

Close Relatives in Palliative Home Death – A Study on Living in the Tension Between Responsibility and Dependent on Healthcare Assistance

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Abstract

Background

There exist official guidelines, regulations, and studies concerning the experience of being at home when a patient approaches the end of life. During the phase, the practical and emotional care provided to the patient is predominantly reliant on their relatives.

Aim

This study aims to explore how relatives perceive their role during the dying process of a family-member with cancer at home.

Method

A qualitative study design employing phenomenological perspective was utilised. Individual in-depth interviews were conducted with five relatives to collect data.

Results

Relatives articulated their believe that it is ultimately the patient's choice to die at home. The informants also highlighted their complete reliance on the support of healthcare professionals during this period.

Conclusion

The provision of care to the family members through effective information dissemination, communication, and follow-ups is crucial, as these factors enhance the relatives' capacity to cope with the situation during the palliative phase.

Background

Both in Norway and internationally, political directives require that all those working in healthcare services collaborate with one another, as well as with patients and their relatives, throughout the patient care pathway [1–3]. The majority of patients in palliative care are critically ill and most of them wish to die at home. Furthermore, Norway is one of the countries in the world where the fewest people die in their own homes [4].

In the context of palliative treatment and care at homecare, having supportive and stable relatives, along with a robust professional network in municipalities, is essential. One of the five defined main objectives in “*Living with Cancer*”, the National Cancer Strategy 2028 – 2022, is to ensure the best possible quality of life for cancer patients and their relatives [5]. This aligns with the World Health Organization's (WHO) description of the goals of palliative care [2,3]. The 2024 guidelines to relatives are expected to significantly impact the municipalities' responsibility for a well-organized and comprehensive service offer for both patients and relatives when the patient dies at home [6]. In the Norwegian Official Report (2017) (NOU) palliative treatment is defined as both life-prolonging and symptom -relieving care, during the period leading up to death [7]. The term *palliation* is challenging to translate directly into Norwegian. It is often used in the context of palliative care, support, and hospice services. How healthcare and social services are organised and managed is also crucial for the ability to plan and implement continuous improvement efforts regarding palliative nursing in the home. Good interprofessional planning and predictability, together with the patient and relatives, are central, particularly when the illness is complex, as is often the case in palliative care [7]. The aim of this study is to explore relatives' experiences of their roles when a family member dies of cancer at home

Studies [8,9] have underscored that the provision of palliative care for cancer patients is organised and implemented differently across Norwegian municipalities. The palliative teams in hospitals are meant to provide guidance during difficult processes, even when patients are at home. Cancer treatment and care have been key focus areas for municipalities in recent years [10]. Many municipalities now employ cancer coordinators with specialised training in the field of palliative care. Typically, the coordinator is

responsible for organising and recognising the holistic needs of patients and their relatives. Research [10,11] indicates that cancer coordinators in municipalities are a crucial resource for ensuring continuity and security for both patients and relatives during at-home deaths.

Studies [12–14] also reveal that relatives of a family member dying of cancer at home face challenges and responsibilities that exceed their expectations. This can be particularly burdensome, especially in reason to medication management. Other findings concerning relatives highlighted that they often experience exhaustion and sleep problems. They are frequently available 24/7; although they receive respite, they find it difficult to escape from the challenges posed by their caregiving role. Concerns and fears surrounding the possibility of the ill person dying alone at night often rob them of sleep. Despite the burdens, relatives frequently hesitate to seek additional help, particularly during the night [13,15].

Relatives and the cancer patients strive for normalcy, hoping to maintain enjoyable everyday experiences throughout the illness period. Having open access to specialised healthcare services is reassuring. Being able to remain at home and receive the necessary assistance is often associated with being less seriously ill [13, 15–19], although this is not necessarily the case.

During the palliative phase and at-home death, relatives require close support from professional healthcare workers to navigate in this vulnerable period [9,17,20]. They express a desire for more consistent follow-up with a better quality of care, in which the fewest number of nurses visit their home, as this contributes to continuity, reliability, and security. Municipalities should strive for an organised team around both relatives and patients, led by the cancer coordinator. Both the patient, the relatives, and the team can receive assistance and guidance from specialized health care services [16,20,21].

Martinsen's [22] theory of care emphasises the phenomena of care and nursing. The theory is based on the idea that care is a fundamental human response to suffering and the need for assistance. Martinsen asserts that care is not merely a technical or professional action; rather, it is a form of existence that involves empathy, closeness, interaction, and relationships.

In summary, previous studies indicate that relatives face challenges during the palliative phase of family member's illness. They have a need for normalcy in their daily lives and require support from professional healthcare workers.

What experiences do relatives have regarding the stresses of life when a family member suffering from cancer is in the palliative phase and dies at home?

Method

Design

The study employs a qualitative design with a phenomenological approach. This allows for an exploration of the world as it is perceived and experienced by those inhabiting this lifeworld [23]. The focus is on the phenomenon of how relatives experience their role as caregivers to family members who die of cancer at home. Since the study centers on the experiences of relatives amidst life's challenges, individual in-depth interviews were a pertinent method for data collection [24, 25]. The aim of the interview was to illuminate both the diversity and nuanced descriptions of the caregiving experience through active listening to what the participants shared [25].

Participants

In the study's sample includes both female and male participants. The interviewees were drawn from five Norwegian rural municipalities, all located on the West Coast of Norway, characterized by high mountains, and long fjords, and numerous ferries which can make access to hospitals challenging. The inclusion criteria stipulated that the home care services and the cancer coordinator had played a central role in the care of the deceased patient. The cancer coordinator in the municipalities obtained consent from the interviewees. Once consent had been secured, they were contacted by the first author, who conducted the interviews. An information letter about this study was sent to the municipal chief, followed by the head of home care services. The cancer coordinator informed the relevant interviewees, who then reacted out to the researcher.

The sample consisted of five interviewees. The bereaved participants included three women and two men, all of whom were immediate relatives (aged over 18) of an adult family member who died of cancer at home. Three of the interviewees were spouses of the deceased, while two were children of the deceased. The interviews were conducted between six months and three years after the death.

Data Collection

To gain insight into the experiences and demographic data of relatives within their lifeworld [22] concerning their role as caregivers, a semi-structured interview guide was employed during individual interviews. The interview guide was developed by the first and third authors and tailored to the specific characteristics of this participant group.

The themes covered included: home death, the illness, home care services, relatives, and the aftermath. Emphasis was placed on openness in engaging with the interviewees' experiences, and the interview guide serves as a framework. This involved being attuned to the participant's narrative and posing follow-up questions to elicit more detailed and rich descriptions [25]. The individual interviews, lasting between 30–60 minutes, were conducted face-to-face in the interviewers' homes, with the exception of one interview that was carried out by telephone at the participant's request. The interview was transcribed verbatim.

Ethical Consideration

All procedures involving human participants were performed in accordance with relevant ethical standards and the principles of the Declaration of Helsinki. A semi-structured interview guide was developed specifically for this study.

The information letter provided details about participation through interviews, confidentiality, voluntary participation, and the right to withdraw at any time, in accordance with Helsinki Declaration [26]. The study was registered with the Norwegian Agency for Shared Services in Education and Research (Sikt), reference number 54893, and was conducted in accordance with the General Data Protection Regulation (GDPR) and applicable Norwegian legislation.

According to Norwegian regulations, approval from the Regional Committees for Medical and Health Research Ethics (REK) was not required for this study, as the study involved interviews with relatives and did not fall within the remit of the Norwegian Health Research Act. All participants received written and verbal information about the study prior to participation. Informed consent was obtained from all participants. Participants were informed that their participation was voluntary and that they could withdraw from the study at any time without providing a reason [27].

Description of Analysis

Giorgis [28] phenomenological analysis method was employed to meet the study's objectives. This analysis method focuses on the phenomena of the study as they are experienced by the individuals, allowing for an understanding of their lifeworld within a specific context. The goal is to describe the essence of experiences and how informants make sense of their encounters, particularly when exploring complex phenomena such as emotions, perspectives, and life experiences. We aim to recount the informant's experiences and the meanings they attribute to them without imposing excessive personal interpretations.

In this analytical model, meaning-bearing units are identified, and the entire text is analysed, rather than just a selected portion, which is common in many studies. Meaning-bearing units are abstracted without organizing the material through coding. The essence here is to listen to the relatives of patients who wish to die at home, as well as to understand their experiences during the final period of their loved ones' lives and the support provided by home care services. Additionally, the analysis encompasses how the time following the death is experienced.

Analysis

Giorgis's [28] analysis method comprises four stages (see Fig. 1 and Table 1). The analysis of the various interviews began during the interviewing process itself. Through reflection on the informants' statements, follow-up questions were posed, allowing the

informants to reflect on their responses and thereby recognise connections within their own lifeworld's. The interviews were analysed separately up to the third analytical stage to illuminate each interviewee's lifeworld.

The first stage involved achieving a comprehensive understanding. The recorded interview was listened to, and the transcribed text was read multiple times to gain a holistic grasp of the content. This overall understanding was documented and revisited several times to consolidate a cohesive impression and overview of the collected data within the interview.

The second stage entailed dividing the text into meaning-bearing units to make the text manageable. Based on the objectives on the study, meaning-based units in the data material were identified, with those pertaining to similar themes being grouped under preliminary sub-units. The purpose of these preliminary sub-units was to create a temporary representation of the data for each interview from a lifeworld perspective. These could comprise words, phrases, or various meanings within the transcribed interview, where the informants' experiences were highlighted and assembled. During this process, the interview text was annotated, particularly when the content shifted in relation to the phenomenon. All meaning-bearing units deemed relevant were numbered and organised into groups

The third stage involved transforming the meanings-bearing units within the preliminary sub-units into the researcher's language. Once the text had been organised under the preliminary sub-units, the transformation of the meanings-bearing units commenced. Each meaning-bearing unit scrutinized closely to ensure that its significance was adequately conveyed in the transformed text.

The fourth stage encompassed analysing across the interviews. The involved synthesising the transformed meaning-bearing units within each preliminary sub-unit across the interviews to derive final sub-units and overarching descriptions in the form of units. This process was essentially circular in nature. Multiple iterations were undertaken before consensus was reached on the two units and four sub-units. The methodology involved examining the part in light of the whole and the whole in relation to the parts, with considerable back-and-forth movement thought the data [27]. The analysis was conducted by the first and last authors, utilising the analytical tool Word's Tracking feature, whereby all interviews were thoroughly reviewed and underwent numerous transformations.

Findings

The analysis yielded two units that provide a comprehensive understanding of the experience of being a relative. The first unit pertains to how and why the decision for a home death is made, as well as living with the responsibilities that accompany this choice. This topic was fundamental across all interviews. The second unit focuses on reliance on professional help within the home. This subject was also central, with all informants indicating that such assistance was essential to their coping. The italicized statements on the right-hand side of Table 1 are direct quotes from the interviewees.

Here: Table 1: Overview of Findings, with Two Units and Sub-Units, Selected Condensed meaning-bearing Units, and some Selected meaning-bearing Units.

Unit 1: The Role of the Closest Relative to Cancer Patient

Sub-unit 1: Relatives considerations for the patient's wish for a home death.

For relatives, the patient's wish to die at home was crucial in the decision for a home death, it was important to fulfil the patient's last wish right to the end. Those who wished to be at the hospital or nursing home during their final days needed to have this arranged.

The palliative team entered the room with us at the hospital and asked my husband what he wanted. He replied that he wanted to go home, and I answered that we would go home.

An informant stated that she was a practitioner and had experienced caregiving, death, and burial of several family members. Another relative, who was a nurse, expressed skepticism toward home death. This individual had experiences from her own work in providing palliative care at home. She was concerned that the other family members were not prepared for what was about to happen or what could potentially occur.

I, who worked in home care, was skeptical because I had witnessed home deaths where the dying individual exhibited reactions before death occurred. I contemplated whether my father and youngest brother were prepared for what was about to happen or what could potentially transpire.

Although she harbored these thoughts, she did not share them with the rest of the family; instead, she was determined to do everything possible to ensure that the time spent with their dying mother, father, and sibling was as good as it could be. Ultimately, being together with the dying individual during their final days was the most fundamental aspect of the palliative period.

Sub-theme 2: The Responsibility of Relatives in the Final days

Relatives had various tasks and responsibilities concerning the dying individual during their final days. These responsibilities included administering enteral feeding, general medication management, administering analgesics, and monitoring the pain pump. This was manageable as long as they had received adequate information from home care services regarding the medications, as well as training on their effects and the appropriate timing for their administration. It was essential for home care services to conduct regular scheduled visits and to be accessible for questions whenever relatives felt uncertain. Relatives desired that home care services would assume responsibility when they felt they were losing control over the situation. They were also tasked with assisting in the maintenance of any fluid intake records and nutritional needs. One relative remarked:

I fell ill 14 days before she passed away and was subsequently admitted to the hospital I remained therefore for a week, during which my son took on the responsibilities at home. They felt exhausted from managing all the various tasks. Being present both in thought and action proved to be a significant challenge.

Relatives expressed that it was challenging to witness the changes in the patient's overall condition. Being present both in thought and action was exhausting for those closest to the individual. Nevertheless, it was regarded as crucial to be there for the dying person, despite the overwhelming nature of the responsibilities involved in the situation.

We conversed about everyday matters that occupied our minds and were present for another; simply being together was of great significance. We prepared meals and shared them as a family. The children frequently ran in and out to see him. We were in each other's company constantly.

It was reassuring that the dying individual received comprehensive care and support from both family members and home healthcare services. It was fundamental to have sessions where normal activities could be undertaken. These could include discussion, reading, as well as planning the funeral.

Theme 2: Being a Relative and Relying on Health professional Support at Home for a Family Member with Cancer

Sub-theme 1: The Professional Support in the Terminal Process

Relatives expressed a desire for home healthcare services to be available at all times and to provide continuity in their care. Effective communication with the home healthcare team, coupled with scheduled visits and the ability to reach out outside of these appointments, instilled a sense of security for the family members. Adherence to scheduled visits contributed to reduced waiting times. It was essential for the relatives to feel acknowledged, to engage in conversation, and to be cared for by the home healthcare team in the manner that was both supportive and reassuring.

There is something about the way the home healthcare professionals conduct themselves. When they arrive and exude a sense of reassurance, it makes you feel secure. They inquire whether I need assistance and if there is anything they can do for me. I could share my thoughts with them and set aside any concerns I may have had. They are very much focused on offering support.

At the home healthcare team's assumption of responsibility for the professional aspects of care was fundamental for the relatives. Nurses who possessed the requisite expertise and competence took on the most responsibility, which provided an additional sense of security. At times, relatives felt overwhelmed by the significant responsibilities and workload involved. The overarching responsibility of the home healthcare team made it easier for them to navigate their challenging period. Continuous and effective communication with the home healthcare providers was crucial for relatives, as it ensured they were adequately informed about the patient's overall condition. However, it became apparent that this communication was not consistently perceived as sufficient

by the relatives. One relative recounted that she would sleep in an attic room when she was home, while her mother rested downstairs. On one of the final nights, she was awakened by the night shift nurse, who informed her that her mother's condition had deteriorated, having been found at the floor during a night check.

I wish someone had told me that I should have slept in the living room with my mother to prevent this.

Predictability in follow-up from a reduced number of homecare personnel provides a foundation of security for both the relatives and the terminally ill during a vulnerable time characterized by significant uncertainty. It was perceived as challenging for relatives when new nurses arrived for consultations. In the final stages, the assistance required could become extensive, occurring at all hours of the day and night, resembling more of a home hospice setting. The family needed time alone together.

The cancer coordinator played a pivotal role in the planning and clinical execution of palliative care at home. The cancer coordinator made early contact with both the patient and their relatives. This fostered a relationship between them and the cancer coordinator, which was significant in supporting the patient's wish to die at home.

It was the cancer coordinator who made the initial contact. There is a certain reluctance to react out; one wants to manage independently.

The cancer coordinator coordinated and facilitated the care, demonstrating flexibility and willingness to assist. One relative recounts the regular walks he took with the cancer coordinator, during which they discussed his experiences in the situation. The relationship proved to be immensely significant for him during a challenging period.

Sub-theme2: Professional Support Following Death

In the period following the death, relatives are left with many thoughts, and this time can often feel more arduous than the final moments spent at home with the dying individual.

When the emptiness and silence arrive, it is impossible to anticipate how it feels. Particularly during the first six months, having regular conversations with someone would have been beneficial.

Relatives who had family and children around them report that they did not feel the need for follow-up conversations with professionals in the aftermath. Conversely, other relatives recognize in hindsight that such support would have been invaluable. If there is any criticism to be directed at those who provided minimal assistance to the relatives, it must be towards the general practitioners. They could certainly benefit from training in this area.

We had no contact with the doctor while she was at home in the final stages of her life, nor afterwards. The death itself was a peaceful and gentle experience for those of us present at the time, fortunately. We consider this a positive memory, even though it is tinged with sadness. We have discussed it since then, and it could not have unfolded in any other way.

Relatives express that they have reflected on this experience subsequently and would make the same choice again, as long as they have the professional support of the cancer coordinator and home care services with overarching responsibility.

Discussion

The wish of the dying family members was pivotal in guiding the relatives' decision regarding home death. Relatives went to great lengths to fulfil the patient's desire to die at home. Previous study [10,11,13,21] have also highlighted this finding. This study reveals that it was fundamental for home care services, particularly the cancer coordinator, to establish early contact with both the patient and their relatives throughout the palliative process. Such early engagement facilitated the relatives' support for the patient's wish to die at home. In municipalities where a support network was familiar to the patient and relatives, there were secure frameworks that benefited both the ill person and their caregivers. The general practitioner was not identified as a substantial source of support in the home. It remains unclear whether this was coincidental. The relationship and connections that had developed over time made the choice of home death easier to navigate. In addition, to organizing and coordinating care whilst working clinically with patients and their relatives, the cancer coordinator also dedicated time to conversation with caregivers [11]. This indicates the relatives had many of their needs met by the cancer coordinator. It has been documented that many patients wish to spend their final days at

home, yet they often hesitate due to uncertainty about the adequacy of support and whether their relatives can manage the required tasks. The assurance of receiving comprehensive, high-quality, and competent care at home is a prerequisite for making the choice of home death [11,19]. Therefore, it may be necessary for the staff- including not only the cancer coordinator- to possess the professional and ethical competence requisite for delivering effective palliative care. Employers have a responsibility to ensure that their employees receive appropriate training [1] so that they can quality assure the treatment provided to patients. Typically, nurses are expected to recognize the limits of their own expertise, practice within the scope of palliative care, and seek guidance in challenging situations [27]. The cancer coordinator, with their postgraduate of master's education, can serve as a mentor for both nurses and relatives in such context [28]. There should be greater emphasis on community-based interprofessional support for relatives, enabled them to feel competent in managing palliative care at home. The ability to create everyday activities is vital for both patients and their relatives, while ensuring that the dying individual receives comprehensive care from community nursing services. Previous studies [13, 15–19] support this findings, and Sørbye [18] emphasises that effective community nursing can contribute to this aspect of care. Relatives, along with the patient, should be afforded the opportunity to maintain their daily routines, including mealtimes and conversations, to the greatest extent possible, whilst municipal nursing assumes the overarching professional and medical responsibility. This approach is likely to provide reassurance for both the relatives and the dying person.

Although municipal nursing holds the overarching responsibility for the dying patient, respondents indicated that they assume significant responsibility in conjunction with a palliative family member when the decision for home death is made. They articulated their responsibilities concerning food, drink, and medication administration, particularly with respect to pain relief and the use of pain pumps. This is aligned with findings from previous studies, which reveal that relatives encounter complex emotional challenges, along with greater responsibility and more intricate tasks than they initially anticipated. Among these tasks are the medication management, maintaining fluid intake records, nutrition and assisting with personal hygiene [13, 15, 17, 27] the responsibility for administering pain relief medication appears to be particularly burdensome for relatives [12, 13].

The study underscores the necessary for relatives to receive comprehensive information regarding the medications, training on how and when to administer them, and assurance that municipal healthcare service is accessible via phone should question arise. Effective pain management during the final phase of life challenges and requires collaboration among multiple professions [4, 7, 9]. According to the respondents, the general practitioners were identified as a weak link in this network. They reported experiencing minimal assistance in that regard, likely due to the fact that the doctor does not engage with patients on a daily basis. Collaborative efforts with cancer coordinators and, potentially, physicians often provide the best foundation for understanding the patient's needs and preferences. Adequate information and close follow-up from community services and cancer coordinators can significantly facilitate the involvement of relatives in the administration of pain relief medication.

Municipal healthcare nursing is responsible for providing palliative care to cancer patients who wish to die at home [12, 28, 30]. Kaasa and Loge [4] highlight the dependence on involved relatives, asserting that it is essential for family members to take on responsibilities in collaboration with the support services. The study indicates that for relatives to assume responsibility and the remain engaged, they must be sufficiently informed. Cancer coordinators and community nurses must enable relatives to utilise their resources effectively through comprehensive care and support. Being relative of a family member with cancer, receiving palliative care at home entails a profound commitment to caregiving. This role involves actively and practically participating in alleviating the loved one's suffering and providing assistance. This aligns with Martinsen's [22] theory of care, which emphasizes the reciprocal nature of giving and receiving care between individuals. Such an exchange necessitates an interactive dynamic among the patient, relatives, and caregivers, found on empathy and closeness.

It is crucial that municipal nursing adheres to established schedules and arrives punctually. Instances where relatives were left waiting led to what was perceived as "wasted time", which was particularly frustrating given the preciousness of the remaining time for both the patient and their family. According to Kaasa and Loge [4] predictability is essential. Previous studies have also indicated that there can be delays in municipal nursing arriving at the agrees-upon times [13, 16]. Concurrently, it is acknowledged that the working hours in municipal care can be unpredictable, with numerous unforeseen events potentially arising throughout the workday. Therefore, it may be prudent to have a consistent team of caregivers designated to provide care for patients who choose to die at home.

The study indicates that information provided by healthcare services should offer family members a realistic portrayal of what the palliative phase may entail. One of the informants recounted that they slept in the attic while their terminally ill mother lay in the

living room. The home care services were called to assist at night as the mother's condition had deteriorated significantly, having fallen out of her bed. In hindsight, the family members expressed a desire for clearer communication regarding the deteriorating of the mother's condition. However, it can be challenging for nurses to anticipate all changes, as each illness progression is unique [4,8]. The study demonstrates that a comprehensive situational understanding, aligning with Martinsen's [22] care philosophy, along with appropriate support for family members, can empower them to cope with the situation and become a resource for both the dying individual and the healthcare providers to possess a robust knowledge base and to communicate effectively with family members.

The findings revealed that while family members were oriented to reality, those with experiential knowledge of palliative care expressed some concern, being aware of how exhausted and drained caregivers can become. Grief and stress can significantly impact concentration and memory, making caregivers more fatigued and less receptive to vast amounts of information. Therefore, information should be delivered judiciously, focusing only on what is essential at the moment, and then gradually introducing additional details. It is easy to forget during periods of bereavement. Furthermore, written materials can be provided so that the family members can refer to them as needed.

While it is the responsibility of healthcare professionals to inform the patient, family members often find themselves in the position of reiterating what has been communicated. Consequently, it may be prudent to provide information to the patient in the presence of their family members.

One finding from the study was that some family members questioned the extent of their own roles and the responsibilities, which at times become overwhelming, particularly towards the end of the palliative phase. They perceived the home as being invaded at all hours, effectively transforming it into a form of home hospital. This arrangement is also more cost-effective for the public health sector than compared to hospitalization [30, 31]. However, this issue has not been as prominently highlighted in previous studies.

It is a natural progression that the need for assistance increases towards the end of life, yet there is also a concurrent need for quality time spent together as a family. For family members, it was crucial that the home care service demonstrated an awareness of the appropriate timing for visits and made judicious assessments regarding how frequently and for how long they should be present. The desire for private family time was pronounced. Family members understood the necessity of the home care visits but acknowledged the challenges faced by nurses, who often juggle multiple patients, in ensuring that families have adequate time alone during a busy workday [30,31]. When home care nurses gain access to the home of the patient and their family, the domestic space increases to be solely a home and becomes an additional «workplace». Consequently, the home care nurse gains significant access to the private lives of both the patient and their family members, albeit temporarily. It is vital for family members to receive thorough information regarding the increasing level of assistance, medication, and oversight. This knowledge base is essential for them to engage as equal partners and become a resource for both the dying individual and the healthcare system. An understanding of the growing need for support facilitates acceptance of the necessity for such assistance. In this context, effective communication and collaboration are fundamental to delivering high-quality care, in a timely and appropriate manner [4].

Relatives in the study express that in the period following the death, they are grateful for the choice of a home death, as it allowed them to fulfil the wishes of the deceased, and that arrangements were made to ensure this occurred in a dignified and appropriate manner. Home healthcare and cancer coordinators have a responsibility to provide necessary care and support for relatives in the follow-up of patients who die at home. Palliative care encompasses not only the management of physical symptoms but also the emotional and psychological aspects of grief and support for the bereaved [5]. The relatives in the study describe a variety of needs for post-death follow-up. Some of the participants expressed a desire for increased dialogue with home healthcare providers or cancer coordinators thereafter. Previous studies have offered limited insights into the period following a death. One study [32] indicates that many relatives feel the need to discuss their experiences after a death occurs. There may be various events during the palliative process that require reflection and clarification, alongside myriad questions and thoughts that necessitate answers. Unresolved questions from the palliative phase can complicate the grieving process. Therefore, follow-up conversations can be vital and should be a service that the relatives are informed about [30,31].

Strengths and limitations of the study

A notable strength of the inclusion of both female and male interview participants, recruited from four district municipalities and variations within the data. However, a larger sample size could have offered greater depth and diversity in the experienced reported. Furthermore, assumptions, motivations, and interests related to the research topic may be subject to misinterpretation

Conclusion

The study concludes that family caregivers perceive that patients wish to die at home. Although caregivers assumed numerous responsibilities throughout the palliative trajectory, medication management, particularly pain relief, was experienced as challenging. Consequently, they sought support from healthcare services at an early stage to ensure appropriate symptom management.

Furthermore, the study concludes that family caregivers receive comprehensive information in advance regarding what the palliative care trajectory entails and are provided with adequate education on medication administration. They also receive sufficient emotional and practical support, assistance, and respite care from competent healthcare professionals. Such support was reported to be particularly strong from cancer care coordinators, whereas the level of support received from general practitioners was perceived to be more limited.

The findings suggest that municipal healthcare services possess a solid knowledge base and demonstrate effective communication skills when interacting with family caregivers.

Declarations

Consent for publication: Not applicable.

Availability of data and materials: The dataset used and analysed during the study is available from the project leader (BHTL.) upon written request and in accordance with ethical approval.

Competing interests: The authors declare no competing interests

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Authors' contributions: The authors contributed to data collection, literature searches, critical review of articles, and the analysis and interpretation of findings, with BHTL and HS leading these tasks. FV played a central role in the final written version of the article. Additionally, BHTL and HS contributed to the design, analysis, and interpretation of the finding

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