Enacting person-centred care in home care services for people with dementia

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Abstract
Aims and objectives: To develop the theoretical understanding of the process of providing person-centred home care for people with dementia.

Background: People with dementia are increasingly cared for at home by family members and home care staff. Care of people with dementia should be person-centred; however, little is known about how home care staff understand and enact person-centred care in their daily work.

Design: Grounded theory.

Methods: Home care staff \((n = 29)\) were recruited from home care services specialised in providing care for people with dementia. Group interviews were conducted, and a tentative theoretical model for providing person-centred home care to people with dementia was outlined. Nine of the participants were then individually interviewed to further develop the model. The analysis was conducted parallel to the data collection, and hypotheses concerning the evolving theoretical model were continuously tested in the following interviews. The COREQ checklist for qualitative studies was used in reporting the study.

Results: Person-centred home care of people with dementia was conceptualised as a series of processes: Getting ready, getting in, giving care, getting out and finalising the story, each with subprocesses. Theatre metaphors were used to describe how the care was provided. A core process, Enacting and re-enacting familiarity, was at centre in all processes.

Conclusions: In the person-centred care of people with dementia, familiarity had to be established and continuously fostered. When familiarity was in place, the care recipient and the home care staff acted as a team to perform the care. The theoretical works of Goffman were used to interpret the results.

Relevance to clinical practice: The study provides a model for person-centred care of people with dementia at home that deepens the understanding of its processes, prerequisites and outcomes. The model can inform education and administration of home care for people with dementia.
1 | INTRODUCTION

Dementia is caused by a variety of medical conditions, most commonly Alzheimer’s disease. It is characterised by progressive cognitive decline and increasing difficulties in managing activities of daily living. Most people with dementia are living at home, with assistance of family and professional carers. Globally, a need to improve the support of people living with dementia and their families has been highlighted (World Health Organization, 2017). Person-centred care has been stipulated as a golden standard for care of people with dementia. However, the theoretical understanding of person-centred care in the context of home care for people with dementia is still limited. Better insights in this area can contribute to increase the quality of care and support for families living with dementia.

2 | BACKGROUND

In Sweden, between 130000 and 150,000 people are living with dementia (National board of health & welfare, 2017), most of them in their ordinary homes (Odzakovic et al., 2019). Half of the people with dementia living at home were estimated to use home care services, such as home help and personal care, safety alarm, meals on wheels, day care service, short-term and respite care, and guide service (i.e. help to go out walking or shopping). Home help and personal care were the most used services (Odzakovic et al., 2019). Most people, including those with dementia, prefer to live in their own homes if possible. The home represents being comfortable, free, and autonomous, surrounded by personal possessions, a familiar environment and a social network (Board, & McCormack, 2018; Hatcher et al., 2019). For people with dementia, the ordinary home can also be associated with risks, as the previously known environment becomes unfamiliar and confusing due to cognitive impairments (Sandberg et al., 2017). Lethin et al., (2019) found that people with dementia living at home had more severe behavioural and psychological symptoms (BPSD) than those living in nursing homes. Family caregivers may contribute to the higher prevalence of BPSD at home, as they are frequently burdened and poorly supported which may affect their capacity to care (Elmståhl et al., 2018; Park et al., 2015). Well-functioning home care services may alleviate family caregivers’ burden (Chong et al., 2017; Etters et al., 2008), reduce risks for those living alone with dementia (Eichler et al., 2016) and postpone a transition to special housing (Polacsek et al., 2020). With the increasing care needs of people with dementia residing in ordinary homes, a need for home care services that are specialised in care of people with dementia has been highlighted (e.g. Bökberg et al., 2015; Davies et al., 2020; Gladman et al., 2007; Jansen et al., 2009).

Home care services for older people in Sweden aid with instrumental and personal activities of daily living and are staffed with licensed practical nurses (LPN) or nurse aids (NA) (Hallberg et al., 2016). During the last three decades, home care services have undergone substantial changes regarding the clients’ care needs, and the content and organisation of work (Szebehely & Trydegård, 2011). A shift from nursing home care towards care in ordinary housing has led to increased care needs among home care service users, and the staff are sometimes faced with decisions and tasks that exceed their resources and competence (Craftman et al., 2018). New management models have resulted in more specified care assignments and work schedules, leaving limited space for staff and care recipients to form the care (Szebehely & Trydegård, 2011). Sandberg et al., (2018) found that home care staff specialised in dementia reported higher job strain than other home care staff. Not being able to provide care according to their own standards was particularly straining. Brown and Korczynski (2017) similarly found that job satisfaction in the face of rationalisation was associated with perceived ability to satisfy clients’ needs.

In the care of people with dementia, a person-centred approach is essential (National board of health & welfare, 2017; Prince et al., 2013). Person-centred care implies that the person, and not the disease, is the primary focus of the carers (Kitwood, 1997). Carers should strive to learn about the life story, views and the preferences of the care recipients and encourage their active participation and autonomy. Carers should also support the care recipients’ social networks and involve them in the care when appropriate (Edvardsson et al., 2008, 2010; National board of health & welfare, 2017). In care homes, nursing staff has described four dimensions of person-centred care: promoting decision-making, promoting a meaningful living, promoting a pleasurable living and promoting personhood.
(Edvardsson et al., 2014). Person-centred care has been associated with decreased occurrence of neuropsychiatric symptoms (Livingstone et al., 2014), and increased ADL performance, quality of life and well-being (Sjögren et al., 2013) in people with dementia in care homes. Further, it has been reported to enhance a positive work environment for residential care staff (Sjögren et al., 2015; Willems et al., 2015). Olsen et al., (2020) found that people with dementia who received home care service described being acknowledged as a person, involved, and in a relationship with the staff as crucial aspects of care. From an organisational viewpoint, it has also been emphasised that the continuity of staff, flexibility of services and multi-professional cooperation are key to achieving person-centred care (Berglund et al., 2019; Rothera et al., 2008; Woolrych & Sixsmith, 2013).

Despite the recent developments in implementing person-centred care for people with dementia and the societal shift from nursing home care towards home care, little is known about how home care staff understand and enact person-centred care in their daily work. Deepened knowledge in this area will inform educational and organisational interventions to improve the care of people with dementia. Thus, the aim of this study was to develop the theoretical understanding of the process of providing person-centred home care for people with dementia.

2.1 | Study context

The study was conducted in five home care service units that were run by a private company with public funding. The five units served different geographical areas of the same urban location in Sweden. Some of the home care employees worked only daytime on weekdays, and others mainly evenings and weekends. Those who worked in the daytime were the contact persons for a few (typically 2–3) care recipients, that is, they performed the care when on duty, and planned the care delivered when they were off duty. The care was planned in individual care plans and through the expenditure of time that was calculated for various tasks. The completion of each visit was registered on a handheld computer (often referred to as ‘the phone’) along with notes concerning any deviations from the care plan that had occurred. The device also had a GPS function which registered the location of the home care staff. This system was newly introduced and not appreciated by the staff, as they felt that it limited their ability to adapt the care to the clients’ current needs. Each of the five units had a dementia team that served the clients with dementia. The home care staff in the dementia teams were handpicked by their employer based on their knowledge, interest and skills in working with people with dementia. They were required to have at least some formal training in care of people with dementia. This was typically obtained through a short web-based course managed by the Swedish Dementia Centre (https://dementcentrum.se/). The dementia teams received biweekly supervision by a project developer within the organisation.

3 | METHODS

3.1 | Design

This study was part of a larger project aiming to describe the implementation of the Swedish national guidelines for dementia care (National board of health & welfare, 2017) in specialised home care for people with dementia. In the present study, a grounded theory approach was applied (Glaser, 1978; Schreiber, 2001).

3.2 | Study participants

With permission from their managers, all home care employees (n = 34) in five home care units that were specialised in care of people with dementia were approached and informed about the purpose and outline of the study. Twenty-nine (n = 29) home care employees agreed to participate in the study and were included. Reasons for rejecting participation were not sought. The participants’ characteristics are presented in Table 1.

3.3 | Data collection

The data collection was conducted in two phases. In the first phase, group interviews were conducted with five groups, each consisting

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of 5–7 participants. They were asked to describe situations in which they had provided person-centred care and care that was not person-centred, and what had promoted or hindered the care to be person-centred. The group interviews lasted for 90 minutes and were led by one of the researchers (authors) while another researcher assisted and took notes. Based on the group interviews, a tentative model was gradually developed (further described in the data analysis section). In the second phase of data collection, individual interviews with nine of the participants from the group interviews were conducted to validate the tentative model and expand the understanding. The interviewer started by presenting the tentative model and asking the participants to comment on it as a whole. The interviewer then went through the processes and asked the participants to describe, based on a particular care recipient with dementia that they had recently cared for, how they had performed the care in each specific process. The individual interviews were audio recorded. One of the researchers led the interview, and another was present to assist the first interviewer, take memos and pose complementary questions. The median length of the individual interviews was 49 minutes (range 33–58). All interviews (group and individual) were conducted in undisturbed premises separate from the participants’ workplace. All researchers (two male and one female) were registered nurses and had previous experience with clinical work and research in care of people with dementia, and conducting qualitative research interviews. They had no previous relationship with the participants, prior to this study.

3.4 | Ethical considerations

The study was approved by the regional ethics review board. The participants received oral and written information concerning the purpose and procedures of the study. They were also informed that participation was voluntary and could be withdrawn at any time during the data collection without stating a reason. Safe storage of the data and anonymous presentation of the study results were guaranteed. Written consent was obtained from all study participants, and their names have been changed in the presentation.

3.5 | Data analysis

Directly after each group interview (in the first phase of data collection), the two participating researchers made audio recorded reflections for about 5–10 min about possible concepts (first-level coding), categories (second level coding) and relationships between categories (third level coding; cf. Schreiber, 2001). Hypotheses were formulated and tested in the following group interviews in a constant movement between data collection and analysis. Through this process, a tentative model was outlined, suggesting that person-centred home care to people with dementia could be metaphorically described in terms of improvisational theatre, with the home of the person as the stage and the people involved as actors improvising on the basis of a loosely formulated manuscript. The performance of care appeared to run through six processes: getting ready, getting in, getting the story together, enacting and re-enacting care, getting out, and finalising the story.

In the second phase of data collection (individual interviews), the participating researchers continued to make brief analytical reflections after each interview. New ideas and hypotheses were tested in the following interviews. The interviews were transcribed verbatim shortly after the completion of all interviews. The transcribed texts were then openly coded and compared with the tentative model. Based on the open coding, subprocesses were formed and some adjustments were made in the previously outlined processes. To explore the theoretical connections between processes and subprocesses, theoretical coding was performed, based on Glaser’s Six C’s: Causes, contexts, contingencies, consequences, covariances, and conditions (Glaser, 1978, p. 74).

3.6 | Rigour

To assure trustworthiness, we have strived to apply appropriate verification strategies throughout the research process, as described by Morse et al., (2002), concerning for example inclusion of informants who were best fit to answer our research question, search for negative cases, concurrent data collection and analysis, theoretical thinking and theory development. The analysis was conducted in constant dialogue between the three authors and the participating home care staff to ensure that multiple perspectives on the emerging theoretical model were considered. The Consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007) were used in reporting the study (File S1).

4 | RESULTS

Person-centred home care of people with dementia was conceptualised as a series of processes and subprocesses, traversed by a core process: Enacting and re-enacting familiarity (Table 2).

The adjusted final processes were as follows: Getting ready, getting in, giving care, getting out, and finalising the story. Establishing and upholding a mutual sense of familiarity was at centre in all processes. Familiarity included familiarity with persons, the care place (care recipients’ home), situations and care tasks. Facilitating and hindering factors to enacting familiarity were seen in terms of personal, material and organisational conditions, such as the skills, values and personalities of the persons involved the environments in which the care and related activities (such as planning, documentation and reporting of care) took place, and the way in which the care was organised, managed and evaluated. The five processes and how they were interrelated and related to the
core process and the facilitating and hindering conditions will be further elaborated below.

4.1 | Getting ready

In this process, the first encounter with a new care recipient was prepared, by gathering information about the person. This information guided the establishment of a relationship with the care recipient and served to detect potential obstacles and pitfalls to providing the care. The information facilitated the subsequent process of getting in, that is to get access to the care recipients’ home and obtaining consent for providing the care.

4.1.1 | Synthesising available information

The written information about the care recipients consisted of a short summary from the home help officer, concerning the persons living conditions, social situation and services granted. There was also a personal care plan that scheduled the care tasks over time. Further the staff made notes about deviations from the care plan in their ‘phones’ (i.e. handheld computers), as for example when a care recipient declined care. There was no time scheduled for oral handovers between shifts, which hindered the exchange of more detailed information and advice. The quality and richness of the written information varied. More detailed information about the care recipients and how they wished their care to be performed facilitated the home care staff’s process of getting ready. However, the written information was often insufficient. This caused the staff to seek further information from colleagues and other sources to get ready.

4.1.2 | Complementing factual information with information about the person

Most often, the home care staff turned to a colleague to complete the written information, by phone or by catching each other on breaks. The lack of scheduled time for oral handovers obstructed this process; however, close and longstanding relationships among the home care staff facilitated the informal ways of obtaining information. Care managers and family carers were seldom used as information sources. Managers, because they lacked the personal and practical knowledge that the home care staff sought on how to perform the care tasks to the care recipients’ liking. The family carers because they were perceived as busy, and their knowledge about the care recipient at risk of being incomplete, biased, outdated and not transferable to a professional caring relationship.

There was a perceived lack of time for reflection, problem-solving and knowledge transferral among staff members and between the home care staff and their managers, resulting in difficulties with upholding and developing the competence and quality of care.

We have very much taught each other by talking together, and now that is gone so we will not be able to keep any competence. We will not be able to develop it, we will not be able to maintain the quality, when we hardly meet before we go out. It is a very short, short information, then get the keys and then go. Then there is five minutes walking time between the errands and then hardly any time afterwards. Before we came in and documented what had been done, and then we could sit down and talk to each other afterwards. But now all is supposed to be documented.
on the phone on site in stairwells and alone like, so we don’t meet each other and have no time to talk to each other. It doesn’t count!

(Emma)

4.1.3 | Preparing ways to establish a relationship

In this subprocess, the gathered information was synthesised to detect and plan possible ways to establish a relationship with the care recipient. The general shortage of information about new care recipients was described both as hindering and promoting familiarity with the person. There was a tension between being prepared and being open to the person and the situation at hand. By having information in advance about the person and their personality and preferences, pitfalls could be avoided and plans for an appropriate approach could be made. But it could also hinder the home care staff from forming an individual view of the care recipients when they met. Thus, it occurred that staff preferred to minimise their preunderstanding of the care recipients.

4.2 | Getting in

The process of getting in concerned being allowed to enter the care recipients’ homes and getting their acceptance for receiving care. This was made through the subprocesses: toning down the care task, findings and using keys to establish a relationship, and convincing of an existing relationship. Getting in was sometimes challenging. The care recipients might be reluctant to let people who they perceived as strangers in, especially if due to cognitive impairments, they did not acknowledge their need for home care services or remember being granted them. The information about the person gathered during the process of getting ready facilitated getting in. Hindering factors were for example disrespectful approaches from the home care staff and the task-oriented and minute-controlled organisation of the services.

4.2.1 | Toning down the care task

In this subprocess, the care task was toned down and the focus was on first establishing a trustful relationship, which was a prerequisite for obtaining consent to receive the care. The home care staff sometimes spent weeks making contact and establishing familiarity before they were let in. It was important not to rush but build the relationship slowly. Proceeding too quickly might result in setbacks. Patience and sensitivity were prerequisites to succeed. It also required moral balancing between honesty about the nature of their calls and simultaneously downplaying their mission. The process was obstructed by the tight work schedule, which did normally not include time for relationship building. Extra time could be granted by the home help officers when needed; however, the system with application and grants of time was poorly fitted to the fluctuating needs of care recipients.

It’s best that one can come in and sit there and sit for a while at the TV with her and then start talking about maybe going into the kitchen and prepare something for her to eat. She has 15 minutes every evening and many have not gotten in by then () That is not gotten in to help her, that is not gotten that far yet. Whilst, when I have been there and done something, it requires 45-50 minutes to achieve anything at all. I mean, it’s supposed to feel good!

(Emma)

4.2.2 | Findings and using keys to establish a relationship

Finding the right ‘keys’ to understand and connect with the care recipients facilitated the process of getting in. Some participants also described searching for common interests to build the relationship on. Keys could be given by the care recipients, their homes, and sometimes family carers. The home gave cues about how the person had lived and what they were interested in. This could generate topics for small talk and provide entries to conversations. It was also important to avoid topics that might upset the care recipient. For example, asking about children could cause distress if a child was diseased or not in touch with the care recipient, and was thus avoided.

4.2.3 | Convincing of an existing relationship

To get in, it was important to convince the care recipient of an existing relationship, despite their cognitive impairments impeding their recall of the home care staff. Establishing familiarity was facilitated by the staff making iterated visits, showing concern, offering assistance in a non-intrusive way, appearing joyful, calm, self-evident, and humble. They tried to signal that it was quite natural for them to visit and take an interest in the care recipient and that they had no intention to control or criticise the care recipient. It was important to avoid approaches that could be perceived as humiliating, questioning, pressing, or threatening by the care recipient, as this would hinder the process towards a trustful relationship. The competence of the staff was found to be a facilitating factor in building familiarity. The experienced staff had found strategies that often worked to ‘get in’. Staff continuity was another facilitating factor in supporting familiarity. Unexperienced staff and a lack of continuity in staffing hindered the development of caring relationships.

4.3 | Giving care

In the process of giving care, the care tasks were more in focus, at the same time sustaining the relationship with the care recipient (re-enacting familiarity) and being attentive to their needs and wishes made possible the completion of care. Giving care
consisted of five subprocesses: *synchronising pace*, *playing along*, *breaking up the task in small pleasures*, *using take 2*, and *facing the audience and critics*.

### 4.3.1 | Synchronising pace

In the subprocess *synchronising pace*, the staff’s pace was adapted to the care recipient. This was necessary, as acting rushed and stressed could cause distress and withdrawal of the consent to receive care. The staff described having developed an ability to be effective and slow at the same time. This was facilitated by the staff being familiar with the homes of the care recipients, and thus able to carry out chores with remained focus on the care recipient and the relationship. *Synchronising pace* was also facilitated by the staff being patient and sensitive to the care recipients’ signals, being able to focus on the present and disregard that they had limited time, and that the time required for completing the care task had been determined with sufficient knowledge about the person.

### 4.3.2 | Playing along

Playing along meant adjusting the role and work task to the person and situation at hand. Kent described it as follows: *I try to start in the same way. Those who are happy and so on, there you just have to step in and go along. It’s much about stepping in and going along (Kent)*.

Playing along included adopting a role according to the care recipients’ expectations and what worked in the situation. This could for example mean accepting to be treated as a daughter or a friend when this made the care recipient content and served the purpose of getting the care task done. There was a fine line between playing along and lying, the latter being neither morally acceptable nor productive. Playing along also included sharing enjoyments with the care recipients, such as jokes or mutually appreciated conversation.

Factors that facilitated or hindered *playing along* concerned the environment, home care staff, caring relationship, care recipients and organisation. The environment, that is the homes of the care recipients facilitated person-centredness in that it provided keys to the person, and strengthened the autonomy of the care recipients:

> A person without a home is easy to run over and a home without its person is also easy to disrespect. But the person and home together become super strong. That, I think, affects us all and educates us who work in the home care services. So that we, like, it becomes a culture in which you do not run over people cause it’s not as easy to do that as in an institutional environment. (Emma)

The home facilitated focussing on one care recipient at a time which endorsed person-centredness. However, the home could also challenge person-centredness when it was cramped, soiled, malodorous and lacking adequate equipment.

There were also hindering and facilitating factors associated with the organisation. Continuity between care recipients and home care staff facilitated *playing along*, while discontinuity hindered. Opportunities to discuss difficult situations such as oral hand overs and supervision also facilitated *playing along*, and the lack thereof hindered. A general focus on performing predetermined tasks, rather than sustaining relationships and responding to shifting needs of the care recipients, and on compensating for inabilities rather than strengthening abilities hindered *playing along*.

### 4.3.3 | Breaking up the task in small pleasures

Breaking up the task in small pleasures concerned offering the care stepwise to the care recipients, starting with suggesting something that would entail a low level of integrity intrusion, and might be tempting and acceptable for the care recipient. One example was starting with offering a foot bath, and then while in the bathroom, suggesting that they might as well shower at the same time. By applying this strategy, the chance that the care recipient would agree to shower increased. The process was facilitated by not emphasising the care recipients need for assistance, but rather make it a natural thing to do things together. Further, it was beneficial to deliver the care in the same way every time, for example always placing the groceries at the kitchen table and letting the care recipient unpack them herself. In this way, familiarity with the care task was promoted.

### 4.3.4 | Using take 2

*Using take 2* meant accepting when the care recipient declined care and trying again later. Due to their memory problems, even a short absence could sometimes be enough for the care recipient changing their mind and accepting the care. However, the tight time schedule limited the possibilities of *using take 2*. Often, *using take 2* also included finding a different approach when trying again. Knowledge about the person and their ‘keys’ facilitated the process of figuring out how the care could be offered in a way that was acceptable to the care recipient. Also facilitating was turning to colleagues for receiving tips and finding common solutions. Not always did the same approach work for all home care staff. Also, a ‘manuscript’ that worked one day might not work the next day. Patience, perseverance and an ability to improvise were facilitating assets in the staff when *using take 2*.

### 4.3.5 | Facing the audience and critics

Giving care also involved *facing the audience and critics*. This implied receiving feedback from the care recipients, family carers, managers, other care professionals and society. Positive feedback came in
the form of appreciation from the care recipients and family carers. This increased the home care staff’s motivation and work satisfaction. Further, productive cooperation with other professionals raised a sense of being trusted and respected as professionals. A perceived lack of feedback from the managers made the staff suspect that their managers were not aware of how they performed their work. The strict management and control of time, and occasional planning that lacked personal continuity with the care recipients, resulted in a sense of not being trusted and acknowledged as persons. Negative feedback from care recipients and family carers was handled by apologising when appropriate, explaining the system (for example the allocation of services), and explaining the disease (for example its impact on the care recipients’ abilities). Facing the audience and critics also involved a general sense of their competence not being acknowledged and valued by society. A sense of self-efficacy facilitated facing the audience and critics. Education contributed to this sense.

4.4 Getting out

Getting out concerned closing the visit in a positive manner and ensuring that the care recipient would be all-right on their own until the next visit. It consisted of three subprocesses: Making a calm exit, initialising me-time and making a clear endpoint.

4.4.1 Making a calm exit

Making a calm exit meant leaving the care recipient in a calm and relaxed mood. This was important for the well-being of the care recipient and decreased the risk of them for example feeling anxious and disturbing neighbours. Making a calm exit was facilitated by giving some extra time, speaking about something that interested the care recipient, giving a foot massage and reassuring that they would be back soon. Diverting the attention and reality orientation, as described in the following excerpt, facilitated keeping the care recipient, giving a foot massage and reassuring that they would be back soon. Diverting the attention and reality orientation, as described in the following excerpt, facilitated keeping the care recipient.

... you say: ‘look over there, at the neighbours, you can see that their lights are off, they’re asleep because it is night. No one are up, no one are awake’. You try to make them see it themselves, that ‘you see it is evening now for sure’. Like that, you’ve got to try to find something that is obvious for them. (Maria)

4.4.2 Initialising me-time

Initialising me-time implied preparing for the time that the care recipient would be alone until the next visit. This meant ensuring that the care recipient had access to what they needed during the time that they would be alone: and the food is on the table, and they have everything they need and so on. But of course, you must check this, so you don’t just run away (Lena). It could also mean getting them seated in front of the television. Knowledge about the person, their habits, and concerns, and how they wanted things facilitated this process, while it was obstructed by the care recipient not feeling comfortable with being alone.

4.4.3 Making a clear endpoint

Making a clear endpoint meant being explicit about leaving the care recipient by telling them and showing them this. The subprocess initialising me-time facilitated making a clear endpoint, by signalling to the care recipients that the endpoint was nearing:

I try to finish up a little and tidy up and like: ‘Now I’m doing the dishes, and is there anything else and...?’ And then: ‘Okay, then I’ll see you tomorrow again’. Because now I work Mondays to Fridays so there is great continuity. I go to the same people four days a week at the least. (Kent)

4.5 Finalising the story

The process of finalising the story took place when a care recipient was transferred to another contact person, home care unit, nursing home or died. The process consisted of two subprocesses: sharing the script and constructing a positive ending.

4.5.1 Sharing the script

Sharing the script concerned handing over the ‘keys’ to the receiving staff, that is to promote familiarity for the new carers. Within the home care unit, this was facilitated by existing routines for transfer of oral and written information about the care recipient and their care. Transferral to other care units was hindered by a lack of routines for information transferral between care staff. The information to the receiving staff was often only that which was given by the home help officers, that is the same level of information that the home care staff had been given at the beginning of their caring. Thus, ‘the keys’ to the person that the home care staff had found was not transferred to the new care unit. Occasionally, the receiving staff were approached in attempts to transfer urgent information. Such attempts were often discouraged by a perceived lack of interest from the receiving staff.

4.5.2 Constructing a positive ending

Constructing a positive ending meant helping the care recipient to accept and prepare for the change (familiarity with the situation), saying
goodbye, and timely introduction of new staff. This was often hindered by rapid decisions and executions of moves that were planned by professionals who had limited personal knowledge of the care recipient. This, for example, could result in that personal assets that were important to the care recipient were not brought with them to a nursing home. The rapid execution of transfers also resulted in that the care recipients were not given enough time to comprehend what was happening. This obstructed the enactment of familiarity to the situation. Constructing a positive ending also concerned making closures when care recipients died. In some cases, but quite rarely, attending the funeral facilitated closure. More often the closure was made by sharing their thoughts with colleagues. Having access to regular group supervision facilitated this process.

5 | DISCUSSION

The aim of this study was to develop the theoretical understanding of the process of providing person-centred home care for people with dementia. The results showed that the care was conceptualised in a series of processes that the staff worked through to deliver the care in a person-centred manner. The core process, enacting and re-enacting familiarity, was central in all processes. It was interesting to find that person-centred care of people with dementia in home care services was conceptualised in theatre terms. This was apparent in all processes to a various extent. In getting ready, the staff did ‘research’ about the care recipient and started to plan their ‘role performance’. In getting in and giving care, they adapted their ‘role play’ to the needs and expectations of the care recipients and the situation and were aware that they ‘acted’ in front of an ‘audience’ consisting of for example family carers and their employer. In getting out and finalising the story, the theatre terms were less pronounced; however, it was clear that the home care staff were constantly aware of how they conducted themselves in interactions with care recipients and in front of audiences. Some of the home care staff opposed to the theatre metaphor because they associated playing a role with being dishonest and not authentic as a person. However, Goffman (1990 [1959]) described all human interaction as a form of role play, and that people adapt their acts to the social expectations adhering to a situation in order to uphold a common understanding of the situation. Familiarity in our results resembles Goffman’s description of common understanding of the situation as a core motive in social interaction. Goffman further described (1990 [1963]) how people who deviate from social norms are often exposed to stigmatisation. Thus, it is vital to display a mask of normality in the interaction with others. Birt et al. (2020) in a recent synthesis of qualitative studies on the social ability of people with dementia showed that they were often very aware of how they presented themselves and the risks of being deviant.

Related to our results, Goffman’s notion of teams is especially interesting. A team is defined as ‘a set of individuals whose intimate cooperation is required if a given projected definition of the situation is to be maintained’ (Goffman, 1990 [1959], p. 108). In our results, the home care staff did not act with the care recipients primarily as their audience. Rather, they appeared to aim at establishing a team with the care recipient to perform the act of care together. Similarly, previous studies have described that day care staff (Gjernes & Måseide, 2019) and family carers (Fletcher, 2020) interact with persons with dementia to support them in presenting themselves in line with social expectations and conceal any deviating behaviour in the face of their audiences. Fletcher (2019) found that in situations where the person with dementia and their audience experienced different realities, and in novel situations, people with dementia were especially vulnerable to exposure of deviance from social norms. In our results, the process getting in can be seen as such a situation where the care receivers might find themselves in a novel situation, and struggle to understand it in the same way as the home care staff do. In our results, the staff appeared to sense this vulnerability and act with extra precaution, reluctant to question the care recipients understanding of the situation and thereby make their deviance visible.

The care was constantly underpinned with moral reasoning. This was most pronounced in the subprocesses of toning down the care task and playing along. In toning down the care task, the home care staff strived to downplay the care task and emphasise their relationship with the care recipient, without being dishonest about who they were and why they had come. In playing along, they were balancing between going along with the care recipients’ conception of reality and orienting them to the factual reality. Moral values that are at stake concern the duty to provide care to a person when needed, being truthful and authentic, and respecting the autonomy and the subjective reality of the person. In their moral reasoning, the staff applied various moral perspectives, such as considering the consequences of actions, moral duties, honouring virtues and respecting principles such as doing good and promoting autonomy. This resonates well with the case-based ethical guidelines proposed by the Nuffield Council on Bioethics (2009). According to this framework, ethical decision-making in the care of people with dementia should involve careful examination of the situation, interests of all stakeholders (the persons with dementia, their family members and professional carers), the ethical values involved and the human rights of the person with dementia. Ethical reasoning should be based on an understanding of dementia as a brain disorder that people with dementia remain the same persons and are entitled to the same rights as other people, and that adequate care and support can enable them to maintain a good quality of life. Further, it is suggested that comparison with similar situations, often in dialogues with others who have knowledge of the situation or problem, may support the decision-making (Nuffield Council on Bioethics, 2009). The frequency and complexity of ethical issues and decision-making in the care of people with dementia highlight a need for staff to reason about ethical issues with colleagues, managers and external supervisors. In the present study, the staff received biweekly supervision where they could bring up difficult situations for discussion. However, in their daily work, they often lacked time and opportunities to discuss difficult situations and were left to solve difficult ethical situations to their own best ability.
The results highlight the complexity of providing person-centred care for people with dementia in their homes. It was common that the care recipients did not accept to receive care unless it was experienced that they had a personal relationship with their home care staff. Thus, the relationship needed to be continuously fostered. In creating relationships, a person-centred approach was a key, including learning about the person and adapting to their needs and preferences continuously. The centrality of the caring relationship is widely acknowledged in nursing and person-centred care theory (e.g., Edvardsson, 2015; Newman et al., 2008). The home care employees in this study showed high awareness about the necessity of establishing relationships, as well as great skills and creativity in building those relationships. The organisation of the home care services, however, appeared to be based on a perspective of care as delivery of certain services, rather than a nursing perspective. Thus, it did not properly account for the resources needed to form and maintain caring relationships, such as time for conversation and continuity in staffing. Further, the degree of detail in the home care staff’s work assignments gave little room for responsiveness to care recipients’ fluctuating needs in a true person-centred sense. Although the need for nursing competence in the form of licensed practical nurses in the home care services has been emphasised in Sweden (Hallberg et al., 2016; SOU, 2019:20), the organisation of work appears not to support them in giving care the way that they have been trained for. Research has shown that home care staff not being able to perform care to their professional standards was associated with job strain (Sandberg et al., 2018), which is likely to contribute to high staff turnover and thus drain home care services of much needed competence.

5.1 | Limitations

The study was based on a relatively small sample, recruited from home care units in a limited geographical area, managed by the same employer. It is possible that a larger sample from more varied contexts could have added more perspectives to the theoretical model. Further studies are required to validate the model and determine its transferability to other contexts. However, the participants involved in this study possessed extensive experience of home care for people with dementia, which strengthens the trustworthiness of the study.

6 | CONCLUSION

Person-centred home care of people with dementia was described in theatre metaphors and conceptualised as a series of processes. In all processes, enacting and re-enacting familiarity was at centre. When familiarity was in place, the care recipient and the home care staff acted as a team to perform the care. The theoretical works of Goffman provided a frame to interpret the results. The staff were striving to provide person-centred care in line with their values, education and supervision; however, the organisation promoted a task-oriented approach rather than person-centredness. The study provides a preliminary model for person-centred care of people with dementia at home to deepen the understanding of its processes, prerequisites and outcomes. More studies should be conducted to see if this model can be further developed. However, as it stands, it already provides rich and useful information about the nature of person-centred care for people with dementia in the community.

7 | RELEVANCE TO CLINICAL PRACTICE AND EDUCATION

The results from this study present an emergent model for providing person-centred care to people with dementia in the home care services. The model can be used to develop educational programmes for home care staff. It can also inform care policymakers and administrators about the prerequisites needed for person-centred care to be realised in the home care services for people with dementia. It is essential to ensure that the organisation supports person-centred care. Further, the results can be used to support practice development in workplaces, for example as a basis for discussions, supervision and interventions to enhance the quality of care.

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CONFLICT OF INTEREST STATEMENT

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

All authors agreed on the final version. David Edvardsson and Per-Olof Sandman were responsible for the conception and design. All authors contributed to the data collection and analysis. Ragnhild Hedman drafted the paper, and all authors were involved in revising its intellectual content.

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REFERENCES


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