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RESEARCH

Family perceptions of the transition from hospital to home palliative care: a phenomenological study

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Abstract

Purpose Home palliative care allows people in a palliative situation to remain in the comfort of their own homes. However, this transition poses significant challenges to family members, requiring logistical, physical, and emotional adaptations. This study aimed to explore the lived experiences of family members caring for a person in a palliative situation at home, focusing on the challenges, emotions, and coping strategies during the transition from hospital to home.

Method A descriptive phenomenological study was conducted with 20 family members involved in the care of patients followed by three community palliative care teams in Portugal. Data were collected through individual interviews and analyzed using Giorgi's method.

Results Three themes emerged: (1) Emotional and Relational Experience of the Family Member, (2) Family's Challenges and Adaptation, and (3) Support for the Family. Despite the burdens, care is viewed as a moral and emotional responsibility. Support from palliative care teams and self-directed learning were key coping strategies.

Conclusions The study deepens understanding of the family experience during the transition to home palliative care, highlighting the complexity of this process and the need for emotional, organizational, and educational support.

Keywords Family · Transitional care · Home palliative care · Experience · Qualitative study

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Background

Global projections indicate a significant increase in the need for palliative care, with approximately 48 million people expected to die each year with serious health-related suffering by 2060 [1]. This growth is associated with an ageing population, a higher prevalence of advanced chronic diseases such as cancer, and the increasing need for integrated approaches to alleviate suffering [2].

Palliative care aims to improve the quality of life of people with life-threatening illnesses and their families by preventing and relieving suffering through early identification, assessment, and treatment of physical, psychosocial, and spiritual problems [3, 4]. To meet growing demand, health systems must integrate palliative care into primary and community care, identify beneficiaries earlier in the disease trajectory, and adopt public health-oriented strategies to ensure equitable access [5].

Home palliative care has been widely recognized as fundamental to ensuring dignity and quality of life for people in the advanced stages of illness. Remaining at home, besides aligning with the preferences of most individuals at the end

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of life, provides a familiar and comforting environment and encourages greater family involvement in care [3, 6].

The transition of palliative care from hospital to home is a complex process that involves not only a change in the care setting but also a shift in the responsibility for care, which is often transferred to the family at a time of great vulnerability [7]. This transition requires effective coordination between hospital and community teams, as well as adequate preparation of the patient and caregiver, in order to avoid disruptions in care continuity, clinical insecurity, and avoidable suffering [2]. Despite its relevance, this process remains undervalued in health systems, and understanding the lived experience of those involved is essential to promote more integrated and person-centered palliative care practices.

The family plays a central and indispensable role in palliative care, often serving as the primary source of emotional, physical, and logistical support. In many cases, family members assume full responsibility for caregiving, frequently without formal training or external support. For this reason, it is essential that health systems actively involve families in care planning and delivery, adopting a holistic, person and family-centered approach that recognizes their needs, capabilities, and emotional burden [8, 9]. A systemic approach by healthcare professionals acknowledges the circular impact of illness on family dynamics, especially in palliative contexts, and enables more appropriate and responsive interventions tailored to the specific needs of each family [10, 11]. Since no single member typically has full insight into family functioning, it is essential to adopt an approach that involves the family as a whole [11, 12], enabling professionals to respond more effectively to their specific needs [11].

The act of caring, on the part of the family, can be experienced as a gesture of love and commitment, but it can also be permeated by feelings of overload, impotence, and anguish in the face of the progression of the disease and the growing needs of the person in a palliative situation [13]. In addition, limited access to formal support resources can aggravate the family's sense of isolation and insecurity, and they often resort to experiential learning and autonomous research to face the challenges of everyday life [14].

Several studies report that family caregivers encounter difficulties in accessing clear and practical information on symptom management, medication administration, and end-of-life decision-making [15, 16]. The transition from hospital to home poses significant challenges for family members, who take on a central role in care, often without the necessary preparation or support [16, 17].

These caregivers take on multiple physical, emotional, and organizational responsibilities, which can profoundly affect their physical and mental health [18]. During the transition of care from hospital to home, family members mirrored that the central concept of being responsible for everything seemed to be a recurring theme and that fulfilling numerous commitments and different social roles, in addition to the caring activity itself, seemed to weigh heavily on family members. Family members were particularly referring to their need for hope, confidence, and security during the transition from hospital to home [19].

In addition, the lack of technical preparation and emotional overload can interfere with the quality of care provided and compromise the well-being of the family member, leading to high levels of burnout and psychological distress [20]. Guo et al. (2022) analyzed the experiences of transition between palliative care settings, revealing that the lack of information and access difficulties increased participants' uncertainty, while continuity of care influenced the perception of safety and intensified the need for emotional and practical support [21].

The transition from hospital to home care often triggers a crisis within the family system. The crisis involves the redefining of roles and the integrating of new caregiving functions, leading family members to experience a wide range of often contradictory emotions and needs, due to the tension, perceived competence, and conflicts associated with these new responsibilities [7, 10, 22]. By involving families and understanding their experiences, nurses help them to find meaning in the experience of their suffering, to construct new meanings for the health-disease process, and to expand knowledge and develop skills in the context of care [23]. In order for nursing care to focus on the needs of the family, it is necessary to recognize the multidimensionality of the family, as well as its capacity for self-organization in the face of transition processes [22].

Although existing studies have explored the experiences of family caregivers in home-based palliative care, few have specifically addressed the critical transition from hospital to home. This period is marked by organizational discontinuities, emotional overload, and uncertainty, particularly when the responsibility for care shifts abruptly to the family. The literature often overlooks how this transition is subjectively experienced by those who become central figures in the patient's daily care at home.

Previous research has examined this transition from the perspectives of patients [24] and health professionals [25], highlighting the organizational, emotional, and relational challenges involved in discharge planning, care continuity, and support at home. However, the lived experience of family members during this critical period remains underexplored. This study aims to fill that gap.

To address this objective, a descriptive phenomenological approach was adopted. This method, developed by Amedeo Giorgi, seeks to understand how individuals experience a given phenomenon in their lifeworld, allowing for the identification of its essential structures through rigorous analysis. In this study, it enables a deeper exploration of how family members perceive and make sense of the transition from

hospital to home in the context of palliative care, without imposing preconceived categories or theoretical frameworks.

Method

Study design

To achieve the study's aim of understanding the lived experiences of family members who care for a person in a palliative situation at home during the transition from hospital to home, a qualitative study was conducted using a descriptive phenomenological approach [26]. Giorgi's descriptive phenomenological method, rooted in Husserlian philosophy, guided data collection and analysis [27]. This approach focuses on describing how family caregivers experience the transition in their everyday reality, aiming to uncover the essential meaning structures of that experience through phenomenological reduction and imaginative.

Participants and sampling method

In Portugal, the transition from hospital to home in palliative care is coordinated between hospital-based palliative care teams and community-based Palliative Care Home Support Teams (PCHSTs), under the organization of the National Palliative Care Network. After hospital discharge, eligible patients with complex needs are referred to these teams to ensure continuity of care and symptom management at home.

This study was conducted in collaboration with three PCHSTs operating in urban and semi-urban areas of the northern region of the country. These teams are composed of physicians, nurses, psychologists, and social workers, and they work in close coordination with hospital palliative care units. Each team receives referrals through hospital liaison mechanisms, evaluates the patient and caregiver situation, and plans home visits accordingly.

Most patients presented advanced oncological or chronic progressive conditions, with high levels of dependency, requiring continuous family involvement in their daily care.

The study sample consisted of family members who were actively involved in providing care at home to individuals in a palliative situation and were recruited through a purposive sampling strategy. Although no fixed time interval was defined, participants were recruited while they were still engaged in caregiving at home and living the process of transition from hospital to home, with variability in how recently the discharge had occurred. Inclusion criteria required that participants were (1) identified by the patient as a family member, (2) recognized by the palliative care team as the primary caregiver at home, (3) willing to participate, and (4) able to provide informed consent. No formal exclusion criteria were applied beyond the inability to communicate effectively in the interview context.

Following ethical approval and authorization from the participating institutions, potential participants were identified with the support of a liaison professional from each team. The first author then contacted eligible participants directly, provided information about the study, and obtained informed consent. All invited participants agreed to take part, and no dropouts occurred during the study.

Data collection

The data (interviews) were collected (carried out) between June 2024 and October 2024. Twenty family members of people in a palliative situation at home integrated into the care of the three community palliative care teams in the northern region of Portugal were interviewed, all of whom consented to participate, and data were collected using a data collection instrument.

A semi-structured interview script was used to collect the data, as it facilitated a personal narrative by the participants [28]. Data were collected using two instruments: (1) a sociodemographic questionnaire to characterize the participants (Table 1) and (2) a semi-structured interview guide composed of open-ended questions designed to explore the family member's experience of caring for a person in a palliative situation at home. All interviews began with a broad question to initiate the narrative: "Given your role as a family member, how do you experience the process of integrating palliative care from the hospital to home?" To deepen understanding of the lived experience, additional probing questions were used during the interviews. For example: "What facilitating and hindering factors have you experienced in this transition?" These flexible prompts supported participants in elaborating on their perspectives, emotions, and the challenges encountered throughout the process. Two pilot interviews were carried out to test the semi-structured interview questions, which were not included in the study. After determining that the interview questions were clear and understandable in the pilot study, the data collection instrument was applied to all family members of palliative care patients integrated into the care of community palliative care teams.

The interviews were conducted individually by the first author in a room in the home of the person in palliative care, were recorded using a voice recorder, and his observations were recorded in a notebook. As the study participants' native language is Portuguese, the interviews were conducted in Portuguese and no interview had to be repeated. Each participant was given a code so as not to reveal the participants' identities and for data security. All interviews were recorded with the participant's permission, and the recordings were transcribed by the researchers within 24 h.

Table 1 General characteristics of the participants ($n = 20$)

Variables	Categories	Absolute value and mean
Sex, *n*	Male	2
	Female	18
Age (*a*)	Maximum e minimum 41–79	Mean 64.1
Nationality	Portuguese	20
	Foreign	0
Marital status	Married	18
	Widowed	1
	Divorced	1
Highest leel of education completed	Primary education	9
	Lower secondary education	3
	Upper secondary education	3
	Secondary education	2
	Post-secondary education (technological specialization course)	1
	Bachelor's degree	2
	Master's degree	1
Employment status	Employed	3
	Unpaid leave	1
	Unemployed	5
	Retired	11
Stopped working due to their relative's illness—duration	30 days	1
	60 days	1
	730 days	1
Relationship to the person in palliative care	Daughter	10
	Wife	8
	Son	2
Ilness of the person in palliative care	Oncological disease	11
	Pulmonar disease	5
	Cardíac disease	2
	Neurological disease	2
Time since transition to home care (*d*)	Minimum and maximum 15–365	Mean 72.25

y years, *d* days

The interviews lasted an average of 40 min (ranging from 30 to 90 min).

Data collection was concluded when the researcher judged that the richness and depth of the experiential descriptions were sufficient to support the articulation of the essential structure of the phenomenon. Although the phenomenon had been phenomenologically clarified after 15 interviews, five additional interviews were conducted to deepen the variation of lived experiences and strengthen the descriptive power of the analysis. This decision was made in alignment with the phenomenological aim of reaching a comprehensive understanding of the lived meanings, rather than seeking data saturation in the traditional sense.

Research team and reflexivity

The research team was composed of three members. One member was a nurse working in a hospital care unit, with 18 years of professional experience in oncology, currently a doctoral student. This member was supervised by two PhD-holding members of the team, who are professors at Nursing Schools (a Coordinating Professor and an Adjunct Professor), both with extensive clinical practice experience. The researchers were independent individuals who were not responsible for the care of patients under palliative care provided by the teams involved in the study, nor were they part of the community palliative care support

teams. All researchers had received training in qualitative research methods and conducted qualitative research.

Data analysis

The data were analyzed using the method of descriptive phenomenology according to Giorgi's descriptive phenomenological method, which involved four main steps. First, the transcripts were read several times to gain a general sense of the participants' lived experience. Second, meaning units were delineated through a second reading of the transcripts, where shifts in meaning were identified and marked. These units remained close to the participants' original expressions. Third, the meaning units were transformed into language sensitive to the phenomenon under investigation through a process of phenomenological reduction. This step aimed to move from the natural attitude to a more phenomenologically informed understanding while preserving the intentional meaning conveyed by participants. Fourth, the transformed meaning units were synthesized into a consistent description of the essential structure of the experience [29]. This structure reflects the invariant aspects of how family members live the transition from hospital to home in the context of palliative care.

Data analysis was conducted in parallel with data collection, allowing for ongoing reflection on the emerging meanings. The first author led the transcription and phenomenological analysis following Giorgi's method. The analysis process was discussed with the research team to ensure rigor, epistemological coherence, and fidelity to the methodological framework. No independent coding or reliability testing was applied, in accordance with the phenomenological stance, which prioritizes depth of understanding over procedural replication.

To manage the data, ATLAS.ti® software (Version 23; Scientific Software Development GmbH, Berlin, Germany) was used. The data obtained were coded using the letter "P," and a number was assigned to each participant.

Ethical considerations

The present study adhered to credibility, dependability, transferability, and confirmability to ensure the rigor and scientific quality of the qualitative research [30].

To ensure credibility, during the interviews, clarifications and confirmations were made regarding the information mentioned by the participants. To avoid influencing the results, the interviewer refrained from referring to personal experiences and assumptions, allowing participants to express their own thoughts and feelings.

Dependability was achieved through the description of participants' characteristics, the selection process, and a clear explanation of the research steps and findings. The second author also conducted individual data analyses to ensure rigor, reviewing all data, including transcripts, data coding, and theme formulation, to strengthen trustworthiness.

Regarding transferability, in order for readers and researchers to assess whether the findings may be applicable to other contexts or populations, a detailed description of the study participants and the research setting was provided. Finally, to ensure confirmability, interviews were conducted by the first author, who was not a member of the community palliative care teams and had no personal or professional relationship with the participants. Confirmability was further supported through an audit trail of data and procedures.

This study was approved by the Ethics Committee of ULS S. João (reference no. CE-17/2024) and by the Ethics Committee of ULS Gaia-Espinho (reference no. 07/2024-1) prior to its commencement.

It was conducted in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (see Supplementary File).

Participant characteristics

A total of 20 family members participated in the study, including 18 women and 2 men, aged between 41 and 79 years (mean age: 64.1 years). Most participants were married and had completed primary education. The majority were retired or unemployed, with three reporting that they had left work specifically to provide care. Relationships to the person in palliative care were mainly daughters and wives. The main diagnoses of the cared-for persons were oncological, pulmonary, cardiac, and neurological diseases. At the time of the interview, all participants were providing home-based care, and the time since hospital discharge ranged from 15 to 365 days. Detailed characteristics are presented in Table 1.

Findings

This section presents the findings from the phenomenological analysis of the interviews with family members who cared for a person in a palliative situation at home following discharge from the hospital. Using Giorgi's descriptive phenomenological method, three essential themes emerged that capture the core meaning structures of the participants' lived experiences during the transition from hospital to home-based palliative care.

The identified themes are:

1. Emotional and relational experience of the family member
2. Family challenges and adaptation

3. Support for the family

The thematic structure is outlined in Fig. 1, offering a conceptual overview of how these themes interrelate in the context of the transition to home palliative care.

Theme 1: Emotional and relational experience of the family member

The experience of caring for a loved one in a palliative situation at home was described by participants as a profoundly emotional and relational journey. It extended far beyond physical caregiving, encompassing moral commitment, existential reflection, and a strong sense of responsibility grounded in love and reciprocity.

For many participants, the explicit wish of the person to remain at home was a decisive factor in the organization of care. Honoring this desire became a guiding principle that shaped the family's efforts, even when it meant significant personal, logistical, and emotional sacrifices. As one family member shared:

> "She insisted on saying that being at home was the greatest joy she could have at that moment. Even when she wasn't feeling well, she insisted on staying at home, and I made an effort to make that possible" (P19).

This statement reveals how the family's actions were structured around the will of the person, reinforcing the relational dimension of caregiving.

At the same time, participants expressed an intense feeling of helplessness as the disease progressed. Despite their best efforts to ensure comfort and presence, the uncertainty of the clinical trajectory and the visible decline of their loved one led to deep emotional distress. One caregiver said:

> "It's heartbreaking to see him suffer. No matter how hard I try, I feel powerless… I know I can't stop things from getting worse" (P8).

This sentiment highlights the internal conflict between the desire to protect and the inevitability of decline.

Caregiving was not described as an obligation imposed from the outside, but rather as a duty that emerged naturally from the relational and emotional bond with the person in palliative care. The role of caregiver was assumed as a moral and human commitment, deeply rooted in shared life history and love. As one participant reflected:

> "I take care of him because it's my human duty… he is my husband, the father of my daughter" (P4).

This type of statement reveals how caregiving was experienced as both an emotional expression and an ethical stance.

The families' commitment to ensuring dignity and comfort during the final stage of life was also strongly emphasized. Participants described a wide range of efforts to create a welcoming and peaceful environment, including physical adaptations of the home and the reorganization of routines. However, beyond the physical changes, comfort was also associated with presence, listening, and emotional availability. As one caregiver described:

> "The living room became the main space, as it was where he could be most comfortable" (P4).

In essence, this theme reveals how the act of caring is lived as a profoundly relational phenomenon where love, suffering, ethical duty, and the desire to protect coexist in a fragile but meaningful balance.

Theme 2: Family challenges and adaptation

The experience of caring for a person in a palliative situation at home is marked by continuous and demanding

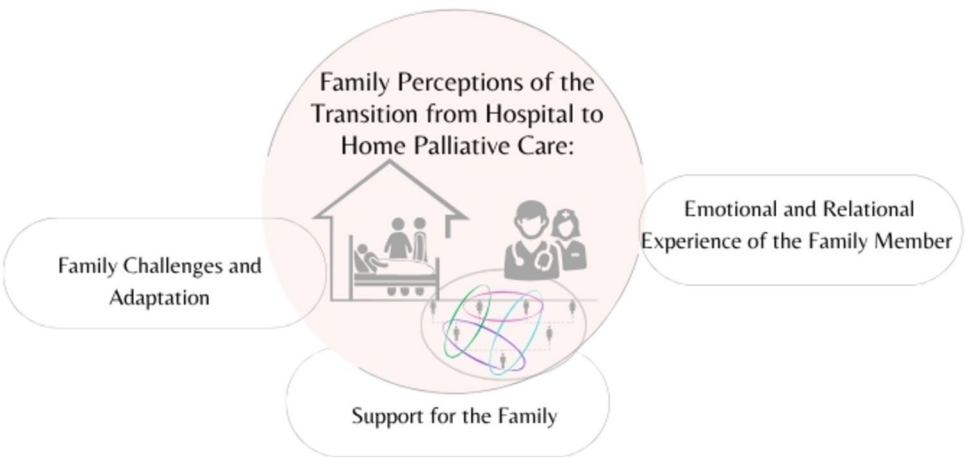

Fig. 1 Thematic structure of the lived experience of family members during the transition from hospital to home palliative care. The three essential themes (1) Emotional and Relational Experience of the Family Member, (2) Family Challenges and Adaptation, and (3) Support for the Family are interrelated and illustrate how caregiving is experienced in the context of home-based palliative care following hospital discharge

adjustments. Participants described how, upon returning from hospital, they were suddenly confronted with new and complex caregiving responsibilities for which they felt unprepared. The transition required immediate adaptation, often without formal guidance or structured support. This abrupt shift gave rise to anxiety, fear of doing something wrong, and a persistent sense of insecurity. As one participant shared:

> "Coming back home brought many uncertainties, because we didn't know if we were doing everything right" (P9).

The need to respond quickly to the progression of the illness meant that family members had to assume tasks they had never performed before, such as transferring, bathing, feeding, or administering medication without any prior training. This lack of technical knowledge was experienced as a source of stress and vulnerability, but also as a catalyst for self-directed learning. Participants actively sought information, improvised strategies, and remained committed to ensuring the best possible care for their loved one. One participant stated:

> "We needed more practical guidance to care for him on a daily basis how to transfer him, how to lift him, how to bathe him" (P7).

As the illness progressed, the physical and emotional demands intensified. Participants reported a growing sense of exhaustion, both physical and mental, compounded by the accumulation of responsibilities and the need for constant attentiveness. This burden often led to feelings of isolation and frustration, especially when caregiving responsibilities were not shared among other family members or supported by external resources. One participant reflected:

> "Lifting him and putting him in bed is a task that requires strength I don't have" (P17).

At the heart of this experience lies the tension between the family's determination to ensure care and dignity, and the reality of their own limits—bodily, emotional, and contextual. Despite this, participants demonstrated remarkable resilience and adaptability, continuously reorganizing their routines and strategies to meet the evolving needs of the person in their care. This theme reveals not only the challenges faced by families but also the dynamic process of adjustment, learning, and persistence that caregiving entails.

Theme 3: Support for the family

The experience of caring for a person in palliative care at home often unfolded in a context of limited resources and fluctuating levels of support. Participants described the transition from hospital to home as a shift not only in location but in the level of professional care and available infrastructure. In the hospital, the continuous presence of trained professionals, specialized equipment, and immediate technical assistance offered families a sense of safety and shared responsibility. At home, however, they faced the challenge of meeting complex care needs with limited tools and support. As one participant shared:

> "I really think she realizes that I can't give her the support she needs, and she has already been able to verbalize that. I believe she needed a professional team with all the necessary resources to meet her needs" (P2).

In response to this gap, participants described engaging in a process of autonomous learning, navigating daily challenges through trial and error, searching for information online, watching tutorials, or drawing on memories of what they had observed professionals doing during hospitalizations. This self-directed learning process revealed their resourcefulness and commitment, but also brought emotional strain and uncertainty. As one participant explained:

> "I have a lot of difficulty preparing food, so I went online to research what a low-residue diet was, because I didn't know. I knew it had to be a high-fiber diet, but I didn't know what that actually meant" (P1).

Despite these difficulties, the presence of the community palliative care team emerged as a critical source of reassurance and support. Participants emphasized the value of clear guidance, emotional validation, and consistent follow-up offered by the team. Their availability, even in unexpected situations, was described as a key factor in reducing anxiety and promoting a sense of security. One participant shared:

> "I was surprised by how the team was always available to help, even in unexpected situations" (P12).

For many, the team's involvement not only supported symptom management but also legitimized the caregiver's experience, offering comfort in the face of vulnerability.

This theme highlights the contrast between institutional and domestic care environments and underscores the centrality of emotional, informational, and practical support in the family's capacity to sustain caregiving at home.

Discussion

The lived experience of family members during the transition from hospital to home-based palliative care was marked by emotional complexity, moral commitment, and systemic fragility. The essence of this experience lies in the tension between honoring the person's wish to remain at home and navigating a fragmented system with limited guidance,

resources, and coordination. This transition was not simply logistical; it represented a profound shift in responsibility, identity, and emotional burden for family members, who became the central figures in organizing and delivering care.

One of the novel insights emerging from this study is the way in which family members assumed caregiving roles through a process of self-directed learning and adaptation, often without structured support from health institutions. In contrast to existing literature that emphasizes caregiver satisfaction or burden, our findings reveal a deeper internal conflict: a caregiving experience simultaneously driven by love and responsibility, yet shaped by fear, exhaustion, and uncertainty. In the Portuguese context, where a strong familist culture places the primary caregiving role on the family, these tensions are intensified by regional disparities in access to community palliative care teams and the absence of standardized transitional protocols between hospital and home. This results in families assuming an active, yet unsupported, role in bridging the gap between institutional care and home-based support.

These lived experiences reveal the essence of what it means for family members to transition from hospital-based to home palliative care marked by love, helplessness, burden, and solitary learning. The following discussion connects these key findings with existing literature, aiming to deepen the understanding of the challenges faced by families and the implications for care organization, professional training, and institutional support. Building on this essence, end-of-life caregiving at home has a significant emotional impact on families, as it is experienced with deep emotional involvement, where family members fulfill the wish of the person in palliative care to remain at home. This process is marked by ambivalent feelings that fluctuate between love, duty, and exhaustion. As identified in the participants' testimonies, the decision to respect the wish of the person in palliative care to stay at home is one of the main factors that drives family members to reorganize their lives. This finding is consistent with the literature, which indicates that the possibility of dying at home, surrounded by family, is one of the most common preferences among individuals in palliative care [6]. Even when faced with difficulties, families often prioritize the person's wishes, well-being, and autonomy. However, family members also report a profound sense of powerlessness in the face of disease progression, as they witness their loved one's suffering and become aware of the limitations of their actions. These results align with previous research describing caregiving as a commitment often undertaken by family members, within a journey marked by an oscillation between the desire to provide the best possible care and the helplessness faced with the inevitability of the illness [31]. The progression of the disease and the deterioration of the cared-for person intensify feelings such as stress, anxiety, and depression, leading family members to experience anticipatory grief and a heightened sense of powerlessness in the face of their loved one's declining condition [32]. At the same time, caregiving is described as a moral and emotional duty, sustained by emotional bonds and a strong desire to ensure dignity and comfort until the end of life. These findings are consistent with previous studies that identify the family caregiver as a central figure in palliative care, often driven by feelings of love, commitment, and reciprocity [33, 34]. Family members often undertake modifications to the home environment that are essential to ensure safety and comfort for the person in palliative care and to facilitate the delivery of care by the caregiver [35]. These changes range from reorganizing the physical space of the home to acquiring equipment such as adjustable beds, wheelchairs, and adapted shower chairs. Previous research has shown that the need to adapt the home can pose a financial challenge for many families, highlighting the importance of support policies that facilitate access to these resources [36].

This emotional and moral commitment is further challenged by the practical demands families face during this transition. The main challenges identified include rapid changes and the need for adaptation, often without sufficient time for preparation, requiring an immediate reorganization of family life. This phenomenon is widely documented in the literature and is considered one of the most significant challenges in the journey of individuals in palliative care. It highlights the complexities, demands, and needs involved in providing care to a seriously ill family member receiving palliative care at home [37–41]. Studies indicate that continuity of care during this transition is essential to avoid gaps in assistance and to minimize the negative impact on the quality of life of both the person in palliative care and their family members [23]. A particularly salient aspect of the transition lies in how unprepared family members feel to assume caregiving responsibilities. Difficulties related to basic tasks such as mobilizing, hygiene, and feeding are widely reported, often resulting in anxiety and insecurity. These findings align with existing literature on home-based palliative care, which emphasizes the need for adequate support to ensure the quality of care and the well-being of both the person in palliative care and the family caregiver [7, 16, 17, 21, 42]. The results of this study are in line with findings from other studies that describe how the lack of preparation for caregiving intensifies feelings of insecurity and stress among family members [39]. Thus, it would be beneficial to implement structured transition programs in which family members receive practical training before hospital discharge, including supervised sessions led by healthcare professionals [43–45]. Close collaboration between qualified healthcare professionals and family members is important to ensure the delivery of high-quality palliative and end-of-life

care, as family members often feel inadequately prepared for their role [46]. This lack of preparation for caregiving contributes to feelings of insecurity and burden. The literature is consistent with the findings of this study and shows that family members often experience high levels of burden, stress, anxiety, and depression due to the intense physical and emotional demands of palliative care [21, 45, 47]. This phenomenon is known as "caregiver burnout," a state of physical and emotional exhaustion that compromises the caregiver's ability to continue providing effective care [48]. In light of this, the implementation of emotional support strategies such as support groups for family members, psychological counseling, and respite care programs could help minimize the negative impacts of caregiving [49]. In addition, it is essential that healthcare teams identify signs of exhaustion in family members and provide early interventions to prevent negative impacts on their mental health [7].

The lived experience also involves a contrast between institutional and home-based support systems. The results highlight the importance of support, as family members compared the resources available in the hospital and at home. They emphasized that care provided in the hospital takes place in an environment where technical and professional support is continuous and readily accessible, ensuring safety for both the person in palliative care and their family. These findings are consistent with the literature, which describes how, at home, this support structure either fades or becomes limited, leaving family members with greater responsibility for managing care and making decisions often without the necessary training or resources [50, 51].

Family members also value access to reliable information and clear guidance, but they often report resorting to the internet or learning through experience and independent research as the only way to acquire caregiving skills. This can compromise the quality of care and the safety of both the patient and the caregiver. These findings reflect the existing literature, which indicates that the lack of specific training for family members can negatively impact the quality of care and increase caregivers' anxiety [16, 21]. A study showed that family members who received practical training reported greater confidence in performing caregiving tasks and better emotional management throughout the process [47]. Thus, it is recommended that healthcare institutions develop structured training platforms, including practical modules on mobility, hygiene, nutrition, and medication administration, to support family caregivers at home [52]. The support provided by community palliative care teams serves as a key factor in relieving caregiver burden and strengthening family members' confidence. When available, this professional support offers not only technical guidance in symptom and medication management but also emotional support and active listening. In contrast, the absence or irregularity of this follow-up is perceived as a source of distress, insecurity, and loneliness. Studies indicate that the integration of specialized palliative care teams significantly improves the quality of life of individuals in palliative care, reduces family caregiver burden, and facilitates symptom management and monitoring of disease progression. The guidance provided by healthcare teams can enhance family members' confidence and empower them to better handle unexpected situations, thereby reducing the risk of complications [53, 54]. The findings also highlight the pivotal role of community palliative care teams in mitigating the emotional and practical burden placed on families during the transition. Participants described the team not only as a clinical resource but also as a relational anchor providing clarity, validation, and a sense of security in moments of uncertainty. This underlines the need to reinforce the availability and responsiveness of these teams across regions, ensuring that families are not left to assume complex responsibilities in isolation. While previous studies have recognized the importance of community-based support in palliative care, our findings offer a more nuanced view of how the presence or absence of this support shapes the emotional experience of caregiving and the family's perception of safety and competence. The Portuguese context, marked by uneven territorial coverage and fragmented referral pathways, further reinforces the urgency of strengthening community-based structures in end-of-life care.

These findings echo elements identified in previous studies that analyzed the transition from the perspective of patients and healthcare professionals [25, 26]. However, the narratives of family members in this study reveal a deeper moral and emotional involvement, as well as a particular vulnerability during the handover of care responsibilities—dimensions that were less evident in the other perspectives.

Strengths and limitations

This study offers significant contributions to understanding the caregiving experience of family members in the specific context of the transition from hospital to home-based palliative care. The phenomenological approach enabled a deep exploration of lived experiences, revealing not only the practical challenges and emotional burdens involved in caregiving at home but also how families navigate this transition, often in the absence of structured support, facing a fragmented system, and assuming new responsibilities with limited guidance.

One of the study's key strengths is the focus on the hospital-to-home transition as a critical period marked by discontinuity of care, emotional vulnerability, and increased caregiver demands. By centering this transition, the findings provide insight into the structural and emotional dimensions

that shape family members' adaptation to caregiving roles at home.

Another strength lies in the implementation across more than one healthcare institution, which allowed for the collection of data in diverse settings and provided insight into interinstitutional coordination, an essential factor in the continuity of care during the transition process.

However, as with any qualitative research, the study has limitations concerning the generalizability of the findings. The purposive sample included a small number of participants, and each caregiving experience was shaped by unique variables, such as illness trajectory, family dynamics, and social context. The fact that only one family member per household was interviewed may have limited the understanding of intra-family variations in perception.

The absence of longitudinal follow-up is also a limitation, as it prevented an exploration of how experiences evolved over time, particularly during the advanced stages of illness or after bereavement. Additionally, the study did not include a family genogram, which could have provided a more comprehensive understanding of caregiving roles and relationships within the family.

Member checking was not conducted in this study. This decision was intentional and aligned with the epistemological foundations of Giorgi's descriptive phenomenological method. In this approach, reintroducing participants at the stage of analysis may compromise the phenomenological reduction by reactivating the natural attitude. Instead, the analysis focused on the researcher's reflective interpretation of the participants' descriptions to access the essential structure of the experience.

In addition, although the time elapsed since hospital discharge varied across participants, all family members were actively engaged in home caregiving at the time of the interview and able to describe their lived experiences of the transition. This variability reflects the diverse rhythms and trajectories inherent to each caregiving situation. The variable "days off work" was not intended as an indicator of recall accuracy but was collected to explore the occupational, economic, and psychosocial impact of caregiving. Continuing to work or the need to stop working can reflect disruptions to the family member's sense of normalcy, autonomy, and overall well-being, which are central to understanding the burden of care during the transition.

Finally, the lack of cultural diversity in the sample limits the exploration of how cultural, religious, or social factors may shape the caregiving experience during this transition. Future research that includes diverse caregiver profiles and cultural backgrounds may contribute to developing more personalized and culturally sensitive interventions that better support families navigating this critical stage.

Conclusion

This study aimed to explore and describe the lived experiences of family members who care for individuals in palliative care at home in Portugal.

The analysis of these experiences reveals a reality deeply shaped by challenges, feelings of powerlessness, a strong sense of duty, and the constant need for adaptation. The complexity of end-of-life care goes beyond technical aspects, involving a significant emotional and relational burden that directly affects the well-being of the caregiver and the quality of care provided.

Despite the emotional motivation and commitment demonstrated by family members, the findings highlight weaknesses in the support provided to families, particularly during the transition from hospital to home, which is often marked by a lack of preparation and guidance at discharge and the absence of regular follow-up at home. The comparison between the hospital and home settings reveals an abrupt shift in context, frequently without the appropriate transfer of knowledge, resources, and emotional support.

The study confirms the importance of integrated and continuous support strategies, focused not only on the person in palliative care but also on the family as a unit of care. Promoting caregiver training programs, strengthening community palliative care teams, and improving access to material and social support are essential steps to reduce caregiver burden, enhance safety, and preserve dignity in the home care process, particularly in the vulnerable phase of care transition.

These findings reinforce the urgent need to invest in public policies and care practices that recognize, empower, and support family members, ensuring that care provided at home is not only compassionate and competent but also sustainable throughout the continuum of care.

It is concluded that the experience of family members involved in home-based palliative care is marked by significant challenges, but also by a deep sense of commitment and love.

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Author contributions SC is the primary investigator and conducted the interviews. SC, CF and BM conceptualised and designed this study. SC, CF, and BM processed the data and verified accuracy of data against the transcripts. SC, CF and BM analyzed the data and interpreted the findings. SC wrote the initial draft. CF and BM provided critical feedback about the draft. All authors reviewed and approved the final manuscript for submission.

Data availability No datasets were generated or analysed during the current study.

Declarations

Competing interests The authors declare no competing interests.

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