

# Caring for One's Wife With Dementia— at Home: Older Husbands' Experiences With Managing Challenges of Everyday Life

SAGE Open  
January-March 2019: 1–13  
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DOI: 10.1177/2158244019834453  
journals.sagepub.com/home/sgo  


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## Abstract

More than 80,000 Norwegians live with dementia. Most caregivers for people with dementia are spouses, and women outnumber men. Due to an aging population, and women's higher risk of dementia as well as men's increased life expectancy, the number of male caregivers will rise. There are some differences in the caregiving roles of men and women. Research suggest that males report lower burden and depression than female caregivers, but some men struggle to adjust to the caregiver role, and men are less likely to access health care services. The aim of this study is to explore the experiences of husbands engaged in caregiving for their home-dwelling spouse with dementia. This knowledge will add to the growing body of research about men in the context of dementia care and may raise gender awareness. The method is qualitative interviews with hermeneutical interpretation. The participants are five husbands recruited from two Hospital Memory Clinics in Norway. The results portray how the husbands managed their everyday challenges, and how they adapted to changes, experiences of loss and bereavement, and how they redefined personal freedom and expanded their responsibilities. Acknowledging the rewards of caregiving, the husbands found their life meaningful and they were thriving in their caregiving role. Health care personnel should recognize and respect the challenging life situation caregiving husbands may experience, calling for personnel to learn from, care for, and collaborate with them, enabling the couple to live a meaningful life together at home as long as possible.

## Keywords

dementia, male caregivers, nursing, home health care, hermeneutics

## Introduction

An estimated 50 million people worldwide are living with dementia. This number is likely to reach 82 million within 2030, and 152 million by 2050 (World Health Organization, 2017). As of 2015, there are approximately 80,000 Norwegians with dementia, and annual increases are probable due to prolonged life expectancy (Godager & Thorjussen, 2016; Strand & Skirbekk, 2014). Thus, by 2030 the number of persons with dementia is estimated to be 112,000, reaching 200,000 by 2060, an equivalent to 3% of Norway's total population (Vossius et al., 2015). The World Health Organization (2017) warns of dementia's overwhelming nature upon all those affected, including family caregivers, as they face increased stress related to physical, emotional, and economic pressures. Many people with dementia and their family caregivers will need support from the welfare systems provided through municipal services (Godager & Thorjussen, 2016). Consequently, the municipalities will

face major increases in nursing and related care expenses in the near future.

In Norway, people with dementia often receive informal care from relatives or friends (Vossius et al., 2015). The majority of persons with dementia live in their own homes in the municipality, and most people wish to remain living at home for as long as possible (World Health Organization, 2012). Informal caregivers play a vital role in the early stages of dementia, particularly older spouses who often become primary caregivers of partners with dementia over long periods of time (Greenwood & Smith, 2015; Hellström, Håkanson,

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Eriksson, & Sandberg, 2017). The provisional shift in long-term care, from institutional to community based, along with positive societal sediments and foundational adjustments encourage people with dementia to live at home as long as possible. This will most likely lead to higher expectations and increased burden among primary caregivers (Atta-Konadu, Keller, & Daly, 2011; Peacock et al., 2009; Stewart et al., 2014).

Historically, women have provided the majority of non-paid care for older people. However, the gender balance is shifting toward increased numbers of older men engaged in informal care (Baker, Robertson, & Connelly, 2010; Milligan & Morbey, 2016). The aging population, coupled with women's higher risk of dementia as well as men's increased life expectancy, all suggest that countries like Norway will experience an increased number of husbands caring for their wives with dementia at home (Hellström et al., 2017; Pöysti et al., 2012; Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014; Strand & Skirbekk, 2014).

Several studies point to that research concerning older male caregivers in dementia care is sparse (Baker et al., 2010; Hellström et al., 2017; Mc Donnell & Ryan, 2013; Milligan & Morbey, 2016). The aim of this study is to explore everyday experiences and opinions of husbands living at home with a spouse with dementia. This knowledge will add to the small but growing body of research-based understanding concerning men in the context of dementia care, and may as well raise gender awareness among health care personnel (Bartlett, Gjernes, Lotherington, & Obstfelder, 2018).

## Literature Review

### *On Spousal Caregiving*

The nature of the disease indicates that people with dementia and their spouses will need municipal support to continue living together at home. Studies on relatives of persons with dementia put forward that caregiving can be challenging and burdensome (Brodaty, Woodward, Boundy, Ames, & Balshaw, 2014; Samsi & Manthorpe, 2014), and family caregivers report high levels of emotional exhaustion, as well as reduced personal accomplishment (Truzzi et al., 2012). Brodaty et al. (2014) suggest that older caregivers often are unaware of available services and may therefore miss the opportunity to ask for municipal health care support.

Furthermore, spouses may experience more stress because their relationship with the person with dementia involves more than only providing care, and older spouses often have their own health problems (Myhre, Bjørnstad Tonga, Ulstein, Høye, & Kvaal, 2018). Spousal caregivers may find it challenging to adapt to the demands of caring, as well as experience deprivation within their marital relationship (O'Shaughnessy, Lee, & Lintern, 2010). Couples may use strategies like normalization, externalizing, sharing, and reframing the experience in light of the past, all

to maintain their relationship (Molyneaux, Butchard, Simpson, & Murray, 2011). Thus, it is important for couples to maintain a good marital life, and experience close relationships, to sustain the notion of being a couple (Hellström, Nolan, & Lundh, 2007).

However, Greenwood and Smith (2016) warn us from assuming that all older caregivers want support or that caring experiences always are negative; caregiving can also be an opportunity to give back and come closer to the person affected by this disease (Peacock et al., 2009). Positive emotions in spousal caring, rewards and benefits, are also found in the research literature. Peacock et al. (2009), for example, suggest that a caring experience can result in the discovery of personal strengths. Caregiving spouses may be in a process of reevaluation and repositioning in their relationship to their partner, as well as within their relationship as a couple (O'Shaughnessy et al., 2010). Positive emotions in spousal caregiving may embrace the ability to cope with stress and reduce distress, feeling well-being and finding a sense of purpose in daily life (Autio & Rissanen, 2018). Finally, according to Davies (2011), it is important to recognize the impact of couples' commitment to each other—when providing support services to individuals with dementia and their families.

### *On Male Caregivers*

Gender influences caregiving husbands and wives as each cross gender boundaries. When supporting the gendered identity of their spouse, it is not simply a task performance, but involves recognition of the other and the importance of masculinity or femininity (Calasanti & Bowen, 2006). Worldwide, the majority of caregivers for people with dementia are spouses, and women outnumber men (World Health Organization, 2012). Despite many similarities in the caregiving roles of men and women, research also provide evidence of gender differences. One example is higher levels of burden and severity of distress among women compared with men (Stewart et al., 2014). Although several studies find that male caregivers report lower burden and depression than female caregivers, research findings also suggest that some men find it difficult to adjust to the caregiver role, and that men are less likely to seek help or access health care services than women are (Akpınar, Küçükgüçlü, & Yener, 2011; Baker & Robertson, 2008; Brown, Chen, Mitchell, & Province, 2007; Cahill, 2000; Greenwood & Smith, 2015; Papastavrou, Tsangari, Kalokerinou, Papacostas, & Sourtzi, 2009; Pöysti et al., 2012).

Understanding the role of the male caregiver challenges the interpretations of men as either ineffective or capable caregivers, or stereotypes like the societal expectancy of caregiving as a female activity and responsibility (Kirsi, Hervonen, & Jylhä, 2004; Siriopoulos, Brown, & Wright, 1999). Although male spousal caregivers report low caregiver burden, they often experience high levels of physical stress (Robinson et al., 2014). Male caregivers may experience

suffering in relation to caregiving, yet they can also find room for masculinity and personal control in their caregiver role. Their suffering can be mediated through preserving personal identity and marital status, as well as finding purpose in their daily experiences as a loving husband (Black, Schwartz, Caruso, & Hannum, 2009). When men request municipal help, their aim is most often to enable them to secure quality care for their wives. However, their own needs as male caregivers are not always understood, a fact that can lead to an experience referred to as “double suffering” (Knutson & Råholm, 2009). Research also documents how husbands, in general, are capable caregivers who more likely than wives tend to adopt task-oriented and problem-solving approaches, finding meaning and satisfaction in effective caregiving for a spouse with dementia (Hong & Coogle, 2014; Pretorius, Walker, & Heyns, 2009).

Research focusing on men caring for a family member with dementia is growing, yet there is also a call for more knowledge on how men manage the challenges of caregiving (Baker & Robertson, 2008; Robinson et al., 2014). Cahill (2000) found that men performing dementia care not only faced substantial physical labor but also gained personal and social rewards from their new life experience—seeming to find enjoyment in their new caregiver role. Hellström et al. (2017) suggest that caregiving may influence the male identity, thus men may find themselves moving from “being a man” to “being a caregiving man.” Furthermore, as caregivers, men often take over their wife’s previous role and responsibilities which may be a major concern for those men inexperienced as “food providers” (Atta-Konadu et al., 2011; Fjellström et al., 2010). According to Samsi and Manthorpe (2014), support should strengthen both the caregiver and the person with dementia, and help them to manage their challenges in everyday life.

## Method

### Aim

The aim of this study is to explore the experiences of husbands living at home with their spouse with dementia. This knowledge will add to the small but growing body of research concerning men in the context of dementia care and may help raise gender awareness among health care personnel. The following research question was explored:

**Research Question 1:** What are the older husbands’ experiences in caring for their wife living with dementia while living at home, and how do they perceive illness-related challenges of everyday life?

### Design

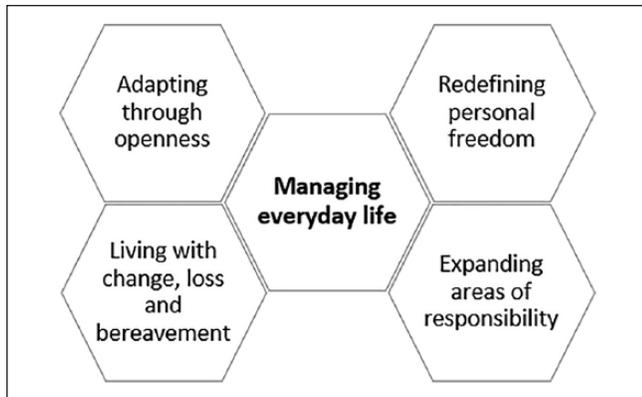
An exploratory design employing qualitative interviews (Kvale & Brinkmann, 2015) to establish a genuine conversation

(Fleming, Gaidys, & Robb, 2003) with each participant was chosen as a tool for data collection. Qualitative exploratory research is advantageous when investigating various aspects of a distinct phenomenon, its manifestation, and underlying processes (Polit & Beck, 2010) and is advisable when knowledge of the phenomenon is limited (Brink & Wood, 1998). The study was founded upon Gadamer’s philosophical hermeneutics, a methodology within the interpretivist paradigm emphasizing how new and expanded understanding can be gained (Fleming et al., 2003; Gadamer, 2004). In the present study, the text consisted of transcribed interviews portraying experiences and perceptions of husbands caring for their home-dwelling wife with dementia. The text was read and explored numerous times while simultaneously a reflexive dialogue with the text, its various parts, and the text as a whole was performed—as well as reflecting on our own professional preunderstanding (Fleming et al., 2003; Gadamer, 2004). Throughout this interpretation process, researchers emphasized continuous questioning of one’s own preunderstanding with the emerging understanding of the text—before formulating final interpretations and study results.

Researchers’ preunderstanding (Gadamer, 2004) should also be presented to the study audience, making the interpretive context available, increasing study transparency (Hiles & Čermák, 2007) and trustworthiness (Guba & Lincoln, 1994; Lincoln & Guba, 1985; Polit & Beck, 2010). In this study, both researchers had professional experience from nursing care for persons living with dementia as well as their family caregivers. Both have conducted qualitative research related to older peoples’ dignity and meaning in life. We also share a common understanding of ontological and ethical foundations of caring as described by Eriksson’s Theory of Caritative Caring (Eriksson, 2018; Lindström, Nyström, & Zetterlund, 2014). This theoretical framework underlines the individual worth of every person, acceptance of our human obligation to serve others with love, and the postulate that we exist for the sake of one another. According to Eriksson (2018), the ultimate goal of caring is to safeguard dignity for both caregiver and care recipient. Our preunderstanding acknowledged the many challenges a caring spouse could encounter in living with and caring for a wife or husband with dementia. However, we also understand that caring for a spouse may be rewarding.

### Data Collection

Participants were recruited from two Hospital Memory Clinics in Norway. Accountable for participant recruitment were clinical nurses and doctors responsible for diagnostic examination and follow-up treatment of the participants’ wives who were diagnosed with dementia. We chose a strategic sampling strategy based on the following inclusion criteria: (a) being the husband and primary caregiver for a wife with mild to moderate dementia who has lived with the



**Figure 1.** Aspects of managing everyday life among older husbands caring at home for their wife living with dementia.

diagnosis for maximum 3 years, (b) living at home together with his wife, (c) willing to be interviewed on their new life situation and challenges of everyday life, and (d) speaking a Scandinavian language or English. Five husbands participated, ages ranging from 72 to 82 years. One interview was conducted with each participant; average time was 75 min (range = 56-119).

Conducting qualitative interviews, we emphasized establishing genuine dialogue with each participant (Fleming et al., 2003; Kvale & Brinkmann, 2015). The interviews were performed by the second author (O.T.), all carried out in each participants' home, utilizing a temporary and modifiable interview-guide as a tool. The following are examples of questions guiding our conversations: Could you please tell me about yourself and your background? How do you experience everyday life now after the onset of your wife's dementia illness? How does dementia affect your everyday life? How do you try to manage the new challenges of everyday life? Follow-up questions added richness and depth to the data collection. The interviews were recorded and transcribed verbatim.

### Data Analysis

The four-step model of Fleming et al. (2003) was utilized as a methodological framework for hermeneutical analysis and interpretation of the data. The analysis was initiated by individually reading, reflecting upon each interview text after all interviews were undertaken. Each text was read several times. Keywords and phrases were noted during each reading. Each new interview text made those already explored more understandable, while simultaneously adding new meaning of their own. Our individual preliminary interpretations were then discussed, seeking common understanding of developing themes and subthemes, contradictions, and inconsistencies in the data, increasing our understanding of the parts and the data as a whole. During this final stage, we identified and formulated a main theme and four subthemes.

### Ethical Considerations

The study was conducted in accordance with the Declaration of Helsinki (World Medical Association, 2013), approved by the Regional Committee for Medical and Health Research Ethics for Southeast Norway. Every participant received verbal and written information concerning all aspects of the study, including their right to withdraw as desired without any consequences concerning further care or treatment for their spouse. Each received a copy of the interview-guide to increase participant understanding of the interview setting and strengthen their position to either accept or decline. The participants could choose whether the interview would be conducted at the research office or in their private homes. As researchers, we assumed responsibility for ensuring participant anonymity and confidentiality (National Research Ethics Committee for Medicine and Health Sciences, 2010), as well as communicating study results in an appropriate language style to preserve the dignity of each participant (Eriksson, 2010).

### Results

The overarching theme was *managing everyday life*. Our interpretation of the husbands' experiences and opinions were that they found their personal ways of managing the illness-related challenges due to their wife's dementia. These men presented themselves as resourceful, and gave the impression that the new caregiving role was a challenge they wanted to manage successfully. Thus, managing their everyday life was connected to pride, joy, and fulfillment. The husbands spoke less about negative feelings, although there were comments about how conflicts caused by memory-loss or aggressive behavior, and the need to always be present, could stretch their patience. They were primarily seeking to be able to live as similar as possible to what their lives were before the disease and compensated for those household chores and activities their wives no longer mastered. For these men, not to manage their new life situation was seemingly no option. We find it important to understand that the participants had good marital relationships prior to the dementia disease, and their love for each other was reflected in the way the husbands adapted to new responsibilities and their reluctance toward receiving help from others.

Furthermore, we identified four subthemes (Figure 1): adapting through openness; living with change, loss, and bereavement; redefining personal freedom; and expanding areas of responsibility. Here we portray more specifically the different managing strategies utilized by the participants, together with experiences from their everyday lives, their hopes, opinions, and future expectations.

### Adapting Through Openness

The husbands' everyday life changed due to the progression of their wife's dementia symptoms, creating a need for

adapting to their new and challenging life situation. In the early stage of this process, choosing openness made it possible for them to share their new challenges and receive support from family and friends, which in turn fostered the husbands' adaptation process. The husbands also learned to appreciate their wives' openness about their illness. It was important to be met with genuine concern, and see others dare to take part of their challenging life situation. Being open about the disease made the husbands' internal struggles more bearable by increasing their external resources:

I must accept her situation . . . with regards to those around us [family, neighbors, friends etc.]. Yes, that . . . she is so open about everything, so everyone . . . they all know she has Alzheimer. She has told many, and still does. She says: "I am forgetful and I have Alzheimer." She is not to blame for any of this. (Edward, 80 years)

They found dementia hard to withhold from others and a crucial reason for choosing this approach. Removing any basis for embarrassment or other need for hiding the truth was often used as a strategy, as husbands perceived several early stage symptoms were already visible to others. In several cases, the men experienced that family and friends were not surprised when informed about the diagnosis:

In the beginning, I was a little embarrassed about the questions she [the wife] would ask. . . . After a while, I knew that our closest family and friends were aware of the situation, and it was no longer a problem, that she would ask these kind of questions. Because I know . . . they know us and appreciate her, and they know our situation. For those who are unfamiliar to her . . . it does not mean a thing what they might think. (Frank, 72 years)

Understanding that people close to them often identified dementia-related manifestations of change long before doctors confirmed her diagnosis seemed to help husbands choose greater openness. The results also indicate how perceptions and comments of others, beyond their close family and friends, were of little consequence.

### *Living With Change, Loss, and Bereavement*

Part of the husbands' adjustment process, accepting the new context of life, did not come easy and developed gradually over time. Thus, the findings suggest they reorganized their lives early in the process even before a sense of acceptance was reached. Moreover, findings suggest that gradual acceptance was nurtured through a process of step-by-step adjustment:

I realize that life has changed . . . and I must accept that . . . I do not regret our situation. I have just "put life on hold" in fact, and I am very much aware that our life situation is different now, and I must try to adjust . . . that is how I feel. (Arnold, 76 years)

Witnessing the ongoing decline of the wife's condition was also a demanding experience for these men. Typically, the ability to remain orientated for time and space gradually worsen among people living with dementia. Decreased capacity for self-care may potentially cause compromising or dangerous situations. The husbands expressed several examples of disorientation experienced by their wives as well as other illness-related challenges, all leading to changes in the lives of both parties:

It was this summer . . . and she went for a walk . . . then she got lost. Yes, she did. And later she told me, not long ago, that she walked down the street from the shop, and then, somehow she walked in the opposite direction than first headed. . . . Then she said: No . . . she stopped and pulled herself together and was able to see where she was headed. So this . . . it develops over time. (Edward, 80 years)

Learning to accept the wife's dementia-related changes as an unavoidable part of their current lives—trying to learn how to live with loss and bereavement—was identified as an important pathway toward moving forward in life. The relationship between husband and wife was altering, especially regarding communication and cooperation. For most wives, a dementia diagnosis was hard to accept, even though the symptoms developed gradually. It was for instance hard to witness how the wife struggled with finding words, especially when she became aware of her own mistakes. Not being able to recognize and define their new, common challenges in everyday life was a threat to their companionship and relationship as a couple:

She is reluctant, and I understand that. I do not use the word dementia too often; but refer instead to a memory-problem. . . . It is an emerging problem . . . I see the problem already, it can get worse . . . and then it can be very hard to establish good cooperation between us. (Thomas, 82 years)

The husbands sometimes felt sad in reminiscing their life-story and mutual interests as a couple and the activities they once shared together. Sharing common experiences gave strength to their sense of togetherness. Experiencing this important relational dimension gradually fading led to a sense of loneliness within the context of their marital companionship. In turn, this could affect also the husbands' choice of actions, here portrayed by one of the participants explaining how, in their present life situation, he chose not to attend the theater:

I would sit there alone and not have anyone to share the experience with. The theater and movies—are all about sharing it with someone . . . that you can talk about it afterwards, for example. We did that in the old days . . . always . . . we sat by the table after coming home from a play, and we could discuss what we saw . . . and the plot . . . for a long time. If I would go alone, I would probably think; now I'm watching something . . . which

she no longer has the opportunity to attend nor enjoy. Somehow, it lacks a sense of dignity, if I go alone. It is probably foolish, and perhaps I must at some point or another, tell myself to take care of myself. (Frank, 72 years)

However, some participants seemed to move forward, trying to accept the loss of conversational sharing and instead search for meaning in sharing the moment here-and-now, for instance, at the concert hall:

I cannot talk with her about what happened yesterday . . . that is difficult. She likes music, and we attend concerts. Her experience with music is limited to the moment. Talking about matters other than here and now requires a line of thoughts, and that she has lost. (Simon, 82 years)

The main obstacle for explorative conversation and discussion in everyday life seemed to be the wife's gradual loss of short-term memory—an aspect their husbands missed. However, understanding how memories of the past were more available to their wives created important opportunities, constituting a base for further sharing through conversation together:

I cannot talk to her about much, because I know she doesn't remember. You can say that my life . . . has been reduced in a way . . . I do not have a conversation partner. We can talk about matters from the past, which she still remembers . . . she is an expert on remembering birthdays, which is quite amazing. So, she . . . does remember somethings. (Arnold, 76 years)

Their altered relationship led to challenges, along with brighter moments as well. Becoming more considerate of their spouse's everyday needs seemed one of the latter. For example, situated in their new caregiver role, one of the participants portrayed how he found his wife's need of help to be charming in a special way—as if her innocence and vulnerability called upon him to take more responsibility for her in a new and caring way. This growing understanding seemed to contribute toward developing a closer relationship between them, giving rise to warmth and loving feelings, even though such relational closeness became challenging during situations when communication problems arose:

We have had a good marriage . . . but perhaps the feelings of closeness are growing even stronger. Like the awakening of an . . . emotional engagement . . . where we experience good feelings. It's something . . . worthwhile . . . of this I am sure. However, I feel it depends upon . . . practical cooperation in daily life. Confrontations can decrease the good feelings . . . If she feels I am too demanding of her . . . It awakens aggression, you see, or perhaps not aggression but anger . . . that hinders, or diminishes one's ability to express good feelings. (Thomas, 82 years)

The husbands shared several statements highlighting the good life they lived together as a couple. Retaining a positive

fundamental attitude to life seemed to prepare them and help them cope with dementia-related challenges of everyday life:

We are doing fine, because we are two. That she forgets does not matter. (Simon, 82 years).

Accentuating the positives and not allowing the negatives of dementia guide their perceptions seemed most valuable in helping these husbands to better master their current life situation and caregiving role.

### *Redefining Personal Freedom*

Another common and gradually more difficult challenge was being away from their spouse for longer periods. Although being away for an hour or so might be unproblematic, being away an entire day or night was perceived as impossible. These concerns were based on how husbands normally helped their wives manage each day, as well as the more challenging experience of finding their caring roles so immersive and time consuming, leaving them with very little personal time or space. The husbands felt an obligation to stay at home to help ease their wife's anxiousness, distress, or somber mood. They thought it was better not to participate in activities alone, thus preventing distressful situations in their wives everyday life:

I went away the whole day attending a course for relatives of people with dementia. Then it became quite bad . . . Then she becomes . . . she becomes very depressed. Then she does not want to live anymore . . . That is a bit challenging. (Simon, 82 years)

Experiencing and understanding the new illness-related vulnerability of the wife seemed to create a shift in the husbands' perspectives. New insights helped them realize the necessity of placing their spouse's needs before their own, although sometimes leaving them with the frustrating feeling of losing their own autonomy:

I do not make decisions based on my needs anymore . . . meaning that she needs me very close, you see. For the time being, I must say the progression is slow, and I do not want to complain. (Arnold, 76 years)

During summertime, the husbands seemed to feel their wives' continuous need for their presence less challenging, as the spouse often was busy with outdoor activities of her own. Thus, in these circumstances, the caregiving husbands felt freer to keep up with their preferred activities, such as gardening or automobile maintenance. Another way of increasing their own personal time was to encourage their wife to attend activities on her own when possible:

She has become a bit reluctant to contact her friends. So, I try to give her a gentle nudge. Since staying with me is not very

inspiring. She needs to meet with others, be stimulated . . . She has always enjoyed Wednesday-meetings at church, she has a friend there . . . Nowadays she thinks it's boring, she kind of dreads going . . . I say she can drink coffee and chat with friends . . . she says she only sits passively and listens . . . and that is not very stimulating for her. But, I still suggest that she goes anyway. (Edward, 80 years)

There were many choices to be made in everyday life. Doing what provided the best outcome for both parties seemed to guide the husbands' decisions. Consequently, the men often renounced activities that they would most like to attend. However, they would prioritize vital interests—sheltering and caring for their own personal needs:

It is not difficult at all to choose and forsake. I register there are certain things one may do without. On the other hand . . . there are certain matters which are very important for my intellect . . . for example, the hour-long TV program called "Dagsnytt 18" [the evening news]. That hour is mine. Whatever programs she likes to watch otherwise is fine, but between six and seven p.m. the TV is mine. It has something to do with me staying connected with society. (Frank, 72 years)

Taking care of themselves seemed important for the husbands, not as a selfish act but rather a strategy toward promoting self-care, helping them prepare for their demanding caregiver role. Maintaining friendships and upholding treasured activities was important for them. The husbands used various approaches to pursue these vital needs—including bringing their wife along when attending activities:

I am a member of an orchestra downtown . . . and I always bring her with me when we have concerts. But, when we rehearse . . . she cannot come along. But, that does not last very long. I also play the accordion . . . and she always attends that group with me. That is positive . . . this is something she thinks is very nice. (Simon, 82 years)

Redefining personal freedom while caring for their increasingly vulnerable wife also seemed to form a foundation for uplifting experiences and personal growth. Increased awareness of their loved one's needs seemed strengthened by a growing focus on what matters to their spouse—stimulating their own inherent love and capacity for caring:

I just discovered that . . . she . . . needs love . . . more than perhaps . . . yes more than ever before. That is the best I can do for her . . . I feel sorry for her . . . I will try to keep our family and home together as it is. That is my driving force . . . you might say. (Arnold, 76 years)

The findings suggest that understanding and accepting the increasing vulnerability of the wife, letting her needs come first, were crucial aspects within their relationship. These strategies helped the husbands redefine and find meaning in their altered personal freedom.

### *Expanding Areas of Responsibility*

The dementia illness had a vital impact on the participants' life, thus increasing the husbands' everyday responsibilities. The husbands' stories seemed to reflect the views of traditional gender role patterns: perceiving household chores primarily a responsibility for the female. Especially the kitchen was seen as the woman's domain and therefore a place where dementia-related symptoms, like problems with memory and upholding structure were identified—calling for the husband to take on new responsibilities compensating for her evolving vulnerability:

Half a year ago, we were arranging a party and that became troublesome. Then I understood that she was no longer able to cook. She no longer saw the big picture, making cooking a chaotic task. I helped her and bought the ingredients. When I put them on the table . . . to imagine what to do in her head was too difficult and she became distressed. Then, when she saw the ingredients . . . she was able to start cooking. (Thomas, 82 years)

Their expanded responsibilities of keeping their home in a state of normality also involved taking on a new role in their spousal relationship—supporting and facilitating their wives in household chores, previously the wives' domain of expertise:

It was a huge transition for me . . . you know . . . life has turned upside down in a way, when a spouse becomes ill. So . . . I have . . . I have not complained yet, I must say she does what she can, and we manage to keep our home clean and . . . we cooperate well. She does the dusting . . . and I do the floors and bathroom and so on . . . We have not considered hiring a house cleaner as of yet. (Arnold, 76 years)

These husbands expressed a desire to live at home together with their spouse for as long as possible—living in the moment, trying not to think too much about the future. They agreed upon receiving more help in the future, as this would enable them to live at home together even longer. The husbands in this study managed their everyday lives without public services. Some had received requests from local health care specialists to consider help from the local public services, asking whether they needed external caregiving support. However, the husbands were determined to manage their everyday lives, and by doing so, communicated an unspoken barrier for accepting or asking for professional assistance, for the time being at least. They also shared their perspectives on what they saw as a realistic future scenario:

At some point, we may both become so frail that receiving outside help may be a necessity. Then, there must be a variety of possibilities, of course. Now, I clean the bathroom. I guess it is not as nice as before . . . but it is adequate, and I feel this is the least I can do. Otherwise, she still does most the work . . . yes, it will be disheartening the day we have to ask for help. (Frank, 72 years)

The husbands furthermore described how their present situation made it a necessity for them to ensure that their wives were always dressed properly:

I must be observant . . . and see that she puts on the right clothes. I have learned to watch where she hangs her clothing. . . . At first I was unfamiliar with caring for her clothing . . . she used to do that herself. So . . . it became a job for me, to understand how . . . It has been . . . not difficult . . . but it has been something . . . a gradual development. It affects me as a spouse, for sure. (Arnold, 76 years)

Experiencing how the wife's memory loss affected her everyday performance, encouraged husbands to lend support in ways that would assist her toward increased positive life experiences. For some of the participants, communication through written notes became a new and helpful form of interaction, and a useful way of adapting to dementia-related challenges of memory-loss:

The burdens of everyday life . . . have become progressively heavier . . . More and more falls on me . . . All that we need to do . . . I must be involved in [preparation] . . . And I have started to write much more. Write notes that I put on the kitchen table four-five days in advance. (Thomas, 82 years)

By reading such notes, the wife was able to participate in daily activities with less confusion. Taking on new responsibilities was also reported as stressful and burdensome at times, often leaving the men limited opportunities to keep up their personal treasured activities. However, a common notion among husbands was the sense of pride they felt contributing to society by performing their caregiver role as well as possible. However, saving their respective municipality money was not as important as keeping their marital relationship strong. This was the most important motivation in managing their caregiver role and responsibilities:

Yes, it requires mutual efforts on both parts [husband and wife] . . . We help reduce municipal costs . . . But one cannot expect society to do everything for you, and caring costs society a lot of money, but society, that is us . . . I feel we must provide for something ourselves as well, not just be demanding. (Edward, 80 years)

As the illness progressed, many feelings and values challenged their relationship as husband and wife. Nonetheless, the participants seemed to appreciate the many opportunities for giving back to their wives, families, and society. Although experiencing a challenging life situation, the husbands seemed to thrive while managing their caregiver roles, for the time being at least.

## Discussion

Findings from this qualitative study illuminate a perspective often neglected, namely, how older husbands manage the

challenges of everyday life when caring for a home-dwelling wife with dementia. This knowledge may help health care personnel to find the best ways to support the husbands as human beings who give of themselves, often sacrificing their own personal needs to be full-time caregivers. However, we must also take into account that caring can be rewarding and that municipal health services must provide support according to the older husbands' and their wives' individual needs and desires (Greenwood & Smith, 2016).

### *Societal Expectations and Support*

Norwegian municipalities provide care services for older people, and the rising dementia prevalence is expected to increase municipal expenses by 4.8 billion Norwegian crowns by 2040 (Godager & Thorjussen, 2016; Vossius et al., 2015). There will also be a higher occurrence of husband caregivers for their wives with dementia (Hellström et al., 2017; Pöysti et al., 2012; Robinson et al., 2014; Strand & Skirbekk, 2014). This type of informal care provided by spouses saves society for considerable economic expenditure. However, we must understand that it was not economics but a desire and will for "giving back" to society that highlighted the husband's responses within this study. Thus, the gratifying experiences (Ribeiro & Paúl, 2008) of spousal caregiving was evident. Another viewpoint we must consider is the expectations from both society and the person with dementia to live as long as possible at home, putting an often invisible pressure upon family caregivers (Atta-Konadu et al., 2011; Peacock et al., 2009; Stewart et al., 2014). Our opinion is that although it is important to understand that the situation of spousal caregivers can be rewarding, we must also recognize that the burden can become unbearable over time, as the dementia disease progresses (Greenwood & Smith, 2015; Hellström et al., 2017).

A challenging part of their marital relationship included the husbands feeling that their personal freedom in many ways diminished, a subject we will discuss further. Most participants considered receiving additional help and support from other family members to enable them with more time on their own. However, we would like to point out the difficulty and emotional dilemma challenges of this nature entail. The husbands were reluctant to ask for family help or access municipal health care services, a finding also identified in previous studies (Akpinar et al., 2011; Baker & Robertson, 2008; Brown et al., 2007; Cahill, 2000; Greenwood & Smith, 2015; Papastavrou et al., 2009; Pöysti et al., 2012). In the early stages of the disease, we see the advantages of health personnel encourage husbands in similar life situations to join caregiver support groups to share their experiences. This might contribute to reduce their reluctance toward asking for support. Although some of the participants hesitated to attend dementia support groups, some were open to additional help from municipal services. We also suggest establishing support groups for men only, making specific gender challenges easier to address.

### *Openness and Knowledge About Dementia*

When spousal relationships are based on positive values and attitudes, people are more likely to express joy in caregiving (Shim, Barroso, & Davis, 2012). We found that acceptance came gradually, nurtured through a process over time as husbands understood more fully how their wives' disease influenced their everyday life, and consequently found ways to adapt. The study underlines how initial phases of the dementia disease raised many challenges for the husbands, nonetheless, they most often managed to handle these well, while adapting to their new life situation. An important adaptation approach was openness concerning the disease. These husbands told family and friends about their situation and most of their spouses were open about their problems, as well.

However, as the disease progressed, the attitude of openness once easily expressed might become more challenging. When the wife's ability to understand the situation faded, the responsibility to inform fell solely upon the husbands. For the most part, husbands experienced acceptance concerning their wives' dementia. Accepting one's situation is the primary key toward enabling the husband to view caregiving in a positive light (Lloyd, Patterson, & Muers, 2014). A few study participants experienced that certain friends were unwilling to speak about their spouse's dementia. Thus, we note the dementia-taboo among the general population, most likely due to lack of knowledge about the disease. The husbands tended to diminish the impact of such experiences, thinking it does not matter much. However, we believe that health care personnel should contribute toward increased public openness and knowledge about the disease (World Health Organization, 2012), with the goal of improving the experience of people with dementia and their families in their everyday interaction within the society in which they live.

### *Managing New Responsibilities*

Research points to how husbands cross gender roles, taking over their wife's previous responsibilities (Atta-Konadu et al., 2011; Fjellström et al., 2010). In our study, the husbands told about new duties regarding household chores, such as cleaning and cooking. However, societal shifts point toward more males being familiar with domestic chores, especially cooking. Therefore, our interpretation is that the most demanding new task was helping their wives with clothing and female appearance. Parts of their new responsibilities were invisible, yet for them, very important, such as helping their spouse maintain their gendered identity (Calasanti & Bowen, 2006). This type of gender role crossing is a new responsibility that can be challenging and difficult to manage. Nevertheless, as these husbands felt they also managed this everyday-task, they expressed satisfaction and contentment. In line with other research (Hong & Coogle, 2014; Pretorius et al., 2009), we found that husbands in this

present study tended to utilize a task-oriented or problem-solving management approach.

### *Managing the Loss of a Companion*

What we found to be the greatest challenge for these couples was having to deal with the loss and bereavement on a daily basis. Myhre et al. (2018) point to that such loss and grief is ambiguous because the person with dementia is still present, but the person they used to know has changed profoundly. The husbands expressed how they repositioned themselves in relation to their partner, concerned with sustaining their marital relationship as best as possible, a tendency also supported by other studies (Hellström et al., 2007; O'Shaughnessy et al., 2010). The challenges of everyday life threatened their marital companionship, and husbands expressed times of sadness as they missed the joy in activities of mutual interest they once eagerly shared together. The all-consuming nature of caring is common, together with multilayered dimensions of mixed emotions such as pride, respect, closeness, loss, and sadness (Stokes, 2015). One way the husbands adjusted to their new life was to search for meaning in here-and-now situations—and another was to draw upon memories of past-shared experiences and converse about these rather than becoming frustrated over daily ventures which were all too soon forgotten. Based on the many positive statements, we found that these husbands seemingly lived meaningful lives together with their spouses.

Other motivating factors which helped sustain the husband's efforts toward a sense of meaning in caring for the wives included marital vows, moral obligations, and their desire to return the love and care they themselves have received during a long and happy marriage (Hellström et al., 2017; Lloyd et al., 2014; Milligan & Morbey, 2016; Shim et al., 2012). Most interestingly, a few of the participants told that their feelings of love toward their spouse grew stronger as they now felt accomplishment in their demanding caregiver role as they strove to preserve their marital relationship. Becoming the caregiver for one's wife has also previously been described as a sign of love, renewing intimacy and closeness to the spouse (Siriopoulos et al., 1999; Stokes, 2015). Their all-encompassing love can be perceived as a major factor in understanding how and why these men find meaning in sustained care—regardless of their many challenges (Stokes, 2015). Looking to Eriksson's Theory of Caring, we recognize the notion of *caritas*, meaning love and compassion manifested through caring for another human being (Eriksson, 2018; Lindström et al., 2014). An essential factor is the couples' shared mutuality in compassionate care, in other words, both parties are able to give and receive love, although in different ways than before. In this study, one husband described his warm feelings toward his wife were difficult to uphold when encountering negative emotions such as suspicion or anger. Nonetheless, recognizing her vulnerability, he found strength in taking responsibility

for her in a new way, explaining how he had now developed even a closer relationship with her than before the onset of her illness.

### *Caring for the Caregiving Husband*

When focusing solely upon the positive findings, there is a risk of missing how the husbands encountered suffering within their caring relationships (Black et al., 2009; Knutsen & Råholm, 2009). The husbands in this study seemed to appreciate their caring role in spite of a loss of personal space, yet this may not necessarily be the case for all caregiving husbands (Hellström et al., 2017). The diminishing of personal freedom affected the husbands' everyday life and they were impelled to redefine their identity as males and spouses. Also important to remember is that their opportunities for sociability could decrease, possibly leading to loneliness over time (Milligan & Morbey, 2016). We believe that Eriksson's theory can be a useful lens toward enabling health care professionals to recognize husbands' caring needs and alleviate or prevent suffering due to the illness of their spouse. Caring for the caregiver is promoted best when respect, tolerance, and compassion is present—inviting the individual into a caring communion, while at the same time supporting him in his caregiver role (Eriksson, 2018; Lindström et al., 2014). In doing so, the husband's ability to manage their everyday life may be strengthened. In our opinion, support provided by compassionate and knowledgeable carers may contribute to safeguard the dignity of both the caring husband and the spouse with dementia.

Baker et al. (2010) point that men's struggles within a caregiver role are linked to traditional beliefs on masculinity and gender roles in caring, where the latter is defined as a feminized activity. Stereotypic attitudes may lead to expectations that although husbands must learn to manage "female" tasks, they should not feel burdened nor ask for unnecessary help. Nonetheless, with increasing awareness and acceptance of male caregiving within the Norwegian society, we consider that gender-based roles in caring are in a process of evolving toward a new understanding in the future due to shifting perspectives through generations (Hong & Coogle, 2014). When making choices in everyday life, the husbands in our study wanted the best outcome for both parties. As a result, they often renounced activities they themselves desired to attend, prioritizing their spouses' need before their own. In accordance with the theory of Eriksson (2018), we find that these results bear a resemblance to the notion of existing for the sake of one another. Still, the men also put forward the importance of taking care of themselves, as maintaining friendships and treasured activities helped renew their personal identity and stamina needed for managing their challenging caregiver roles.

The husbands wanted to be independent of municipal assistance and manage on their own, thus revealing a reservation for asking for help. How men construct their caring

role affects their male identity; this may explain why older men find it more important than women to manage well and why they can be reluctant to seek outside support (Milligan & Morbey, 2016). The risk of managing care all by themselves is that the caregivers' social life can be restricted and thereof the risk of feeling isolated increases (Bjørge, Kvaal, Småstuen, & Ulstein, 2017). A strategy forwarded and found wise by the husbands in this present study was to seek help, eventually, foreseeing the progression of the dementia illness. They believed that receiving future professional support would enable them to retain some time for themselves, aiming toward minimizing their burdens, as well as allowing more quality time together with their beloved wives.

### *Study Limitations and Strengths*

This study has several limitations; within the timeframe set for participant recruitment, only five husbands gave their consent to participate in the study. Extending the recruitment period would have increased the possibility of recruiting a larger sample. This would have strengthened the study, as a larger sample would most likely have led to greater breadth and depth in the data collection. However, restrictions related to timeframe and the possibility to extend the recruitment period excluded this option. The included sample of Norwegian husbands appeared resourceful. They articulated themselves well and did not want to be pitied. There is a chance that those who came forward to participate in interviews were husbands who mastered the challenges of everyday living and felt good about their caregiving role. Husbands not participating in the study may have different experiences and perspectives. The small sample may therefore give a view with a bias toward positive, more resilient, and resourceful caregiving husbands. The results cannot be generalized into a broader population of caregiving older husbands. Nevertheless, qualitative studies, even with small samples, can generate new in-depth understanding of phenomenon we have limited knowledge of (Brinkmann, 2012).

Also important to remember is that how couples understand their roles and marital obligations may differ, in various countries and cultures, as well as between generations (Hong & Coogle, 2014). Our study, conducted within the Norwegian context, explores and describes what we think is valuable experiences among this present sample of caregiving husbands—findings that can be used by professional caregivers within municipal health care services to support these men and thereby also their wives with dementia. However, this knowledge may also be helpful for caregivers in other countries, cultures, or contexts with similarities to the Norwegian society.

Furthermore, the strength of our study is knowledge about how these participating husbands looked for opportunities to improve the life situation of both themselves and their wives—insight men in similar circumstances may find valuable. The findings also present an important argument for

respecting the challenging life situation caregiving husbands may experience, calling for health care personnel to learn from, care for, and collaborate with them, enabling the couple to live a meaningful life together at home as long as possible.

## Conclusion

A main finding in our study is the duality in all areas of the couple's daily life. Despite their challenges related to memory loss, household chores, openness, personal freedom, as well as experiences of losses, husbands caring for their home-dwelling wives with dementia were determined to uphold a positive perspective. Adaptation through openness; living with change, loss, and bereavement; redefining personal freedom; and expanding areas of responsibility were important strategies toward managing the illness-related challenges of everyday life. Understanding the vulnerability of the wife created new insights, perspectives, and motivation. Awareness of the needs of their beloved spouse fostered the husbands' inherent love and capacity for caring, helping each to redefine their personal freedom and caring relationship as a foundation for personal growth. By actively choosing to acknowledge the many rewards of caregiving, the husbands found their ongoing life situation manageable, as they seemed to thrive in their new caregiver role. Health care personnel should recognize the efforts made by caregiving husbands at home, and learn how they experience everyday life—as well as acknowledge their efforts to manage illness-related challenges. Inviting them into a caring communion of collaboration may strengthen the perceived dignity of husbands engaged in caregiving for their home-dwelling wives with dementia.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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