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Lethin, Connie; Rahm Hallberg, Ingalill; Karlsson, Staffan; Janlöv, Ann-Christin

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PO Box 117
221 00 Lund
+46 46-222 00 00

Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease

Connie Lethin, MSc, RN (PhD-student)¹, Ingalill Rahm Hallberg, PhD, RN, (Senior Professor)², Staffan Karlsson, PhD, RN, (Senior lecturer, Associated professor)¹
Ann-Christin Janlöv, PhD, RN, (Senior lecturer)³

¹Department of Health Sciences, Lund, Sweden, ²The Pufendorf Institute of Advanced Studies, Lund, Sweden, ³School of Health and Society, Kristianstad University, Sweden

Correspondence to:

Connie Lethin, Department of Health Sciences, Faculty of Medicine, Lund University, PO Box 157, 221 00 Lund, Sweden. E-mail: connie.lethin@med.lu.se

Abstract

Background: Family caregivers' experiences of formal care when caring for persons with dementia through the process of the disease is sparsely investigated.

Aims: To investigate family caregivers' experiences of formal care when caring for a person with dementia, through the stages of the disease.

Design: A qualitative approach with focus group interviews.

Methods: Four focus group interviews were conducted in October 2011 with 23 spouses and adult children of persons with dementia, and analysed with content analysis.

Results: The participants' experiences of formal care when caring for a person with dementia were captured in the theme "Family caregiving requires collaboration with formal care to get support adjusted to needs specific to the stages of dementia". This can be broken down into the categories "The dementia diagnosis – entry into formal care as a novice family caregiver", "Needing expanded collaboration with formal care to continue care at home" and "Being dependent on a nursing home and trying to maintain involvement".

Conclusion: Family caregiving requires collaboration with formal care to get support adjusted to the individual's needs, specific to the stages of dementia. Caregivers experience a transition process with three main turning points: the dementia diagnosis; when they realize increased need for formal care to continue caring at home; and when the person with dementia is moved into a nursing home. The interviewed caregivers experience formal care reactive to their needs and this often promoted unhealthy transitions. Formal care needs to be proactive and deliver available care and support early on in the dementia trajectory. Interventions should focus on facilitating a healthy transition for family caregivers through the trajectory of the dementia disease to ensure their well-being.

Key words: family caregivers, experiences, formal care, dementia, Alzheimer's disease, trajectory, nursing, qualitative research, focus groups, transition theory.

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Introduction

Family caregivers' experiences of formal care when caring for persons with dementia through the process of the disease have been sparsely investigated. Their experiences of formal care are most often investigated separately in different contexts, such as once the diagnosis is set, at home, in day care or in a nursing home (NH). Further, few studies focus on family caregivers' experiences of collaboration with formal care when caring for persons with dementia throughout the process of the disease. Moreover, studies on the topic are from different cultures, often with different care and service systems, primarily from Australia, Canada, the Netherlands, Sweden and the United Kingdom (1–5). To assist family caregivers (hereafter referred to as “caregivers”) and improve formal care and support throughout the process of dementia, more knowledge is needed about caregivers' experiences of formal care through the process of the dementia (6, 7).

The care of persons with dementia through the process of the disease is mainly provided at home by caregivers (8, 9). Caregivers are unpaid individuals who support or provide care to a person who is dependent due to long-term physical or mental illness or disability, or to age-related problems (10). The care of a person with dementia provided at home often involves longer hours and more intense care compared with the amount of formal care provided, and also compared with the care of persons without dementia (11). Of all persons with dementia in Sweden, it is estimated in 2012 that 58% live at home, while 42% live in an NH (12). Caregiving may include helping the person with dementia with activities of daily living (ADL) and coping with changed behaviour (3, 6). Becoming a caregiver to a person with dementia can be seen as a transition through the process of the dementia disease as described in the transition theory by Meleis (13). A transition is characterized by a turning point of change, from a fairly stable state, through a period of experiencing instability, uncertainty and distress, to another fairly stable state.

Caregiving for a person with dementia is sometimes experienced as positive (14, 15) yet it can be both physically and mentally demanding and many caregivers find it more than they can manage (7, 14, 16). Caregivers are at increased risk of stress, strain, depression and other health complications (16) and have higher mortality compared with those caring for persons without dementia (17). Caregivers often request information about the dementia disease, prognosis and how to deal with behaviour they perceive as difficult (3, 18) which has been reported to relieve caregiver strain. Respite care for the person with dementia has likewise been shown to relieve caregiver strain (19). Caregivers often find it difficult to navigate the system of care and service and find the right person to contact for support with different caregiver tasks (9, 20). Furthermore, caregivers can experience strain when caring, and this strain often increases prior to moving the persons with dementia to an NH (21). Moving the person with dementia to an NH does not always mean relief, in terms of stress and strain, for the caregiver. Support during this care phase is also important.

Dementia progresses along a continuum, from early in the dementia disease to the end-of-life stage (22). As the dementia disease progresses the caregiver has different needs for support from formal care. There is a need for knowledge about caregiving when caring for a person with dementia, especially regarding collaboration between caregivers and professionals involved in the care (20, 23). Such knowledge is important for developing and improving formal support for caregivers. To develop best practice, caregivers' own descriptions of how they experience formal care through the process of the disease are essential. The aim of this study was to investigate caregivers' experiences of formal care when caring for a person with dementia, through the process of the disease.

Method

Design

This study has a qualitative approach with focus group interviews, analysed with content analysis. Content analysis was chosen as a flexible method which involves both manifest and latent interpretation (24). This study was a part of a European study, “RightTimePlaceCare (RTPC)”, performed in 2010–2013 in eight countries, Estonia, Finland, France, Germany, the Netherlands, Spain, Sweden and the United Kingdom (25). The structure and development of the focus groups in all countries is described elsewhere (26). In this study, focus group interviews were carried out in Southern Sweden. In Sweden, social services are provided at home, covered by the municipality, and regulated by the Social Service Act (27). Home nursing care is provided by county councils and regulated by the Health and Medical Services Act (28).

Sample

A strategic sample of 23 spouses and adult children of persons with dementia, of various age and gender participated. Participants all had experiences of the process of the dementia disease (parts or whole), and there were variations in care and service and municipal size. Inclusion criteria for the person with dementia were age ≥ 65 years, primary dementia diagnosis, Mini-Mental Test ≤ 24 (29) and living at home with support from formal care and social services, or in an NH (Table 1). The criterias for the caregivers was that they should be living either with the person with dementia at home or visit them at least twice a month at home or in the NH. Recruitment from four municipalities (10,000–113,000 inhabitants) in southern Sweden was conducted by a contact person in each municipality; a registered nurse specialized in dementia. The dementia nurse contacted likely participants, informed them about the study and the focus group interviews, and asked them to give permission for researchers from Lund University to contact them.

Table 1. Demographic characteristics of family caregivers in the focus groups (n=23).

	<i>Group 1</i> (n=4)	<i>Group 2</i> (n=6)	<i>Group 3</i> (n=7)	<i>Group 4</i> (n=6)
Gender (man/woman)	1/3	3/3	4/3	2/4
Age of the family caregiver, range, years	50–70*	51–80*	45–88	60–80
Age of the person with dementia, range, years	71–98	73–88	72–92	68–87*
Memory problems for the person with dementia, years	5–15	2–10	1–15	1.5–10
Relation (spouse/child)	1/3	3/3	4/3	5/1
Living condition for person with dementia (at home/ at the nursing home)	1/3	3/3	3/4	4/2
Support from the municipality at home	Accompanying staff	Home care, day care	Respite care, respite care at home	Respite care at home, day care

*One family caregiver who did not answer the question about age

Data collection

Data were collected in October 2011 through focus group interviews (n=4), with one focus group per municipality, and four to seven participants per group. We selected focus group interviews (30) as a method to get participants to disclose positive and negative experiences of formal care in discussion with others, and to understand differences in perspectives. An interview guide was developed with questions about caregivers' experiences of formal care in the context of caregiving at home or in an NH. Further questions covered collaboration, communication and information related to formal care through the process of dementia, and suggestions for improvement. A pilot interview was conducted to validate the procedure and the interview guide. No changes were needed after the pilot interview. Two of the researchers, both experienced registered nurses, conducted the focus group interviews, one as moderator (A.C.J.) and the other as observer (C.L.). The moderator gave information about the aim of the interview, and led the interview using the interview guide. The observer helped the moderator keep participants on track and observed the interaction within the group (30). To gain depth in the interviews, probing questions were asked. The participants were all active, discussed the questions with each other and shared experiences through the process of the dementia disease. The interviews were recorded and transcribed verbatim. The time per focus group interview varied between 124 minutes and 140 minutes.

Quality criteria

Trustworthiness was established by ensuring credibility, dependability, conformability and transferability (31). Credibility was established by descriptions given by caregivers of their experiences of formal care when caring for a person with dementia. To achieve variation, we selected participants with varying age, gender and experiences of formal care, and from different municipalities in southern Sweden. All four researchers have knowledge of the context of Swedish care and service systems. To ensure that results were repeatable and consistent and to strengthen the conformability of the findings (32), all authors independently read the interview texts and identified meaning units responding to the research question, which should ensure that the data are dependable. Sub-categories, categories and themes were discussed between the authors until agreement was reached. Quotations were included to show similarities and differences in the transcribed interview texts. To make the results transferable, the context and sample concerning recruitment as well as the data collection method are described. The procedure of analysis of the interview texts is described in detail, thus enabling the reader to follow the authors' involvement in the analysis. The result may be transferable to other groups, for example caring of persons with fatal diseases with deterioration in cognitive functions.

Analysis

The interview text was analysed with content analysis as described by Graneheim & Lundman (32). The transition theory (13) was used for interpretation in the analysis. Initially the first author (CL) read each interview. Thereafter CL read all interviews several times to get a sense of the whole. Meaning units were identified and later condensed and labelled with codes. The codes were sorted into sub-categories based on differences and similarities and, thereafter, into categories, i.e. at the manifest content level. Thus an overall picture and an underlying meaning, latent content and theme emerged (Table 2). The co-authors (I.R.H., A.C.J., S.K.) independently reviewed the interviews and discussed the codes in depth with the first author in development of the sub-categories, categories and theme, until consensus was reached.

Table 2. Meaning units, condensed meaning units, codes, subcategories, category and theme.

<i>Meaning units</i>	<i>Condensed meaning units</i>	<i>Code</i>	<i>Subcategory</i>	<i>Category</i>	<i>Theme</i>
“So I have a hard time knowing how to deal with the person in question, with dementia. What you can say, what you can do, what you can’t do. That’s what I think is a big problem when you don’t have any experience.” (FG1, son)	Lacking preparedness and knowledge about dementia	In need of preparedness and knowledge	Experiencing strain may need support form formal care	The dementia diagnosis – entry into formal care as a novice family caregiver	“Family caregiving requires collaboration with formal care to get support adjusted to needs specific to the process of the dementia disease”
“She has escaped four times this summer, so that’s why I can’t go anywhere, you see.” (FG2, husband)	Husband can’t leave the house/patient	To be a guardian			
“In the past, we used to have a lot of friends. They disappear ... the friends. But why do friends disappear? Even the grandchildren have disappeared.” (FG3, husband)	Friends and next of kin don’t visit anymore	Loss of next of kin	Disappointment of formal care implies experiencing of isolation		
“Then I have two brothers but they live in Stockholm. So it has to be me ...” (FG1, daughter)	Daughter feels that it’s her responsibility to take care of their mother	Enforced caregiver responsibility by relatives			

FG = focus group

Well aware of the danger of pre-understanding, the researchers strived to put themselves in the caregivers' situation when interpreting the text to understand it unconditionally when searching for meaning and essence. The moderator and co-authors are researchers in the field of elderly care and psychiatry and experienced in conducting focus group interviews. The observer has experience in working with persons with dementia and caregivers in the municipality and county council.

Results

The participants' experiences of formal care when caring for a person with dementia were captured in the theme *"Family caregiving requires collaboration with formal care to get support adjusted to needs specific to the process of the dementia disease"* consisting of three categories: "The dementia diagnosis – entry into formal care as a novice family caregiver", "Needing expanded collaboration with formal care to continue care at home" and "Being dependent on a nursing home and trying to maintain involvement".

When family caregiver's enter the role of caregiving, they enter a new life situation with new demands, entailing a transition from novice to carer. The dementia diagnosis is a first step in the dementia disease process and becomes their formal entry into the role as caregiver and of starting collaboration with formal care. The need to be prepared and the need for information about the dementia disease, so as to better equip them to handle the persons cognitive impairment, becomes urgent. Caregivers proceed in their transition from independency to dependency as the dementia disease progresses. They rely on other next of kin to enable them to keep on caring at home and retain independence. Continuing caring for the person with dementia at home implies having to establish collaboration with various formal care providers. Finally, when the person with dementia moves to a NH and becomes totally dependent on formal care, there is a new transition for the caregivers as they need to build trusting relationships with the NH staff. It is important for the caregivers to communicate with the staff and be involved in the care of and care planning for the person with dementia.

The dementia diagnosis – entry into formal care as a novice family caregiver

Early in the dementia disease the next of kin to the person with dementia had to enter a new role as a caregiver without being prepared. During this transition they also had to start collaborating with formal care, not knowing their expectations. Awareness of their need for support from the formal care system had increased, including care for the person with dementia and support for themselves. The importance of knowledge about dementia disease and information about available care and services was emphasized. They experienced strain and weariness and realized that they were no longer able to manage the care on their own and had to apply for formal care and services. Some participants emphasized that formal care was accommodating and informative about available services. Others had to fight for care or services, both for themselves and for the person with dementia. Some mentioned that they had not been listened to when requesting aid, equipment or respite care at home. Practical strain was described especially by male participants, who found it hard to meet new demands, such as planning the household and preparing meals. A husband related:

You are terribly disabled [as a man]. Suddenly you need to do the shopping and planning ... the menu and cooking. It takes such a terribly long time when you have no training. We have to educate ourselves. (Focus group (FG) 4)

In this new role as caregivers, the participants had feelings of being alone and isolated because formal care was not supportive as expected. The participants also experienced increased isolation when relatives and friends no longer came to visit. One husband said, “We used to have a lot of friends. They disappear ...” (FG3). To make new friends was a necessity when trying to create a new life. Disappointment related to formal care was expressed when participants themselves had to find out how the formal care system worked and who to contact. Spouses experienced feeling desperate when hospitals had neglected to make care plans before discharge. A wife said: “My husband got a stroke and he couldn’t stand on his feet. Two days later, they sent him back from the hospital without any care planning.” (FG4). The dissatisfaction over the lack of formal recognition of their importance as caregivers was discussed:

Son 3: I think I’m the “spider in the net”.

Daughter 2: Yes, that’s what we are!

Son 3: You have to do everything yourself. You have to contact the social worker (SW), the dementia nurse, you have to find out everything yourself. Nobody offers to help.

Daughter 2: Yes, that’s my experience too. Absolutely! (FG1)

Needing expanded collaboration with formal care to continue care at home

Increasing cognitive impairment of the person with dementia implies an increased dependence, a loss of freedom and an expanded need for caregivers to collaborate with formal care. In this transition the caregivers tried to keep their independence for as long as possible, but needed improved collaboration with formal care to be able to continue care at home. When the cognitive impairment of the person with dementia increased, there was an increased need for assistance or supervision to manage ADLs and prevent accidents (for example, when the person with dementia needed assistance in the shower or left the house unattended). The home situation was characterized by collaboration with different care providers. The caregivers utilized formal care (home care, respite care, day care) to support their everyday lives. Having a contact person to facilitate communication with different formal caregivers was essential in this process. Even when they utilized formal care, the caregivers tried to avoid extended involvement from formal care and strived to manage by themselves as much as possible. They complemented formal care with care from relatives and neighbours to keep their independence and avoid “being a burden to society”.

Son 3: I think it has a lot to do with integrity. You want to manage on your own for as long as you can, to keep things the way they are.

Daughter 4: She [the person with dementia] decides everything herself. She has always done that and she’s allowed to do that now as well. (FG1)

Some participants left the person with dementia at home alone when going to work, which became a worry. At times, the person with dementia left the house and could not find their way back home. Then neighbours and friends were described as valuable support. A woman: “Everybody knew her because she went out with the dog all the time and she couldn’t find her way home in the last years. Neighbours and friends came with her.” (FG2). When the caregiving situation at home became increasingly problematic, communicating with others in dementia associations could be comforting. The struggle to avoid dependence on formal care had consequences for the participants, such as feeling inadequate in the care they were able to

give. These efforts also meant worrying about the future and their own capacity to continue in their role as caregiver. One husband said, “It’s really hard and at night you stay awake and think about ... for how long can I keep doing this?” (FG2). As the dementia disease progressed, participants needed improved collaboration with different formal caregivers. Responsive social workers were described as giving a sense of security and confidence, as in this quote: “I was exhausted. I had to feel that I could sometimes have time off. I asked for help one day ... and got help the next day!” (wife, FG3). SWs were sometimes reluctant to collaborate, for example when they denied a participant a request, such as for extended support in the form of respite care. To have to struggle and fight for care and support was exhausting. Lack of collaboration and repeated resistance to requests for extended care made participants feel pushed to the limit. Some even described suicidal thoughts. On the other hand, participants who got respite care at home expressed feelings of freedom and relief: “This is just respite care. They [staff] just stay with him, you see. But this I appreciate a lot ... this help.” (wife, FG2)

Being dependent on a nursing home and trying to maintain involvement

The move of a person with dementia to an NH is a difficult time in a caregiver’s life, bringing with it separation from their beloved ones which leads into a new transition. Being involved in the care, and being consulted as experts on the needs of the person with dementia make it possible for caregivers to build a trusting relationship with the NH staff. Participants emphasized the importance of still being involved in the person with dementia’s life, and being encouraged to have some influence over the care at the NH. Trust and security were built when staff members were viewed as responsive to both the participant and the person with dementia and their expressed care needs. Having adequate communication with staff at the NH was described as an important prerequisite to being involved. The participants expressed confidence in formal care when they felt the person with dementia was well taken care of and the staff were engaged and interested in the person with dementia’s life and well-being. They also expressed confidence in formal care relating to NH staff requesting communication with the participants if they needed information about the person with dementia. A daughter said: “They even called and asked why he didn’t want to have his pyjama pants ... [laughter]. They always call and ask, and that feels secure!” (FG3). When, by contrast, participants experienced a lack of communication with NH staff they felt excluded from the care and lost confidence in formal care. Some participants had to call staff all the time, or had to stay at the NH to check the care of the person with dementia. Shortness of NH staff and lacking continuity among staff made the participants feel insecure and concerned about whether the person with dementia was well cared for. Shortness of staff was described as influencing activities for the person with dementia.

Daughter 3: On their home page, it says that there are two planned activities each day. It’s also stated in ... [the person with dementia]’s care plan. You are believed to think that this need for stimulation and activities was satisfied in an NH, but that’s not the case.

Daughter 5: The staff have to take care of all practical things and don’t have time to take walks with the person with dementia or do puzzles.

Son 6: It seems to be a problem that there is shortness of staff and so much to do. So even if there’s a will there’s no time. (FG2)

Discussion

The findings indicate that caregiving requires collaboration with formal care to get support adjusted to individual needs, specific to the stage of the disease the individual is in. Formal care was described to be reactive to caregivers needs instead of having a proactive approach. Experiences of formal care during the process of the disease when caring for a person with dementia can be understood by Meleis transition theory (13). During transition, most people are vulnerable and need support to adjust in order to counteract unhealthy transition processes. In this study the participants seemed to be in an extensive transition process including three marked turning points related to their caregiving and their experiences of formal care in the disease process.

The dementia diagnosis was a first turning point and the first contact with formal care. At this point the caregiver as the main caregiver is responsible for the care of and services to the person with dementia. Caregivers at this point are novices at caregiving, which places them in an unstable position when transitioning into the caregiver role. According to transition theory, healthy transition processes include exploring the meaning of the transition and modifying expectations to make them realistic. Healthy transition processes also mean restructuring life routines in response to the new situation, which allows the caregiver to regain a sense that their life is predictable, manageable and pleasurable. Developing knowledge and skills, creating new choices and finding opportunities for personal growth are included in a healthy transition process (13). Caregivers in this study expressed a need for preparedness through knowledge about dementia which would prepare them for the caring role. They also needed support from formal care to manage the transition in a healthy way. Being prepared for what is in store may protect caregivers from adverse outcomes, such as depression, and may provide help with coping (33). An unstable period during the transition will stabilize when caregivers' needs are met. Caregivers in this study were in need of information, knowledge, care and support. They experienced formal care as reactive to their needs. When care and support were unavailable early in the dementia process, the caregivers struggled with the transition process which was not healthy (13). Several of the caregivers found it exhausting trying to find information, care and services. They did not know who to contact within the formal care system. They also experienced the care system as fragmented, with different professionals and organizations being responsible for different types of care and services, as reported elsewhere (20, 34). With increased caregiver strain, as well as unmet needs for formal care and support, caregivers will lack preparedness to provide care and planning for the future (33), leading to an unhealthy transition not facilitated by formal care. In order to facilitate a healthy transition process it is essential that formal care take a proactive approach, providing structured delivery of available options for care and support early in the process of the dementia disease. Interventions to facilitate the transition may be through reminiscence, to integrate the transition into the life course, and role supplementation, to facilitate development of new knowledge and skills. This can be evaluated by measuring process indicators for caregivers' well-being for early detection of difficulties at critical points in the transition, using various assessment instruments (13). A contact person/case manager (35) who can assist navigation through the care and service system may facilitate and promote a healthy transition process for the caregiver when the diagnosis is set.

As the disease progresses the caregiver has increased need for formal care. This is the second turning point in the transition. The participants and formal care at this point shared the responsibility for the care of their person with dementia's care with formal care, implying compromised independence for the participants. Their needs for care and support changed individually. Collaboration with formal care increased to enable them to continue caring at

home. This turning point, meant a new period of instability in the transition process. In such processes, a healthy transition can be described as creating healthy environments. The environment needs to be safe and secure, as well as enable the caregiver to accomplish daily routines. To accomplish a healthy transition related to compromised independence, a caregiver has to find new meaning in their situation (13). Caregivers in this study became in need of care for the person with dementia, help with ADLs and day care or respite care. Their independence gradually became compromised as they adapted to the new situation. At this point, as previously, the participants experienced formal care as being reactive to their needs rather than foreseeing them. Caregivers also experienced insufficient communication and collaboration between professionals in care and services, as also reported in a previous study (36). At this point, professionals should enable a healthy transition, be proactive and provide tailor-made care adapted to individual needs in the caring situation. Professionals also need to communicate and collaborate about care and services with both the caregiver and the person with dementia in understanding and with each other. This can facilitate a healthy transition and the provision of person-centred and tailor-made care when caregivers experience an increased need for formal care to be able to continue caring at home.

Our study revealed a third turning point, of the process in the dementia disease, when the person with dementia moved to an NH because of extensive care needs. At this point, the caregiver, who has had the main responsibility for the care of the person with dementia, is pushed to leave their loved one in the hands of NH staff. They became dependent on the NH staff but tried to stay involved in the care of the person with dementia. This turning point puts caregivers in a new unstable period of their transition. A healthy transition in this process can be described as mobilization of personal resources. Personal inner resources may change during the transition and new resources may be necessary to promote adaptability, coherence, well-being and a healthy life style (13). A trusting relationship with and confidence in formal care seems to stabilize the transition if caregivers are invited by NH staff to be involved in the care of the person with dementia. Professionals need to be proactive and listen to and consult the caregivers as the experts regarding the needs and habits of the person with dementia. In this study, many participants expressed that they felt involved in and informed about the care of the person with dementia and that they trusted the staff. Being involved in the care meant having the possibility to participate in care planning and being listened to, which made caregivers feel confident in the professionals. This is consistent with the findings of Graneheim et al. (4). By contrast, when NH staff did not respond, and sometimes did not even react, to the caregivers' needs the caregivers felt they were being ignored by formal care. They experienced a sense of being abandoned, exploited and unappreciated by formal care, all of which led to an unhealthy transition. One study showed that the staff and caregivers seemed to find it hard to understand each other's expectations and roles (4). Caregivers in our study who were given the opportunity to build trusting relationships with staff at the NH became confident in formal care. It was most important for them to be involved in the care of the person with dementia to remain confident in formal care, which is in line with the findings of Lopez et al. (37). In summary, it is important that professionals should be proactive to facilitate a healthy transition when the person with dementia is moved to an NH because of extensive care needs. Caregivers need to be involved as experts in the care of the person with dementia to build trusting relationships with NH staff. Interventions should monitor the whole transition and measure caregivers' well-being (13).

This study has limitations. There were a wide range of disease processes in the sample, with memory problems ranging from 1½ to 15 years. This may have influenced the results, since it implies a wide range in caregivers' length of experience with formal care. For some participants their experiences were actual, while the experience was retrospective for

others which may have influenced their memory. All participants were born and lived in Sweden, which could limit the results as knowledge from other countries may be valuable. Transferability of the results to other countries may also be limited as other countries may have different care and support systems. In the pilot group, three out of four participants had experience of home care and one participant had experience of both home care and NH care. Both manifest and latent content analysis was chosen to answer our research question. In the study, eleven participants had experience of formal care at home while twelve had experience of formal care both at home and at an NH. Our findings may have been different if separate groups had been selected for home versus NH care, to gain a deeper understanding of each group, or if separate spouse/child groups had been chosen.

Conclusion

The findings indicate that family caregiving requires collaboration with formal care to get support adjusted to individuals' needs specific to individual disease process. Caregivers experience a transition through the process of the disease, with three main turning points: the dementia diagnosis; the point when they realize increased need for formal care in order to continue caring at home; and the point at which the person with dementia is moved into an NH. The participants in this study experienced formal care as being reactive to their needs, leading to unhealthy transitions for the caregiver. Caregivers need formal care to be proactive and deliver available options of care and support early on in the process of the disease to facilitate a healthy transition. Interventions should focus on facilitating the transition to assure caregivers' wellbeing. This can be evaluated by measuring process indicators for early detection of difficulties at critical points in the transition, using assessment instruments for anxiety, depression, connectedness, empowerment and integrity.

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Author contributions

Study design: I.R.H. , Data collection: C.L., A.C.J., Data analysis: C.L., I.R.H., S.K. and A.C.J., Drafting of manuscript: C.L., Critical revision: I.R.H., S.K. and A.C.J., Supervision: S.K. and A.C.J.

Ethical approval

The study was approved by the Regional Ethics Committee in Lund, Sweden, 2010/538. Family caregivers gave written informed consent before the interview.

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References

1. Cahill SM, Gibb M, Bruce I, Headon M, Drury M. I was worried coming in because I don't really know why it was arranged. *Dementia* 2008; 7: 175-89.
2. Lilly MB, Robinson CA, Holtzman S, Bottorff JL. Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada. *Health Soc Care Community* 2012; 20: 103-12.
3. de Jong JD, Boersma F. Dutch psychogeriatric day-care centers: a qualitative study of the needs and wishes of carers. *Int Psychogeriatr* 2009; 21: 268-77.
4. Graneheim UH, Johansson A, Lindgren BM. Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: insights from a meta-ethnographic study. *Scand. J Caring Sci* 2014 Jun; 28: 215-24.
5. Hennings J, Froggatt K, Payne S. Spouse caregivers of people with advanced dementia in nursing homes: a longitudinal narrative study. *Palliat Med* 2013; 27: 683-91.
6. Rose KM, Lopez RP. Transitions in dementia care: theoretical support for nursing roles. *Online J Issues Nurs* 2012; 17: 4.
7. Zwaanswijk M, Peeters JM, van Beek AP, Meerveld JH, Francke AL. In formal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *Online J Issues Nurs* 2013; 7: 6-13.
8. Edberg A-K. *Att möta personer med demens*. (To meet persons with dementia). Lund: Studentlitteratur; 2002.
9. Ward-Griffin C, Hall J, Deforge R, St-Amant O, McWilliam C, Oudshoorn A. Dementia home care resources: how are we managing? *J Aging Res* 2012; 2012: 590724.
10. Health-EU, Information on public health. European commission 2012 [cited 2013]. Definition in formal caregiver. Available from: http://ec.europa.eu/health-eu/care_for_me/carers/io_en.htm (last accessed 9 December 2014).
11. Wimo A, Sjolund B.M, Skoldunger A, Johansson L, Nordberg G, von Strauss E. Incremental patterns in the amount of informal and formal care among non-demented and demented elderly persons: results from a 3-year follow-up population-based study. *Int J Geriatr Psychiatry* 2011; 26: 56-64.
12. The National Board of Health and Welfare. *Demenssjukdomarnas samhällskostnader i Sverige 2012*. (Societal costs of dementia in Sweden 2012) [cited 2015]. Available from: <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19444/2014-6-3.pdf> (last accessed 9 May 2014).

13. Meleis AI. *Transitions Theory: Middle Range and Situation Specific Theories in Nursing Research and Practice*. 2010, New York, Springer Publishing Company.
14. The National Board of Health and Welfare. *Nationella riktlinjer för vård och omsorg vid demenssjukdom 2010 – stöd för styrning och ledning*. (National guidelines for care and service in dementia 2010 - support for governance and management). Västerås, Edita Västra Aros, 2010.
15. Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S. Long-term care placement of dementia patients and caregiver health and well-being. *Jama* 2004; 292: 961-7.
16. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci* 2009;11: 217-28.
17. Schulz R, Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry* 2004; 12: 240-9.
18. Prorok JC, Horgan S, Seitz DP. Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies. *Cmaj* 2013; 185: E669-80.
19. Pinquart M, Sorensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *Int Psychogeriatr* 2006; 18: 577-95.
20. Wiles J. Informal caregivers' experiences of formal support in a changing context. *Health Soc Care Community* 2003; 11: 189-207.
21. Bleijlevens MH, Stolt M, Stephan A, Zabalegui A, Saks K, Sutcliffe C Changes in caregiver burden and health-related quality of life of in formal caregivers givers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study. *J Adv Nurs* 2014; doi:10.1111/jan.12561.
22. Moise P, Schwarzing M, Um MY and the Dementia Experts' Group. Dementia Care in 9 OECD Countries: A Comparative Analysis. In: OECD Health Working Papers (Moise P, Schwarzing M, Um MY eds), 2004. p. 110.
<http://www.oecd.org/health/health-systems/33661491.pdf> (last accessed 18 December 2014).
23. Jansson W, Nordberg G, Grafstrom M. Patterns of elderly spousal caregiving in dementia care: an observational study. *J Adv Nurs* 2001; 34: 804-12.
24. Krippendorff K. *Content analysis : an introduction to its methodology*. Thousand Oaks, Calif.: Sage; 2004.
25. Verbeek H, Meyer G, Leino-Kilpi H, Zabalegui A, Hallberg IR, Saks K. A European study investigating patterns of transition from home care towards institutional dementia care: the protocol of a RightTimePlaceCare study. *BMC Public Health* 2012; 12:68.
26. Karlsson S, Bleijlevens M, Roe B, Saks K, Martin MS, Stephan A, et al. Dementia care in European countries, from the perspective of people with dementia and their caregivers. *J Adv Nurs* 2014; doi: 10.1111/jan.12581.
27. SFS 2001:453. Social Service Act. 2001. Swedish Government.
https://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Socialtjanstlag-2001453_sfs-2001-453/ (last accessed 18 December 2014).
28. SFS 1982:763. Health and Medical Services Act. Swedish Government.
https://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Halso--och-sjukvardslag-1982_sfs-1982-763/

29. Folstein MF, Folstein SE, McHugh PR. Mini-mental state. A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975; 12, 189-98.
30. Krueger RA, Casey MA. *Focus groups : a practical guide for applied research*. Thousand Oaks, Calif.: Sage Publications; 2009.
31. Lincoln YS, Guba EG. *Naturalistic inquiry*. Beverly Hills, Calif.: Sage; 1985.
32. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004; 24: 105-12.
33. Schumacher KL, Stewart BJ, Archbold PG. Mutuality and preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes. *Nurs Res* 2007; 56: 425-33.
34. McCormack B, Mitchell EA, Cook G, Reed J, Childs S. Older persons' experiences of whole systems: the impact of health and social care organizational structures. *J Nurs Manag* 2008; 16: 105-14.
35. You EC, Dunt D, Doyle C, Hsueh A. Effects of case management in community aged care on client and carer outcomes: a systematic review of randomized trials and comparative observational studies. *BMC Health Serv Res* 2012; 12: 395.
36. Sutcliffe CL, Roe B, Jasper R, Jolley D, Challis DJ. People with dementia and carers' experiences of dementia care and services: Outcomes of a focus group study. *Dementia (London)* 2013, 1-9; doi:10.1177/1471301213511957.
37. Lopez RP, Mazor KM, Mitchell SL, Givens JL. What is family-centered care for nursing home residents with advanced dementia? *Am J Alzheimers Dis Other Dement* 2013; 28: 763-8.
38. Elo S, Kääriäinen M, Kanste O, Pölkki T, Utriainen K, Kyngäs H. Qualitative content analysis: a focus on trustworthiness. *SAGE Open* 2014, 1–10. doi:10.1177/2158244014522633.