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Development of older men's caregiving roles for wives with dementia

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This secondary analysis of qualitative interviews describes how older Swedish men approach the caregiver role for a wife with dementia, over time. An increasing number of male caregivers will become primary caregivers for partners living with dementia at home, and they will likely be caregivers for an extended period of time. It has been stated that caregiving experiences influence how older men think of themselves. The theoretical starting point is a constructivist position, offering an understanding of older caregiving men's constructions and reconstructions of themselves and their caregiver roles. Seven men, who were cohabiting with their wives, were interviewed on up to five occasions at home during a 5- to 6-year period.

The findings comprise three themes; *me and it*, *me despite it*, *it is me*, depict how these men gradually take on and normalise the caregiving tasks, and how they develop and internalise a language based on their caring activities. The results provide understanding about the relationship between men as caregivers and how this influences them as individuals. By careful attention to each caregiving man's individual needs rather than making gendered assumptions about men and caring, the aim of the caregiver support for men might best target men's own meaning to the caring in their the everyday practices.

Keywords: constructivism, dementia, gender, informal caregivers, older men, secondary analysis.

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Introduction

Old age is the most prevalent risk factor for dementia (1). The concept of trajectory could be used to refer to both the journey that the person with dementia undertakes [i.e. the illness trajectory, e.g. (2)] and the journey that a family caregiver embarks on when accepting the responsibility to become a caregiver [i.e. the care trajectory, e.g. (3)]. Wilson (4) conducted a cross-sectional study on caregiving experiences with 20 caregivers, and she described eight different stages of the lived experiences of being a caregiver to a relative with dementia. The stages are noticing, discounting and normalising, suspecting, searching for explanations, recasting, taking it on, going through it and the final stage turning it over.

An increasing number of older spouses will become primary caregivers for partners living with dementia at home, and they will likely be caregivers for an extended period of time. Among them will be a growing number of male caregivers. It has been stated that caregiving experiences influence how older men think of themselves (5). Changing historical and social conditions have required a reconceptualisation of gendered roles and responsibilities and the identification of particular domestic spaces (i.e. the kitchen) as either 'feminine' or 'masculine', and studies display a distinct upward trend in men's domestic work time (6), particularly in Sweden (7). However, for current generations of older men, the caregiver role often means entering a 'new world', and adapting to the caregiver role has been recognised as a struggle (8,9).

Looking at traditional domestic gender roles, housework is an important resource of gender production for all women and the reverse, avoiding housework which is 'not masculine' (e.g. cooking, shopping, cleaning) and instead spending time on more 'male' tasks like home repair or lawn and garden care will be a key way in

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which men produce masculinity (10). Hence, the reversal of the male tasks in performing caring activities may generate new understandings about oneself as a man. For example, Authors x and x (11) showed that among older men, caring for an ill wife influenced their male identities over time, that is moving from 'being a man' to 'being a caregiving man'.

In this article, the primary focus is on older men's approaches to their caregiver roles over time when caring for a wife with dementia. Research in the dementia context of older men's caregiving has so far largely focused on male vs. female caregiving, for example in the area of burden and depression (12), or on help-seeking patterns (13). Pöysti et al. (12) showed that husband caregivers, who at the same time were older and had significantly higher comorbidity, experienced less of a burden. Brown and Chen (13) have shown gender differences in help-seeking patterns among spouses caring for a partner with dementia and characterised husband caregivers as 'care managers' when involving others in care in order to keep the relationship, albeit changed, with their partner with dementia. On the other hand, the wife caregivers' reason for seeking help was to keep 'continuing care' at home.

Previous research focusing exclusively on how caregiving is experienced and understood by men is sparse. Harris (14) was one of the first researchers who explored male caregiving in dementia. She suggested a typology in male caregiving, that is approaches to caregiving. These include the worker (modelling the role after the men's work roles), the labour of love (merging the caregiver role with their deep feelings towards their wives; devotion, not duty), sense of duty (developed sense of responsibility and duty) and at the crossroads (new caregivers, most often in crisis). Since then, the research area has been growing and has highlighted different aspects of husband caregiving, for example Russell (15), Kirsi et al. (16) and Sanders & Power (17), who have shown multifaceted perspectives of husbands as 'capable and competent' (15, p. 354) caregivers without being compared to female caregivers. Kirsi et al. (16) have differentiated male caregiving activities in the dementia context into two main domains: activities performed *on behalf of* (for example cooking) and activities performed *for* (for example personal care) the wife. Both domains have strong connections to a female sphere. One traditional female sphere seems to be cooking. Boyle (18) has shown that men refrain from being involved in this activity when caring for a wife with dementia.

To sum up, research in the dementia context of older men's caregiving has so far largely focused on relational aspects (i.e. adjustment to their new marital relationship), the caregiver role (i.e. how to cope with the burden) and caregiver support, which is summarised in three recent reviews (19–21). However, most studies are cross-sectional. Longitudinal studies about older men as caregivers are

sparse, with only few examples (22). Experiencing a life-changing situation, such as becoming a caregiver for a wife with dementia and being so over a longer period of time, may challenge and influence the sense of self, the personal values and the way the caregiver role is approached. Hence, experiential studies with longitudinal design can make important contributions to the understanding of men's relations to caring activities and thus of how these men should be supported in their caregiver roles, without being treated as a mere contrast to female caregiving.

Aim

The aim of this study was to describe how older Swedish men approach the caregiver role of a wife with dementia, over time.

Methods

This study used a secondary analysis (23) of a subset of male caregivers, who participated in a longitudinal grounded theory study that aimed at explore the ways in which people with dementia and their spouses experience dementia over time, especially the impact it has on their interpersonal relationships and patterns of everyday life (24). The focus of the original study, which in total consisted of 152 interviews with spouses living with dementia, was the dynamics of couplehood in dementia rather than either the caregiver or care receiver. However, the main study, with its large data corpus, evoked new research questions in the area of caregiving roles, for example aspects of caregiving related to gender. These aspects were not explicitly addressed in the original study without requiring further analysis. Thus, this study intended to extend the original work with these aspects also relevant for couplehood in dementia (25).

The theoretical point of departure is a constructivist position that offers an understanding of older caregiving men's constructions and reconstructions of themselves and their caregiver roles. This constructivist perspective (26), which has previously been proven useful for interpreting reconstruction of roles and relations in the context of informal caregiving (27), acknowledges the need to appreciate the dynamic and changing scenarios of informal caregiving, over time (28).

Participants and data

The original study (24) was based on repeated individual and joint interviews that were conducted over a period of 5–6 years. Inclusion criteria were that the spouse with dementia should have been informed of a diagnosis of dementia, be cohabiting with a partner in their own home, and a nurse at a memory clinic should have judged the person competent to decide whether or not to

take part in the study. If both in the couple were interested in taking part, an information letter was forwarded. After approximately 1 week, the first author contacted the couple and asked if they still wanted to participate. If they agreed, a date was set for the first interview. One couple declined participation at this stage. In this way, 20 people with dementia (eight females and 12 males) and their spouses were included in the study.

For this substudy, the individual interviews with all male caregivers who had been interviewed more than once were selected (one man was excluded because he was only interviewed once). In total, the data set consists of 30 individual interviews with seven men (see Table 1 for sample characteristics and data collection). The mean age of the wife with dementia was 77 years (range 65–84). Their scores on Mini Mental State Examination (29) varied from 21 to 30 at baseline, and they had experienced memory problems since up to approximately 3 years. At the time for the first interview, the men mainly supported their wives for example in keeping track of appointments. If we use, Wilson's caregiving model (4), the included men were in the later stages of their caregiving trajectory, namely in the stages taking it on, going through it and the final stage turning it over.

Data collection

The semi-structured interviews were structured around the themes of the home, the memory disturbance, the quality of everyday life, the relationships with their ill partners, and dignity and autonomy. The themes were used as 'sensitising concepts' (30,31), and the questions were not fixed but rather focused on the areas of interest to the respective spouse. The interviews were approximately 45 minutes long and were performed in a conversation format. The interviews were digitally recorded and transcribed verbatim.

Informed consent

Prior to the first interview, participants gave their oral and written informed consent to participate in the study.

Careful information about the study was given before each of the interviews, with opportunities for to ask questions, clarify issues and withdraw if they so desired. Each of the following interviews was preceded by renewed consent, following repeated information regarding the voluntary nature of participation and the right to withdraw from the study at any time without having to present a reason. The principles of process consent were applied (32). The Ethics Committee at Linköping University, Sweden, approved the study (no. 01-175).

Analysis

Several steps guided the thematic analysis of data (33). The analysis was conducted in Swedish until the write-up of the thematic analysis. First, the transcripts were coded in relation to the study aim. Each of the transcribed interviews was read carefully to identify each particular participant's description, which entailed the systematisation of the data in order to reach a preliminary understanding of what the informants expressed. Segments of the transcripts were highlighted and coded to develop clusters of meaning-related content, on the basis of the variety of topics that we identified as relevant (34,35), for example *feeling safe* with its meaning-related content (e.g. the quote 'She is feeling well when I'm at home/.../She feels safe then'.) or *incontinence* (e.g. the quote '...she has some problems with incontinence, I think. She washes almost every day'.). Next, preliminary themes were identified from the coded data clusters, for example *A need for company*. At this step of analysis, the interviews were coded on the basis of the variety of topics that were identified as relevant for this specific study (i.e. how the men approach the caregiver role, for example their wives increasing need of company or how they manage housework). Once the interviews were coded, the authors proceeded to identify how these topics were inter-related to one another for each and every one of the participants over time, and the preliminary themes were reviewed (33, pg. 91). Finally, the themes were reassessed against the interviews in order to establish their relevance to the data as a whole (35).

Table 1 Sample characteristics

Informants' pseudonyms	Study participant's age at baseline	No. of years married at baseline	Living arrangements	Former occupation	No. of interviews
Arne	77	43	House	Taxi driver	4
Carl	71	24	Apartment	Accountant	3
Ingvar	84	60	Apartment	Carpenter	3
Nils	79	57	Apartment	Military officer	5
Olof	68	47	House	Controller	5
Paul	85	55	House	Entrepreneur	5
Robert	85	8	House	Foreman (public transportation)	5

The first author had the main responsibility for the analysis. Trustworthiness was achieved through peer review of developed clusters and codes, by the other authors. Iterative reflexive discussions in the author group were integral to the analysis and were continued until consensus was reached on the presented themes and representation of data as a whole (35). In addition, we have looked for disconfirming evidence (36) in order to make sure that the findings do justice to the husbands' perspectives.

Findings

The analysis reveals three themes disclosing how the participating men approached their caregiving practices, and how they adjusted over time to their roles of being the main care provider: *Me and it*, *Me despite it*, *It is me*.

Me and it – a distance between the self and the care practices

In the beginning of their wives' illness trajectories, the men tried to keep a distance to caring activities and the impacts these deeds could have on their daily lives. They predominantly spoke about caregiving tasks in relation to planning and using strategies to help the wife to maintain household chores and social activities. Arne's wife had worked as an accountant and had recently retired. At the time of the first two interviews, Arne supported his wife in continuing to manage the household economy by simplifying the task. He removed other documents and papers from the table so that his wife could concentrate on the task at hand without being distracted. This also illustrates how the men tried to keep the division of labour the way it always had been in their marriages. Other examples of this were letting the wife cook, do the dishes and the laundry while the men mainly took responsibility for the shopping and gardening. Paul, who had been living with his wife for 55 years, described in the first interview how they divided the household chores at home:

Yes, she does it you see and takes care of the food, and I do the shopping and bring it home, prepare it, and if we need to take something out of the freezer [refers to the freezer in the basement], we take it out in the evening, take something out for the dinner the day after.

Paul described that his wife was in charge of most of the areas in their household. However, because his wife had not been allowed to drive after being diagnosed with Alzheimer's disease, he usually did the shopping and kept track of the things they stored in their freezer.

In order to master the everyday chores and caregiving activities, together with the emotions related to their wives' illness and their changed life situations, the men deliberately used reasons when approaching problems of

noncompliance. By trying different tactics, they sought to understand whether their strategies were useful. The men described their strategies as rational and task-oriented, and some also described their roles as managerial or organisational. There were also descriptions of a 'take-charge' attitude that the men related to their previous occupations. This is particularly highlighted by Nils in the first interview, who had served earlier as a military officer:

Making decisions, yes, that has always been a part of me. Some say that I always have been somewhat dominating...and I guess that comes from my job...-I've been training soldiers for 42 years.

By making decisions about how to organise their households, the men allowed their partners to be actively involved in household chores the way they always had. Robert, who had married his second wife eight years ago, had cared for his first wife, who had had a severe stroke. During his first wife's illness, he took over most household chores in addition to her personal care. His current wife had worked as a housekeeper in an institution, and for her, it was very important to keep doing the cooking and baking. At the time of the first interview, they still shared most household tasks. However, when his wife baked, Robert needed to support her as she easily forgot which ingredients she had put into the bowl, or for how long the cake had been in the oven, but he gave her the sense of still being the housekeeper.

Care work was approached and described as a job. This was useful for separating emotional spousal bonds from task-oriented problem-solving, especially when they dealt with body-related tasks. Olof talked at the first interview about what to anticipate for caregiving in the future:

The other symptoms will appear, that you have read about, then it actually will be hard for me, you see, that you'll almost be a nanny for her, you understand that it will be like that, that I think, it will be hard, really.

However, the strategies to maintain a sense of a preserved orientation as a man, despite the caregiving responsibilities, were not only reflected in what the men said they would do, but also by the way they talked about what it meant to be a caregiver for a wife living with dementia. Keeping the discussion on a rational level was a way of keeping their emotions at bay.

Me despite it – caregiving moves closer

Due to the illness progression and the fact that the men were getting more familiar with the new life situation, the caregiving had come closer to the men, and they were in turn moving closer to caregiving. This was shown by the way the men talked about the caregiving tasks, and the household chores at home. However, sometimes they also referred to caregiving as 'it', as if

they were keeping a distance to caregiving. Arne, Carl, Ivar and Olof shared similar experiences of their daily lives, namely that their wives had become more dependent on their presence. This changed the way they handled their household chores. Arne's main responsibility had always been gardening and growing vegetables, while his wife had taken care of the indoor chores. Lately, she had started to spend time with him in the garden, a place he nowadays also used as a retreat when his wife had one of her outbursts of rage, a behaviour that challenged both in the couple. At the time of interview number three, his wife had started to visit a day care centre regularly and during these days, Arne tried to do as much he could, both in the garden and indoors:

I try to do as much as possible, at this time of the year when you have to take things indoors it takes time. But as I say, these three days are valuable, for sure. I think that, I dread the winter and how it will be then if I can't, I will check if she will be able to have Fridays [at the day care center] as well.

What he seemed to dread was the fact that during the winter, he would not be able to spend time alone in the garden when his wife was angry with him. When they were indoors, he put great effort into helping her to maintain her earlier chores. Over time, he had taken over most tasks, except one, ironing, which she still managed.

The men had developed strategies for coping with the wives' illness, and their own situations. Strategies used were to reorganise cooking, cleaning and shopping in ways that differed from how their wives earlier did, but in a way that the men could feel satisfied with. For example, they described using more prepared and fast food than before.

Even though caregiving was described as tasks that needed to be carried out, the men expressed emotions related to their partners' disease or the caregiving difficulties. Carl's marriage had not always been happy, and from time to time, there had been many quarrels. They had earlier talked about divorcing or living in separate apartments, but after his wife was diagnosed with Alzheimer's disease, he could not think of leaving her: 'I have thought of breaking up earlier, you see, but as it is now I can't think of abandoning her. Absolutely not...' [Carl, interview no. 1]. This was Carl's second marriage, and both he and his wife had children from previous marriages. All the children agreed that Carl and his wife should divorce, mainly because of Carl's own health problems. Eventually, at the time of the fourth interview, the couple had separated and withdrawn from the interview study. Carl had also withdrawn from his caregiving role.

In order to deal with the difficult emotions, the men described that focusing on practical aspects and blocking the emotions by not thinking of them were used as

strategies to cope with the emotions. Another way of coping was to find their own time and place where they could relax and leave the caregiving responsibilities for a short time. Carrying out distracting activities such as hobbies helped them to see themselves as not only caregivers, but as the persons they were before. However, even though they recognised the importance of finding a place for themselves, this also gave them a bad conscience. Olof had a membership in a motor club and went regularly to their meetings. In the second interview, he talked about feeling guilty when leaving his wife alone for a few hours, as he knew that she depended on him:

Interviewer: Are you worried then, when you are away?

Olof: Yes, I am, I can't avoid it, but she doesn't do anything she shouldn't do, not anything dangerous in any way, nothing has happened.

Over time, his wife got support from the home-help service and they stayed with her when he went to the club. As shown in the excerpt above, a diminishment of social life that included social isolation, feelings of loneliness and a reduction of social and bodily contact were explicit in all the men's narratives. Accepting this was a demarcation line where caregiving became internalised in their practices.

It is me – being a caregiving man

Following the progression of caregiving, and the adaptation to lives together with wives with dementia, the men gradually shifted, from talking about themselves in relation to caregiving as 'I have to...' to 'we need to...' and 'our situation'. Hence, the caregiver role had become a part of their lives and who they were. The caregiving was now an internalised part of their everyday lives, and they embraced the full responsibility and the challenges, which is demonstrated by Ivar here during the third interview:

Interviewer: Do you think you need any help [referring to formal support]?

Ivar: No, we don't need that kind of help, no that's something that I might think about a little and it's, I worry so much how it will, how it will go/.../it is unavoidable, they still haven't found any cure. I worry about that sometimes, how the hell will she manage because she is incredibly dependent on me, so if I should disappear, then...[crying].

Reciprocity in different aspects, such as marital vows and long-lasting relationships, was a moral obligation and hence a motivation for taking caregiving responsibility. But caregiving was also seen as a way of expressing love and devotion, even though the men approached it

differently especially when it came to tasks related their wives personal spheres. Robert's wife was incontinent, and he felt committed to care for her body, and make sure she always had access to clean underwear, especially when she visited the day care centre. He provided support for his wife; he did so in a way that was often not obvious to her in order to maintain her self-esteem:

Robert: I put that in the bag too.

Interviewer: Yes

Robert: So they (here referring to the staff at day care) have something to change...

Interviewer: Of course.

Robert: And it is incontinence supplies and stockings and panties and things like that.

Olof, on the other hand, was not prepared to help his wife with personal care himself; he instead organised for home help.

During the caregiving trajectory, the men's stories shifted from descriptions of household chores into descriptions of changes in the relationship and of their own feelings. They also described feelings of pride over all the things they had learned after the wives became ill, such as cooking and other household chores. In addition, they worked out different strategies in order to manage both their own and shared everyday lives.

Discussion

Listening to and interpreting men's stories about their caregiving over time show that they adjusted to the caregiver role, moving from keeping a distance, elaborating and negotiating, to finally appreciating their role as caregivers. Several critical transition points can be identified in the men's stories about their caregiving experience. These points include change in their partners' health, decision-making about providing and continuing to provide care, learning new skills, and changes in the relationships to their partners due to the progression of the dementia disease. It is interesting to note that the transition points in the men's caregiving career include descriptions of how new responsibilities were based on changes in the role as well as the need to acquire skills and strategies to adjust to the changes in care and support.

The men's descriptions gradually shifted their ways of talking about themselves and their caregiver roles. They described that providing care to a partner is a natural part of being in a loving relationship, which was linguistic expressed as being part of a couple (37). In order to meet the needs of their partner, one must learn new skills throughout the caregiving career. What was earlier regarded as women's work gradually developed into their most important commitment, and hence, the caregiving

tasks were gradually normalised in day-to-day activities and practices.

Even though caregiving was challenging, the men described that they faced their responsibilities and felt pride in doing a good job. As they became more familiar with caregiving, they developed their caregiving skills. In order to do that, they used approaches from their (earlier) work lives, which for the men seemed to provide a sense of control over what may otherwise be an overwhelming situation. In a study examining the gendered nature of caregiving, Calasanti and King (38) argued that male caregivers embody a style of caregiving that focuses on tasks characteristic of occupationally based masculinity. In their study, men treated caring as if it was a job in which they could achieve 'mastery' in a way that was consistent with their personal identity. This can be understood in the light of personal control to which theories about masculinity, and hence, the 'defence' of one's own male identity can be intricately linked (39). The self-made adjustments of the housekeeping in order to find alternative solutions of practical problems that were described by these men can be seen as strategies in which personal control is operationalised as autonomy, referring to a sense of freedom in initiating and carrying out personal choices (40). In other words, having control over the circumstances of life as a caregiver for a wife with dementia can be seen as a coping strategy.

In exploring the ways gender might influence, or be influenced by caregiving, the men in our study later in their caregiving trajectories willingly crossed gender boundaries related to domestic work because of their devotion to their marriages and caregiving for their wives. Revealing this has important implications for theory and knowledge development about masculinity and caregiving. However, it also goes beyond the more traditional way of describing men's motives for undertaking caregiving (41–43), or gender-specific difficulties relating to caregiving such as men's experiencing less emotional distress, physical and psychological effects than their female counterparts (22, 44). It is nonetheless important to bear in mind that the consequences of loss of male identity, relationships, personal time and a 'normal' everyday life, while still fully appreciating the responsibility of care like the men in this study must not be seen as a natural pathway for all men. Dementia is a chronic illness, among others, such as multiple sclerosis or Parkinson's disease. This means that the findings from this study could be transferred to other caregiving men. Rather, stories from men might be dependent on particular circumstances such as socio-economic, cultural or ethnic belonging, and on previous participation in domestic work.

Study limitations

The men in this study, together with the interviewing researcher, coconstructed themselves within the interview

narrative, from the particular lens of caregiving as the priority of the marital relationship and how they fulfilled these commitments. The coconstruction of 'reality' in interview situations is by no means unique (45). However, this aspect is important to bear in mind when judging the results of this study, as the caregiver role for these men is likely only one of several roles upon which their male identities rest. This study is based on a secondary analysis. Hence, in order to acknowledge the fit between the current aim and the available data, the distance between the aims and how the data sets were generated was considered (22).

Conclusion and implications

This study has shown that (older) men who act as caregivers for wives/partners with dementia gradually take on and normalise the caregiving tasks in day-to-day activities and practices. Moreover, along the caregiving trajectory, they develop and internalise a language based on their caring activities.

These results potentially help us to understand the relationship between men as caregivers and how this influences them as individuals, and what needs to be addressed in terms of caregiver support. Based on the results, we therefore suggest that health professionals seek to achieve overall balance of care arrangements for the men in sophisticated ways, to encourage personal growth and the normalisation of caregiving tasks. Rather than 'taking over', as for example addressed by Authors x and x (11), health professionals need to be very sensitive to the men's ambivalence regarding their own caregiver roles, for example, do personal care for their wife (16), and where they are in their caregiving trajectory, as their needs for support might shift over

time, moving from *me and it* to *it is me*. By careful attention to each caregiving man's individual needs rather than making gendered assumptions about men and caring, the caregiver support for men may best target men's own meaning to the caring in their the everyday practices.

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Author contributions

Ingrid Hellström was responsible for the study conception/design and data collection for the study. Ingrid Hellström, Cecilia Håkanson, Henrik Eriksson and Jonas Sandberg were participated in the analysis of data, the drafting of the manuscript and the critical revisions for important intellectual content, including the final submitted version of the manuscript.

Ethical approval

The Ethics Committee at Linköping University, Sweden, approved the study prior to commencing (No. 01-175).

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