


Caregiving for frail home-dwelling older people: A qualitative study of family caregivers' experiences

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Abstract

Background: The increasing frailty of home-dwelling older people can lead to rising expectations from their family caregivers due to various demographic developments and political guidelines. European data show that 60% of home-dwelling older people receive informal care. Frailty among older people is a state of vulnerability, increasing the risk of adverse health outcomes, declining daily activities and needing long-term care.

Aim: To explore family caregivers' lived experiences with caring for frail, home-dwelling older people.

Methods: We conducted a phenomenological study to obtain in-depth descriptions of the phenomenon. We interviewed nine family caregivers, five men and four women between 52 and 90 years old, in-depth in their homes. We used a hermeneutical phenomenological approach described by van Manen and followed the COREQ checklist.

Results: The phenomenon's essential meaning is described as striving to adapt throughout the caring relationship. The interrelated themes describe different caring relationships, caring for a family member and letting go of the primary caring responsibility.

Conclusions: Family caregivers describe care as meaningful yet demanding. In our study, the varying condition of frailty was an additional challenge in care. By addressing these challenges, healthcare providers can better support and help family caregivers to withstand their caring relationships. The Norwegian Centre for Research Data approved the study (Ref.61202).

KEYWORDS

caregiving, community nursing, family care, frailty, in-depth interview, older people, phenomenology

1 | BACKGROUND

As people live longer, they are more likely to experience health challenges associated with ageing, such as physical frailty, cognitive

decline and chronic illnesses. These conditions require assistance and support, often falling on family members to provide care. Family caregivers may face heightened expectations because older relatives require more intensive and prolonged assistance as they age (Lekan

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et al., 2021; Pickard, 2015; White paper 24 (2022–2023), 2023). Frailty among older people is a state of vulnerability, increasing the risk of adverse health outcomes, leading to declining daily activities and requiring long-term care (Andrew et al., 2012; Fried et al., 2001; Pinquart & Sörensen, 2011; WHO, 2016). The frailty syndrome, thus the decreased reserve and reactivity to internal and external stressors—physical, mental and social—is becoming a crucial geriatric syndrome. As for the physical part of frailty, the syndrome includes three of five symptoms of unintended weight loss: low grip strength, fatigue, low walking speed and low physical activity level (Fried et al., 2001). The Fried et al. criteria concern physical frailty, and in the past decade, the definition of frailty has evolved, implying the need for a more holistic approach (Endal et al., 2023; Rasiah et al., 2022; Sieber, 2017).

There is a growing concern about providing adequate quality care for older individuals worldwide (Hoogendijk et al., 2019; Kojima et al., 2019). This issue has been recognized politically, for example, by the World Health Organization (WHO), calling for collaboration between governments, society, academia, media and the private sector to support good lives for older individuals and their families (WHO, 2020). Data from Ageing Europe show that 60% of home-dwelling older people receive informal care from relatives, friends and neighbours (Eurostat, 2019). In the rest of Europe, health policy has increasingly considered family members' vital contribution to caregiving for frail, home-dwelling older people and the relationship between care responsibility and frailty (Plöthner et al., 2019; Szebehely & Meagher, 2018).

There is no formal duty of care for family members, but spouses and adult children are essential sources of informal care. Healthcare providers are legally obligated to offer necessary information, support and respite to family caregivers since they are crucial in caring for older people (Municipal Health and Services Act, 2011; Norwegian Directorate of Health, 2017; Patients' Rights Act, 1999). Nordic welfare states offer formal home-based care at a relatively low cost, but the ageing population and limited resources challenge this model (Rostgaard et al., 2022; Szebehely & Meagher, 2018; Verbakel, 2018). Due to the state's high involvement in long-term care services in the Nordic countries, family caregiving has a more supplementary role than in many other European countries. Even if many people provide services, they are not intensive and can, for example, be combined with work (Rostgaard et al., 2022).

Family caregiving refers to unpaid assistance to other people because of health conditions or limitations associated with ageing. A small but growing number of family caregivers with advanced care duties receive a salary for care granted and paid by the local authorities (Statistics Norway, 2018). Caregiving for frail, home-dwelling older adults can be challenging and demands great physical and emotional effort. It can be overwhelming for caregivers who must balance work and family responsibilities. Studies have shown that caregiving can adversely affect caregivers' quality of life because of the weight of their responsibilities (Chappell et al., 2021; Munkejord et al., 2020; Ringer et al., 2017). The relationship between care

Implications for Practice

What does this research add to existing knowledge in gerontology?

- This article provides detailed descriptions and sheds light on understanding the lived experiences of family caregivers caring for frail older relatives.
- It highlights the intertwined nature of caregiving responsibilities and interpersonal relationships.

What are the implications of this new knowledge for nursing care with older people?

- The implications of this new knowledge for nursing care with older people include recognizing the additional challenge of caring for frail individuals and the importance of explicit expectations for family caregivers and healthcare providers.
- It highlights the need for adequate cooperation, support and timely interventions to improve the well-being of family caregivers and enhance their caregiving experience.

How could the findings be used to influence policy or practice or research or education?

- Implications for practice: Implement holistic care approaches that address caregiving's physical, emotional and social aspects. Expand respite care services to provide caregivers with regular respite and support.
- Implications for research: Future research could consider longitudinal studies to track family caregivers' evolving needs and experiences over time, providing insights into the long-term impact on caregiving, including caregiving experiences among diverse caregiver populations.
- Implications for education: Include caregiver support and communication training in the education of healthcare providers to improve interactions with family caregivers.
- Implications for policy: Advocate for policies that recognize and support family caregivers.
- Sustainable practices: Healthcare providers could prioritize meeting family caregivers' unaddressed needs to support them and help them withstand the caring situation, avoiding or postponing institutionalization.

recipients and caregivers is essential in how caregivers experience their role (Sardella et al., 2021).

Previous research shows that family caregivers can offer invaluable support in everyday life but may be overwhelming to manage

within the home environment (Spang et al., 2023). Family caregivers' continual help and support can be pivotal for maintaining a balance that allows living at home (Bjerkmo et al., 2022). Yip et al. (2022) highlighted that support from formal and informal caregivers is diverse. Some older adults relied heavily on their informal caregivers for help, but others feared burdening them. A meta-analysis (Moral-Fernández et al., 2018) found that spouses, adult children and parents-in-law have different needs and struggle with different issues. Systematic reviews (Plöthner et al., 2019; Ringer et al., 2017) highlight caregivers' significant responsibility towards frail home-dwelling older people, and there is broad agreement that respite prevents caregiver responsibility (Munkejord et al., 2020; Ringer et al., 2016; WHO, 2016). For example, respite, in which the care recipient is admitted to residential care to give the caregiver a break, can sometimes increase caregiver stress. Shea et al. shed light on the importance of flexible and responsive person-centred care, including meaningful activities to enhance respite quality (Shea et al., 2017).

No studies describe family caregivers' experience with caring for an older frail person in detail. Few studies attempt to clarify the process of becoming caregivers, and many investigate the caregivers of older people with dementia (Lin et al., 2012; Moral-Fernández et al., 2018). Understanding the first-person perspective and utilizing phenomenological concepts and methods can provide valuable insights into unmet needs. This insight into family caregivers' situation might inform discussions about sustainable healthcare services.

The study aimed to explore family caregivers' lived experiences with caring for frail, home-dwelling older people. The research question was: How do family caregivers experience caring for frail, home-dwelling older people?

Our study draws on Heidegger's (1962) and Martinsen's concepts Martinsen (2003) of care. Heidegger (1962) describes care as a fundamental existential condition concerning people's attachment to the world and other people, elucidating the motives of love, duty and reciprocity. Caring expresses personal commitment and has a practical side, entailing emotional involvement to look after or provide for others. People understand and depend on others by sharing a familiar lifeworld in which we primarily understand ourselves through relationships. Heidegger (1962) describes care by using *fürsorge*, as related to others and is future-oriented, actively caring for someone needing help. Martinsen (2003) describes caring as showing concern for each other through relationality, practicality and morality. As a philosophical tradition, phenomenology offers a valuable approach to studying the lived experiences of individuals and understanding the essential meanings they attribute to a particular phenomenon, such as caring for family members living with frailty. In the context of this study, a hermeneutic phenomenological approach was adopted, drawing upon the method developed by van Manen (2014).

2 | DATA COLLECTION

Head nurses at two geriatric outpatient clinics in rural Norway recruited the participants. This study is part of a PhD project, and

the participants in this study were family caregivers to frail, home-dwelling older people recruited from the same clinics. Participants had to be family caregivers to participants who fulfilled the following criteria:

- 65 years or older;
- had received home healthcare for 3 months;
- mini-mental state examination score ≥ 18 ; and
- fulfilled three of five criteria of Fried et al. (2001) for frailty: unintentional weight loss (4.5 kg in the past year), self-reported exhaustion, weakness (grip strength), slow walking speed and low physical activity.

Nine spouses, daughters, sons, in-laws and siblings, 52–90 years old, five men and four women, participated. According to Morse (2015), considering the whole data set, the sample size depends on the phenomenon's nature, scope and complexity. Further, the participants varied in age, sex, health status, level of home care services, home help and place of residence. We strove to ensure rich descriptions of the phenomenon being investigated. Providing a comprehensive account of one's experiences and relevant background details can assist readers in comprehending and contrasting them with other circumstances.

Some were related to and were caregivers for the same care recipient. Some lived with the care recipient, others visited and some corresponded by phone or messages. Table 1 shows the participants' characteristics. The first author conducted all interviews in the participants' homes to provide a comfortable and familiar environment, and the interviewer used open questions to encourage conversations about their experiences in caregiving. Interviews typically began by introducing the research project and inviting the participants to describe their experiences as family caregivers. We developed a thematic interview guide of open questions such as: 'How is a typical day for you?', 'How was yesterday?' and 'Can you tell a little about your experiences as a family caregiver?' The interviewer arranged the interviews as conversations rather than sessions of questions and answers to be open, sensitive and attentive to the experiences participants lived in and through. The interviews were individual, except for a married couple interviewed together, and lasted between 36 and 94 min. With consent, interviews were digitally recorded, anonymized and transcribed verbatim.

3 | DATA ANALYSIS

The analysis followed Van Manen's (2014) iterative and inductive framework for phenomenological data. Van Manen describes the phenomenological method not as a controlled set of procedures but as a way towards human understanding (Van Manen, 2014). The method was to read and rewrite, present preliminary interpretations and questions and highlight important sections to restore the structure of meanings embodied in the human experience represented in the text. Writing and rewriting were at the core of the first author's

TABLE 1 Characteristics of the nine study participants.

Characteristics	n
Sex	
Male	5
Female	4
Age (years)	
50–59	5
60–69	0
70–79	2
80–89	1
90–99	1
Relationship	
Adult caregivers	3, two sons and 1 daughter
Siblings	1 sister
In-laws	2 daughter-in-laws
Spouses	3 husbands
Time spent with caring	
24/7	3
Daily visits/phone calls	4
Weekly visits	2
Type of living and place	
Lived in their own home	9
Lived with the care recipient	3
Lived at an attached to the care recipient	2
Lived in the same municipality	3
Lived in another municipality	1

reflection and deeply interwoven with the analytical process. First, the first author read the interviews to get an overall impression. Participants sometimes described significant experiences narratively, forming detailed stories with a beginning, middle and end that conveyed meaningful and often painful events they had experienced with the care recipient. After reading each interview in detail, the first author wrote short reflective notes, supported by reflections from a research diary that helped to identify key concepts that were common or immersed and warranted further investigation. The first author wrote a condensed text and heading looking for the core and the variation, attempting to identify significant common concepts and topics. In some interviews, the core was prominent. In others, it was a minor part.

The first author drafted the analysis and discussed the emerging themes with the other authors. Further, the first author wrote thematic drafts (Van Manen, 2014 p.377) and explored them across the interviews. We clarified, concretized and abstracted the content and developed themes in several rounds. We further refined the themes through reflective writing, aiming to describe the lived meanings of care. We introduce the study's overall finding by describing caregiving as striving to adapt throughout the caring relationship, including three interrelated themes: (1) close

and distant—different caring relationships, (2) the tables have turned—caring for your family and (3) starting to let go—yet being deeply connected. The overall findings summarize the whole, and the three interrelated themes describe nuances and variations of caregiving, including quotes.

4 | ETHICAL CONSIDERATIONS

This study was sent to the Regional Committee for Medical and Research Ethics, and they found that the study was outside their field. Further, the Norwegian Centre for Research Data (Ref. 61202). approved it. Relevant hospital and university authorities approved the study as well. The interviews and transcripts were conducted in Norwegian. Selected quotes were translated into English. Data were stored and managed according to the guidelines provided by the University of Bergen. Participation was voluntary and only allowed with written consent. This study followed ethical guidelines and the Helsinki Declaration (World Medical Association, 1964).

5 | FINDINGS

5.1 | Striving to adapt throughout the caring relationship

Caring for frail, home-dwelling older people presents significant challenges to family caregivers. These challenges require constant effort and attention because of the unpredictable nature of frailty-associated health problems. Family caregivers must remain vigilant and adaptable to ensure the best care for their loved ones. The diverse range of frailty-related health issues further complicates immediate and long-term care planning. Family caregivers often struggle with worry and grief when they see their loved ones' health deteriorating and embodied changes. In emergencies, caregivers often reach their limits to provide care at home. Nevertheless, they find that things change when the person gets better and they get back some energy. Despite these challenges, they feel a strong obligation to care for their loved ones and go to great lengths to do so. Caregivers express a need for support and respite from healthcare providers to make the caregiving role more manageable.

5.2 | Close and distant—Different caring relationships

The care process started when the participants noticed the first signs of illness and suspected that things were no longer as they should be. The participants' lives changed when a previously independent family member required help. The responsibility for care stemmed from love and gratitude to their relative. Participants described caregiving as manageable initially. Some participants lived far from the care recipient. One woman cared for her sister, who had recently

declined help from healthcare providers when returning home from respite care to heal after a fall, living alone in the house where they grew up. Without the opportunity to drop by daily, concerns grew about whether she could manage independently.

I have to know she has food. I know her routines. She will not manage without milk for several weeks. She is used to deciding for herself and does not want strangers in the house. I think she will stay home as long as she can manage in one way or another. She will never leave home as long as she can make herself coffee and a slice of bread and go to the bathroom

(sister, 79 years old).

Even though participants appreciated the closeness and ability and possibility to provide care, the dual role of being a family member and caregiver might lead to frustration. Participants became annoyed when the care recipient declined the service offered, and care recipients living alone without contact with neighbours or friends was particularly stressful. They tried to persuade them to accept home healthcare but had to respect their wish not to let strangers into their house.

Spousal caregivers describe having the same responsibility for caring for their loved ones as they have for themselves. Moreover, everyday life consisted of planning and facilitating the day for their loved ones. Being this close, the care recipients' symptoms, such as pain, cough and insomnia, greatly affected the caregivers and disturbed their sleep and well-being. Even if the participants wanted to help, they needed to have some time alone, do handicrafts, read or walk and gather strength to endure the situation.

I usually wake up early, at 5 or 6. And then I think it can be good to get started. Take a proper shower, and then I walk in the neighborhood for half an hour or an hour. We have suitable terrain nearby. I am making breakfast for my wife when she wakes up. And then I shop for groceries. There was a time when she was better, and we took turns making dinner daily, but now it is just me

(husband, 90 years).

Participants had to deal with their future hopes and prospects changing since caregiving was meaningful yet all-consuming. They did what was needed and had no choice but to carry on. Family caregivers with a distant relationship did not express this dilemma but had other concerns, such as whether the care recipient had fallen or was acutely ill without anyone noticing. Participants were worried about the future and how the situation would evolve in both cases.

Although healthcare providers provided help and support, participants addressed the lack of information from the nursing home or hospital, many helpers and the lack of continuity in home healthcare. Coordinating care and navigating complex healthcare services were burdensome. Family caregivers provided care but worried about

doing something wrong. Having familiar health personnel available for support during the follow-up process was comforting, especially when dealing with multiple agencies such as hospitals, doctors and pharmacies. This enabled a sense of ease and shared responsibility in caring for the person since someone knew their health history and the systems involved.

Home nursing comes every morning, and that is a blessing. Because they help her, and if something occurs, we can talk to them. We have a perfect arrangement here, and we can confer with them. Here, we know people, and they know us – that means a lot. We are doing immensely well here

(husband, 90 years old).

The family caregivers expressed their satisfaction with the services offered by health-care providers. They highly appreciated the support and assistance provided by those who visited, answered questions, and gave advice. This unwavering support was pivotal for the caregivers in withstanding the challenging situation of caring for their relatives at home.

5.3 | The tables have turned—Caring for your family

Some events are turning points in which the participants recognize their former caregiver as a care recipient for whom they were responsible. Participants described events that changed the situation, in which they realized how ill their loved ones had become. One son had experienced that his mother was sent home from the hospital too soon and unable to care for herself.

It went so fast. The shock, the person you relied on and looked up to all your life, was almost like a child. She [the mother] was very sick after the infection, unable to care for herself or go to the toilet. It was a strain and a difficult step for both to take. The most prominent strain was that I had to decide that she should go to the nursing home. It is probably the way it is that family caregivers decide it. We both cried, but I knew no other way

(son, 54).

This event is a poignant reminder of the significant changes and challenges that family caregivers face, often leaving them feeling helpless. In this case, the son was struck hard by the severity of his mother's illness, realizing he could not provide the necessary care and support at home. Reluctantly, he had to take his mother out of the comfort of her own home, which he described as a betrayal. Her physician admitted her to an emergency room at a nursing home. This experience was emotionally taxing for him, knowing that caring for his mother in the future would be difficult. Other participants in the event shared

similar experiences, recognizing the extent of their care recipients' dependence on them and how it affected their lives. Gradually, these events led to a newfound understanding of the challenges of being a family caregiver.

Some participants described guilt for not understanding the depth of the care recipients' despair.

They [the parents-in-law] stayed at the nursing home but wanted to return home. One night, I woke up to him calling for us in their bedroom window. We searched for her in every room and outside. After a while, she entered the house, wearing her coat. She had been out and about, saying she had found a place down on the pier, where she had planned to jump into the sea, to take her own life ... That was a terrible moment. She had asked whether there was anything [pills] to get for her head. She had expressed despair, but we had not perceived that she had been in such despair

(daughter-in-law, 56).

This event was a groundbreaking experience since the family had arranged for the frail older couple to live safely at home but now realized this was not the case. Afterwards, they learned that the care recipient had escaped at night when she was in the nursing home without them having been contacted, either when it happened or on discharge. Knowing this could make them better prepared for what awaited them. New and escalating care responsibilities cause various emotions for the caregivers, such as unpredictable prognosis, lack of information and the future both parties face. They realised the situation was out of their control even if they tried to prepare.

5.4 | Starting to let go—Yet being deeply connected

Participants witnessed the care recipients' discomfort and embodied changes. The participants realized they had to start letting go, albeit feeling connected and morally responsible for the care recipients receiving adequate care. The family caregivers' experience of not doing enough pervaded their lives, and they could no longer separate their needs from those of the care recipients. Family caregivers expressed that they unintentionally had reduced their self-care, manifested through fewer meals and sleeping to make time pass when the person they cared for received care elsewhere. Being at home was especially important for spousal caregivers, who had shared a long life. They did their best to help, knowing their partner lived on borrowed time. Spousal caregivers described the bonds to the care recipients as vital, describing a life that seemed inseparable from their sense of self. They had shared a long life and grown together, and separating from the long-term partner would be life-changing since the marriage meant security and an anchor in a time characterized by profound changes, and merely talking about transitioning to a nursing home was tough.

Adult child caregivers described putting their lives apart to care for their frail older parents and feeling torn between caring for their children, partners, work, household and social life. Some described it as a relief the day it was over and yet the worst imaginable scenario.

I think they [parents] have an almost insatiable need. I sometimes think it would have been easier if they were dead. It is not easy to say, but now I am honest. I have a terrible conscience when I think like that, and I would have thought it was horrible if it had happened. I am terrified of it at the same time. I have had several events where I had to call an ambulance. So, if the home nurse calls me in the morning, I get scared. So, it is not something I want, but the thought is there. Because then I can start my life. Do you understand?
(daughter, 55 years).

Participants balanced living their own lives and caring for their loved ones, realizing that their personal lives were intertwined, making unwinding impossible. Although participants found care meaningful and wanted to provide it, they expressed being overwhelmed by the needs of the care recipients. Participants' experience of failing to balance being a family caregiver drained their energy, entailing an overwhelming care responsibility unsustainable for the long term. Family caregivers negotiated whether institutional living would benefit the care recipient or themselves. They asked themselves whether selfishness, worry for their loved ones or both made them consider a nursing home.

6 | DISCUSSION

This study aimed to explore family caregivers' lived experiences with caring for frail home-dwelling older people. The overall finding is that striving to adapt throughout the caring relationship, highlights family caregivers' multifaceted challenges. A significant aspect is the need to adjust and cope with older people's varying health conditions and the unpredictable nature of daily life. Caregivers must navigate complex healthcare systems and make critical decisions about their loved ones' well-being, which often puts them in a position of uncertainty since they lack guarantees that healthcare providers will be readily available or able to take over if needed.

The results of this study show that a caring relationship is experienced in different ways, all of which include interweaving existential, physical, emotional and relational aspects by being close and distant in different caring relationships, experiencing that the tables have turned when caring for your family and starting to let go yet being deeply connected as a balancing act between care and self-care.

This study aligns with Heidegger's (1962) perspective on care as a fundamental existential condition that involves people's connection to the world and others. Care is driven by love, duty and reciprocity, expressing a personal commitment and practical involvement in providing for and supporting others. Caregivers in

this study demonstrate accepting the consequences of their commitment through their actions, such as helping, comforting and accepting the role of caregiving. This study also highlights the attachment of family caregivers to their relatives, which is relevant to care practices.

Both Martinsen (2003) and Heidegger (1962) emphasize the dynamic relationship between caregiver and recipient, promoting the care recipient's overall well-being. The caregiver's role is not limited to meeting immediate needs but extends to actively supporting the care recipient's well-being.

Our findings suggest that practical care has implications for both parties when frailty creates an imbalance in the relationship since one party must assume the role of the caregiver, entailing understanding and meeting the unique needs of the person being cared for, doing what is best for them in their situation (Martinsen, 2003). However, in a welfare state like Norway, providing practical care may not be time-consuming and can be done outside work hours (Rostgaard et al., 2022).

Based on our findings, *close and distant—different caring relationships* started when family caregivers first noticed signs of illness or frailty in their loved ones. Martinsen (2003) refers to this as relational care in which both parties give and receive care with each other's best interests in mind. Bjerkmo et al. (2022) emphasize how family caregivers' continual help and support were pivotal for frail older people being able to continue to live at home. This has similarities with other studies, where caregivers expressed wanting to do the right thing (Zarzycki, Seddon, et al., 2023).

Our findings also underscore that caring for a loved one can be a challenging but rewarding experience. Family caregivers devote significant time and energy to caring for their relatives. Vangen and Herlofson (2023) state that having a solid parent-child relationship is crucial for providing informal care, which suggests that family solidarity across generations is still present. This indicates that caring for others is more of a personal choice rather than a societal obligation. According to a recent systematic review, the love of the care recipient was found to be a significant motivator for caregivers (Zarzycki, Morrison, et al., 2023; Zarzycki, Seddon, et al., 2023). Additionally, when caregivers felt appreciated for their efforts, they gained a sense of purpose and fulfilment (Moral-Fernández et al., 2018).

Our findings highlight that family caregivers increasingly take on responsibility and communicate with healthcare providers, like doctors, physiotherapists and nurses, to coordinate their loved ones' treatment and care. Managing complex healthcare services, fragmented information and care continuity becomes a significant responsibility. The lack of support and guidance amplifies their concerns about unintentional mistakes or missing crucial symptoms. The caregivers describe their caregiving experience as a lonely responsibility, emphasizing the need for improved communication and collaboration between caregivers and healthcare providers. This is similar to previous research showing that physical frailty is commonly linked to care responsibility, with accompanying symptoms such as anxiety and depression (Zarzycki, Morrison,

et al., 2023; Zarzycki, Seddon, et al., 2023; Plöthner et al., 2019; Szebehely & Meagher, 2018).

Prior research has indicated that home-based care is favoured by both care recipients and caregivers (Munkejord et al., 2020; Ringer et al., 2016). Our study reinforces this and emphasizes the significance of having access to support and assistance from familiar healthcare providers who possess knowledge of the patient's health history and relevant systems. Family caregivers were especially grateful for this assistance, as it enabled them to obtain answers to their inquiries and advice, while also affording them the opportunity to receive additional help on short notice when caring for their loved ones at home. This unwavering support was pivotal for the caregivers in withstanding the challenging situation of caring for their relatives at home.

Our finding, *the tables have turned—caring for your family*, illuminates events as turning points in which family caregivers expressed a moral responsibility to support relatives who want to stay home. Following Martinsen (2003), moral care implies recognizing and respecting the care recipient, implying solidarity with the other person and trying to understand dependence. By doing so, family caregivers provided care intending to enable their relatives to live the best life possible with frailty.

However, continuing living at home was not always possible, and family caregivers had to ensure that the care recipients received adequate care. Our findings showed that challenges can arise despite family caregivers' efforts to prepare, such as one woman's experience with her parents-in-law, where her mother-in-law's safety was a concern when her mother-in-law walked out at night, trying to jump from a pier. Caregivers must balance this asymmetrical relationship, preserving autonomy and dignity while planning future care. Even in countries like Norway, with solid welfare systems, caregivers still bear the responsibility for home-based care of frail older individuals (White Papers 15 (2017–2018), 2017; White paper 24 (2022–2023), 2023). This aligns with Andersen et al.'s (2020) findings, which highlight caregiving as an inherent aspect of life, driven by concerns about frailty and older individuals' dependency.

Our findings reveal how the experience of care changes as frailty develops, leading to altered relationships and increased responsibility. Previous research highlights that the caregiving relationship reaches a breaking point when caring for older relatives at home is no longer feasible (Spang et al., 2023). Furthermore, the tight relational bonds between caregivers and care recipients can create difficulty for caregivers to ask for respite, but involving familiar healthcare personnel in the follow-up process can ease the difficulties. Studies have demonstrated that respite care services which offer meaningful and adaptable activities can significantly enhance the quality of care provided to loved ones. This can help alleviate the stress experienced by family members responsible for caring for their loved ones (Munkejord et al., 2020; Plöthner et al., 2019; Shea et al., 2017).

Our finding, *starting to let go—yet being deeply connected*, sheds light on caregivers' emotional struggles and difficult decisions while striving to provide the best care for their loved ones. According to

Ringer et al. (2017), family caregivers' needs should be recognized. Existential issues about the current and future situation need to be raised and awareness created of their reactions to care. Previous studies highlight that caregiver responsibility poses a compelling risk since family caregivers report a lower quality of life (Chappell et al., 2021; Pinquart & Sörensen, 2011; Stefánsdóttir et al., 2022). We assume that the caregivers in our study might have the same experiences.

In our study, the family caregivers put themselves in the care recipients' place for as long as possible by preparing meals or doing housekeeping. The family caregivers' experience of not doing enough characterized their lives. They could not risk getting sick, so some participants tried to take better care of themselves, for example, by starting yoga to overcome stress or sharing care with others. Participants had to deal with changing their future hopes and prospects since caring was meaningful but all-consuming. It has become evident that they can no longer maintain the same level of care as the recipients' conditions continue to decline, such as the daughter's ambiguous experience between deep worry and shame when thinking about freedom and relief when her caring responsibility ends.

This study highlights that family caregivers feel both responsible for and connected to the frail older person as both a caregiver and a close family member. Norway has strong political support for older individuals living at home, encouraging family caregivers to be actively involved (White Papers 15 (2017–2018), 2017; White paper 24 (2022–2023), 2023). Our findings indicate that caring for relatives can impact a person's ability to balance a longer career, their own health and social engagement. Vangen et al. indicated that caring for others is more of a personal choice than a social obligation in the Norwegian context (Vangen & Herlofson, 2023). However, countries in other parts of the world might have a different social system and caring context. One recent systematic review found that caregiving responsibilities persist because of the value of positive recognition and confirming social and cultural norms (Zarzycki, Morrison, et al., 2023). This indicates that relational and social ties are essential for family caregivers.

Previous studies reveal that family caregivers assume significant responsibility for their relatives' care at home, often lacking adequate information and support. Despite the challenges, their strong emotional connection and love for their relatives make it challenging to prioritize self-care (Ris et al., 2019). Respecting the wishes of older individuals and their families has been emphasized in previous research as a key component of effective rehabilitation, facilitating continued living at home (Ohta et al., 2021). This may also involve training and information to prepare for potential deterioration or decision-making adjustments. It is widely agreed that sustaining older people's residence at home, with family caregivers providing care and older individuals participating in self-care, necessitates fresh insights, including the perspectives of frail older individuals and their family caregivers (Grenier et al., 2020; Skilbeck et al., 2018).

Combes et al. (2021) emphasize the significance of future care planning, highlighting the need for frail older individuals to grasp advanced care planning's relevance and its importance in understanding

their needs. Healthcare providers should prioritize living well in the present and making decisions based on relationships. Supporting this, Munkejord et al. (2020) underscores the importance of providing family caregivers with information and psychological support to cope with their situation.

By incorporating Heidegger's insights into the understanding of caregiving, we can recognize the profound significance of care as a deeply rooted and meaningful aspect of human existence. Care goes beyond mere assistance or support; it reflects our essential connection to others and the world and encompasses the emotional, practical and relational dimensions of our engagement with caregiving. Combining Martinsen's emphasis on relationality, practicality and morality with Heidegger's concept of *fürsorge* and future-oriented care, a comprehensive understanding of caregiving emerges.

We conducted this study with family caregivers of frail older individuals in rural Norway, using Fried et al.'s well-established frailty criteria (Fried et al., 2001). Trustworthiness was essential throughout the research process (Creswell et al., 2021). To increase credibility, the first author used her clinical experience when planning and preparing the interviews and the interview guide, and all authors read and participated in the analysis. Only the first author analysed the data set, which might be a limitation. A reflexive attitude was maintained throughout the research process to ensure confirmability. We were aware of our role in interacting with the participants, empirical data, theoretical perspectives and previous understanding that we brought into the project. The few participants might have limited the range of experiences described. Nevertheless, through rich descriptions and background information to describe the complex phenomenon of caregiving for frail, home-dwelling older people, we consider our findings strong (Morse, 2015).

7 | CONCLUSION AND IMPLICATIONS FOR PRACTICE

This study underscores the intricate nature of caregiving for frail older individuals living at home. Family caregivers navigate the dual roles of close family members and caregivers, and as the care recipient's condition worsens, discussions about future care options, including nursing home care, become vital. In practice, this study highlights the need to acknowledge and address the challenges faced by family caregivers. Healthcare providers could offer support, resources and services to help caregivers manage their responsibilities while preserving their well-being.

Implications for practice: Implement holistic care approaches that address caregiving's physical, emotional and social aspects. Expand respite care services to provide caregivers with regular respite and support.

Implications for research: Future research could consider longitudinal studies to track family caregivers' evolving needs and experiences over time, providing insights into the long-term impact on caregiving, including caregiving experiences among diverse caregiver populations.

Implications for education: Include caregiver support and communication training in the education of healthcare providers to improve interactions with family caregivers.

Implications for policy: Advocate for policies that recognize and support family caregivers. Implementing these recommendations can yield better outcomes for both caregivers and care recipients.

Sustainable practices: Healthcare providers could prioritize meeting family caregivers' unaddressed needs to support them and help them withstand the caring situation, avoiding or postponing institutionalization.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no competing interests.

DATA AVAILABILITY STATEMENT

The data supporting this study's findings are not publicly available due to privacy or ethical restrictions.

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