

RESEARCH ARTICLE

Staff's perspectives on the organization of homecare services to people with dementia—A qualitative study

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Abstract

Aims: The aim of the study was to explore the experiences of homecare staff about the impact of the organization of homecare services for people with dementia.

Design: This study has a qualitative, exploratory design based on a phenomenological-hermeneutic approach, using individual in-depth interviews with homecare staff to collect data.

Methods: A convenience sample of 14 homecare staff from five municipalities participated in the study. Main topics introduced: (a) how homecare services for people with dementia are organized and (b) challenges in respondents' everyday practice of caring for people with dementia. Interviews were conducted from October to December 2017.

Results: Three main themes were identified from the interviews. (a) Complexity and need for individualized facilitated homecare services; homecare services were described as complex in regard to both the patient and the service. The complexity of the service made it challenging to tailor the service to the individual patient. (b) The importance of trust and relationships; establishing trust in the relationship between the patient and the staff resulted in better-quality care. This was crucial for identifying the patient's need for help. (c) Organizational challenges; homecare services could be vulnerable to changes in the organization. Practical tasks and following the daily scheduled task list were often prioritized at the expense of an individually tailored service.

KEYWORDS

complexity, continuity of care, dementia, homecare, homecare services, nurses, nursing, person-centred care, staff

1 | INTRODUCTION

The number of people with dementia worldwide is increasing due to ageing population (Samus et al., 2018; WHO, 2019). Dementia affects people's ability to care for themselves and to manage everyday

life. As the disease progresses, those with dementia often need extensive support and care. For these persons to enjoy good everyday lives, person-centred care is needed (Livingston et al., 2017). People with dementia often receive public assistance over a number of years, preferably in their own homes, and this requires

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well-coordinated service with professional expertise (Melby et al., 2018; Prince, 2016).

Homecare service in Norway offers support and assistance to patients at different ages and with various health conditions and needs. Each municipality is responsible for organizing homecare services to be person-centred and adapted to the individual patient (Ministry of Health & Care Services, 2015b, 2018; Norwegian Directorate of Health, 2017). Municipalities throughout Norway differ in size and geography from urban municipalities within a small geographic area and large populations, to small municipalities with a few hundred residents covering a large area.

The provision of homecare services is a publicly funded statutory requirement and involves 24-hr service. These services are provided free of charge, and individual patients receive homecare services based on assessments of their needs. There is, nevertheless, no upper limit on how much help one patient may receive.

Traditionally in Norway, people with dementia in need for extensive care were cared for in nursing homes. In recent years, there has been a trend towards this population of patients remaining at home for longer periods and receiving homecare services (Ministry of Health & Care Services, 2015b, 2018). To enable the patients to live at home for longer periods before requiring institutionalization, well-coordinated and customized services are necessary. In this regard, we lack knowledge about the impact of the organization of home care for customized services for people with dementia. The staff in homecare services have first-hand knowledge about the everyday effects of the organization of the services offered. Their experiences can, therefore, provide an important contribution to new knowledge about how to organize homecare services in the best way to meet the needs of people with dementia living at home.

1.1 | Background

Homecare services for people with dementia have traditionally been characterized by little specialization and few adaptations to the challenges posed by dementia, especially for people with severe dementia (Bokberg et al., 2015). Studies have indicated that homecare service received by people with dementia tends to be standardized and generalized, with the same types of assistance given to almost all patients regardless of individual situations and needs (Bokberg et al., 2015; Larsen et al., 2019; Turjamaa et al., 2014). The focus has been on the patient's physical needs and daily tasks rather than on personalized care (Morrissy et al., 2018; Turjamaa et al., 2014). Furthermore, previous research has revealed that patients experience homecare service as fragmented and based on routines, with little or no adaptations to the individual patient's needs (Morrissy et al., 2018; Prince, 2016; Turjamaa et al., 2014). People with dementia in Norway often receive homecare services for many years and with frequent visits during a single day (Corbett & Williams, 2014). The assurance of receiving seamless homecare services that maintain continuity of

care is important for both the patient, family members and the staff (Donnelly et al., 2017; Gorska et al., 2013; Jansen et al., 2009; Jasper et al., 2018).

Trusting relationships between patients and caregivers are critical for people with dementia in order to continue to live in their own homes (Ministry of Health & Care Services, 2015b; Samus et al., 2018; Turjamaa et al., 2014). A limited number of staff visiting the same patient could contribute to an experience of continuity of care and were considered essential for building relationships and trust between people with dementia and the staff (Aasgaard et al., 2014; Donnelly et al., 2017; Gorska et al., 2013; Jasper et al., 2018; Turjamaa et al., 2014). Moreover, continuity of care appears to be important in regard to staff recognizing the patient's needs and providing high-quality care services to this population (Gorska et al., 2013; Jasper et al., 2018; Ministry of Health & Care Services, 2018; Toot et al., 2013). Although continuity of care is prioritized and desired both nationally and internationally, achieving it seems challenging (Gjevjon et al., 2014; Ministry of Health & Care Services, 2015a; Prince, 2016). It appears that visiting the same patient repeatedly over time can be emotionally challenging for staff, especially when the patient does not agree with the health care provided or is dissatisfied with it (Sandberg, 2018; de Witt & Ploeg, 2016). A Norwegian study showed that the day-to-day continuity of care was low and that the number of nurses visiting the patient was unnecessarily high (Gjevjon et al., 2014).

The amount of time available to spend in a patient's home is considered a key component of caring for people with dementia (Jansen et al., 2009) and may be particularly important for patients' experiences of quality of care (Aasgaard et al., 2014). Use of time is a significant factor in establishing trust between patient and staff and may be necessary in order to provide meaningful help for this group (Aasgaard et al., 2014). People with dementia may have limited opportunities to communicate their own needs, and they are dependent on the staff's ability to assess their requirements for assistance (Bokberg et al., 2015; Ministry of Health & Care Services, 2015a). The fact that staff rarely have enough time to do their work may result in unmet needs for people with dementia (Melby et al., 2018). In addition, a lack of time can make it difficult to establish good relationships between the patient and the staff and may result in insecurity for the patient thereby the potential for necessary help to be refused by the patient (Gorska et al., 2013).

Homecare services for people with dementia should be tailored to the individual patient and should, to a greater extent, involve the patient in decision-making and use his or her physical and mental resources (Bokberg et al., 2015; Kogan et al., 2016; Turjamaa et al., 2014). Limited resources for providing adapted and comprehensive assistance to people with dementia may result in their early admittance to nursing homes (Donnelly et al., 2017; Jansen et al., 2009). Therefore, how homecare services for people with dementia are organized is important from both a resource and a patient perspective.

The aim of the study was to explore the experiences of homecare staff about the impact of the organization of homecare services for the quality of care offered to people with dementia. The research questions were as follows: (a) How are the homecare services for people with dementia organized? and (b) What is experienced as challenging in providing homecare services for home-dwelling people with dementia?

2 | THE STUDY

2.1 | Design

This study has a qualitative, exploratory design based on a phenomenological-hermeneutic approach (Laverty, 2003), using individual in-depth interviews with homecare staff to collect data. Qualitative in-depth interviews are considered appropriate for examining people's experiences and for obtaining diversity and nuances in the responses to research questions (Malterud, 2012).

2.2 | Sample/Participants

A purposeful sample of 15 homecare staff recruited from a convenience sample of five municipalities in one Norwegian county was included. These municipalities were recruited based on their previous research collaboration with the research team. The homecare services leader in each municipality recruited the participants. The only inclusion criterion for the participants was that they were members of the staff in homecare services; their selection was based on their potential to contribute important and balanced information to the study. The participants included both leaders and staff of various ages, educational levels and years of experience. One participant withdrew from the study and, hence, 14 interviews were included in the final analysis. The participants' characteristics are presented in Table 1.

2.3 | Data collection

Participants were interviewed using open-ended questions and were encouraged to speak openly about their experiences of offering homecare services to people with dementia. Two main topics were introduced in the interviews: (a) how homecare services for people with dementia are organized and (b) challenges in the respondents' everyday practices of caring for people with dementia. The third and fourth authors (IHF and BL) conducted the first interview together, while IHF performed the next 13 interviews. All interviews were conducted in homecare services offices and lasted from 45–60 min.

After a preliminary analysis of the interviews, the amount of data was considered saturated (Malterud, 2001) as few new meaning units emerged towards the end of the data-collecting phase.

TABLE 1 Participants characteristics (N = 14)

Gender	
Male	1
Female	13
Age	
30–40 years	6
41–50 years	3
≥51 years	5
Education	
Registered nurse	9
Assistant nurse	4
Social educator	1
Years of experience working in homecare services	
5–10	2
11–20	6
≥21	6
Staff specialized in dementia care	3
Staff working in specialized homecare services for people with dementia	8
Staff's daily work assignment	
Working in patients' homes	8
Service coordinator	1
Both day-care centre and patients' homes	1
Leader	4

The interviews were conducted during October to December 2017.

2.4 | Ethical considerations

The study was approved by Norwegian Center for Research Data (NSD no. 55316). All participants were informed about the study, as well as the possibility to withdraw from it at any time, and all gave their written informed consent.

2.5 | Data analysis

The interviews were audio-recorded and transcribed by a professional transcriptionist and further analysed using systematic text condensation supported by NVivo.10 software (QSR International, 2020). The method of analysis used was based on Malterud's four steps of text condensation (Malterud, 2012).

The procedure comprises the following steps (Malterud, 2012):

1. Total impression—from chaos to themes. To acquire a full overview of the material, the first author (KAH [Registered Nurse]) read the whole data set twice. Then, KAH and IHF listened to all the interviews and compared them with the

transcribed text to identify preliminary themes. Subsequently, the listed themes were discussed in the research group to identify themes corresponding to the research questions for inclusion in further analysis.

2. Identifying and sorting meaning units—from themes to codes. Meaning units were identified and organized in coding groups. Nine themes that were identified in the first step were categorized into six coding groups.
3. Condensation step—from codes to meaning. An interpretation of the meaning units was made, and, in this process, we identified nuances of what the informants had said in the interview sorted under each coding group. Also, during this process, new themes and subgroups representing the informant's voice were created.
4. Synthesizing—from condensation to descriptions and concepts. Next, the condensed and interpreted material was summarized into analytical text representing the results of the study.

The research group, including all authors, worked closely and discussed the material during the process of analysing it. The themes, code groups and subgroups that were identified from the analysis are listed in Table 2.

2.6 | Rigour

All authors contributed to ensuring that data were correctly collected, to interpreting the material and to reporting the findings. The first (KAH), second (AMMR) and third (IHF) authors collaborated on the analysis of the data, where interpretation was conducted to the best of their ability and in line with what the participants had expressed. Additionally, all authors participated in writing the article

and in the final reading. Consolidated criteria for reporting qualitative studies (COREQ) have been followed to the best of our ability to maintain quality at all stages, from planning the interviews through the analyses and to reporting the findings at the end (Tong et al., 2007).

3 | FINDINGS

This section reports the staffs' experiences of the organization of homecare services for people with dementia in five municipalities in Norway. In the following, we present the main themes that were identified from the interviews.

3.1 | Complexity and need for individualized facilitated homecare services

Homecare service was described as complex in regard to both the patients and the service itself. People with dementia receiving homecare services were described as complex patients, often with multimorbidity including somatic and psychiatric diseases in addition to cognitive impairment and advanced age. Additionally, the participants stated that the service itself is complex because it includes a compound group of patients with various diseases and different needs for help. One participant said: *"the daily scheduled task list may contain palliation and cancer care just as much as care for people with dementia."* The staff need to cope with many different tasks and act as coordinators between various health services, other health professionals and patients' family members. Another participant stated: *"We are doing everything; I don't know what we're*

TABLE 2 Main findings identified as themes, code groups and sub-groups

Themes	Code groups	Subgroups
Complexity and need for individualized, facilitated homecare services	Organization of homecare services	
	<ul style="list-style-type: none"> • Assessment of services 	A focus on patient needs Employees report a need for a change in services Complexity of homecare services
	<ul style="list-style-type: none"> • Services for people with dementia 	Poorly customized services Services adapted to people with dementia
Relationship and trust	Competence in dementia	
	<ul style="list-style-type: none"> • Confidence building 	Customization and flexibility Confidence-building measures
	<ul style="list-style-type: none"> • The importance of time 	Time used as a tool for establishing confidence and providing health care Priority of using time Time to assess the patient
Organizational challenges	<ul style="list-style-type: none"> • Continuity within staff 	Continuity as requested by staff Continuity for the benefit of the patient
		Challenges in establishing trust Challenges related to maintaining continuity Time as an organizational resource

not doing." The complexity of the service made it challenging to tailor it to the individual patient. According to the participants, there was a need for customized and individualized facilitated homecare services to meet the various complex needs of people with dementia.

3.2 | The importance of trust and relationships

Establishing a relationship and trust between the person with dementia and the staff emerged as important both for the patient's acceptance of necessary homecare and for the staff's ability to provide quality care. The staff identified the need to spend sufficient time in the patient's home and continuity of care as significant elements for achieving a trusting relationship. Spending time in the patient's home was considered particularly important when the patient began receiving homecare services. As one participant said:

If I have no time to do anything but hand out medication and then leave, I won't gain the confidence of a person with dementia. To ensure the patient's trust, we must get inside, sit down, and talk. Then, staff will be allowed to help more and more. Especially patients that are new, if we only come for quick visits ... it takes so long to get familiar and get the opportunity to help ... because they think they can manage everything on their own and do not want help. It takes time to build trust.

People with dementia do not necessarily recognize the staff from one day to another, and a limited number of staff visiting each patient were described as critical for the patient to become familiar with them. This made it easier for the person with dementia to accept the health care provided. Establishing trust in the relationship between the patient and the staff resulted in better-quality care. One of the staff said:

When the (severity of the) disease increases, it becomes more difficult to help them. We have been talking about the fact that we must spend more time while they are still ... a little healthier. And don't start spending that time when it's too late.

The participants described taking the time to establish a solid relationship with the patient as crucial for identifying the patient's needs for help and, hence, being able to deliver adequate homecare. In cases where the patients had reduced ability to communicate their needs, spending extra time in their homes was necessary to observe them and identify their needs for homecare services. One informant said: *"You can't be completely sure of the answers you get from a person with dementia; you have to go a little below to find out how things are. We must be like detectives."* Systematic assessment was described as time-consuming and time to assess and observe the patient was not defined and systematically added to the providers' daily scheduled task list.

3.3 | Organizational challenges

The staff experienced important challenges associated with the organization of homecare services for people with dementia. Although homecare service for people with dementia was organized in different ways, the staff felt that the service was vulnerable to changes, and it became difficult to maintain necessary adjustments. *"In weekends and like it has been this summer, there are few of the staff at work and they (people with dementia) are distributed to different scheduled task lists, preferably geographically."* The staff described that practical tasks and following the daily scheduled task list were often prioritized at the expense of an individually tailored service and person-centred care. Due to the complexity of the situations of persons with dementia, time pressures and many patients to visit, the shift was challenging. The patients' needs for additional time were rarely considered. The staff was responsible for the total use of time, and they experienced additional time pressure when the patient needed more time than had been scheduled for the visit. One participant described the situation this way: *"After all, it's medication, it's dressing... everything really. It means that we cannot spend more time than necessary because everyone needs help. No, it is busy days. It is hard to see what else it should be. It is like this everywhere."*

4 | DISCUSSION

In the following, we discuss the findings in relation to previous research and their potential clinical and organizational implications.

4.1 | The complexity of homecare services challenges an individually tailored service to people with dementia

The participants describe a dual complexity, where the homecare service is experienced as a complex service with a need for continuous planning and coordination to assist a complex group of patients of different ages, with various diseases and different needs for help. People with dementia are described as complex patients, often with multimorbidity combined with cognitive impairment and advanced age. The need for coordination, planning and organization of the homecare service can exceed the capacity the service has to adapt to the individual patient (Fjørtoft et al., 2020). This may explain why homecare services have traditionally been minimally specialized and adapted to people with dementia (Bokberg et al., 2015) and have been described as providing the same type of help to most patients (Bokberg et al., 2015; Larsen et al., 2019; Turjamaa et al., 2014). Although the complexity experienced by the staff can be challenging, the need for a tailored service for people with dementia is emphasized.

Previous research has identified that a trusting relationship between the staff and the person with dementia and continuity of care with a limited number of staff visiting the same patient are critical for

maintaining quality care for people with dementia. The same applies to sufficient time to spend in the patient's home (Gorska et al., 2013; Jansen et al., 2009; Jasper et al., 2018; Samus et al., 2018; Toot et al., 2013; Turjamaa et al., 2014). The results of our study, where staff experienced continuity of care (visiting the same patient) and enough time for each patient as important factors in the organization of homecare services for people with dementia, are consistent with these findings. The participants emphasized that this group could have challenges communicating their needs for help. Therefore, continuity of staff and sufficient time to observe and identify the patients' needs for help were considered necessary. Establishing a trusting relationship was particularly critical when the patient began receiving homecare services for him or her to accept the necessary help and care in the long term.

Although the results of this study show that staff attempt to tailor services to the needs of the individual patient, a traditional organization and the complexity of homecare services can challenge an adapted service for people with dementia.

4.2 | The need for a customized and well-coordinated homecare service for people with dementia

National guidelines in Norway have emphasized that people with dementia should receive a person-centred and well-coordinated homecare service that addresses their needs for comprehensive care (Ministry of Health & Care Services, 2015b, 2018; Norwegian Directorate of Health, 2017). Care services based on a person-centred philosophy implies that treatment and care for the patient must be based on the patient's individual life story, preferences, resources and abilities. To understand and fulfil the individual's needs, one must always strive to understand the situation from the patient's perspective (Brooker, 2003). Although this has been the gold standard of care for several years, the results of our study reveal that it remains challenging to achieve this goal in homecare services.

Therefore, it is important to ask the question: What factors cause the challenges in providing individualized facilitated and tailored care for people with dementia in homecare services?

The participants in the present study experienced time pressure and prioritization of the daily scheduled task list as supplanting personalized care. This aligns with previous research that found that homecare service may easily be tailored only to the patient's obvious physical needs and everyday tasks (Morrisby et al., 2018; Turjamaa et al., 2014). This may contribute to homecare service that is only minimally customized to the individual patient (Dawson et al., 2015; Gorska et al., 2013; Jansen et al., 2009; Jasper et al., 2018; de Witt & Ploeg, 2016). Since the amounts of time required to drive between patients' home and to complete statutory documentation can be underestimated on the daily scheduled task lists (Holm & Angelsen, 2014), the combination of large geographic distances between patients and little time allocated for documentation may affect the time available for the individual patient. This can result in

unnecessarily difficult conditions for tailoring the homecare services to the individual patient.

Different ways of organizing homecare services for people with dementia were mentioned by the staff, but it seems that a homecare service tailored to persons with dementia is vulnerable to changes in the organization. An adapted service for this group of people can easily be at the expense of the daily scheduled task list (Morrisby et al., 2018; Turjamaa et al., 2014), and the result may be an experience of fragmented service based on routines (Morrisby et al., 2018; Prince, 2016; Turjamaa et al., 2014). Considering that Norwegian municipalities differ considerable in geographic size and population, local adaption and different ways of organizing homecare services for people with dementia should receive increased attention in the future.

4.3 | Limitations

The first author's work experience as a nurse in homecare services may have influenced how the material was analysed and interpreted, as the first author may have a predefined understanding of how the homecare service works and what the challenges might be. Conversely, this work experience may have contributed to a richer understanding of the data material because the first author detected nuances in the material that could be difficult for others to find. Moreover, the fact that leaders of the homecare services recruited the participants for the study may have resulted in a biased selection of participants from the staff. This could have been a selection of staff that shed light on only one aspect of the service. However, the leaders were instructed to select participants based on their potential to contribute with important and balanced information. None of the authors knew any of the participants beforehand. A limitation of the study is that none of the participants have validated the analysis process and results.

The main strengths of the study include the number of participants and their representation of different municipalities; their heterogeneity in regard to age, professions, educational levels and background; and a rich body of data material transcribed following the audio-recording of the interviews. Individual interviews ensured that the participants could speak freely. All these factors enhance the transferability of our findings (Malterud, 2001).

5 | CONCLUSION

To organize homecare services tailored for people with dementia is a challenging process, considering the complexity of both the services and the patients with dementia and multimorbidity. The findings of this study show that the staff recognized the importance of an adapted and customized service for people with dementia. However, they experienced organizational limitations such as lack of available time and deficits in the continuity of care. These limitations made it difficult to achieve a trustful relationship with the patients, which

they conceived as a necessary step towards a person-centred care service. The traditional way of organizing the homecare service can challenge the ability to provide a person-centred care service to people with dementia. Other non-direct care-related tasks such as driving and administrative work must be made more visible on the daily scheduled task lists to allow for allocating sufficient time for person-centred care. Each municipality should be given greater opportunities for local adaptation of organizing services for people with dementia, while at the same time clarifying the knowledge about patients' needs for individually adapted homecare service. Future research should focus on how the homecare service could implement person-centred homecare service of good quality for people with dementia.

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CONFLICT OF INTEREST

There are no conflicts of interest to report in this study.

AUTHOR CONTRIBUTIONS

All authors contributed to ensuring that data were correctly collected, to interpreting the material, and to reporting the findings. The first (KAH), second (AMMR) and third (IHF) authors collaborated on the analysis of the data, where interpretation was conducted to the best of their ability and in line with what the participants had expressed. Additionally, all authors participated in writing the article and in the final reading.

DATA AVAILABILITY STATEMENT

The data sets generated and/or analysed during the current study are available for researchers in cooperation with the data owner, the research centre for age-related functional decline and disease—Innlandet Hospital Trust.

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