Being 'alone' striving for belonging and adaption in a new reality – The experiences of spouse carers of persons with dementia

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Abstract

Background and aim: Spouse carers of a person with dementia report feeling lonely and trapped in their role, lacking support and having no time to take care of their own health. In Sweden, the support available for family carers is not specialised to meet the needs of spouse carers of people with dementia. The aim of the study described in this paper was to explore spouse carers' experiences of caring for a partner with dementia, their everyday life as a couple and their support needs.

Methods: Nine spouse carers of a partner with dementia living at home were recruited through a memory clinic and a dementia organisation. Semi-structured interviews were conducted with

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the participants, focusing on their experiences of providing care, their support needs in relation to their caring situation, their personal well-being and their marital relationship. The interviews were transcribed and underwent qualitative content analysis.

Results: The analysis resulted in one overall theme *Being 'alone' striving for belonging and adaption in a new reality*, synthesized from four sub-themes: (1) *Being in an unknown country*; (2) *Longing for a place for me and us*; (3) *Being a carer first and a person second*; and (4) *Being alone in a relationship*.

Conclusions: The training of care professionals regarding the unique needs of spouse carers of people with dementia needs improvement, with education, in particular, focusing on their need to be considered as a person separate from being a carer and on the significance of the couple's relationship for their mutual well-being.

Keywords

spouse carer, dementia, persons with dementia, marriage, support, experience, qualitative content analysis

Background

Globally, dementia is the leading cause of dependency in everyday living with the person with dementia having increasing care needs as the disease progresses (Alzheimer's Disease International, 2018). Due to the extensive range of disabilities associated with dementia such as memory and language decline, disorientation and behavioural symptoms such as aggressiveness and resistance, a person with severe dementia can require 24-hour supervision (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). Informal (family) carers, primarily a child or spouse of the person with dementia, provide the majority of such supervision. Research has shown that spouse carers of persons with dementia can experience more negative effects from their care role than other family carers (Ask et al., 2014; La Fontaine & Oyebode, 2014; McCabe, You, & Tatangelo, 2016) and demonstrate higher levels of unmet needs and lower levels of service utilisation compared to carers of persons with other disabilities (Thompson & Roger, 2014). This paper reports a qualitative study that explores spouse carers' experiences in caring for a partner with dementia, their everyday life and their support needs.

Dementia has a devastating effect on the person with the condition, and also affects the quality of life of spouse carers who may provide care and support to their partner over a number of years (Chiao, Wu, & Hsiao, 2015; Johannessen, Helvik, Engedal, & Thorsen, 2017; Liu et al., 2017; Wadham, Simpson, Rust, & Murray, 2016). Research has found that spouse carers of persons with dementia can report a quality of life that is lower than the person for whom they care (Wadham et al., 2016), and commonly perceive their caring responsibilities as too overwhelming to maintain (Swedish Family Care Competence Centre, 2014). Furthermore, research has shown that carers often do not receive the type of support they want and need (Phillipson, Jones, & Magee, 2014; Tyrrell, Hilleras, Skovdahl, Fossum, & Religa, 2017). In their review of research on spouse carers of persons with dementia, La Fontaine and Oyebode (2014) concluded that the marital relationship is often strained, the carer can feel trapped in their situation, lonely, lacking in support and have no time to take

care of their own health. In addition, spouse carers report feeling that they are losing their partner due to difficulties in sharing thoughts, emotions and experiences, leading to reduced intimacy and a sense that they are no longer married (Eloniemi-Sulkava et al., 2002; Kaplan, 2001; Pozzebon, Douglas, & Ames, 2016). Tuomola, Soon, Fisher, and Yap (2016) found that spouses reported insufficient rest, guilt, a loss of sense of self and an acceptance of their caring role as their destiny, while Tyrrell et al. (2017) found that due to the person with dementia's need for constant supervision, spouses' social life and recreational activities were significantly reduced. Other research has similarly found that the lives of spouse carers of persons with dementia become so focused on their caring role that they abandon leisure activities and social relations leading to isolation, distress, self-criticism, guilt, depression and lower life satisfaction (Liu et al., 2017; Pertl, Lawlor, Robertson, Walsh, & Brennan, 2015; Wawrziczny, Pasquier, Ducharme, Kergoat, & Antoine, 2017).

Spouse carers can also report positive caring experiences. For example, studies have found that caring for a partner with dementia can be regarded as a good thing to do and that the carer is happy to provide care (Han & Radel, 2016; Shim, Barroso, & Davis, 2012), while Merrick, Camic, and O'Shaughnessy (2016) found that both spouse carer and the partner with dementia wanted to maintain their relationship. Clearly, there is a qualitative difference between a care relationship that is an extension of a shared lifetime together as a couple, as opposed to being an adult child or sibling carer, and some research has focused on the significance of this relationship. Hellström, Nolan, and Lundh (2005) proposed the concept of 'couplehood', in which couples should be viewed as a unit, rather than two separate individuals. Strategies for maintaining 'couplehood' suggest engagement in the relationship and co-activities (Bielsten & Hellström, 2017a, 2017b; Han & Radel, 2016; Hellström, Nolan, & Lundh, 2007; Merrick et al., 2016). Such strategies are also highlighted in other recent research as ways to maintain a good relationship (Hernandez, Spencer, Ingersoll-Dayton, Faber, & Ewert, 2017; Myhre, Bjornstad Tonga, Ulstein, Høye, & Kvaal, 2017; Riley, Evans, & Oyeboode, 2018). Williams (2011, 2015) has focused on the quality of emotional communication between spouse carer and partner with dementia and tested a novel home-based intervention (Caring About Relationships and Emotions: CARE) to improve communication and thus support the marriage. Findings demonstrated that both communication between spouse carer and partner with dementia improved after the CARE intervention (Williams, Newman, & Hammar, 2017).

In a Swedish context, the number of residential beds for persons with dementia is low at 15% of the total dementia population (National Board of Health and Welfare [NBHW], 2016), meaning that the majority of persons with dementia live in the community with most cared for by their spouses. The municipalities have the responsibility for offering support to informal carers of persons with dementia (NBHW, 2016; Sweden Ministry of Health and Social Affairs, 2001). However, the support offered varies in quantity and quality across municipalities (Swedish Agency for Health Technology Assessment and Assessment of Social Services, 2015; NBHW, 2012), and is not based on an understanding of the distinct needs of different sub-groups of carers, such as those of spouse carers. The present study used in-depth interviews among spouse carers of partners with dementia to develop an understanding of their distinct support needs and to understand such needs in the context of the spousal relationship. The aim of the study was to explore spouse carers' experiences in caring for a partner with dementia, their everyday life and their support needs.

Methods

Design

The study was qualitative with an inductive approach using semi-structured interviews as data collection method.

Sampling and participants

Participants were recruited from two sources: two memory clinics and two local support groups of a dementia organisation. The memory clinics and the support group were based in two different, medium-sized cities in an urban area of Sweden. Inclusion criteria were a spouse partner of someone with a diagnosis of dementia, living together in the community in ordinary housing, aged over 65 years and Swedish speaking. Nine carers participated in the study, four men and five women, aged between 65 and 94 years with a mean age of 75.9 years. Three participants were recruited via two memory clinics and six via a dementia support group. Sample size was not decided at the outset of the study but determined when data saturation was reached in the analysis of interview data, identified when variation in the data diminished to the extent that no new perspectives on our study aim were found. This occurred after nine interviews, thus terminating the recruitment process.

Materials and procedure

Schedules for semi-structured interviews (Polit & Beck, 2016) were developed, focusing on spouses' experiences of living with a partner with dementia, their relationship as well as their support needs. The primary questions in the schedule are shown in Table 1. Not all questions were asked of every participant, since follow-up probing questions depended on participants' answers to the primary questions. Thus, the table should be seen as a guide in the interviews.

Table 1. Interview questions.

Area of focus	Questions
Marriage	<p>How do you think your marriage works now when your partner has dementia? What is different from before he/she got dementia? How do you handle that? Do you express your feelings (verbal or non-verbal) to your partner? How? Does your partner express feelings (verbal or non-verbal) to you? How? Do you talk about or express feelings of each other? How do you express tenderness to your partner? How does your partner express tenderness to you?</p>
Communication	<p>How does your partner communicate to be understood? Are you able to interpret your husbands' communication (verbal and non-verbal)? When you do not understand your partner or he/she do not understand you, how does it make you feel? What do you do then? What works best?</p>
Support	<p>What kind of professional support do you have today? What do you think about the support you get? What kind of support would you say that you need? What kind of support would you like to have to be able to take care of your own health?</p>

Potential participants were given an information letter describing the study by their partners' physicians at the memory clinic or by the convener of the local support group of the dementia organisation. Approximately 50 information letters in total were provided to the memory clinic and dementia organisation, although not all were disseminated; as such, an exact response rate cannot be determined. Those individuals expressing an interest in participating in the study were then sent a letter of confirmation including contact information for the first author who later contacted them to reserve a time and place for the interview. The interviews were carried out by one of the co-authors (MSM) in the participants homes ($n = 7$) or by telephone ($n = 2$), at a time convenient to the participant and when the care-recipient was not present. The interviews lasted from 32 to 72 minutes with a mean of 51 minutes.

Data analysis

The interviews were analysed with latent qualitative content analysis as described by Graneheim and Lundman (2004). Interviews were read several times as a whole to get a sense of overall content. In the first step of the analysis, meaning units, or words, sentences or phrases that related to the aim of the study were identified. In the second step, the meaning units were condensed and thereafter abstracted and labelled with codes. Codes were discrete objects, events or other phenomena in the meaning units and were understood in relation to the context of the study. The third step consisted of comparing the codes to identify differences and similarities. Four sub-themes were revealed in the data. From the subthemes, the researchers derived the overall theme in this analysis. The sub-themes and the overall theme linked underlying meanings and created a red thread throughout the condensed meaning units, codes and sub themes on an interpretative level that expressed the latent content of the text. The overall theme and subthemes are presented in the result section. An example of the analysis is seen in Table 2.

Ethics

The Regional Board of Research Ethics (record number: 2016/446) approved the study, and The World Medical Association Declaration of Helsinki was carefully followed. All names in the quotations in the results section are fictitious.

Results

The nine participants were aged between 65 and 94 years, four were men and five were women. They had been caring for their partners from two to eight years. None of the participants had prior experience of, or training in, caring for persons with dementia. All participants received formal care support to some extent, but the type and level was not documented in the study.

The analysis of the interview transcripts identified one overall theme *Being 'alone' striving for belonging and adaption in a new reality*, synthesized from four sub-themes;

Being in an unknown country, Longing for a place for me and us, Being a carer first and a person second and Being alone in a relationship.

Being in an unknown country

The spouses described themselves as being in an unknown country as they lacked knowledge of dementia and its causes. Despite their lack of knowledge, the spouses found themselves

Table 2. Example of the analysis process.

Meaning unit	Condensation	Code	Sub-theme	Theme
I have a cottage on the countryside where I like to take relatives or friends. It would also feel good to go there and work in the garden. So, that is my dream about doing other things. To live like we lived before. But as it is now, it is impossible.	Take relatives or friends to their cottage in the county and to work in the garden is not possible because having to care for his wife.	Being able to socialise and doing things for oneself is not possible.	Being a carer first and a person second.	Being 'alone' striving for belonging and adaption in a new reality.
Because you want someone to ... well, make plans with or something ... That will never work. Because this with having a conversation, that ... However, he likes hugs (smiles) ... but to talk about things is no longer there. No, it's gone. I rather talk with the dog, as I get better answers from her than from him.	Want someone to talk with and make plans with, but it is not possible anymore. Rather talk to the dog.	Alone and missing conversations and talk about plans with the partner.	Being alone in the relationship.	

having to create a structure around the care of their partner, a completely new situation for them. However, they believed that society in general and even the health and social care professionals they contacted lacked knowledge about dementia, which made their task even harder. They perceived that home care staff had generally insufficient knowledge about caring for persons with dementia specifically, as well as little knowledge about the individualised care for their partner with dementia. Frequent changes in home care staff led to a lack of continuity and knowledge about care for their partner. Repeatedly providing background information about their partner's care was demanding and frustrating. Spouse carers wondered if informing and supervising home care staff was as burdensome as providing care themselves. One spouse said:

But if someone additionally new will come, then I need to be with them to instruct all the time, and that is more stressful than if I should do it myself. I have done it in six, almost seven years now anyway ... (A1).

The spouses also described that they had to fight for the county council and the municipality to understand not only their situation as spouses, but also their partner's situation. They commonly received some information in the early stage of the disease, but did not receive further information as the disease progressed. Discussions during visits to their primary care provider were focused on the partner with dementia, and mainly concerned medical treatment. Thus, problems in their everyday life were not addressed. As both physical and verbal aggression could appear, this lack of knowledge and lack of interest from health and social care professionals was strongly questioned. The spouses did not feel

comfortable raising concerns about aggression at primary care visits as their partners were commonly present, but the care staff did not raise the issue. One spouse said:

There is very little focus on this disease. Both when it comes to hospital care and in the county council – all of it! I need to fight for it all the time (C3).

It was also mentioned that social workers generally had a poor understanding of a couple's situation, despite the fact they controlled decisions about the type and amount of care a person with dementia would receive, as well as the respite care they would be allowed. Spouses noted that this affected their quality of life as either not enough support was provided or it was not sufficiently individualised for their situation, or both. Decisions were made from an organisational point of view where every minute was counted. The social workers seemed to perceive that all persons with dementia, despite their respective conditions, would have the same needs. Spouses questioned the system and viewed themselves as being 'outsiders' or not fitting the 'model'. These concerns were made worse by people who believed that their partner had caused the disease by unhealthy living. One spouse said:

I can feel ashamed. It's almost as if he [the partner] has caused this by himself, and he hasn't done that! No one causes a dementia disease. I think this is a shame. We [society] need to talk more about this (E5)!

Another participant said:

What the heck, we live in Sweden, they should Yes, it is hard, because people don't understand what I am talking about. Many . . . I think . . . sometimes I think they believe that I am lying. Just because they know nothing about dementia and how it is. Yes, that is how it is (C3).

The spouses also raised a concern over their own lack of knowledge of dementia and caring for someone with dementia. They described not being prepared for the complex task of caring for a person who was severely ill. They were dissatisfied that although they received some information when their partner was diagnosed, they felt abandoned in dealing with their everyday life in later stages of the disease. One spouse said:

I mean, the community has follow-up procedures in other areas. When it comes to children that are being badly treated and so on. And for us . . . Now, Charles is not violent, but he gets angry. But there are those who are very violent to their partner. (I9).

Spouses also described a fear of doing things wrong when caring for their partner and making the situation worse. They wondered if they were causing problematic behaviours such as aggression or could even believe they were responsible for making the disease more severe. This lack of certainty raised feelings of guilt. Education about caring and dementia was seen as crucial if they were to improve their understanding of their partners' behaviour. One spouse said:

So, I long for education, education. Why is it this way with dementia? What can I expect from the future? I know that it won't be any better. That's the only thing I know! And the

engagement, and the understanding ... The more education I can get, the more I can understand about this. (B2).

The spouses longed for different strategies to handle problematic behaviours or approaches they could use with their partners when they were feeling sad. Spouses described how they used 'trial and error' to find ways that worked. Some ways were successful, others were not.

The spouses described that it was important to be active in order to get support. It was important to ask questions about the disease, what to expect in the future and how to find the strength to hold on and keep going. Their own lack of knowledge, and that of formal carers and other people, made spouses feel lonely and insecure in their role as carers. One spouse said:

And then I have been thinking by myself, ... that it is a great pressure on spouses in these kind of situations. First, I know nothing about this disease, I have been reading, and have had counselling and that. But anyway, I feel lost and alone! (H8).

Longing for a place for me and us

The spouses had a desire to meet others in the same situation as themselves. The municipality carer support group for informal carers for persons with dementia was generally appreciated as it made them feel that they were not alone and they could exchange thoughts with others in similar circumstances. However, the support group did not suit everybody and was described as helpful to a certain point. They also needed to talk about individual concerns. One spouse said:

Yes, the support group is one way to get in touch with people. But, the thing is that I have been there two times. First, I had individual counselling there and that was good. But in the group sessions ..., and that is like I don't know ... It didn't suit me ... (D4).

The spouses could get individual sessions to talk with a nurse counsellor who had received training relating to families of persons with dementia, but it was still difficult to raise sensitive matters such as sexual issues. They were also afraid of raising concerns that would cause them embarrassment if they were judged to have handled situations in an inappropriate way. The individual sessions were helpful and focused on solutions for the problems in daily care. However, spouses wanted to talk about themselves as human beings and their life journey, which was commonly neglected, as the nurse counsellor's training did not extend to such issues.

The support group and the individual counselling were nevertheless a way to expand the participants' knowledge about dementia, discuss living with a partner with dementia as well as caring for that person, and were described as easing feelings of guilt and helping to normalise their feelings. One spouse said:

I think my feelings of guilt, Marie at the support group has helped me with those. I don't feel so guilty at all now (G7).

Social media such as Facebook provided a way to interact with similar people when they could not go out to meet others. Of those who participated in social media groups, they felt supported in sharing and discussing their situation.

Also, having a rich social life with close friends and relatives was considered important for a sense of normality and belonging. To have someone to turn to who they believed honestly cared about them as a couple was considered important in itself, but also as a means to help them to vent their frustrations. However, it was considered even more valuable to talk to someone with experience of being a spouse of a person with dementia. One spouse said:

They (relatives) always ask when we meet how it is. Yes, we know your situation. That is enough too! I could talk to them if I needed, and also my old colleagues, we meet quite often, but I don't want to burden them. It is easier to talk to someone who has insight and knows how it is (F6).

When choosing to socialise with friends, they explained that they were selective based on the extent to which the friends' understood their situation. For example, their partner's behaviour was not viewed as potentially damaging if they chose sympathetic friends and family with whom to go out to a restaurant or when visiting someone's home. Spouses wanted to meet other couples in the same situation and to do fun things together. Going to a restaurant or going on trips with family or friends were enjoyable and without fear of being embarrassed when arranged by people that understood dementia. One spouse described the situation so:

What I feel is that I wished that there was somewhere, somewhere Roger and I could go. Where it would be a place for couples with dementia, and where both Roger and I could get something out of it. I mean, music, joy. Maybe dinner. Also socialising with others like us (D4).

Being a carer first and a person second

Spouses described the importance of being seen as a person and not just a carer, despite always placing their partner's needs above their own. They described always being on duty and unable to leave their partner alone, as they believed it was too stressful to worry about their partner when they were not around. However, being around and in control was also considered stressful for the couple as it led to irritation from their partners for being supervised all the time and not understanding why. One spouse said:

I feel like a shadow all the time. When things are good and when things are bad ... and that is to avoid things to happen (A1).

Commonly respite care and day care were available, and they were perceived as essential for both partners. To be able to rest when their partner with dementia was not at home was necessary in order to keep going, but such time was also important for completing tasks such as grocery shopping, or visiting the dentist or the hairdresser.

At the same time, respite or day care could be a source of stress because the staff at the care facilities might call to ask questions about the care of their partner with dementia or ask for solutions when the person was upset or anxious. Consequently, the spouses felt insecure about going somewhere where they could not be reached and worried that care staff would have to send their partner with dementia home. One spouse said:

And then he goes to respite care and then he nags about where I am and what I do, and when he is going home ... So they phoned me and told me that he was so anxious. I was in another town

to see my friend, and was also going to visit another friend the following week, but I cancelled ... So I don't know ... It seems that I need to be around ... (F6).

The spouses wished to have time for themselves and to do things to ease their stress. They felt strengthened by physical activities and outdoor activities, which were perceived as easing the stress of their situation. One spouse said:

That frustration ... ! It helps to run! And, like someone told me: boxing training. You can punch the bag and let out your anger by swearing. I am going to get gloves and a bag to punch and let my frustration out (G7).

Being the primary carer for their partner with dementia was described as being exhausting as they did not have any or only very little time for themselves. Some spouses wanted to give up while others described themselves as being depressed. Being unable to sleep properly and having no time to rest during the day led some spouses to wish their partner could be moved into a nursing home. Some even wished that they or their partner would die. One spouse said:

I hope that she could pass away, so I can think about myself and our sons and grandchildren (D4).

Another spouse said:

If I get a heart attack lying on the floor, than it is nothing, instead it is a blessing I almost said (B2).

The spouses described feelings of guilt when they longed for time for themselves and when they felt overwhelmed from the responsibility of caring for their partners. Anti-depressive medications were commonly used by participants and were described as helpful but also as flattening all their feelings. One spouse said:

Just because when I am with my grandchildren, oh well ... I want to be able to laugh and be happy and so on with them, but I am kind of deadened (G7).

Spouses also worried that stress would affect their own health because they felt it led to memory problems, irritation and fatigue. At times, being both mentally and physically exhausted made it impossible to care for themselves when they finally had the time. To get a minute or two by themselves, they described escapes such as going to the bathroom and locking the door to relax for a while or going out on short errands such as emptying the rubbish.

Being alone in a relationship

Spouses described missing their partners as if they had already lost them. They experienced grief and frustration from no longer being able to share their life with the person they love. This included no longer being able to share thoughts, talk about everyday things, make plans for the future and also the loss of their partner's support. One spouse said:

Yes, you are alone with the responsibility anyway. It's tough I think ... (B2).

Communication was described as being hard in general, but it was considered important to include their partners in communication and in plans as it seemed the right thing to do even though it commonly didn't work. One spouse said:

I try to include him in all that happens. I tell him what we shall do and so on. Like, 'now we shall do this', but I know that he won't remember. But for me it feels good to talk with him about things and how and when this is going to happen (C3).

Spouses noted the importance of avoiding asking their partner to respond when they were unable to answer, as otherwise the partner would often become upset or confused, resulting in conflict. When conversation was hard, they stopped talking to each other. One spouse said:

So if we sit and ... we always eat in front of the TV, as we don't talk anymore (G7).

Conversation was also described by the spouses as unrewarding because they did not receive adequate answers. As a result, they had less interest in making conversation, felt emotionless and lacked feelings of affection. It was described as coming to a point where it was too exhausting to be nice. One spouse said:

I am rude, and mean sometimes, and he [the partner] shouldn't have to put up with that. But then I think: 'he will forget anyway' (E5).

Some spouses thought that their partner was more like a child than a spouse, and thus they did not initiate conversation with her/him. One said:

He is like a four year old with all the help he needs. And I thought ... Well, then I will think of it as out of a four year olds perspective: this is how it is to be a four year old. It actually is a good comparison (F6).

The spouses missed the intimacy they enjoyed previously with their partners such as touching each other like a normal married couple. They longed to hug and kiss and to be intimate. Spouses were somewhat conflicted about a sexual relationship with their partner. They no longer had the desire of it because the partner was different from the person they had fallen in love with. Some participants also expressed a concern that they would be accused of sexual abuse as their partners sometimes did not recognize them and could be aggressive. One spouse said:

But to be really honest, I would never do that! I am afraid that she would accuse me of abuse or something if I would try something like that (A1).

Even though they might miss it, intimacy was no longer realistic given that their relationship with their partner was now like that of a parent with a child. As one spouse said:

It is almost a 'mother-child' relationship. He wants to know ... To be close all the time. It is not like, as you have as a married couple, instead it's almost ... I am more of a parent, and it scares me to death since I have been his wife for 50 years (F6).

Spouses did however describe their history of a long, loving relation as the ‘glue’ that kept them together. Their willingness to take care of their partners was based on their promise to each other ‘in sickness and in health, for better and for worse’.

Discussion

The results of this study revealed that spouse carers of persons with dementia experienced feeling alone in their relationship, struggling with being a carer for their partner while at the same time trying to preserve their individual identity and a life of their own. They wanted education about and support in caring for a partner with dementia, but felt that even the care professionals they encountered were too inexperienced to respond to anything except the clinical aspects of their partner’s condition. The spouses were unable to get the help they needed to adapt to the changing needs of their partners and to adequately respond to and support their partners. Research by Tyrrell et al. (2017) and Johannessen et al. (2017) produced similar findings to those obtained in our study. A ‘standardised care package’ was offered to carers, which was not individualised to spouses or the person with dementia’s needs. The focus of the package was mainly on practical assistance rather than support for the unique needs of the couple. Peterson, Hahn, Lee, Madison, and Atri (2016) also found that carers were open to alternative sources of information and support such as internet resources or printed materials, but they expected that care professionals would recommend and guide them to specific sources.

Our results also indicated that the information, education and support available to our participants was felt to be insufficient, and that the spouses described themselves as outsiders, with their needs and problems viewed as strange. As national guidelines for dementia care in Sweden (NBHW, 2017a), as well as previous national and international research (Bokberg et al., 2015; Hallberg et al., 2016) suggests, education for care professionals on the care of people with dementia is generally lacking, and education in this area needs to be prioritised if the quality of care and support provided is to improve.

Our results demonstrated that spouses’ lack of knowledge about dementia and caring for someone with dementia made them mistrust and question themselves when they made decisions about the disease or problematic behaviours, such as aggression in their partner. Previous research has shown that carer burden and distress are strongly associated with symptoms of agitation, depression, anxiety and irritability in persons with dementia (Sadak et al., 2014). Our participants also described feeling stressed, feeling lonely and experiencing depression, which echoes findings from earlier studies (Kaplan, 2001; Tuomola et al., 2016). Such feelings could be connected to a number of our participants’ experiences as carers, such as their descriptions of being a carer first and a person second, their sense of ‘always being on duty’ and feeling demoralised to the extent of wanting to die or wishing their partner might die. Our participants also described missing sharing their thoughts and discussing everyday issues with their partner, with the result that they felt alone in their relationship and missed their partner even though the partner was present (Eloniemi-Sulkava et al., 2002; Pozzebon et al., 2016). The participants in our study also longed to socialise with other couples in the same situation, but there were few opportunities. They avoided being in public in order to prevent the embarrassment associated with socially inappropriate behaviours by their partners. Several researchers (Dassel, Carr, & Vitaliano, 2017; Vitaliano, Murphy, Young, Echeverria, & Borson, 2011) found that spouse carers of persons with dementia have an accelerated rate of frailty and decline in cognitive health compared to

spouse carers of people without dementia, which might be connected to the higher levels of stress they experience.

As Bielsten and Hellström (2017a, 2017b) and Merrick et al. (2016) reported, when couples maintained their relationship or 'couplehood' and a sense of 'we/us' instead of 'I/me', their situation seemed less demanding (Daley, O'Connor, Shirk, & Beard, 2017). Our participants longed for the company of other people in the same situation as themselves, and carer support groups partly helped to assuage that longing. Some carers met their need for socialising with others in the same situation as themselves by using social media. In a study by Johannessen et al. (2017), carers of people with frontal lobe dementia wanted technological solutions to enable more interactions with health professionals, while O'Connell et al. (2014) found that rural spouse carers, or those having difficulty leaving their partners alone, appreciated video conferences with other spouses.

Despite the challenges of caring, our participants described feeling valuable and wanted to care for their partners. They spoke of having had a long life together and of their promise to care for their spouses. This finding is supported by most research in the area (e.g. Ludecke et al., 2018). Wadham et al. (2016) underlined the importance of a decades-long relationship as a basis for sustaining couplehood during challenging times.

Implications for policy and practice

Our study suggests the support care professionals currently provide to spouse carers of persons with dementia could be improved in a number of ways. They could provide guidance that helps spouse carers to better understand not only their current situation, but also to anticipate what might develop in the future. For example, guidance could be offered on the stresses associated with caring and strategies to manage it, information could be provided about how dementia progresses and how to deal with behavioural problems that may arise, and the importance of respite care, spending time with friends and self-care could be emphasized, along with the range of support and assistance that is available. Since social media was reported by our participants as a way to socialise with others in a similar situation to themselves, care professionals could advise spouse carers about this option.

Hernandez et al. (2017) reported the importance of practitioners reinforcing the couples' bond with each other to help them cope and reflect together. Spouses need help creating co-activities to promote engagement. It may also be beneficial to assist spouses to reframe their perceptions of their role in their marriage in a positive way, for example, in order to counteract the damaging perception, as found in our study, that they are like a parent caring for a child.

While it is easy, on the basis of our findings, to provide suggestions as to how care professionals might improve their communication with and the support they provide to spouse carers of persons with dementia, it will take organisational resources such as more and better training and education for care professionals in order to transform the current situation. Previous research (Johannessen et al., 2017; Peterson et al., 2016) and national dementia strategies for Sweden (NBHW, 2017b) suggest that in designing support interventions for family carers, it is essential that there is full engagement with the carer's perspective, and the importance of understanding the carer's perspective should be reinforced in future training and education programmes for care professionals.

Study strengths and weaknesses

Our study used a qualitative approach in which semi-structured interviews were carried out with participants. The semi-structured interviews provided opportunities for probing questions to deepen the spouses' descriptions of their experiences. The empirical examples presented in quotations and analysed in this study provide rich illustrations of spouses' experiences of their everyday lives with a partner with dementia.

To analyse data by qualitative content analysis (Graneheim & Lundman, 2004) was helpful in structuring the text and gave the opportunity to move back and forth between the whole and parts of the material at different levels of abstraction to increase trustworthiness. Trustworthiness was also increased by performing the analysis in cooperation with other co-authors, and while the first author (LMH) and the second author (CLW) compared and discussed the steps in the analysis, agreements and disagreements emerged. When disagreements emerged, the issue was discussed with the other authors in the study, who also audited the analysis process (KM and MSM) until agreement was reached among the group.

The use of convenience sampling to recruit participants from within the same urban area of Sweden may have resulted in a relatively homogenous group of spouse carers of people with dementia, which may limit the transferability of our findings. Future studies planned by the current research team will seek to increase the level of diversity in our samples so as to, e.g. compare couples in which the person with dementia is newly diagnosed with those at later stages of dementia. Information of and a variation in the length of the spousal relationship is also warranted, as the needs and preferences of spouse carers may differ when dementia is diagnosed in a relatively new relationship in comparison to a long-established relationship.

Conclusion

Being a spouse carer of a person with dementia is a multifaceted experience. The support offered by care professionals to such spouse carers should always be individualised and developed in partnership with spouses instead of being provided as part of a 'one-size fits all' approach for all family carers. Supporting the couple is of great importance, but it is also crucial to support the spouse carer as both a carer and as a person who is not defined by their caring role. Being a spouse of a person with dementia means losing shared experiences with a lifetime companion and an unwelcome transformation of one's primary relationship. A lack of preparation for this transformation and a lack of necessary skills for caring for a person with dementia creates additional stress for the spouse carer that could be reduced by improving care professionals' training and education so that their communication with and the support they provide to spouse carers of a person with dementia is enhanced.

Contributions

Study design: LMH; acquisition of data: MSM and LHM; analysis: LHM, CW, MSM and KM; and drafting of the article: LHM, CW, MSM, and KM.

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References

- Alzheimer's Disease International (2018). *World Alzheimer Report 2018. The state of the art of dementia research: New frontiers*. London, UK: Alzheimer's Disease International.
- Ask, H., Langballe, E. M., Holmen, J., Selbaek, G., Saltvedt, I., & Tambs, K. (2014). Mental health and wellbeing in spouses of persons with dementia: The Nord-Trøndelag Health Study. *BMC Public Health*, 14, 413. DOI: 10.1186/1471-2458-14-413.
- Bielsten, T., & Hellström, I. (2017a). An extended review of couple-centred interventions in dementia: Exploring the what and why – Part B. *Dementia (London)*, 18, 2450–2473. DOI: 10.1177/1471301217737653.
- Bielsten, T., & Hellström, I. (2017b). A review of couple-centred interventions in dementia: Exploring the what and why – Part A. *Dementia (London)*, 18, 2436–2449. DOI: 10.1177/1471301217737652.
- Bokberg, C., Ahlstrom, G., Leino-Kilpi, H., Soto-Martin, M. E., Cabrera, E., Verbeek, H., ... Karlsson, S. (2015). Care and service at home for persons with dementia in Europe. *Journal of Nursing Scholarship: An Official Publication of Sigma Theta Tau International Honor Society of Nursing/Sigma Theta Tau*, 47, 407–416. DOI: 10.1111/jnu.12158.
- Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. B. (2012). Behavioral and psychological symptoms of dementia. *Frontiers in Neurology*, 3, 73. DOI: 10.3389/fneur.2012.00073.
- Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review*, 62, 340–350. DOI: 10.1111/inr.12194.
- Daley, R. T., O'Connor, M. K., Shirk, S. D., & Beard, R. L. (2017). 'In this together' or 'Going it alone': Spousal dyad approaches to Alzheimer's. *Journal of Aging Studies*, 40, 57–63. DOI: 10.1016/j.jaging.2017.01.003.
- Dassel, K. B., Carr, D. C., & Vitaliano, P. (2017). Does caring for a spouse with dementia accelerate cognitive decline? Findings from the health and retirement study. *Gerontologist*, 57, 319–328. DOI: 10.1093/geront/gnv148.
- Eloniemi-Sulkava, U., Notkola, I. L., Hamalainen, K., Rahkonen, T., Viramo, P., Hentinen, M., ... Sulkava, R. (2002). Spouse caregivers' perceptions of influence of dementia on marriage. *International Psychogeriatrics/IPA*, 14, 47–58. DOI: 10.1017/S104161020200827X.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105–112. DOI: 10.1016/j.nedt.2003.10.001.
- Hallberg, I. R., Cabrera, E., Jolley, D., Raamat, K., Renom-Guiteras, A., Verbeek, H., ... Karlsson, S. (2016). Professional care providers in dementia care in eight European countries; their training and involvement in early dementia stage and in home care. *Dementia (London)*, 15, 931–957. DOI: 10.1177/1471301214548520.

- Han, A., & Radel, J. (2016). Spousal caregiver perspectives on a person-centered social program for partners with dementia. *American Journal of Alzheimers Disease and Other Dementias*, 31, 465–473. DOI: 10.1177/1533317515619036.
- Hellström, I., Nolan, M., & Lundh, U. (2005). We do things together': A case study of couplehood in dementia. *Dementia (London)*, 4, 7–22. DOI: 10.1177/1471301205049188.
- Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining 'couplehood': Spouses' strategies for living with dementia. *Dementia (London)*, 6, 383–409.
- Hernandez, E., Spencer, B., Ingersoll-Dayton, B., Faber, A., & Ewert, A. (2017). We are a team: Couple identity and memory loss. *Dementia (London)*, 18, 1166–1180. DOI: 10.1177/1471301217709604.
- Johannessen, A., Helvik, A. S., Engedal, K., & Thorsen, K. (2017). Experiences and needs of spouses of persons with young-onset frontotemporal lobe dementia during the progression of the disease. *Scandinavian Journal of Caring Sciences*. DOI: 10.1111/scs.12397.
- Kaplan, L. (2001). A couplehood typology for spouses of institutionalized persons with Alzheimer's disease: Perceptions of "We"-"I". *Family Relations*, 50, 87–98. DOI: 10.1111/j.1741-3729.2001.00087.x.
- La Fontaine, J., & Oyeboode, J. R. (2014). Family relationships and dementia: A synthesis of qualitative research including the person with dementia. *Ageing and Society*, 34, 1243–1272. DOI: 10.1017/S0144686X13000056.
- Liu, S., Li, C., Shi, Z., Wang, X., Zhou, Y., Liu, S., . . . Ji, Y. (2017). Caregiver burden and prevalence of depression, anxiety and sleep disturbances in Alzheimer's disease caregivers in China. *Journal of Clinical Nursing*, 26, 1291–1300. DOI: 10.1111/jocn.13601.
- Ludecke, D., Bien, B., McKee, K., Krevers, B., Mestheneos, E., Di Rosa, M., . . . Kofahl, C. (2018). For better or worse: Factors predicting outcomes of family care of older people over a one-year period. A six-country European study. *PLoS One*, 13, e0195294. DOI:10.1371/journal.pone.0195294.
- McCabe, M., You, E., & Tatangelo, G. (2016). Hearing their voice: A systematic review of dementia family caregivers' needs. *Gerontologist*, 56, e70–e88. DOI: 10.1093/geront/gnw078.
- Merrick, K., Camic, P. M., & O'Shaughnessy, M. (2016). Couples constructing their experiences of dementia: A relational perspective. *Dementia (London)*, 15, 34–50. DOI: 10.1177/1471301215513029.
- Myhre, J., Bjørnstad Tonga, J., Ulstein, I. D., Høy, S., & Kvaal, K. (2017). The coping experiences of spouses of persons with dementia. *Journal of Clinical Nursing*, 27, e495–e502. DOI: 10.1111/jocn.14047.
- National Board of Health and Welfare (NBHW) (2012). *Effects of support to informal carers who cares for older persons with dementia or frail older persons*. Stockholm, Sweden: National Board of Health and Welfare. In Swedish: Effekter av stöd till anhöriga som vårdar äldre med demenssjukdom eller sköra äldre.
- National Board of Health and Welfare (NBHW) (2016). *Statistics of residential care for persons with dementia*. Socialstyrelsen. Retrieved from www.socialstyrelsen.se. In Swedish: Statistik om särskilt boende för personer med demens.
- National Board of Health and Welfare (NBHW) (2017a). *Swedish national guidelines for dementia care. Support for management*. Stockholm, Sweden: National Board of Health and Welfare. In Swedish: Nationella riktlinjer för vård och omsorg för personer med demenssjukdom- Stöd för styrning och ledning.
- National Board of Health and Welfare (NBHW) (2017b). *A national strategy for dementia. Basis and suggestions for prioritized areas to year 2022*. Stockholm, Sweden: National Board of Health and Welfare. In Swedish: En nationell strategi för demenssjukdom. Underlag och förslag till plan för prioriterade insatser till år 2022.
- O'Connell, M. E., Crossley, M., Cammer, A., Morgan, D., Allingham, W., Cheavins, B., . . . Morgan, E. (2014). Development and evaluation of a telehealth videoconferenced support group for rural

- spouses of individuals diagnosed with atypical early-onset dementias. *Dementia (London)*, 13, 382–395. DOI: 10.1177/1471301212474143.
- Pertl, M. M., Lawlor, B. A., Robertson, I. H., Walsh, C., & Brennan, S. (2015). Risk of cognitive and functional impairment in spouses of people with dementia: Evidence from the health and retirement study. *Journal of Geriatric Psychiatry and Neurology*, 28, 260–271. DOI: 10.1177/0891988715588834.
- Peterson, K., Hahn, H., Lee, A. J., Madison, C. A., & Atri, A. (2016). In the information age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. *BMC Geriatrics*, 16, 164. DOI: 10.1186/s12877-016-0338-7.
- Phillipson, L., Jones, S. C., & Magee, C. (2014). A review of the factors associated with the non-use of respite services by carers of people with dementia: Implications for policy and practice. *Health & Social Care in the Community*, 22, 1–12. DOI: 10.1111/hsc.12036.
- Polit, D., & Beck, C. (2016). *Nursing research; generating and assessing evidence for nursing practice* (10th ed.). Philadelphia, PA: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Pozzebon, M., Douglas, J., & Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: A synthesis of the qualitative research. *International Psychogeriatrics/IPA*, 28, 537–556. DOI: 10.1017/S1041610215002239.
- Riley, G. A., Evans, L., & Oyeboode, J. R. (2018). Relationship continuity and emotional well-being in spouses of people with dementia. *Aging & Mental Health*, 22, 299–305. DOI: 10.1080/13607863.2016.1248896.
- Sadak, T. I., Katon, J., Beck, C., Cochrane, B. B., & Borson, S. (2014). Key Neuropsychiatric symptoms in common dementias prevalence and implications for caregivers, clinicians, and health systems. *Research Gerontology Nursing*, 7, 44–52.
- Shim, B., Barroso, J., & Davis, L. L. (2012). A comparative qualitative analysis of stories of spousal caregivers of people with dementia: Negative, ambivalent, and positive experiences. *International Journal of Nursing Studies*, 49, 220–229. DOI: 10.1016/j.ijnurstu.2011.09.003.
- Swedish Agency for Health Technology Assessment and Assessment of Social Services (2015). *Education for relatives of people living at home with dementia. Report number 2015_12*. In Swedish: Utbildning för anhöriga till hemmaboende personer med demenssjukdom. Retrieved from https://www.sbu.se/2015_12
- Swedish Family Care Competence Centre (2014). *Education for informal carers to cohabiting persons with dementia*. Stockholm, Sweden: Swedish Family Care Competence Centre. In Swedish: Utbildning för anhöriga till hemmaboende personer med demenssjukdom.
- Sweden Ministry of Health and Social Affairs (2001). *The Social Service Act*. Stockholm, Sweden: Ministry of Health and Social Affairs.
- Thompson, G. N., & Roger, K. (2014). Understanding the needs of family caregivers of older adults dying with dementia. *Palliative & Supportive Care*, 12, 223–231. DOI: 10.1017/S1478951513000461.
- Tuomola, J., Soon, J., Fisher, P., & Yap, P. (2016). Lived experience of caregivers of persons with dementia and the impact on their sense of self: A qualitative study in Singapore. *Journal of Cross-Cultural Gerontology*, 31, 157–172. DOI: 10.1007/s10823-016-9287-z.
- Tyrrell, M., Hilleras, P., Skovdahl, K., Fossum, B., & Religa, D. (2017). Voices of spouses living with partners with neuropsychiatric symptoms related to dementia. *Dementia (London)*, 18, 903–919. DOI: 10.1177/1471301217693867.
- Wadham, O., Simpson, J., Rust, J., & Murray, C. (2016). Couples' shared experiences of dementia: A meta-synthesis of the impact upon relationships and couplehood. *Aging & Mental Health*, 20, 463–473. DOI: 10.1080/13607863.2015.1023769.
- Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M. J., & Antoine, P. (2017). Do spouse caregivers of young and older persons with dementia have different needs? A comparative study. *Psychogeriatrics*, 17, 282–291. DOI: 10.1111/psyg.12234.
- Williams, C. (2011). Marriage and mental health: When a spouse has Alzheimer's disease. *Archives of Psychiatric Nursing*, 25, 220–222. DOI: 10.1016/j.apnu.2011.02.003.

- Williams, C. (2015). Maintaining caring relationships in spouses affected by Alzheimer's disease. *International Journal of Human Caring*, 19, 12–17.
- Williams, C. L., Newman, D., & Hammar, M. L. (2017). Preliminary study of a communication intervention for family caregivers and spouses with dementia. *International Journal for Geriatric Psychiatry*, 33, E343–E349. DOI: 10.1002/gps.4816.
- Vitaliano, P. P., Murphy, M., Young, H. M., Echeverria, D., & Borson, S. (2011). Does caring for a spouse with dementia promote cognitive decline? A hypothesis and proposed mechanisms. *Journal of the American Geriatrics Society*, 59, 900–908. DOI: 10.1111/j.1532-5415.2011.03368.x.

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