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Mohrsen Busted, Laila; Nielsen, Dorthe Susanne; Birkelund, Regner

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The experience of being in the family of a person with early-stage dementia - a qualitative interview study

Laila Mohrsen Busted1,2, Dorthe S Nielsen2,3, Regner Birkelund1
1 The Department of Regional Health Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark
2 The Health Sciences Research Center, UCL University College, Denmark,
3 Migrant Health Clinic, Odense University Hospital, Center for Global Health, University of Southern Denmark

Abstract

Background: A dementia diagnosis has a major effect on the lives of many people in addition to the patient. Persons with dementia often depend on their families to maintain their independence and well-being. When illness strikes one family member, it disrupts the entire family and has consequences for all family members. To improve caring for families with dementia, we need to better understand how family members experience being in the family of a person suffering from dementia.

Aim: To explore the experience of being in the family of a person suffering from early-stage dementia.

Method: A qualitative study was conducted with 17 family members to persons with dementia. The study used semi-structured interviews and data were analysed using Braun and Clarke’s model for thematic analysis.

Results: Through analysis and interpretation of the data, four themes were identified: (1) Living with a stranger in the family. (2) Being trapped in a changed relation. (3) Being short on time. (4) Depending on each other in a new way within the family. The findings show that dementia illness has a large impact on relations within and across the family and relatives are forced to change their roles within the family.

Conclusion: The results of this study contribute to extending the knowledge about dementia and its impact on the family members by illustrating changes in the interactions within the family. Support from health care professionals may be beneficial in aiding family members to cope with the new situation within the family following the dementia diagnosis.

Introduction

Dementia is a disease in which the family plays a significant role in caring for and protecting the family member suffering from dementia (1). Kaakinen (2015) defines a family as two or more individuals who depend on one another for emotional, physical and economic support (2). The members of a family are self-defined and can include spouses, children and extended family or friends. Family members can also be important resources and collaborators for healthcare systems taking care of the person with dementia (3). The WHO finds that the impact of dementia falls most heavily on the family member who assumes the primary role for providing care but that the entire family is the cornerstone of caring for relatives with dementia (4). Help from family caregivers allows persons with dementia to remain living in their own homes and communities, and the family is recognized as an important factor in maintaining the independence and well-being of persons with
dementia (5). The person with dementia is then dependent on family members and the health care system for care and protection to maintain his or her daily life at home.

Dementia is overwhelming not only for the people who suffer from it but also for their caregivers. Since dementia affects memory function, thinking behaviour and the ability to perform everyday activities, the demands of caring for a person with dementia can cause frustration for family caregivers helping the individual with daily activities, which can lead to feelings of burden and stress for the caregivers (4). A dementia diagnosis has a major effect on the lives of many people in addition to the patient (6). Caregiving is described as physically and emotionally demanding, and caregivers experience a burden that has significant implications for their own health and well-being (7). People suffering from dementia have complex needs, and their relatives are at constant risk of becoming burned out (5); therefore, living with dementia within the family is both an individual concern and a family matter. According to the literature on illness in families, the entire family is affected when one member of the family becomes ill (8). Each person in a family plays a specific role in the family’s everyday life and routines; thus, when illness strikes one family member, it disrupts the entire family and has consequences for all family members. Caregivers of persons with dementia are at risk for mental and physical health problems because of caregiver burden.

Studies have examined how caregiving affects different types of relationships within the family. The spouse of a person with dementia experiences changes in the marital relationship and loses both a partner and a marriage (9,10). In some families, providing care for a person with dementia has a profound effect on the relationship of married couples; it is a confusing time because of the changes to roles and identities, as one spouse becomes more of a parent and the other becomes more of a child (9). Spouses may experience distress and anxiety long before their partner is diagnosed with dementia, and the greatest challenge described by spousal caregivers is disturbed communication that increases negative perceptions of relationship quality (11). Furthermore, the literature reveals that adult children experience caregiving as extra work and experience burden as roles change. Some adult children have very difficult life situations and may experience a significantly higher burden than the adult spouses of people with dementia, as the adult children are more likely to have multiple demands related to their own home, interests, work and the caregiving role, all of which contribute to their burden (12,13). One study describes the experience of being an adult child caregiver as more upsetting, more challenging and more stressful than that of being a spouse caregiver. Caring for a parent adds a responsibility that entails stress and anxiety for adult children, leading to increased burden (14). Younger children of persons with dementia describe not liking their ill parent anymore, and they express a preference for other illnesses or even death because of the difficulties involved in managing the changed personality of their parent (15). Caring for a person with dementia poses several challenges. However, research finds that caregivers can have good psychological well-being, despite the various challenges associated with caregiving, and that family members have the capacity to cope, adapt and grow through their experiences (12,16,17). Being the family member of a person with dementia can have negative consequences for the family and the family members as caregivers while simultaneously creating positive meaning for the family members as caregivers. Providing care to a family member seems to be a complex phenomenon.

The experience of being in the family of a person with dementia differs for spouses and adult children, and the research finds that stress seems to increase conflict in the family, particularly conflict between siblings (18). Since previous research has focused primarily on individual family members’ experiences and perspectives, studies from a family perspective that explore the interplay in family relationships when a family member has dementia are warranted. After a person with dementia is
diagnosed with dementia, it is important for nurses and other health care workers to know about the lived experience of being in a family with a person with dementia as a socially embedded phenomenon and to understand how family caregiving impacts the family as a unit. To enable the adoption of a family approach and to support families suffering from dementia, there is a need for empirical studies focusing on how families as a unit experience having a family member with dementia. More research knowledge that elucidates the family’s experiences is needed for nurses and other health care workers to understand and recognize the challenges, worries and concerns that arise within and across the family so that they can provide appropriate care and support. The aim of this study was to explore the experience of being in the family of a person suffering from early-stage dementia.

Method

Design
The study used a qualitative design inspired by a hermeneutic phenomenological approach to provide rich and detailed accounts of the lived experience of being in the family of a person with dementia (19). The study was conducted by using semi-structured interviews inspired by Kvale and Brinkmann, and the data were analysed using Braun and Clarke’s model for thematic analysis (20). Thematic analysis is a tool unbounded by theoretical commitments for identifying, analysing and interpreting patterns within a qualitative paradigm across data in relation to participants’ lived experience, views and perspectives to understand what participants think, feel and do (21).

Participants
The participants were relatives of a person with dementia over 65 years of age. The participants’ ages ranged from 42 to 76 years old. In total, 12 different families were invited to participate in the study. One husband, one sister, five wives, five daughters, three sons and two daughters-in-law were interviewed about their experience having a relative diagnosed with dementia and being a family. See table 1 for a description of the participants and their relation to the person with dementia.

The participants were recruited from an educational course at a university hospital, where the relatives were invited to an evening meeting about Alzheimer’s disease and other dementia illnesses. The meeting was held by the consulting doctor at the memory clinic. The audience was primarily family members of persons with dementia who had been diagnosed within the last year, but it also included family members who had only recently accepted the diagnosis given to the person with dementia. The first author introduced the study after the consulting doctor’s presentation, and the participants gave their consent to be contacted in the following days by sharing their telephone number. To be eligible for the study, the participants had to be a family member of a person with dementia who was diagnosed within the last year or they had to have recently accepted their family member’s diagnosis. In total, 17 informants from 12 families participated in the study; see table 1 for a description of the participants.
Table 1: Description of the participants.

<table>
<thead>
<tr>
<th>Family</th>
<th>Informant, age</th>
<th>Relation to the person with dementia, diagnose and age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family A</td>
<td>Wife, 76</td>
<td>Husband with Alzheimer’s disease, 85</td>
</tr>
<tr>
<td>Family B</td>
<td>Wife, 68</td>
<td>Husband with Lewi Body disease, 72</td>
</tr>
<tr>
<td>Family C</td>
<td>Husband, 70</td>
<td>Wife with Alzheimer’s disease, 74</td>
</tr>
<tr>
<td>Family D</td>
<td>Son, 49</td>
<td>Mother with Alzheimer’s disease, 70</td>
</tr>
<tr>
<td></td>
<td>Daughter-in-law, 42</td>
<td></td>
</tr>
<tr>
<td>Family E</td>
<td>Daughter, 56</td>
<td>Mother with Alzheimer’s disease, 87</td>
</tr>
<tr>
<td>Family F</td>
<td>Daughter, 57</td>
<td>Mother with Alzheimer’s disease, 89</td>
</tr>
<tr>
<td>Family G</td>
<td>Daughter, 51</td>
<td>Mother with Alzheimer’s disease, 77</td>
</tr>
<tr>
<td>Family H</td>
<td>Wife, 74</td>
<td>Husband with Alzheimer’s disease, 81</td>
</tr>
<tr>
<td></td>
<td>Son, 52</td>
<td>Husband/father with Alzheimer’s disease, 82</td>
</tr>
<tr>
<td></td>
<td>Daughter-in-law, 48</td>
<td></td>
</tr>
<tr>
<td>Family I</td>
<td>Wife, 76</td>
<td>Husband/father with Alzheimer’s disease, 82</td>
</tr>
<tr>
<td></td>
<td>Son, 52</td>
<td>Mother with Alzheimer’s disease, 71</td>
</tr>
<tr>
<td>Family J</td>
<td>Daughter, 57</td>
<td>Mother with Alzheimer’s disease, 71</td>
</tr>
<tr>
<td>Family K</td>
<td>Wife, 67</td>
<td>Husband with Lewi Body disease, 69</td>
</tr>
<tr>
<td>Family L</td>
<td>Sister 72,</td>
<td>Sister/mother with Alzheimer’s disease, 76</td>
</tr>
<tr>
<td></td>
<td>Daughter, 51</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Son, 47</td>
<td></td>
</tr>
</tbody>
</table>

Data collection
The data were collected from November 2016 to February 2017. The interviews were conducted in a location chosen by the participants. One participant chose to be interviewed in her workplace in an undisturbed office, while the rest of the participants invited the interviewer to their homes. For both practical and ethical reasons, the interviews were sometimes conducted individually and sometimes conducted as dyad or group interviews. All the interviews were audiotape recorded and transcribed verbatim by the interviewer. The interviews lasted between 29 and 75 minutes. An interview guide was developed based on topics established in the existing literature about family members’ experiences of being a relative of a person with dementia. During the interviews, the participants were
asked open-ended questions such as, “Please tell me how it has been for you as a person to be a family member to your father with dementia, and please tell me how it has been for you as a family?” and “What has been most challenging for you as a relative to your mother, and what is most challenging for you as a family?”.

Data analysis

Braun and Clarke’s six-stage process of thematic analysis was used to identify the challenges experienced within the family. As an inductive approach to the thematic analysis was used, the codes and themes were developed from the data content. First, the data were read and reread several times; then, coding and analysis were performed. In the second step of the analysis process, the data were coded using broad codes such as “spouses’ feelings” and “adult children’s feelings”. In the third step of the six-stage process, a broad pattern of meaning was identified, and the codes were revised to add more detail, producing more complex codes such as “changing roles in the relationship” and “feeling trapped in the relationship”. The codes were then collated to develop potential themes. In the fourth step, the themes were reviewed and verified in relation to the coded extracts, and a thematic map of the analysis was created. In the fifth stage of the analysis process, initial themes were identified by the first author and discussed with the second author who independently read and coded the interviews. All three authors participated in detailed discussions aimed at identifying and refining the themes to obtain agreement in the sixth stage, and the final themes related to the research question were written as an analytic narrative. For an example of the analysis process from reading the data to creating the themes, see table 2. The findings were discussed in relation to existing research and interpreted according to theoretical perspectives.

<table>
<thead>
<tr>
<th>The Data</th>
<th>Codes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>“It’s like another man, according to his personality” (wife, family K).</td>
<td>The person with dementia is changing into someone you do not know</td>
<td>Having a stranger in the family.</td>
</tr>
<tr>
<td>In the beginning, he (my brother) thought we all exaggerated the situation… He was of the opinion that our father was old and couldn’t remember but that it was just normal …” (son, family I)</td>
<td>Difficult agreeing within the family on the new situation and how to deal with this changed behaviour.</td>
<td></td>
</tr>
<tr>
<td>We have our roles in the family; my brother takes care of my mother’s finances, my sister takes care of helping her buying new clothes and when it comes to not being well, she calls me. It has always been like that” (daughter, family E).</td>
<td>Naturally finding roles within the family</td>
<td></td>
</tr>
<tr>
<td>“he only wants ME to put it on and is quite aggressive to me. But, I am doing it…” (wife, family H).</td>
<td>Need for unwanted changed role to become a care assistant.</td>
<td>Being trapped in a changed relation</td>
</tr>
<tr>
<td>“He can’t complete the tasks anymore. To say it rudely, he has become lazy….! Now, it is me who must tell him to do this and do that around the house, and to do it now—or do it myself...” (wife, family B).</td>
<td>Need for unwanted changed role to become a handy man.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Need for unwanted changed role to become a guardian.</td>
<td></td>
</tr>
</tbody>
</table>
“I always make sure he wears a phone, so I can track him on Find My iPhone... It is hard to accept to it myself” (wife, family K)

“...make sure to hold on to love and stay positive, they say... Yes, of course, I would love to, but I am used to another husband who isn’t stupid...!” (wife, family K).

“We (the family) spend a lot of time with each other, I believe that if there is something I would like to do with her, I must do it now...” (daughter, family G)

“When my husband says, he would like to go for a walk, I leave what I am doing at once. Then, we go. One day I may not have the chance to go for a walk with him. Then I must go alone... I need to get the best out of the time right now...” (wife, family I)

“...pleas tell us if you need something...” (son, family D).

“I don’t want to lose going to the theatre with my good friends once a month... if so I have nothing at all” (wife, family A)

“...If I’m going out, it can’t be at the expense of my children...” (husband, family C)

Awareness of the time running out

Need to enjoy the remaining time at any expense.

Pledged to enjoy the remaining time as a strain

Adult children not knowing how to help parents and being dependent of the healthy parent to tell how to help.

Need for social relationships and being dependent of the adult children to accept and support the decision to keep social life.

Not asking for help from adult children

Being short on time

Depending on each other in a new way within the family

Ethical considerations

The participants were introduced to the study both verbally and in writing, and they all gave written consent to participate. The researchers respected situations in which the participants wanted to include another family member in the interviews and conducted the interviews individually, as a married couple and as group interviews. All the participants were assured that their participation was voluntary and that they could withdraw from the study at any time without giving any reason. The participants also received assurances of anonymity and confidentiality (22). The Danish Data Protection Agency approved the study in accordance with the Act on Processing of Personal Data No. 2015-57-0016. Ethical clearance was obtained from a Danish Regional Committee on Health Research Ethics (S-20162000-158), and approval was not required according to Danish law. The study was conducted in accordance with the Helsinki Declaration.

Findings

The analysis identified four themes that clearly illustrated some of the most common experiences the families described: Living with a stranger in the family, being trapped in a changed relation, being short on time and depending on each other in a new way within the family.

All the family members experienced many challenges when the personality of their relative with dementia changed. Even small changes in personality were experienced as significant changes by the
family as a whole. The roles within the family changed by necessity when the family members were forced to assume the roles typically held by the person with dementia, and the family had to adjust to this new and unavoidable situation.

Living with a stranger in the family
The trajectory of dementia was expressed as an emotionally difficult time with many suspicions and frustrations. The personality of the person with dementia had changed over time before his or her diagnosis, and at the time of diagnosis, it became clear that the radical changes in the person with dementia were inevitable. The wife of a person with dementia explained that she felt that she had to become acquainted with a new husband: “He’s like another man, according to his personality” (wife, family K).

Some of the interviewees expressed frustration with their own feelings, including not liking the new and strange personality of the family member suffering from dementia and feeling irritated by the individual’s new personality. The participants also described feelings of love and loyalty towards the person with dementia, which made their feelings ambivalent and difficult to manage. It was common for families to experience disappointments and wonder what was happening for a long period of time since the behaviour of the person with dementia changed.

Some of the participants explained that sometimes when other family members came to visit, the relative with dementia made an effort to become the person he or she used to be, causing confusion among family members since they experienced different behaviour from the person with dementia. This could result in disagreements and misunderstandings within the family because some of the family members did not see the parent’s changed behaviour, while others did. A son expressed this disagreement with his brother: “In the beginning, he (my brother) thought we all exaggerated the situation… He was of the opinion that our father was old and couldn’t remember but that it was just normal…” (son, family I). This type of disagreement in the family was challenging and impacted the relationships between all members of the family, and the family members described the difficulty involved in coming to agreement on how to cope with the new situation and the risk for potential conflicts between the family members.

Being trapped in a changed relation
The family members noted that they found themselves assuming different roles within the family in relation to the person with dementia. Some of the roles were distributed naturally in many of the families according to their family history. “We have our roles in the family; my brother takes care of my mother’s finances, my sister takes care of helping her buying new clothes and when it comes to not being well, she calls me. It has always been like that” (daughter, family E).

However, as the behaviour, physical ability, and psychological capacity of the person with dementia changed, the family members explained that they found themselves adversely trapped in a changed relation with the person with dementia as family roles continued to change. The participants described the different roles to which individual family members had to adjust and noted that family members were not always comfortable identifying with these roles. This change could be challenging for the individual family members and the family as a whole. This situation required a level of agreement within the family to acknowledge the necessity of dividing the new roles among family members, and time was required to determine who would do what in order to compensate for the person with dementia.
One role that family members assumed was the role of a care assistant. According to the respondents, when the family member with dementia lost the ability to take care of himself or herself, relatives began checking on him or her. Relatives then became responsible for helping with personal hygiene and make-up, making sure the person with dementia had clean clothes, assisting with showers or ensuring there was food in the house. Helping the person with dementia could be a very difficult experience for the relative. A wife explained how her husband with dementia wanted her to put on a uridine: “he only wants ME to put it on and is quite aggressive to me. But, I am doing it…” (wife, family H). The consequences of assuming the role of a care assistant threatened the habitual relationship between spouses; wives had difficulty considering their husbands as men, and the marriage was challenged because the couple was not having an intimate relationship. Adult children had difficulty seeing their mother or father as a parent, and the relationship changed such that adult children began to consider the parent as a child they had to look after to ensure that his or her basic needs were met.

A second role that family members assumed was that of a handyman. Family members had to assume household and financial responsibilities to compensate for the person with dementia and his or her inability to manage the family’s finances and the practical functions of the house, and many family members noted that this was a challenge. The person with dementia lost the ability to do what he or she used to do, and this forced family members to adapt to new roles that they did not choose but that were necessary to compensate for the lost abilities of the person with dementia. Those duties could include gardening, housekeeping, and managing finances. This new role was described as difficult to adapt to and clearly generated some frustration in the relationship between the person with dementia and the family. The adult children found themselves maintaining two houses, which became a challenge for their own family and their work life. The changes in roles impacted close relations. A wife expressed her frustrations: “He can’t complete the tasks anymore. To say it rudely, he has become lazy...! Now, it is me who must tell him to do this and do that around the house, and to do it now—or do it myself...” (wife, family B). This quote underlines the difficulty that family members experience in accepting the unwanted situation in which a person with dementia can no longer do what he or she used to do and in which a family member must adapt to an undesirable role that involves delegating and performing tasks to compensate for the person with dementia.

Family members found themselves in a third role, that of a guardian. The family members’ relationship with the person with dementia changed from being equal and built on love to a relationship with a strange person who they were forced to monitor and supervise. The participants responded to this change in different ways; for example, they began calling the house to make sure the relative with dementia was home or they began checking on the person with dementia. The family members explained that they began replacing candles in the house with battery-powered candles. According to one son of a mother with dementia, “There are so many things she can’t manage anymore, so we cut the bread to prevent her from cutting herself, remove old food so she won’t eat it... We don’t find our role as relatives’ care-requiring but visit-requiring...” (son, family D).

Family members also became guardians because of their concern that the person with dementia could become lost. Stories about people with dementia becoming lost caused many worries for the participants. One wife ensured that her husband with dementia always carried a phone in his pocket when he left the house, so he could be monitored via GPS: “I always make sure he wears a phone, so I can track him on Find My IPhone... It is hard to accept it myself” (wife, family K). It is often embarrassing for relatives to admit this concern to themselves. It is an ambivalent feeling, as guardians find it necessary to protect the person with dementia and keep him or her safe while...
simultaneously feeling paternalistic towards the person with dementia because they must monitor the person they love.

The above findings underline that the relation between relatives and a person with dementia changed from building on love and affection to focusing on control and monitoring. Losing a relative is difficult for family members, and they automatically assume these roles without recognizing that they are doing so. Family members may find themselves trapped in an obligated relation with the person with dementia and the rest of the family because they had to accept a new role and relationship and could not see any way to avoid it.

Being short on time
When family members acknowledged the dementia diagnosis and what it means, they also acknowledged that the time they had remaining with their family member was running short, and this had a primarily positive meaning for the family. The possibility that the person with dementia might one day lose the ability to speak, recognize the family and die from dementia motivated the families to get the most and the best out of their remaining time together. A daughter expressed, “We (the family) spend a lot of time with each other. I believe that if there is something I would like to do with her, I must do it now...” (daughter, family G). Having a loved relative diagnosed with dementia and acquiring knowledge about dementia was a wake-up call for the family and had an impact on the relations within the family.

The family members experienced the dementia diagnosis as a state that could bring something positive to the family; some family members explained that the illness brought their family closer together and that they found themselves in a situation in which they could talk about their feelings with the person with dementia and focus on doing things together to create good memories. Family spirit became more valued by the family members. One wife explained: “when my husband says he would like to go for a walk, I leave what I am doing at once. Then, we go. One day I may not have the chance to go for a walk with him. Then, I must go alone... I need to get the best out of the time right now...” (wife, family I).

Getting the best out of their remaining time together was an expectation for individual family members and an obligation to the lived relationship with the person with dementia, and it involved making sure to enjoy the moments experienced in the present. Living up to one’s expectations and the pressure from the rest of the family to get the best out of the remaining time could also be experienced as exhausting. One wife explained how her adult children encouraged her and her husband to hold on to the love in their marriage: “...make sure to hold on to love and stay positive, they say... Yes, of course, I would love to, but I am used to another husband who isn’t stupid...!” (wife, family K). Her husband’s behaviour had changed so much that she felt challenged and found it difficult to find the love that she previously had for her husband. The expectations became a burden to the healthy spouse, and it was a challenge to meet the adult children’s expectations along with the other obligations of everyday life. The situation in which some family members prioritize spending and enjoying the remaining time with the person with dementia to create happy family memories while other family members are burdened and experiencing difficulties may be challenging for the family. Family members’ expectations for one another could create negative challenges and conflicts in the relationships between family members.

Depending on each other in a new way within the family
The family members depended on each other in different ways. A healthy parent depended on his or
her adult children, and adult children depended on the healthy parent and their siblings. Complex relationships evolved within the family of a person with dementia as roles and expectations for each other changed. Family members gradually became aware of new dependencies within the family.

During the interviews, it became evident that in families without a healthy parent, the adult children were dependent on their siblings. The adult children often felt challenged; they experienced despondence and worried about what to do or how to help their parent with dementia in the best way. These challenges could create frustration and discontent in families and could cause family members to feel that they or their families were insufficient or cause them to feel guilt towards the parent with dementia for not being good enough as children. Some of the families tried to find ways to cope with everyday life through helping, caring, delivering groceries and visiting frequently. One way to quickly share information among family members after spending time with a parent with dementia was to send texts or pictures to each other on the telephone. This approach seemed to work for the adult children, but the overload of information and the many texts and pictures also seemed to increase their feelings of stress, as the family members were often reminded about the situation with their parent with dementia, leading them to feel obligated to do something soon.

In families with a healthy parent, the adult children depended on the healthy parent. There was a clear pattern of adult children wanting to help or to do something for the parent with dementia to help or support the healthy parent, but it was difficult for the adult children to determine what to do or how to help. The adult children could easily recognize when a healthy parent was exhausted or burdened but found it difficult to identify ways to help the healthy parent. One son explains how he despairingly felt powerless, saying to the healthy parent, “please tell us if you need something...” (son, family D). Adult children depended on the healthy parent to speak up and articulate the need for help. When the healthy spouse did not know what to ask for, this often led to no support being given or an additional burden on the healthy spouse because the type of support needed was misunderstood.

During the interviews, it also became evident that in families with a healthy spouse living with the person with dementia, the healthy parent depended on understanding from the adult children. Adult children needed to understand the conditions of the dementia disease to comprehend the changed situation in the family. The healthy parent needed support for respite care or simply for breathing room to occasionally take breaks from the person with dementia to rest and replenish his or her energy. As one wife explained, “I don’t want to lose going to the theatre with my good friends once a month... if so—I have nothing at all” (wife, family A). Healthy spouses experienced caring for a spouse with dementia as a full-time job at their own expense. Maintaining a social life with friends—feeling alive and prioritizing their own social needs—was very meaningful for healthy spouses, but, at the same time, they experienced feelings of guilt and selfishness because it involved leaving the person with dementia at home. Depending on adult children to help healthy spouses maintain a social life and to support and confirm that it is okay to insist on maintaining breathing room could relieve some of the guilt that healthy spouses experience. However, this form of dependency was not present in all the families. In most cases, the healthy parent preferred to request help from volunteers or health care workers rather than asking his or her adult children: “...If I’m going out, it can’t be at the expense of my children...” (husband, family C). This seems paradoxical; the adult children wanted to help the healthy parent, and the healthy parent needed help. However, healthy parents would not impose on their adult children by asking for help and, instead, sacrificed their need for a social life, thereby increasing their own burden. In addition, the adult children were left with feelings of despair and powerlessness.
Discussion

Changes within the family
Overall, the findings of our study clearly show that dementia illness has a large impact on relations within and across the family. The most important findings relate to how relatives were forced to change their roles within the family. We also reveal an important change in the dependency between siblings and a healthy parent. Surprisingly, some families had positive narratives about how dementia brought their family closer together. This finding is supported by Peacock et al. (2010), who found that caring for a family member with dementia is full of opportunities, for example, giving back, discovering personal strengths and becoming closer to the person with dementia (23). However, the most common feelings among the families in our study were despair, disappointment and sadness. Our findings illustrate how a family’s feelings of ambivalence towards their loved family member’s changed behaviour can lead to confusion and disappointment among the family members. When it becomes clear to the family that the person they love and know so well has dementia and is at risk of experiencing a change in personality, the family becomes aware that they might lose the person they used to know. The experiences expressed in this study by the family members appear to be related to grief. Chan (2013) notes that anticipatory grief regarding dementia may occur before the death of a family member, as the median life span after diagnosis is 5-8 years (24). Chan found that caregivers experience grief reactions such as anticipation and ambiguity about the future, anger, frustration and guilt. The findings in the current study regarding having a stranger in the family indicate that there is a level of uncertainty in families during the early stage of dementia that extends beyond the family members’ uncertainty about the future. Dementia may seem to be an unpredictable condition, highlighting the need for family support to cope with grief and uncertainty and increase knowledge about the condition and how to cope within the family.

These findings can be linked to Bowen’s family systems theory and practice, which focuses on the patterns families develop to defuse anxiety when high levels of external stress determine the degree of anxiety (25). According to the current study, a dementia diagnosis within a family may be perceived as a high external stressor for the family. Bowen describes the process of triangling, which occurs when the inevitable anxiety in a relation between two people in a family is relieved by involving a vulnerable third party who either takes sides or provides an outlet for the anxiety. Under calm conditions, it is difficult to identify triangles, but triangles clearly emerge in a family under stressful conditions. This study shows that when families are aware that a family member has dementia and has begun to exhibit changes in behaviour and personality, conflicts among family members are possible when they discuss what is happening and what to do about it. In this context, a triangle may represent the person with dementia, the spouse and the adult children individually or as siblings, or it may represent the person with dementia and his or her adult children individually. When family members ally with people in their family, such as other siblings, or when a healthy parent allies with the person with dementia, the triangling process feeds on itself and can become problematic if the third party’s focus shifts to criticizing or worrying—or to expecting unfeasible actions from each other. For example, in this study, adult children encouraged their healthy parent to stay positive and hold on to love. Family members may be at risk for increased anxiety by expecting too much from each other or disagreeing with each other when coping with uncertainty and grief in different ways, and the family is at risk for potential conflict.

Changing roles
Our findings show that family members find themselves in new roles as care assistants, handymen and guardians in relation to the person with dementia. As the dementia condition progresses and the
family becomes familiar with the changing personality of the person with dementia, family members undertake activities the person with dementia used to do to maintain everyday life in the family. Our findings regarding the experience of being a guardian, which involves observing the person with dementia closely and monitoring his or her activities, are similar to the findings in a study by Esandi (26) that explores the impact of Alzheimer’s disease on the structure and dynamics of the family unit. Esandi explains that noticing and being attentive to the person with dementia is not a pleasant situation but a necessary action to protect both the person with dementia from danger and to protect oneself from unnecessary concern. Changes to roles within families of people with dementia are also seen in Clemmensen (27), in which roles within the family appear unintentional and arise naturally from the family’s history and current circumstances and can be identified as protective roles or decisive roles. Being a guardian seems to be a way of protecting the person with dementia while being decisive, as a situation may require family members to assume responsibility for protecting the person with dementia when he or she can no longer manage certain activities. Undertaking these roles seems to happen gradually and unintentionally, and family members may not be aware that they have assumed a role until they are confronted. When family members realize they have taken on a role, they seem to find that it is difficult to resign from the role and therefore feel as if they are trapped in a changed relation.

The adult children in our study assumed great responsibility for caring for their parent with dementia through visiting frequently to ensure he or she was not in danger and ensuring that there was food in the house. This result is similar to findings described by Kjällman-Alm et al. indicating that being an adult child can be frustrating and a burden (28). Taking responsibility for a parent’s household in addition to their own household, having a full-time job and taking care of their own children while taking care of a parent is a burden on adult children. This study clearly shows that the most difficult part of being the adult child of a person with dementia is managing the changing roles—the adult child must assume responsibility for his or her parent with dementia. The reciprocal dependency between healthy spouses and adult children or between siblings illustrates the potential underlying risk for conflict among family members when interpreting the situation, understanding what is actually happening and deciding what to do about it. Conflict in families has been explored in a study by Peisha et al., who found that conflicts are most often grounded in a failure to communicate with each other (18). This could explain the situations observed in this study in which there seems to be a delicate balance between the risk of overloading other family members with information and showing consideration for others by keeping them informed.

In light of the findings of this study and according to Bowen’s theory, support from a health care professional may be beneficial in aiding family members to cope with the new situation within the family following the dementia diagnosis. This type of support may benefit both family members as individuals and the family as a whole by focusing on the ability of family members to support each other in a healthy way.

**Limitations and strengths**

The potential limitations of this study include the recruitment of participants from 12 different families. Considering fewer families and including several other members of a family could offer a more thorough and nuanced view of the experience of being in the family of a person with dementia from the perspectives of different family members. Such an approach could provide different perspectives from both spouses and siblings within a family. The interviews were conducted both individually and in groups of two or three, and the choice of some of the participants to be interviewed
together was respected. This could represent a potential limitation since the interaction between the participants could make it more likely that some information was not shared than if the interviews were all conducted individually. The participants were a homogeneous group, which was an advantage for the study. The similar experience of being a family member of a person with dementia was shared by all the participants but expressed in different ways. This provided many different views and perspectives on being part of such a family and contributed to a rich and thorough description of the experience of being in the family of a person with dementia. The adoption of Braun and Clarke’s method for the analysis process provided a detailed description and a pragmatic approach to conducting the thematic analysis. The threshold for reaching data saturation is difficult to define in qualitative research (29). Data saturation in this study was obtained through rich and thick data descriptions in the interviews, which contributed to identifying the four themes that clearly address family members’ experiences and perceptions of having a loved relative diagnosed with dementia.

**Implications for practice**
The insights obtained from family members about having a person in the family diagnosed with dementia represent important knowledge for health professionals caring for persons with dementia and their families. Dementia caregiving should consider how dementia impacts the family. This study suggests that the family needs support to cope with the new situation within the family. Families need support to help family members acknowledge and become aware of the roles they assume and the functions of those roles so that the family can decide whether individual family members are able to cope with their new roles in the long term. Families need support to help them acknowledge how family members depend on each other and to become aware of how their interactions can be both stressful and caring for each other. Family Health Conversations may be a solution for families dealing with a dementia diagnosis, as these interventions are designed to occur early in the dementia illness process. Family Health Conversations create a context in which the family can narrate and reflect on each other’s stories and increase their understanding of and ability to manage the illness experience and related consequences (30). This approach could represent a way to decrease the strain and burden experienced by families of persons with dementia. There is a need for further research to obtain new knowledge concerning families with dementia and how to meet their needs for support as a family.

**Conclusion**
The themes found in this study are interconnected and illustrate the complexity of the experience of being in the family of a person with early-stage dementia. Family members experience living with a stranger in the family because of the changes that occur in the personality of the person with dementia. Family members also experience being trapped in a changed relation in which they assume roles as care assistants, handymen and guardians to the person with dementia. It is challenging for a family to acknowledge the necessity of dividing up new roles and determining who will do what tasks. Family members experience being short on time, which implies that they must get the best out of their remaining time with the person with dementia both as an individual in relation to the person with dementia and within the family. However, attempting to get the best out of the remaining time may be experienced as a difficult responsibility by some family members. Finally, family members experience being dependent on each other within the family; healthy spouses depend on adult children for understanding, care and support, and adult children depend on the healthy spouse or their siblings to be involved in the family situation. There is a paradox in the way that family members hesitate to help each other; a healthy spouse needs help in the early stage of dementia for respite but will not
bother or burden adult children, while, simultaneously, adult children want to help the healthy spouse but do not know how. This study contributes to extending the knowledge about dementia and its impact on the family members of a person with dementia. The findings add to the existing body of research on family members’ experiences with and perspectives on being a family member of a person with dementia and on the interactions and challenges within the family of a person suffering from early-stage dementia. This study confirms the need for further research in the field of family nursing in dementia care.

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