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## EMPIRICAL STUDIES

# Perceptions of providing safe care for frail older people at home: A qualitative study based on focus group interviews with home care staff

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## Abstract

**Background:** Providing safe care is a core competence in healthcare. The concept usually refers to hospitals but, consistent with the increasing importance of integrated care, the provision of safe care needs to be extended to the context of home care, and more research is needed concerning home healthcare providers' perspectives in this context.

**Aim:** The aim of this study was to describe care providers' perceptions of providing safe care for frail older persons living at home.

**Method:** A qualitative methodology was chosen. In total, 30 care providers agreed to participate. Data were collected through five focus group interviews and analysed using a phenomenographic approach.

**Results:** Three themes regarding care providers' perceptions of providing safe care emerged from the data: 'safe care is created in the encounter and interaction with the older person', 'safe care requires responsibility from the caregiver' and 'safe care is threatened by insufficient organisational resources'. The findings show that providing safe care is an endeavour that requires a holistic view among the care providers as well as effective collaboration within the team, but insufficient competence or a lack of time can make it difficult to safeguard the psychological and existential needs of older persons.

**Conclusion:** Providing safe care in home environments encompasses more than just risk reduction. The findings highlight the importance of establishing and integrating team-based and person-centred care into home care settings. Traditional communication structures for inpatient care also need to be adapted to the cross-disciplinary work in municipalities. Care providers should be given the opportunity to develop and maintain their competences and to prioritise relationship-oriented care.

## KEYWORDS

community care, home care, interprofessional care, phenomenography, providing safe care, qualitative approaches, teamwork

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## BACKGROUND

Home care is a growing healthcare sector across Europe (1). As patient safety is a key element of high-quality healthcare, providing safe care is a core competence for improving care quality in home care settings (2, 3). The majority of home care recipients are older persons (4–6), and enabling ageing in place while frailty is increasing necessitates various kinds of support, the involvement of multiple care professionals (7, 8) and significant dependence on informal caregivers (9). In Sweden, this support includes home help services and at-home nursing and rehabilitation services. Since such services are provided by three different municipal care organisations governed by two different legislations (10, 11), integrated care is essential (12). However, the division of responsibility leads to the fragmentation of care (13, 14) and to communication challenges between organisations and professions (15). In this complex care setting, a previous study (16) found that preserving a feeling of at-homeness, being able to influence their own care and being able to trust care providers are essential prerequisites for older persons to be able to feel safe at home.

Safe care is described in terms of error prevention and protection from harm. It is a major universal concern throughout the continuum of care and of critical importance in home care (17, 18). However, because the concept of safe care was developed within hospital care (19), the application of the concept to home care can be challenging due to the lack of a mandate to control and adapt the home environment to ensure safe care (20).

Home care providers describe their work as lonely (13) and challenging in terms of avoiding adverse events (21, 22), executing delegated routines (23), managing medication and balancing the adaptation of the home environment for safety with respect for the patient's autonomy (15). In light of this, the lack of research into care providers' perspectives on ensuring safe care in patients' homes is surprising (24, 25). Studies show that home care is associated with both a perceived unlimited responsibility on the part of care providers (26) and care recipients' lack of compliance with care processes (27). It is also linked to the duality of delivering care in the private space of a patient's home, which encompasses both opportunities, such as patients' feelings of comfort and control of their lives, and barriers, such as the difficulties of providing care in a place not designed for that purpose. Additionally, care provision at home is influenced by the psychological, social and emotional interactions between care providers and the older person (28, 29), but it has a strong connection with both the care system and the individual caregivers' approach to providing care (24, 25). Thus, providing safe care at home presents extensive and unique challenges and is not fully understood.

To summarise, home care is a complex interactive process that involves care professionals with various competences from different health and service organisations who converge at the older person's home. Despite the complexity of the situations in which care providers find themselves while working in a person's home and their critical impact on care safety, research into their perspectives on how to provide safe care at home is limited. To increase the knowledge base, a group interview study was performed with the aim of describing care providers' perceptions of providing safe care for frail older people living at home in ordinary housing.

## MATERIALS AND METHODS

### Study design and approach

Data were collected through five focus group interviews, which were analysed according to a phenomenographic approach (30, 31) with the goal of collecting a variety of experiences of a specific phenomenon (32, 33).

### Participants and settings

Various relevant municipal care services in an urban area and a rural area in western Sweden were invited to join the study. Purposive sampling was used to include care providers who have been employed for at least the previous 6 months at their current workplaces.

Unit managers shared an information sheet with the staff and offered the opportunity to participate in the study. If interested, the care providers received additional verbal information from the first author. Care providers were asked for written consent if they agreed to participate in the study. The participants were assured that the data would be analysed at the group level and that they could withdraw at any time without consequence.

Focus group interviews were conducted with a total of 30 care providers (two men and 28 women). For detailed demographic data, see Table 1.

### Data collection

The interviews were conducted between November 2018 and March 2019 at the respective care units. Focus group interviews were used for data generation to enable investigation of the phenomenon through insight into the participants' experiences of providing safe care. The groups were homogenous in terms of the participants' work units, and the participants' discussions

**TABLE 1** Characteristics of the participants in the five focus group interviews

Characteristics	Group 1: Healthcare professionals N = 7	Group 2: Healthcare professionals N = 4	Group 3: Care workers N = 6	Group 4: Care workers N = 9	Group 5: Rehabilitation staff N = 4
Location of work unit	Urban area	Rural area	Urban area	Urban area	Urban and rural areas
Profession	Psychiatric nurse (n = 1) district nurse (n = 1) nurse assistant (n = 1) Registered Nurse (n = 4)	Paediatric nurse (n = 2) geriatric nurse (n = 1) district nurse (n = 1)	Nurse assistant (n = 6)	Support worker (n = 5) nurse assistant (n = 4)	Physiotherapist (n = 3) physiotherapy assistant (n = 1)
Age (years)	31–61	26–63	30–48	27–56	29–53
Time working in current unit	6 months – 7 years	18 months – 28 years	6 months – 10 years	6 months – 11 years	10 months – 7 years
Care providers' roles and duties in older people's homes in Sweden	Preventive work, basic medical treatment and nursing in a person's home; home healthcare does not involve physicians		A range of support services that may include anything from light housekeeping duties to personal care and meal preparation		Home rehabilitation that does not require advanced technical resources

and interactions were supported by the interviewer to promote reasoning and reflection of the phenomenon being discussed (34).

The group discussions were based on a semi-structured interview guide. Two key interview questions guided the interviews: 'How do you provide safe care for frail older persons in their own homes?' and 'What opportunities for and barriers to the provision of safe care do you perceive?' In addition, the participants were asked to give examples of safe and unsafe situations in home care and what they wanted to change in order to provide safe care at home. Each interview lasted approximately 1 hour, and was audio recorded and transcribed verbatim by the first author.

## Data analysis

The analysis was performed using a phenomenographic approach, which aims to describe a variety of people's experiences or perceptions of the surrounding world and can be viewed as a system of conceptual order that references people's collective intellect (30, 31). The analysis followed the four steps described by Alexandersson (35). In the first step, all the interviews were listened to and read thoroughly several times to gain an overall impression of the material. In the second step, variations in the material were noted, that is, similarities and differences in participants' perceptions were identified. In the third step, the statements were sorted into descriptive categories of conceptions by bringing quotes with similar perceptions together. In the fourth step, the categories were

abstracted into three themes that describe the underlying meanings of the categories. Each theme describes the participants' perceptions of providing safe care for frail older people at home. This work was performed mainly by the first author in close cooperation and discussion with the co-authors.

## RESULTS

The analysis of the focus group interviews with home care providers produced three themes, each comprising two or three categories, which describe the variety of study participants' perceptions of providing safe care for frail older people at home (Table 2). The themes mirror the perceptions of the care providers as a group, regardless of their work unit or role in older people's homes. However, some statements were more common in connection with specific professional roles, and this has been highlighted.

### Theme 1: Safe care is co-created in the encounter and interaction with the older person

This theme deals with the care provider's approach to the encounter and interaction with the older person and comprises of two categories: 'To consider the complex needs of the older person' and 'To respect the older person's self-determination while reducing risks in care situations'.

**TABLE 2** Themes and categories that emerged from the analysis

Theme 1	Safe care is co-created in the encounter and interaction with the older person
Category 1.1	To consider the complex needs of the older person
Category 1.2	To respect the older person's self-determination while reducing risks in care situations
Theme 2	Safe care requires responsibility from the caregiver
Category 2.1	To be aware of and fulfil one's assignment
Category 2.2	To be committed
Category 2.3	To collaborate within the group and across professional boundaries
Theme 3	Safe care is threatened by insufficient organisational resources
Category 3.1	To handle inadequate communication structures
Category 3.2	To handle lack of competence
Category 3.3	To handle time pressure

### Category 1.1: To consider the complex needs of the older person

Providing safe home care was associated with the care providers' ability to adopt a holistic view and not only focus on physical shortcomings. The participants considered that ensuring the older persons' social and emotional well-being requires more attention to psychological and existential needs. They stated that a holistic view in caring means listening to the older person with the desire to understand their complex needs.

You cannot force yourself into their home... You have to listen and feel... what the person himself wants and thinks. I think it is all about communication and respect... it helps them [older people] mentally and physically as well. Many of them need mostly social interaction; they need someone to talk to them in a nice way so... they feel safe...

(Care worker)

### Category 1.2: To respect the older person's self-determination while reducing risks in care situations

Providing safe care was strongly associated with ensuring and respecting the older person's self-determination. This effort was sometimes challenged by contradictory decisions made

by the older person that the care providers saw as endangering their health. These could be about managing medication independently despite insufficient compliance with handling instructions or an unwillingness to follow prescribed exercises. In such situations, the participants expressed a responsibility for protecting the older person by explaining the purpose of a recommended course of action and motivating them to make decisions that do not jeopardise their safety at home.

It is so good when you have succeeded in a goal that the patient himself has expressed. I never force, but I try to reflect...so that they understand why [they] need to do these boring exercises... or why that training must be so frequent.

(Rehabilitation staff)

The participants stated that they were often more concerned about the safety of care than the older persons themselves were. However, they expressed the need to be creative in finding ways to provide safe care when confronted with inadequate environmental conditions, such as light deficiency, cramped space or the absence of a shower. They also described the duality of the involvement in care of the older person's relatives. For example, engaged relatives could provide essential information to ensure safety, but their abilities sometimes did not correspond to the care interventions they wanted to take on.

I have a patient whose wife absolutely wants to take care of [him]... She has dementia ... But she absolutely wants to manage medication treatment for her husband. I feel worried about him because he does not really get the medicine he needs... She forgets.

(Healthcare professional)

### Theme 2: Safe care requires responsibility from the caregiver

The second theme includes concepts that deal with the participants' individual attitudes towards providing care and their collaboration with colleagues and other professionals. The theme comprises three categories: 'To be aware of and fulfil one's assignment', 'To be committed' and 'To collaborate within the group and across professional boundaries'.

#### Category 2.1: To be aware of and fulfil one's assignment

The participants considered that providing safe care at home required identifying their responsibilities in the



person's home, which was experienced as more challenging than providing care within a hospital. The care provider's awareness of the need to maintain up-to-date documentation was described as one of the crucial prerequisites for providing safe care at home. Having control of the doctor's referral, medication prescriptions, event reports and care routines enabled them to be aware of what to do, how to perform an assignment and how to approach each older person.

There are different care recipients. It is very important to read about each person, what they need.

(Care worker)

The participants underlined the importance of not only being aware of one's assignment but that this also must correspond to the actions they were responsible for in line with the older persons care plan. They stressed the risk of harm to the patient if they neglected their responsibilities or assignments in the delivery of care.

They [care workers] are very careful during training and aware that they have to look at the prescription, but somehow... when they work, they do not read the prescription. That is harmful to the patient.

(Healthcare professional)

The statements in this category appeared mainly among the groups consisting of healthcare professional and rehabilitation staff and relate to difficulties in delegating medical tasks or rehabilitation exercises with older people to team members if they felt uncertain about whether the assignments should be performed or not.

### Category 2.2: To be committed

The participants associated the provision of safe home care with the care providers' individual interests in working with people, their flexibility, their engagement and their willingness to adapt care efforts and find the 'silver linings' for the well-being of older people. A recurring statement was the participants' desire to feel they were a 'good person', but this was seen as potentially problematic as it could sometimes involve care providers exceeding the limits of their responsibilities and professional roles. For example, it might entail rehabilitation staff ensuring the older person's nutritional needs before training sessions, care workers going personally to the health centre to book an appointment for the older person or healthcare professionals hanging up curtains or throwing out trash.

Commitment was described as a complex process that assumed the ability to balance personal and professional roles.

To be professional is a nice word, but it is... to keep a certain distance and not sit down and have coffee [with the older person] during a half-time break. We do not have this time either... But we may talk about our children, and problems, and everything. I do not do it, I keep a distance. But then, I can probably say how many children I have and a little... if it is my patient, who I have known for several years, of course... In this case, we talk in a different way, but... You have to separate the roles.

(Healthcare professional)

### Category 2.3: To collaborate within the group and across professional boundaries

Providing safe care was connected to collaboration within and between professional groups and care organisations. Insufficient collaboration led to a gap in care responsibilities, a lack of information and the absence of technical aids while also risking suffering for the older person and creating work environment problems for the care providers, who needed to spend a lot of time working to compensate for these issues. Even though these issues emerged among all the professional groups, they were mainly expressed by care workers who described feeling exposed when providing safe care for older people at home without sufficient collaboration with other professional groups and care organisations. A mutual understanding of each other's competence was perceived as reducing barriers to information transfer, increasing trust, improving the delegation of tasks and improving preventive work by identifying issues earlier. According to the majority of the participants, the joint meetings – so-called team meetings – were a way to solve the problems described above and thereby improve collaboration.

I can sometimes feel that... not everyone knows what a physiotherapist does, which care efforts we can provide... We work with many areas... I think about collaboration between nurses and us... we know just as little about what they do.

(Rehabilitation staff)

Providing safe care at home was also related to the feeling of having an open atmosphere in the working group.

The participants said that their own well-being and ability to provide care were dependent on being able to openly express feelings and ask for help when needed. The participants valued the opportunity to reflect and receive support when they became stressed or found themselves in a new or unmanageable situation.

It is important to be able to reflect and feel support in the group. To feel you can express that you may not always be able to manage this or that you need a little [help]...

(Healthcare professional)

### Theme 3: Safe care is threatened by insufficient organisational resources

The third theme deals with the participants' experiences of ensuring older people's complex needs in their homes without sufficient resources and comprises three categories: 'To handle inadequate communication structures,' 'To handle lack of competence' and 'To handle time pressure'.

#### Category 3.1: To handle inadequate communication structures

Providing safe care at home was associated with the ability to contact other professionals or care organisations in order to receive information, obtain technical aids and help the older person to get in touch with the right care provider. The participants stated that they faced challenges in knowing whom to contact and in getting in touch with the care professions or care organisations whose involvement was deemed necessary.

I called... I wanted to ask them [another profession] to come and see [the older person] to get help both for her well-being and for our work environment, so we can perform our job... No, I was just sent back and forth. In the end, I got so crazy... How should I act, what should I say... to get help?

(Care worker)

The communication problems occurred due to different documentation systems and the absence of communication channels. The problems were apparent for all care providers, but especially among the care workers who suggested the establishment of a specific telephone number and scheduled time to get in touch with other care professionals and care organisations.

#### Category 3.2: To handle lack of competence

Most of the participants associated providing safe care at home with the care providers' competence, which was described in terms of education relevant to work assignments, professional development and good language skills. Reorganisations and high staff turnover were noted as risk factors for providing safe care because they led to a loss of competence among care providers. Lack of competence increased strain, feelings of insecurity and frustration among colleagues in the local work group and in the interdisciplinary team.

There have been a lot of new staff who have no experience of working in home care ... It feels very heavy. Because we can also lose knowledge from the team, which makes it even more demanding and creates more work for home health care workers. There are many care assignments that you maybe were able to delegate to the worker in home care services but which you have to take back.

(Healthcare professional)

#### Category 3.3: To handle time pressure

The participants reported that older persons' needs could suddenly change due to their physical or mental condition or due to previously unplanned, but ordinary, activities. Under such circumstances, tightly regulated schedules reduced the opportunity to adapt their work to the older person's individual needs. Situations in which they had to spend more time than planned could affect the care efforts for other older persons and increase feelings of stress.

I should be at her [older person's] home for twenty minutes during lunchtime. She asked, 'can you put a salmon into the oven and cook potatoes'?... I stayed there for forty minutes... and I cannot say, 'no, I will not do it'. Sometimes, it can be a situation in which you cannot say 'no', but then you have to maybe reduce some other care interventions ... for other [older persons] in order to cope with the work day.

(Care worker)

Additionally, time pressure affects the ability to provide safe care in terms of the older person's needs for social interaction and well-being, quality of life and mental health. It can also lead to diminished continuity and limited risk-reducing actions.

## DISCUSSION

The aim of this study was to describe care providers' perceptions of providing safe care for frail older people living at home. The findings showed – in line with earlier research (36) – that home care providers must be adaptable to the older person's private home environment and creative in terms of finding ways to provide safe care in such settings. Issues like inadequate communication structures, lack of competence and time pressure required more from the care staff than just awareness of which care interventions should be provided; they also demanded extra attention, respect and understanding for the needs, points of view and expectations of the frail older person and their relatives in order to improve the older person's well-being and prevent their risk of harm. Encounters with the older person were affected by the care provider's awareness of their own assignment and commitment, and it follows that providing safe care at home is dependent on the sense of responsibility of the care provider and their caring values – that is, whether the care should be task oriented or relationship oriented.

Consistent with previous research (27), the study showed that the care providers experienced challenges in avoiding the occurrence or risk of harm in situations in which they disagreed about safety with the older person. Such situations could lead to ethical dilemmas among care providers due to the tension between the generally accepted definition of safe care as the absence of preventable harm (18) and respect for the older person's autonomy and right to self-determination. The care recipient's involvement in their own care is a key issue for ensuring safe care (2) and is important for the older person's feeling of safety in the home care setting (16). Thus, one solution to reaching an agreement about safe care with older persons was the co-decision of care goals, which – in line with a study by Gustin (37) – makes it easier for care providers to guide older persons in their healthcare and everyday activity choices. Joint decisions presuppose shared decision making, which, according to McCormack and McCance (38), is one of the prerequisites for person-centred care (PCC). Moreover, PCC improves care providers' ability to work proactively (39), which highlights its significance in providing safe care (40, 41), particularly of older people (42).

In the home care setting, which is experienced as a problematic space to control (20), providing safe care was associated with the care provider's flexibility in adapting care activities to the older person's complex and varied needs, which confirms previous research (36). However, to identify individual needs, the care providers have to be willing and able to listen to the older person. Commitment can be a way to focus on the personhood of older people and

to, thus, create positive relationships with them, which is a part of providing PCC (43). Healthful relationships between care providers and older people who receive care at home are supported by values of understanding, mutual respect and the right to self-determination. (38). These values should, thus, improve the ability of care providers to treat older people's physical, mental and emotional well-being as being indivisible. These findings, by showing a connection between providing safe care and the care providers' commitment, could act as a starting point for a discussion on how to support a move from disease- and task-oriented care towards relationship-focused care, which enables the identification of older persons' individual expectations and their involvement in the care processes (43), resulting in more holistic and collaborative care.

However, a move towards holistic care may prove problematic due to care providers' experience of collaboration issues, which have also been described in previous studies (13–15). There is, thus, a need for improvement in the exchange of information and knowledge across professional boundaries (44) to support safe care for older people at home. However, since collaboration in home care is complicated by the involvement of different care organisations (10), competent multidisciplinary work requires strategies to improve their coverage and compatibility (45).

Findings from this study stress the importance of an open atmosphere in the team and of open communication between different professions and care organisations. Such processes might have a positive influence on beliefs and values in care delivery, which is considered essential for ensuring a patient safety culture (46) and, thus, an important strategy in improving safe care at home (47). Moreover, the findings highlight the importance of applying integrated care in home care settings by co-creation and co-production of care among both the care professionals and the older person and their relatives (48).

The results – in line with previous research (44, 49) – highlight the care providers' concerns of not being able to consider the older person's needs and expectations due to inadequate communication structures, lack of competence and time pressure. For example, time pressure could worsen an older person's feeling of control in their home (26) and complicate the development of a trusting relationship (16). Time pressure also influences care providers' stress, which, according to Jarling et al. (26), could lead to an ethical conflict between time allowances and the needs of the older person. Furthermore, the participants were dissatisfied with their job situations due to high staff turnover, which, in line with previous studies, exacerbated the relationship between unsafe care and insufficient organisational support (24, 50). In the context of



PCC, competence is more than an assignment or a demonstration of a desired behaviour – it is a holistic approach that includes knowledge, skills and attitudes. Unlike task-oriented care, the holistic approach to caring is consistent with the fundamental values of PCC (38).

The current study contributes to previous research by highlighting care providers' attempts to compensate for organisational shortcomings by finding ways to promote safe and relationship-oriented care using their individual competences and taking greater responsibility. Additionally – again, in line with previous research (26, 50, 51) –, the study illuminates the fact that home care providers are in a vulnerable situation due to their constant need both to prioritise between tasks and relationships and to make decisions under challenging conditions. This emphasises the need for supporting care providers to apply PCC as it can increase their personal and professional satisfaction (52) and contribute to the reduction in job stress and strain (53).

The phenomenographic approach describes a variety of people's experiences or perceptions of the surrounding world rather than exploring the processes involved in the formation of these differences (54). Nonetheless, we considered it important to illuminate some varieties in care providers' perceptions with regards to their specific roles in this care setting in relation to their clinical importance. For example, all care workers perceived a lack of collaboration and communication structures, but the awareness of the importance of their own assignment corresponding to the responsibilities documented in the older person's care plan was more prominent among healthcare professionals and rehabilitation staff. This illuminates an interesting difference in attitudes between professional roles, in which licensed professionals, such as healthcare and rehabilitation staff, stressed responsibility, while the home care providers who struggled with unmet prerequisites for completing their assignments stressed the need to improve communication between the different groups of care providers. This situation highlights the need to improve safe care at home by finding ways to support collaboration in multidisciplinary home care teams. This process should include both adequate transfer of up-to-date information, which requires adapted communication channels and a high level of interaction between team members, and common goals among all the professional groups (55).

Frail older people are in a precarious position in society (56). Neglect of their desires for control, self-determination and more positive relationships with their care providers can both increase their vulnerability (16) and worsen their care providers' ethical stress in home care settings (57). This reality underlines the importance of ensuring policy makers are aware of their responsibility to support home

care organisations by allocating sufficient resources to enable PCC.

## Strengths and limitations

The choice to use focus group interviews in the study was based on their advantages in accessing participants' inner experiences, known as the second-order perspective, which is the basis for applying a phenomenographic approach (58). During the focus group interviews, the participants were able to reflect and interact with each other, which can be assumed contributed to more extensive data compared to individual interviews (59, 60). A wide variety of perceptions were collected to serve the phenomenographic approach by involving care providers from three different care organisations (31). The authors who led the group interviews have professional experiences of healthcare, which was advantageous in terms of knowledge of the home care context and the ability to guide the discussion in a direction consistent with the study's aims.

Data collection using focus group interviews could be a limitation as it creates the risk that participants feel unable to be open about their experiences or that they describe them superficially, which could result in a failure to capture the full variety of their perceptions. However, in this study, participants shared both positive and negative experiences, suggesting that they felt an open atmosphere and could freely describe their perceptions of providing safe care at home.

Data analysis using a phenomenographic approach is an interactive process and could be affected by the researcher's pre-understandings (58). To ensure correct data analysis and achieve a high level of trustworthiness, the first author worked in close collaboration with the three co-authors, who have broad experience of healthcare and extensive research experience. The research group continually discussed the relations and hierarchies of the statements in the descriptive categories to evaluate the consistencies between the original data and the findings and to minimise the influence of subjective interpretations. To enable readers to assess the trustworthiness of the analysis, the study results have been illustrated by representative quotations. The results of this qualitative study cannot be generalised (61) but they may be applicable to similar situations and contexts.

## CONCLUSIONS AND CLINICAL IMPLICATIONS

Safe care for frail older people at home is multidimensional and encompasses more than risk reduction. This

study showed that providing safe care at home entails organisational prerequisites that enable an open atmosphere within each working group and that support the care providers in their commitment to prioritising relationship-oriented care towards a person-centred practice.

These findings highlight the importance of establishing routines to initiate PCC and integrate it into home care settings. This involves shared decision making; healthful relationships between care providers and older people who receive care at home; and adequate communication and collaboration structures within cross-disciplinary work in primary and municipality care. Care providers should also be given the opportunity to seek, maintain and develop their competences and to apply their professional skills in encounters with older people at home without time pressure.

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### CONFLICT OF INTEREST

The authors declare that they have no conflict of interests.

### AUTHOR CONTRIBUTIONS

AS, HW and EL: Study design and study planning. AS and HW: Conducting the group interviews. AS, HW, EL and LJ: Data analysis and drafting of the manuscript. All authors were active in reviewing and editing the manuscript.

### ETHICAL APPROVAL

Approval was obtained from the regional Research Ethics Committee (Ref. 149–17). All data were handled according to the General Data Protection Regulation (GDPR).

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