sought to obtain a sample with maximum variation in age, gender and country of origin. However, it was difficult to find relatives of people with dementia with a minority ethnic background; thus, the sample strategy became a mixed purposeful sampling including snowball and opportunistic sampling techniques (Patton, 2002: 230–245). The final sample of relatives consisted of ten women and two men. Six of the women and both men were children of the person living with dementia (aged 25–55), and the remaining four women were spouses (aged 65–78). The relatives originated from Afghanistan, Pakistan, China, Vietnam, Turkey, Lebanon, Sri Lanka and Chile.

Health personnel

To obtain knowledge on views and experiences among health personnel, we initially recruited 18 health personnel (mainly nurses and nursing assistants) from community-based home care and nursing homes in Oslo. These service providers, 15 women and three men, in the age range of 35–55, were represented in four FGDs, held at the participants' workplace, to allow participants to share opinions, compare experiences and find associations between health personnel in similar positions (Malterud, 2012). To obtain more nuanced information, we broadened our sample of health personnel and made a purposive selection of 27 health professionals, including 18 women and nine men in the age range of 38–62, originating from seven different countries in addition to Norway. These participants represented different parts of Oslo and six different counties in the northern, western and south-eastern parts of Norway. The sample represented occupational groups such as general practitioners (GPs), doctors, nurses, auxiliary nurses and leaders

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in nursing homes, and they participated in three FGDs, three DYIs and seven IDIs. The IDIs, including the DYIs, were conducted with the GPs, doctors and nurses in specialised care and one of the experienced dementia co-ordinators, *i.e.* those who could provide an in-depth account of situations where they engaged with older people and relatives during assessment of symptoms, diagnostics and follow-up. The FGDs were conducted with nurses (including representatives of dementia teams) and auxiliary nurses.

Ethics

The Health Research Act and the guide to the Act provided by the Norwegian Ministry of Health and Care Services define what falls within and outside the concept of 'medical and health research' in Norway. The Regional Committees for Medical and Health Research Ethics in Norway were approached and concluded that approval was not needed for this study. The study was approved by the Data Protection Official for Research at Oslo University Hospital and reported to the Norwegian Centre for Research Data. Informed written consent was obtained from all participants. Confidentiality was ensured by the removal of names and other identifying information from transcriptions and analyses.

The research team

The research team consisted of three researchers with different backgrounds. The first author (MS) is a registered nurse with a PhD in the field of global health. At the time of study, she was head of research at NAKMI. The second author (RSS) is a registered nurse with an MPhil in Health Economics, Policy and Management and is employed as a senior adviser at the former NAKMI, now Unit for Migration an Health at the Norwegian Institute of Public Health. The last author (RI) is a specialist in Clinical Geropsychology and a researcher at Norwegian Social Research (NOVA) at Oslo Metropolitan University. The authors have a specific interest in older people and in topics related to migration processes; thus, their academic positions may have influenced the analytical process. To avoid inherent biases, we took descriptive and analytical notes throughout the research process, and the coding process involved two of the co-writers reading the transcribed interviews several times to acquire an overall impression of the content and to negotiate the final themes. We believe that the different backgrounds of the researchers (researcher triangulation), combined with two researchers actively involved in all stages of the analytical process, represented a way of limiting biases and served as a source to validate the findings throughout the study.

Data production

The FGDs with the older immigrants lasted 90–120 minutes and took place at their respective organisations or at the researchers' workplace. Seven out of the nine FGDs consisted of participants speaking the same language, and in one of these, a research assistant that was fluent in the language moderated the group in the participants' mother tongue. The other groups consisted of participants who spoke

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good or adequate Norwegian. An assistant who spoke the mother tongue of the participants was present in these groups to help clarify when needed. Open questions related to perceptions and understandings regarding aetiology, possible treatment of dementia and different care practices were addressed using a semi-structured guide containing relatively few themes to allow time for in-depth discussions and new themes to be discovered.

Family care-givers had the choice to have the interview in their home, at the research centre or at the clinic/nursing home where their relative resided. These semi-structured IDIs lasted 60–150 minutes, and as not all the participants spoke fluent Norwegian, some of the relatives were offered an interpreter. Questions related to how the family had interpreted and managed the condition from initial symptoms until the present situation; whether, how and to what extent they had sought help and co-operated with existing services and health personnel; and views on best possible care and responsibility of care were addressed. Some of these findings will be published elsewhere.

The IDIs and DYIs with health personnel in specialised care lasted 60–120 minutes and were conducted in Norwegian at the participants' workplace. The semi-structured interview guide was to a certain extent adjusted to the profession/position held by each participant. The questions focused on the health personnels' interactions with older people and relatives with immigrant backgrounds, including questions related to encounters with explanatory models and behaviours representing different types of rationalities.

The FGDs with nurses and nurse assistants consisted of five to eight participants, lasted for approximately 120 minutes, and were conducted in Norwegian at the health workers' workplace. A semi-structured guide containing questions related to experiences in caring for people with dementia with immigrant backgrounds, co-ordination of relevant services and health-care workers' need for knowledge was used.

All the interviews and the focus groups were tape-recorded and transcribed verbatim.

Analysis and interpretation of text

To optimise the analytical process and to maintain a systematic approach to the material, the researchers wrote descriptive and reflective logs that informed and inspired the ongoing analytical discussions between the researchers (Kvale and Brinkmann, 2015: 341). Data from the initial FGDs with older immigrants from ten different countries were analysed and discussed before the interviews were conducted with relatives and health personnel, thus serving as an inspiration to identify themes and questions in consecutive interviews. The material was analysed and interpreted based on Kvale and Brinkmann's (2015: 242–244) descriptions of three different contexts of interpretation: (a) self-understanding, (b) critical common-sense understanding and (c) theoretical understanding. With the aim of reproducing the participants' own understanding, the interviews were transcribed verbatim after the interviews were conducted. The first step of analysis involved two of the co-writers reading the transcribed interviews several times in their entirety to acquire an overall impression of the content. This process involved

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searching the entire material for patterns and deviances and for similar and contrasting statements, both within and between the groups. Units of meaning, inspired by the objectives, the interview guide and discussions between the authors were identified by colour coding to structure participants' utterances in the texts. Based on the discussions related to which themes each unit of meaning represented, the researchers formulated, in a condensed form, what meaning the subjects themselves expressed through their statements (Kvale and Brinkmann, 2015: 242–243). The next step, which involved a critical common-sense understanding, went beyond reformulating the subjects' self-understanding and included a wider frame of interpretation. At this level, further attentive reading and discussions sought to uncover nuanced meanings related to the initial meaning units. By adding general knowledge about the content of the statement, we made it possible to amplify and enrich the interpretation of the participants' statements (Kvale and Brinkmann, 2015: 243). The meaning units were subsequently condensed by identifying patterns and variations, underpinned by illustrative excerpts and quotes from the material. Thus, the analysis moved from units of meaning to the generation of preliminary themes. This second context of interpretation is reflected in the presentation of two main themes and six sub-themes in the findings: (1) perceptions of cognitive impairment and dementia, including the sub-themes (a) memory problems and disorientation as part of normal ageing, (b) dementia as a preventable and/or transient condition, and (c) dementia/cognitive impairment as a sign of 'madness' or spiritual influence; (2) implications of culturally inspired perceptions and norms, including the sub-themes (a) avoiding exposure, (b) perceptions complicating treatment and care, and (c) the influence of 'culture' *versus* education. In the last phase, the different sub-themes were linked together and described through central themes reflecting the objectives of the study. This more comprehensive interpretation involved contextualising the critical common-sense understanding by using theoretical frameworks and previous research moving our analysis to a higher level of abstraction. This third context of interpretation is reflected in the Discussion (Kvale and Brinkmann, 2015: 244).

In the Findings section, quotes are presented with a code for each participant. We used the following abbreviations: FGDO, focus-group discussion with older immigrants; FDGH, focus-group discussion with health personnel; DYI, dyad interview; IDIR, in-depth interview with relatives; and IDIH, in-depth interview with health personnel. The participants were given a number, and for the FDGs and DYI, they were also given a letter for the person.

Findings

Perceptions of cognitive impairment and dementia

The findings show that there were some common patterns with regards to how dementia or age-related cognitive impairment were understood among the relatives and among the group of older adults (both groups described as 'lay participants' in the findings). Some of these patterns were also reflected in the interviews that sought to capture the experiences of health personnel. One of the perceptions was that cognitive impairment, such as memory loss and disorientation, is a natural

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part of ageing and thus not interpreted as a *disease* in the frame of a biomedical model. Another pattern of perceptions included viewing dementia as a potentially transient psychological or physical illness, which could include a belief in a (medical) cure. Some of the respondents explained dementia or symptoms of dementia as having a psycho-social origin associated with isolation, while some observed dementia as a condition in line with and with similar risk factors as other lifestyle diseases. The variety of perceptions has different implications regarding how different groups of respondents relate to the symptoms and the associated care needs. Since the data material is rather extensive, we have emphasised the presentation of quotes illustrating important and relevant themes in the material (both patterns and deviances); thus, not aiming to include an equal number of quotes with regards to all the participating groups. Every quotation is marked to inform from which group of participants the statement derives.

Memory problems and disorientation as part of normal ageing

Memory problems and slight disorientation, being the symptoms most commonly associated with dementia, were by a majority of the lay participants (both older immigrants and relatives) talked about as a condition they associated with 'old age' or 'very old age'. Thus, symptoms of cognitive impairment among older persons were among many seen as natural and not something that would inspire a visit to the doctor. Some described their family member as 'moving into childhood again', often associated with a weak perception of time and a decreased capability of taking care of themselves. Some would say 'they just move around', 'they forget things', 'they do strange things', 'they keep talking about the past'; descriptions that were expressed in a way that generalised and normalised a variety of mental or behavioural disturbances. One of the GPs being interviewed, having an immigrant background himself (South-East Asia), emphasised that in his experience, there are cultural differences related to how, when and whether people categorise symptoms of cognitive impairment as a disease. Many of his patients with a background from countries in Asia tended to consider memory loss to be within the frame of a 'normal' reduction of memory getting older, even those with rather pronounced memory loss:

> …in for example the culture I am from, [people believe] it is inevitable that when you become older you start to forget things, so it is not necessary to talk to any doctor about such symptoms … you are just old and can't remember anymore … But it is not common to have such type of [pronounced] memory losses when you are only around 70 years old. (DYI1b)

Among the different groups of lay participants, advanced symptoms of dementia, such as personality changes or loss of language, often marked the difference between 'normal ageing' and the development of an illness. However, respecting older people, including allowing people to become old in their own way, without drawing much attention to it, was often agreed upon as a value. Nevertheless, many tended to agree that if the person verbally or non-verbally became 'noisy' or aggressive, help from public services could be considered. A man in a group consisting of men from Asia concluded:

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> Due to respect, we say that if he [the person with dementia] will not listen to you, just leave it, it does not matter that much. So … we do not pay that much attention … [to behaviours of concern]. But if the person for example starts to become aggressive, then we must go and locate [public] help. (FGDO2d)

As indicated above, many of the lay participants differentiated between memory problems and slight personality changes and major changes in behaviour involving aggression and acting out.

Dementia as a preventable and/or transient condition

Some of the participants among the relatives, as well as in the groups of older immigrants, understood cognitive impairment/dementia as a potentially preventable lifestyle illness, which could include a belief in a medical cure (partly) based on the biomedical paradigm. For example, some of the participants in one of the FGDs with older men from Asia engaged in a discussion where dementia was portrayed as a condition in line with other preventable lifestyle diseases. One of the men underlined the importance of avoiding risk factors, which he, as well as others in the group, believed could potentially prevent dementia:

> Maybe it is not that good with all that fat and all that sugar … exercise is important. Personally, I am more than 70 years old and do not have any of these [age-related] illnesses. So I hope I will continue like this, because I walk an hour every day. (FGDO2e)

Participants in some of the FGDs with older immigrants pointed to the importance of social contact to prevent or delay the onset of dementia, as well as the development of advanced symptoms. In a group of male and female participants from Eastern Europe, a man expressed it like this: 'Dementia for a single male immigrant … that is a disaster!' (FGDO8a), referring to a notion that symptoms would progress much faster being alone. Similarly, another member in the group refers to social isolation as a risk factor for the development of dementia: 'I think that memory deteriorates if one doesn't share a community with others' (FGDO8c). Based on this view, group members advocated networking and meeting places for older immigrants to delay or prevent what they considered unnecessary mental deterioration and development of dementia.

In an in-depth interview with the daughter of a father with advanced symptoms of dementia, she told how the whole family was worn out and that she was aware of the prognosis. After a long process of explaining and negotiating with her mother, the mother agreed to apply for a nursing home. However, the mother only wanted to try it out for a period to see whether it could ease his condition: 'My mother thinks that maybe after half a year, dad will be well and come home from the nursing home, that's her plan' (IDIR10).

Some of the health personnel also talked about experiences interacting with relatives conceptualising age-related cognitive impairment as a condition potentially being transient. One of the GPs refers to some of his experiences with relatives: 'The problem is that they have no [biomedical] knowledge of the disease. So, for example, they think that you can become healthy again, recover from dementia' (DYI3a)

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An interesting finding within this perspective is that 'lay knowledge' tended to be portrayed as either within or outside the biomedical model among health personnel; no one seemed to reflect on the often-rational overlap between explanatory models.

Dementia/cognitive impairment as a sign of 'madness' or spiritual influence

Some symptoms, in particular those corresponding with pronounced behavioural problems, were referred to by many lay respondents in the FGDs as a sign of 'madness'. A respondent in a group of women from Pakistan explained:

> Some will make fun of such persons [persons with dementia], for people that do not understand the situation, they seem to be somewhat mad. (FGDO5f)

Sometimes behaviour of concern was linked to evil spirits or some type of possession. For example, a daughter (IDIR3), who had immigrated to Norway with her family from an Asian country many years ago, recounted that when her mother developed symptoms of dementia, it was natural for her to seek help through the formal care system. The daughter had no faith in magic implements but found dolls and magic objects at her mother's home provided by members of her parents' social network. The daughter also received allusions about the need to exorcise a devil. The example shows that different perceptions of dementia and means for 'cure' can exist in parallel, thus implying complex challenges for relatives.

Several lay respondents (both older people and care-givers) referred to karma, destiny and God as representing somewhat basic and thus unalterable causes of the existing symptoms. In an FGD with female participants from the Middle East and Africa, one participant claimed that dementia was related to the last stage before death, saying 'he is on his way to another world, being close to death' (FGDO1b), which inspired a discussion that referred to dementia as a somehow mystical condition before death. Those who understood dementia in this way described it as a condition that could make people avoid the person with dementia, or it could lead to extra veneration for the older person. The veneration related to the belief that the person with dementia had the capacity to see and communicate with others being dead, thus representing a connecting link with the dead. One FGD member expressed it as follows: 'We think that when the body is weak [in a terminal phase], they [the dead ones] come from the other side and follow them [with dementia] through death' (FGDO1b). Thus, when a person with dementia was in what was considered a liminal state, relatives and acquaintances could come to ask the person with dementia to bring greetings to their dead family members.

Among lay respondents, both in the FGDs with older immigrants and among the relatives, there was a tendency for younger adults with dementia to be perceived differently than older people. The condition could be highly stigmatised in this age group, as described by one respondent:

> …dementia among younger is a taboo in the third world, but not so much for people over 60. Then, they are old … and dementia is considered a natural phenomenon when ageing. (FGDO3a)

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In an FGD with male respondents from Asia, a man concluded that many immigrants considered dementia natural, but the explanation was different for relatively young persons:

> It may be seen as a punishment for bad behaviour. They don't think that there are medical reasons … they begin to think about what the person has done in earlier lives. (FGDO3b)

Being young implies a lack of a natural explanation, thus making the condition more difficult to comprehend and easier to think of as madness or a sort of punishment. A relative with a background from another Asian country said that some of the older persons from her community hold views reflecting strong taboos about dementia:

> When it is 'mental', it is a taboo, hush, hush … I talked with a person who thought about it [dementia] almost as exorcism – that bad spirits had taken up residence in the body. (IDIR3)

Health personnel also confirmed that they encountered a variety of causal explanations. A GP with extensive experience with older immigrants explained that he experienced many different views related to symptoms and causal explanations of dementia:

> It can be different views … it can have religious overtones, seeing it [symptoms] as a punishment from God, or being the destiny. (IDIH6)

However, as mentioned both by lay respondents and health personnel, within each family there could exist a variety of explanations, *e.g.* depending on the age and education level of that person, as well as to what degree explanatory models were influenced by religion. Both older adults in the FGDs and relatives of people with dementia stressed the importance of information to families of persons with dementia, including not only information to help families understand the illness and related behaviour but also advice about how to take care of the person with dementia and where to find help. In an FGD with immigrants from Eastern Europe, some participants suggested systematic health controls (screening) to identify people with dementia representing minority ethnic groups, while others emphasised a general need for information: 'It is a need of informing families about the possibilities to access knowledge [about dementia], and to participate in seminars and groups]for relatives]' (FGO8b).

Implications of culturally inspired perceptions and norms

Avoiding exposure

Among those who recognised dementia as a medical condition and where some would (partly) ascribe the symptoms to a biomedical explanatory model, dementia could still be a condition difficult to talk about. Several described the general stigma associated with dementia or other mental conditions and how the whole family

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could be viewed negatively if a family member had dementia. One of the men in a male FGD from Asia elaborates:

> If it is known that this family has a person that have such a disease … then it becomes worrisome, if you are to get your children married … if you are to establish contact in regards to marriage, then it becomes difficult. (FGDO2a)

Thus, if people tended to explain dementia by using stigmatised explanatory models, avoiding exposing the diagnosis could be a strategy. Further, the symptoms in itself could cause relatives to try to prevent exposure of the person with dementia. In a FGD with women from Asia, the participants recounted how the families would try to keep people with dementia away from others because the symptoms, such as loss of behavioural control, would cause embarrassment and shame. In one group of women with a background from Pakistan, one member summarises the situation as follows:

> The view is a bit negative … you feel ashamed if you have a relative with that diagnosis … you will not take him out of the house for example, and if you get visits yourself, it is normal that you will keep him in a separate room until the others [the guests] have left. You feel embarrassed … because these people can say anything, laugh and cry in a way that is embarrassing. You do not know whether he will say or do something wrong, so it is better to keep him locked away. (FGDO5f)

Thus, wanting to avoid embarrassing situations or wanting to protect the family's good name and 'value' may inhibit the perceived possibility of being open about a family member with dementia. Another reason that was mentioned for not talking about dementia was that it would contradict social norms, meaning that revealing such a diagnosis outside the family would be considered disloyal towards the family member with dementia.

Perceptions complicating treatment and care

How family members understand and manage dementia may also have implications for the interaction between health personnel and relatives during a diagnostic process. A nurse in home-based services underlined the importance of exploring people's frames of reference in regards to dementia, since a diagnosis may be viewed as a provocation if it is associated with an explanatory model carrying stigma:

> If a diagnosis is associated with God's punishment, the children might protest … dad has been kind! (FGDH5c)

In general, lay participants, in particular from Asia and Latin America, emphasised a strong norm implying that you are to help your family members without complaining or even verbalising it as a problem, independent of the type of symptoms and potential causes. This expectation would often imply not seeking support beyond the extended family. Health personnel underlined that providing help could become complicated due to the combination of shame and the strong cultural

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norm implying that the relatives are the ones who are to provide help. A nurse from home-based services elaborates:

> …in particular that generation [older immigrants], there is a lot of shame around this, and you are meant to manage by yourself … Therefore, you may end up providing [public] help very late, and the whole situation can be extremely difficult. (FDGH6d)

Several of the nurses in home-based services mentioned that in general it could be difficult to evaluate the physical and cognitive condition of some of the older adults with immigrant backgrounds. This difficulty was because many did not speak Norwegian (or had lost their second language) and/or because the relatives would not communicate problems but rather seek to compensate for the person's loss of functions. A nurse elaborates:

> It is often difficult for the relatives to open up, talking about the problems that the older person has. And they assist a lot, so it can be difficult to understand what the older persons actually manage themselves. (FDGH6c)

A GP underlined that in his experience, different causal explanations could cause different responses but that many of the responses would exclude the use of any form of medical treatment:

> Either it [the response] can be a form of trivialising the symptoms in a way, or they relate it to God's will … and then it is not meant for us to do anything about it. They do not want us [doctors] to be active because the outcome will become as God wants. (IDIH6)

This, as well as other examples, shows that due to religion or socio-cultural norms about family care, independent of how dementia is understood, relatives may take on increasing amounts of care-giving work without articulating the caring as a problem or contacting health-care services. Further, if the symptoms are considered to be related to, for example, spiritual causes, there is no use approaching the biomedical health-care system, being unable to address the actual cause.

On the other end of the spectrum, there were examples provided by doctors, nurses and family care-givers of unrealistic expectations of cure among relatives of older adults who received a diagnosis. A doctor working in a nursing home tells about his experiences:

> Some relatives have totally unrealistic perceptions of the development of dementia … Some tend to believe that everything can be treated and shall be treated, independent of whether it is a severe dementia … In other such severe cases you would normally renounce investigation and treatment, but among some of the immigrants … for them that is totally incomprehensible. (DYI3b)

Some of the nurses told of similar expectations associated with older people coming for short- as well as long-term stays at nursing homes, with relatives viewing this

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type of institution as somewhere one could possibly be cured of dementia. A nurse in one of the FGDs refers to her experiences:

> They have quite high expectations … many relatives seem to think that we can do a miracle. That they become … when they come here [nursing home] … they become well. They don't accept dementia as something that is not treatable. (FGDH3e)

As the quote illustrates, becoming a resident in a nursing home, potentially combined with medication to modify symptoms of dementia, can produce expectations of cure.

Additionally, among the GPs, there were examples of unrealistic expectations of cure among patients and relatives, as such expectations could be difficult to modify. A GP elaborates:

> I try to orient them about what kind of disease this is, and the prospects and prognosis and things like that. That it is nothing that can be cured … they think that they can get treatment here [GP's office], and then they will become well. (DYIH2a)

The quotes above illustrate that depending on the perceived causal explanation, people may view the symptoms as curable. On the other hand, if the symptoms are related to karma or some sort of punishment from God, the relatives might not want the health-care system to interfere in any way.

The influence of 'culture' versus education

Some of the more experienced health personnel (specialists working in diagnostic clinics or GPs working in areas with many immigrant patients) emphasised that even though some of the older people with immigrant backgrounds related symptoms of dementia to 'exotic causes' such as the 'evil eye' or karma, it did not necessarily mean that ethnic Norwegians (lay people) had more (biomedical) knowledge of dementia. A GP refers to a course with relatives of people with dementia:

> In general, I don't think Norwegians know so much more about it [the pathology of dementia] … but we may experience it as if these other explanations are more based on superstition. (IDIH2)

Similarly, another experienced doctor, working with diagnostics of dementia in a hospital clinic, emphasised that based on his experience, the differences in understanding of dementia seldom related much to culture but rather to level of education:

> I have been working a long time now, with people from different cultures. I do not know … I think they are pretty similar to us (laughs). I cannot justify saying that there are crucial, basic differences … It has a lot to do with the level of education. You see, people with low education here in Norway [ethnic Norwegians] also have a very diffuse understanding of dementia … how the brain works and what

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> dementia really is … Education dominates everything … culture is not that important [for how dementia is perceived]. (IDIH4)

Another experienced GP and nursing home doctor supported this view by underlining that 'people coming from a village in Pakistan cannot be compared with people representing the intellectual elite in Iran' (IDIH6), and thus, according to his experience, there were major differences in the types and level of understanding.

There were also examples of people changing their perceptions of dementia, and thus, related (health-seeking) behaviour could change based on new knowledge or reflections around experiences with handling of the condition. In an FGD with Asian women, one woman encouraged a discussion about such changes by talking about a friend from the same country with dementia and how the family used to avoid telling about his condition. After some time, however, this attitude changed: 'now, when someone visits, they tell about their father, so that the visitors do not react negatively if he says something strange to them' (FGDO3c).

As in other similar narratives, such changes suggest that even though people might carry explanatory models or values that inspire a certain type of health-seeking behaviour, experiences based on encounters with family, friends or health personnel might reshape perceptions and thus relationships, values and norms.

Discussion

Cognitive impairment and old age

This study shows cross-cultural similarities as well as variability in conceptions and management of dementia, knowledge that may help adjust and improve treatment and care within relevant health services. In line with other studies (Morhardt *et al.*, 2010; Botsford *et al.*, 2011; Mukadam *et al.*, 2011*b*; Johl *et al.*, 2014; Uppal and Bonas, 2014), our study shows that age-related cognitive impairment, such as memory loss and slight disorientation, is often explained without referring to a condition that needs to be diagnosed and treated. An interesting finding across studies on this topic is that while explanatory models containing stigmatising associations (*e.g.* punishment from God) seem more prevalent among minority ethnic groups (in studies from the Western world) than in the majority, the view that dementia is part of normal ageing seems to be prevalent across *all* ethnic groups (Botsford *et al.*, 2011). Viewing dementia as part of normal ageing may imply that the symptoms are not considered an illness; thus, the symptoms do not inspire help seeking within the frames of the professional part of the health-care system (Kleinman, 1980). As illustrated in our study, the symptoms have, however, to correspond with the image of being 'old'; otherwise, the signs of dementia are likely to be interpreted as an illness inspiring other types of explanatory models. Our study also shows that different understandings of dementia link to the severity of symptoms or different stages of the condition. There was, for example, a tendency that people would interpret forgetfulness and slight disorientation as a normal part of ageing, while personality changes, including aggression and acting-out, would change the interpretation of the condition. This finding is in line with other studies from Norway and elsewhere (Mukadam *et al.*, 2011*a*, 2011*b*; Mazaheri *et al.*, 2014;

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Næss and Moen, 2015). For example, in a study among Pakistani immigrants in Norway, cognitive decline was often seen as a side-effect of old age, as long as the cognitive changes could be normatively linked to the ageing body and mind. However, when the behaviour became overly confused, violent and unmanageable, a distinction between normal and abnormal tended to be made (Næss and Moen, 2015). Similarly, in a cross-cultural comparison of African Americans, Chinese and Latino family care-givers' perceptions of dementia, there were striking similarities of thought with regard to the normality of cognitive symptoms until the symptoms were so serious that control seemed lost (Mahoney *et al.*, 2005). Among African Americans, initial symptoms such as memory loss or disorientation were described as *old timer's disease*, whereas Latinos described symptoms of cognitive impairment with the term *el loco* (craziness) and the Chinese with the term *hu tu*, meaning becoming forgetful in old age (Mahoney *et al.*, 2005). As symptoms of dementia progressed and families lost control over the situation, cultural differences emerged. Normalisation of symptoms appeared to be most prolonged among African Americans; stigmatisation of the condition, implying a search for help outside their community, was most pronounced among the Chinese, while preserving family care and worries about the 'American way' of institutionalising the older person were most pronounced among Latinos (Mahoney *et al.*, 2005). Such dynamic understandings are in accordance with the idea that people may adhere to different explanatory models as symptoms change or develop over time and where the symptoms correspond or do not correspond to certain inherent categories (*e.g.* age, gender, severity of symptoms) (Robinson, 1990; Good, 1994).

Conceptualisations and management of dementia

Our study illustrates conceptualisations of dementia that draw on explanatory models based on social, psychological, spiritual as well as physical factors. Similar to our findings, broader psycho-social causes such as social isolation and loneliness, but also 'lack of care', including poor diet and physical deterioration, have been cited as lay conceptions of dementia across minority ethnic groups in review studies (Mukadam *et al.*, 2011*b*; Uppal and Bonas, 2014). A qualitative study among Iranian immigrants in Sweden found that having a 'hard life' or having experienced traumatic events could be seen as causes for the condition (Mazaheri *et al.*, 2014). Further, some related the condition to low education or intelligence quotient (IQ), a cause that could be used as a way of distancing from the condition (Mazaheri *et al.*, 2014). In line with the findings in our study, spiritual causes such as Gods will, karma or supernatural curses/punishment, psychological causes such as 'craziness' (Morhardt *et al.*, 2010; Mukadam *et al.*, 2011*b*; Regan *et al.*, 2013; Johl *et al.*, 2014; Mazaheri *et al.*, 2014) and underlying physical illnesses such as diabetes or heart diseases are cited as lay conceptions among minority ethnic groups in other studies (Mukadam *et al.*, 2011*b*; Regan *et al.*, 2013; Uppal and Bonas, 2014). Explanatory models containing psycho-social or spiritual explanations have in many different countries and contexts found people to present late or in crisis to dementia services, or not at all (Botsford *et al.* 2011; Jutlla, 2013; Uppal and Bonas, 2014). In our study, spiritual explanations tended to have negative and fatalistic connotations, potentially preventing families from approaching public services. However, we

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also found examples of people who see symptoms of dementia as a sign of an extraordinary capacity and thus not in need of 'treatment' or care outside the family. A similar interpretation was found in an American Indian tribe, where general symptoms of dementia were interpreted as a normal part of ageing but where hallucinatory symptoms were positively viewed as 'supernormal' in the sense that the condition facilitated communication with the supernatural world (Henderson and Henderson, 2002). Thus, the tendency of presenting late or in crisis to dementia services may be related to the shame and guilt associated with the causal explanations, but also to the fact that the professional part of the health-care system cannot or should not address the underlying causes (Botsford *et al.*, 2011; Jutlla, 2013; Uppal and Bonas, 2014). In line with the findings in our study, a review article on ethnicity and pathways to care in dementia concludes that viewing dementia as a family concern may partly relate to the perceived cause, such as lack of social stimulation, lack of care or family problems, and partly relate to what can be described through the concepts of *familism* or *filial piety* (Mukadam *et al.*, 2011*b*). These concepts refer to a strong identification and solidarity with family members (nuclear and extended) and respect for parents and for older persons, and involve strong normative feelings of attachment, responsibility and reciprocity (MacKenzie, 2006). In our study, these potentially reinforcing factors were exemplified through the belief that the symptoms of dementia can be prevented or slowed down through social stimulation, and the strong norm implying that you are to help your family members independent of potential causes.

Studies among minority ethnic groups in Scandinavia show a strong sense of familial responsibility and a tendency to view problems related to dementia as a personal or family concern (Antelius and Kiwi, 2015; Næss and Moen, 2015; Antelius and Plejert, 2016). For example, in a study among Iranian immigrant caregivers in Sweden, the authors underline that filial piety, as well as the perception of dementia being caused by lack of social interaction, created ambiguity towards the use of formal care (Antelius and Kiwi, 2015). Thus, as suggested by the authors, avoiding nursing homes may not only be a result of trying to avoid shame associated with not fulfilling standards of filial piety; rather, it can be a rational and conscious choice to keep the family members socially active at home, and thus retain health (Antelius and Kiwi, 2015). Similarly, studies show that those who conceptualise symptoms of dementia as caused by potentially transient or modifiable physical illnesses, such as diabetes, will often seek help for what they consider to be underlying causes and not for the cognitive impairment *per se* (Mukadam *et al.*, 2011*b*; Uppal and Bonas, 2014). In our study, this materialised in a rather unexpected finding: some relatives expressed high expectations of cure after engaging the professional part of the health-care system.

However, linking dementia to underlying physical diseases may also be due to stigmatising associations. For example, in a study among key service providers and families living with dementia in a South Asian community in Scotland, family members described a link between dementia and other medical conditions, such as diabetes and glaucoma. Associating dementia with other medical conditions seemed to make the condition easier to accept, less stigmatising and facilitated a focus away from 'supernatural explanations' (Bowes and Wilkinson, 2003). In a Norwegian study among Pakistani immigrants, the biomedical perspective was

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found to be difficult to adopt because, among other reasons, it implied turning something considered 'normal' into the category 'disease' – which called for other and more stigmatised explanatory models (Næss and Moen, 2015). Thus, it seems important to bear in mind that established aetiologies often work to protect against stigma; thus, people may revert to folk models or combine folk models and biomedical models in an attempt to explain cognitive decline in the least stigmatising way (Hinton *et al.*, 2005; Næss and Moen, 2015). In other words, cultural constructions of illnesses should be understood as multi-dimensional and continuous, including 'selective constructions' in adherence to potentially changing individual, social or cultural needs (Henderson and Henderson, 2002).

Interplay between ethnicity, culture and socio-economic factors

Our study shows that it is not easy to categorise either groups or explanations as corresponding to specific explanatory models. Rather, the findings show that what we tend to believe as coherent causal explanations may overlap; they may change over time as symptoms develop or gradually change as a response to new transnational ideas, practices and opportunities (Schiller *et al.*, 1995). Such change is exemplified in the Norwegian study on dementia among Pakistani immigrants, where the core of the traditional Norwegian-Pakistani identity claims had a strong influence on how symptoms of cognitive decline were interpreted and responded to. The findings show how the families 'negotiate dementia' in the space between their own imported, culturally defined system of treatment and care, and the Norwegian health-care culture. Although the use of institutions was not considered a culturally and morally coherent care alternative, the negotiation was characterised by an inclination to define 'normal ageing' as a 'disease' when the symptoms grew out of control (Næss and Moen, 2015). This is similar to examples of negotiated practices found in our study and indicates that people with immigrant background can redefine both symptoms and care needs in response to the case history and the prevailing explanatory models in the host community.

Another important dimension, which might explain the variety of conceptions of dementia, is exemplified in a quantitative study of 92 family care-givers from four different ethnic groups, representing African-American, Anglo-European American, Asian-American and Latino. The authors identified three different explanatory models: a biomedical-inspired model in which symptoms were attributed to underlying pathological brain processes, an explanatory model in which symptoms were attributed to psycho-social stress or a normal effect of ageing, and a mixed model in which dementia was explained by biomedical labels as well as psycho-social explanations (Hinton *et al.*, 2005). Both minority and non-minority care-givers incorporated elements that drew upon explanations not corresponding with the biomedical model, but it was more common among minority care-givers and among those with less formal education (Hinton *et al.*, 2005). In our study, some of the more experienced doctors described it as common among ethnic Norwegians, in particular among those not highly educated, to hold low levels of knowledge of the pathophysiology behind dementia, thus leaning towards other types of conceptualisations. These clinicians emphasised that in their view, education, and not ethnicity or culture, was the factor that influenced the

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interpretation of symptoms to the greatest extent. We argue that the concepts of culture seem relevant in an attempt to explore different understandings of dementia, as individuals may share certain cultural reference points (Botsford *et al.*, 2011). However, people's understanding and response to dementia will likely vary between and within groups because of the interplay of multiple factors, such as age, social class and level of education (Botsford *et al.*, 2011; Mukadam *et al.*, 2011*b*). In other words, it seems important to bear in mind that education may be an equal or even more influential factor than culturally based perceptions, and that beliefs that do not (fully) correspond with biomedicine are prevalent also among majority populations (Botsford *et al.*, 2011). For example, in a quantitative study on knowledge and perceptions of dementia in four ethnic groups in Denmark, higher education and degree of Danish acculturation contributed significantly to 'basic knowledge' of dementia (Nielsen and Waldemar, 2016). Similarly, in a quantitative study investigating dementia awareness among 675 elderly Korean-American people, individuals with higher levels of education and acculturation had greater knowledge of dementia and were less likely to normalise the symptoms (Jang *et al.*, 2010). Additionally, immigrants are involved in transnational practices because they are located within transnational social fields (Schiller *et al.*, 1995); thus, explanatory models may become modified or changed as a response to the meeting with the 'clinical reality' (Kleinman, 1980) in the host country. For instance, expectations of cure after 'treatment' in a nursing home may indicate a belief in a transient or modifiable physical or mental illness, but it can potentially also be the result of high expectations of what an advanced health-care system may actually cure.

Another important point is that what may have been portrayed as lay conceptions of dementia in earlier research may correspond well with how dementia is constructed in the professional part of the health-care system today. Updated research shows that lifestyle factors such as hypertension and obesity at mid-life are risk factors for the development of dementia, while smoking, depression, physical inactivity, social isolation and diabetes are potentially modifiable risk factors in later life (Livingston *et al.*, 2017). Some of these factors not only correspond well to 'lay conceptions' of understanding (even though one may not know the pathological changes in the brain) but also correspond to ideas behind family models of care, such as addressing cognitive changes through impeding or minimising social isolation and depression. Thus, the 'clinical reality' is dynamic and constantly changing. However, this movement does not seem to be recognised in this or in other studies, as 'lay conceptions' tend to be categorised outside the biomedical understanding without reflecting on the often rational overlap between explanatory models.

Strength and limitations

By triangulating sources (different health-care providers, relatives of people with dementia, older immigrants), health-care settings (*e.g.* GP centres, nursing homes, day-care centres, home-based services, geriatric and psychiatric polyclinics, and hospital-based memory clinics), methods (FGDs and IDIs) and analysts (two researchers reading and analysing all the transcripts), we examined variations and

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contradictions as well as the consistency of different data sources. Theme saturation was reached due to the extensive triangulation in the study, as reoccurring themes were discussed and validated with different participants throughout the study. The number of included participants is rather high to be a qualitative study, and one of the limitations may be that we have not managed to provide 'thick descriptions' of all the different perspectives presented.

Conclusion

The findings show a spectrum of beliefs and interpretations that derives from explanatory models carrying many stigma to explanatory models that portray dementia as a condition with reversible symptoms which is possible to cure within the professional part of the health-care system. Health-seeking behaviours are correspondingly different: from denial, hiding or compensating for symptoms within the family, to a proactive claim for (bio) medical treatment. Thus, lay conceptions of dementia are undoubtedly influenced through the cultural perspective in which the symptoms are viewed. However, migration processes, contextual factors such as (changing) values and norms, education, health literacy and income, time and interaction with the clinical reality in the host country will influence how people interpret symptoms, how they conceptualise and describe them, and when, where and whether they choose to seek help. Furthermore, the progressive and constantly changing symptoms that construct the condition over time will influence how people relate to the person living with dementia.

As in all other person-centred care, one needs to explore how people relate to their illness, the rationale for why people think and behave in a certain way in different phases of the illness trajectory, and, thus, how different and potentially changing explanatory models may influence patterns of care. By investigating how all people with dementia and their families understand and manage the condition, one may facilitate access to relevant and adapted information. Furthermore, by exploring how people relate to their illness, health personnel may challenge explanatory models that create unrealistic expectations of cure, as well as models that, due to stigma or normalisation of symptoms, prevent the use of public care when needed.

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Ethical standards. The Health Research Act (2008) and the guide to the Act provided by the Ministry of Health and Care Services (English translation) define what falls within and outside the concept of 'medical and health research' in Norway. Approval for this study was not needed from the Regional Committees for Medical and Health Research Ethics in Norway. The study was approved by the Data Protection Official for Research at Oslo University hospital and reported to the Norwegian Centre for Research Data (NSD). Informed written consent was obtained from all participants. Confidentiality was ensured by the removal of names and other identifying information from transcriptions and analyses. Participants were informed that they could withdraw from participation at any time, for any reason, without negative consequences.

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