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Dementia and migration: Family care patterns merging with public care services

Introduction

During the second half of the last century, the global population of people aged 60 years or over almost tripled from 205 million to 606 million, and the average global human life expectancy increased by 20 years from 46 years in 1950 to 66 years by 2000 (Rechel et al., 2011). The steady increase in migration to Europe means that Europe's populations are increasingly diverse linguistically, ethnically and culturally. People who migrated to Europe, both those who came in the 1960s and 1970s, and those who joined family members later in life, are now older adults and are facing challenges of old age, both physically and mentally. This may demand adaptive and innovative thinking with regard to care for the older population, in particular if policy is to be based on an understanding of the life situations, family structures and socio-economic situations of those belonging to minority and immigrant populations (Krilic, 2013).

This study focuses on ageing among the immigrant population in Norway, and specifically on the views and practices in regards to responsibilities and forms of care when people suffer from dementia or cognitive impairment. Dementia is a serious global public health challenge according to the Global Alzheimer's and Dementia Action Alliance (GADAA) (GADAA, 2016). Norwegian health authorities estimate that approximately 80,000 people are living with dementia in Norway, a country with 5.2 million inhabitants, and that around 10,000 persons get the disease each 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 could double by 2040–2050 (Norwegian Institute of Public Health, 2014). In 2016, immigrants and their children born in Norway made up 16 per cent of the total population. The immigrant population is on average much younger than the general population. Half of the immigrants in Norway are between 20 and 40 years old and only nine per cent are above the age of 60 (Statistics Norway [SSB], 2016). However, according to SSB, the number of older immigrants (aged over 67 years old) will increase tenfold from around 30,000 to 300,000 in 2050 (SSB, 2013). Knowledge on dementia and immigrant groups in Norway is lacking in most areas, partly because it has not been possible to link registers that connect medical diagnoses and ethnic backgrounds until recently. Additionally, even though aging in an unfamiliar landscape potentially poses different challenges, migration and ethnicity have not been a priority for dementia research in Norway. However, a recent study (Diaz, Kumar & Engedal, 2015) showed that significantly lower proportions of patients with immigrant backgrounds were diagnosed with dementia by their general practitioner (GP) compared with ethnic Norwegians. The causes for this difference are unclear, and the authors pointed to factors such as genetic differences (*i.e.* being less disposed to dementia) or language and communication barriers that might reduce availability to diagnosis and relevant care as possible explanations. In their research briefing, Moriarty, Sharif and Robinson (2011) pointed to the possibility that black and minority ethnic populations do not use relevant services because of experiences with health personnel lacking competence to cope with differences in language and culture. Experiences of social isolation when receiving services with little ethnic diversity among service users and staff, and few attempts to provide culturally sensitive care, can lead to certain groups refusing services such as nursing homes (Moriarty et al., 2011). Another factor can be stereotypical views about the role and extent of family support among black and minority ethnic people with dementia.

Some immigrant groups originate from societies with kinship, family structures and cultural norms that differ from those of the majority population, and these will bias expectations about ageing and care for older family members (McClearly & Blain, 2013). However, research shows that family structure and relations are diverse both within and between immigrant and ethnic minority groups as well as in majority populations (Ajrouch, 2005). Immigration history, political/economic conditions in the host country and individual life histories are all factors that influence whether immigrants face old age and illness living alone, with a spouse, or live in multigenerational households where they may be looked after by other family members (Burholt, 2004). Further, socio-economic and cultural heterogeneity among immigrant groups imply a diversity of experiences in terms of how services are perceived and used and how potential inequalities are experienced. Differences in language skills, education levels and cultural proximity make some members of a group better equipped to negotiate access to relevant services (Zubair & Norris, 2015).

Changing demographics are another factor influencing families and their ability to provide care. The shift from a high-mortality and -fertility society to a low-mortality and -fertility society causes an increase in the number of living generations and a decrease in the number of relatives that can live together with their extended family (Harper & Levin, 2005).

Structural influences, such as immigrant families being divided in the migration process, can make it difficult to provide 'traditional' care for the extended family. However, such changes do not necessarily mean that the role of the family in supporting the older family members is less important. On the contrary, some longitudinal studies suggest that the role of the family is more important than ever, but that there have emerged many new roles as well as competing demands attached to the roles for different family members in different settings (Harper & Levin, 2005).

While there is increasing research on the health of immigrant populations in Norway

(Attanapola, 2013), issues surrounding ageing and care for older immigrants have received less attention. A few studies (Næss & Moen, 2015; Thyli, Hedelin & Athlin, 2007, Thyli, Hedelin & Athlin, 2014) and reports (Disch & Fauske, 2011; Ingebretsen, 2011, Ingebretsen, 2010; Ingebretsen & Nergård, 2007; Ingebretsen & Romøren, 2005) have provided insight into the care needs of older immigrants in Norway, and the availability of care services for them. These reports and studies document considerable diversity in the life and living situations of older immigrants, which is explained by socio-cultural diversity, but also in terms of differences in linguistic abilities. What seems to be a general characteristic in the Nordic countries is that relatively few older members from ethnic minority groups seem to live in care facilities, such as nursing homes (Plejert, Jansson & Yazdanpanah, 2014). We have identified only one study on cognitive impairment/dementia among immigrant groups in Norway (Næss & Moen, 2015). This study explored how Norwegian-Pakistanis cope with dementia and relate to the Norwegian healthcare system, and found that values associated with a 'traditional family' have a significant influence on how this group manages the disease. In particular, nursing homes are discouraged in terms of being an alternative to family care. However, the findings show that people might be willing to use different types of public care in cases with severe dementia and dependency (Næss & Moen, 2015). Using a transnational approach to analyse patterns of care requires that one needs to let go of the conviction that social life takes place naturally within the nation-state. Immigrants are involved in transnational practices because they are located within transnational social fields (Schiller, Basch & Blanc, 1995). Even though it might be common to consider care alternatives through the lens of cultural or religious norms, a gradual convergence between more traditional patterns and care patterns representing major groups in the host country is likely.

Aim and Methods

This study is part of a comprehensive study on older immigrants and dementia in Norway, where the overall goal is to assist the Norwegian Directorate of Health design appropriate strategies for care of older immigrants with dementia. Target groups for this project are immigrants over the age of 50, next of kin for immigrants with dementia (family caregivers), health personnel and care workers, and decision and policy makers.

One of the objectives addressed within the larger frame of the study, was to explore perceptions and experiences of the phenomenon of cognitive impairment/dementia among different groups of older adults with immigrant background. Questions related to perceptions regarding aetiology and perceptions and experiences regarding accepted and common treatment and care practises were initially addressed in nine Focus Groups Discussions (FDGs) with healthy older immigrants from 10 different countries. The groups consisted of 34 women and 17 men between 50-80 years, from Pakistan, India, Afghanistan, Iran, Turkey, Algeria, Mexico, Chile, Poland and Bosnia (51 persons). These questions, particularly those referring to the understanding of the disease, will be published in another article. The knowledge provided through these FDGs has helped understand and contextualize the findings from the rest of the data, and have served as an inspiration for the development of new questions and interview guides for the subsequent parts of the study.

The objective of this paper is to explore and describe the views and experiences of family members and professional caregivers regarding the care provided to immigrants with dementia or age-related cognitive impairment. One part explores the views and experiences of care services among relatives of immigrants with dementia, and the other part seeks to expand the insight into the experiences of health personnel working with immigrants with dementia/cognitive impairment in different parts of Norway.

Thus, this paper combines the results of two parts of this larger study, and these two

datasets are presented together. Some of the main findings are presented in a Norwegian report (Ingebretsen, Spilker & Sagbakken, 2015).

Design

Research on views and experiences, both in relation to health personnel, patients and relatives are scant; therefore, the research team considered qualitative methods as the most adequate approach to address the above-described objectives. Through individual in-depth interviews (IDI) and dyad interviews (2 persons interviewed at the same time), as well as FGDs, we sought to gather the participants' own descriptions of experiences and perceptions in relation to the treatment and care of people with cognitive impairment/dementia and an immigrant background. Because most of the previous studies on ageing and immigration seem to be based on small, convenience, and ethnic-specific samples (Torres, 2006), we sought to include a larger group of respondents representing a variety of countries of origin.

Choice of Concepts

Research from Norway and elsewhere (Diaz et al., 2015; Daker-White, G., Beattie, A. M., Gilliard, J., & Means, R., 2002) shows that a lower proportion of patients with an immigrant background are diagnosed with dementia, as well as a general underutilisation of relevant treatment and care services. One of the barriers documented relates to the recognition and attribution of initial dementia symptoms (Mukadam, Cooper & Livingston, 2011). In general, few Asian participants in studies from the United Kingdom (UK) and the United States of America (USA) associate biomedical terms such as 'dementia' with symptoms indicating cognitive impairment observed in their relatives (Mukadam et al., 2011). A systematic review exploring constructions of dementia in South-Asian communities confirms that there is no specific term for 'dementia' in this region of the world (Uppal & Bonas, 2014). Based on this knowledge, we decided to focus on 'cognitive impairment' and use this term alongside

‘dementia’ throughout the research process.

Sample Strategy

To obtain experiences from a variety of relevant respondents, we applied a purposeful sampling strategy aiming at maximum variation (Patton, 2002). In order to explore perceptions and care experiences, twelve relatives, between 25-75 years old, who had family members living with dementia were recruited for IDIs with the assistance of health personnel in different parts of the healthcare system. This was either related to where the person with dementia/cognitive impairment was under diagnostic investigation and/or treatment, or through health-care services, such as nursing homes where their relative was residing. Among the relatives, there were 10 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 originally came from Afghanistan, Pakistan, China, Vietnam, Turkey, Lebanon, Sri Lanka and Chile.

To obtain knowledge on the experiences on caring for people living with dementia with an immigrant background, 18 health personnel (mainly nurses and nursing assistants) were recruited 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. Later in the research process we decided to broaden our sample of health personnel and made a purposive selection of 27 health professionals, 18 women and nine men in the age range of 38-62. These health personnel represented different geographical parts of Oslo, and included six different counties (Troms, Buskerud, Rogaland, Sør-Trøndelag, Oslo, Akershus), in Northern, Western, and South-East parts of Norway. To access participants that had experiences with older immigrants with dementia or cognitive impairment, we combined an approach where we sent an information letter about the study to all general practitioners centres in four districts of Oslo with a high proportion of immigrant populations, and through

using existing network and contacts within the field. When recruiting in other parts of Norway, we called or sent information letters to persons and institutions that seemed relevant, like community health centre for refugees, nursing homes or home-based services in areas with significant immigrant population. The sample included general practitioners (GPs), doctors, nurses, auxiliary nurses and leaders (nurses) in nursing homes. They were represented in three FGDs, seven in-depth interviews and two dyad interviews. The participants worked in GP centres, nursing homes, short-term nursing homes, day-care centres, home-based services, geriatric polyclinic, psychiatric polyclinic, ‘memory clinics’ (diagnostic departments in hospitals), in a community health centre with services for refugees, or were part of a primary health-care dementia team. The participants represented health personnel (originally) from seven different countries in addition to Norway.

The Research Team

The research team consisted of three researchers with different background. Mette Sagbakken (MS) is a nurse and have a PhD degree within the field of global health. At the time of study, she was the research leader of The Norwegian Centre for Migration and Minority Health (NAKMI). She holds a position as an associate professor at the Oslo and Akershus University College. Ragnhild Storstein Spilker (RSS) is a nurse with an MPhil in Health Economics, Policy and Management, and is currently employed at NAKMI. Reidun Ingebretsen (RI) is a specialist in clinical Geropsychology and a researcher at the Norwegian Social Research Center (NOVA) at Oslo and Akershus University College.

Data Production

The initial FGDs with older immigrants took place at their respective organisations or at the researchers’ workplace. The group sessions lasted 90–120 min. In one of the FGDs with older immigrants, an assistant speaking the local language moderated the group, with the researcher

being present. In five of these focus groups, the group discussions were conducted in Norwegian (every participant speaking adequate Norwegian). An assistant who spoke the mother language of the participants were present to help translate and explain when needed. In the remaining focus groups, all spoke good or fluent Norwegian. Questions related to perceptions regarding aetiology/cause, possible treatment and care practises were addressed (to be published in another article). These FGDs with healthy older immigrants helped inform questions asked in interviews with relatives and health personnel, and helped contextualize data in consecutive interviews.

Family caregivers 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 IDIs lasted 60–150 min. Not all the participants spoke fluent Norwegian and some of the relatives were offered a translator. However, all relatives preferred to do the interview in Norwegian, mainly because they mastered the language adequately and partly because of a skepticism of using interpreters (due to confidentiality issues). The FGDs with health personnel took place at the participants' workplace and lasted approximately 90–120 min (all in Norwegian). In the extended, consecutive part, seven IDIs, two dyad interviews, and three FGDs with different health personnel were conducted at the workplace of the participants. Both the IDIs and the FGDs lasted 60–90 min. The dyad interviews consisted of health personnel that of practical reasons were interviewed at the same time. All the FGDs consisted of five to eight participants and the interviewer encouraged a discussion around each of the introduced themes.

A semi-structured guide was used during single interviews, dyad interviews FGDs. The interview guide in the FGDs had less themes/were less structured to allow time for discussion and new themes to be discovered. The questions in the guides were partly inspired by a literature review, partly by perspectives provided from the initial FGDs with older adults

with immigrant background; and partly through exchanges of experiences with experts in the field (health personnel, researchers, non-governmental organisation representatives) who served as a resource group throughout the research period. The questions were all formulated to address the objectives of the study. The approach was flexible in the sense that the interviews and discussions were also governed by the answers and themes introduced by the participants. In regards to the participating health personnel, the interview guide was adjusted to the profession/position held by each participant to a certain extent. The aim was to gather descriptions in regards to participants' perspectives/experiences in relation to care for persons with dementia in their specific position/workplace, and to interpret the meaning of these descriptions. The questions addressed both challenges/difficulties and possibilities/resources that could be described in the meeting with patients and families with a different linguistic and cultural background. Questions were also related to exploration of what type of approaches or potential adjustments that were used to solve or use the potential challenges or resources.

The interviews with the relatives were adjusted to their situation as family caregivers and the situation of the person suffering from cognitive impairment or dementia. Questions related to how the family had managed the symptoms/disease from initial symptoms until the present situation, how and to what extent they had initiated help/cooperated with existing services/health personnel, views on best possible care, responsibility of care; including family care versus use of public help. All the data were tape-recorded and transcribed verbatim.

Analysis and Interpretation of Text

The analysis was not an isolated process, but rather a continuum starting from the beginning of the study until its completion. To optimize the analytical process and to maintain a systematic approach to the material, the researcher doing the interview wrote a reflection log concentrating on the overall impression of each interview. Reflections included a focus on the

context of the interview, the structure of the interview, what worked well and what could improve. The reflection log also centered on the thematic content of the interviews and inspired reflections on our understanding of the different themes and subthemes in the analytical discussions between the researchers.

The theoretical underpinning is phenomenology as this methodology attempts to understand the meaning of events and interactions within the frames of how individuals make sense of their world. The data was analysed and interpreted, based on the descriptions by Kvale and Brinkmann (2009) of three different interpretation contexts: 1) self-understanding; 2) critical common sense understanding; and 3) theoretical understanding. With the aim of reproducing the participants' own understanding, the interviews were transcribed verbatim. The first step of analysis entailed the rereading of the transcribed interviews several times in their entirety by two of the co-writers to acquire an overall impression of the content. This process involved searching the entire data material for similar and contrasting statements. Units of meaning inspired by the objectives, interview guide and discussions between the authors were identified by colour coding to structure the participants' utterances in the texts. After discussions related to which themes each units of meaning represented, the researchers formulated what the subjects themselves understood to be the meaning of their statements in a condensed form. 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 between the researchers uncovered 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. Thus, this part of the analysis moved from units of meaning and generated preliminary themes by labelling the short sentences with subthemes to structure the text further. In the last phase, the different subthemes were linked

together and described in central themes that reflected the focus 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.

Ethics

The Health Research Act and the guide to the Act provided by the Norwegian 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. 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.

Trustworthiness

To optimize the analytical process and to maintain a systematic approach to the material, the researchers wrote reflections logs that informed and inspired the ongoing analytical discussions between the researchers. Data from the initial FGDs with older immigrants from 10 different countries were analyzed and discussed in the beginning of the study and served as an inspiration to identify themes and questions in consecutive interviews. We believe this initial familiarity with different ways of articulating and perceiving the phenomenon of cognitive impairment/dementia served as an important contribution to secure internal validity in the overall study. The use of triangulation served to strengthen the trustworthiness of the

study. By triangulation of sources (different respondents; relatives and different health care providers), and different health care settings (e.g. homebased services, nursing homes) we examined variations and contradictions as well as the consistency of different data sources. Through method triangulation (FGDs and IDI's) we elucidated complementary aspects of the same phenomenon through approaching topics in depth (IDI) and through FGDs inspiring new associations and perspectives. Through analyst triangulation (two researchers reading and analyzing all transcripts) we reduced the influence of selective perception and blind spots in the interpretive analysis. By drawing on different types of theory and empirical studies, we believe we manage to support and provide a nuanced discussion.

Findings

Views and Practices Concerning Family Responsibility and Models of Care

Deep rooted expectations

Even though a varied picture of expectations, experiences and practices concerning family relationships and professional care was identified, some clear patterns were also found. One of the patterns identified among relatives was associated with their expectations, which included a felt social pressure that family members should take care of an older relative affected by dementia/cognitive impairment. For many, there was a strong norm associated with taking care of "their own". Deviating from that pattern could lead to feelings of guilt and shame. Other participants explained the expected norm more simply in terms of feeling responsible for their parents because their parents had taken care of them when they were children. There were many examples of family members providing extensive care for people living with dementia and different models of co-operation between family members sharing the responsibility. One example was extended family members living together and sharing

some of the caring tasks within the house where the person with care needs was living. In other cases, the person living with dementia was moved between relatives' houses. This was done in cases where relatives wanted to adhere to traditional care patterns, but were unable to do this because of their health problems or work commitments. Health personnel recognised this solution as a way of lightening the burden, but described how such arrangements made it difficult to collaborate and communicate with the relatives, and thus provide follow-up and additional care. One health professional elaborated on such cases, as experienced in the home-based services:

“...in some of the cases I was involved in, [...] the relatives relieved each other through moving the person with dementia in between the homes, to avoid them from being totally exhausted [...], but then it became difficult for us to communicate with all these homes. Where was the person in need of care at the moment?” (FGD with health personnel).

Other participants provided examples of family members trying to face the burden alone. A relative refers to a family member, living in another part of the country that tried to care for the person with dementia in the context of her core family:

“She (family member) was totally exhausted, had responsibility for her own children, to follow them to school and kindergarten. Her GP advised her to apply for help from the home-based services, but she did not want to receive such help. She worried about what people around her would think about that.” (IDI with relative).

Even though most participants emphasized the importance of providing care for their own family member, many described challenges difficult to overcome, thus expressing some ambivalence related to the exercise of care provided by the family. A son, being one of the family members providing care reflects this complexity:

“My culture provides an important platform for how to provide care, not to say anything wrong about the Norwegian way of doing it, but we have a more family oriented culture... But we do not have mechanisms for how to manage stress, to handle all these tasks – and the migration process

has in many ways isolated us...” (IDI with family caregiver)

The ideal of providing care according to a family oriented model, in another cultural context, and with less family members available, can cause unmanageable care situations involving exhaustion and stress. Even if care tasks felt unmanageable, a perceived social pressure to provide care could lead to resistance or ambivalence in regards to seeking or receiving public help. Several participants talked about the dilemmas between caring for their parents, children and work commitments. One of the female relatives acknowledged that the combination of work, children and taking care of parents living with dementia was too difficult, but concluded that, “these expectations (to take care of parents) are deeply rooted, no matter how we think about it.” (IDI with family caregiver).

Many relatives were described by health personnel as indispensable caregivers, both in collaboration with health personnel and alone. Several mentioned how some relatives managed to cope with tasks considered unsolvable by the home-based nurses, as exemplified below:

“I just had a patient that only had this [...] one relative in Norway. But it was incredible what she managed to do for that old man. She managed what the home-based services did not manage, such as making him shower and making him do things that they did not. [...] I did not understand where she got the strength from, really, and she had been doing this for quite some time. It was quite impressive.” (FGD with health personnel).

Examples provided from health personnel of skilled and devoted relatives confirmed the impression from many of the interviews with family members describing the importance of having an active role in providing care.

Ambivalence towards the use of formal care

Relatives that were reluctant or seemed ambivalent to use help from public services expressed insecurity in regards to whether the older person would be properly understood,

and treated in a way that safeguarded their values and traditions. Another finding that was characteristic across the groups of relatives was that nursing homes in particular seemed to be associated with a risk of inadequate individualised care. In one of the FGDs with health personnel, where all the participants had immigrant background, participants referred to examples from the media of stories of insufficient food as well as physical and even sexual abuse in nursing homes. According to their experiences, such stories confirmed the bad reputation of nursing homes, which scared many relatives from using them. Health personnel also provided examples of relatives who, because of dissatisfaction, ended established public care and sent the older relative to nursing homes or private help in their country of origin. A female caregiver describes how providing care through a nursing home only would be an option if the relatives were exhausted:

“When you do not have an alternative, when you are alone, and without any other help at home, then you need help... First of all, we want the family to contribute to the utmost, but when they do not have any more strength left themselves, then there is no other alternative [...] when the family does not manage to look after the patient anymore, then the nursing home is the last resort.” (IDI with family caregiver).

Extended family members living scattered and thus having difficulties to ask for relief, made it difficult to fulfil the role as the primary caregiver among some of those that wanted to. Some of these caregivers had accepted help from home-based services as well as nursing homes, but were still holding on to some of the caring tasks and thus parts of the caring role. Some received for example help from the home-based services, but played an active role in situations or days where the person living with dementia had special needs or did not want to receive help from the nurses. A spouse, living with a person with dementia, elaborates how they have adapted a flexible approach in regards to whether the family or the nurses attend to daily needs: “Sometimes he does not want to (receive care), they try to change his diaper, but

it is a lot of trouble... Sometimes it is ok... but often it is me or the children that needs to clean him and shower him..." (IDI with family caregiver)

There were also several instances where the person with dementia was living in a nursing home, and where the relative had moved into the institutional residence together with their spouse or parent for long periods. Such decisions were a result of the situation being too difficult to handle at home, and by moving in, the relative would still be able to participate in the care. One health professional from one of the nursing homes elaborates:

"We have examples of relatives that moves into the room. They share the shift, and they are there day and night. [...] they get a folding bed or a mattress... so we try to facilitate ... but we are not used to relate to relatives in that way. [...] It reminds me of the children's department at the hospital, the parents were always there." (FGD with health personnel).

Thus, a relative being present in the nursing home and taking shifts in caring for the older person was a solution that was adapted to fulfil at least parts of the expectations of family care. According to health personnel, the social pressure of caring for the older adults could also lead to situations where relatives claimed to be present as caregivers, but where, e.g. home-based services discovered neglect in the care for the older person. Another health worker from home-based services relates such an experience:

"We attended [...] a collaborating meeting with a person with dementia from another country with poor language skills [...] It was a particularly challenging situation because there were relatives present that claimed they were there and took care of that person, but they didn't, so that was very difficult." (FGD with health personnel).

Health personnel also gave examples of being refused by relatives to get permission to visit older immigrants in their homes in cases of suspicion of cognitive impairment, and where neighbours had provided so-called 'notes of concern' about the care situation of the elderly. Some of the described problems, however, seemed to relate to language barriers as

well as differences in preferred ways of communication.

Language and Communication Barriers

Both health personnel and relatives were concerned about language or communication barriers. This often related to relatives not mastering the Norwegian language and/or the person living with dementia not managing to communicate because of his/her condition, and/or not knowing the Norwegian language, or having lost the (second) Norwegian language due to his/her condition. Health personnel told how some of the patients in nursing homes, not knowing any Norwegian, were dependent on relatives to be able to express themselves. A nurse elaborates:

“It is not easy; there are some (patients) that have lived here for several years without the ability to communicate with the staff. Some may know some English, but that also disappears after a while. It is incredible that it (the care) actually works, and one can imagine how frustrating and depressing it must be not being able to communicate anything to anyone. In such cases, we use relatives a lot; to be able to at least communicate something.” (FGD with health personnel).

Another topic, raised by staff in home-based services, was difficulties related to ‘home-visits’ (conducted by nurses to assess the situation for an older person) involving older adults with an immigrant background. The challenges could be partly due to concrete language problems, and partly be due to difficulties in findings ways of communication where they were able to access adequate information about the person with cognitive impairment/dementia. A nurse from a home-based service elaborated the difficulties in understanding the situation and needs of the patient:

“It is a challenge (home visits with relatives present). I get a kiss on the cheek and a kiss on the hands and there are a lot of smiles (addressing relatives), but whether I get what I came for ... and if there is cognitive failure in addition [...] what do I really get to know? I think I only access very general information.” (IDI with health personnel).

Several health personnel shared how it could be difficult to entertain both the fact that the relatives wanted to do most of the caretaking or gave the impression that they wanted to, and difficulties related to the language and in getting a clear picture of the situation. A health worker working with people living with dementia at home described how she struggled to find good ways to collaborate with the relatives:

“These relatives would like to do as much as possible; so then, I call once in a while and ask how it goes. ‘Oh, everything is fine.’ (Refers to common answers while laughing.) I have invited... I have conversation groups, both for spouses and for children [...], but they do not come. However, I do offer. I also arrange evenings where we cover relevant themes, and I say, ‘this will be good for you!’ ” (IDI with health personnel).

On the other hand, some of the relatives objected to the form in which collaborating meetings between family members and health personnel tended to take place, such as groups of several relatives coming together. A daughter told how it would not suit her father to sit in a group and talk about how to support his wife (she was shaking her head): “For him to sit in a kin group... No, he would not have been comfortable. It is not his style to put words to feelings, so then you do not sit down and talk in a group of strangers. ” (IDI with relative). Some relatives mentioned that the “methods of communication and cultures” were different and that many would feel uncomfortable “talking about everything”; in other words being open about challenges and problems in regards to care for a family member living with dementia. Other relatives related that it went against their ideals of family loyalty to talk about family problems to strangers and thus preferred private counselling.

However, there were also examples of relatives that had good experiences participating in joint meetings with relatives as well as attending specific courses for relatives (‘pårørendeskole’), or using services such as the “dementia hot-line” (telephone service where qualified people answers question in relation to dementia and dementia care). These

relatives were positive to such services because they provided basic knowledge on dementia as well as suggestions for how to provide care. However, as pointed out by one of the users of the “dementia hot-line”, the service would have been far more accessible if she had been able to speak in her mother language. Also health personnel addressed how limited language skills, among women in particular, could make relevant information less accessible as well as complicate the collaboration with health personnel.

Female Caregivers in an Immigration Context

The role of female caregivers frequently came up during the interviews and FGDs, and the role of women appeared important to the understanding of views and practices, including potentially conflicting ideas. The findings indicate that many women may end up in a position with limited choices because of gendered roles and expectations. Both relatives and health personnel presented many examples of expectations and demands that were difficult to fulfill. Relatives who were not directly involved and could witness the person living with dementia and his/her care needs would often not realise the need for help from public health services and blame the family (women in particular) for not managing the needs of their relative. A daughter told how she had to seek acute help for her mother who was suffering from progressive dementia, including increasing behavioural problems. Even though the situation seemed out of control, she had to face strong criticism:

“Everyone thinks I am mean; say that I have a hard heart [...]. I fell out with my brothers because where I come from... to endure is to endure. They just say that the parents need help and that the children have to endure. But I have other things (*i.e.* responsibilities) in my life too, so if I only endure, it is not fair to my kids. [...] I have had to accept a lot of criticism, bad criticism.” (IDI with family caregiver).

Health personnel mainly described relatives who were present in nursing homes as important resources, but challenges related to conflicting ideas and co-operation between the

family members could influence their collaboration with the family. During one of the FGDs with health personnel, different scenes of conflicts emerged:

“I have experienced, not once, but several times [...] where the son sat out in the hall and screamed to his sisters, that the father was not supposed to be here and...there was no limit... They (sisters) were working full-time, which is what is different here (in Norway). ” (FGD with health personnel).

Another FGD participant in the same discussion added another example:

“In another case (referring to another family) we had to make sure to differentiate the information we gave to the female and male relatives [...] it was very difficult for us [...] it (the care situation) could create huge conflicts between them ... they would close the door and we did not know what was going on. ”

Even though relatives mainly were described as resources, several health personnel questioned the role of female caregivers. A nurse described a case where the whole family spent a lot of time at the nursing home, but where the daughter had to change her way of living taking the main responsibility:

“In this case, the whole family more or less moved in and stayed with us for two years. The daughter, however, resigned from her job and everything. For her, it was somehow natural... [laughter]. But when I think back, it was clearly the son that dominated, and it was her that was affected...” (FGD participant).

The topic of female caregivers engaged both relatives and health personnel, and during the FGDs with health personnel, a person with an immigrant background started to talk about her own situation concerning the expectations she felt about taking care of her in-laws. Because of her position as a full-time worker and being a mother of small children, taking care of her in-laws was not an option:

“I am married and I have children. Normally we are supposed to take care of our older relatives. I am supposed to take care of my in-laws. Eh, but now I work, right? I do not have the possibility to do that because I work full time... and I have children. ” (FGD participant).

Health personnel in home-based services also raised the issue that some, in particular

women, were unable to attend meetings or activities for relatives because the person with dementia was totally dependent on that particular caregiver. Not being able to attend such meetings impeded and complicated the collaboration between the next of kin and the home-based services. In particular, women seemed to end up in situations with different types of conflicting pressures as articulated by a daughter who wanted to continue with her work and could no longer manage care for her father at home. However, she struggled with the dilemma of continuing to work and providing proper care, as she considered the health care for older adults to be poor:

“I believe that it is the government’s responsibility to provide proper assistance. We (women) are encouraged to work, but the offer to provide care for the older persons is not adequate.” (IDI with family caregiver)

Independent of whether the relatives managed to agree on adequate solutions, these types of situations seemed to be an expression of conflicting needs taking place in a context with conflicting values and new and demanding roles.

Discussion

Some studies suggest that the meanings, and consequently patterns of family caregiving, are largely ethno-culturally based (McClearly & Blain, 2013; Botsford, Clarke & Gibb, 2011). Other studies suggest that the factors are highly complex and that lack of awareness of services; barriers related to availability and accessibility; stigma; language barriers, and culturally inappropriate services are all important reasons why ethnic minorities show different patterns and tend to use formal health-care services in dementia care to a lesser extent (McClearly & Blain, 2013; Mukadam et al., Cooper & Livingston, 2011). Our findings emphasise this picture of complexity and show that a combination of expectations and practices is rooted in cultural values and traditions, communication and language barriers, but also immigration processes and changing socio-economic positions—including gender roles.

Some of the most consistent findings seem to relate to the perceived obligation of taking care of “one’s own”, in combination with new social roles and demands, and where the otherwise commonly used nursing homes are associated with poor care and seen as the “last option”. This finding is supported by a qualitative study from Norway, not focusing particularly on dementia, but that explored perceptions of age and health among older immigrants representing nine different immigrant groups. The study found that the most important issue when growing old in a new homeland as an ethnic minority immigrant was to be surrounded and cared for by one’s family (Thyli et al., 2014). For many, the family was seen as the only option when needs for care increased because of changes in age and health status, and feelings of fear and distrust, language barriers, and preferences for familiar care were cited reasons (Thyli et al., 2014). These perceptions might help explain the difficulties in accepting the nursing home as a solution, as it may represent the most distant form of care-giving compared with family care.

However, there might be more similar patterns than we tend to believe. Although it is common among ethnic Norwegians to choose nursing homes as a residence for family members living with dementia (Ministry of Health and Care Services [HOD], 2015), studies show that relatives in this group also want to play an active role in caring for the older person with dementia (Rognstad, Sagbakken & Nåden, 2015). Relatives in a study from Norway expressed that they to a little degree are included as collaborating partners and miss a continuous dialogue with health personnel. The transition from the role of being an active, responsible caregiver to being excluded is perceived as very difficult (Rognstad et al., 2015). This suggests that ‘total institutionalisation’ (Goffmann, 1961), where the relatives do no longer have a role nor play an active part in the caring process, is perceived as disagreeable by most relatives.

In another study, ethnic Norwegian relatives of older subjects with dementia expressed

concerns related to the care recipients in the nursing homes not being able to promote their wishes and preferences for activities and everyday life habits (Kuosa, Elstad & Normann, 2015). The study showed that this inability related to problems with communication caused by cognitive impairment, but also to the older immigrants being unaccustomed to express their needs to a third party (health personnel) representing public authority and not a caregiver in the sense of being close. As suggested by the findings in the present study, 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 & Conner, 2013). A Swedish study suggested that the visits and presence of relatives might be even more important for an immigrant with dementia because the family members are able to speak their mother tongue, recall memories and mediate needs (Rosendahl, Söderman & Mazaheri, 2016). In addition, there might be stronger culturally based reservations, both for the patient and the relative, to receive care from someone not being a member of the family. The most commonly examined aspects of cultural values and traditions are those of familism and filial responsibility (McClearly & Blain, 2013). These concepts refer to a strong identification and solidarity with family members, both nuclear and extended, and involve strong normative feelings of dedication, attachment, responsibility and reciprocity (MacKenzie, 2006). A strong sense of familism and filial responsibility might explain some of the hybrid solutions of ‘sharing burden’ strategies exemplified in the present study: namely relatives moving into the nursing homes or relatives moving the person living with dementia between relatives’ homes, sometimes combined with the use of home-based services. In a study of Korean immigrant family caregivers in American nursing homes, nursing home placement meant “not fulfilling filial piety”. In this study, participants’ negative perceptions about nursing home placements implied that relatives were taking care of parents living with dementia at home for many years before

considering a nursing home placement. After placing their family member at a nursing home, relatives expressed strong feelings of guilt and labelled themselves as “unfilial” or “bad” (Kong, Deatruck, & Evans, 2010).

A recent study on cognitive impairment among Norwegian-Pakistanis in Norway shows that the core of what is interpreted as the ‘traditional family’ has a significant influence on how they relate to the Norwegian health-care culture (Næss & Moen, 2015). The findings show how Norwegian-Pakistani families “negotiate dementia” in the space between their own imported, culturally defined system of cure and care, and the Norwegian health-care culture. This negotiation is similar to the negotiated practice found in our study, and can be taken as an inclination that people with immigrant backgrounds are willing to use public care, but redefine and make use of the services in their own way. Transnational migration is described as the process by which migrants both reshape and sustain interconnected social relationships and values, which link together their societies of origin and their new settlements (Schiller, Basch & Blanc, 1995). This study exemplifies how immigration is not equivalent with immigrants adapting to the host population’s practices, but that practises may merge in a way that creates new patterns. Thus, there will be a continuing way in which immigrants construct and reconstitute their embeddedness in more than one society (Schiller et al., 1995), which exemplifies the flexible nature of ethnicity (Phillipson, 2015). In other words, even though relatively few older members from ethnic minority groups use care facilities today, minority groups that have stayed in Norway and other countries for several decades might gradually move towards more use of public services. However, using these services on their own premises creates new ways and new needs of providing care. Instead of only focusing on barriers felt by immigrants, one may need to focus on how representatives of the health-care system can manage to adjust their services more flexibly in accordance with the needs expressed by relatives with immigrant as well as ethnic Norwegian backgrounds; being the

core in all person centred care.

One challenge that may have to be addressed relates to ethical and juridical issues in a situation where family care patterns merge with public care services, and where the responsibility for providing adequate and satisfactory care may be blurred at any time. This also relates to the situations described where relatives express that they are in charge of the caregiving, but where representatives of public services discover neglect in the care for the older person and/or are refused by relatives to visit older immigrants in their homes in cases of “notes of concern”. Within this picture, it is important to realize that even though people do not actively ask for help, it does not necessarily imply that people are not in need of help.

Another important challenge in this field is how to identify and collaborate with family members that may live with unwanted or overwhelming care situations due to strong social norms or pressures. As illuminated in this study, women in particular might be exposed to undue pressure in regards to taking care of relatives with dementia. Jutlla (2013), an influential researcher in this area, emphasises that even though identity roles can open up new possibilities because of migration, cultural norms about traditions and gendered roles in general most often seem to be strengthened. Decisions about who should care for older adults are still often made in accordance with a hierarchy of obligation running from the (female) spouse being the first choice and the daughter and daughter in-law being the second or third choice (Harper & Levin, 2005; Jutlla, 2013). Those who have migrated for social reasons, such as family reunification, can find it difficult to get help from formal or informal networks on the outside, which makes the task of care even less manageable (Jutlla 2010). As indicated in our findings, women might feel trapped by expectations in their respective communities and thus find themselves in a situation with conflicting pressures related to gendered norms and socio-economic demands of the host country and gendered norms and traditional caring responsibilities with bases in the country of origin. In line with our study, a review article on

dementia care among ethnic minorities from the UK concludes that adult daughters or daughters-in-law in particular frequently combine extensive caring responsibilities with paid employment, even though they do not necessarily live close to the person affected by dementia (Moriarty et al., 2011). Thus, even if there are structural barriers or geographical distance between relatives, perceived obligatory and reciprocal relationships might still exist between parents and children. Because families are becoming more fragmented and nuclear (Harper & Levin, 2005), the responsibility of care can be negotiated based on strengthened cultural norms (*e.g.* gender roles), or the negotiation can take new forms and be based on an assessment of each person's position, geographical location and skills (Jutlla, 2013). There will also be a diversity in needs and preferences between people who migrated when older, and former labour migrants (and those who accompanied them) who have “aged in place”, and thus have stronger connections to the host country (Warnes & Williams, 2006). Either way, it seems important to be aware that the pressure exerted on individual caregivers— and women in particular—can be large. In an immigration context, potential caregivers might feel obliged to conform to the traditional caregiver role, but without the support from a wider extended family and in the context of other pressing roles and duties. The ability to take autonomous decisions, in line with women having an ethnic Norwegian background, may not be a realistic scenario for women originally from societies that are more patriarchal. However, social capital in the sense of education, income, and language abilities, both before and after immigration, can represent an advantage as well as a disadvantage in (re-)negotiate their identity, including women's family commitments, in different social and cultural contexts (Phillipson, 2015). As exemplified in our findings, women who combine work and family life might rationalise not taking care of older parents, while others suffer double burdens or are pushed into a situation where they have to quit paid work. Thus, the “culture” or “ethnicity” category may easily disguise other facets of identity and differences, such as

migration history, gender, education, language abilities and socio-economic status (Iliffe & Manthorpe, 2004), which are categories that might explain—or partly explain—the differences in needs and caring patterns illustrated in this study. Critical medical anthropologists Scheper-Hughes and Lock (1987) have introduced a framework for an understanding of an individual's body from three perspectives; as single bodies, as social bodies, and as subjects influenced by a body politic. The relationship between individual and social bodies involves more than collective representations of values embedded in the culture. The relationships are also about power and control, and the body politic denotes possible ways in which an individual can be influenced and manipulated by socio-cultural or -political processes that serve to preserve a group's identity or boundary (Scheper-Hughes & Lock, 1987). As indicated in the findings of this study, some women might feel pressured to represent and consolidate perceived values and standards of the larger group, and correspondingly neglect individual needs and preferences. Consequently, health personnel should be wary of stereotyping and generalising groups through “othering” ideologies and rather try to explore, understand and adjust to the present set of needs, as well as to be aware of how and by whom these needs are articulated.

In a study on Alzheimer's disease and successful linkages between formal and informal care systems (Carpentier & Grenier, 2012) it is suggested that due to the heterogeneous nature of populations and family situations the medical system must adapt. This implies that one need to move from a model of standardized programs to an approach that includes the unforeseen, the uncertain as well as diverse viewpoints and positions. However, to be able to understand such complexities a client centered “bottom-up” approach is needed, not only among researchers, but also among health personnel.

Conclusions

To understand fully the contribution and needs of family care within ethnic-minority

communities, it seems important to consider not only the availability of household and kin members, but also their understanding of obligation and reciprocity underlying the perception of care. It is also important to be aware that the role of family members does not have to be either/or. Rather, many relatives may want to, or have to, play a role as a caring and participating relative, and still work and otherwise partake in society. It also seems important to realise that caregivers, women in particular, might feel obliged to conform to a traditional caregiver role, but without the support from a wider extended family and in the context of other pressing roles and duties.

Even though merging private and public services as described in this study might involve both ethical and juridical challenges, it also represents a window of opportunity to inspire new and flexible ways of thinking about care for older immigrants. Increased collaboration and care sharing with relatives might facilitate better and more coherent care; subsequently, different immigrant groups could pave the way for needs also expressed by families with an ethnic Norwegian background. As in all other person-centred care, the questions to ask in tailoring services to individuals are related to what type of information and support the person with dementia and his/her family members need; what language is most usable for them, what needs and preferences are important to address, what types of resources in regards to family care are available, and in what way these resources can be merged with public care services to provide the most optimal care. Different models of care, including new and dynamic forms of collaboration between relatives and health personnel, represents an innovative way of thinking about care and should be addressed in future research.

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