



Risks as dilemmas for home care staff caring for persons with dementia

Linda Sandberg, Lena Borell & Lena Rosenberg

To cite this article: Linda Sandberg, Lena Borell & Lena Rosenberg (2020): Risks as dilemmas for home care staff caring for persons with dementia, *Aging & Mental Health*, DOI: [10.1080/13607863.2020.1758914](https://doi.org/10.1080/13607863.2020.1758914)

To link to this article: <https://doi.org/10.1080/13607863.2020.1758914>



© 2020 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 25 Apr 2020.



Submit your article to this journal [↗](#)



Article views: 2108



View related articles [↗](#)



View Crossmark data [↗](#)

Risks as dilemmas for home care staff caring for persons with dementia

Linda Sandberg, Lena Borell  and Lena Rosenberg 

Department of Neurobiology, Care Sciences and Society (NVS), Division of Occupational Therapy, Karolinska Institutet, Huddinge, Sweden

ABSTRACT

Objectives: Many persons with dementia live at home with support from home care services. Despite this, research is scarce concerning how risks in daily life among persons with dementia are perceived and handled by home care staff. This study aimed to explore how home care staff identify risks in the everyday lives of persons with dementia, and to inquire into how they reasoned about their own actions related to those risks.

Method: A qualitative approach was applied for the study. Both individual interviews and focus groups were conducted with home care staff ($n = 23$). Data was analysed using a constant comparative method.

Results: Identifying, reasoning and acting upon risks in the everyday lives of persons with dementia were related to several dilemmas for the home care staff. These dilemmas are described and elaborated on in three categories: 1) Strategies for tracking risks, 2) Dilemmas concerning where to draw the line and deciding when to act, and 3) Dilemmas when acting on risks.

Conclusion: The study provides new knowledge about the dilemmas that staff in home care services may face and how they reason about managing risks in the homes of persons with dementia. The study shows that the staff had to weigh risk and safety against the autonomy of persons with dementia. Based on these findings, we want to highlight the importance of competence among home care staff and the organizational conditions that must exist in order to manage the challenges of risky situations.

ARTICLE HISTORY

Received 30 October 2019
Accepted 13 April 2020

KEYWORDS

Dementia; Alzheimer's disease; home care services; risk assessment; activities of daily living

Introduction

It has been estimated that 158,000 persons in Sweden live with a dementia disease. These numbers are expected to nearly double over the next 20 years (Wimo et al., 2014). A recent study showed that 72 per cent of all people diagnosed with dementia live in ordinary housing (Odzakovic, Hydén, Festin, & Kullberg, 2019). This should be seen in addition to the fact that 75 per cent of all people 80 years or older in the Nordic countries live in single households (Nordic Welfare Centre, 2013a, 2013b). According to the Swedish Social Services Act, care for older persons (over the age of 65) should support day-to-day existence and ensure that these persons have a reasonable standard of living (SFS, 2001, p. 453, chapter 4, section 1).

In 2018, 22 per cent of persons 80 years or older in Sweden received home care (The Swedish National Board of Health and Welfare, 2019). Persons working in home care are referred to in various ways in different countries, for example 'home care aides' or 'home carers', and their profession is largely unregulated (Hewko et al., 2015). In this paper, staff working in the homes of older persons are referred to as 'home care staff'. In a Swedish setting, home care staff provide a wide range of support services in the everyday lives of persons with dementia (or cognitive impairments), such as personal care, house cleaning and laundry (Sandberg, Nilsson, Rosenberg, Borell, & Boström, 2018). Social activities can also be included in home care

services, such as providing accompaniment for walks (Nilsson et al., 2018). This means that home care services for persons with dementia can include typical everyday activities taken for granted in a home, as well as other caring duties such as supervising medications (Gransjön Craftman, Hammar, von Strauss, Hillerås, & Westerbotn, 2015; Hjalmarsen, 2014).

When working in the homes of persons with dementia, home care staff are exposed to situations in which the person with dementia faces risks, for example risks in relation to activities such as cooking, managing money (Gilmour, Gibson, & Campbell, 2003), driving (Hunt, Brown, & Gilman, 2010), or getting lost while walking outside of the home (Robinson et al., 2007). The most common risks reported in the literature are risks to physical safety, such as falls (Muir, Gopaul, & Montero Odasso, 2012; Taylor, Stevenson, & McDowell, 2018) and mismanagement of medication (Douglas, Letts, & Richardson, 2011; Taylor et al., 2018). However, psychosocial risks such as depression, loneliness (Stevenson, McDowell, & Taylor, 2018) or abuse from others are also mentioned (Taylor et al., 2018).

In a review on risk concepts and communication in dementia care, Stevenson et al. (2018) concluded that there is substantial variability in the construction and perception of risk and that the concepts are often socially constructed. Depending on the perspective, risks can be seen and perceived as having both negative and positive sides. In

CONTACT Lena Rosenberg  lena.rosenberg@ki.se

dementia care, the tolerability of risk is often determined through a process of balancing the rights and needs of the person with dementia against the risks (Stevenson et al., 2018). The present study focuses on risks in everyday life from the perspective and experiences of home care staff, and applies a broad understanding of the concept of risk, as presented by Clarke et al. (2009), who suggest that risks are 'issues of uncertainty of future outcomes from actions' (p. 90). This perspective implies that risk is basically a subjective experience that has an impact on how risks are handled. In a previous study by the present research group, risky situations were described in terms of how persons with dementia themselves experienced risks as unfamiliar and confusing, and how they tried to reduce the risks by seeking recognition and clarity (Sandberg, Rosenberg, Sandman, & Borell, 2017).

In the care of older people, there has been a tendency to prioritize physical safety and minimize risks (Gilmour et al., 2003; Morgan, 2010; Robinson et al., 2007). Care providers are often faced with ethical challenges in balancing between trying to reduce possible risks and protect persons with dementia and, at the same time, taking into account the individual's autonomy and quality of life (Clarke et al., 2009; Evans et al., 2018; Stevenson et al., 2018). It has been argued that this can lead to patronizing persons with dementia and overlooking their social and psychological well-being (Clarke & Mantle, 2016). Still, only a few studies have investigated how risks for persons with dementia living at home can be handled in general terms; for example, reducing such risks through 'supervision' of the person with dementia (Bowen, McKenzie, Steis, & Rowe, 2011; Horvath et al., 2005; Lach & Chang, 2007; Ledgerd et al., 2016), as well as by 'keeping an eye' on the person (Lach & Chang, 2007). Changes made to the physical environment to reduce risk, as described in the literature, include modifying the home environment by, for example, placing grab bars in the bathroom to prevent falls or using bright colours to highlight key objects (Bowen et al., 2011; Coracoran et al., 2002; Gitlin, Kales, & Lyketsos, 2012; Horvath et al., 2005; Lach & Chang, 2007; van Hoof, Kort, van Waarde, & Blom, 2010). To our knowledge, there are no previous studies focusing on how home care staff identify, reason and handle situations involving risk for persons with dementia. Given the significant role of home care staff in the lives of persons with dementia living at home, the aim of this study was to explore how home care staff identified risks in the everyday lives of persons with dementia, and to inquire into how they reasoned about their own actions related to those risks.

Methodology

Design and methods

A qualitative approach using strategies from constructivist grounded theory method (Charmaz, 2014) guided the data generation and the analysis to answer the research inquiry. A constructivist grounded theory approach was chosen as it acknowledges the researcher's involvement in the construction and interpretation of data and is suitable for studying socially constructed phenomena in everyday life

Table 1. An overview of the 23 participants.

Participants	Individual interviews <i>n</i> = 12	Focus group discussions <i>n</i> = 11	Total <i>n</i> = 23
Working as n (%)			
Nurse assistant*	7 (58)	4 (36)	11 (48)
Care assistant	5 (42)	7 (64)	12 (52)
Gender n (%)			
Male	3 (25)	3 (27)	6 (26)
Female	9 (75)	8 (73)	17 (74)
Working with persons with dementia in home care services (years)			
Mean	10.5	9.7	10.1
Median	10.0	8.0	10.0
Range	0.5–17.0	4.0–24.0	0.5–24.0

*Requires specialized education of 1–1/2 years at upper secondary school level.

(Charmaz, 2014). Data consisted of individual interviews as well as focus groups with home care staff.

Research context and participants

The study was conducted in a home care context, and the participants consisted of home care staff recruited from two agencies for home care services in a larger city in Sweden. The agencies operated in both the central and the suburban parts of the city. A total of 23 home care staff members agreed to participate in the study. Most participants had gone through a short web-based course related to person-centred care for persons with dementia. In accordance with the guidelines from The Swedish National Board of Health and Welfare (2010), they had one hour for group reflection and supervision once a week as part of their job. All participants provided care to persons with different types of functional limitations, including cognitive impairment and dementia. The inclusion criteria were that participants had at least six months of experience working as home care staff caring for persons with dementia and that they were working day shifts. For more information about the participants, see Table 1.

Data generation and data analysis

In order to obtain rich data for the study, both individual interviews (Kvale & Brinkmann, 2009) and focus groups (Kreuger & Casey, 2015) were conducted. Data generation and data analysis were conducted in a parallel process (Charmaz, 2014). The data generation was performed in two steps: first, the individual interviews and, thereafter, the focus groups.

As part of the recruitment process for the individual interviews, home care staff at the two agencies for home care services were verbally informed of the study by the first author (LS) at a staff meeting. The staff was informed that the interviews were to take place during working hours, that interviews would be audio-recorded, that participation was voluntary and that they could withdraw from the study at any time. They were invited to raise questions about the study, and written information about the study was handed out. Twelve home care staff members from the two different agencies agreed to participate. For more information about the participants, see Table 1.

All individual interviews were conducted by the first author (LS) in a quiet and secluded location at the participants' workplace. The interviews were semi-structured with open questions, and an interview guide accompanied the

interviews (Kvale & Brinkmann, 2009). All questions related to concrete situations that participants might have encountered in their roles as home care staff for persons with dementia. Examples of these questions include: 'Do you visit any persons with dementia where you are worried about risks?', 'Can you give an example of a situation you have experienced that you found risky?', 'How did you handle this situation?'. Follow-up questions were posed, based on the answers from the participants, in order to obtain thick descriptions and examples of situations involving risk (Creswell, 2000). The interview guide was revised through the process of data collection and parallel analysis to capture new topics relevant to the research inquiry (Charmaz, 2014). Demographic information about the participants was collected verbally. All participants agreed to be contacted by telephone for supplementary questions if needed. The participants were all interviewed once, with one of the participants also doing a follow-up phone interview with supplementary questions. The interviews lasted between 25 and 61 min, with a median length of 48 min. Two interviews had to be finished before the interview guide was completed because the participants had to return to their work duties. The audio-recorded interviews were listened to several times and transcribed verbatim by the first author (LS) (Kvale & Brinkmann, 2009). The individual interviews were analysed with open coding in which parts of the text sharing similar content were assigned a unique code (Charmaz, 2014). The codes were continuously compared with each other to find substantive similarities and differences related to the purpose of the study, and codes with similar meaning were merged together into preliminary categories. This constant comparative process, in which the authors moved back and forth between the categories and the data, was performed in order to ensure that the analysis was grounded in data. This process resulted in four preliminary categories that captured the content and meaning of the individual interviews.

In the second step, focus groups were conducted in order to explore how home care staff reasoned about risks together with their colleagues, and to thus provide more depth to the findings that emerged from the individual interviews (Kitzinger, 1994; Kreuger & Casey, 2015). Based on theoretical sampling (Charmaz, 2014), home care staff from two units in one of the included agencies were invited to take part in focus groups and eleven persons agreed to participate in the study. The units operated in the city centre and were selected based on a convenience sampling (Creswell, 2000). Two focus groups were conducted with persons from two pre-existing working groups, the first focus group consisting of six participants and the second of five. For information about the participants, see Table 1. One focus group was carried out at the workplace of the home care staff, and the other in a location near the participants' workplace. The first focus group was moderated by the last author (LR), and the first author (LS, who was new to focus group methodology) had the role of facilitator. In the second focus group, these roles were reversed. Both focus groups were introduced by the moderator, who explained the purpose of the study, and the participants were encouraged to discuss the topics with each other during the session (Kitzinger, 1994; Kreuger & Casey, 2015). The moderator led the focus group by

guiding the discussions, and the facilitator took charge of practical arrangements, kept field notes and contributed follow-up questions when needed. An interview guide based on the preliminary findings of the individual interviews guided the discussions in the focus groups (Charmaz, 2014). Initially, similar questions to those in the individual interviews were asked in order to obtain new insights into what risks the participants identified in the lives of the persons with dementia they cared for and how they handled those risks in their roles as home care staff. Thereafter, questions were asked to further explore topics from the individual interviews. Examples of such questions were: 'Can you give examples of what you do to detect risks in the everyday life of a person with dementia?', 'What is it you notice in such a situation?', and 'Can you talk about the interplay between you and the person with dementia in a risky situation?'. Both focus groups lasted 110 min. The participants were offered some snacks during the focus groups and there was a short break in the middle of the sessions.

The audio-recorded focus groups were listened to and transcribed verbatim by the first author (LS) (Kvale & Brinkmann, 2009). Thereafter, the focus group material was analysed with focused coding (Charmaz, 2014), which means that codes conceptualized from the analysis of the individual interviews were used. However, open coding was used when needed to allow for new findings to emerge. This meant that new codes emerged, and that somewhat new properties of the categories were developed. During the whole process of the analysis, analytical sessions among the three authors were regularly conducted to enhance the trustworthiness of the findings.

Ethical considerations

The study was carried out in accordance with the ethical requirements of informed consent, voluntariness and confidentiality. The study was approved by the Regional Ethics Committee in Stockholm, Sweden (No. 2009/1540-31/2 and No. 2014/1014-31/4). The findings are presented in such a way that neither the participating home care staff nor the persons with dementia they assisted can be identified.

Findings

The findings showed that the home care staff identified a number of risks in the everyday lives of persons with dementia and demonstrated how they reasoned about their own actions related to risks. Risks that were mentioned by the home care staff included, for example, personal hygiene, such as when a person with dementia who did not wish to take a shower for several months could be at risk for ill health, or risk in terms of a possible injury, for example when a person was not able to safely handle the gas stove, candles or cigarettes. Another risk described by the participants was related to living alone, for example persons who would leave their homes and be outdoors in the cold and not be able to find their way back home. Examples of situations and objects in the specific home environment that, according to the participants, suggested risk will be described in more detail below.

The analysis also showed that identifying and acting on risks in the everyday lives of persons with dementia was associated with dilemma for the home care staff. This will be elaborated on in the following three categories: 1) Strategies for tracking risk, 2) Dilemmas concerning where to draw the line and deciding on when to act, and 3) Dilemmas when acting on risks. These categories illuminate a process of tracking, identifying and acting on risk as part of their daily work in the homes of persons with dementia.

Strategies for tracking risks

The participants stressed the importance of paying attention to how the abilities of people with dementia decrease over time and emphasised that new risks may arise as a result. The participants described how they saw themselves as an 'alarm system' that could detect risks, and they also spoke of themselves as sometimes being the only advocates who could alert others to actions that might need to be taken to reduce these new risks.

One participant said: *'We [home care staff] are the only alarm system, we visit them several times a day to see how they are doing'*. The participants also stated that most persons with dementia had an installed safety alarm in their home, but that they often were unable to use the alarm as the dementia disease progressed. In regard to detecting risks, the participants pointed out the importance of continuity in having the same staff members make visits to a person's home. By this, they meant that continuity in their visits was essential to detecting if a person's actions in everyday life changed over time, as such changes could introduce new risks and potentially hazardous situations.

Keeping track of possible risks was described as a challenging task, as risks could occur suddenly and unexpectedly and could happen when the person with dementia was alone and there was no one that could provide support.

An interesting strategy reported by the participants was that they made extensive efforts to identify risks that manifested when they were not present in the home, which was typically most of the time. The participants expressed that the strategy they used for doing so was to search for risks in the environment and to be attentive to risks during all home visits. They stated that they looked for signs of risks; for example, a carpet edge that might cause a stumble or misuse of household appliances that could cause a fire. In one of the focus groups, the moderator (LS) asked:

How do you go about discovering risks in someone's home?

P1: Some risks are quite ... you see it when you're there, that someone stumbles on the carpet, and you just, yeah, okay. And with others, it might be the coffemaker, that it's always smoky ...

Moderator: Yes, that a good example. You come in and there is smoke.

P2: When you know them well, when you have been there several times, you notice what they do and then you can notice things that are dangerous, dangerous things.

According to the participants, they took on the role of actively looking for tracks, or signs of risks, in the homes of the persons they cared for in order to help prevent

potential accidents. Examples of tracks in the home environment were burn marks on pots and pans, or an odour caused by a previous fire; for example, the odour of plastic due to the person attempting to heat a container of plastic material on the stove. In addition, they said that they also registered and kept track of what had not happened that could serve as signs of possible risks; for example, they looked for forgotten meals and food in the fridge that not had been eaten. Another example was to look in the rubbish bin to find out if the person with dementia had actually eaten or not. The participants expressed that detecting risks in the homes of the persons with dementia involved dilemmas related to safety and the personal privacy of the person, as well as to their own role as home care staff.

Dilemmas concerning where to draw the line and deciding on when to act

The findings show that what the participants perceived to be a risk-bearing situation was not always obvious because each situation was complex and included several dimensions. It was, for example, sometimes unclear where the line should be drawn for when a situation was too risky and needed to be addressed by them, and in addition, these situations were interpreted differently among staff members. There were also examples mentioned in the focus groups of how the participants interpreted situations differently; for example, when, and under what conditions, a person with dementia was in need of a locked cabinet to keep their medications in.

The participants expressed how they faced, on the one hand, ethical dilemmas regarding risks in relation to the wishes and rights of the person with dementia and, on the other hand, their responsibilities as home care staff. An example of this, discussed in one of the focus groups, was related to not taking away responsibility from the person with dementia, and how this in turn could result in not being protective. They shared a story about a woman with dementia who was in a relationship with a younger man, and the participants described how they feared that the woman was being used by the man to fund his daily living expenses. The specific dilemma the participants faced was in deciding whether this was a personal matter for the woman or if the right thing to do was for them to step in and take action to protect her interests.

Another issue for discussion as an example of an ethical dilemma was the participants' concern about the lack of control that persons with dementia had over their own situations. One of the participants expressed this as such: *'I sense that they feel they have no control over life any longer – this is what concerns them most. They experience that there is someone else in charge'*. These discussions in the focus groups revealed in several ways how the participants struggled to respect the will of the person with dementia within their work role. This was, for example, stated like this: *'No one can just go in there and control the person just because she/he has dementia; we cannot go there and just do what we want. We must also respect their will; you cannot just force them in a certain direction'*. This also meant that staff were faced with situations in which they expressed experiencing dilemmas, and this was interpreted as also including feelings of powerlessness, since they

worried that something bad could happen to the person with dementia, but still felt that they had no right to act in certain situations. In one of the focus groups, they talked about risks related to managing money:

P1: I think about the risk when they hide their money and can't find it and then find it again (laughter). We had a lady who went to the bank and withdrew all her money, 20,000 [SEK] something and then took the bus home.

P2: Oh dear ...

P1: And then they hide the money somewhere. Or they can sometimes take all their money, because they are so afraid that someone will take it, so that they carry it with them all the time, large sums.

P3: Or they hide the money and forget about it ...

P4: Yes, exactly.

P5: Someone has 'taken' it.

P1: Mmm ... but you can't stop them from going out and going to the bank.

Overall, we found through the analysis that participants, in all kinds of daily situations, weighed the risks of not taking action against the consequences of, in fact, taking action. In doing so, the dilemmas for the participants became where to draw the line, make a decision for a given situation and say 'this is too risky'. One participant stated the type of questions she usually asked herself:

Is this particular situation a risk? How likely is the risk to lead to an incident? When and by whom should the risk be addressed? What consequences might be the result if the unwanted happens? What type of impact can averting and preventing risks have?

Such findings also show how the very difficult and complicated questions were left to the home care staff to make decisions about on their own for each situation they identified as being a risk.

Dilemmas when acting on risks

Through the analyses, we found that the home care staff not only tracked risks in the home environment of the persons with dementia, but that they also tried to reduce risks in different ways. For example, the participants described how they intentionally used themselves to reduce risk, for example, by talking in a nice and soft voice. The intention behind this was to influence the mood of the person by promoting calmness to, for example, prevent the person from becoming anxious and leaving the home between visits from the home care staff. They also gave several examples of actions that could be taken to reduce risks in the home of persons with dementia, such as rearranging the home to make certain objects visible and accessible, or removing or putting away and hiding other objects. For making an object visible, one example was to leave a walker close at hand when leaving a person alone in the hope that doing so would lead to the person using the walker, thereby reducing the risk of falling. The participants also reported making notes with reminders to be placed where the person would see it, in the hope of reducing

risks. One example was a note near the door that said, 'Don't go out until your son or the home care staff arrives'. This was done to reduce the risk that the person would go out on her own and not find her way back home. The participants expressed that trying to influence the moods and actions of people with dementia, as in the examples above, could also be fraught with dilemma since doing so might mean compromising personal privacy. One participant gave an example of appealing to the person's sense of guilt in a situation when the older person needed to eat but did not want to:

It may sound nasty, but sometimes you can actually use this feeling of guilt and say 'Now when I have cooked this for you, shouldn't you at least have a taste?'. And often, when they have tasted the food, they eat. You just stay there and help to keep focus on the food.

According to the participants, removing objects such as carpeting, matches or candles was a common way of reducing risks. However, removing such objects also created dilemmas and could also result in new risks, for example, as in the case of a person with dementia who had difficulty remembering whether or not she had taken her medications. In this case, the family was hiding the medications, which caused the woman to worry about not being able to find her medications and to start looking for them everywhere. This meant that the woman was doing things such as climbing up to look in the top kitchen cupboards, which involved the risk of falling. The participants also explained that in order to protect the person with dementia from risks, they sometimes limited access to different areas of the home. For example, in one case the home care staff had locked the door to the basement, as they explained that there was a potential risk of the person falling and injuring himself. Although the home care staff sometimes removed objects and restricted access to spaces in order to reduce risks, they reported trying to change the homes of persons with dementia as little as possible. Making such changes created dilemmas for the participants. As one participant said: *'You try to keep the home as intact as possible for them to recognize themselves'*.

Further, the findings showed that home care staff saw the risk of a fire in the home of the person as being the most explicit example of when it could be necessary to act against the will of the person with dementia and, for example, remove a gas stove, regardless of the person's own wishes. One of the participants said, *'a fire hazard is a fire hazard'*, and by this meant that such a risk could not be permitted to exist. Another recurring example of a serious risk was when a person with dementia went out repeatedly and could not find his/her way back home. Leaving the home and not being able to find their way back was seen as an indication of having reached the threshold of being able to live at home. When this happened, the participants agreed that the time had come for the person with dementia to move to an accommodation where they could be constantly watched over.

Discussion

This study provides insights into how home care staff reason and reflect about risks that they identify in their work with persons with dementia who live at home. The home

care staff described how they took on the responsibility of reducing potential risks both when they were present in the homes of persons with dementia and when they were not present. The findings of this study demonstrated a complexity of risks to pay attention to. This indicates that home care staff have to handle a difficult work situation, which has also been discussed in earlier research (Gransjön Craftman, Grundberg, & Westerbotn, 2018; Hewko et al., 2015). The strong motivation for the home care staff in this study to care about the person's safety can be understood in light of the background that many old people in Sweden live alone (The Swedish National Board of Health and Welfare, 2016) and that the home care staff may be the only visitors that people with dementia have on a regular basis.

The findings also show how the strong experience of responsibility of caring for the safety of persons with dementia sometimes created dilemmas for the participants in this study, as witnessed in their reasonings about actions such as hiding or removing objects that could potentially cause accidents. To 'set the scene' by rearranging objects in the home of a person with dementia was seen by the study participants as a way of guiding the person's actions when he or she was alone. However, the home care staff stressed the importance of not taking over and of respecting the person's own will. This dilemma has been reported before by Stevenson et al. (2018), who described it in terms of an act of balancing the well-being of the person versus risk from harm. This also relates to a previous study by the research group Sandberg et al. (2017), which found that it was a challenge for persons with dementia to accept support and assistance in various forms as this could suggest that they were no longer in charge of their own lives, and that it is thus important that support and assistance are given in a dignified way.

The findings of the present study show that home care staff were left alone in the work situation in the person's home and had to make difficult judgements about when and how to act on risks. Morgan and Williamson (2014) found the magnitude of these ethical issues to be so huge that it is too much for a single person to be responsible for making these types of decisions on their own. This burden on the single care provider can also be related to the experience of high job strain among home care staff shown in a previous study (Sandberg, Borell, Edvardsson, Rosenberg, & Bostrom, 2018), and may also have a negative impact on the quality of care provided.

Based on the findings of this study, the question could be raised of whether it is ethically sound that home care staff members should have to face these difficult dilemmas alone. It is known from previous research that home care staff work alone on a regular basis (Lundgren, Ernsth-Bravell, & Kåreholt, 2016), and there are often no supportive structures or routines in place to provide support to solve the dilemmas described in this study. Since home care service is a type of care that will increase as the overall population gets older, there is a strong need to develop new opportunities for learning in home care and for supporting home care staff.

The findings also provide some insight on the reasoning of staff members by showing how they carefully weighed the risk of not taking action against the consequences of taking action. The participants described how they

struggled to respect the will of a person with dementia, and, in some cases, it was necessary for them to accept the existence of a risk in order to retain something of value in the life of a person with dementia, as reported by Clarke and Mantle (2016). However, if the risk was considered to be too high, it was not possible to indulge the desire of the person with dementia.

Previous research (Stevenson et al., 2018; Stevenson & Taylor, 2017; Taylor et al., 2018) has shown that there are a number of risks related to health and well-being for a person with dementia who lives alone; for example, the risk of repeatedly getting lost outside of the home, of causing a fire, or of malnutrition. Based on the findings from this and previous research (Ulmanen & Szebehely, 2015), it is possible to question the policy of ageing in place for persons with dementia with complex care needs and comprehensive requirements for support in everyday life, and who also experience a number of risks in daily living.

Limitations

The findings of this study come from data from both individual interviews and focus group discussions. This combination of data sources resulted in rich descriptions of situations that included risk and examples of how these situations were perceived and handled by home care staff. However, the findings are based on the views and experiences of participating individuals, and the findings should thus be interpreted with caution. The inclusion of participants was initially based on convenience sampling within two home care agencies, but in order to deepen and further understand the preliminary findings based on analysis of the individual interviews, we decided to conduct focus groups. Based on the idea of theoretical sampling (Charmaz, 2014), we recruited two pre-existing working groups of home care staff in order to understand how they reasoned and acted upon risk within their work. There is no consensus in the literature concerning the use of pre-existing groups as focus groups (Barbour, 2005; Hofmeyer & Scott, 2007), although the use of such groups has been advised against, especially in marketing research (Hofmeyer & Scott, 2007). However, in health care research, Dahlin Ivanoff (2002) and Rosenberg, Kottorp, and Nygård (2012) successfully conducted focus groups with pre-existing groups. The participating home care staff had quite extensive experience working in home care services with persons with dementia (an average of ten years). Their solid work experience provided rich descriptions and many examples that shed light on the research inquiry. A theoretical sampling from additional home care agencies in other geographical areas could have provided a broader spectrum of experiences related to risk among people with dementia. Further, ethnographic fieldwork with participant observations could be a useful method to further explore dilemmas for home care staff and to understand more about the actions they said that they took to handle risky situations in the homes of persons with dementia.

Conclusion

This study adds knowledge to previous research on how home care staff reason about and act upon risky situations

involving persons with dementia who live at home. The findings illuminate a process of tracking, identifying and acting on risk as part of the home care staff's daily work in the homes of persons with dementia. Identifying and acting on risks were associated with several dilemmas for the home care staff; for example, they had to weigh aspects of risk and safety against the autonomy of persons with dementia. Based on these findings, we want to highlight the importance of competence among home care staff and shed light on the organizational conditions that must exist in order to manage the challenges of risky situations for persons with dementia living at home.

Acknowledgements

We thank all the participants for sharing their experiences of working with persons with dementia.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This research was financially supported by FORTE (2014-4674; 2016-07089), by the Doctoral School in Health Care Sciences at Karolinska Institutet and by the Strategic Research Area Health Care Science (SFO-V) at Karolinska Institutet.

ORCID

Lena Borell  <http://orcid.org/0000-0001-6899-1013>

Lena Rosenberg  <http://orcid.org/0000-0003-1727-369X>

References

- Barbour, R. S. (2005). Making sense of focus groups. *Medical Education*, 39(7), 742–750. doi:10.1111/j.1365-2929.2005.02200.x
- Bowen, M. E., McKenzie, B., Steis, M., & Rowe, M. (2011). Prevalence of and antecedents to dementia-related missing incidents in the community. *Dementia and Geriatric Cognitive Disorders*, 31(6), 406–412. doi:10.1159/000329792
- Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). London: SAGE Publications.
- Clarke, C. L., Gibb, C. E., Keady, J. P., Luce, A. M., Wilkinson, H. P., Williams, L. M., ... Cook, A. (2009). Risk management dilemmas in dementia care: An organizational survey in three UK countries. *International Journal of Older People Nursing*, 4(2), 89–96. doi:10.1111/j.1748-3743.2008.00149.x
- Clarke, C., & Mantle, R. (2016). Using risk management to promote person-centred dementia care. *Nursing Standard*, 30(28), 41–46. doi:10.7748/ns.30.28.41.s47
- Coracoran, M. A., Gitlin, L. N., Levy, L., Eckhardt, S., Earlands, T. V., Shaw, G., & Kearney, P. (2002). An occupational therapy home-based intervention to address dementia-related problems identified by family caregivers. *Alzheimer's Care Quarterly Winter*, 3, 82–90.
- Creswell, J. (2000). *Qualitative inquiry and research design – Choosing among five traditions*. London: SAGE.
- Dahlin Ivanoff, S. (2002). Focus group discussions as a tool for developing a health education programme for elderly people with visual impairment. *Scandinavian Journal of Occupational Therapy*, 9(1), 3–9. doi:10.1080/110381202753505809
- Douglas, A., Letts, L., & Richardson, J. (2011). A systematic review of accidental injury from fire, wandering and medication self-administration errors for older adults with and without dementia. *Archives of Gerontology and Geriatrics*, 52(1), e1–10. doi:10.1016/j.archger.2010.02.014
- Evans, E., Perkins, E., Clarke, P., Haines, A., Baldwin, A., & Whittington, R. (2018). Care home manager attitudes to balancing risk and autonomy for residents with dementia. *Ageing & Mental Health*, 22(2), 261–269. doi:10.1080/13607863.2016.1244803
- Gilmour, H., Gibson, F., & Campbell, J. (2003). Living alone with dementia: A case study approach to understanding risk. *Dementia*, 2(3), 403–420. doi:10.1177/14713012030023008
- Gitlin, L. N., Kales, H. C., & Lyketsos, C. G. (2012). Nonpharmacologic management of behavioral symptoms in dementia. *JAMA*, 308(19), 2020–2029. doi:10.1001/jama.2012.36918
- Gransjön Craftman, Å., Grundberg, Å., & Westerbotn, M. (2018). Experiences of home care assistants providing social care to older persons: A context in transition. *International Journal of Older Persons Nursing*, 13 (4), 1–8.
- Gransjön Craftman, Å., Hammar, L. M., von Strauss, E., Hillerås, P., & Westerbotn, M. (2015). Unlicensed personnel administering medications to older persons living at home: A challenge for social and care services. *International Journal of Older People Nursing*, 10(3), 201–210. doi:10.1111/opn.12073
- Hewko, S. J., Cooper, S. L., Huynh, H., Spiwek, T. L., Carleton, H. L., Reid, S., & Cummings, G. G. (2015). Invisible no more: A scoping review of the health care aide workforce literature. *BMC Nursing*, 14(1), 38. doi:10.1186/s12912-015-0090-x
- Hjalmarson, I. (2014). *Vem ska bestämma vad i hemtjänsten? [Who should decide what in home care?]* Stockholm: Stiftelsen Stockholms Läns Äldrecentrum.
- Hofmeyer, A. T., & Scott, C. M. (2007). Moral geography of focus groups with participants who have preexisting relationships in the workplace. *International Journal of Qualitative Methods*, 6(2), 69–79. http://www.ualberta.ca/~iiqm/backissues/6_2/hofmeyer.pdf
- Horvath, K. J., Hurley, A. C., Duffy, M. E., Gauthier, M. A., Harvey, R. M., Trudeau, S. A., ... Smith, S. J. (2005). Caregiver competence to prevent home injury to the care recipient with dementia. *Rehabilitation Nursing*, 30(5), 189–197. doi:10.1002/j.2048-7940.2005.tb00109.x
- Hunt, L. A., Brown, A. E., & Gilman, I. P. (2010). Drivers with dementia and outcomes of becoming lost while driving. *American Journal of Occupational Therapy*, 64(2), 225–232. doi:10.5014/ajot.64.2.225
- Kitzinger, J. (1994). The methodology of focus groups: The importance of interaction between research participants. *Sociology of Health and Illness*, 16(1), 103–121. doi:10.1111/1467-9566.ep11347023
- Kreuger, R. A., & Casey, M. A. (2015). *Focus groups: A practical guide for applied research* (5th ed.). Thousand Oaks, CA: Sage
- Kvale, S., & Brinkmann, S. (2009). *Den kvalitativa forskningsintervjun. [The qualitative research interview]*. Lund: Studentlitteratur AB.
- Lach, H. W., & Chang, Y. P. (2007). Caregiver perspectives on safety in home dementia care. *Western Journal of Nursing Research*, 29(8), 993–1014. doi:10.1177/0193945907303098
- Ledgerd, R., Hoe, J., Hoare, Z., Devine, M., Toot, S., Challis, D., & Orrell, M. (2016). Identifying the causes, prevention and management of crises in dementia. An online survey of stakeholders. *International Journal of Geriatric Psychiatry*, 31(6), 638–647. doi:10.1002/gps.4371
- Lundgren, D., Ernsth-Bravell, M., & Kåreholt, I. (2016). Leadership and the psychosocial work environment in old age care. *International Journal of Older People Nursing*, 11(1), 44–54. doi:10.1111/opn.12088
- Morgan, S. (2010). Positive risk-taking: A basis for good risk decision-making. *Health Care Risk Report*, 16(4), 20–21.
- Morgan, S., & Williamson, T. (2014). *How can 'positive risk-taking' help build dementia-friendly communities? Inspiring social change*. York: Joseph Rowntree Foundation.
- Muir, S. W., Gopaul, K., & Montero Odasso, M. M. (2012). The role of cognitive impairment in fall risk among older adults: A systematic review and meta-analysis. *Age and Ageing*, 41(3), 299–308. doi:10.1093/ageing/afs012
- Nilsson, I., Luborsky, M., Rosenberg, L., Sandberg, L., Boström, A. M., & Borell, L. (2018). Perpetuating harms from isolation among older adults with cognitive impairment: Observed discrepancies in home-care service documentation, assessment and approval practices. *BMC Health Services Research*, 18(1), 800.
- Nordic Welfare Centre. (2013a). *Nordens Vålfärdscenter. Så bor 80+ i Norden [This is how people 80+ live in the Nordic countries]*. Retrieved from <https://nordicwelfare.org/publikationer/sa-bor-80-i-norden/>
- Nordic Welfare Centre (2013b). *Nordens Vålfärdscenter. Så bor 80+ i Norden*. (Report No.:200). Ödeshög: Nordic Welfare Centre.

- Odzakovic, E., Hydén, L.-C., Festin, K., & Kullberg, A. (2019). People diagnosed with dementia in Sweden: What type of home care services and housing are they granted? A cross-sectional study. *Scandinavian Journal of Public Health, 47*(2), 229–239. doi:10.1177/1403494818755600
- Robinson, L., Hutchings, D., Corner, L., Finch, T., Hughes, J., Brittain, K., ... Bond, J. (2007). Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. *Health, Risk & Society, 9*(4), 389–406. doi:10.1080/13698570701612774
- Rosenberg, L., Kottorp, A., & Nygård, L. (2012). Readiness for technology use with people with dementia: The perspectives of significant others. *Journal of Applied Gerontology, 31*(4), 510–530. doi:10.1177/0733464810396873
- Sandberg, L., Borell, L., Edvardsson, D., Rosenberg, L., & Boström, A.-M. (2018b). Job strain: A cross-sectional survey of dementia care specialists and other staff in Swedish home care services. *Journal of Multidisciplinary Healthcare, 11*, 255–266. doi:10.2147/JMDH.S155467
- Sandberg, L., Nilsson, I., Rosenberg, L., Borell, L., & Boström, A.-M. (2018a). Home care services for older clients with and without cognitive impairment in Sweden. *Health & Social Care in the Community, 27*(1), 139–112. doi:10.1111/hsc.12631
- Sandberg, L., Rosenberg, L., Sandman, P.-O., & Borell, L. (2017). Risks in situations that are experienced as unfamiliar and confusing – The perspective of persons with dementia. *Dementia, 16*(4), 471–485. doi:10.1177/1471301215603836
- SFS. (2001). *Socialtjänstlag [Social Services Act]* (p. 453). Stockholm: Riksdagen.
- Stevenson, M., McDowell, M. E., & Taylor, B. J. (2018). Concepts for communication about risk in dementia care: A review of the literature. *Dementia, 17*(3), 359–390. doi:10.1177/1471301216647542
- Stevenson, M., & Taylor, B. J. (2017). Risk communication in dementia care: Professional perspectives on consequences, likelihood, words and numbers. *The British Journal of Social Work, 47*(7), 1940–1958. doi:10.1093/bjsw/bcw161
- Taylor, B. J., Stevenson, M., & McDowell, M. E. (2018). Communicating risk in dementia care: Survey of health and social care professionals. *Health & Social Care in the Community, 26*(2), e291–e303. doi:10.1111/hsc.12519
- The Swedish National Board of Health and Welfare. (2010). *Nationella riktlinjer för vård och omsorg vid demenssjukdom 2010 – stöd för styrning och ledning [National guidelines for care and nursing in dementia 2010]* (Report No.: 2010-5-1). Västerås: Swedish National Board of Health and Welfare.
- The Swedish National Board of Health and Welfare. (2016). *Brakarundersökning 2016: Så tycker de äldre om äldreomsorgen 2016. En rikstäckande undersökning av äldres uppfattning om kvaliteten i hemtjänst och särskilt boende [User survey 2016: What the elderly think about elderly care in 2016. A nationwide survey of older persons' perceptions of home care quality and special housing]*. Stockholm: National Board of Health and Welfare. Retrieved from www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20356/2016-10-2.pdf
- The Swedish National Board of Health and Welfare. (2019). *Vård och omsorg om äldre. Lägesrapport 2019*. Retrieved from www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2019-3-18.pdf
- Ulmanen, P., & Szebehely, M. (2015). From the state to the family or to the market? Consequences of reduced residential eldercare in Sweden. *International Journal of Social Welfare, 24*(1), 81–92.
- van Hoof, J., Kort, H. S. M., van Waarde, H., & Blom, M. M. (2010). Environmental interventions and the design of homes for older adults with dementia: An overview. *American Journal of Alzheimer's Disease & Other Dementias, 25*(3), 202–232. doi:10.1177/1533317509358885
- Wimo, A., Jönsson, L., Fratiglioni, L., Sandman, P. O., Gustavsson, A., & Sködlunger, A. (2014). *Rapporten om samhällskostnader i Sverige 2012 [Financial report: Social costs in Sweden, 2012]* (Report No.: 2014-6-3). Stockholm: The Swedish National Board of Health and Welfare.