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Preparing for home death in rural areas - the experience of family caregivers providing palliative cancer care

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ABSTRACT

Palliative care policies worldwide support people's wishes to spend their final days at home with family caregivers playing a vital role. In Norway, 16% of the population lives in rural areas where palliative end-of-life care is especially challenging due to geographical barriers and limited access to healthcare resources. Research on rural family end-of-life care for people with cancer is sparse. Therefore, the purpose of this study was to investigate what resources are needed for rural family caregivers when providing end-of-life care and preparing for home death for a person with cancer. Thirteen semi-structured in-depth interviews with family caregivers in seven rural municipalities in Northern Norway were conducted from February to April 2023. The thematic analysis revealed three key themes supporting caregivers' resilience: end-of-life care and home death require available resources in family caregivers; the availability of reliable professional follow-up services for end-of-life care; support from family and social networks compensate for lacking healthcare resources. Holistic healthcare for rural populations should consider aspects like distance and cost while involving the entire family and their social network. Local palliative care beds and telehealth services should be available to support rural family caregivers.

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Introduction and background

Cancer is the leading cause of death globally [1]. Many people with incurable cancer prefer to die at home, where they feel comfortable and familiar [2–4]. Achieving home death is often associated with a feeling of safety, serving as a key indicator of quality palliative care [4,5] and embodying the ideal of a "good death". International palliative care policies support home death [6]. However, in rural areas where half of the world's population lives [7], many people do not achieve this goal [7,8]. The definition of "rural" varies based on geography, population density, and healthcare access [9]. While the number of home deaths has declined in many countries, in Canada, the UK, and the Netherlands, it has increased due to a policy shift towards home-based palliative care [10]. In Norway, 16 % of the population lives in rural areas [11], often in communities with a high elderly population and limited access to healthcare. In 2023, the Norwegian Cause of Death Registry reported 11,200 cancer deaths, with only 14% occurring at home [12], and home death rates in Norway have remained stable over the last decades [13,14]. Recent recommendations in a Norwegian white paper on palliative care state that people who wish to die at home should have the option to do so [13]. Nevertheless, this goal has not been fully achieved.

Planning for home death in rural areas is especially challenging due to significant geographical barriers and limited access to healthcare services and palliative care resources [1,15]. For both cancer and non-cancer patients, residing in rural areas is a significant predictor of poorer outcomes in end-of-life care [8,16]. Caring for people in rural areas presents unique challenges compared to urban settings [9]. Professional home care support is sparse in rural areas, particularly during evenings and nights [4,17]. The absence of interdisciplinary palliative care teams and the limited availability of earmarked beds for palliative care in hospitals and nursing homes hinders effective care in rural areas [14,18,19]. Furthermore, the quality of rural palliative care and the option to die at home rely heavily on families' networks [16,20,21]. Family caregivers face more unmet needs in providing palliative care than in urban areas [22]. In rural settings, the connection between place and identity is perceived to be stronger than in urban areas,

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making it likely that residents view dying at home as central to achieving “a good death” [4].

Dedicated family caregivers are vital in enabling people to die at home [23,24], where family caregivers (spouses, partners, family members, friends, or neighbours) assist with daily living activities and medical tasks [25]. In rural areas, these caregivers often provide essential support during end-of-life care [26,27], assisting with emotional and social needs and accessing healthcare services [28]. Family caregivers often feel unprepared for the challenges of end-of-life care [29] and do not fully understand what it means to have a loved one dying at home [30]. Their responsibilities involve navigating complex medical, psychosocial, spiritual, and practical issues [4,17,18]; they participate in end-of-life decision-making, act as advocates, and deal with challenging medical interventions [31]. These caregivers may experience significant emotional distress [32,33], such as prolonged grief, depressive symptoms, anxiety, and chronic pain [34], emphasising the need for emotional and advisory support [18].

Previous research indicates that age, marital status, caregiver support, pain management, and professional assistance influence the likelihood of dying at home [34]. Other important factors include access to palliative care, few or no hospitalisations during the end-of-life period, capable informal caregivers, and resources to meet physical and psychological needs in their residence [35]. The likelihood of dying at home increases when general practitioners (GPs) are part of interdisciplinary teams and provide home visits, and when the ill person receives intensive home-based nursing care [14,36]. Men, people with higher incomes and those living in smaller communities often prefer dying at home and are more likely to do so [37].

Few studies have explored the experiences and perspectives of family caregivers involved in home deaths in rural areas, indicating the need for further research to improve end-of-life care and support home deaths in these communities [14,38]. Therefore, the purpose of this study is to investigate what resources are important for rural family caregivers providing end-of-life care and preparing for home death for a person with cancer. Understanding these needs is essential for developing targeted interventions that support family caregivers and help fulfil people’s wishes to die at home.

Study design and methods

This study employs an exploratory design guided by Gadamer’s hermeneutics [39]. We followed the principles of Gadamerian nursing research outlined by Fleming et al. [40]. These principles informed the development of the interview guide, the identification of our preconceptions, the engagement in dialogues with participants, the analysis of the interview texts, and the assurance of the study’s rigour [39,40].

It is crucial to understand how caregivers cope with stress when caring for a family member with cancer and how impending death influences their resilience [41]. This challenge affects the entire family and its environment [42]. The palliative care framework addresses these issues holistically, focusing on the quality of life for patients, families, and caregivers [43]. We employed a family resilience framework grounded in the family systems approach [42,44,45] to enhance our understanding of how families confront, endure, navigate, and recover from adversity [44,46]. This perspective views family resilience as an interconnected system influenced by significant stressors and social contexts, promoting adaptive responses from all family members while strengthening the family unit [44]. It also considers families as dynamic systems with unique functions, goals, and patterns that shape both daily life and long-term outcomes [45]. Unlike individual resilience research, which typically focuses on personal coping traits and often views family influence solely as a risk factor [46], this framework acknowledges that all familial relationships contribute to individual resilience. It balances the examination of both strengths and vulnerabilities, exploring how chronic illness, loss, and trauma interact with risk and protective factors at individual, familial, and broader sociocultural levels over time [46].

This study is part of a larger doctoral research project focusing on rural family caregiving at the end of life. For this specific study, we included only participants who had chosen to fulfil the ill family member’s wish to die at home. We conducted qualitative interviews to explore the lived experiences of rural family caregivers, gaining insight into their life world. Gadamer emphasises the need to recognise and be mindful of our perceptions, thoughts, and preconceived opinions about specific topics or situations to achieve understanding [39,47]. Therefore, we needed to critically reflect on our research roles [48,49]. The three female authors are specially trained nurses with extensive experience in end-of-life and family care. The first author is a PhD candidate, while the second and third authors are experienced qualitative researchers. When reporting our study, we adhered to the COREQ guidelines [50] (Additional file 1).

Settings

The study took place in Northern Norway, primarily located north of the Arctic Circle, covering 35% of

Norway's mainland and home to approximately 9% of its population [51]. The research focused on seven rural municipalities with populations ranging from 1,074 to 14,869. These municipalities are part of a larger region comprising 80 municipalities with 483,501 residents representing Norwegian, Sami, and Kven cultures, where low population density significantly impacts healthcare delivery [52]. Each municipality organises primary palliative care differently, relying on general practitioners, district and cancer nurses, and palliative care teams. Due to limited hospice services, end-of-life care is typically provided locally at home, nursing homes, or rural medical centres [52]. Specialised palliative treatment and care are available at regional hospitals, often necessitating long journeys for rural residents. Additionally, the area's elderly demographic, limited healthcare services, and harsh winter weather often lead to closed roads and bridges, cancelled flights and ferries, and poor road conditions, further complicating access to care in Northern Norway.

Recruitment and participants

The participants were selected using purposeful sampling [53], and after receiving approval from local healthcare leaders, community cancer nurse coordinators recruited participants based on the following inclusion criteria: adult family members of a person with cancer who provided home-based palliative end-of-life care and planned for the ill family member's home death in rural areas of Northern Norway, in municipalities situated at least a 45-minute drive from the nearest hospital.

We asked the recruiting personnel to distribute written informed consent forms. To explore the phenomenon from different angles, we aimed for variety in age, gender, proximity to municipal centres, family relationships, geographic regions, and cultural background. After receiving the signed consent forms, the first author contacted the participants by phone to make appointments. All participants maintained their consent throughout the study. Thirteen family caregivers (two men and eleven women, aged 37 to 76) were included. All participants had provided end-of-life care for a family member living with cancer, aiming at fulfilling the ill person's wish to die at home. The participants included nine spouses, three daughters, and one sister, with an average duration of palliative care of 6 months. Four of the thirteen participants were professional healthcare workers, and many family caregivers had relatives and friends employed in healthcare services. More than half of the study participants reported that their family members died in institutions such as hospitals or community facilities. People from diverse cultural backgrounds, including Norwegian, Sami, and Kven, were recruited (see Table 1).

Interviews

The first author conducted semi-structured, in-depth interviews with rural family caregivers between February and April 2023. Based on information power [54,55], we stopped data collection when we considered the existing amount of data was sufficient [55]. The first and third authors developed the interview guide (Additional file 2) in collaboration with a user representative with experience as a family caregiver. The interview guide was tested in a pilot interview to enhance subsequent interview procedures and refine follow-up questions [56]. According to the participants' wishes, the interviews took place mainly in their homes, workplaces, or hotels. Only the participants and the interviewer were present during the interviews. All interviews were audio recorded [53] and lasted between 60 and 90 minutes, allowing participants to share their opinions through dialogue [40]. Initially, the participants were invited to tell as much as possible about their experiences [57]. Active listening and follow-up questions were employed to prevent misunderstandings and clarify participants' perspectives [58]. Reflexive journaling [59] and field notes were utilised to document thoughts and preconceptions and to develop our follow-up questions before conducting new interviews. The first author transcribed the first interview. A research organisation transcribed the interviews based on an agreement with UiT, the Arctic University of Norway, and a data processing contract was signed to ensure confidentiality. The first author validated the transcripts.

Table 1. Participants.

Demographic characteristics of participants	(*n* = 13)
Mean age, Years	62,5
Age 30–39	1
Age 40–49	2
Age 50–59	3
Age 60–69	4
Age 70–79	3
Spouse/partner	9
Children/siblings	4
Males	2
Females	11
The average duration of palliative care	6 months
Home deaths	6
Death at nursing home facilities	6
Death at hospital	1

Ethics

The study was conducted according to The Helsinki Declaration [60]. The Regional Committees for Medical and Health Research Ethics (REK Nord) and the Norwegian Centre for Research Data (NSD, now SIKT) granted permission for the study (reference no. 838782). The interviewer and the participants had no contact before written informed consent was given [61]. The participants were verbally informed about the purpose of the study and their right to withdraw at any time [60]. All participants gave their informed consent.

Discussing sensitive topics, such as end-of-life issues and dying, can be emotionally challenging [62,63]. Recognising participants' vulnerability, we weighed the potential benefits and risks [62]. Thus, we instructed the recruiting personnel to ensure that at least six months had passed since the death of a family member before approaching potential participants. During the interviews, the participants were encouraged to take a break or stop the interviews if necessary. Almost all the participants showed signs of emotional distress during the interview, however, after eventual breaks, they wanted to continue. We arranged follow-up services for the family members [62] by involving a cancer nurse who could provide support if needed.

Thematic analysis

The hermeneutic approach [39,40] supported our understanding of what influenced home death in rural areas, as perceived by family caregivers. The first author conducted the initial analysis, while the other authors validated and refined the themes. The analysis process involved a circular movement between examining the text's parts and the whole, leading to a constantly evolving understanding [39]. Theoretical assumptions were part of our pre-understanding [64], and we found the family resilience theory helpful in further illuminating our findings.

We used Braun and Clarke's inductive reflexive thematic analysis approach, which involves six steps [65,66]. The first and third authors familiarised themselves with the dataset by reading all interviews multiple times [65], noting significant passages related to the research question [67]. The first author developed a coding system using the computer-assisted qualitative data analysis software program NVivo (version 14) [68] to organise the large dataset and enhance the efficiency of the analysis [69]. During initial coding, meaningful information units from the transcripts were identified and labelled. All data relevant to the research question received thorough and repeated attention throughout the coding process. Related codes were organised into carefully reviewed and refined themes to express meaningful narratives, rather than merely summarising the topics [69,70]. The identified themes were named, and the selected quotes illuminated the content of the themes, adding depth to the findings [69]. The quotes were translated from Norwegian to English while maintaining their original meaning. To ensure trustworthiness, we followed Braun and Clarke's 15-point checklist for reflexive thematic analysis [69]. Initial themes were discussed with a user representative, whose feedback helped refine the themes.

Results

The analysis identified three themes that reveal important resources for supporting end-of-life care and home death in rural areas. These include the personal resources of family caregivers, access to reliable professional follow-up services, and support from family and social networks. Due to long distances and limited resources, family caregivers in rural areas faced challenges related to logistics and access to healthcare. They had to be strong when trying to fulfil their loved ones' wishes to die at home, supported by local healthcare services, family, and friends.

End-of-life care and home death require available resources in family caregivers

All participants expressed a strong motivation to make it possible for the ill family member to stay at home during the final stages of life, and they made considerable efforts in planning for palliative care and home death. They needed strength and capacity to fulfil their loved ones' needs and wishes. The enormous responsibility of managing difficult medical, practical, and emotional situations called for specific personal characteristics and skills, such as being physically and mentally strong, resourceful, and able to cope with various challenges. In addition, they mentioned personal knowledge and former experience with caregiving as strengths.

Family caregivers' motivation arose from viewing the home environment as a natural, private, and safe place for end-of-life care: He was in the living room. We got the bed in there. How much more liberating it was instead of being in an institution. Sitting and drinking coffee. I am so glad we made it happen. (P3, sister) Participants did not perceive nursing homes in rural areas as a suitable place to die as palliative care beds were lacking. Several caregivers noted that strict schedules, limited space, and restricted visiting hours in nursing homes hindered family togetherness.

Family caregivers perceived that the Norwegian healthcare system lacked resources to provide palliative care at the end of life. Therefore, they were prepared to take on this responsibility: Some relatives think: … others have to fix that … ″Healthcare- Norway″ must take care of it. But it's not like that, and then you have to stand up. (P6, daughter)

Additionally, prior knowledge and experience in caring for chronically ill family members and providing palliative care strengthened the family caregivers. Some caregivers felt more secure in their caregiver role because they had worked as health professionals and were familiar with healthcare services.

> Then they came and gave her morphine straight away, and she stopped having pain. And then, they came down from the health center and followed up the whole time. Yes, and [I] know the paramedics who were here. We know them very well. (P12, M. spouse)

However, balancing being a family caregiver with expectations attached to the professional role as a nurse or doctor could be challenging due to emotional distress and intimacy issues:

> When you have two roles, right, you have to be both a professional and you have to be a sister. It is not always easy to combine these roles. It's not. Because you are so emotionally affected by the situation, and you don't always think like a professional either. (P3, sister)

Not all participants who were educated healthcare workers had experience with palliative care. They felt incapable of taking on the responsibility for pain and symptom control:

> Yes, I'm a nurse, and I've done a lot of things, but I don't have the first-hand knowledge of a cancer nurse after a year of specialist training and experiences in the field. It is, after all, a [professional] field of its own. (P10, F. spouse)

Access to essential equipment, medications, and other treatment remedies was crucial yet challenging for family caregivers responsible for providing high quality palliative care, *"He needed these blood bags. There was an overflight, and then the plane didn't come down. And then the blood bags went to another location. It's how it is living rurally"* (P5, F. Spouse). Understanding how to obtain the necessary equipment was more manageable for those who were familiar with the system:

> I was able to quickly get a specialized toilet chair when he suddenly needed it because I was familiar with the system. I knew exactly where it was, so I didn't have to wait until the next day. In that sense, I had some sneaky advantages. (P10, F. spouse)

Family caregivers had to neglect their own needs and sacrifice their desires to ensure the safety and well-being of the ill family member. As their lives became more limited, taking breaks and engaging in social and work activities became essential. However, several caregivers indicated that fulfilling their family member's wish to die at home had made them stronger:

> You want her to have the best, as good as possible … It was tough. It was a full-time job … but I think I became stronger from this experience and gained the strength to complete what I had to do, both in helping her and doing other things. (P12, M. spouse)

Family caregivers needed more than just a strong desire to fulfil their loved ones' wish to die at home. In addition, their personal and financial resources, financial support from the welfare system, and permission from work were crucial in providing end-of-life care. A financial buffer system and economic stability were considered advantageous. Some expressed that travelling long distances to be available for an ill family member was costly. Extra costs arose due to bad weather conditions and closed roads.

Financial assistance from the welfare system, such as care allowances, was intended to compensate for lost earnings. Caregivers highlighted the importance of receiving timely information and efficient case processing when applying for these allowances. Some expressed regret that the financial support from the welfare system arrived too late.

For some participants, taking sick leave was necessary to care for their ill family members. This was often a challenge in rural areas, where obtaining an appointment with a general practitioner could be time-consuming. Participants found that flexible working conditions, supportive leaders, self-employment, or home offices enabled them to manage the demands of caregiving alongside their work responsibilities

The availability of reliable professional follow-up services for end-of-life care

Support from municipal healthcare services varied based on the resources available in each municipality. Initially, caregivers preferred to handle the care of their ill family members on their own, seeking minimal assistance. However, as the illness progressed and with the end of life approaching, caregiver burdens increased significantly.

> But you put yourself on hold … I was very reflective and thought about what I could and could not do. In a way, I had the option to sit down if I wanted to, had the option to call for more help if I wanted to, and as I said, I got to a point where I did that. (P10, F. spouse)

Participants often reported a greater need for professional support, including homecare services, cancer nurses, general practitioners, palliative teams, and more specialised services in rural or central hospitals, which were not always available:

> They said that home nursing did not have enough knowledge about that type of disease, lung cancer, and he could not die at home. He could get delirium here. What do you do then? I said people should be allowed to die at home in [place name] municipality. (P5, F. spouse)

Family caregivers considered the availability of flexible healthcare services essential for providing end-of-life care and planning for death at home. Some caregivers noted that healthcare resources were easily accessible, as healthcare workers in rural districts were known for their quick response times during acute incidents. When necessary, ambulances, air ambulances, or helicopters could be used to manage long distances and harsh weather conditions:

> There are very long distances, but then you have good people in the ambulance … it goes quickly if you call the ambulance. They fix it quickly - the doctor and an air ambulance. The most challenging thing here is the weather because the road can be closed quickly, which happens quite often (light laughter). But then you have the Sea King coming. It usually works out. If you have been living here for a long time, you are accustomed to it being like that. (P9, F. spouse)

Providing 24/7 services could be challenging for rural municipalities due to the lack of home care nurses in the late evening hours and at night. As a result, they implemented backup systems that allowed family caregivers to call the nearest community healthcare institution for assistance:

> We also had a sort of back-up plan if the pain pump stopped or if any other issues arose. When there was no nurse here, a nurse at the nursing home had been trained and could change the needles, reset the pump, or change the cassette. (P10, F. spouse)

The participants stressed the importance of being assisted by nurses with expertise in palliative care. If their district lacked specialised nurses, they contacted cancer nurses employed in other municipalities. In addition, palliative care units at the local hospital, specialised healthcare services, and palliative teams were consulted for advice on symptom relief and nutritional issues. However, the family caregivers were familiar with the lack of specialised expertise and appreciated working with experienced general nurses:

> It's a plus of living here- the nurses get very multifaceted experiences. They are generalists and specialists in many things. (P10, F. spouse)

Reliable and empathetic relationships with healthcare providers were essential for family caregivers. One caregiver shared:

> He [name], a doctor here, is very good at following up on the patients who are very ill. He comes by every day and often several times a day. And the home nursing here is also very good, so we were satisfied with the follow-up we received from healthcare services. (P9, F. spouse)

Another caregiver mentioned that their relationships gave them a sense of safety and comfort: *"It was very safe and warm because everyone knows each other so well when it is so local. In such settings, everything flowed naturally because no one dominated; everyone was humble and careful. It was a very nice setting* (P13, daughter). However, not all rural family caregivers used available community support services due to their previous relationships with healthcare workers. They felt uncomfortable because they perceived the relationship as being too close.

Some participants valued having a direct line to the local hospital. If they needed immediate transport to the hospital, they did not need to go through the municipal emergency system.

> But I felt so confident that someone would take action immediately if something was wrong; it was just a matter of calling a number. Since we had the direct number to the hospital and the department there, we could come whenever there was an issue; we just called, and when the fever rose, or something occurred, we came in straight away. Then I did not feel alone. (P7, M. partner)

Effective collaboration between professionals involved in different aspects of the treatment was crucial for providing good-quality palliative care. Family caregivers felt safe when healthcare personnel from specialised services supported community professionals and ensured a smooth flow of information: *"The home care nurses were very well prepared and explained that they had spoken to the hospital, received information, and had a contact somewhere. So, if there were things they wondered about, they could call. So, I felt very safe providing palliative care at home"* (P10, F. spouse).

When the healthcare system failed to offer sufficient support at home, family caregivers felt that institutional care was necessary to ensure the well-being of the ill family member. This could happen if the treatment did not relieve distressing symptoms or if complications occurred:

> But if she had stayed at home for the last three days as we had planned, I think I would have had a worse experience. So, it is almost as if I think that when you come to that, perhaps the next of kin should also be prepared, as it may not be the best option to stay home during the last days. Otherwise, we would need to have more people available. (P6, daughter)

Nevertheless, some caregivers continued to feel unsafe when their ill family member was transferred to hospitals or nursing homes. They expressed a need to monitor and guide healthcare staff because they did not trust the quality of the care provided.

Support from family and social networks compensates for lacking healthcare resources

Insufficient competence, long distances, and limited access to specialised healthcare posed barriers to providing palliative care and enabling home deaths in rural areas. Family caregivers often depended on support from their family and social networks. Knowledge, family size, and the proximity of family members was essential in enabling end-of-life care at home. One family caregiver noted that collaborating in end-of-life care had made her family stronger. In some families, the primary caregiver coordinated a support network for the ill family member to ensure close relatives being available for assistance. Thus, the primary caregivers did not feel entirely alone with the responsibility, allowing them to take breaks and continue working life while the ill family member was cared for 24/7.

> So, the children and children-in-law, everyone took their turn so that I did not need to carry the whole load. I think it is completely different if you are alone. If you must stand there without someone else watching and coming in to relieve the pressure and saying, "I can take the evening shift" or "I can step in this night. (P7, M. partner)

Having a large family living in the local community was helpful. Family members who did not live nearby often travelled long distances to support the primary caregiver. The competence and support of family members who were professional healthcare workers were highly appreciated. One family caregiver received telephone support from her niece, an oncologist helping her to provide pain relief for her husband. Nevertheless, not all family members were available for support as they had moved to other areas for work or education. A family caregiver expressed her gratitude to her cousin, specialised in palliative care, who moved in with the ill family member, making it possible for the carer to continue in her working life.

In many ways, providing end-of-life care in small rural communities was more manageable for family caregivers. Supported by their network, caregivers could take breaks from the challenging caregiving tasks and tend to their children and household chores. They felt less isolated when surrounded by neighbours, friends, and colleagues who offered practical assistance, such as cleaning, shopping, cooking, shovelling snow, and supplying wood. One family caregiver shared that the support from friends made it possible for the loved one to spend the final stages of life in a familiar environment:

> So, it was really a collaboration between the village and the family, good neighbors and the home care service . . . so many volunteered. The municipality promised they would fix things. If there was a need, they should pay night shift workers. But they didn't need to because people [showed up]». (P13, daughter)

Friends and neighbours also provided emotional support to both the ill person and the caregiver, helping them navigate challenging situations. Particularly, the participants appreciated the support from friends and neighbours who were healthcare workers:

> But when he got worse, there was a retired nurse who took night shifts so that my cousin could get some sleep. Dad enjoyed that because he [the retired nurse] was a friend of him. There was no such thing as being embarrassing or weird because they were friends. He was so professional in his role that it became completely natural. (P13, daughter)

However, not all family caregivers received support from their network, especially in the last days and weeks. For some, it was not easy to ask for help:

> . . . but then I think, if we needed help with something and asked, we would have got it. But it wasn't like people suddenly appeared and did a lot, I don't know how natural that is either. (P6, daughter)

Others had expected that neighbours and friends would make contact by their own wishes. At the same time, they accepted that it was difficult for people, as death and dying were considered private matters.

> I've noticed that people become very cautious and hesitant to make contact when they realize that someone is approaching death. They seem reserved and afraid of being intrusive or burdensome. It's not that

> they don't want to help, but they are afraid of getting in the way during this private and intimate period [of life]. That's how I understand it… (P4, F. partner)

Discussion

The purpose of this study was to investigate what resources are needed for rural family caregivers providing end-of-life care and preparing for home death for a person with cancer. Family caregivers reported that various medical, practical, and emotional challenges significantly affected their daily lives. They endured, navigated, and recovered from adversity with the help of various resources, including personal strengths and support from support systems and familial relationships [44,46], such as healthcare services, family, friends, and neighbours.

Resources such as personal skills and knowledge were essential for building resilience, providing effective palliative care, and preparing for a home death. Being resilient meant maintaining their physical and mental health while prioritising the complex needs of the ill family member. Previous research has underscored the importance of resilience in family caregivers of people with serious illnesses [71,72]. Roper et al. [71] found that caregivers of seriously ill family members rely on psychological resilience to handle stress when trying to adapt to the unpredictable and often overwhelming demands of palliative care. Dionne-Odom et al. [72] observed that caregivers of family members with advanced cancer who perceive themselves as resilient are better equipped to make informed decisions, manage stress, and fulfil their caregiving responsibilities. According to Walsh [46], building resilience and accepting uncontrollable circumstances can help families concentrate on future opportunities, making the situation more manageable. In our study, family caregivers faced significant challenges due to living in rural areas, including limited access to healthcare resources, long distances and difficult journeys to specialised healthcare services. This aligns with a study on family caregivers of cancer patients in rural areas, where long journeys to regional hospitals posed challenges such as poor roads and harsh weather [17]. These conditions create a double burden for family caregivers, who must manage unpredictable tasks while accompanying loved ones to distant specialised services [21].

Our findings show that previous experiences as informal caregivers or working as a health care professional contributed to caregivers' resilience. Similar findings were reported in the study by Barlund et al. [17], indicating that these experiences helped caregivers identify when hospitalisation was necessary. In our study, this dual role could be challenging as family caregivers frequently struggled to balance family care with the expectations and demands of their professional role.

The study revealed that the family's economic situation and financial welfare support made them less vulnerable, playing a crucial role for family caregivers providing end-of-life care at home. This finding aligns with other research, showing that limited financial resources can hinder access to palliative care, as caregivers may need to leave their community and face additional expenses [17,73]. However, when caregivers understand their rights, like the Attendance Allowance, they feel less anxious about their jobs and can focus more on supporting their loved ones [17].

For the rural caregivers in our study, having access to resources like flexible local healthcare services available 24/7 was essential. They greatly appreciated the follow-up visits from healthcare workers outside their regular working hours. Several studies highlight the importance of after-hours services in providing home-based palliative care [73–75]. When community support is insufficient, caregivers may experience heightened stress and anxiety, potentially resulting in unnecessary hospital admissions [75]. The findings in our study indicate that familiarity with healthcare personnel in the community helped family caregivers manage emergencies more effectively. Nysæter et al. [10] found that effective end-of-life care and home death require relational continuity and predictable care provided by skilled healthcare professionals.

Our study reveals that cancer nurses' specialised knowledge is crucial for families providing end-of-life care at home. In rural settings, nurses are vital in supporting families in home-based palliative care [7,19,76]. They bridge the gaps between various healthcare services by providing information and assistance with treatment and practical tasks, enhancing the quality of care [77]. Ervik et al. [78] found that committed cancer nurses with palliative expertise play a vital role in the daily care of cancer patients and their families by developing local solutions tailored to geographical conditions and families' needs. In our study, health care workers from other municipalities were hired to make home death possible if the community lacked services. Limited resources and a shortage of specialised healthcare professionals in rural areas have been noted in previous studies [7,28]. Salehi et al. [28] reported that fewer healthcare professionals choose to work in rural areas, impacting the availability of services. Additionally, Nysæter et al. [10] found that inconvenient working hours in home-based care decreased the availability of skilled nurses, leading to a lack of continuity in care.

For the caregivers in our study, having immediate access to specialised healthcare services and the option for "open return" to hospitals was vital. As their loved ones approached the end of life and required additional medical support, many caregivers experienced feelings of insecurity, resulting in transfers to hospitals or care facilities. However, these institutions did not always have qualified staff available, particularly during holidays, which compelled caregivers to monitor their loved ones closely, even in these settings. Barlund et al. [17] found that family caregivers often distrusted institutional end-of-life care, causing significant stress and exhaustion and making it difficult to fulfil their family roles. In our study, assistance from family and social networks was essential for family caregivers in providing end-of-life care and preparing for a home death. They particularly valued support from persons with relevant healthcare experience, as demonstrated in the research by Johannesen et al. [18].

Our findings indicate that practical and emotional support from their network strengthened the resilience of family caregivers. According to Neergaard et al. [79], possessing a strong social support network and living with others significantly affect the likelihood of dying at home. Kirby et al. [16] concluded that rural communities demonstrate greater resilience due to their accepting attitude towards death and increased willingness to meet caregivers' needs. This helps alleviate the impacts of limited access to palliative care expertise [16]. Our study revealed that social support is crucial for those offering informal end-of-life care because it helps them cope with their responsibilities. Without such support, caregivers must rely on their own resources, including psychological resilience, optimism, and the material assets they possess. However, adapting to stressful events seems more challenging without utilising additional community and societal resources [71].

In our study, knowledge, family size, and emotional closeness were crucial in enabling a dignified death at home. In the absence of local palliative care services, families formed a support team to share caregiving responsibilities, ensuring the dying family member was never left alone and allowing the primary caregiver some respite. Being together during the dying process enhanced family resilience and strengthened family bonds. This demonstrates that resilience is not only connected to managing stress but also supports relational growth [46]. This supports Johannesen's conclusion that end-of-life care and home death are significant experiences that bring families closer together [18]. Our findings suggest that family cohesion significantly enhanced family resilience. By collaborating on end-of-life care, taking turns, and supporting each other, they felt empowered coping with their responsibilities.

Walsh [46] emphasises that family resilience involves viewing families as functional units or systems rather than merely assessing individual members as separate resources for personal resilience. Moreover, robust familial relationships enhanced individual resilience [46] as they prepared for a home death. Family resilience is strengthened through mutual support, cooperation, and a shared commitment, respecting each member's individuality when facing challenges [44,46]. These dynamics enable families to come together during crises, handle stress, and adapt more effectively [42,46]. Mehta et al. [42] highlight the importance of a family system's approach in palliative care, stressing that family boundaries are vital for addressing diverse needs and promoting adaptation. Healthcare professionals must understand these dynamics to effectively interact with families and by anticipating their reactions to various interventions [42]. Not all family caregivers in our study were supported by their families. In some families, the adult children had moved to other parts of the country and were unavailable for practical support. Nevertheless, close friends and neighbours often acted as extended family, bolstering the resilience of family caregivers. Kirby et al. [16] present similar findings, indicating that local community support in rural areas is stepping in for non-available family support.

In our study, the home was frequently viewed as a natural, safe, and comforting environment for end-of-life care and death, where family members could maintain their daily life routines alongside their loved ones. This perspective resonates with Martinsen's [80] idea of home being shaped by natural rhythms commonly threatened by illness. These rhythms include daily routines, seasonal changes, the various phases of life and death, and everything in between [80]. When the care recipients in our study had to be transferred to institutional care due to the need for more advanced medical care or acute incidents, family togetherness was threatened, and feelings of unfamiliarity emerged when they were no longer staying at home. A Norwegian study by Staats et al. [81] explores what constitutes a home for persons nearing the end of life. The authors conclude that a safe and caring environment is crucial in this stage of life.

In our study, as in the study of Fiva et al. [82], people approaching the end of life and their caregivers face significant challenges due to geographical disparities, local healthcare resources and economic issues. Although equal rights and access to health services are fundamental human rights [83], our study shows that living in rural areas may sometimes jeopardise these fundamental rights. Nevertheless, family caregivers' resilience, bolstered by other family members and community support, may compensate for some challenges in rural end-of-life care, making home death possible.

Strengths and limitations

We consider it a strength that seventeen *thirteen* participants with various lived experiences were recruited from seven rural municipalities in Northern Norway. The participants offered in-depth insights, meanings, and contextual nuances about the actual phenomenon [59]. Participants of different ages and genders, from diverse geographic regions, with different cultural backgrounds and varying relationships with their ill family members, were included to explore the phenomenon from various angles. Cultural diversity among rural participants may have shaped the results, as varying backgrounds influence needs during this life stage. Moreover, resourceful caregivers might not represent those with fewer resources. The limited number of male participants highlights the predominance of women as family caregivers, reflecting gender norms in healthcare that may constrain the findings [84]. Zygouri et al. [84] observed that women often undertake caregiving roles without complaint, underestimating their need for support and professional assistance. Additionally, Northern Norway residents are historically known for their resilience in coping with harsh climates and resource scarcity. Furthermore, the inability to recruit immigrants could represent a limitation. Most participants provided family caregiving within the restrictions of the COVID-19 pandemic, possibly influencing the participants' lived experiences and the results of our study. To ensure the quality of the interviews, we focused on obtaining rich, detailed descriptions by showing sensitivity to the specific places and situations involved [59,85]. We dedicated sufficient time to develop the interview guide, and performing a pilot interview enhanced trustworthiness [56]. The first author, who conducted the interviews, is an experienced cancer nurse trained to care for seriously ill patients and their families. The other two authors provided similar skills to the research process and extensive qualitative research experience. Additionally, their collective background in rural nursing prompted a critical reflection on our roles as researchers [48,49], recognising our preunderstanding [39,48,49] and how it could influence our results. When analysing the research data, we ensured trustworthiness using a well-known approach based on Braun and Clark's analysis method [65,66] following their 15-point checklist for reflexive thematic analysis [69]. In reporting our study, we adhered to the COREQ guidelines [50]. The involvement of a user representative provided a valuable first-person perspective on the findings' interpretations [86]

Conclusion

Family caregivers in rural areas providing home-based palliative end-of-life care for people with cancer encounter numerous challenges. Resources that bolstered their resilience were essential for navigating end-of-life care, including personal strength and support from professionals, family, and community. This was demonstrated by how they endured, navigated, and recovered in challenging situations while providing end-of-life care by utilising personal, professional, community, and family resources. They needed good physical and mental health, caregiving skills, financial resources, and strong relationships with other family members and their community network. Unfortunately, not all caregivers in rural settings have these resources, adding to their emotional distress when trying to fulfil their loved one's wish to die at home. The scarcity of healthcare professionals and palliative care expertise in rural areas, coupled with the long distances to urban centres, may hinder the possibility of home death.

It is crucial to allocate resources to support caregivers' resilience in handling their responsibilities. Implementing tools like the Carer Support Needs Assessment Tool (CSNAT) to map caregivers' needs should become routine. Additionally, supporting families financially, helping them to obtain their legal rights and guaranteeing social security are essential. Rural caregivers need access to education and information about end-of-life care. Holistic healthcare for rural populations should consider factors like distance and cost while involving the entire family and their social network. Local palliative care beds and telehealth services should be available to relieve rural family caregivers. Training healthcare personnel to understand family dynamics during end-of-life care is vital for supporting family caregivers. Although fulfilling the wish to die at home is important, people should have access to institutional care facilities if needed. According to the Norwegian government's plans of reducing nursing home facilities and prioritising home services, recognising the role of family carers becomes increasingly important, especially when aiming to increase the number of home deaths in rural areas. In addition, ongoing discussions are needed to evaluate whether a home is the best environment for dying, given the existing resource constraints.

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