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“Good Care Means That You Make People Happy”. A Qualitative Study on Perceptions Regarding Good Dementia Care Among People with Different Ethnic Backgrounds in Norway³

*It is in the mind of the marginal man that
the conflicting cultures meet and fuse.*

Robert E. Park

The purpose of this study was to explore perceptions of good dementia care among people with different ethnic backgrounds in Norway. The study had a qualitative design. Individual semi-structured interviews were carried out with twenty family caregivers with different ethnic backgrounds, five representatives of immigrant communities, and five representatives of health and care personnel working with people living with dementia. Thematic analysis was used to identify themes in the interview material. Data analysis revealed five themes related to the elements of good care: combining institutional and family care; attributes and formal/informal competencies of caregivers, ensuring patient-centered, holistic care; dignity-preserving care and the special role of food. Most of the study participants emphasized elements of care that constitutes what can be described as patient-centered care. To the best of the authors' knowledge, this is the first Norwegian study on the perceptions of good dementia care among people with different ethnic backgrounds.

Keywords: dementia care, Norway, different ethnic groups, qualitative methods

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³ The study was funded by Stiftelsen Dam (Extrastiftelsen). The funder had no role in the design of the study or the collection, analysis, and interpretation of data.

Introduction

Dementia

Dementia is considered to be one of the greatest health challenges in the contemporary world (WHO 2017). It is a clinical syndrome, progressive in nature, characterized by deterioration of memory and other cognitive functions. Dementia affects behavior and the ability to perform everyday activities (WHO 2019). The incidence of dementia is increasing worldwide (2015: 47.47 million, 2030: 82 million, 2050: 152 million) (WHO 2019), and in Norway (2020: 101.118 thousand, 2030: 139.770 thousand, 2050: 238.499 thousand) (Ageing and Health 2020). Dementia is caused by underlying diseases and Alzheimer disease accounts for 60–70% of all dementia cases (WHO 2017). Most dementia forms are progressive, but it is highly individual how fast the symptoms develop (Bartley et al. 2018). In many countries, dementia constitutes one of the main reasons for institutionalization of older people (Klich-Rączka 2019). The last stage of dementia most often requires 24-h institutional care. Caring for people living with dementia can be very demanding for both informal family caregivers (Chiao et al. 2015; Brodaty, Donkin 2009) and for employees working in institutional care (Bidewell, Chang 2011).

Good dementia care

Many previous international studies on good dementia care focus on elements that constitute good care in the home environment and in nursing homes according to family and professional caregivers (Helleberg, Hauge 2014; Ericson et al. 2001; Sellevold et al. 2013; van Zadelhof et al. 2011). In a study from Sweden, Iréne Ericson et al. (2001) found that family and professional carers have the same goals regarding the provision of the best possible care for persons living with dementia. Most of all, both groups of caregivers focus on the individual needs people living with dementia have and opt for a more personalized model of care. Kristin Mjelde Helleberg's and Solveig Hauge's study on Norwegian nurses and care workers' perceptions of good care shows that good care can be described like a dance between the patient and the caregiver. It is something which is spontaneous, with room for personal interpretation and improvisation, but it also involves strict rules and procedures to enable the dance to take place (Helleberg, Hauge 2014: 5). Other studies conducted among care workers (Sellevold et al. 2013; Edvardsson et al. 2010), family caregivers (Pickard 1999; Edvardsson et al. 2010) and people living with dementia (Milte et al. 2015), emphasize that good care is characterized by the reciprocity of expression of emotions in the relationship between the patient and

the care provider, and where dignity, respect and support of the personhood of people living with dementia are acknowledged. Rachel Milte et al., who conducted a study on the meaning of the quality of residential care from the perspective of people with cognitive impairment and their family members, show that a patient's personhood can be supported by providing individualized care through access to meaningful activities, supportive healthcare and opportunities to feel useful and valued (2015: 13–14).

Dementia care and ethnicity

In most societies the family is responsible for care provision given to dependent family members, but the forms and scope of care vary greatly depending on the existing cultures of care (Fine 2015) and patterns of responsibilities between the state and the family (Saraceno 2016). Ethnicity seems to be an important factor explaining differences in people's interpretations and responses to dementia as well as perceptions regarding dementia care (Botsford 2015; Mendes 2015). However, ethnicity provides only a partial explanation of the differences in how people approach dementia and dementia care. Ethnic groups are not homogenous and not all members of the group follow all the social norms that are characteristic for the group (Botsford 2015). In a review of articles on service needs, service provision and models of good practice in dementia care among minority ethnic groups, it was found that most studies did not examine intra-group differences (Daker-White et al. 2002). The same review shows that care workers tend to look at caregivers from minority ethnic groups in a stereotypical way, and see the care giving in those groups as a result of family obligations and religious beliefs (Daker-White et al. 2002: 104). However, family structures and relations are diverse within and between ethnic groups (Ajrouch 2005; Berthoud 2001).

Good dementia care refers to moral norms and the codes of conduct followed by a society or a group. However, moral norms as well as other societal norms always evolve and change (O'Brien 1999). According to Jodi O'Brien, moral norms are "eternally in the process of being reshaped to fit shifting social, personal and physical environments" (1999: 27). Studies show that social and moral norms related to family caregiving often change during the migration process due to the initiation of migrants into two different, sometimes conflicting cultures and care regimes (Czapka, Sagbakken 2020; Radziwinowiczówna et al. 2018). According to a Norwegian study on dementia in families with different ethnic backgrounds, immigrant children were ready to satisfy their parents' care needs by providing care in the family. However, at the same time, they seemed to accept the help provided by the state (Czapka, Sagbakken 2020).

Migrants in Norway

Immigrants and Norwegian-born people with immigrant parents make up 18.2% of the total population of Norway (Statistics Norway 2020b). Poles, Lithuanians, Somalis, Swedes and Pakistanis form the five biggest immigrant groups (Statistics Norway 2020b). Due to a relatively short history of immigration, Norway's immigrant population is much younger than the general population. According to Statistics Norway (SSB), 4% of immigrants and as many as 16% of the general population were 67 years old or older in 2019 (Statistics Norway 2020a). However, a significant rise in the number of older migrants is expected. It is predicted that one in four immigrants in Norway will be aged 70 or more by 2060 (Statistics Norway 2020a). Additionally, some immigrant groups are now ageing and younger generations face the challenge of caring for elderly family members.

This article presents data collected in 2018 as part of a larger project: “Ageing, dementia and the need for care: a qualitative study on experiences and responses to cognitive impairment among families of different cultural backgrounds living in Norway”. The main aim of the study was to look at experiences of ageing, and in particular understanding and responses to cognitive impairment and dementia among families from different ethnic groups living in Norway. The aim of this part of the study is to describe perceptions of good dementia care among people with different ethnic backgrounds.

Methods

Study settings and participants

Data was collected over a period of one year (2018–2019) in Oslo and Akershus. In order to gain a comprehensive understanding of the studied phenomena, including perceptions and beliefs regarding dementia care among people with different ethnic backgrounds, multiple data sources were used. Author 1 interviewed participants from five groups: 1) individuals from minority ethnic groups with family members who a) had been diagnosed with dementia or b) had no diagnosis but experienced memory loss; 2) Norwegian families with family members who had been diagnosed with dementia; 3) transnational caregivers from minority ethnic groups who provided care to family members living with dementia; 4) key representatives of immigrant communities; and 5) representatives of health and care personnel working with dementia patients. The authors believed that the inclusion of these five groups of participants would enable them to better understand the studied phenomena.

A convenience sampling method was used to recruit participants. The first two groups of participants were recruited by contacting nursing homes, a memory clinic, day centers, dementia coordinators, as well as the personal networks of the researchers. Channels, such as internet forums and personal networks were used to recruit participants who were involved in transnational caregiving, while information about the project was published on internet forums for migrants.

In total, fifteen families with minority ethnic backgrounds and five ethnic-Norwegian families were interviewed. The participants with minority ethnic backgrounds originally came from Somalia, Poland, Croatia, Pakistan, India, Austria, North America, Turkey and one of the islands in the Atlantic Ocean. Seven participants were involved in transnational caregiving providing various forms of care across borders.

Expert sampling through the aid of already established networks was used to recruit the last two groups of participants. Author 1 interviewed five key representatives of immigrant communities with Polish, Somali, Turkish and Pakistani backgrounds. The recruited participants were active members in their minority ethnic groups and Norwegian society. In order to gain more insight into the immigrants' perceptions of good dementia care, author 1 interviewed five representatives of health and care personnel with different ethnic backgrounds working with dementia patients. Table 1 presents the socio-demographic characteristics of the study participants.

Table 1. Socio-demographic characteristics of the study participants

No.	Ethnic background	Sex	Role	Age	Education	Employment status
1	Polish	F	Family caregiver (to her mother)	60–70	University	Employed
2	Somali	F	Family caregiver (to her mother)	20–30	Student	Student
3	Somali	M	Family caregiver (to his cousin)	–	Secondary education	Employed
4	Archipelago in the Atlantic Ocean	M	Family caregiver (to his father)	30–40	University	Employed
5	Pakistani	F	Family caregiver (to her husband)	60–70	Secondary education	Retired
6	Indian	M	Family caregiver (to his wife)	60–70	University	Employed
7	Kurdish	F	Family caregiver (to her husband)	40–50	Primary school completed	Employed
8	Croatian	M	Family caregiver (to his mother)	50–60	Secondary education	Employed

No.	Ethnic background	Sex	Role	Age	Education	Employment status
9	Polish	F	Transnational caregiver to her mother	40–50	University	Employed
10	Polish	F	Transnational caregiver to her mother	50–60	University	Employed
11	Finnish	F	Transnational caregiver to her father	40–50	University	Employed
12	British	F	Transnational caregiver to her mother	40–50	University	Employed
13	US	F	Transnational caregiver to her mother	60–70	University	Employed
14	Polish	F	Transnational caregiver to her mother	30–40	University	Employed
15	Austrian	F	Transnational caregiver to her father	30–40	University	Employed
16	Norwegian	M	Family caregiver (to his wife)	70–80	University	Retired
17	Norwegian	F	Family caregiver (to her mother)	40–50	Secondary education	Employed
18	Norwegian	F	Family caregiver (to her husband)	70–80	Secondary education	Retired
19	Norwegian	F	Family caregiver (to her mother)	40–50	University	Employed
20	Norwegian	M	Family caregiver (to his mother)	50–60	University	Employed
21	Polish	F	Nurse working in a nursing home	30–40	University	Employed
22	Norwegian	F	Nurse working in a nursing home	20–30	University	Employed
23	Norwegian	M	Doctor	50–60	University	Employed
24	Ethiopian	F	Assistant nurse working in a nursing home	30–40	Secondary education	Employed
25	Polish	F	Professional caregiver	20–30	Secondary education	Employed
26	Turkish	F	Key representative of the Turkish community	30–40	University	Employed
27	Pakistani	F	Key representative of the Pakistani community	40–50	University	Employed
28	Polish	F	Key representative of the Polish community	50–60	University	Employed
29	Polish	F	Key representative of the Polish community	60–70	University	Employed
30	Somali	F	Key representative of the Somali community	20–30	Secondary education	Employed

Source: the authors.

Interview guides and data collection

Four different interview guides were developed by author 1 and discussed with author 2. Subsequently, they were translated from English into Norwegian and Polish. They included questions related to understandings of dementia in minority ethnic groups, the seeking of formal care, perceptions regarding good dementia care and experiences of care provided by health services.

Most of the interviews were conducted by author 1 in English, Polish or Norwegian. Author 2 conducted one interview with a Norwegian family caregiver, and a research assistant carried out an interview in Punjabi with a Pakistani family caregiver. The interviews were conducted at venues chosen by the participants and lasted between 45 minutes and 2.5 hours.

During the recruitment process and the interviews author 1 paid special attention to the importance of self-reflexivity (Finley 2003) and continuous negotiation of the insider – outsider position (Breen 2007; Merton 1972). Due to her minority ethnic background she was perceived by the participants from minority ethnic groups as “one of us”. They would often say: “we, migrants”, “you know how it is”, “I am sure you understand me, you are not Norwegian”. Since she represented a Norwegian institution, the participants also often treated her as “one of us” but working for “them”. It was manifested in statements like “tell them that we love our older parents”, “can you talk to the commune?”, “can you explain to them that we don’t eat bread for lunch?”. Additionally, questions such as “what are you going to do with the results?” indicated that author 1 was perceived as an outsider during the interview. Author 1 reflected on the research process by conducting a constant internal dialogue with herself, and by discussing the interviews and the analysis with author 2 and other colleagues. By practicing self-reflexivity, author 1 was aware of her positionality and the way it influenced the research process and analysis.

Data analysis

The interviews were transcribed verbatim and translated into English by author 1 and a research assistant. Thematic analysis was performed following Braun and Clark’s (2006) six steps: becoming familiar with the data; generating codes; searching for themes; reviewing the themes; defining and naming the themes; and writing up the analysis. The interview transcripts were coded by author 1 for beliefs and perceptions regarding good dementia care. The coding followed an abductive approach (Timmermans, Tavory 2012). In this process, the researcher used a coding frame which was based on existing knowledge and added new elements that appeared in the data. The codes were categorized and clustered by

author 1. In the fourth phase the themes were reviewed by author 1 and author 2 in order to assure a clear distinction between the themes. In the subsequent part of the analysis the themes were refined.

Ethical considerations

The study was reported to the Norwegian Data Protection Officer for Research (NSD). The researchers followed the internal protocol of Oslo Metropolitan University regarding data security. All respondents were provided with written and verbal information about the study, including securing confidentiality, and gave written informed consent to participate in the study. They were informed that they could withdraw their participation at any time without giving any reason.

Results

The participants talked about different characteristics of good dementia care. Five themes were identified: combining institutional and family care; the attributes and formal/informal competencies of caregivers; ensuring patient-centered, holistic care; dignity-preserving care, and the special role of food.

Combining institutional and family care

The participants talked about different elements of both good institutional dementia care and good family care. They also explained why a combination of family and institutional care at some point was necessary to secure good care. Most of the participants believed that family-based care and support was better than institutional care because it was provided by familiar people and in familiar settings. Many participants said that the family knows their relatives living with dementia best and therefore they can provide the best care. In general, care provided at home was perceived as “good care”, but only until the situation was unmanageable for the family and no longer beneficial for the person living with dementia. In some cases, providing good home care was possible due to help received from the municipality. One of the Norwegian family caregivers explained that he could provide what he perceived as “good care” to his wife at home because he got help from the state in the form of safety devices and an elevator:

All the support we get in the form of supporting materials (*hjelpemidler*) is very good for us and we wouldn't be able to manage without it [M16].

Many participants talked about combining family care with using a day center and/or home-based services, and how this tended to work well. The Polish family caregiver explained that she was able to provide good care to her mother living with Alzheimer's because the mother was regularly driven to a day center. The participant worked every day, and her mother could not stay alone at home. Some of the other participants talked about the importance of the help they got from home-based services, relieving them of many duties and enabling them to continue providing care at home.

Some of the interviewed families were not able to provide what they perceived as good care to their relatives due to work-, health- or family-related reasons. One of the Norwegian participants, whose mother suffered from Alzheimer's, said that her mum would most likely prefer to live at home with her family around, but the participant and her family had no possibility to provide care and the mother was placed in a nursing home:

I don't want to live in a house where it stinks of urine because it does stink. And I don't want to change diapers on my own mother. She has suffered from swallowing trouble. (...) I don't want a person with these health problems in my family, with my husband, with my sons [F19].

She explained further that her mother was in a stage of Alzheimer's where she needed professional help. Since the participant was aware that her mother could not live on her own and the family was not able to provide appropriate care, she believed that institutional care was the best possible care in that situation.

The findings show that even participants coming from countries that have traditionally been more inclined towards family care believed that in cases of severe dementia their relatives could get better help in a care institution than at home. In some cases, family caregivers realized the need to turn to institutional care as dementia progressed and as they learnt more about the illness. When asked about the future, one of the interviewed young Somali family caregivers, said:

The future? ... well ... I don't know, but at some point she (mother) will end up in a nursing home. The doctor told us about the illness, so we know that [F2].

The participant explained that she had a big family and the family members supported each other, and that they managed to cope with the caring tasks. She also described the value of having a good relationship with her mother's doctor from the memory clinic. He had guided the whole family through all the stages of the mother's illness, including the fact that he prepared them for the situation that at some point the mother would have to be placed in a nursing home to assure the

best possible care for her. At the beginning, they were very skeptical about institutional care due to their lack of knowledge on dementia and lack of knowledge about the Norwegian health care system and care culture. They tried to satisfy the mother's care needs by providing care in the family, but with time they seemed to accept the help provided by the state.

All representatives of the health and care personnel believed that at least the final stage of dementia required institutional care, but that it should not mean that the family is excluded from caring. On the contrary, according to many participants representing both family caregivers and healthcare personnel, the combination of institutional care and family care, tailored to patients' progressive needs, would often provide the best possible care. A nurse with a Syrian background explained how she felt about patients who were seldom visited by the family: “Many Norwegian dementia patients get very few visits, and that makes me a bit sad”. She elaborated further on this and said that institutional care should be complemented by family care contributions, for example regular visits or taking patients for a walk. Another participant, a nurse from one of the African countries, claimed that “good care” implied a balance between “no visits” and “too many visits”. She said that many migrant families visit their relatives so often that it negatively affects both the work of personnel and the wellbeing of patients; the patients become tired with too frequent visits and the personnel are unable to perform the necessary care tasks.

All the participants, who were relatives to people living with dementia, stressed the importance of collaboration between the professional and family carers to ensure what they saw as good dementia care. However, opinions differed in terms of the form, frequency, and the scope of that collaboration. For example, one of the Somali family caregivers wished to be involved in all caring activities, but a nurse from the home care services did not want him to disturb her in her work due to time constraints. One of the Norwegian participants, whose mother lived in a nursing home, wished to be regularly informed about her mother's condition and if there was anything she could contribute, for example, by buying her new clothes.

The attributes and formal/informal competencies of caregivers

The well-educated participants and the ones who had knowledge about dementia and dementia care, stressed the importance of multifaceted formal competencies and the skills needed in order to provide good care for people living with dementia.

Three nurses interviewed spoke about the need for staff training in dementia care. They explained that what they learnt through nursing studies was often not enough to work effectively with patients living with dementia. One of them

talked about an insufficient awareness among staff of dementia and intercultural care, which may cause distrust and lead to misunderstandings between the staff in nursing homes and the members of patients' families.

One of the Norwegian participants, whose mother was staying in a nursing home, talked about the personnel's lack of particular communication skills with people that have lost their language and the need for an interdisciplinary workforce in nursing homes:

I think ... the people working there, some of them are nurses, most of them are nursing assistants. I see the need for more physiotherapists. I see the need for social workers. People, who have skills in communicating with people with a loss of cognitive function. That is not included in the curriculum of nursing studies. What do they learn about communication techniques with people who are without the language? [F19]

The participant often visited her mother in a nursing home, where she could observe how the staff organized their work and what was lacking. She had many ideas on how to fill the gaps. For example, she stressed the need for training the staff in communicating with people with cognitive impairments. She believed it would allow the staff to recognize and respond to patients' needs, and in this way provide better care.

The findings show that the participants, who provided care across borders, placed particular emphasis on the importance of appropriate formal and informal competences among caregivers. Due to geographical distance, however, the participants had limited possibilities to control the situation. One of the Polish women who was interviewed explained:

I know that my mum is taken care of. Our Ukrainian carer is very nice, very competent and responsible. She knows how to care for my mum [F10].

The participant explained that the Ukrainian caregiver had knowledge of dementia, and in addition, she had worked as a caregiver before. It made the participant trust the carer's competencies, and as a result, she believed that her mother received "good care".

Other participants associated attributes such as "being kind and nice" as important characteristics for a dementia caregiver. To show or provide "love", "patience", "empathy", "warmth" or being like a "sunbeam" were other important features emphasized when describing important attributes. Several also stressed the significance of having a personal relationship with people living with dementia.

Ensuring patient-centered, holistic care

Many participants emphasized that “good care” first of all implied care tailored to the individual patient. A representative of the Somali community explained that people are different and they may have different needs:

It depends on how each person defines it (good dementia care) and what they need. It is different for different people (...). When I say, “someone takes good care of you”, I do not mean someone who provides food and drinks, I mean love, comfort and all that may be, all that you may need [F30].

The participant gave a few examples to illustrate what personalized care meant for her. For instance, she believed that people had different lifestyles and this should be respected by caregivers; for example meal times or leisure activities.

Many participants talked about recognizing and meeting individual patients’ physiological as well as emotional needs. A Polish participant, whose mother was suffering from Alzheimer’s, said:

Good care means that we care about the physical, emotional and psychological wellbeing of the individual. The emotional aspects are very important. For example, it is very important for my mum that someone talks to her all the time [F1].

The participant explained that it was not enough to serve meals, give medicines and help ensure personal hygiene. Her mother had many other needs that needed to be taken care of; emphasized by the participant when she said “we are all more than a body”.

Some of the representatives of migrant communities as well as family caregivers stressed the importance of a holistic approach in relation to dementia patients’ needs. Important elements of “good care” were “being with that person, so she knows she is not alone” (a representative of the Pakistani community), “keeping her active” (a representative of the Turkish community).

All the participants working in nursing homes talked about aspects of “feeling patients’ needs”, as one Polish nurse explained:

Good care means that you help them with what they need and you are there for them. You have to feel their needs. You have to put yourself in their shoes. You cannot just work in a nursing home. It is more than work. You must be there for the patients [F21].

The participant highlighted the importance of empathy in recognizing patients’ needs, and emphasized the ability, but also the will to understand the particular

life situations of patients and their particular needs. Some of the relatives of people living with dementia complained about the attitudes of health and care personnel working in nursing homes. A participant from one of the Balkan countries expressed his opinion in the following way:

Many people working in nursing homes have that “I don’t care” attitude. They need to show some understanding, some empathy [M8].

The participants’ mother was staying in a nursing home and he often visited her. His impression was that the personnel had a very indifferent attitude towards patients and did not know or address either the overall or the particular needs of the patients because of lack of engagement.

Patient-centered care requires that time is invested in getting to know the patient. Many of the participants, representing healthcare personnel as well as family caregivers, talked about the meaning of time shared with people living with dementia. One of the nurses working for home services explained that she always found time to talk to a patient, drink coffee and eat biscuits “even if the plate was dirty”. She could see that spending time together, even if it was only for some minutes, made patients happy. Two other nurses talked about their frustration resulting from the fact that they did not have enough time for patients due to staff shortages in the nursing homes. The Austrian and Finnish transnational caregivers talked about “the quality time” they spent with their parents living with dementia. The Austrian participant explained that good dementia care “is to try to make the time that is left (before a person passes away) as good as possible”, showing that investing in time together with the person living with dementia constitutes an important form of good care.

Dignity-preserving care

It was very important for some of the participants that the care provided preserved the dignity of patients. A young man that was providing care for his father, who came from one of the islands in the Atlantic Ocean, explained what good care meant for him:

(...) that he gets a better life. That he feels good about himself. He has contributed to building the country. That he gets a dignified old age. It is about his dignity [M4].

The participant stressed the fact that his father had worked in Norway for many years and that he deserved something in return – good care that would preserve his dignity. He mentioned having bad experiences with people from the municipality

who coordinated dementia care. They spoke Norwegian although “he (the father) had forgotten many Norwegian words and it is very difficult for him to communicate in that language”. According to the participant, people from the municipality were disrespectful to his father, this was because, due to the language barrier, they did not include him in conversations. The participant was aware that it would be difficult to bring an interpreter each time the dementia coordinator or nurse visited his father. For this reason, he decided to provide care without help from the municipality to make it easier for the father. However, he worried about the future, especially about the point in time where the father would have to be moved to a nursing home.

According to one of the Somali participants, the health authorities did not care about his cousin’s needs, and they tried to force “the Norwegian way of caring for dementia patients” upon him, which implied not being flexible nor inclusive with the patients and their relatives. The participant explained that his cousin felt ignored and powerless, and he described how he tried to strengthen a sense of self-dignity in his cousin who was living with dementia:

I like to show him (...) that he is no different than I am and that he has the right to receive medical care from the government. He has been a good and active citizen; he was never involved with drugs or drunk alcohol before. He was a very clean person [M3].

The quote illustrates that migrants may feel guilty when they get ill, and they need help. The participant explained that his cousin’s memory problems were neglected by the GP for a few years and that he often felt like “a second-class citizen”. Therefore, the participant was very skeptical about placing his cousin in a nursing home in Norway, as he was afraid that the cousin would not be treated with respect.

Some of the other participants talked about dignity in the sense of treating their relatives/patients living with dementia “like before”. One of the Norwegian participants, whose mother was staying in a nursing home, said:

You need to treat them like before. Inside she was still my mother. She still had feelings as before, only her condition changed her [M20].

Many of the interviewed family caregivers stressed that in order to provide good care it is important to treat people living with dementia like adults even if they sometimes behave in irrational ways.

The special role of food

Food was a special theme present in most interviews. The participants gave various reasons why food was important in caring for people living with dementia. They included health, cultural value, religion, and respect for the individual. Well-educated participants often mentioned “healthy” or “nutritious” food as a sign of good care. One of the interviewed Norwegian women, whose mother lived in a nursing home, criticized the staff working there for serving too many cakes to patients:

There was a meeting last year when we (the relatives) asked “can we change food times for meals and would it be possible for you to drop the daily cake and put in some fruit instead?” I asked them at that time, “what do you do with the fruit?”. They said “Ah, well, we have fruit every Saturday if we remember to order it (...)”. Every day they had a cake in the afternoon. I couldn’t believe my ears” [F19].

According to the participant, such a diet was very unhealthy for patients who spent most of the time inside and who were at risk of obesity. Two participants working in nursing homes spoke about the challenges they faced serving food delivered by catering companies to patients. One of them said “it is not good care if patients have to eat undercooked vegetables that are impossible to chew”. She explained that the food was provided by the catering company and the staff’s role was to heat it in the microwave.

For many other participants, food was an important factor that could increase the quality of life; thus making people living with dementia more content. Therefore, they should be served the food they liked. The participants from minority ethnic groups often talked about the serving of mainly typically Norwegian food in nursing homes or day centers. One of the nurses working in a nursing home explained:

We celebrate Norwegian holidays in the nursing home and we try to respect Norwegian traditions. A few days ago, we served *fårikål* (sheep in cabbage), aquavit and beer [F21].

The participant was aware that older patients with minority ethnic backgrounds might have different dietary preferences, and that many were not used to the food traditionally served at Norwegian institutions. One of the Polish participants who provided care for her mother living with dementia, talked about their experience with food served in a day center for elderly people. They were often served meat on Friday, which was problematic because the participant’s mother was a Catholic and she practiced the Friday Fast, including abstaining from meat, other than fish,

on Fridays. For the participant, serving food that met people’s religious dietary requirements was an important element of what constituted “good care”.

The findings show that for two participants from minority ethnic groups food was associated with respect, and thus also with good care. A family caregiver, whose father came from one of the islands in the Atlantic Ocean, talked about home-based services and what he considered to be a lack of respect for his father living with dementia. He said: “They serve bread for lunch. They don’t respect him”. He believed the personnel in charge of the home’s services should have asked about his father’s dietary preferences, and not take for granted that bread (a typical constituent of the lunchtime meal for many Norwegians) was a valid option. Not adjusting to his father’s dietary preferences seemed to create distrust towards Norwegian care institutions and the quality of care provided.

Discussion

The main aim of this qualitative study was to explore how good dementia care was described by family caregivers, key representatives of migrant groups, and representatives of health and care personnel, working with people with dementia.

Our study shows that the participants, who were representative of different ethnic groups, shared a very similar definition of good dementia care and believed that its most important element was to recognize the individual needs of people living with dementia and to tailor the care accordingly, which is one of the principles of patient-centered care (Kitson et al. 2013). Despite the similarities, we also found some differences in participants’ perceptions of the elements that are important for providing good dementia care. Our findings suggest that good care was associated with a caring situation where the family were the main contributors. However, a combination of family care and home-based services, providing assistance in the shape of necessary equipment and other types of care relief, was seen by many participants as the best possible care, which is in line with other studies on dementia care (Helleberg, Hauge 2014; Ericson et al. 2001; Szluz 2022) and dementia care focusing on migrants (Sagbakken et al. 2018). Our study suggests that migrants’ social and moral norms related to family caregiving often change with time. The second generation of migrants are exposed to the culture of care of the country of immigration and they tend to accept some of its elements.

The findings also show that some participants with minority ethnic backgrounds, both family and professional carers, were skeptical about institutional care due to culturally defined family caring obligations and negative experiences with the Norwegian health care services, perceived as poorly adapted to the needs of people with minority ethnic backgrounds. With regard to this, our findings are

in line with studies from Denmark and Norway (Nielsen et al. 2020; Sagbakken et al. 2018; Naess, Moen 2014). A Danish study suggests that migrants avoid institutional care for two reasons. First, they want to follow the cultural norms related to family obligations of care, and second, the available services for people living with dementia rarely meet the specific needs of people from minority ethnic groups (Nielsen et al. 2020). A Norwegian study on dementia and migration shows that migrants often associate nursing homes with poor care and they are treated as the last option (Sagbakken et al. 2018).

Our study highlights the importance of collaboration between families and institutional caregivers in providing good dementia care. According to many of the study participants, it is appropriate to involve the family in decision-making and to recognize their needs and contributions. Family involvement is considered to be an important element of patient-centered care (Gerteis et al. 1993), however, it is not clear how healthcare professionals should support it (Wolff, Jacobs 2015).

Our findings show that some participants, both family caregivers and professional caregivers, tended to believe that good dementia care implies involving competent care givers with formal education in geriatric care and good knowledge of dementia. Other participants valued a different type of knowledge, attributes and informal competences resulting from a personal relationship with the person living with dementia. Working effectively with people living with dementia and their families, recognizing their needs, requires care workers who are knowledgeable and skilled in dementia care.

As evidenced from our findings, all the participants believed that good dementia care should be tailored to individual patient's needs, which reflects one of the main principles of patient-centered care. These findings are in line with several international studies (Ericson et al. 2001; Helleberg, Hauge 2014; Hamiduzzaman et al. 2020) that explore the expectations and views of family caregivers and healthcare staff regarding good dementia care. A systematic review and meta-analysis of literature on the effectiveness of person-centered care in relation to people with dementia shows that individualized, person-centered care may improve the quality of life of people living with dementia (Kim, Park 2017).

In our study, we found that treating persons with dementia with respect and preserving their dignity is considered to be an important element of good care. At the same time, it is one of the key points of patient-centered care (Coulter, Oldham 2016). Scandinavian studies show that ensuring dignity is considered important both in care provided by home-based services (Søvde et al. 2019) and in nursing homes (Sagbakken et al. 2017; Nâden et al. 2013).

Additionally, our study highlights the importance of food in good dementia care. Numerous previous studies have emphasized the special role of meals in institutional care settings (Evans et al. 2005; Cooney 2012; Milte et al. 2017). Meals

can be a source of positive emotions and enjoyment when patients are served food they used to like when they were younger (Hanssen, Kuven 2016). In the case of patients with minority ethnic backgrounds, serving traditional food may increase the feeling of being respected and taken care of (Hanssen, Kuven 2016). According to Milte et al. (2017), food is not only about meeting the nutritional requirements of people with dementia, but it can significantly influence their quality of life. Therefore, food should be adapted to the special needs of people living with dementia, and to their personal preferences. The Norwegian participants in our study, as well as health and care personnel, emphasized food maladjustment for dementia patients in nursing homes. Dementia patients often suffer from dysphagia and they may need texture modified foods (Ilhamto et al. 2014). It also often happens that staff in nursing homes have no time to adapt the food delivered by catering companies to the needs of dementia patients. Understanding one's food preferences and religious dietary restrictions is another element of good, personalized dementia care (Mendes 2015; Daker-White et al. 2002; Warburton et al. 2009). According to studies conducted in South Africa and among ethnic Norwegians and the Sami in Norway (Hanssen, Kuven 2016), traditional food positively influences the social, mental and physical wellbeing of people living with dementia. Our findings suggest that food preferences are seldom considered in caring institutions, which is against one of the principles of patient-centered care that should involve providing choices and preferences.

The findings shed light on perceptions regarding good dementia care among people with different ethnic backgrounds in Norway. They may facilitate interaction between various actors involved in care provision to people living with dementia, as well as assure better care planning.

Conclusions

The findings imply that the perceptions of good dementia care coincide with the notion of person-centered care that is respectful of all persons and has a focus on the quality of the care that patients receive. It is about respecting people's values and putting people at the center of care while, to provide high-quality person-centered dementia care, care providers should focus on patients' individual needs. The study also shows the appreciation of specific attributes and informal competences among caregivers, and it emphasizes that sometimes they may be as important as other qualifications. And, although the participants' individual definitions of good care have many common elements, they also differ. These differences are the result of the uniqueness of human experiences.

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