

Improving everyday life of people with dementia living at home: Health care professionals' experiences

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Funding information

The study received funding from Regional Research Funding in Norway.

Abstract

Aim: This study investigates what health care professionals experience is important for improving everyday life of people with dementia living at home.

Background: A prerequisite for living at home is that people with dementia and their relatives can handle everyday life together despite the challenges that dementia poses.

Methods: This qualitative study conducted focus group interviews ($n = 14$), and the data were analysed using qualitative content analysis.

Results: The analysis identified one theme—need for enhanced competence to develop and implement individual plans—and three categories: challenge in identifying cognitive decline; need to timeously facilitate an active and meaningful everyday life; and need for consistency, continuity and coordination in dementia home care.

Conclusion: Increased expertise is needed among health care professionals to contribute to the development and implementation of individual plans in dementia home care. To achieve this, health care professionals' competence and how dementia home care is organized must be seen in conjunction.

Implications for Nursing Management: Routines should be established for identifying cognitive failure early and providing support and guidance at the beginning of the process. There is a need for nurse managers to facilitate increased advanced competence regarding dementia care for a professional home care service and to consider how home services can be organized to ensure continuity and security for people with dementia and their relatives. Creating and implementing an individual plan which can be a starting point for identifying individual needs and wishes and for coordinating an individual user's services.

KEYWORDS

dementia, home care, individual plans, organization, person-centred care

[Correction added on 2 November 2022, after first online publication: The last name of the second author has been corrected in this version.]

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1 | INTRODUCTION

Health care professionals, such as nurses, physiotherapists and occupational therapists who work daily with people with early and middle stage dementia living at home, experience how home care services affect patients and their relatives. People with dementia and their relatives, such as spouses, sons and daughters, are often closely connected, and the services provided will influence the whole family. Through the insights of health care professionals working in home care, day-care centres and dementia coordinator teams, this study will call attention to key areas for service improvement.

Dementia is a major health challenge. Over 55 million people were living with dementia worldwide in 2021, and this number is predicted to increase to 78 million by 2030 (Gauthier et al., 2021). Dementia has a huge economic impact. Keeping persons with dementia at home and avoiding unnecessary hospitalizations and early relocation to long-term care facilities have a high priority in the health system. An estimate of the number of people with dementia living at home varies from 50% to 70% in high-income countries to 94% in low- and middle-income countries (Prince et al., 2015). In Norway, two thirds of the 100,000 people with dementia live in their own homes (Gjøra et al., 2021), and in Norway, as in many other countries, there has been an expansion of home care services (World Health Organization, 2020a, 2020b).

The possibility of living at home improves the quality of life of people with dementia (Nikmat et al., 2015; Olsen et al., 2016). However, a systematic review points out that impairments to the activities of daily living and caregiver burden are risk factors for hospitalization (Toot et al., 2017). Other studies suggest that people with dementia experience problems with staying at home due to relationships with caregivers, the need for togetherness, the lack of plans/structures for everyday life and safety challenges, such as falling, starting fires and getting lost (Mazurek et al., 2017; Thoma-Lürken et al., 2018). Additionally, nutritional challenges, satisfying medication requirements and toilet use can cause problems (Abreu et al., 2019; Mole et al., 2018). Moreover, relatives may perceive home care as task oriented and fragmented (Landmark et al., 2013; Nordtug et al., 2021) and undergo limitations regarding individual customization (Tretteteig et al., 2019).

Norwegian government documents and international reports note that the services offered to people with dementia should be more person centred and that relatives are not sufficiently supported. Furthermore, transitions in services often result in a lack of continuity and safety (Alzheimer's Disease International, 2021; Norwegian Ministry of Health and Care Services, 2018, 2020). A review of 23 randomized controlled studies showed that it is paramount to identify the needs of each family to ensure that they receive a personalized plan promptly (Zabalegui et al., 2014). A plan must be based on an individual's interests, wishes and activity habits because people with dementia may utilize their own resources for a long time. Consequently, they may experience security, well-being and mastery (Brooker & Kitwood, 2019; Norwegian Ministry of Health and Care Services, 2015, 2020). A scoping review that aimed to map gaps and priorities in dementia care in Europe found, among other things, that

the gaps include fragmented non-person-centred care pathways, limited knowledge and skills and poor communication and information sharing (Martin et al., 2020). Health care professionals are crucial resources who meet people with dementia and their relatives at home and in day-care centres, where they gain insight into the daily lives of those involved, including patients' pleasures and challenges. These experiences enable health care professionals to communicate about appropriate services to ensure quality care and adequately contribute to improving the everyday lives of people with dementia living at home and their relatives. Therefore, it is critical to listen to health care professionals' experiences. To the best of our knowledge, there are few articles regarding home care services for people with dementia from health care professionals' perspectives.

Therefore, the aim of this study is to investigate what health care professionals experience is important for improving everyday life of people with dementia living at home.

2 | METHODS

2.1 | Design

This study has a qualitative design with an explorative and interpretative approach. Focus group interviews were used, as such interviews are considered an effective method for unearthing the spectrum of informants' experiences and feelings. Such interviews elicit further reflections on one's perspectives in the context of other convergent and divergent group views (Krueger & Casey, 2014). Health professionals have certain characteristics in common related to encounters with people with dementia, and experiences could be shared, discussed and enlightened. In focus group interviews, spontaneous interactions and common reflections can enhance new insights into a topic, and the type and range of data can be enriched compared with individual interviews (Gundumogula, 2021).

2.2 | Sample

This study used purposive sampling and is part of a larger study regarding people with dementia living at home (Malmedal et al., 2020; Moe et al., 2021; Nordtug et al., 2021) conducted with the Centre for Care Research in mid-Norway and three municipalities in this region. Stakeholders from one small, one medium-sized and one large urban municipality cooperated with the research group when they were planning and conducting this study. Accordingly, the sample represented a variety of sizes of Norwegian municipalities and health care services related to people with dementia in those municipalities.

Informational letters were sent to the heads of home care services and forwarded to employees (nurse leaders, coordinators for people with dementia, rehabilitation teams and nurses at day centres) in the municipalities. There were 14 health care professionals who accepted the invitation (Table 1 depicts informant details). Overall, the health care professionals had varied experiences in caring for

TABLE 1 Educational background of health care professionals

Informants by education	Focus group 1	Focus group 2	Focus group 3
Registered nurses (4), nursing leaders (2)	2	3	0
Trained nurses (5), occupational therapists (2), physical therapists (1)	2	3	4
Total	4	6	4

TABLE 2 Example of the analysis process

Meaning unit	Code	Subcategory	Category	Theme
M: What plan are they offered in the first phase? When is contact established?	Done in different ways First contact made when relatives become tired. They have to tread carefully.	Different offers in first phase. Health care professional feel uncertain.	The need to timeously facilitate an active and meaningful everyday life	A need for enhanced competence to develop and implement individually plans
I: This is done in very different ways. Sometimes it is when we see relatives become tired. Then, we ask if they want to talk. We have to tread carefully. It is difficult to know how to proceed. I have a contact person in the dementia team with whom I can consult. Otherwise, we do not have much contact. This may be for the first year. Then, there will be contact as the disease develops.	It is difficult for them to know how to proceed.			

people with dementia and cooperating with their relatives in home care, day centres and as members of the municipal dementia team.

2.3 | Data collection

A semi-structured interview guide was used with open-ended questions regarding how health care services can contribute to improving everyday life. It served as a question checklist and ensured that the same questions were asked in all interviews. The questions included: What is important for people with dementia in the early stages of the disease? How can health services contribute to meaningful everyday lives for people with dementia? What are the characteristics of a well-organized service for people with dementia and their relatives? There were rich reflections in the focus group, and the questions allowed the informants to contemplate and talk freely. There were short summaries and follow-up questions during the interviews to ensure that the statements were correctly understood. The interviews were conducted and moderated by the authors, who all had experience leading focus group interviews. Three focus group interviews (45–60 min) took place between May and June 2018 at the university or in a meeting room at the municipal health service.

2.4 | Analysis

The authors audiotaped, transcribed and analysed the interviews using qualitative content analysis, as inspired by Graneheim and Lundman (2004). First, all the authors read the transcripts, discussed the preliminary results, provided interpretation input and helped ensure that the informants' context and data were correct. The first and last authors thoroughly read the transcribed interviews, and the text was divided into condensed meaning units. Each of the authors identified keywords separately to form an overall impression of the interviews and then discussed possible codes and subcategories for each interview. The condensed meaning units were labelled with a code, and NVivo 12 was used as a tool in the coding. The aim of the study guided the authors when codes in all the interviews were compared across data and subcategories were defined.

The first description of the subcategories was discussed with all the authors. Subsequently, the first and last authors reflected on the underlying meanings at an interpretative level and talked about them with all the authors. The authors continuously moved between the whole text and parts of it until there was agreement on the formulation of subcategories–categories and one theme. See Table 2 for an example of the analysis process.

2.5 | Rigour

All authors discussed the analyses and wrote and provided a final reading of the manuscript. The consolidated criteria for reporting qualitative research, the COREQ checklist, were used to ensure that each step in the research process was aligned with the quality requirements (Tong et al., 2007).

2.6 | Ethical considerations

The study was approved by the Norwegian Centre for Research Data (Project Number 58922) and was conducted according to the Helsinki Declaration (World Medical Association, 2018). The informants were provided written and oral information about the study's purpose and informed that their participation was voluntary and that they could withdraw without any consequences. They were informed that audio recordings would be deleted after transcription and all data were anonymized. Thus, citations refer only to the relevant focus group, not to professions or individuals. Informed written consent was obtained from all participants.

3 | RESULTS

Through analysis, we identified one main theme: need for enhanced competence to develop and implement individual plans. Three categories were also identified: (1) challenge in identifying cognitive decline, (2) need to timeously facilitate an active and meaningful everyday life and (3) need for consistency, continuity and coordination in dementia home care (Table 3).

3.1 | Need for enhanced competence to develop and implement individual plans

A theme that permeated the health care providers' experiences was the need for increased competence to develop and implement individual plans. Without greater competence concerning the challenges faced by people with dementia and their relatives, the precondition for developing and implementing individual plans was absent. This theme was latent for all categories.

3.2 | Challenges in identifying cognitive decline

3.2.1 | Some individuals remain undiagnosed for a long time

Health care professionals observed that many people with dementia long remained undiagnosed. Sometimes, cognitive failure was discovered only when the spouse became ill and was hospitalized. Health care professionals in day-care centres thought that people

TABLE 3 Overview of results

Subcategory	Category	Theme
Some individuals remain undiagnosed for a long time	<i>Challenge in identifying cognitive decline</i>	Need for enhanced competence to develop and implement individual plans
Collaboration with relatives and general practitioners on a diagnosis		
Follow-up time after diagnosis	<i>Need to timeously facilitate an active and meaningful everyday life</i>	
Competence is crucial		
Need for customized and concrete plans		
Significance of day-care centres and collaboration	<i>Need for consistency, continuity, and coordination in dementia home care</i>	
Volunteers need training and support		

with dementia tried to hide their cognitive failures, living with cognitive declines for a long time. They also reported that it is difficult to detect cognitive declines when the provision of home care nursing is spread among many health care professionals. Thus, few professionals could follow up and observe people with dementia handling different daily situations. One informant commented, 'If home care service is used ..., there are little "drips of worry," but no one sees the whole situation' (FG3). Furthermore, spouses can hide challenges: 'It is shameful', an informant in the same focus group said. They knew of situations in which individuals had managed to hide their spouses' cognitive challenges from their children for a long time.

3.2.2 | Collaboration with relatives and general practitioners on a diagnosis

Some informants worried that not everyone wanted to be diagnosed; thus, they had to build trust before proposing a medical examination. They were unsure how to collaborate with relatives concerning the diagnosis of possible cognitive failure. One informant said, 'We have to tread carefully. ... It is hard to know how to proceed' (FG1). According to informants, there are major distinctions among registered general practitioners (RGPs) regarding how they relate to dementia diagnoses. Some gave medical referrals, provided information about the municipality's offerings to people with dementia and some were elusive and waited too long to diagnose dementia.

3.3 | Need to timeously facilitate an active and meaningful everyday life

3.3.1 | Follow-up time after diagnosis

There were various experiences regarding the timing of follow-ups and facilitation after diagnosis within the three municipalities. One informant said that people with dementia initially receive adequate follow-ups from the specialist health service, but it often takes a long time before they or their relatives contact the health services in the municipalities. Some health care professionals stated that either people with dementia or their relatives must seek help. Additionally, younger individuals often found the information they needed online. Other health care professionals explained the consequences of a lack of early facilitation:

The husband was diagnosed, and nothing happened. Then, they lived unaware of what the diagnosis truly meant. When there was a crisis in the end and he became almost violent, then there was talk about nursing interventions (FG3).

Some health care professionals felt that a 6-month follow-up meeting after diagnosis (after referral by the Norwegian Directorate of Health, 2019) was too long. They suggested that a home visit should be offered no later than 14 days after diagnosis. One said, ‘Six months is a long time when you are sitting there with a diagnosis. What are we doing now?’ (FG2). They also stated that people with dementia and their relatives should be aware of the services in their municipality early on: ‘They have to get all the information on the table right away to determine what is right for them’ (FG2). Furthermore, they expressed that the health service had to act early to gain a health-promoting and preventative effect: ‘Otherwise, relatives become exhausted, and the people with dementia are so cognitively impaired that they cannot benefit from health-promoting activities’ (FG2). Creating trust early in the illness by assuring the involved individuals that health care professionals ‘will go the distance with them’ is a crucial contribution to the process, informants reported (FG2).

3.3.2 | Competence is crucial

Several informants noted that it is very important to have expertise in dementia diagnoses and the challenges that people with dementia and their relatives face. In each interview, it emerged that the lack of competence in dementia management among personnel was a challenge. ‘The problem is that they don’t know anything about dementia’ (FG3). One informant believed that home health care professionals did not sufficiently address users’ challenges before implementing home care nursing interventions. ‘They treat everyone as if they are cognitively healthy, but they are not. The personnel are not updated ... before they visit the individuals. ... They have no tools, and so it will end in nothing’ (FG3). Health care professionals emphasized that

competence enhancement also takes place, but simple solutions are often chosen because of time limitations. When people with dementia are not allowed to perform tasks they still can and employees take over, people with dementia become prematurely dependent, health professionals stated.

3.3.3 | Need for customized and concrete plans

For people with dementia to experience safety, participation and improved everyday lives, health care professionals remarked that home health care services must ensure participation and predictability through customized and concrete action care plans. ‘We need to write down precise action [care]plans, so we do not have to ask questions’ (FG1). One goal was to create security and coherence so people with dementia were in a good mood when health care professionals left. Informants pointed out that many small things make everyday life meaningful.

We do not have to put dinner on the table, even if they cannot do it themselves. Maybe it is enough that we present the potato, carrot and two fish cakes so that they can see them, and then they can do it themselves. They can use their own resources as long as possible because that is the activity (FG2).

3.4 | Need for consistency, continuity and coordination in dementia home care

Health care professionals pointed out that home health care services should be organized in a certain way so people with dementia have specific carers. One said, ‘There are often quite a few workers they have to deal with. It is important to cut down the number of persons they have to deal with’ (FG3). The many home health care professionals visiting individuals result in a lack of continuity. ‘It is a little scary when once-a-week day-care activities are what maintain continuity in relation to the user’ (FG3).

In one focus group, several informants were part of the dementia team in a municipality. They believed they served roles as supervisors for the home care service; one stated, ‘But where there are persons who are followed up over a long period, it is mostly the home care service that takes over, and then we are supervisors for the home care service, I think’ (FG2). Through collaborations between the dementia team and home care services, customized services are created in which the transferred skills strengthen the home care service.

3.4.1 | Significance of day-care centres and collaboration

Several informants emphasized the importance of day-care centres for people with dementia:

A lady lay on the couch for several months. She used strong medications that needed to be reduced and started exercising at our day-care centre. She finally jogged up the stairs and became active. She is with us two days a week and jogs around and is fine (FG2).

In day-care centres, people with dementia can go for walks, talk and have a meal together. The staff accumulate knowledge about each individual and what they need, but report that their knowledge is rarely requested for other parts of the service. One informant who worked at a day-care centre said, 'The communication between the day-care centre and the nursing home when they have to move is important, but they do not want to listen to us' (FG3). The informants stated that there should be a routine meeting between the different care levels so each level provides information about the care recipient that is useful to the next level.

3.4.2 | Volunteers need training and support

Volunteers are a notable resource for people with dementia. One informant stated: 'We would not manage (to create an active everyday life) without them' (FG1). However, they noticed that it was a challenge to recruit sufficient volunteers. They were also concerned that not all persons fit together and that work must be done to correctly match the volunteer with the person with dementia. One informant remarked, 'You cannot take just anyone to do whatever' (FG1). Health care professionals were concerned that volunteers needed to be trained and it should be a prerequisite that there are good contact points among volunteers, relatives and health care services.

4 | DISCUSSION

This study investigates what health care professionals experience is important for improving everyday life of people with dementia living at home. The findings showed that obtaining a dementia diagnosis can take time due to challenges related to mapping cognitive failure and uncertainty about when to intervene. To facilitate an active and meaningful everyday life for persons with dementia, heightened expertise among health care professionals is needed, contributing to the development and implementation of individual plans that identify and ensure the use of individuals' resources.

4.1 | Challenges with diagnosis and differences in follow-up

According to the World Health Organization (WHO) Fact Sheet about Dementia 2021, Alzheimer World Report 2021 and the Dementia Plan 2020 and 2025 (Norwegian Ministry of Health and Care Services, 2020), early diagnosis is very important, but in line with our study, remains a challenge. Many people live for a long time with

cognitive failure without receiving help. The informants added that it can be difficult to detect cognitive failure due to a lack of continuity in home care services. Furthermore, there is a stigma attached to a dementia diagnosis; therefore, both people with dementia and their relatives often try to conceal it (Larsen et al., 2017). It can also be a challenge for relatives to contact the health care system when people with dementia do not think they need help. To change attitudes about dementia, societal measures are necessary (Lopez et al., 2020). Providing information about dementia to the population and working towards a dementia-friendly society can be a step further to lower the threshold of asking for help.

Our study shows that health care professionals have different opinions about how soon after diagnosis people with dementia and their relatives should receive a follow-up. A survey by the Norwegian Directorate of Health (2018) revealed that 55.3% of all municipalities in Norway have routines for systematic follow-up. Most municipalities' routines consisted of regular visits every 6 months or once a year. It seems that there are large variations among the municipalities represented in this study, and in some municipalities, limited attention may be given to both relatives and people with dementia in the early phase of the disease.

4.2 | Need for an individual plan

The main element of person-centred care is dignity. The person's perspective should be understood, their integrity must be respected and people with dementia should be included in a social environment (Blake et al., 2020; Brooker & Kitwood, 2019). Person-centred care must be visible and genuine for both people with dementia and their relatives when a diagnosis is first provided, in which all resources and help are clear and a concrete care plan is made, as our informants clearly stated. The need for a care pathway with individuals plans is also stated internationally (Martin et al., 2020; WHO, 2017). The plans can be at various levels, for example both a concrete plan for the coming day and the next week and a plan that can gain legitimacy as an individual plan aligned with current national professional guidelines from the Norwegian Directorate of Health (2020). The coordination reform in 2009 clearly stated that the 'Individual Plan will continue to be a key measure to ensure good interaction and co-operation' (Meld. st 47, 2008–2009, p. 48). This plan should be available for those who need long-term care and coordinated services and ensure that all persons receive a comprehensive, coordinated and individually tailored range of services. The Dementia Plan 2025 (Norwegian Ministry of Health and Care Services, 2020) confirms that people with dementia are entitled to individual plans and demonstrates that only 47% of the municipalities in Norway have systems to offer such plans. In our sample, the health care professionals had limited experience with including people with dementia and their relatives in writing individual plans. Another recent study concluded that people with dementia and their relatives are unsure how they can influence care when the care and support they receive are described as mainly predetermined and based on routines (Hoel et al., 2021).

4.3 | Competence and how dementia home care is organized must be seen in conjunction

The World Alzheimer Report 2021 states that increased education about dementia will have a significantly positive impact on the quality of life of people with dementia and their relatives (p. 186). Home care services have many users who are frail and have complex and demanding needs (Morland, 2020), which means that a high level of expertise is required. Giving care to people with dementia is a complex because of the persons' cognitive decline, which can make observations and communication challenging. In our study, it was pointed out that the number of health care professionals who aid people with dementia was large, resulting in limited continuity and expertise. Furthermore, people with dementia have reduced abilities to remember faces (Spoletini et al., 2018), which can make the situation even more difficult. Thus, the number of health care professionals visiting one individual should be limited (Gjevjon et al., 2013).

Service organizations are crucial to developing person-centred care (Brooker & Kitwood, 2019; Brooker & Latham, 2015) and promoting the continuity of dementia home care. To aid people with dementia living at home, the way dementia home care services are organized must change. Not everyone can observe, assess and initiate measures for people with dementia; to do this, one needs specialized competence and knowledge (Polacsek et al., 2020; Sandberg et al., 2021). People with dementia need fewer carers with specific competences which people with dementia and their relatives can learn to trust. Our findings suggest that there is the necessity to look more closely at how services for persons with dementia living at home are organized and coordinated.

Collaboration on an individual plan is a key place to start, both to clarify individual wishes and needs and for health care professionals to gain an overview of various actors' roles in dementia home care. Our results also suggest that day-care centres and volunteers must be integrated into the service to a greater extent to ensure a common understanding of the person's needs in every part of the health care system. This indicates that health professionals' competence and knowledge about the care recipient and how home care is organized for people with dementia must be seen in conjunction.

4.4 | Strengths and limitations

This study sought the views and experiences from participants in one part of Norway. The experiences may vary in other parts of the country or in countries with different health care systems. Although the selection of informants was limited, they covered a large geographic area, had varied competence and experience and represented dementia teams, day-care centres and home care services. Varied experiences in caring for people with dementia increase the opportunity to illuminate the issue from distinct perspectives.

5 | CONCLUSION

To improve the everyday lives of people with dementia and their relatives, health care professionals reported that health services in municipalities need good routines to identify cognitive decline early and should provide support and guidance at the beginning of the dementia process. When people with dementia are diagnosed, they should immediately be offered customized activities and individualized plans to enhance their everyday lives. A prerequisite is staff continuity to ensure that persons with dementia and their relatives can learn to trust a few familiar health care professionals. To achieve this, the organization of dementia home care and enhancement of health care professionals' competence in dementia care must be seen in conjunction.

Further research is needed that focuses on the connection between the organization of dementia home care and the quality of care for people with dementia and their relatives. This could include evaluating measures so new ways of organizing dementia home care can be tested.

6 | IMPLICATIONS FOR NURSING MANAGEMENT

Routines should be established for identifying cognitive failure early and providing support and guidance at the beginning of the process. There is a need for nurse managers to facilitate optimal advanced competence regarding dementia care for the professional home care service and to consider how home services can be organized to ensure continuity and security for people with dementia and their relatives. Nurse managers need to be stakeholders for creating and implementing an individual plan which can be a starting point for identifying individual needs and wishes and for coordinating an individual user's services.

ACKNOWLEDGEMENTS

We are grateful to the staff who participated in the study and shared their thoughts and experience in the focus group interviews. We also extend our thanks to the project's reference group from the Centers from Development of Institutional and Home Care Services.

CONFLICT OF INTEREST

The authors report no conflicts of interest in this work.

ETHICS STATEMENT

The study was approved by the Norwegian Centre for Research Data (Project number 58922). The informants were given written and oral information about the study's purpose and informed that their participation was voluntary, and they could withdraw without any consequences. They were informed that audio recordings would be deleted after transcription and all data were anonymized. Thus, citations refer only to the relevant focus group, not to professions or individuals. Informed written consent was obtained from all participants.

DATA AVAILABILITY STATEMENT

The data are not open and available as the study is based on personal experiences from the participants and the participants were not asked about this. They are promised full anonymity and by openness, anonymity can be challenged.

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How to cite this article: Alnes, R. E., Malmedal, W., Nordtug, B., Steinsheim, G., & Blindheim, K. (2022). Improving everyday life of people with dementia living at home: Health care professionals' experiences. *Journal of Nursing Management*, 1–9. <https://doi.org/10.1111/jonm.13819>