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RESEARCH ARTICLE

The Shift in Existential Life Situations of Adult Children to Parents with Dementia Relocated to Nursing Homes

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Abstract:

Background:

Previous research describes spouses and adult children of people with dementia as a homogeneous group using one term: family caregivers. Recent research shows that the needs and experiences of spouses and adult children differ, therefore they cannot be studied as a homogeneous group.

Aims:

The aim of the study was to describe the shift in existential life situations of adult children of a parent with dementia relocated to nursing homes.

Design:

This is a qualitative study with an interpretive approach.

Methods:

Face-to-face interviews were held with 11 adult children aged 48-65 years. The interviews lasted 30–60 minutes and data were analysed using interpretive content analysis.

Findings:

The adult children described how they experienced their life situation before and after their parents' relocation. Before relocation they described feelings of powerlessness, loneliness in their responsibilities, loss and guilt. After relocation they had feelings of freedom, ongoing responsibility, living with loss and having a new relationship with death.

Conclusion:

The most important finding in our study was that adult children developed a different relationship with death than before the parent became affected by dementia. It is essential that healthcare staff understand and address the adult children's existential life situations and the suffering they are experiencing. Healthcare staff need to be conscious about adult children's needs for support to address their existential life situations before and after their parents relocate to nursing homes.

Keywords: Adult Children, Dementia, Existential, Nursing Homes, Qualitative Methods.

INTRODUCTION

Previous research has described the spouses (wives and husbands) and adult children (daughters and sons) of people

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with dementia as a homogeneous group using one term: family caregivers. This is problematic as recent research has found that their needs and experiences differ, for example, their needs for social support and assistance [1], and that adult children have greater levels of burden [2] than spouses. Research relating to spouses' and adult children's existential life situation is limited but it is important to explore their experiences separately as we know that these differ but we do not know how. In response to this gap, Høgsnes *et al.* [3] performed a qualitative study describing the existential life situation of spouses when a wife or husband with dementia was relocated to a nursing home. Recognising that the experiences of adult children to a parent with dementia may differ from those of spouses, the present study will instead explore the existential life situation of this group.

BACKGROUND

Family caregivers (*i.e.* spouses or adult children) of persons with dementia experience increased levels of stress and burden [4, 5], that is, their physical, psychological, social, financial [6] and existential life situations are affected [7, 8]. Supporting a person with dementia has a greater impact on daily life for adult children than for spouses, and adult children have previously been reported to experience lower caregiver esteem [9]. The quality of support and need of help from social networks differ between spouses and adult children [4]. This may be related to how the impact is much more acute on adult children's daily lives when caring for the parent with dementia as they have added difficulties such as juggling caring for their own family and working at the same time [5, 10]. Being an adult child of a parent with dementia means acting in the parent's best interests and includes accepting great responsibility in the presence of grief. Their lives are also affected by a continuing feeling of loss, and the anxiety that they, in the future, may become affected by the disease [11]. However, being a daughter or a son to a parent with dementia is also described as a positive experience, as it allows them to spend and enjoy more time together and be close and appreciate each other, resulting in decreased feelings of distress [12].

To relocate the parent with dementia to a nursing home is a difficult decision for the adult child [4]. The relocation process involves realising that the care situation is burdensome, accepting the inevitable decision to relocate and reorienting to the changes [13]. The adult child may also continue to feel the same degree of responsibility that they did before their parent's relocation [14]. The time spent waiting for a placement for family caregivers is a transition that involves feelings of crisis and control, and the time after relocation involves maintaining continuity and adjusting to the change. When a person with dementia is relocated to a nursing home it is important that healthcare staff integrate spouses and adult children as partners in care as they have extensive experience of dementia care [15].

Existential concerns are those that are about people's desire to create and maintain meaning in life [16 - 18], to make their own choices in life and to have meaningful relationships [18]. It is about sustaining purpose and hope [16, 17], and achieving feelings of peace [19]. Existential concerns for both spouses and adult children have been explored by Albinsson and Strang [7], and for spouses alone [3, 8]. Høgsnes *et al.* [3] found that spouses of people affected by dementia who were relocated to nursing homes experienced existential isolation, guilt and shame, and that they, before relocation, had been exposed to threats such as psychological and physical violence. In a recent literature review conducted by the researchers of this study it was shown that there are no known studies that exclusively describe the experiences and life situation of adult children of people affected by dementia when their parents relocate to a nursing home.

AIM

The aim of the study was to describe the shift in existential life situations of adult children when a parent with dementia was relocated to a nursing home.

METHODS

Design

In this study, a qualitative method was used to achieve an understanding about the perceptions of adult children to a parent with dementia living in a nursing home in relation to their life situation. Data were collected with face-to-face interviews to offer an opportunity for participants to tell their stories and to achieve new knowledge about their situation**.** The interviews were analysed with interpretive content analysis [20].

To improve trustworthiness in the present study it was essential to collect rich and appropriate as well as have credibility in analysis and description of findings [21]. Ethical approval for the study was received from the Ethics

Committee of the Faculty at Umeå University (Dnr: 2011-91-31 Ö).

Participants

Purposeful sampling was employed to ensure information-rich cases [22]. Qualitative studies that obtain purposeful samples are more likely to provide in-depth information that is well-suited to the purpose of the study [22]. To recruit participants, the healthcare manager in the municipality was contacted through a letter outlining the background information and purpose of the study. After obtaining the manager's approval, the adult children were identified by nurses at two nursing homes, and a social worker in the municipality who was engaged in family caregiving. These individuals informed the adult children both verbally and in writing about the purpose of the study and asked their permission to be contacted by the first author (LH). For adult children who indicated an interest in participating, the time and place for the interview was agreed upon and written consent was obtained at the time of the interview. The study participants included 11 adult children of a parent with dementia living in a nursing home who spoke and understood Swedish. Demographic data are presented in Table **1**. The adult children were caring for a parent living in a nursing home located in a municipality with approximately 60,000 inhabitants in a rural area of Sweden.

Table 1. Demographics of adult children.

Interview number (IN 1-11)	Age Mean age=59 (48-65)	Gender Women (n=8) Men (n=3)	Time since the parent with dementia moved to a nursing home Median time=2 years (3 months-6 years)	Relationship Married=6 Not married=3 Divorced=2	Number of children (2-4)
1	65	Woman	3 months	Married	2
2	64	Woman	3 years	Married	2
3	58	Woman	5 years	Married	3
4	58	Woman	15 months	Not married	2
5	56	Woman	4 years	Married	2
6	48	Man	2.5 years	Not married	2
7	52	Woman	3 months	Not married	3
8	64	Man	5 months	Divorced	4
9	60	Woman	6 years	Married	2
10	64	Man	3.5 years	Married	3
11	60	Woman	7 months	Divorced	2

Data Collection

Face-to-face interviews were conducted and an open-ended question was asked: "Tell me about your life situation today." The participants were then asked to describe what their lives were like before and after the parent moved to the nursing home. Through follow- up questions, such as "Can you tell me more?", "What did you think?" and "How did you feel?" the depth of the interviews was established. Reflecting about their life situations sometimes evoked strong feelings, so it was important for the interviewer to provide time after the interview for the adult children to talk about their feelings. For some adult children who needed further support, permission for them to make contact with the municipality family consultant was established prior to the study. The interviews were conducted by the first author (LH) in the setting most comfortable for the adult children; namely, in their home or in a private room at the university. Each interview lasted approximately 30 to 60 minutes, and all of the interviews were audio-recorded and transcribed verbatim by the first author (LH).

Analysis

In the present study an interpretive content analysis was completed based on the method described by Krippendorff [20]. In order to interpret conversations about existential concerns it is of great importance to obtain a sense of the participants' feelings to achieve rich information. To sustain these interpretations at different levels, the analysis process was reflexive and interactive, which meant including what emerged within, among and throughout the texts [23]. The interviews were first listened to, read and reread by the first author to get a sense of their content. Text relevant to the aim of the study was marked, condensed and labelled with codes. An example of the analytical process adopted in this study is presented in Table **2**. Codes with similar content were grouped together in two domains and abstracted into preliminary themes. To achieve a deeper interpretation, we used a reflective process that involved working back and forth among the meaning units, codes and preliminary themes. To improve credibility, all authors were involved in the analysis process, from reading and coding the interviews to the final step, in which the themes were discussed and reformulated until consensus about the final themes were reached.

Table 2. Example of the analytical process for the two domains with meaning units, condensed meanings units, codes and themes.

Domains	Meaning units	Condensed meaning units	Codes	Themes
Before relocation	So I think it has been a huge responsibility lying on me, and just because she refused help from someone outside the family and it was so tough, it was tough like And I was forced to take care of everything, such as cleaning, shopping and washing clothes because there was nobody else who could do it.	It has been a responsibility especially after she has refused help from others. I was the one with the whole responsibility because she couldn't handle cleaning, shopping and washing clothes.	Whole responsibility	Being powerless
After relocation	But it is tragic, so extremely tragic that it has to be like this. It is better that you die in the step (suddenly/abruptly) than having to the body ending before the head (mentally)	It is tragic that it has to be like this. It is better to die abruptly. The body should go before the head somehow.	Die gradually	Having a new relationship with death

FINDING

The findings of this study showed that the adult children's existential life situation was about living with an altered relationship with death, feelings of never-ending responsibility, and being imprisoned. The findings are presented as four themes within two domains (Table **3**). The themes are illustrated with quotations and marked with each interview number (IN 1-11; cf. Table **1**).

Table 3. Overview of domains and themes.

Domains	
Before relocation	After relocation
Themes	
Being powerless	Feelings of freedom
Feelings of loneliness in their responsibility	Having ongoing responsibility
Feelings of loss	Living with losses
Feelings of guilt	Having a new relationship with death

Before Relocation

Being Powerless

The adult child cared for their own home and family while having the added responsibility of caring for their ill parent. This was complicated and generated feelings of powerlessness because it meant supporting someone who did not understand that he or she needed help. Participants perceived themselves as "beating their heads against a brick wall" (IN 1).

"You feel greater demands periodically than you can cope with ... so yeah, it is as it is; you might get a little snappish and ... feel inadequate" (IN 2).

To experience this kind of powerlessness made them feel completely exhausted, inadequate, and constantly anxious. Their life situation became limited as they were constantly disrupted, for example, if the ill parent called on the telephone up to 150 times in one day, sometimes with one to a few minutes between calls:

"Like when she called all the time, and she began to cry and said: 'Can't I call you anymore?' I said, 'Of course you can, but it's better you call when you get an answer than calling the answering machine a hundred times.' But at the same time, I understand that she thinks she hasn't called because she doesn't remember calling" (IN 8).

Feelings of Loneliness in their Responsibility

Participants described that they had the whole responsibility for caring for their ill parent, and some felt compelled to do it because no one else would. The ill parent could express that he or she would not accept help from anyone other than the adult child, which made the child feel alone in their responsibility. Cooperating with the community healthcare service could be a struggle and they felt like they were the only person with the ultimate responsibility for the ill parent:

"I looked in the kitchen after the home care services had been there in the morning and arranged his breakfast with sour milk. But he (the father) could not get up from the chair he was sitting in (in another room). I was crazy about it and so mad because I had been enduring for so long and I struggled just to be able to have a conversation with the home care service" (IN 10).

Feelings of Loss

Feelings of loss were described in terms of seeing their parent transform into an unknown person. The parent's personality could change from being someone who is kind and happy to a totally helpless person who behaved inappropriately. "There was a time when she had been out in her nightdress, a neighbour told me. At that time I felt that this is not my mum, she would never do that normally … she would never go out undressed" (IN 4). The loss entailed sadness, and the participants found it hard to go about their lives realising that the parent they knew was fading away.

Feelings of Guilt

The adult children's life situations were embossed with feelings of having bad consciences because they felt they should always be doing more. Even if they knew they had done their best, they experienced guilt and shame. Being unable to have a conversation and discuss things with the ill parent also generated feelings of guilt because the adult children felt they were forced to make decisions over their parents' heads. Feelings of betrayal were also present in their relationship with the parent, who had always been there for them:

"Then you have such an incredibly bad conscience and you are ashamed of yourself. What have I done to my mother, my mom who has always been there for us, and we had a good childhood and everything. And now I am doing this to her" (IN 3).

After Relocation

Feelings of Freedom

The relocation to a nursing home enabled the adult children to relax and let go of worry, and they felt they were slowly recovering their sense of freedom. They had full confidence in the staff and that the parent was in a safe environment and that their basic needs were being satisfied: "I can relax and travel without one foot at home, and psychologically I feel much better. Everything is because she is in a great place with her stuff, and I don't need to worry at all, so things can take their natural course" (IN 10). The feeling of freedom also included feelings of emptiness: "But earlier, when she called constantly, then I felt very stressed by that, which meant after the relocation I felt as I had forgotten something and wondered about why I felt so free" (IN 8). At the same time much of the self-imposed demands they had seemed to stop, and the adult children felt that they were freer to take care of themselves and their own families.

Having Ongoing Responsibility

The adult children continued to assume responsibility after their parents moved to the nursing home. They continued to wash clothes, ensure that the parents took their medicine and make sure that their parents' apartments were cleaned. By visiting the ill parent often, they were able to control the new situation while they socialised with the parent. A feeling of moral responsibility was also expressed related to the consequences of the relocation, prompting them to continue to visit and support the other parent. Feelings of guilt for having betrayed the parent were also a part of this moral responsibility because they knew that moving to a nursing home would have been the worst scenario from the ill parent's point of view. They also felt guilty about how often they should visit the parent and they felt that they should visit more often than they did, and they asked themselves, did they visit because they felt a genuine desire to do so? Taking responsibility for the parent's happiness and well-being at the nursing home by keeping the parent engaged in activity was also essential: "I feel like it mainly is we or I who have to be sure that she doesn't feel bored" (IN 8).

Living with Losses

The adult children described the loss of the parent they had always known and how they coped by holding on to their memories of the healthy parent in their hearts. For example, situations occurred at the nursing home in which the parent had done strange things. This was described by participants as something they could cope with because it felt as though the staff members were talking about a completely different person:

"Occasionally, I sit there and look at her, and the feeling for her comes over me, and I have to take a walk in the corridor, because then I remember how it was before" (IN 3).

Some adult children tried to accept the 'new' parent and they described how, through physical contact or calling before visiting the nursing home, they attempted to optimise the chance that the ill parent would remember them; however, not being recognised by a parent was described as an extremely difficult loss:

"That she does not recognise you, that's one thing, but not being able to give her a hug that perhaps could help her remember you, that's tough" (IN 6).

Having a New Relationship with Death

Participants described that they experienced that death took on a new form: "Now she is there, and death is dressed in new clothes, in a way" (IN 7). This new relationship with death was related to their parent's forthcoming death, but also to the adult children's own mortality. As the dementia disease progressed, they felt that their ill parents were already dead:

"No, it is a hassle to see a human so filled by life as all human being are, and then it is nothing and then I can't understand the way you have to live; there are no meanings at all" (IN 6).

This was challenging, especially when the ill parent told them that they were socialising with people who had died many years before but they did not remember that they had died: "At times, she hung out more with people who were dead than with people who were living" (IN 9). Thoughts about the participant's own mortality were associated with seeing their ill parent deteriorate. They described having a fear about the risk of developing dementia themselves, and worried about their siblings' health.

DISCUSSION

This study provides a picture of adult children's existential life situations before and after the relocation to a nursing home of their parents affected by dementia. Our study confirms the findings of previous research about, for example, adult children's caregivers' distress [24], changed relationships [25], and guilt over placement [14]. The present study, supported by Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken [26], highlights the sense of powerlessness felt by adult children; they were completely exhausted and worried as they began to realise the impact of the disease on their life situation. Feelings of responsibility described to a great extent the practical responsibilities related to taking care of the ill parent before and after relocation, although the participants also expressed feeling a moral responsibility to provide care, especially after relocation. This sense of responsibility meant feelings of having a guilty conscience and a duty to make sure that the parent was cared for, which included ensuring that the nursing home staff were doing their jobs properly [7]. Even if the responsibility was basically voluntary and something the participant wanted to do, feeling alone in their responsibility, together with feelings of duty, trapped them in a situation that wore them out [11], and the decision became less voluntary [27]. The feeling of freedom meant sharing the responsibility with the staff at the nursing home, and this space that was created in their life situation could, according to Frankl [28], generate an opportunity to resume their previous relationship as child and parent. The duality between freedom and responsibility after the parents' relocation can be interpreted as an indication that the adult child no longer felt alone in their responsibility and therefore were freer to choose whether they were willing to take on that responsibility. According to Frankl [28], it is through responsibility that humans discover meaning in life, and feelings of guilt may deepen the relationship, which, in turn, according to Sand, generates personal growth [29]. Feelings of loss and living with loss affected the adult children from the beginning of the parent's disease to after their relocation to a nursing home. Such losses can be explained in terms of ambiguous loss, the loss perceived when a person is physically present but psychologically absent [30]. Dupuis [31] described this ambiguous loss as an on-going process with three phases: anticipatory, progressive and acknowledged loss. The anticipatory loss relates to the uncertainty of the future, the progressive loss describes the pain that the adult child feels watching the deterioration of the parent effected by dementia parent, and the acknowledged loss is characterised by the realisation that the parent is no longer present psychologically. The process of living through these phases was also expressed by the adult children in our study, but what differs is that the feeling of loss began some time before their parent's relocation. Our results indicate that when the ill parent no longer existed psychologically the adult children felt that they could no longer fully participate in the ill parent's life. This might be understood as feeling that their parents had abandoned them, which is consistent with the findings of Kjallman-Alm [11]. This interpersonal separation compels the adult children to encounter existential isolation, which is the price they have to pay to separate themselves from the ill parent [18]. Feelings of loneliness may be an expression of existential isolation, and an indication that the adult children are preparing themselves to live their lives without the parent. The feeling of loneliness as an indicator of the preparation to part from the ill parent may be a way accept the loss of a the parent and an important transition that adult children and other family caregivers have to go through or, as Dupuis [31] describes, as a coping strategy to go on with life.

The adult children felt pushed into a life situation in which they had to manage being in an additional relationship with death. Death was viewed as an extended process and as an end to suffering that would ameliorate the feeling of meaninglessness. If this pre-death grief and ambiguous loss remains unresolved, grief can be complicated and prolonged even after the parent has died [32]. An interesting finding in the present study was that the participants described having developed a new relationship with death, one that involved having to deal with situations in which the ill parent talked about people who had already died as if they were living and had visited them. According to the German philosopher, Heidegger [33], humans basically avoid talking about death because of the painful vulnerability that death arouses in them. In our study the adult children became distressed when their parents socialised with and spoke about people who had been dead for several years. This situation may awaken a conflict related to the adult child's own perceptions about death and therefore they became distressed and could not endure these kinds of conversations. The healthcare staff at nursing homes are accustomed to dementia patients who socialise with death in an everyday context and treat this as normal, although they need to understand that this situation is new and different for the adult children. The adult children's avoidance of conversations about death might be an obstacle to developing the courage to confront their own death and to making meaning out of a life that is limited.

Methodological Consideration

In qualitative studies, trustworthiness is established through such concepts as credibility, dependability and transferability [34]. These concepts underpin the entire process of this study from planning the study to analysing data and, finally, presenting the findings. Trustworthiness was also improved by having all of the authors involved in the entire research process.

The representativeness of this relatively small sample of 11 adult children of persons with dementia was balanced with the information-rich interviews gathered by using purposeful sampling. A retrospective approach can be seen as a limitation; however, the adult children participating in the study said that they thought it was important to participate because they felt they could help other people in the same position. According to Coughlin [35], such motivations encourage participants to provide accurate and complete information in interviews. In our study, the length of time since the parent with dementia had relocated to a nursing home was between 3 months to 6 years. There is a risk that the different lengths of time may have affected the participants' descriptions; however, there was no difference in the number of codes before and after relocation in terms of the length of time since the relocation. The use of open-ended question was a strength of the study, because it gave the participants opportunities to freely talk about their experience of living with a parent with dementia; however, the interviews were also guided with follow-up questions.

In this study of adult children's existential life situations, different themes emerged than those reported in a similar study of the existential life situations of spouses [3]. This difference highlights the importance of studying the two groups individually.

CONCLUSION

The most important finding in our study reveals that adult children developed a new and different relationship with death compared to that of before the parent became ill with dementia. Furthermore, adult children need support and help from healthcare professionals when existential issues such as powerlessness, loneliness, loss and guilt are present. More research is necessary regarding the development of this particular knowledge in order for healthcare staff to recognise and address these needs.

Implications for Practice

Healthcare staff in nursing homes are accustomed to communicating with spouses and adult children about the life situations of patients affected by dementia, but to talk about existential issues can feel strange and awkward. It is essential for staff to understand and address the adult children's existential life situation and the suffering they are experiencing, and recognise that the their existential life situations are not the same as the existential life situations of spouses of dementia patients [3] and for that reason the adult children need individualised support. Future studies are needed to focus on how healthcare staff perceive adult children's existential life situations.

CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

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Declared none.

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