



**Separation characterized by responsibility and guilt: family caregivers' experiences with palliative care for a close family member with severe dementia in long-term care facilities**

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Keywords:	Dementia, Ethical Decision-making, Family Caregivers, Guilt, Long-Term Care Facility, Nursing Home, Palliative Care, Phenomenology, Qualitative Research, Responsibility
Abstract:	<p><b>Aim and objectives:</b> The aim of this study was to explore family caregivers' experiences with palliative care for a close family member with severe dementia in long-term care facilities.</p> <p><b>Background:</b> Dementia not only affects individuals but also affects and changes the lives of close family members. An increasing number of dementia-related deaths occur in long-term care facilities; therefore, it is critical to understand how healthcare professionals support and care for residents with dementia and their families at the end of life.</p> <p><b>Design:</b> A qualitative design with a phenomenological approach was adopted.</p> <p><b>Methods:</b> In-depth interviews were performed with 10 family caregivers of residents in three Norwegian long-term care facilities.</p> <p><b>Results:</b> The family caregivers' experiences with palliative care for a close family member with severe dementia in long-term care facilities were characterized by responsibility and guilt. Admission to a long-term care facility became a painful relief for the family caregivers due to their experiences with the poor quality of palliative care provided. The lack of meaningful activities and unsatisfactory pain relief enhanced the feelings of responsibility and guilt among the family caregivers. Despite the feelings of insecurity regarding the treatment and care given during the early phase of the stay, the family caregivers observed that their close family member received high-quality palliative care during the terminal phase. The family caregivers wanted to be involved in the care and treatment, but some felt that it became a heavy responsibility to</p>

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	<p>participate in ethical decision-making concerning life-prolonging treatment.</p> <p>Conclusions: The family caregivers experienced ongoing responsibility for their close family members due to painful experiences with the poor quality of the palliative care provided. When their expectations regarding the quality of care were not met, the palliative care that was offered increased their feeling of guilt in an already high-pressure situation characterized by mistrust.</p>



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14 **Abstract**  
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18 Keywords: Dementia, Ethical Decision-making, Family Caregivers, Guilt, Long-Term Care Facility,  
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20 Nursing Home, Palliative Care, Phenomenology, Qualitative Research, Responsibility  
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## 23 Introduction

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28 Dementia not only affects individuals but also affects and changes the lives of close family members  
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30 (World Health Organization, 2012). Worldwide, 47 million people live with dementia, and this  
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32 number is estimated to increase to 131.5 million by 2050 (Prince et al., 2015). An increasing number  
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34 of dementia-related deaths in the United States and Europe occur in long-term care facilities  
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36 (Houttekier et al., 2010; Reyniers et al., 2015), and therefore, knowledge regarding how healthcare  
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38 professionals support and care for residents with dementia and their families at the end of life is  
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40 highly important.  
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44 Dementia is often under-recognized as a life-threatening illness (Mitchell et al., 2009; Murphy et al.,  
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46 2016; van der Steen et al., 2014) that requires a palliative care approach to improve comfort and  
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48 quality of life (van der Steen et al., 2014). People living with and dying from dementia have  
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50 substantial healthcare needs, including increased infections, shortness of breath, swallowing  
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52 difficulties and pain, which the person with severe dementia may not be able to clearly express  
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54 (Davies, Klapwijk, & van der Steen, 2018; van der Steen et al., 2014; Widera & Bernacki, 2015). Even  
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56 though palliative care for persons with dementia shows similarities with palliative care for persons  
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58 with other life-threatening diseases, there are differences, rendering palliative care for persons with  
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3 dementia unique. Communication problems with the individual, the recognition of dementia as a  
4 terminal illness and large elements of uncertainty, such as the person's wishes for the end of life  
5 care and prognosis, exist (Davies et al., 2018; van der Steen et al., 2014). In most Western countries,  
6 most persons with dementia die in regular long-term care facilities and do not receive specialist  
7 palliative care (Houttekier et al., 2010), which may also often be the case in Norwegian long-term  
8 care facilities; currently, few facilities are employed with special expertise in palliative care. The  
9 disease trajectory of dementia can be protracted and unpredictable (Gill, Gahbauer, Han, & Allore,  
10 2010; World Health Organization, 2012), and therefore, limiting palliative care for dementia to the  
11 very last stage of life could be problematic (Davies et al., 2018; van der Steen et al., 2014). Providing  
12 adequate care is challenging as persons with severe dementia can no longer verbally express pain  
13 and discomfort (Brorson, Plymoth, Örmon, & Bolmsjö, 2014; Burns & McIlfratrick, 2015; Midtbust,  
14 Alnes, Gjengedal, & Lykkeslet, 2018). Pain can result in behavioural symptoms, such as agitation,  
15 physical aggression and reaction to care (Davies et al., 2018; Midtbust et al., 2018). To integrate a  
16 palliative care approach in dementia care and highlight issues specific to dementia, the European  
17 Association of Palliative Care (EAPC) published a white paper providing a definition of optimal  
18 palliative care for persons with dementia. The optimal treatment of symptoms, providing comfort  
19 and person-centred care, communication, and shared decision-making are considered the most  
20 important domains in palliative care for persons with dementia. The great value of the collaboration  
21 between healthcare professionals and family caregivers when end of life care decisions are made  
22 has also been noted (van der Steen et al., 2014). The EAPC definition of optimal palliative care for  
23 people with dementia emphasizes family care and involvement. As dementia progresses, family  
24 caregivers are faced with increasing challenges over a period of many years and find themselves  
25 providing increasing amounts of care and support as the disease progresses (Lloyd-Williams, Dening,  
26 & Crowther, 2017; Muders, Zahrt-Omar, Bussmann, Haberstroh, & Weber, 2015; Thompson &  
27 Roger, 2014).

## Background

Earlier studies note that many family caregivers of residents with dementia find end of life experiences difficult and burdensome (Muders et al., 2015; Peacock, 2013; Thompson & Roger, 2014). The experiences of grief and loss over the caregiving journey (Arruda & Paun, 2017; Peacock, 2013; Thompson & Roger, 2014) and feelings of burden and guilt are described in the caregiving literature (Hennings, Froggatt, & Payne, 2013; Peacock, 2013; Seiger Cronfalk, Ternstedt, & Norberg, 2017; Thompson & Roger, 2014). Feelings of guilt are often associated with long-term care facility placement and transferring care responsibility to healthcare professionals (Hennings et al., 2013; Sarabia-Cobo, Pérez, de Lorena, Nuñez, & Domínguez, 2016; Seiger Cronfalk et al., 2017; Thompson & Roger, 2014). Although family caregivers often express feelings of guilt and a troubled conscience associated with long-term care facility placement, they also feel relief (Seiger Cronfalk et al., 2017; Thompson & Roger, 2014).

Receiving information regarding the diagnosis and disease trajectory of dementia is crucial for the families of persons dying from dementia, but studies indicate that family caregivers appreciate easier contact with healthcare professionals and earlier and more comprehensive information regarding end of life issues (Hennings, Froggatt, & Keady, 2010; Muders et al., 2015). A significant challenge faced by family caregivers is assuming the role of surrogate decision makers, and many caregivers feel unprepared for and unsupported in this role (Hennings et al., 2010; Muders et al., 2015; Peacock, 2013; Saini et al., 2016; Thompson & Roger, 2014). Towards the end of a resident's life, family caregivers are in a difficult situation involving both grieving for their close family member and being required to make decisions on their behalf regarding care and treatment (Hennings et al., 2010). During the end of life period, family caregivers also have significant personal needs. Family caregivers need frequent contact with healthcare professionals and seek empathy, reassurance, understanding and guidance from these professionals (Hennings et al., 2010; Muders et al., 2015).

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3 As shown above, earlier studies have noted that family caregivers of persons with severe dementia  
4 find the caregiver role difficult and burdensome. Less is known regarding how they experience the  
5 palliative care of their close family member in long-term care and how they experience being a  
6 family caregiver in this context. Therefore, the aim of this study was to explore family caregivers'  
7 experiences with palliative care for a close family member with severe dementia in long-term care  
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## 18 Methodology and methods

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22 We employed a phenomenological research approach grounded in the philosophy of the German  
23 philosopher Edmund Husserl who is regarded as the founder of modern phenomenology. His  
24 phenomenological philosophy intended to fully capture everyday experiences, which are the lived  
25 experiences or the lifeworld (Dahlberg, Dahlberg, & Nyström, 2008). The lifeworld is described as the  
26 common everyday world into which we are all born and live (Husserl, 1970). The overall aim of  
27 phenomenological lifeworld research is to describe and elucidate the lived world in a way that  
28 expands our understanding of the phenomenon as it is experienced by the informants (Dahlberg et  
29 al., 2008). In the present study, we attempted to find the meaning of the experiences or "...the  
30 particular lived meaning discerned in concrete descriptions..." (Giorgi, 2009, p. 102). During the  
31 research process, it is of crucial importance to adopt a phenomenological attitude characterized by  
32 setting aside any preunderstanding of the phenomenon under investigation (Giorgi, 2009).  
33 Consequently, the phenomenological attitude is intended to be reflective, open to the phenomenon  
34 and "actively waiting" for the phenomenon and its meaning(s) to be revealed (Dahlberg, 2006).  
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## 51 Participants and recruitment

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55 The management teams of four long-term care facilities in mid-Norway were asked to help us recruit  
56 family caregivers of residents with severe dementia for the study. To ensure variation in the sample,  
57 two long-term care facilities in a mid-sized city and two long-term care facilities in smaller  
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3 municipalities were asked to participate in the study. The long-term care facilities had 48 to 78 beds  
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5 and different units, such as short- and long-term wards. These facilities had residents with different  
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7 diagnoses and care needs, but most residents had a dementia diagnosis or some form of cognitive  
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9 failure. Three long-term care facilities also have a special dementia care unit, which usually houses  
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11 fewer residents and is adapted to residents with dementia diagnoses. The head nurse at each long-  
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13 term care facility was asked to send an information letter requesting participation in the study to  
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15 family caregivers of residents with severe dementia six to eight weeks after the death of the  
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17 resident. The request was sent to the individuals designated the nearest relatives in the resident's  
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19 journal or the person who had the most frequent recent communication with the resident. Over a  
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21 period of two years, approximately 40 letters with requests for participation were sent to relatives  
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23 of residents from four long-term care facilities. During this period, eight interviews were conducted  
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25 with 10 relatives from three of the four long-term care facilities. For a request in which one daughter  
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27 had consented, three siblings arrived; hence, the interview was conducted with the three siblings  
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29 together. The participants included one widower, one widow, five daughters and three sons. The  
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31 average age of the participants was 64.5 years (range 57-81), and their close family member lived in  
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33 long-term care facilities from three weeks to 10 years. The deceased family members had an average  
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35 age of 89 year (range 78-99), and all had symptoms of severe dementia characterized by profound  
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37 cognitive impairment, inability to communicate verbally and complete functional dependence.  
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## 45 Design and data collection

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48 The data were collected using in-depth interviews based on a phenomenological approach (Dahlberg  
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50 et al., 2008). The first author conducted the interviews. She sought rich and varied descriptions of  
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52 the family caregivers' experiences by asking open questions, providing the relatives time and space  
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54 to speak without interruption, listening actively, and asking for further elaboration from the  
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56 informants when appropriate. To balance openness and focus during the interview, we used a semi-  
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58 structured interview guide (Dahlberg et al., 2008) as shown in table 1. Two interviews were  
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3 conducted in a suitable meeting room at a public institution, and the other six interviews were  
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5 conducted at the family caregivers' home. The interviews lasted from one to two and a half hours  
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7 and were recorded and transcribed verbatim. Observations, such as laughter, crying or irritation,  
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9 were noted during the transcription.  
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13 TABLE 1 Interview guide

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| 14<br>15<br>16<br>17<br>18<br>19<br>20<br>21<br>22 | <ol style="list-style-type: none"><li>1. What are your experiences with the palliative care provided to your close family member in the long-term care facility?</li><li>2. How did you experience being taken care of as a relative?</li><li>3. What could you possibly have wished to have been different?</li></ol> |
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## 30 Data analysis

31 The data analysis was inspired by Giorgi's descriptive phenomenological step-by-step model (Giorgi,  
32 2009). The procedure began by reading all interview transcripts to obtain an impression of the  
33 whole. Then, each interview was reread, and the text was divided into parts or meaning units related  
34 to the aim of the study. The meaning units were grouped into categories and sub-categories, which  
35 were transformed into condensed descriptions. We sought more complex and richer lifeworld  
36 descriptions by asking questions "of the data" as follows: What is this about? What similarities and  
37 differences appear? What may be the meaning of the experiences? Finally, we searched for  
38 similarities and differences across the individual descriptions. Gradually, through discussions within  
39 the research group, an overall general structure of meaning consisting of three themes emerged. All  
40 authors participated in the discussions and analysis. The NVivo 12 qualitative data analysis software  
41 was used to facilitate the data management.  
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## Ethics

The research project was carried out in accordance with the guidelines of the Helsinki Declaration (World Medical Association, 1964). Permission was granted by the Norwegian Science Data Services (ref. 44973). The informants provided written informed consent to participate in the study after receiving written and verbal information. Participation was voluntary, and the informants could withdraw at any time without consequences.

## Results

### Separation characterized by responsibility and guilt

The general meaning structure of the family caregivers' experiences with palliative care for a close family member with severe dementia in long-term care facilities was characterized by experiences of responsibility and guilt. The family caregivers experienced ongoing responsibility for their family member with dementia. The time preceding admission to the long-term care facility was described as a difficult time during which the family caregivers had to rearrange their lives to care for their close family member. The admission to the long-term care facility was an ambivalent experience. On the one hand, the family caregivers were exhausted and relieved by the admission. On the other hand, the family caregivers felt guilty for being unable to care for their relatives at home. After admission, the family caregivers experienced the poor quality of the palliative care provided, which again caused more feelings of guilt and responsibility. The lack of meaningful activities and pain relief were challenging for both the residents and their family caregivers. Despite the family caregivers' feelings of insecurity regarding the treatment and care given during the early phase of the stay, they experienced that their close family member received high-quality palliative care during the terminal phase of the disease. The family caregivers often wanted to be involved in the care and treatment at the end of life, but some family caregivers found it difficult to be asked to participate in

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3 ethical decision-making concerning life-prolonging treatment. The separation characterized by  
4 responsibility and guilt is described in the following themes: difficult transition, painful relief and  
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9 ambiguous farewell.

### 10 11 **Difficult transition**

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13 The family caregivers described a difficult period during the time prior to admission. The family  
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15 caregivers had to rearrange their lives to provide full-time care for their spouses or parents with  
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17 dementia. A widow spoke about her husband who had to be cared for day and night, and the burden  
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19 at home combined with work exhausted her. Adult children experienced difficult situations involving  
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21 fights between parents and stated that they sometimes had to visit them night and day when the  
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23 situation became too demanding. These participants experienced their close family member as  
24  
25 confused, hallucinating and aggressive. For many people, realizing that their close family member  
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27 needs to live in a long-term care facility is a difficult process. A widow stated that she had promised  
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29 her husband, who previously resided at a short-time unit but refused to stay, that he would not have  
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31 to reside in a long-term care facility. She stated the following: *“At that time, we did not know that he*  
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33 *would be in so much need for care”*. In tears, she stated that she had thought she could make it but  
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35 realized over time that it was impossible. The time surrounding the admission was exhausting for the  
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37 relatives. A widower stated that the doctor and nurses encouraged him to apply for placement in a  
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39 long-term care facility for his wife, but it was impossible for him as follows:

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46 *“To write why she should live outside our home was not easy. I simply couldn’t do it; they (the*  
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48 *healthcare professionals) had to do it”*.

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50 Several of the family caregivers described admission as a hardship. They described the residents’  
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52 homesickness and their own feelings of guilt because they could no longer take responsibility for  
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54 them at home. Even though it was a difficult process for many family caregivers, the adult children in  
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56 particular described this experience as relieving and reassuring that their parents were finally  
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58 granted a place at a long-term care facility.  
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## Painful relief

After admission, the family caregivers continued to feel a great sense of responsibility. Some respondents stated that they visited their close family member every day for years and felt guilty and restless if they were prevented from visiting. It was especially difficult for the spouses to be separated, and their experience with the poor quality of palliative care made them feel guilty and responsible. A topic that concerned all family caregivers was the possibility of living a meaningful life in the long-term care facility. Some respondents found that the physical environment and lack of activities provided limited opportunity for a meaningful life. A widow stated that for many years, she had urged healthcare professionals to take her husband out for walks as follows:

*"I insisted time after time that he has to be active. The TV was his only activity. I insisted that they should take him out in the garden, but they rarely did".*

Many family caregivers had the same experiences, and one stated that she felt that the healthcare professional used the TV as a means to avoid helping the residents be active. However, there were great differences among the healthcare professionals. A daughter described a special nurse who had a natural talent in determining what her mother needed. She said, *"It is crucial to determine what is important for the individual, and this nurse in particular was very talented at that".*

The family caregivers were worried about situations in which the lack of care and pain relief had painful consequences for the resident. Providing pain relief and medication that eased the symptoms were challenging for family caregivers in a negative way. A widow stated that she felt that her husband was a test subject for different medications and that he generally received too much medication, which caused him to sleep all the time. As his wife, she felt that it was a painful experience to visit him when he merely slept all day and felt that he was drugged. She stated that *"Sometimes I thought there was no point in visiting him; he was just sleeping in his chair".* Similarly, a son stated that the healthcare professionals never succeeded in finding the proper medication for his mother. After several hip operations, she lived with severe pain that she was unable to express

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3 verbally, and the pain was revealed through anger and aggression. He wanted her to have optimal  
4 pain relief but felt that the healthcare professionals were only concerned with his mother being  
5 manageable when they tended to her. The son stated that he understood that it was difficult to  
6 provide medication when his mother could no longer express herself but disagreed with how the  
7 healthcare professional assessed and managed his mother. He considered some of the healthcare  
8 professionals' approaches heavy-handed and rough when they tended to her, which led to his  
9 mother becoming aggressive, and she could both bite and hit the personnel. He felt that these  
10 situations could have been avoided if the healthcare professional had adopted a calmer and gentler  
11 approach. He stated the following:  
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24 *"There were some heavy-handed, but others were just born to be there. They were caring, careful*  
25 *and spoke very low and calm.... You saw who she liked and didn't like"*  
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29 Although the family caregivers also experienced that many members of the healthcare professional  
30 team provided high-quality palliative care to their close family member, their experiences of  
31 variation in the skills of the healthcare professionals made them feel guilty and still burdened by a  
32 heavy responsibility for leaving their close family member at a long-term care facility.  
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### 39 Ambiguous farewell

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42 Despite their feelings of insecurity regarding the treatment and care given throughout the disease  
43 trajectory, the family caregivers largely expressed gratitude for the palliative care given during the  
44 terminal phase. Although it was still challenging for some family caregivers, several stated that they  
45 were the most satisfied during this period of their close family member's stay in the long-term care  
46 facility. A daughter stated that she had previously found it difficult to find a healthcare professional  
47 in the unit, but when her mother was terminally ill, she was impressed by the attentive presence of  
48 the healthcare professionals both towards her mother and herself. She found that her mother had  
49 satisfactory relief from her medical symptoms and that the healthcare professional did everything in  
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3 their power to make her mother as comfortable as possible. Another daughter stated that the  
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5 healthcare professionals had a special medication kit when her father was in his terminal phase. This  
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7 kit contained the most important medication needed at the end of life, and she stated the following:  
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11 *“It was incredible because I felt that we didn’t have to wait for the doctor to provide him with*  
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13 *morphine. That was great”.*  
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16 A son and a daughter called attention to a special nurse working in a temporary position who was  
17  
18 responsible for their mother in her terminal phase. She was described as *an angel*. She was caring,  
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20 comfortable and a keen observer who provided the necessary treatment. They also appreciated that  
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22 she spent much time in the room with them, spoke with them, and ensured that their mother was as  
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24 comfortable as possible. The presence of a healthcare professional during the terminal phase was  
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26 highly important for the family caregivers to feel comfortable. Although some family caregivers also  
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28 spent 24 hours a day with their close family member during the terminal phase, they needed relief,  
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30 support and care from the healthcare professional. Several family caregivers stated that they slept at  
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32 the long-term care facility and at home in turns and that it was important to be contacted if there  
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34 were any changes. A widower stated the following:  
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39 *“In the beginning, I sat there day and night. Then, they hired an extra night guard who would sit with*  
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41 *her. I sat until midnight; then, I went home. We had an agreement that they would call me if there*  
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43 *were any changes. They were supposed to call no matter what. In addition, they did some nights, and*  
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45 *I had to come running, whereas the night before she died, I sat there all night”.*  
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49 Similarly, several family caregivers noted that they were able to relinquish the responsibility and  
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51 relax at home because they were assured that they would be contacted if their close family  
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53 member’s condition deteriorated.  
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56 Even though the informants experienced a positive farewell with their relatives, not all managed to  
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58 eliminate the feelings of guilt and responsibility. All informants in this study described different  
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3 meetings with healthcare professionals when their close family member was in the terminal phase.  
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5 The family caregivers initially regarded these meetings as beneficial in providing helpful information;  
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7 they were asked to contribute and advise regarding decision-making. For some family caregivers, it  
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9 was still difficult to answer questions regarding life-prolonging treatment. A son described the  
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11 difficulty of making decisions involving the terminal phase. He stated that it was difficult after a  
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13 meeting in which he and the healthcare professional had very different opinions regarding the  
14  
15 follow-up care for his father. His father was very ill, and the doctor stated in the meeting that they  
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17 did not want to continue life-prolonging treatment but that they should make continuous  
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19 assessments of his condition throughout the week. The son found this information to be very  
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21 difficult, but simultaneously, he realized that his father was elderly and sick, and he had also  
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23 expressed that he was tired of life. Although they agreed on what was best for his father, he still had  
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25 the feeling of being the one who made the decision that his father should die. He stated the  
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27 following: *“to press the button”, I felt that it was me who did it...and that has been hard to think*  
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29 *about”.*  
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35 Even though the family caregivers wanted to participate in the decision-making process concerning  
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37 care and treatment during the terminal phase, some family caregivers felt that it was a heavy  
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39 responsibility to answer questions concerning life-prolonging treatment. Nevertheless, they largely  
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41 developed a strong appreciation for the palliative care given towards the end of life. The  
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43 respondents had a chance to say farewell, and many described this time as the period during which  
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45 they felt the most secure about their close family member.  
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## 50 Discussion

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54 The purpose of this study was to explore family caregivers' experiences with palliative care for a  
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56 close family member with severe dementia in long-term care facilities. The major findings indicate  
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58 that the family caregivers experienced ongoing responsibility for their close family member with  
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3 dementia. Several respondents described feelings of guilt because they could no longer take  
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5 responsibility for their close family member at home. The admission to the long-term care facility  
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7 resulted in a separation characterized by further responsibility and guilt due to the poor quality of  
8  
9 palliative care. Despite the painful experiences related to the lack of meaningful activities and pain  
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11 relief during the early phase of the stay, the family caregivers felt that their close family member  
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13 received high-quality palliative care during the terminal phase. During this phase, the respondents  
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15 wanted to be involved in making decisions concerning care and treatment at the end of life, but  
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17 some family caregivers felt that it became a heavy responsibility to participate in ethical decision-  
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19 making concerning life-prolonging treatment.  
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24 A basic tenet of palliative care philosophy and a key point in the EAPC definition of palliative care for  
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26 patients with dementia is that the resident and family constitute the unit of care (Steel & Davis,  
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28 2015; van der Steen et al., 2014). Thus, in addition to caring for the person with dementia,  
29  
30 healthcare professionals must also anticipate and respond to the needs and expectations of family  
31  
32 caregivers. Given the prolonged and unpredictable disease trajectory, family caregivers of persons  
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34 with dementia may have unique needs and experiences compared with other caregiver groups (Gill  
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36 et al., 2010; Muders et al., 2015). When the family caregivers were no longer able to care for their  
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38 close family member with dementia at home, the admission to a long-term care facility became a  
39  
40 difficult transition. Due to cognitive impairment, persons with dementia may have difficulty  
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42 understanding the need to move to a long-term care facility. The findings in both this study and  
43  
44 other studies highlight that feelings of burden and guilt are common among family caregivers of  
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46 residents with dementia (Hennings et al., 2013; Peacock, 2013; Seiger Cronfalk et al., 2017;  
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48 Thompson & Roger, 2014). Such feelings are often associated with placement in long-term care  
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50 facilities and the perceived lack of fulfilment of their responsibility to their close family member  
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52 (Hennings et al., 2013; Sarabia-Cobo et al., 2016; Seiger Cronfalk et al., 2017; Thompson & Roger,  
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54 2014). Entrusting responsibility for their close family member to healthcare professionals was a  
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56 difficult process for the informants in our study. However, the feelings of relief and assurance also  
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3 indicated that the family caregivers entrusted their close family member to healthcare professionals  
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5 with the confidence that their needs would be well-attended. Trust is a fundamental element in  
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7 caring (Martinsen, 2005), and healthcare professionals' appearance in meetings with residents and  
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9 their family caregivers affects trust and the experience of being taken care of (Jakobsen, 2011;  
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Martinsen, 2005).

Such meetings between family caregivers and healthcare professionals may be understood in the  
context of the Danish philosopher K.E. Løgstrup's ontological ethics. His ethics are rooted in the  
following fundamental feature of human existence: interdependence. All human beings depend on  
others for survival and development, and in each meeting between people lies the unarticulated  
ethical demand of taking care of the life that is placed in our hands (Løgstrup, 1997). Although the  
family caregivers in our study emphasized that some healthcare professionals provided high-quality  
palliative care, painful experiences due to the lack of meaningful activities and pain relief made it  
challenging for them to trust the professionals and feel secure regarding the care for their family  
member. The ethical demand presupposes that all interaction between people involves basic trust  
but trust also encompasses making oneself vulnerable or "laying oneself open" according to  
Løgstrup. Therefore, we react strongly when our trust is "abused" as Løgstrup described (Løgstrup,  
1997, p. 9). When the family caregivers dared to "lay themselves open" by transferring the  
responsibility of caring for their close family member to the professionals, any experiences of  
distrust led to feelings of further guilt and continued responsibility. The fact that family caregivers  
hold themselves responsible for monitoring and evaluating the quality of care has also been noted in  
other studies (Hennings et al., 2013; Seiger Cronfalk et al., 2017) and highlights that family  
caregivers' continuing responsibility endures far beyond admission to long-term care. These findings  
indicate that the family caregivers did not completely transfer the responsibility of care before they  
felt safe that their close family member received high-quality palliative care.

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3 Despite distrust and feelings of insecurity regarding the treatment and care given during the disease  
4 trajectory, the family caregivers largely expressed gratitude for the palliative care given during the  
5 terminal phase. The presence of competent healthcare professionals was highly important for the  
6 family caregivers to feel comfortable. They cherished the professionals who were caring, provided  
7 the necessary treatment, and ensured that their close family member was as comfortable as  
8 possible. Additionally, this study and a previous study noted the importance of notifying family  
9 caregivers of changes in the residents' conditions to increase family caregivers' sense of comfort  
10 (Lopez, Mazor, Mitchell, & Givens, 2013). Some informants in our study noted that they were able to  
11 relinquish the responsibility because they trusted that their close family member received high-  
12 quality palliative care and felt assured that they would be contacted if their family member's  
13 condition deteriorated. The family caregivers also had significant personal needs towards the end of  
14 the life of their close family member. The presence of healthcare professionals was highly important  
15 for the family caregivers to feel safe and comfortable. Although the family caregivers spent most of  
16 the day with their family member during the terminal phase, they needed relief, support and care  
17 from healthcare professionals. Similarly, other studies show that family caregivers appreciate  
18 healthcare professionals who are in frequent contact with them, provide information, and ensure  
19 that their close family member is as comfortable as possible (Hennings et al., 2010; Muders et al.,  
20 2015). These findings show that the skilled healthcare professionals became trustworthy and that  
21 the family caregivers were able to transfer some of the caregiving responsibility to the professionals.  
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23 Despite the experiences of good palliative care during the terminal phase, not everyone was able to  
24 eliminate the feelings of guilt and responsibility due to expectations from healthcare professionals to  
25 participate in discussions regarding life-prolonging treatment. Moral questions concerning ethical  
26 decision-making increased the family caregivers' responsibility and guilt. They were ambivalent  
27 regarding what was the most appropriate level of treatment and felt uncomfortable making  
28 decisions that might hasten death. Previous studies show that family caregivers of individuals with  
29 dementia feel unprepared and unsupported in the role of surrogate decision maker (Hennings et al.,  
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3 2010; Muders et al., 2015; Peacock, 2013; Saini et al., 2016; Thompson & Roger, 2014). The findings  
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5 of our study, which are also supported by the findings of studies identified in the literature review,  
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7 show that family caregivers find themselves in the unenviable situation of both grieving for their  
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9 close family member and simultaneously being required to make decisions on their behalf regarding  
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11 care and treatment (Hennings et al., 2010). Although family care and involvement are basic tenets of  
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13 the palliative care philosophy and the EAPC definition of palliative care for people with dementia  
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15 (Steel & Davis, 2015; van der Steen et al., 2014), healthcare professionals must be aware of the role  
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17 of surrogate decision maker, which may be experienced as a burden by the family caregivers. Given  
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19 Løgstrup's ethical demand that we care for the life placed in our hands, healthcare professionals in  
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21 such situations need to have a deeper understanding of the impact of these burdensome  
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23 experiences on the family caregivers to support them in such difficult situations.  
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28 The EAPC recommendations regarding optimal palliative care for people with dementia recognize  
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30 advanced care planning and shared decision-making as core domains, which require ongoing  
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32 communications regarding preferences for future care among the resident with dementia, family  
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34 caregivers and healthcare professionals from the early stages of the dementia trajectory (van der  
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36 Steen et al., 2014). Advanced care planning and early discussions about palliative care have been  
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38 shown to result in improved outcomes for both the persons with dementia and their family  
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40 caregivers (Dixon, Karagiannidou, & Knapp, 2018), but the findings in this study indicate that family  
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42 caregivers need support from healthcare professionals in their new role as proxy decisions makers.  
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44 Understanding the progressive course of dementia and palliative care treatment options may be a  
45  
46 difficult and time-consuming process. This finding is consistent with Løgstrup, who states that an  
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48 ethical decision needs time to mature (Løgstrup, 1997, pp. 148-163). Therefore, it is of great  
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50 importance to provide time and space for such sensitive discussions with family members to build a  
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52 trusting relationship. During the disease trajectory, these discussions may gradually progress to  
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54 considering more specific decisions about end of life care, thus gradually preparing the family  
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56 caregivers for their role as proxy decision makers. As death approaches, it is of crucial significance  
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3 for the family caregivers to have confidence in the professionals to make the proper decisions. The  
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5 dialogue should be characterized by equality and trust but in such a way that the family caregivers  
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7 are assured that it is always the doctor who makes the final decision regarding treatment. If the  
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9 healthcare professionals succeed in building such a relationship of trust, the family caregivers may  
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11 relinquish the heavy responsibility and have the time to provide a safe farewell.  
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## 14 15 Strengths and limitations

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18 We consider it a strength that we were given the possibility of gaining insight into the experiences of  
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20 family caregivers with different relationships to the deceased person with dementia who resided in  
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22 different care units. In addition, we think that our close cooperation and reflection within the  
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24 research group throughout all stages of the research process were a strength in this study. Some  
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26 limitations should be acknowledged; particularly, the recruitment of informants was difficult.  
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28 Although managers at four long-term care facilities sent letters with requests for participation,  
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30 informants from only three facilities are represented in this study, which may have led to less  
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32 variation in the interview data. Few informants consented to participate in the study, and they may  
33  
34 not have wanted to participate for several reasons. The interviews were conducted relatively soon  
35  
36 after the time of the patients' deaths, and some family caregivers might not have been ready to  
37  
38 share their experiences at that time. Another reason may be that some find it difficult to share  
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40 negative or painful experiences in an interview. The findings in this study indicate that family  
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42 caregivers are faced with a great care burden over a period of many years and that it may be an  
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44 addition burden to share their experiences with an unknown researcher.  
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## 51 52 Conclusion

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55 This study presents family caregivers' experiences with palliative care for a close family member with  
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57 severe dementia in long-term care facilities. The findings indicate that family caregivers experienced  
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3 ongoing responsibility for their close family member with dementia. The admission to a long-term  
4 care facility was an ambivalent experience, and the family caregivers felt not only relieved by the  
5 admission but also guilty for no longer being able to care for their close family member at home.  
6  
7 After admission, the separation became a painful relief due to painful experiences with the poor  
8 quality of palliative care. When the family caregivers experienced distrust and that their  
9 expectations regarding the quality of care were not met, the palliative care that was offered added  
10 additional guilt and responsibility in an already high-pressure situation. Despite the mistrust and  
11 feelings of insecurity regarding the treatment and care provided during the disease trajectory, the  
12 family caregivers largely expressed gratitude for the palliative care provided during the terminal  
13 phase. The respondents wanted to be involved in the care and treatment at the end of life, but some  
14 felt that it became a heavy responsibility to participate in ethical decision-making concerning life-  
15 prolonging treatment.  
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## 32 Implications for practice

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35 The findings of this study contribute to an understanding of how family caregivers experience  
36 ongoing responsibility for the palliative care provided to their close family member in long-term care  
37 facilities. The family caregivers did not manage to fully transfer the responsibility for palliative care  
38 before they felt safe that their close family member received high-quality palliative care. During the  
39 terminal phase, family caregivers are in the unenviable situation of both grieving and being required  
40 to participate in ethical decision-making concerning life-prolonging treatment. Healthcare  
41 professionals need to have a deeper understanding of the impact of these burdensome experiences  
42 on the family to be able to support them.  
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57 We thank all participants for sharing their time and experiences by participating in our study.  
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### Conflicts of interest

The authors declare that there are no conflicts of interest.

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