‘What matters to you?’—a qualitative study on the views of nursing home residents with dementia regarding the health care they receive

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Abstract

Aims and Objective: This study’s aim is to examine what matters to nursing home residents with dementia by exploring their perceptions of nursing home health care through the conceptual lens of person-centred care.

Background: Dementia is a major contributor to nursing home placement. To understand the meaning of living with dementia, the inclusion of persons with dementia in research studies is essential.

Methods: In total, 35 in-depth qualitative interviews were conducted with people who have dementia and live in nursing homes. A thematic analysis was applied to analyse the data. Checklist for qualitative studies: Consolidated Criteria for Reporting Qualitative Research (COREQ) https://www.equator-network.org/reporting-guidelines/coreq/.

Results: The analysis revealed one overarching theme with four sub-themes. Different matchings of person-centred care and routines in health care being the overarching theme. The four sub-themes were as follows: (a) understanding of the interplay between disabilities and ageing; (b) participating based on one’s own preferences and needs; (c) incongruence between the person with dementia’s preferences and needs and health-care support; and (d) working conditions: the relationship between residents and health-care providers. Despite the substantive focus of researchers on person-centred care and the positive impact on the nursing home health care of those who receive it, the results showed that nursing home residents still want more person-centred care.

Conclusions: The results indicate that the incongruence between general routines and individual preferences and needs, as well as the demand to operationalise the person-centred dimensions of health-care behaviour in nursing homes, must be resolved. Health care in nursing homes must focus on enabling residents to participate in daily activities and sustain their personhood and sense of self.
1 | BACKGROUND

A person with dementia experiences a decline in memory, problem-solving, language and skills that affects their ability to perform everyday activities. Dementia is a main contributor to nursing home placement (Alzheimer’s Association, 2019; García-Ptacek et al., 2017). High-quality health care delivered by health-care providers via a municipal service is important for people with dementia (García-Ptacek et al., 2017). The World Health Organization (2018) defined quality health care as effective, efficient, integrated, person-centred, equitable and safe. Milte et al., (2018) presented five key domains significant for cognitively impaired residents in nursing homes: feeling at home, own room, care staff being able to spend enough time with residents, feeling at home in shared spaces, and staff being very flexible regarding care routines. Providing care for people with dementia is particularly complex and challenging, and here, the residents’ preferences and needs are critical. In research, including the views of people with dementia is necessary to secure relevant findings (Kelly et al., 2015). Edberg et al., (2008) mentioned the difficulties associated with care of people with dementia, referring to environmental factors such as the system, community attitudes, other staff and residents’ family members as contributors. Regarding care of people with dementia, three main sources of strain have been identified: being unable to reach the person beyond the facade of dementia, difficulty protecting patients and having to balance competing needs (Edberg et al., 2008, 2015). Quality of health care and well-being improve with a positive attitude that focuses on individual patients’ abilities (Gerritsen et al., 2019).

To understand life with dementia, it is essential to include persons with dementia in research studies. With their perspectives, important values and unique insights highlight how people with dementia experience living with this disease. Providing a person with dementia, the opportunity to participate in relevant research is also essential to address their vulnerabilities (Alzheimer Europe, 2019). Individuals with cognitive impairment can provide valuable information about their care experiences (Bartlett et al., 2019). According to Bolt et al., (2021), many studies have focused on how people with dementia not living in nursing homes feel about their futures and being cared for by others and how to adjust care provision to match their standards. However, research is needed with respect to those living with dementia in nursing homes and their perspectives on received health care. Bolt et al., (2021) stated that health-care providers should build equal and trustful care relationships with persons with dementia and their family caregivers; one should acknowledge ‘(see)’ the person with dementia and become well acquainted with them. Research based on the question ‘What matters to you?’ will provide important knowledge in the field of dementia care.

1.1 | Conceptual framework as a lens for understanding: Person-centred care

A person-centred approach is important to improving health care in nursing homes. Nicholson (2020) stated that there is a poor understanding of the complexities of living with dementia and the multifactorial interventions needed to provide holistic and effective support. A combination of a biopsychosocial approach with person-centred care (PCC) principles in health care for people with dementia has been called for (Nicholson, 2020). Kitwood (2007) criticised the biomedical approach to care for people with dementia for showing an insufficient understanding of individuals’ mental and emotional states. Kitwood (2007) stated that a humanistic, ethical approach in which the illness is not the primary focus is vital to patients. Kitwood (1998) provided the groundwork for supporting the experience of sustained personhood: it focuses on how people are recognised as unique individuals. Washburn and Grossman (2017) suggested the need for a relationship between the health-care provider and the care recipient—out of respect for the
recipient’s personhood and as evidence that his or her perspectives are being considered.

PCC can be seen as a set of techniques for working with clients (e.g., nursing home residents), a set of values, a means of communication and/or an aspect of health-care quality (McCormack, 2003). To provide the best care, health-care providers should be respectful of each person’s preferences, needs and values, ensuring that the person’s unique values guide clinical decisions and that the person is engaged with his or her own care process (McCormack, 2003). Person-centred processes deliver care through a range of activities, including working with patients’ beliefs and values, engaging authentically, being sympathetically present, sharing decision-making and providing holistic care (McCormack & McCance, 2017). Eklund et al., (2019) stated that person-centred care and patient-centred care might be the same; however, the goal of person-centred care is a meaningful life, while the goal of patient-centred care is a functional life. Eklund et al., (2019) enumerated nine themes present in person- and patient-centred care: (a) empathy, (b) respect, (c) engagement, (d) relationship, (e) communication, (f) shared decision-making, (g) holistic focus, (h) individualised focus and (i) coordinated care. Patient experience is a central pillar of quality in health-care improvement (Ocloo et al., 2020). Barry and Edgman-Levitan (2012) proposed the question ‘What matters to you?’ as well as ‘What is the matter?’ The question ‘What matters to you?’ can be used for personal goal setting, serving the ideal that—in the context of this study—the nursing home residents are given opportunities to determine and strive towards personal goals (Olsen et al., 2020). The question ‘What matters to you?’ prompted us to explore the topic of residents’ perceptions and experiences of what matters to them regarding health care in their nursing homes. To the authors’ knowledge, no studies have used the question ‘What matters to you?’ for nursing home residents with dementia regarding their own experiences with nursing homes as health-care institutions. The question ‘What matters to you?’ was introduced by Barry and Edgman-Levitan (2012) as a way of implementing PCC. The present study’s aim is to examine what matters to nursing home residents with dementia by exploring their perceptions of nursing home health care through the conceptual lens of person-centred care. Greater insights into nursing home residents’ perceptions will benefit health-care receivers, health-care providers, researchers and stakeholders in the field of dementia care. This study contributes to the development of the body of knowledge concerned with residents’ preferences, needs and values.

2 | METHODS

2.1 | Study design and setting

This article is one of two from a larger qualitative study on what matters to nursing home residents with dementia regarding the nursing home as a home and as an institution for health-care services. The authors refer to a previous publication from this larger study: ‘What Matters to You’ When the Nursing Home is Your Home. A Qualitative Study on the Views of Residents with Dementia Living in Nursing Homes (Nygaard et al., 2020). While the aforementioned article focuses on the residents’ perspectives of nursing homes as their home, this new article highlights what matters to nursing home residents with dementia by exploring their perceptions of nursing home health care through the conceptual lens of person-centred care. The study takes a qualitative design that is hermeneutical perspective based. According to Gadamer (2004), understanding is influenced by prejudices, and the present must be understood in light of the past. Our understanding of an experience is a fusion of the present and past based on the polarity between familiarity and strangeness (Brinkmann & Kvale, 2015). Analysis of the interviews was based on a hermeneutical perspective, which guided the interpretation of the residents’ responses based on their experiences (Gadamer, 2004).

This study aims to improve the understanding of dementia and its impact on individuals, health-care providers, families and the broader community (Carmody et al., 2015; Eriksen et al., 2016). Qualitative approaches can capture the interest of health-care providers, who have been ‘underexploited’ as a way to improve care. Because several studies recommended using a qualitative design to address issues for those experiencing dementia, qualitative interviews are used. This study was conducted in nursing homes (n=3) in a large municipality in Norway. All three nursing homes have units dedicated to people with dementia, which is where the study’s residents lived. The residents did not express similar experiences with the nursing homes as their health-care institution. The differences between the nursing home facilities exist mainly because when they were built. This manuscript was prepared in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) https://www.equator-network.org/reporting-guidelines/coreq/ (Supplementary File 1).

2.2 | Residents and recruitment

In total, 35 nursing home residents all diagnosed with dementia participated, representing a convenience sample (Ilker et al., 2016). Ethical guidelines require that either the residents or their caregivers be able to understand the written and oral information about the study and be willing to participate in it (World Medical Association, 1964).

The inclusion criteria were being diagnosed with dementia, being long-term residents and being able to express themselves. The exclusion criteria were short-term stay. The participants were recruited by the manager of the nursing homes, and the team leaders in each unit identified potential residents for inclusion. The residents and their caregivers were informed about the study’s goals and asked whether they wanted to participate. The residents provided oral and written consent, and their caregivers verbally agreed to residents’ involvement. Given the severity of cognitive impairment in three of the participants, written consent was obtained from their caregivers. Two residents declined. One spouse stated that her husband was unable to express what mattered to
him. In two interviews (P23 and P32), the residents’ daughters were present because they were visiting. The daughters remained quiet during the interviews. The terms participant and resident are used synonymously, and in the current study, resident refers to nursing home residents. The quotations from the residents illustrate their experiences of the phenomenon of interest. Quotes are presented in italics followed by a number referring to which of the 35 residents gave the quote.

Malterud et al., (2016) proposed the concept of information power as a guide for adequate sample sizes for qualitative studies: the more information the sample holds that is relevant to the actual study, the fewer residents are needed. Malterud et al., (2016) suggested that information power address sample specificity, use of established theory, dialogue quality and strategy of analysis. All available residents were interviewed, and the sample size yielded sufficient information power based on the study’s aim, the sample specificity and the quality of the interviews (Malterud et al., 2016). Saturation from having sufficient information power was achieved before the last four interviews, which yielded no new information.

2.3 | Data collection

The first author, who conducted the interviews, in addition to running PhD has more than 20 years clinical practice as a nurse in dementia care. The interviews were conducted in the residents’ rooms, where they spoke freely and felt safe. The first author introduced herself and the project before starting the interviews, and the first author had not met any of the residents previously. Unstructured, in-depth, qualitative interviews were conducted in the form of an extended conversation between the researcher, first author and residents. The interview guide consisted of the following three main questions: (a) What is a nice day for you in a nursing home? (b) What matters to you regarding the health care you receive? (c) What must the health-care provider be able to do to meet your needs? Or do you have any suggestions for changes in the unit? The researcher had a general topic in mind for the unstructured interviews, related to the main interview question, ‘What matters to you (regarding the health care you receive)?’ Additionally, the first author formulated specific questions as the interviews proceeded in response to what the residents said to encourage them to answer at length and in vivid detail (Rubin & Rubin, 2012). Follow-up questions were added to explore topics related to the PCC framework. The follow-up questions were about whether the residents perceived health care as being individualised, respectful, allowing for the negotiation of care and offering them choices and involvement in health-care decisions of importance to them. Throughout the interviews, the first author observed how the residents were feeling and whether they became uneasy and/or expressed that they wanted to end the interviews. The interviews were conducted between October 2018 and April 2019, typically in the morning or early afternoon. The interviews ranged from six to 60 minutes in length, averaging 44 minutes. Only one interview lasted for six minutes; the rest were 36 minutes or more.

2.4 | Data analysis

The first author audio-recorded the interviews and then transcribed them verbatim. The field notes made after the interviews were not included in the analysis. The data were subjected to a thematic analysis, a method developed by Braun and Clarke (2006) to identify, analyse and report themes and describe patterns across qualitative data (Braun & Clarke, 2006). The authors—all female and, at the time, included three nurses and a physiotherapist—made their preunderstandings and existing knowledge about the context explicit. All authors have extensive clinical and/or research experience within the field of health care for older people and people with dementia. Accordingly, the first author had a preunderstanding of everyday life in a nursing home. Furthermore, the researcher’s preconception was that the quality standards of care for nursing home residents were being poorly met. All the authors’ experiences meant that there were probably certain things that ‘blinded’ to; however, the authors were also well positioned to understand the context and perform the study (Beedholm & Frederiksen, 2019; Berger, 2015). For example, the research question was based on an identified knowledge gap and on personal interest. The first author did not share her preunderstandings with the residents, allowing open discussion of both positive and negative experiences. Trustworthiness was strengthened through established theory and quotations. To promote reflexivity, in an early phase, the first author wrote a ‘researcher identity memo’ to clarify her preconceptions. This memo was the beginning of a reflexive mapping process that continued throughout the research process. In this ‘diary’, the researcher wrote her thoughts, observations, methodological considerations and decisions, including the rationale and logic behind them and reflections on situations in terms of her own interests or values (Berger, 2015). Awareness of nursing home procedures and knowledge of the preferences and needs of residents and caregivers helped the researcher better understand the context. The researcher was open about her background as a nurse and her professional work experience in the field. The use of theory may have helped the researcher maintain a distant and reflected approach to the data; however, it could have shrunk the researchers’ theoretical perspective. The authors attempted to present the analysis process transparently based on Braun and Clarke (2006) six phases of thematic analysis: (a) Become familiar with the data. All four authors separately read and reread the transcripts and noted coding; then, in a face-to-face meeting, the authors discussed, compared and shared their overall understandings of the data to determine its essential meanings. (b) Generate initial codes. The authors separately generated initial codes on the transcripts manually and then met to compare their codes and construct a mutual coding tree (see Table 1). No software was used for the thematic analysis, as all the co-authors wanted to read the manuscript several times when coding and they wanted transparency and closeness to the data as well as to write and link memos to assist with the audit trail. The authors’ choice to
and under the following headlines: identified central quotations and inserted them into a common matrix—fied central quotations and inserted them into a common matrix—and Johnson (2000). (c) Search for themes. The authors identified software was based on the reflection presented by John Guba (1985): credibility, transferability, dependability and confirmability. Credibility was ensured through unstructured, in-depth qualitative interviews, a detailed and descriptive analysis of the data and quoting the residents’ responses to substantiate the findings, thus enhancing their transferability. To increase dependability, the transcripts were reviewed several times and then coded and checked by each author. Interpretations were also based on a consensus among the authors. Confirmability was reached by substantiating each emergent sub-theme with quotes extracted from the residents’ statements.

### Funding and ethical considerations

The Regional Ethical Committee considered the current study to be outside the scope of the Norwegian Health Research Act (ref. REK (Sør-Øst) 2017/1591-3). The Health Research Act and the guide provided by the Ministry of Health and Care Services define what is considered medical and health research in Norway. The present study was registered by the Norwegian Centre for Research Data. This work received funding from the Research Council of Norway (grant number OFFPHD prnr 271870), Oslo Metropolitan University, and the municipality in which the study was conducted. The funders had no role in the study’s design, data collection and analysis, publishing decisions or manuscript preparation. Both the residents and their caregivers were also informed that they were free to withdraw their permission to be involved at any time during the interview (World Medical Association, 1964).

### RESULTS

In total, 35 residents were included. Table 2 shows the background characteristics of the residents.

In the analysis, one overarching theme and four interrelated sub-themes emerged (Table 3).

The overarching theme, Different matchings of person-centred care and routines in health care, indicates tension between a health care focused on maintaining residents’ personhood, interests and wishes...
and a health care characterised of routines. The different matchings are presented in the four interrelated sub-themes (Table 3). The residents experienced the nursing homes as health-care institutions that adhered to fixed, generalised, daily routines that permitted little individualised variation or choice.

3.1 Understanding of the interplay between disabilities and ageing

The residents missed the feeling of being an individual with their own preferences and needs and missed personalised and tailored PCC. They talked about their previous lives as being part of their identity, indicating that it was important for health-care providers to have knowledge of their past to understand and support their current needs. They reported, however, that the health-care providers seemed to forget the person behind the dementia disease and their age, expressing that their feelings and experiences of being affected by dementia and living in a nursing home in general were not taken into account.

Most residents focused on their life stories and feelings of sustained personhood. Some talked about their past lives and what they were proud to have achieved, and they wished the health-care providers were curious about that. They seemed happy with these memories, as the following shows:

*I am 87 years old and have sailed around the world and lived a very rich life….Now I am a dependent person who need help with everything.* (Participant [P] 35)

With a certain awareness of their situation, some reflected on their age and the decay of their bodies, expressing that they could not contribute as they had before. For some, this was a relief; for others, it created feelings of despair. One interviewee stated the following:

*I look at my arms, which have become so thin.* (P25)

Another said the following:

*I cannot lift my arms higher than that [a bit up] If I’m going to comb my hair then I have to do it like that [bending his head].* (P35)

One resident described how health-care providers failed to support her comfort and well-being:

*I could only imagine if they had the time to turn the duvet probably to make it more comfortable for me when I feel hot and sweaty; I would be happy. [But] I am dependent on them.* (P14)

Being seen and heard is important in health care for the residents of nursing homes, who like opportunities to express their thoughts, preferences and needs, which was reported as important to give their lives a feeling of contentment despite dementia. Talking about politics in the nursing home, for example, can be a sensitive issue. One resident said the following:

*We talk the most. What we don’t talk about and [what] I don’t think is appropriate is political. I think there’s no point in talking about that.* (P19)

Some residents reported that it was difficult to express their needs and feelings because they feared the consequences from the health-care providers. It might be, for example, that they would not get the help they needed or that the health-care providers would not be nice to them. The residents feared that the health-care providers would take it as a criticism if they mentioned what they wanted. One resident said the following:

*Here, I feel like I want it. Nobody complains about me, and I don’t complain about them. I am fine, and it is no use for me to complain. It is no use...* (P19)

3.2 Participating based on one’s own preferences and needs

The residents appreciated engaging in their own care. Some highlighted the importance of opportunities to participate in daily tasks based on their needs and abilities. It was important for the residents to decide when to get up in the morning, when to go to bed, whether to enjoy alcohol or which clothes to wear, for example. Their statements indicated that they were required to follow the nursing home’s routine and that their own preferences were seldom taken into account.
The residents felt that it was important to have some control and choice regarding everyday life. One resident stated the following:

Here, I am my own master. When I get up, when I want to go to bed, I say we will go to bed for nine hours, and then, it will be quiet. (P8)

It could be difficult for residents to understand that they must do something they do not want to from a health perspective, for example. The residents referred to the practical consequences of such measures, suggesting they felt a lack of control and power. One resident said the following:

They [health-care providers] think I drink too little. I think [I drink] four glasses of water or milk or whatever. When you go to bed, you have to pee half the night. (P12)

The routines at the nursing home could also be a barrier to the perceived quality of care. Some residents wanted to decide when to get up in the morning, for example. One interviewee said the following:

They [health-care providers] wake you up. If you are not up well before breakfast, then you will be awakened. I often sleep poorly at night and therefore prefer to snooze a little longer in the morning. I would like to be asked if I had slept badly and therefore need to sleep a little longer in the morning to have a good day. (P1)

The interviews reflected how the residents expressed themselves as unique individuals. Dressing nicely and using a bit of make-up, for example, were important for the residents’ well-being and experiences of health care. One resident said the following:

Sometimes, we want to decorate a little extra, and then, you know ... Must look a little pretty too... I think it is fun to wear good clothes then too. (P22)

Some residents enjoyed alcohol when they lived in their own home and wanted to continue drinking it in the nursing home. The interviews indicated that residents felt a lack of PCC and shared decision-making in the nursing home. One resident spoke about a fellow resident who enjoyed a beer daily, something that was important to her:

This drinking should not have been legal, she says, but to drink half a beer every day, it does no harm. That's what she likes, so it doesn't hurt anyone. (P12)

Taking care of themselves and contributing to self-care mattered to the residents; however, they also indicated that it was good to get help when needed:

Those [residents] who are unable to stand up from bed themselves who have a painful back and are otherwise helpless and hurt in the joints, are given help to come up to dress. Otherwise, we try as best we can to manage ourselves. It's kind of the best thing to get up yourself. (P14)

The residents focused on how they were recognised as unique individuals rather than patients; they wanted to be cared for as a person. One resident wanted to help set the table but was unsure whether the health-care providers liked her to do so:

A good day is that I get up in the morning and set the tables, but I don't know if they [health-care providers] perceive it as help ... I am not so sure, actually. (P33)

Conversely, the residents who had limited abilities to contribute to daily activities expressed appreciation that the health-care providers did not expect the residents to contribute to daily activities.

The health-care providers do every job. We're just having fun here ... We do nothing ... the only thing we do is take the knife and fork... The bread slices are ready to be eaten. There is lovely food, and those who work in the kitchen here should have had a gold medal. They do a fantastic job. (P16)

### 3.3 | Incongruence between the person with dementia's preferences and needs and health-care support

It seemed important that the health-care providers combine interpersonal competences and practical skills in their daily practice to meet the compound, complex and very different preferences and needs of the residents. The incongruence between the residents’ preferences and the health care they received has an important impact on the residents’ well-being. The health-care providers reported they would ‘work separately’ to cope with dementia rather...
than ‘working together’. One resident expressed that little attention was paid to how it felt to be naked in front of the health-care providers when receiving help with showering:

One thing I have learned is that it is no use being shy here in the house. Then they come and tear off all my clothes. They [health-care providers] also stand and wash me here and there, you know.... and then they hear it back. Then, I say that if you are going to shower me then you should stand here naked too. Then you can just undress, and I will shower you too, I tell them. (P19)

More than one resident cited showering as being uncomfortable. Another was not satisfied with the showering and wished to be dried on her back afterwards:

I'm not so excited about it [showering] because I get so cold... Better to wear clothes, I think... There are usually two [health-care providers], but only one manages the shower then. Also, it is so nice to be dried on my back ... I am itching my back very well then. (P22)

Sleep is important to health. Some residents talked about their experiences with sleeping pills. One resident was not excited about using sleeping pills:

I've never slept so well. I have sleeping pills, but I'm not that fond of it. (P12)

Another resident had used sleeping pills for several years before moving into the nursing home and wanted to continue using them:

I get sleeping pills and I have had them for many years from my GP, ... 'and I should have them here [nursing home] too', I said [laughs]. I'm a bit stubborn then. I told the nurses I should. I have had [the sleeping pills] for over 15 years. Sure enough, I got the [sleeping pills] then. 'I am over 90 years' I said, 'and why should I not feel good in my 90 years because I cannot sleep at night'? They said, 'Yes, that's true. You should get them'... So now I usually sleep at least half the night. (P31).

Most residents praised the food:

You can enjoy every meal because there is a lot of good food. (P22)

One resident was sceptical about food in the nursing home that he was not used to:

Nothing to say about it [the food] I must say, as it is foreign, a bit on the edge of the Norwegian [food]. (P28)

It was important that the health-care providers followed up on the residents’ dental status so that the residents could enjoy their meal experience. One resident reported mouth pain:

Sure, the food is good. I have a little pain in my teeth now. The dentist has taken care of them, but they are bad. (P26)

Many residents had issues with ill-fitting hearing aids. Some felt that the ability to hear properly was not prioritised by the health-care providers. One stated the following:

They [the health-care providers] say I have it [hearing aid] here, but I don't know. I have heard nothing more. (P25)

Some residents found hearing aids painful, and others preferred to not wear the aids at all. One resident said the following:

I don’t use them [hearing aid]. I think I hear what I want to hear. (P26)

3.4 | Working conditions: the relationship between residents and health-care providers

Several residents highlighted the importance of developing a relationship with and confidence in the health-care providers, as well as health-care providers’ knowledge about each resident. The residents observed that the health-care providers were busy, so they did not want to disturb them unnecessarily. At the same time, having proper access to health-care providers was identified as a significant need for many residents. One expressed this need as follows:

The girls are so kind. I ask for something, then they say they can do it, but I can’t stress too much on them either, I mean. Something small I must be able to do myself. (P7)

Another resident stated that there were many health-care providers to deal with:

There are so many names. I do not know who is who from the other. Now, I have been here for 10 years, I think, as a patient.... even so, I do not know the person who cares for me. (P12)

What mattered to the residents was trusting the health-care providers so they could alert them to whatever they felt was important. Most sought respect from their caregivers, regardless of disability. One resident expressed a complete lack of confidence in the health-care providers, saying she felt they did not care about the residents:

It’s hard to talk to them [health-care providers] about anything special. I dare not tell them what they should
Some residents experienced kindness from health-care providers, but one felt they lacked knowledge about each resident:

Care? Yes, they are good, very good... and they do not follow you up ... Yes, the team leader is a very good lady, very nice lady, but she is too weak, she doesn’t dare set the agenda. The thing is not solved; they just keep going. There is so much she could do... They are good at what they can, but they manage too little. (P35)

Health-care providers sitting down with the residents were much appreciated. One resident said the following:

When they have time to sit down, they do. She who visited me earlier in my room, she is good to talk to. (P12)

The residents saw that the health-care providers were busy, so they tended to make allowances for them. One resident said the following:

They [health-care providers] have a lot to do, you know. (P2)

One resident mentioned that they were not getting the help they needed:

Those [health-care providers] who help here say, ‘You can’t always ask for immediate help’. They have so much to do with so many who have dementia, so I shouldn’t ask for help until I’m completely helpless. (P14)

The experience of being seen by the health-care providers was something the residents missed. One resident said the following:

You have a lot of questions you should have asked; you will not have time before they [health-care providers] disappear. I have missed that many times. (P12)

Another mentioned the individual differences in how the health-care providers spent their time:

At that short-term nursing home, there were many [health-care providers] who came [into the room] and talked in the first place, but that eventually diminished, I will tell you. So, there are not that many... We did not see a nurse who came with coffee - not a single one. There are two very different worlds, here [in the long-term space] and over there. They sat watching football. No good experience with that place compared to here. Here they come right away. (P31)

Other residents were very pleased, and one said the following:

The health-care providers have earned a gold medal. (P16)

4 | DISCUSSION

The current study aimed to examine what matters to nursing home residents with dementia by exploring their perceptions of nursing home care. The results of this study show that health care in nursing homes must follow a more person-centred approach, even though some residents expressed satisfaction with the health care they received. Ebrahimi et al., (2020) stated that even though there is a consensus about the relevance of a person-centred perspective, a translation of the PCC framework into practice is needed, particularly in aged care facilities, where the coexistence of disability, cognitive decline, and chronic conditions, often framed as frailty, challenge older people’s everyday lives and the provision of care, as shown in the statements in the results section. To illuminate and discuss the results, this study used the earlier-presented person- and patient-centred-care conceptual framework. Eklund et al., (2019) which enumerated nine themes present in person- and patient-centred care: (a) empathy, (b) respect, (c) engagement, (d) relationship, (e) communication, (f) shared decision-making, (g) holistic focus, (h) individualised focus and (i) coordinated care.

According to Eklund et al., (2019), empathy means entering the person’s or patient’s world, putting yourself ‘in the shoes’ of the person and including the sub-themes of compassion, emotional support and understanding. Some residents in this study found it difficult to express their needs and feelings because they feared the consequences of the health-care provider. The residents reported that they missed the experience of being seen and heard and relayed that their needs and desires were overlooked, exemplified by the statement from a resident whose need for hearing aids was not prioritised by health-care providers. The results in the current study might indicate that the residents asked for more emphatic skills in health care.

Eklund et al., (2019) stated that respect means the person or patient is approached with a respectful attitude, which includes respecting beliefs and values as well as supporting dignity by, for example ‘respecting patients’ choices’ (Eklund et al., 2019). Some residents in this study talked about lost dignity as nursing home residents, although they were proud of their earlier achievements before attending their nursing home. They wanted health-care providers to be curious about their achievements and life before they became nursing home residents, and they asked for more respect based on their beliefs, values and choices. The residents missed the possibilities of enjoying a beer daily, and they referred to the negative experience when little attention was paid to their discomfort regarding their nakedness before health-care providers when receiving help with showering.
Engagement in patient-centred care means to give one's time to the person or patient, not only the allocation of time in an objective sense, but also to be present and committed (Eklund et al., 2019). Indeed, health-care providers must spend the time necessary to listen to and understand patients’ preferences and needs (Eklund et al., 2019). The residents’ perception of health-care providers’ heavy workload might indicate dilemmas that often occur when health-care providers fulfil professional tasks while maintaining relationships and respecting residents’ needs and preferences (Olsen et al., 2019). In the interviews, the residents repeatedly stated the health-care providers were busy. Many felt that they could not ask for more help, because someone else always took priority. The residents expressed how it was strenuous to repeatedly describe to new health-care providers how to carry out relevant procedures for them. The residents found that some health-care providers performed tasks as expected but did not provide emotional support, which is essential to PCC. This might correspond to what Nakrem et al., (2013) discussed regarding the difficulty health-care providers in nursing homes face when required to meet the demands of performing tasks while providing emotional support.

Relationship is according to Eklund et al., (2019) a general sense rather than specific forms of relationship, such as being friends and caregivers. The theme relationship includes topics such as partnership, mutual trust and therapeutic relationships and might be a core component of PCC for people with severe Alzheimer’s disease to ‘prioritize the relationship to the same extent as the care tasks’ (Eklund et al., 2019). In line with the results in the current study, Grøndahl and Aagaard (2016) required health-care providers at nursing homes to work with residents in new ways—in partnership with patients and to facilitate patients’ decision-making. The current study revealed the daily routines of a nursing home were not based on partnerships with the residents to know their preferences and needs. For example, the residents were awakened by health-care providers to get up for breakfast, even though they were tired and desired to wake up when they wanted. The residents in this study missed meaningful social relationship and a sense of connectedness, as well as receiving understanding and respect from others, which might help confirm their value as human beings. Relational competence concerns communication and establishing a relationship with the patient, along with maintaining this relationship satisfactorily during encounters (Afifi & Coveleski, 2015). Health-care providers’ relational competency considering the PCC models includes the abilities to listen, have empathy, be reflective and know oneself (Eklund et al., 2019; McCormack & McCance, 2006). Some residents thought that they did not receive appropriate care when they wanted it. Despite the issue of limited time, the residents referred to health-care providers as kind. The PCC concept seems to have stronger roots in health-care settings where more time is spent with the patients, such as long-term care facilities (McCormack & McCance, 2017). However, the residents stated that developing personal relationships might require more resources and, as stated in the results, ‘time to sit down and talk with them.’

The theme of communication means a two-way interaction between the carer and the patient where information is being conveyed and shared and includes the sub-themes of communication and the exchange of information. This must involve a process of negotiation that takes account of individual values to form a legitimate basis for decision-making, the success of which rests on good processes of communication (Eklund et al., 2019).

In Davison et al., (2019), focusing on factors that facilitate or impede adjustment to residential aged care from the perspectives of residents with dementia, their families and health-care providers, some residents believed that having some degree of choice in their daily lives would help them adjust to residential aged care. However, there were limited opportunities to communicate choices within such a ‘regimented’ environment. The residents in this study wanted to do away with regimentation if it meant having more choices. The residents in this study perceived health-care providers had a heavy workload and little time to talk with them. Organisational conditions can reinforce a task-oriented care approach, which is generally viewed as the opposite of a patient-oriented approach (Olsen et al., 2019). The results show residents’ reported a lack of resources. Finding a balance between organisational and administrative routines and the expectations of older people’s needs can facilitate individualised care. The residents regarded this balance as challenging because they noticed that the busy health-care providers did not find the time to communicate with them. This aligns with previous research showing that, although PCC may be adopted by practitioners on a theoretical level, it does not necessarily become embedded in everyday clinical life (Naldemirci et al., 2017).

The theme of shared decision-making means that the person or patient actively participates in his or her care. This theme includes the sub-themes of empowerment, autonomy and involvement in treatment and recognising the person as the centre of care should encourage staff to respect and support the person’s decisions (Eklund et al., 2019). The residents accepted that they had no choice but to stay in the nursing home because of their deteriorating health; however, few experienced their lives as meaningful, which is the goal of PCC (Eklund et al., 2019). Furthermore, in the current study, the residents felt that their health-care providers did not express expectations of what the residents could manage, such as participation in their own care, preparing food and setting the table.

The theme of holistic focus refers to a tendency to acknowledge the person’s or the patient’s whole life, which includes the sub-themes of biopsychosocial perspective, the nonmedical issues considered relevant and the impact’s context. A biopsychosocial perspective with ‘recognition of the patient as a whole person in his or her biological, psychological and social context’ is a dimension of patient-centred care (Eklund et al., 2019). The residents expressed challenges with perceiving themselves as a whole person and maintaining their personhood or sense of self, interests and wishes despite living with an illness and experiencing declining health. According to Kitwood (1997), in line with the results in this study,
the most important task in dementia care is maintaining personhood in the face of failing mental powers. The residents wanted, for example, to be asked about their life story before attending nursing homes, since their life story is part of their identity and knowledge of their past might be important. resident understanding and support of their current needs. This accords with Kitwood (2007), who stated that an illness should not become the primary focus for health-care providers.

The theme of individualised focus can be understood concerning the theme of holistic focus and involves seeing something particular in the person’s or patient’s life where specific aspects of patient’s life and patient’s preferences are considered relevant. The residents’ stories even indicated a loss of identity, feelings of resignation and worthlessness. These results correspond with the findings of Eklund et al., (2019), suggesting that person-centred health care indicates the need for a shift from a biomedical, paternalistic health-care model to a more holistic approach. The biomedical model emphasises the resident as playing a passive, dependent role, whereas the health-care providers are the decision-making experts, while the person-centred model places the resident in the position of (shared) decision maker. This approach seems to correspond with Bolt et al., (2021) findings regarding the perspectives of people with dementia as being cared for by others, which underscores the importance of being engaged in meaningful activities and seen as unique individuals. The results of this study indicate that a pressured work situation is a lack of resources and has a negative impact on individualising the nursing home care. Furthermore, the way in which ageing, and the individualisation of services are constructed in policy strongly influences how PCC is constructed at the micro (personal) level. Exploring residents’ views may shed light on how policy that focuses on PCC is interpreted and practised in nursing homes. By explaining the contexts in which intended and unintended outcomes are likely to occur, we can use this knowledge to influence the implementation of PCC including the individual focus. At the system level, organisational factors play an important role for coordination of care. Factors such as a lack of resources and conflicting organisational goals are viewed as barriers, whereas organisations that incorporate a general person-centred culture are viewed as facilitators (McCormack & McCance, 2006; Moore et al., 2017). The interviews showed that PCC practices should be understood based on the complex interplay between many factors at the individual and system levels (McCormack, 2003).

Last but not least, the theme coordinated care means that care is planned and coordinated across health-care providers, time and situations as well as integrated across the health system, medical and supportive services (Eklund et al., 2019). The results in the current study give little information with respect to the theme of coordinated care. However, the residents wanted that the daily care was coordinated in a way that make it possible with smaller group of health-care providers, since they experienced difficulties with know who is who from the other. In addition, the residents called for the health-care providers to coordinate the daily care to make it possible for health providers to sit down and have time to listen to want matters to them regarding their preferences and needs for health care.

As shown in the results in the current study, the components of PCC may be differently constructed and valued by various stakeholders and residents for disparate reasons. PCC is viewed as good, but it is also a means of achieving more efficient health care. However, residents and health-care providers may have varied opinions about which elements or outcomes matter the most (Dwamena et al., 2012), as shown in this study.

4.1 | Strengths and limitations

Data describing people’s experiences of their own situations always involve multiple meanings that depend on subjective interpretations; this is a strength of this study. The large number of participants is another strength. Through a thematic analysis, the four authors engaged in valuable dialogue, seeking agreement regarding the data. Patient groups, such as those from ethnic minorities, were not included in the sample, and the residents were not asked to provide feedback on the results. However, the inclusion of several researchers in a reflective analytical process should enhance a study’s trustworthiness (Lincoln & Guba, 1985). No software was used for the thematic analysis.

5 | CONCLUSIONS

The main challenge regarding health-care quality in nursing homes is finding a balance between the general routine and the residents’ individual preferences and needs. The results indicate that health-care providers may not have the necessary temporal resources to deal with the key aspects of the patient experience because they are affected by wider organisational systems and national forces. Despite health-care providers’ substantive focus on PCC, the results show that nursing home residents are asking for more PCC. Health care in nursing homes should enable residents to participate in daily activities, support decision-making and sustain their personhood and sense of self.

6 | RELEVANCE TO CLINICAL PRACTICE

The practices of health care should consider including specific professional approaches to build relationships and engage residents in activities. The results indicated that health care in nursing homes must follow a more person-centred approach allowing the negotiation of health care based on what matters to the residents. Health-care providers should give residents a voice while caring. The present study can inform education, the health profession and policy, as well as enhance service delivery and governance.
COMPETING INTERESTS
The authors declare that they have no competing interests.

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CONFLICT OF INTEREST
There are no conflicts of interest in related to this study.

AUTHORS’ CONTRIBUTIONS
All authors designed the study. The first author coordinated the project and conducted the interviews and was responsible for analysing the data and writing the initial draft of the manuscript. All the authors participated in interpreting the data and drafting the manuscript. The four authors contributed to the data analysis and interpretation and critically revised the manuscript to enhance its content. The four authors read and approved the final draft of the manuscript.

ETHICAL APPROVAL
This study was registered by the Norwegian Centre for Research Data, No. 54978.

CONSENT FOR PUBLICATION
The consent form that each resident signed included a statement explaining that the data would be presented in a way that concealed their identities.

DATA AVAILABLE ON REQUEST DUE TO PRIVACY/ETHICAL RESTRICTIONS
The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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**SUPPORTING INFORMATION**

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

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