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Maintaining or letting go of couplehood: Perspectives of older male spousal dementia caregivers

Olga Ásrún Stefánsdóttir MSc, Adjunct, PhD candidate[1] |
Mai Camilla Munkejord PhD, Professor, Research Professor[2,3,4] |
Eydís Kristín Sveinbjarnardóttir MSc, PhD, Associate Professor[1]

[1]School of Health Sciences, University of Akureyri, Akureyri, Iceland

[2]Dept of Business Administration, Western Norway University of Applied Sciences, Bergen, Norway

[3]NORCE, Bergen, Norway

[4]Centre for Care Research West, Western Norway of Applied Sciences, Bergen, Norway

Correspondence
Olga Ásrún Stefánsdóttir, School of Health Sciences, University of Akureyri, Norðurslod 2, 600 Akureyri, Iceland.
Email: olgastef@unak.is

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Abstract

Despite the negative implications for their own health, spouses continue to support each other and maintain their couplehood for as long as possible, including when one of them develops a severe illness. However, with some exceptions, the experiences of older male spousal caregivers have been largely overlooked, and our knowledge of the relational aspects of spousal dementia care is scarce. To respond to this knowledge gap, this article explores the following research questions: How do older male spousal caregivers of wives with dementia talk about changes in their couplehood? What transitions or phases in the relationship can be identified as the caring process evolves and the wife's health continues to deteriorate? To answer these questions, we analyse in-depth interviews with eight purposefully selected men aged 67–92 years old from Iceland and Norway. Our findings reveal that the participants felt that they were gradually losing their couplehood in the sense that they lost their shared everyday life routines, intimacy, joint activities, meaningful communication, and dreams and hopes for the future. Four phases of the dementia caring process were identified: the denial phase, the battle phase, the new reality phase and the redefinition phase. We hope that our findings spur more research on relational challenges as experienced by spouses caring for partners with cognitive decline. In conclusion, we argue that interdisciplinary clinical guidelines for a couple-centred approach in elder care should be developed to urge professional care providers to pay attention to the various changes and challenges that dementia couples undergo to meet not only the health and care needs of dementia patients but also those of their spouses.

KEYWORDS

couplehood, dementia, grounded theory, older male spousal caregivers, phases, relationship

INTRODUCTION

We live in an ageing society with an increasing prevalence of dementia. Worldwide, most persons with dementia are cared for by family members while living at home [1. Despite the availability of formal home-based care services, family care is of the utmost significance for persons with dementia in Nordic countries [2,3. Thus, in most couples in which one of the partners develops dementia, the healthier spouse becomes the primary caregiver [2–4.

Many studies have explored the experiences of spousal caregivers. Research has shown that spousal caregivers experience a higher degree of depression, a greater financial burden and lower levels of mental well-being than other family caregivers, such as adult children or in-law children [5. Spousal caregivers for partners with dementia often experience more challenges than the caregivers of persons with other chronic illnesses [6,7. Spousal dementia caregiving often causes a striking decline in the care provider's physical and mental health [8–11. Similarly, research has indicated that spousal dementia caregivers experience mental and physical fatigue [12, insomnia, lack of energy and emotional distress [9 and even accelerated cognitive decline [13.

Despite the steady increase in the number of male caregivers, research on family caregiving has focused mainly on women's experiences, whereas male caregivers have been largely overlooked. However, some studies of men who care for close family members do exist. According to a systematic literature review of male dementia caregivers [14, these studies have explored the diversity of men's caregiving experiences, highlighting, e.g., interconnections between increasing care tasks and changes in male carers' gendered identities [2,15,16. Another study highlighted male caregivers and their experiences of grief, loss of intimacy, loss of meaningful communication, loss of joint activities and loss of meaning in their lives [17. Furthermore, it has been revealed that, as couples age, the gender gap in spousal care seems to narrow because, after retirement, men focus more on home- and family-related issues, including care work, than when they were professionally active [18.

Towards a relational approach to spousal care

We know that spouses strive to support each other and to maintain their couplehood for as long as possible despite the negative health implications of spousal care, including when one of them develops dementia [8,19]. Despite this insight, we know little about the relational aspects of spousal dementia care. However, a study from the UK identified that a continual re-evaluation and repositioning of the relationship occurs as the caring process evolves [20]. Moreover, a longitudinal study from Sweden indicated that couples in which one partner had dementia and the other partner was the primary caregiver undertook considerable efforts to maintain their relationships in four main ways: 'talking things through'; 'being appreciative and affectionate'; 'making the best of things' and 'keeping the peace' [21.

In this article, we employ a relational perspective on spousal dementia care to respond to the need for more detailed knowledge about how couplehood changes are experienced when caring for a partner with dementia. Due to the limited knowledge about male caregivers, we have chosen to focus on men's voices to explore the following research questions: *How do older male spousal caregivers of wives with dementia talk about changes in their couplehood? What transitions or phases in their relationship can be identified as the caring process evolves, and the wife's health continues to deteriorate?*

By answering these questions, our aim is to shed light on couplehood changes as experienced by men caring for wives with dementia. As elaborated below, four phases of couplehood changes were identified: the denial phase, the battle phase, the new reality phase and the redefinition phase. These phases are not necessarily linear or progressive. Nevertheless, they can be perceived as insightful metaphors for a painful process that older male spousal caregivers and their couplehood can undergo when caring for spouses with advancing dementia. In conclusion, we discuss implications for clinical practice.

MATERIAL AND METHODS

Design

This study is a qualitative, constructivist grounded theory study. Constructivist grounded theory was chosen because it offers a systematic and rigorous approach to data collection and analysis [22–24. Moreover, a constructivist approach was selected because it helps the research team obtain a deep understanding of a phenomenon, in this case, the relational aspects of spousal dementia care, grounded in the participants' views and experiences.

Participants

We purposefully selected male participants aged 67 years old or older with extensive experience caring for a spouse with cognitive decline who eventually (had been) moved to a nursing home (NH). The age limit (67 or older) was

TABLE 1 Table of participants.

Informants' pseudonyms	Study participants' ages	No. of years married (second marriage*)	Medical diagnosis of the spouse	Living arrangements of the male caregivers (after the wife was relocated to the NH)	Former occupation of the male caregiver
Boas	67–69	40	Alzheimer's	At home	Gardener
Geir	75–79	55	Alzheimer's	At home	Entrepreneur
Gunnar	85–89	65	Alzheimer's	Nursing home	Firefighter
Asmund	85–89	65	Alzheimer's	At home	Accountant
Kristjan	85–89	57	Parkinson's	At home	Fisher
Stefan	85–89	39	Stroke	At home but had applied to go to the same NH as his wife	Farmer
Bjorn	90+	20*	Alzheimer's	Nursing home	Mechanic
Emil	90+	67	Stroke	At home	Economist

chosen because this age has long been used to define ‘older people’ in both Iceland and Norway [25,26. In total, eight men aged 67–92 years old (mean age 84) were interviewed. The ages of the wives ranged from 66 to 88 years old (mean age 81). The caring period at home before the ill spouse was moved to the NH ranged from four to ten years after formal diagnosis. The couples had been married between 20 and 65 years (Table 1).

Following Kvale and Brinkmann [27, the authors acknowledge that older couples in which one partner suffers from a severe illness, such as cognitive decline, are a vulnerable population.

This study obtained formal ethical permissions from the Icelandic National Bioethics Committee (VSN-18–149) and the Norwegian Centre for Research Data (NSD-48366). Both Icelandic law and Norwegian law emphasise the importance of ensuring confidentiality with the participants, protecting their interests and ensuring that they have been well informed about the study's purpose and contents [28,29. Thus, in line with the Helsinki Declaration [30, which states that everyone should have a free choice to participate in research, the participants were thoroughly informed about the study's aim with information letters about the research and interviews and that they could withdraw their participation at any time with no explanation. None of the participants dropped out of the study. Efforts have been undertaken to present the results carefully and respectfully. All of the names in the article are pseudonyms.

Data collection

Data were collected through individual in-depth interviews (one interview with each participant). The project team consisted of three women: two experienced researchers and a research fellow who is a family therapist and who has worked with older couples. The first author conducted the interviews in Iceland, and the second author conducted the interviews in Norway. The interviews lasted 45–120 minutes and took place face to face in the participants' homes in 2018 and 2019. They were audio recorded and transcribed. An interview guide included questions about background information and their life as a couple (e.g. experience of intimacy or distance in the relationship, activities that they had used to engage in as a couple, experiences of communication). They were also asked how and when they realised that something was ‘wrong’ with their spouse, how they adapted to their spouse's declining condition, the nature and experience of the increasing care tasks that the participants had engaged in over the years, and their thoughts about the future. Reflection notes were written following each interview.

Data analysis

In accordance with Charmaz [22, a constant comparative method was used, meaning that data analysis occurred in parallel with the data collection. Moreover, when all of the interviews were transcribed, the authors read the transcripts while noting themes that attracted their attention. Then, the authors met for a collaborative analysis workshop to discuss the data and agree on possible analytical foci for the article. After this workshop, the first author performed the second-round analysis, coding each interview line by line. Next, targeted coding was performed. In addition, analysis sheets were written that provided an overview of all of the codes, including the themes, subthemes and quotes, as illustrated in Table 2. Finally, we developed the four categories elaborated in the results section and illustrated in the analytical model of the dementia caring process, focusing on the evolution of the couplehood. NVivo software was used to manage the data in their entirety and the coding process. The authors discussed the analyses and preliminary findings on several occasions. The interviews were detailed and provided insightful data on couplehood changes that men might undergo when caring for a wife with dementia. Thus, our eight interviews allowed us to answer our research question in a satisfactory manner [22,31,32. The first author wrote and revised the article in collaboration with the second author, while the third author contributed to the revisions.

RESULTS

The analysis revealed four different phases that participants described as they became primary caregivers for their wives with dementia and struggled to maintain or let go of their couplehood. These phases are represented in Figure 1.

The denial phase: trying to maintain couplehood, pretending everything was normal.

The caring process started in the participants' homes when the spouse showed the first signs of illness, and suspicion arose that things were no longer as they should be. The participants explained that it was difficult to watch their wives become ill. Therefore, they tried to pretend that everything was 'normal', for example, by saying, when the wife did not remember where she had placed something, that 'everybody gets slightly forgetful in old age', or when she was no longer able to get out of bed by herself or dress, that 'it is normal to get slightly frail in old age'. However, incidents outside of the home caused the participants to wonder what was happening to their spouses. Asmund, for instance, said, 'See, if you went to a shop, then you couldn't turn around because she would disappear, and I had no idea where she had gone'. Similar things occurred to Geir and his wife. He described a situation in which he had gone to the bank with his wife. Both needed to sign some documents. This moment was when he understood something was wrong: when he put the documents in front of his wife, she was not able to figure out how to sign her name, even when he tried to help her. Geir said that, before this incident, he had not noticed anything unusual about his wife. When remembering this thought, he was moved to tears. Boas, in contrast, explained that, when the early signs of his wife's illness appeared, he was in denial, explaining, 'It's such a slow process that one does not realise it'. Friends had tried to tell him that they saw changes in his wife, but he did not want to listen, thinking, 'Yeah, okay, isn't that just age? I mean, do you understand?' He added, 'When you live in such proximity [as a couple does], you do not always see things in the proper light'. The first thing that he noticed, however, was that his wife had stopped performing the handicrafts that she had been very engaged in for her entire life. He described the process as follows:

> I remember asking her, 'Why have you stopped knitting and crocheting'? Then, she said, 'I've just done enough of that throughout my life, so now I've just stopped'. I thought that was a reasonable explanation. I did not think about it for long. Then, as time passed, one finally started feeling and seeing things clearly that, in hindsight, appeared odd.

The battle phase: struggling to become a carer while holding on to the husband role.

The participants explained how the real struggle began when they realised that their spouse's health was declining rapidly. Her weakening health caused everything to change in the couplehood, and all of the foundations of their relationship, such as trustful communication and mutual support, disappeared. The time spent on extensive care tasks at home before relocation to a nursing home ranged from four to ten years after their wife received a formal diagnosis.

Soon after the diagnosis was made, the participants experienced that their spouses were no longer able to fulfil a marital role as before. This realisation created an imbalance in the couple relationship since it was difficult to maintain intimacy while also being obliged to

TABLE 2 Maintaining or letting go of couplehood during the care process.

Themes	Subthemes	Quotes
The denial phase	Trying to maintain couplehood, pretending everything is normal	'This is such a slow prelude that you don't truly realise it. Of course, this was a hell of a shock at first when you were turning on something. However, one thought it would not be so steep'. 'When you are very intimate with your spouse, you do not always see things in the right light'. 'It took a long time until I noticed that she did not remember things, and then I noticed that she never found anything that she was looking for'.
The battle phase	Struggling to become a caregiver while holding onto the husband role	'She just fell completely out of the world; she cannot do anything, not even read. She was a terrific craftswoman, but it is all gone now'. 'I take care of her a lot, and I need to help her. She is so lacking in health'. 'I naturally needed to help her slightly, and I always had to help her get to bed. She stopped being able to spread the duvet over herself'. 'I naturally have only one word to say about this. I feel terribly bad'.
The new reality phase	Coming to terms with letting go of couplehood	'It is much easier since she was admitted to the NH. I do not have to sort out everything anymore. It was a lot less of a burden on me, I find. A less heavy load on me'. 'It is naturally a significant change to be alone, and this is more than saying that, after having the same woman by my side for 60 years'. 'I thought she would come back … I thought the respite care [for his wife] would help me, but then I saw that, after 6 weeks, it was nothing but rest because she always gets worse in a new place'.
The redefinition phase	Letting go of the past and reorganising oneself for a new future	'Yes, that feeling is quite natural. I do not know if you feel so good about being at home with all your stuff that it is unfair that she is not allowed to enjoy it for as long as possible'. 'You have long been aware of what is going on. It's just a matter of working it out'. 'When she moved to the nursing home, then you knew that she was well taken care of. I used to visit her quite a lot, but you could do more stuff after she moved there. You did not have to stay at home all the time, as I had to before when she lived at home. However, after she relocated to the nursing home, I could do more fishing, gardening, carpentry, such things'.

attend to everything in the household. The participants described that it was suddenly impossible to make joint decisions about what to eat or what to do or even simply to have an open conversation about any issue. In other words, in addition to remaining in the role of husband, the participants increasingly had to take on the role of primary caregiver for their wives. Boas's experiences illustrate this situation. He said, 'There are no conversations that you have with these people [with cognitive decline]. Not like people generally do at the breakfast table, small talk, how the kids are doing and plans. That is long gone, all of it'.

The boundary between the husband and the caregiver roles was not always clear, but in the battle phase, the caregiver role seemed to become the dominant role. The participants explained how they took responsibility for increasingly more care and domestic tasks in the household for which their wives had previously been responsible. They were planning and preparing food, planning everyday activities, cleaning, and doing the laundry. They increasingly had to assist their wives with personal care tasks, for example, reminding her to go to the toilet or helping her take a shower or dress and undress. The participants explained that they had met the new challenges in a courageous way: they 'had just done what needed to be done' or they had 'no choice but to grapple with it'. Boas expressed this attitude in the following manner:

> Boas: My role in the past three years has been just caring; that is my experience.
>
> Researcher: How does it feel to suddenly find oneself in the position of no longer recognising your spouse like in the past and perhaps having no chance to maintain being a husband—only being in the role of a caregiver?
>
> Boas: I do not know. That is just my role. I do not have any other explanation for it.

A different example that might illustrate the battle phase was described by Kristjan. His wife was diagnosed with

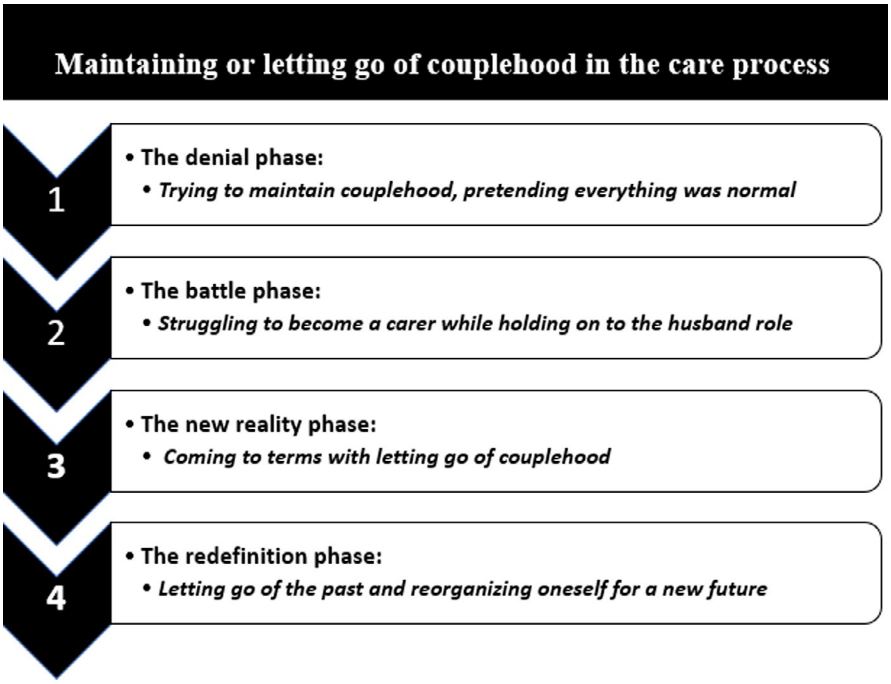

FIGURE 1 Analytical model of the caring process, focusing on the evolution of couplehood.

Parkinson's disease at the age of 66. She was struggling with other ailments as well. Her illness developed very quickly. Kristjan said that, for many years, he had cared for his wife from dusk until dawn, administering her medications and assisting her with all of her daily life activities and functions. He had always been 'on the alert' and had not been able to leave the house unless someone else arrived to cover for him. Kristjan explained that he loved to go fishing but was increasingly prevented from doing so because of care duties and responsibilities at home. He felt stuck in the caregiver role. Therefore, his struggle was increasingly about creating his own space, unlike the other participants, who described how they sought and longed for more time and more intimacy with their wives.

The new reality phase: coming to terms with letting go of couplehood.

The participants in this study received very little informal support. They said that most of their friends had passed away and that their children or grandchildren either lived far away or were busy with their own lives if they lived closer. Thus, although some of the participants received some practical help from children, grandchildren or neighbours with tasks such as buying groceries, transport to the hospital or house cleaning and although most of them received regular professional home care (from once per week to six times per day), they felt alone in the role as the primary caregiver most of the time. None of the participants had received formal or informal social support, such as participation in support groups, group therapy or other initiatives, which could have empowered them in a very challenging process.

Thus, eventually, the participants felt that they had no choice but to be forced to apply for NH accommodations for their wives. For most of them, this felt like 'surrendering' or 'being forced to let go' of their couplehood. When receiving the message that their wife had finally been accepted into an NH, the participants chose two different strategies: some of them decided to remain at home, whereas two of them, both in Iceland, agreed that they needed and wanted to move into the NH with the wife. The men who stayed at home explained that they quite soon started to feel relieved and that it was like a burden had been lifted off their shoulders. Boas, for example, worded this feeling as follows: 'It is much easier [for me] since she was admitted to the NH. I do not have to sort out everything anymore. It is a lot less of a burden on me, I find. A much less heavy load on me'.

However, along with the relief, the participants also experienced grief and anxiety about the future. During the process of watching their wives becoming increasingly ill, they had undergone emotional ups and downs. Some of them admitted that they had not talked about these emotions with anyone before being interviewed by the researcher. In some cases, the participants did not have anyone but their wives to talk to because their friends had passed away. In cases in which the participants had children and grandchildren, they said they could not speak openly with them as they had done with their wives. Therefore, to avoid loneliness, the participants needed to remain in their spouses' company. Moreover, the relocation of the participants' wives to an NH created various pressures. For instance, husbands were often not allowed to choose NH accommodations suited to the wife's needs. Thus, the wife was placed in an NH far from the family home and visiting her became time consuming and cumbersome in some cases. Emil's wife, for instance, was placed in an NH 30 km from their home. He had to travel by bus to visit her, which consumed most of his time and energy. Unlike the other participants, Gunnar and Bjorn wanted to move into the NH with their wives. Gunnar explained that he had been determined to do so since his wife was accepted into the NH. He had told the person in charge that the NH director had to take either both of them or neither of them. The mere idea of his wife moving away, leaving him alone at home, had terrified him. He added:

> It would have been the end of life for me … completely impossible. Her life has revolved around my needs all our years together, and then I am supposed to just dump her? A week after my wife received approval for NH accommodation, she [the NH director] called and said that I could join her in the NH … I wanted to take care of her as she has taken care of me for so many years.

Bjorn also expressed that he wanted to move with his wife into the NH when she was admitted, but his request was refused: 'Suddenly, she was considered a 'patient', whereas I was considered okay, which was not the case'. Bjorn explained how unfair it felt to be separated from his beloved wife. After a brutal 18-month struggle, he was finally accepted at an accommodation but in another service next to the NH where his wife lived:

> Researcher: How happy were you about that decision making by the system?
>
> Bjorn: I was not happy, and I threatened to run away from that place!
>
> Researcher: Do you consider it essential, given your circumstances, that the authorities should allow couples to move to an NH together if they wish to?
>
> Bjorn: Yes, if they, like us, want to be together, then I find it essential that we should be allowed to be together. I think it should be possible. However, [for the time being], this is how it is, and we do not have a say.

The redefinition phase: Letting go of the past and reorganising oneself.

After the participants' spouses had lived in the NH for a certain period, some of the participants underwent a redefinition phase. This phase entailed allowing oneself to let go of the past and reorganising oneself for a different relationship with the wife. The participants in this phase continued to visit their wives in the NH regularly, but they no longer had expectations of having intimate communication or interactions with her. Being able to reconcile oneself with this situation and reorganise oneself required considerable effort. Several participants described that they had struggled with feelings of guilt after their wives moved into an NH. Boas described this feeling in the following way:

> Yes, this feeling [of guilt] is valid. I do not know whether it is the feeling that you are doing well at home with all your stuff, and it is unfair that she does not get to enjoy that anymore. It is just a question of working through it when it happens.

Kristjan's story was different from those of the other participants because his wife died six months before the interview was conducted. He explained that, in the beginning, after she moved into the NH, he had visited her every day. Later, he had gone to see her three days per week and then a couple of days per week. When she died, he was ready to reorganise his life and engage in his hobbies, which included gardening, carpentry, and fishing. He proudly gave a guided tour to the researcher of his garden and pointed out a new tool shed that he had just built with his own hands.

Other participants had greater difficulty coping with their new situations. Gunnar and Bjorn decided that their only goal, until the end, was to live with their wives in the NH. Beyond that point, they had no plans. Stefan, whose health was also deteriorating, had applied for admission to the same NH as his wife. However, instead, he was offered an accommodation in another NH, which made him unhappy. He had therefore started a battle like the one Bjorn described above. Geir, Emil, Boas, and Asmund had not yet reached the phase of accepting their new life situations. Finding a way to redefine the new position can be a long process, and it can be difficult to experience that one's beloved spouse is disappearing despite still being physically present. Boas explained this experience as follows:

> It is hard to find words to describe how it is to be in such a situation. The feelings people have … is like losing one's spouse … that is how I feel. You have a completely different

> person in your hands that you do not know. You treat her entirely differently and interact with her entirely differently. There is obvious affection and all that. It is just a completely different landscape.

DISCUSSION

This study found that older men who became full-time caregivers for their wives felt that they were gradually losing their couplehood. They sensed that they had lost their shared everyday life routines, intimacy, joint activities, meaningful communication, and dreams and hopes for the future. Some of them also experienced an existential crisis: Who were they? How would they be able to continue living without their wives as they used to know them? Four phases in the transformation of the couple's relationship were identified. Experiencing these phases was emotionally challenging for the participants, who attempted to maintain sound and intimate relationships with their spouses as much as and for as long as possible. It should be noted that, when the condition of the ill spouse worsened, it was increasingly less possible for the husbands to maintain their marital relationships, and at times, they felt tired and powerless, as was also found in a study by Sanders and Power [33. In particular, the transition from being the 'husband' to becoming the 'primary caregiver' was challenging to endure. Several of the participants described feelings of loss, grief and despair when faced with their spouse about to become a different person than the one they used to know. Feelings of grief, loss and despair among spousal caregivers were also identified in Bielsten and Hellström [34. The loss of intimacy and togetherness with the wife was also a challenge. The participants, moreover, told how they struggled with these challenges alone and that they had no one to talk to about these issues, not even their children. At the time of the interviews, none of the participants received any formal social or health-related support that could have assisted them in coping with the relational grief process that they were undergoing. Furthermore, although most of our participants felt relieved after their spouses had moved into an NH, they often felt lonely. Some of the participants insisted on remaining physically close to their wives and had relocated or wanted to relocate to the NH with her.

Our findings are supported by Carlsen and Lundberg [35. They emphasised that caring for a close family member can be regarded as a choice and a meaningful task, particularly if the family caregiver feels acknowledged and supported by healthcare professionals. However, it can be problematic if formal care services are focused on the sick person only and not on the couple as a significant unit.

CONCLUSION

The four relationship phases analysed and explored in this article provide a lens to grasp the relational aspects of dementia care. Moreover, our findings suggest that not only the needs of the patient but also those of the healthier spouse should be considered. Some spousal caregivers require more practical help, while others need more social support to cope with relational changes and losses in their marital lives. It is also important to note that some spouses want to move into the nursing home together with their sick partner. However, further research is needed to establish how nursing homes could be better equipped to welcome and include not only the patient but also the healthier spouse.

Interdisciplinary clinical guidelines for a couple-oriented approach in elder care should be developed to enable professionals to understand the emotional and relational changes that dementia couples experience. Moreover, professionals should be enabled to support and sustain what dementia couples have and what they can do, rather than what they do not have or cannot do [4. Only in this way can we develop professional elder care services that enable older couples to maintain their couplehood and meaningful everyday lives for as long as possible—as well as when dementia strikes. Previous research has indicated that healthcare professionals must respect the spousal relationship and its importance despite changing circumstances [9,36,37. The four different phases identified in this article can provide important steps forward to help professionals support couples working through these different phases. Services should focus not only on the health needs of the ill person but also on the social and emotional needs of the caregiver and on the relational struggles occurring between them. It is now time to develop and implement a couple-centred approach in professional elder care in Nordic countries and beyond.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

The first author conducted the interviews in Iceland, and the second author conducted the interviews in Norway. All authors read the data and met for a collaborative analysis workshop to discuss possible analytical foci for this article. After this workshop, the first author performed the second-round analysis, coding each interview line by line. The authors discussed preliminary findings on several occasions. The first author wrote and revised the article in collaboration with the second author, while the third author contributed to the revisions.

ETHICAL APPROVAL

The study's necessary permissions in Iceland were obtained from the National Bioethics Committee (VSN-18–149) and in Norway from the Norwegian Centre for Research Data (NSD-48366).

ORCID

Olga Ásrún Stefánsdóttir https://orcid.org/0000-0001-5208-4320
Mai Camilla Munkejord https://orcid.org/0000-0002-5700-7639
Eydís Kristín Sveinbjarnardóttir https://orcid.org/0000-0002-8183-5370

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