



ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

Who cares for the carer? The suffering, struggles and unmet needs of older women caring for husbands living with cognitive decline

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Abstract

Background: The Nordic welfare states have been called the 'caring states'. However, increasingly, less money is spent on long-term care for older persons than on care for younger persons. Additionally, a strong de-institutionalisation of care coupled with an ageing at home ideology means older persons are expected to remain in their own home, even when they are frail and in need of comprehensive care. As a result, family members, particularly older women, are increasingly expected to take on caring roles, sometimes at the expense of their own health and wellbeing.

Aim: The aim of this article is to examine the experiences of older women caring for a spouse living with cognitive decline in a Nordic context.

Methods: A qualitative study was designed, in which 11 women in Iceland and Norway were interviewed in their own homes about their past and current experiences as care partners.

Findings: Our participants reported that despite receiving home-based care services from the municipality, living with a husband with cognitive decline consisted of constantly being on the alert and assisting with various practicalities. It entailed being woken up night after night, always having to repeat the same bits of conversation, dealing with accusations of infidelity, episodes of aggression, and sometimes hallucinations, violence and fear. The women needed more information, more assistance and time away from care, and emotional and psychological support.

Conclusions and implications for practice: The care partners were not treated as persons with their own care needs, and their voices were not heard. A relational person-centred approach in home-based elderly care is needed, placing the couple, not the individual, at the core of service provision. A tool for systematic collaboration between home care services and families should be developed so that both partners' needs may be met in a more coherent and holistic way.

Keywords: Family care, care partner, couple-centred care, dementia, Norway, Iceland

Introduction

The Nordic countries – including Norway and Iceland, where this study takes place – have a comprehensive public social and healthcare system where persons in need of care may apply for public services, such as home help and home nursing care, at a relatively low cost. Until recently, families with an excessive care burden had the opportunity to apply for, and expected to be granted, a permanent room in a nursing home for the person with comprehensive care needs. In recent years, however, institutional care has been reduced (Daatland, 2014; Sigurdardottir and Kåreholt, 2014). One reason, of course, is that home-based care is more cost-effective than institutional care (Sigurdardottir and Kåreholt, 2014; Sørbye et al., 2016). Additionally, in several policy documents, home-based care is presented as a solution preferred by families themselves (Sigurdardottir et al., 2012; Askheim et al., 2017; Stefansdottir and Sveinbjarnardottir, 2019).

Although the Nordic welfare states have been called the ‘caring states’ (Vabø and Szebehely, 2012), and although there are still comprehensive welfare arrangements, increasingly less money is being spent on long-term care for older persons than on care for younger persons (Hermansen and Gautun, 2013). Moreover, in Finland, in contrast to the long-established tradition of public provision, only those with the most comprehensive needs have access to formal home care services (Sihto, 2018), partly due to the outsourcing of care to private providers (Puthenparambil, 2018). In other parts of the Western world, the decline in access to professional care in this field is even more pronounced (Armstrong-Esther et al., 2005; Leichsenring, 2012; Winterton and Warburton, 2012; Edgell, 2013; Tatangelo et al., 2018). This development is leading to a situation where globally, family carers play an increasingly significant role in caring for older persons living at home.

Taking care of a frail family member has long been perceived as something people just do because it is expected (Alvsvåg and Tanche-Nilssen, 1999; Janlöv et al., 2006; Sørensen, 2015; Sihto, 2018). Such expectations, however, are shaped in relation to gender, age and kinship. Accordingly, informal caregiving is most prevalent among middle-aged daughters caring for a parent and among older women caring for their spouses (Dahlberg et al., 2007; Sigurdardottir and Kåreholt, 2014). A study from Denmark indicates that although care partners of persons living at home with dementia may be exhausted, older women in particular feel they are expected by the public authorities to take on more care tasks and responsibilities, despite the effect on their own wellbeing (Sørensen, 2015). Additionally, recent research from Finland documents that caring continues to be a deeply feminised issue and that women face greater expectations to care for family members than men do (Sihto, 2018).

Dementia is often represented as a ‘family illness’ that should be attended to within the family setting (Sørensen, 2015). Facing the growing care needs of a spouse living with cognitive decline, however, can be very challenging (Janlöv et al., 2006; Sørensen, 2015; Riekkola et al., 2018). Research indicates that partners of persons with dementia experience relatively high rates of depression, stress and physical illnesses (Etters et al., 2008; Tatangelo et al., 2018). Moreover, a large quantitative study from Europe found that family carers of persons with dementia report high levels of unmet needs, particularly the need for company, information and daytime activities (Kerpershoek et al., 2018). Additionally, a recent systematic literature review on the needs of care partners of older people who received home care services concluded that care partners want to feel more empowered through, for example, closer collaboration with professional carers (Anker-Hanssen et al., 2018). A study on family caring more broadly, however, found that although caregiving is seen both as a duty and as a strain, it is also regarded as a choice and as a meaningful task, particularly if the family carer feels acknowledged by the professional caregivers (Carlsen and Lundberg, 2017).

Politicians and stakeholders may want to pursue the ageing-at-home ideology despite the high pressure this puts on households with frail older family members. In Iceland, the Ministry of Welfare published a report emphasising the importance of empowering and increasing the function and opportunities to participate in society among frail older people in order increase their quality of life (Ministry of Welfare,

2016). In Norway, family care is perceived as a scarce resource that should be sustained, especially in view of the current demographic development (Ministry of Health and Care Services, 2012-13). Moreover, an ongoing reform in Norway called 'A full life - all your life' (Ministry of Health and Care Services, 2018) not only aims to promote opportunities for people to use their resources and have their needs met at all stages of their later years but also is represented as a reform for family members. It is stated that 'care should be provided for caregivers to help those who are looking after their loved ones to prevent exhaustion' and that 'better cooperation' is needed between family caregivers and health and care services (Ministry of Health and Care Services, 2018, p 15). However, if these ambitions are to be achieved, it is necessary to develop more person-centred care services. Person-centred care refers to holistic, respectful and empowering care services that consider the relationships between all care providers, service users and others significant to them in their lives (McCormack and McCance, 2017). To be able to develop person-centred care services for older couples in which one partner is living with dementia, we need to listen to and learn from the care partners.

Aim

The aim of this article is to provide a deeper understanding of the struggles, suffering and unmet needs of care partners by listening to the voices of older women living with and caring for a spouse with severe cognitive decline. With our findings, we hope to contribute to insights that may foster improved services that are more attentive to the needs of both the care recipient and the care partner.

Research methods

Design

A qualitative interview study was designed. The research team conducted in-depth interviews in Iceland and Norway with older women caring for a spouse with comprehensive care needs. Our interview guide contained questions about their life as a couple and as family, how and when they discovered something was wrong, their experiences with having to provide gradually more care for their spouse, and questions about their collaboration with other informal carers and formal care services in home-based and institutional care settings.

Data collection

In total, 11 women were interviewed for the purpose of this article, nine in Norway and two in Iceland. Participants were recruited in slightly different ways: in Norway, the first author contacted a local newspaper in Western Norway in 2018. A feature article was published inviting readers to contact the researcher if they wanted to share their story. Several potential participants called, of whom six women were interviewed. In addition, while conducting an earlier study on home-based care, the first author had interviewed three older women caring for their spouse with cognitive decline in another municipality. Since the findings from these interviews had not previously been used in publications, it was decided to include them. In Iceland, the second author contacted nursing homes to identify spouses whose partner had recently been offered a room there. In total, 12 care partners were interviewed in 2018 and 2019, of whom two women had experience caring for a husband with cognitive decline. The narratives of these two women were included in the analysis for this article.

All interviews took place in the participants' own home. The researchers brought flowers, and coffee and biscuits were often served. We informed the interviewees that participation in the study was voluntary, that they could withdraw without reason at any time and that their anonymity would be secured in publications. While the interview recordings lasted from 45 minutes to more than two hours, the visits often lasted somewhat longer and included informal talk and sometimes a tour of the home. After each interview, the researchers wrote notes about key themes emerging in the interview and reactions and interpretations of the interview situation. The recordings were transcribed.

Participants

The women interviewed for the purpose of this article were aged between 70 and 92 years and had provided intensive care for their spouse for between one and 13 years. At the time of the interview,

some of the husbands still lived at home, either full or part time, and some had moved permanently to a nursing home. Four women were widows at the time of the interview. The husbands had been diagnosed with, for example, Lewy body dementia, Alzheimer's or frontotemporal dementia. Most had experienced loss of memory and abilities of daily living but also a change in personality as well as aggression and hallucinations. The participants received formal services from their municipalities.

Data analysis

This study is interpretative and constructivist (Haavind, 1999; Kjørup, 2001; Charmaz, 2006). This approach assumes that multiple realities exist and that our perceptions of reality are co-created by actors participating in various arenas. The primary means of data collection was open-ended interviews. When meeting the participants, the researchers asked (most of) the questions in the interview guide but also listened carefully to the participants' stories in order to grasp what was important to them. Some of the interviews therefore took unexpected turns while following their thread. When the interviews had been transcribed, the first author read and reread the transcripts from Norway (in Norwegian language), while the second and third authors (re)read the transcripts from Iceland (in Icelandic language). As a means of preparation for our common analysis workshop held in Iceland in the spring of 2019, the researchers made an extensive table in English presenting key data on all participants, including those who had been initially interviewed for an earlier study. During this first round of thematic analysis, the themes 'struggles', 'suffering' and 'unmet needs of care partners' and related subthemes were identified. During the analysis workshop, the researchers discussed and compared the preliminary findings. Additionally, they defined the research questions and themes to use when pursuing the coding of data in the subsequent rounds of analysis (Graneheim et al., 2017). It should be noted that in this study, some of the participants told their stories in retrospect, whereas others described when they first noticed something was wrong and shared their everyday life experiences at the time of our interview. Our analysis showed that this did not seem to make much of a difference in terms of the content or vividness of the participants' stories.

Ethics

The project team consisted of two experienced researchers and a research fellow who is also a family therapist. Formal ethical permissions to undertake this study both in Norway and in Iceland was obtained, as it had been for the earlier study from which interviews were taken. Written consent was obtained from all participants in Iceland, while in Norway oral consent from all participants was obtained. We omitted all persons' names from the data when transcribing the interviews to protect the identity of the participants. The data were stored on personal computers in password-protected files and were accessed only by the three members of the research team.

Results

Introduction

The main findings of the women's narratives from the moment they noticed the first changes in their husband's condition will be presented. Their struggles, suffering and unmet needs will be illustrated through stories about having to cope with increasing care needs as well as changes in their husband's personality and incidents of aggression and violence. Each theme includes quotations to give voice to the participants. The article ends with a summary of the main findings, conclusions and implications for the practice field and, finally, a brief discussion of the limitations. Table 1 presents an overview of the main themes and subthemes identified in the analysis, which will be expanded on in the following text.

Table 2: Main themes and subthemes

Internal factors		External factors
Struggles	Suffering	Unmet needs
<ul style="list-style-type: none"> • 'We tried to live as normal' • 'I was just in the act with him' • 'I'm stuck!' 	<ul style="list-style-type: none"> • 'His personality totally changed!' • 'Why don't they move him against his will?' 	<ul style="list-style-type: none"> • 'Lack of support and time off from caring' • 'Lack of information and voices not heard'

Struggles

'We tried to live as normal'

The women reported that when they noticed the first changes, such as loss of memory, loss of sense of direction, panic attacks, nightmares or episodes of hallucinations, they did not understand what had happened. Several of them admitted that in the beginning, they had not spoken about the changes but rather wanted to cope on their own. Grete, for instance, whose husband was later diagnosed with frontotemporal dementia, said about the early period of his condition:

'We tried to live as normal. I want to emphasise that: how you try to hide the problems the first years. You know, we had many friends, and we used to socialise a lot, and suddenly he did not want to go here or he did not want to visit there... And I tried to hide, invent excuses... It is a terrible load for the partner.'

'I was just in the act with him'

As the condition of their husband worsened, the women experienced that their everyday life consisted of looking after their spouse and feeling trapped in endless, meaningless conversations with them. Gunna, for example, said: *'I couldn't do anything! I was just in the act with him. Repeating the same sentences again and again...'* For most of the participants, the days (had) consisted of helping with practicalities such as meals, exercises or personal hygiene. Moreover, several of the women had regularly been woken up by their husband at night – he was thirsty, needed help peeing in a bottle, or thought it was already morning and wanted to get up in the middle of the night. Gunna said: *'I never slept a whole night! I was always on the alert, ending up tired and completely without soul...'* Felicia had the same experience: *'It was like 'Felicia! I am thirsty!' 'Felicia, come here!' 'Felicia!' all the time... He could wake me up five times every night. It was an extremely strenuous time.'* The participants (with only one exception) said that at certain points, they felt totally flat, exhausted, wrecked or like a zombie. Three of them, Felicia, Grete and Berit, were even hospitalised due to heart attack-type symptoms, which turned out to be a consequence of a long period of insomnia and stress.

'I'm stuck!'

Several women felt bound to the home 24/7 regardless of whether they received regular home nursing support even two or three times a day. At the time of the interview with Doris, her husband David alternated between living with her for four weeks followed by living in respite care for two weeks. Although they received home nursing three times a day while David was at home, Doris felt very limited in her everyday life:

Doris: *'I'm stuck! It's very hard, because I can't go anywhere. If I need to hang clothes on the clothesline or whatever, I always have to tell him where I go: "David, now I'm going to the clothesline!" "I'll just go to the mailbox!" "I need to go to the toilet!" "I need to fetch something in the basement!" It's tiring. And if I'm not back within a few minutes, he'll start shouting: "Doris, where are you? WHERE ARE YOU?" The panic...'*

Researcher: *'Because he doesn't remember what you told him?'*

Doris: *'Either he doesn't remember, or he thinks I'm away for too long: "Where are you now?" "I'm right here, like I told you!" And he: "Okay, okay..."'*

Moreover, Doris did not have a driver's license and was unable to push her husband's wheelchair anywhere far. She was therefore confined to the house for weeks at a time and said that she had not been anywhere with her husband outside their home for several years.

Suffering

'He totally changed his personality!'

Several care partners had experienced recurring episodes of jealousy, accusations of infidelity and verbal and physical violence from their husband because of his disease. Grete, for instance, shared:

'He totally changed his personality! He became aggressive. So, one of the first things I did was to remove his weapons... He had a lot of them, he really loved hunting... I also had to hide the knives. And, I had to lock the bedroom door at night when I slept. I was simply afraid of him.'

Researcher: *'You slept in a separate bedroom, with the door locked?'*

'Yes. But, I have to add that we did have separate bedrooms even before [her husband suffered from insomnia when he was younger]. But, yes, I was really afraid of him. He was aggressive (and violent), so that's why I hid the weapons and stuff.'

Grete explained that her husband repeatedly accused her of cheating on him. The first time this happened, she was shocked. They were on a day trip quite far from home when Gunnar out of the blue accused her of having an affair. She denied it, but Gunnar was convinced he was right.

Several of the care partners' husbands had been troubled with repeated hallucinations, which could be both scary and difficult to cope with. Katharina, whose husband Knut was diagnosed with Lewy body dementia, explained:

'Sometimes he perceived me as an enemy or an intruder in the house. But more often, he thought I was someone else he knew, and he would talk to me as if I were one of his former colleagues, or a hunting companion, one of his brothers, or something like that... At times, he seemed to be all right again. He would be at home, lighting the fire in the log burning stove, emptying the dishwasher, and clearing snow in front of the house. He was very slow compared to before, but still, he was helping out! But then again, the hallucinations came back...'

After not telling anyone about their situation for a long period of time, Katharina involved a neighbour who turned out to be very supportive: *'He was so kind to me. He always came like a flash when I called for help... He had a deep voice and could be quite authoritative, so Knut actually listened to him.'*

Katharina recalled the episode that made her 'give in': They had eaten supper together, but during the meal, Katharina noticed that Knut had changed the way he talked to her. She understood that this time, in the mind of her husband, she was transformed into a spy from the second world war. After the meal, he politely but firmly asked her to leave the house. It was dark and cold outside. Katharina continued:

'Then he sat by the kitchen table with the lights off. He turned on the outdoor lights by the front door in order to control the entrance. First, I thought that he would soon forget about it, but every time I approached the front door, he talked to me through the window telling me firmly that "no, you can't come in! You must stay somewhere else!" In the end, I called the neighbour.'

That evening, neither she nor her neighbour was able to convince Knut to open the front door, and Katharina was invited to the neighbour's house. After some time, when she knew Knut had fallen asleep, she went back home to prevent her husband from being worried if she was not there when he woke up. The next morning, Katharina realised she was no longer able to cope with the situation and phoned the municipality to get help. Soon thereafter, Knut was admitted to the nursing home full-time. However, in several other cases in this study, full-time nursing home admission was not offered even if it was clearly needed, as will be illustrated by the following story.

'Why don't they move him against his will?'

Felicia's story illustrates how invading it can be to care for a husband with comprehensive needs and how reluctant Norwegian authorities currently are to offer a nursing home bed to older persons with significant care needs, especially if the patient is married to a woman (regardless of her own state of health). Felicia's husband, Fredrik, woke up one morning paralysed and with cognitive loss. After a few weeks in rehabilitation, he came home. From that moment on, Felicia's life was all about caring for her husband, assisting him in doing various exercises, and helping him with everything. *'It was an extremely strenuous time'*, she said. Her husband required that she be by his side at all times, including during the night. She had the opportunity to take a quick bicycle trip to buy the necessary groceries every morning when the home nursing staff came to help her husband get up, but that was it. Otherwise, she was stuck in care work.

Felicia gradually became exhausted, and after more than two years in this situation, she collapsed. She developed what is termed 'broken heart syndrome' and went into psychosis. She was hospitalised for two weeks. When returning home, she resumed the all-consuming care work. Soon, the same thing happened all over again: she collapsed, had heart attack-type symptoms and was hospitalised again. After that incident, Felicia did not return home. She had told her husband repeatedly that she wanted him to move into a nursing home, but he refused. In addition, she had clearly told both the staff in a local nursing home and the homecare nursing staff that she was no longer able to cope with the situation. Her husband was offered a room in a nursing home, which he turned down.

As a consequence, Felicia moved into their summer house located in a quite isolated area. She was there alone with her walker when the researcher visited and interviewed her for this study. She intended to stay in the summerhouse until her husband moved out of their home, if that ever happened. *'Why don't they test his cognitive abilities, and why don't they move him against his will?'* she asked the researcher and added with a deep sigh: *'But, who cares about the carer, anyway?'*

Felicia's husband, Fredrik, remained in their home, receiving home nursing five times a day and once per night, while Felicia, in order to survive, remained to their summerhouse located in the countryside.

Unmet needs

'Lack of support and time off from caring'

Several of the care partners said that they needed emotional or psychological support. Lina, for instance, had been hit hard twice by her husband as a consequence of his cognitive decline. Being hit by her beloved husband led to her having panic attacks. One of her daughters had contacted a psychologist. Lina said that meeting the psychologist had been very helpful, but she had not been able to afford to continue the sessions. Jeanne, on the other hand, said that she could have used a respite stay, and Doris mentioned that it would have been very useful to attend a support group for care partners of spouses living with dementia.

In addition, as indicated above, several care partners said that they needed time off from caring. Doris, for instance, had read in a newspaper that the municipality had established a dementia team for next of kin. 'Finally', Doris had thought, and phoned to ask how she could get in touch with the team. She explained:

'I thought perhaps where there was an opportunity to get some relief. Perhaps someone could come home so that I could go out – just for meeting a friend or taking a coffee in a café. But, no, that was impossible. But, I could get a course. "A course? But, who is going to take care of my husband while I attend the course? A course is not what I need. I've taken enough courses!"'

Lack of information and voices not heard

Several of the other participants, however, said that they needed more information about their husband's disease and about available care services. Jeanne, for instance, said that she did not know

anything about how she could contribute to improving her husband's condition, nor did she know which services were available to them. For instance, could her husband get access to rehabilitation or regular access to an occupational therapist? How could he receive some training while being on respite care in the local nursing home? How could they get a wheelchair that they would be able to use outside the home?

Most of the care partners agreed that they were not able to find the information they needed on the internet. Rather, they relied on others, primarily the professionals providing home services for their spouses, to obtain the information, support and assistance they needed. However, several of the participants in this study explained that the home care staff rarely talked to them except when they themselves needed assistance regarding how to use some of the more technically advanced equipment. Thus, the care partners' needs largely remained unmet.

Discussion and implications for clinical practice

As stated, the Nordic states are increasingly spending less money on long-term care for older persons than on care for younger persons (Hermansen and Gautun, 2013). This development is coupled with the assumption that older persons prefer to remain in their own home even when they become frail or sick and need care (Munkejord et al., 2018). Consequently, due to our still-gendered perceptions of caring, older women in particular feel that they are expected to live at home with and take care of their husband even if he suffers from severe cognitive decline (see also Sørensen, 2015 and Sihto, 2018). Globally, due to gender injustice, women spend two to 10 times more time caring for others than men do (Heise et al., 2019).

Previous studies indicate that taking care of a spouse with dementia may be so difficult and so overwhelming that the care partner often struggles in an unbearable situation (Janlöv et al., 2006; Eters et al., 2008; Hegli and Foss, 2009; Edgell, 2013; Landmark et al., 2013; Anker-Hanssen et al., 2018; Tatangelo et al., 2018). This study both confirms and elaborates on previous research: participants said that their days caring for a husband with dementia consisted of constantly being on the alert and assisting with various practicalities. Some felt like prisoners in their own home; others talked about being woken up night after night and/or having to deal with accusations of infidelity and/or episodes of aggression, hallucinations, violence and fear. Several participants explained that when caring for their partner with cognitive decline, they were not only exhausted but also stressed or depressed. Some had been sent to the hospital due to heart attack-type symptoms that they related directly to the heavy care burden. The participants hence not only struggled but at times even suffered while trying to cope with the care burden placed on their shoulders.

Caring for a family member may feel meaningful and rewarding, as found by Carlsen and Lundberg (2017). However, this study reveals that when caring stopped feeling meaningful and rewarding, the care partners felt that the professional home care staff did not care about them. Nothing was done to adapt the services provided to their needs as a couple. 'Well, you are not sick, are you?' one of the home nurses had said to Doris one day when she felt particularly down.

Moreover, the participants reported that brief visits from the homecare staff were not enough – they needed more information, more assistance and more time off from care. Additionally, they needed emotional and psychological support. Importantly, although the participants, particularly in Norway, reported that their spouse (had) received extensive home-based services, the services provided by the municipality were not necessarily those the care partner thought they as a couple needed.

The title of this article asks 'who cares for the carer?' This study indicates that some older women caring for a spouse with severe cognitive decline in Norway and Iceland felt that nobody shared the burden with them in a satisfactory way. In other words, they felt abandoned by the so-called 'caring states'. Hence, a relational person-centred approach, placing the family (or in some cases, more specifically, the couple) and not the individual patient at the core of service provision, is needed (for

example, McCormack and McCance, 2017). Practicing person-centred care in a couple-friendly way entails a) that professional carers are taught and encouraged to listen to the experiences of both care recipients and care partners and to acknowledge the contributions made by family carers in general, and b) that the type of services offered by the municipality, as well as when and where they are to be provided, should be decided in close collaboration between formal and family caregivers.

The findings in this article are supported by the ongoing reform in Norway called 'A full life - all your life' (Ministry of Health and Care Services, 2018). As mentioned in the introduction, important goals in this white paper are first to provide care to family carers in order to prevent exhaustion, and second to improve the collaboration between family carers and public health and care services. Additionally, the Ministry of Welfare in Iceland published a report emphasising the significance of empowering older people by giving them opportunities to participate in society (Ministry of Welfare, 2016). Moreover, national alliances for informal carers have been established in different countries, including Norway, Denmark, Sweden and Iceland (stories emerging from this study of caring in situations other than cognitive decline will be analysed in future articles). These alliances are working hard to inform and strengthen the position of informal carers. They are also running support groups for informal carers and struggling to ensure that unpaid care is recognised as central to the sustainability of long-term care systems. In Europe, the organisation [Eurocarers](#), established in 2006, has adopted 10 guiding principles, including recognition, social inclusion, choice, information, support and time off. Eurocarers is working towards the implementation of these principles in all policy areas relevant to carers.

Conclusion

The research findings and policy papers referred to above, as well as the work of third sector associations such as Eurocarers and national informal care alliances, should serve as an inspiration for service innovation in long-term care in the years to come. As members of a modern welfare society with egalitarian and age-friendly ambitions, we cannot accept the burden the public healthcare systems currently place on the shoulders of family carers, particularly on older women caring for husbands with cognitive decline. We must join forces and take action.

Limitations

This study does have limitations, one of which is that we interviewed only care partners and not professional caregivers. Ethnographic fieldwork and interviewing professional carers in home-based care in Norway and Iceland would have been helpful in terms of exploring the similarities and differences in their experiences compared with those of care partners. Moreover, we did not interview care recipients. Despite these limitations, and although we cannot make generalisations, the study does provide a deeper understanding of older women's struggles, suffering and unmet needs when caring for a spouse with severe cognitive decline. Moreover, these insights may contribute to the development of home-based services that are more attentive to the needs of care recipient and care partner.

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