European Journal of Oncology Nursing 81 (2026) 103139

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Living the transition: Experiences of patients receiving palliative care from hospital to home – A phenomenological study

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ARTICLE INFO

Keywords:
Palliative care
Home care services
Hospitalization
Phenomenology
Patient-centered care

ABSTRACT

Purpose: Transitions from hospital to home in palliative care are emotionally and organisationally complex, influencing patients' dignity, safety, and continuity of care. Although previous studies have focused largely on professionals and informal caregivers, patients' own perspectives remain insufficiently understood. This study aimed to explore the lived experience of adults receiving palliative care during the transition from hospital to home.

Methods: A descriptive phenomenological design guided by Giorgi's method was used. Twenty adults (n = 20) recently discharged from hospital and receiving home-based palliative care were purposively recruited from three specialised community palliative care teams in northern Portugal and participated in in-depth individual interviews.

Results: Four essential themes described the transition experience: reconstructing home as a place of care and meaning; transforming relationships, highlighting the role of family and professionals; navigating loss and adaptation, where dependence evokes fear yet promotes acceptance; and system fragilities, including limited continuity and coordination, contributing to insecurity and distress. Overall, the transition was experienced as a tension between autonomy and vulnerability as patients reconstructed daily life in the context of serious illness.

Conclusions: Improving transitional palliative care requires integrated and relationally attuned models that ensure continuity and timely support across care settings. Nursing practices should actively involve patients and families, strengthen home-based support, and promote dignity and safety during the transition from hospital to home.

1. Introduction

The increase in life expectancy and the growing prevalence of chronic and incurable diseases have placed palliative care at the center of public health policies and practices. It is estimated that, globally, more than 56 million people require palliative care each year, a number that is likely to increase with the aging of the population and the evolution of degenerative and oncological diseases (World Health Organization, 2020). In this context, it is becoming increasingly urgent to ensure care responses that integrate not only symptom control and psychosocial support, but also continuity of care throughout the course of the disease.

One of the most critical stages in this journey is the transition from hospital care to home care. This transition represents much more than a mere change of physical location: it is a process deeply experienced by the person in palliative care, involving changes in routines, family dynamics, perceptions of safety, feelings of autonomy, and sometimes confrontations with the fragility of support systems (Cruz et al., 2025b).

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https://doi.org/10.1016/j.ejon.2026.103139
Received 12 December 2025; Received in revised form 4 February 2026; Accepted 7 February 2026
Available online 9 February 2026

Studies have shown that poorly planned or insufficiently monitored transitions can result in feelings of abandonment, avoidable hospital readmissions, and avoidable suffering for the patient and their family (Dhaliwal and Dang, 2024).

Despite growing scientific interest in transitions in palliative care, most studies focus on the effectiveness of organizational models or the perspectives of professionals (Cruz et al., 2025a) and caregivers (Liebzeit et al., 2023; Pettersson et al., 2021; Salifu et al., 2021a). There is still little research that gives voice to people in palliative care, seeking to understand how they experience and feel about this process. However, it is precisely this subjective and experiential dimension that can offer richer contributions to truly person-centered care.

In recent years, several studies have explored the experiences of transitions between care settings among people receiving palliative care, highlighting the challenges associated with interinstitutional coordination and the emotional and organizational impact on patients and families (Mertens et al., 2022; Salifu et al., 2021a). Nevertheless, there remains a lack of evidence centered on the lived experience of the person during this process, particularly within the portuguese context, which underscores the relevance of the present study.

Previous research has examined the transition from hospital to home in palliative care from different perspectives, highlighting the complexity of this process. Studies involving health professionals and family caregivers describe organizational fragmentation, communication gaps, and emotional strain associated with discharge and continuity of care (Mertens et al., 2022; Pollock et al., 2024; Salifu et al., 2021a; Morey et al., 2021). Systematic reviews have also emphasized the importance of relational and contextual factors in shaping these transitions (Feliciano and Reis-Pina, 2024; Saunders et al., 2019). However, while these studies provide valuable insights into the structural and relational dimensions of transitions, the lived experience of patients themselves how they perceive and give meaning to this process remains insufficiently explored, particularly in Southern European contexts.

The present study builds on this existing body of knowledge and seeks to deepen understanding of the patient's lived experience during the transition from hospital to home within palliative care. Through phenomenological analysis of participants' narratives, the study aims to identify the essential meanings that structure this experience, thereby contributing to a more comprehensive understanding of the phenomenon and informing humanized, integrated practices that respond to the needs and wishes of people at the end of life.

2. Method

2.1. Study design

To address this aim, the study was guided by the following research question: How do patients receiving palliative care experience the transition from hospital to home? Given this focus, a qualitative phenomenological study was conducted (Cohen, 1987). Descriptive phenomenology was adopted to explore the complex phenomenon of human experience, emphasizing how the lifeworld is described through participants' voices (Giorgi, 1997).

2.2. Participants and sampling method

2.2.1. Setting

The study was conducted within three community palliative care teams in northern Portugal that provide home-based follow-up to patients after hospital discharge. These multidisciplinary teams support patients and families in managing complex symptoms, coordinating care, and ensuring continuity of palliative support at home.

2.3. Population and inclusion criteria

The study population consisted of patients receiving community-based palliative care following discharge from hospital. Inclusion criteria were: (1) diagnosis of a life-limiting or palliative-stage condition; (2) age ≥18 years; (3) currently receiving home-based care from a community palliative care team; (4) previous hospital admission within the last six months; (5) ability to understand the study objectives and provide informed consent; and (6) willingness to participate.

2.4. Sampling method

A purposive sampling strategy was used to ensure inclusion of participants with diverse diagnoses and durations of follow-up in community palliative care, allowing a comprehensive understanding of the phenomenon. Sample size determination followed principles of data sufficiency consistent with descriptive phenomenology, with initial sufficiency reached after 15 interviews and subsequently confirmed through additional interviews, resulting in a final sample of 20 participants, as detailed in the data collection and analysis process.

2.5. Recruitment

After obtaining ethical and institutional approvals, potential participants were identified by a liaison nurse from each community palliative care team according to the inclusion criteria. The liaison nurse made the initial contact, briefly explained the study, and asked whether the patient was willing to be approached by the researcher. Only after patients expressed interest and gave permission for contact did the first author personally visit them at home to provide detailed information about the study, clarify any questions, and obtain written informed consent before starting the interview. In total, 20 eligible patients were invited to participate; all agreed to take part, and none declined or withdrew.

2.6. Data collection

Data were collected between May and October 2024 through individual, in-depth interviews with 20 patients receiving home-based palliative care, all followed by three community palliative care teams in northern Portugal. Data collection was based on a semi-structured interview guide, which encouraged participants to narrate their lived experiences of the transition from hospital to home (Kakilla, 2021).

The interview guide comprised two parts: a brief sociodemographic questionnaire (Table 1) and open-ended phenomenological questions designed to elicit participants' descriptions of their own experiences. All interviews began with the broad question: *"Can you describe how you experienced the process of moving from hospital care to receiving palliative care at home?"* To deepen understanding, follow-up questions were asked, such as: *"What did this transition mean to you?"*, *"How did you feel and adapt during this process?"*, and *"What factors helped or made this transition more difficult?"*

These questions were formulated to facilitate a descriptive account of the lived experience, consistent with Giorgi's phenomenological method (Giorgi, 2014). Two pilot interviews were conducted to ensure the clarity and relevance of the questions; these were excluded from the analysis.

All interviews were conducted face-to-face at participants' homes by the first author, who had no clinical relationship with them. No family members or informal caregivers were present during the interviews. Interviews lasted between 30 and 90 min (mean 40 min; median 45 min; interquartile range 35–60 min), were audio-recorded with consent and transcribed verbatim within 24 h. Observational notes were made immediately after each interview to support reflexivity and contextual understanding.

Given the clinically fragile condition of participants, specific risk mitigation strategies were implemented throughout data collection. Interviews were conducted by the first author, an experienced nurse trained in palliative care and qualitative research, with continuous attention to signs of emotional or physical distress. Participants were

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

Variables	Categories	Absolute value and mean
Sex, *n*	Male	11
	Female	9
Age *(y)*	Minimum and maximum 55 – 94	Mean 77,1
Nationality	Portuguese	20
	Foreign	0
Marital status	Married/Cohabiting	13
	Single	1
	Widowed	6
	Divorced	0
		0
Education level	Primary education (1st cycle	15
	Lower secondary education (2nd cycle)	1
	Lower secondary education (3rd cycle)	0
	Upper secondary education	2
	Short-cycle tertiary education	0
	Bachelor's degree	1
	Licentiate degree	1
	Master's degree	0
	Doctoral degree	0
Employment status	Employed	0
	On unpaid leave	0
	Unemployed	0
	Retired	18
	Medically incapacitated	2
Stopped working due to ilness *(d)*	90 days	1
	360 days	1
Ilness	Oncological disease	11
	Pulmonary disease	5
	Cardiac disease	2
	Neurological disease	2
Referral time to Palliative Care *(d)*	Minimum and maximum 30 -1095	Mean 155,5
Time integrated in the Community Palliative Team *(d)*	Minimum and maximum 15 - 365	Mean 72,25

(y) years *(d)* days.

informed that they could pause or terminate the interview at any moment without providing justification. If distress emerged, the interview was stopped immediately and emotional support was provided. When necessary, concerns were communicated with the participant's consente to the respective community palliative care team to ensure follow-up and continuity of support. At the end of each interview, participants were given time to debrief and were reassured of ongoing access to professional support through their care team.

Data sufficiency was achieved after 15 interviews, when no new meaning units emerged and the phenomenological structure appeared stable across cases. This assessment was based on ongoing analytic monitoring, whereby newly conducted interviews were systematically examined for the emergence of novel meaning units or variations in the evolving phenomenological structure. Five additional interviews were subsequently conducted as a confirmatory step, and no new meanings or structural variations were identified, supporting the completeness and stability of the findings and ensuring methodological rigor (Vagle, 2018).

2.7. Research team and reflexivity

The research team consisted of three members, one of whom was a nurse in a hospital care unit with 18 years of professional experience in oncology, a doctoral student, and two PhD-level team members who are professors at nursing schools (Coordinating Professor, Adjunct Professor) with extensive experience in clinical practice. The researchers were independent individuals who were not responsible for the care of people in palliative care situations and who were not part of the community palliative care support teams. All researchers received training in qualitative research methods and conduct qualitative research.

The dual role of the researchers as clinicians and investigators was carefully managed throughout the study. The first author, who had previous clinical experience in palliative care, maintained a reflexive stance to ensure that her professional knowledge did not influence data collection or interpretation. Clear boundaries were established between clinical and research contexts, with all participants recruited and interviewed outside any direct care relationship. This approach helped to preserve the authenticity of participants' narratives and the ethical integrity of the research process. Similar ethical reflections on managing the clinician–researcher dual role in sensitive research have been highlighted by Salifu (2025).

In addition, reflexivity was actively supported through systematic bracketing procedures. Prior to data collection, the first author engaged in written reflexive notes to identify and suspend pre-understandings arising from her clinical background. During data collection and analysis, a reflexive journal was maintained to document emotional responses, assumptions, and analytic decisions. These reflexive records were regularly discussed with the supervisory team, supporting critical self-awareness and minimizing the influence of prior clinical experience on interpretation.

2.8. Data analysis

Data were analyzed using Giorgi's descriptive phenomenological method, which involved four stages (Giorgi, 2014). First, transcripts were read repeatedly to obtain a holistic understanding of the participants' lived experience. Second, meaning units were identified by rereading the texts and marking transitions in meaning relevant to the phenomenon under investigation. This process generated a series of meaning units, initially expressed in the participants' natural language. Third, these meaning units were transformed into phenomenological language appropriate to the phenomenon under study, while remaining faithful to the meanings expressed by participants. These transformations allowed the researchers to articulate the situated structures that described each participant's individual experience. Fourth, through a process of imaginative variation and comparison across all situated structures, the researchers integrated the transformed meaning units into a general descriptive structure that captured the essential meanings of the lived experience. From the transformed meaning units, convergent aspects were clustered and synthesized into thematic structures that expressed the essential meanings of the lived experience. Through iterative reflection and discussion among the researchers, four essential themes were formulated, ensuring that they remained faithful to the participants' narratives and to the phenomenological essence of the transition experience.

Data analysis was conducted concurrently with data collection. The first author transcribed all interviews verbatim, and three researchers independently read and analyzed the transcripts following all stages of Giorgi's descriptive phenomenological method. Independent analytic interpretations were compared in regular analytic meetings, and discrepancies were resolved through discussion and return to the original transcripts until full consensus was achieved, ensuring fidelity to participants' meanings.

Throughout this process, an audit trail was maintained, including reflexive notes, iterative versions of coding schemes, and records of

analytic decisions. A working codebook, inductively developed and refined during analysis, supported consistency across cases. ATLAS.ti® software (Version 23; Scientific Software Development GmbH, Berlin, Germany) was used to manage and organize the data, and each participant was coded with the letter "P" followed by a number to ensure confidentiality.

2.9. Ethical considerations

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.

All participants received oral and written information about the study aims, procedures, voluntary nature of participation, and their right to withdraw at any time without consequences for their care. Written informed consent was obtained from all participants before data collection. Given the clinical vulnerability of participants, interviews were conducted with continuous attention to signs of distress, and participants were reminded that they could pause or terminate the interview at any moment.

Confidentiality and anonymity were ensured throughout the study. Audio recordings and transcripts were stored securely, and identifying information was removed during transcription.

2.10. Rigor and trustworthiness

This study adhered to credibility, consistency, transferability, and reliability to support the scientific rigor of qualitative research (Lincoln and Guba, 1985).

Credibility was supported through in-interview clarifications and confirmations of participants' meanings. Interviews were conducted by the first author, a doctoral student with over 18 years of professional experience as a nurse, trained in qualitative research and supervised by senior nursing researchers. To minimize the influence of prior assumptions, the interviewer adopted a reflexive stance, intentionally avoiding references to personal clinical experiences and allowing participants to freely express their meanings and perspectives.

Consistency was ensured through detailed documentation of participant characteristics, the recruitment process, and all stages of data collection and analysis. In addition, the second and third authors independently reviewed interview transcripts, coding processes, and theme development, enhancing analytic rigor and reliability.

Transferability was supported by providing a rich description of the study context and participant characteristics, enabling readers to assess the applicability of the findings to other settings.

Dependability and confirmability were strengthened through an internal audit of the data and analytic procedures. Two senior members of the research team (CF and BM), who were not involved in data collection, systematically reviewed the audit trail, including interview transcripts, reflexive notes, coding iterations, theme development records, and analytic memos. This audit examined the coherence between raw data, meaning units, thematic structures, and the final phenomenological synthesis. The audit process confirmed the transparency and consistency of analytic decisions, with minor refinements discussed and agreed upon within the research team.

Transcripts were not returned to participants for verification. This decision was made due to the clinical fragility of participants and the potential emotional burden associated with revisiting detailed narratives of illness and transition experiences in a palliative care context. In line with descriptive phenomenological methodology, analytic rigor was ensured through independent analysis by multiple researchers, reflexive bracketing, and a comprehensive audit trail, rather than participant transcript verification. Findings-level member checking was considered but deemed ethically inappropriate given participants' health status and the risk of undue burden.

The study was conducted in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines. To enhance analytic transparency, a supplementary file is provided illustrating the phenomenological progression from meaning units to thematic structures, with examples of analytic transformation and illustrative participant quotations.

3. Findings

The results of the study are discussed in two sections. The first part presents information on the sociodemographic characteristics of people in palliative care (Table 1), and the second part presents the findings obtained from interviews with participants.

3.1. Characterization of participants

The study included 20 patients receiving home-based palliative care after hospital discharge, all of whom were living at home and followed by community palliative care teams in northern Portugal. Eleven participants were male and nine were female, aged between 55 and 94 years. Most were married, retired, and had completed primary education. Cancer was the most frequent diagnosis (n = 11), followed by pulmonary (n = 5), cardiac (n = 2), and neurological (n = 2) diseases.

On average, participants had been receiving palliative care for 155.5 days (range: 15–365 days). Although some had been followed by community teams for up to one year, several experienced intermittent hospital readmissions during this period. Therefore, all participants had recent and meaningful experiences of the transition between hospital and home, consistent with the study's focus. Detailed characteristics are presented in Table 1.

Beyond their sociodemographic characteristics, participants' narratives revealed the meaning and depth of their lived experience of transitioning from hospital to home. The phenomenological analysis generated four essential themes that capture the essence of this experience.

The phenomenological analysis generated four essential themes that capture the lived experience of patients receiving palliative care as they transitioned from hospital to home. These themes represent the essential meanings that structure this experience: (1) Reconstructing home as a place of care and meaning; (2) Transforming relationships through the transition to home care; (3) Navigating loss and adaptation, and (4) System fragilities affecting continuity of transitional palliative care.

Fig. 1 presents these themes and subthemes in an integrative diagram that illustrates their interconnections within the overall phenomenological structure.

3.2. Theme 1: reconstructing home as a place of care and meaning

Participants described the transition from hospital to home as a turning point in their illness trajectory, marked by contrasting emotions of relief, vulnerability, and rediscovery. Returning home was not merely a change in setting but a process of reconstructing meaning transforming the home from a familiar physical space into a place of care, safety, and identity. The movement between the hospital and home triggered reflections on autonomy, belonging, and dignity, revealing the ambivalence of feeling both comforted and exposed in a space once taken for granted.

The theme *"Reconstructing home as a place of care and meaning"* encompasses the ways in which patients redefined the significance of home after hospitalization, comparing its atmosphere, rhythms, and relationships with those of the hospital environment.

3.2.1. Home as a place of comfort, safety, and dignity

Participants reported that returning home restored a sense of comfort and tranquility after the confinement and routines of the hospital. The presence of personal belongings, the familiarity of the environment, and proximity to loved ones fostered a feeling of safety and emotional

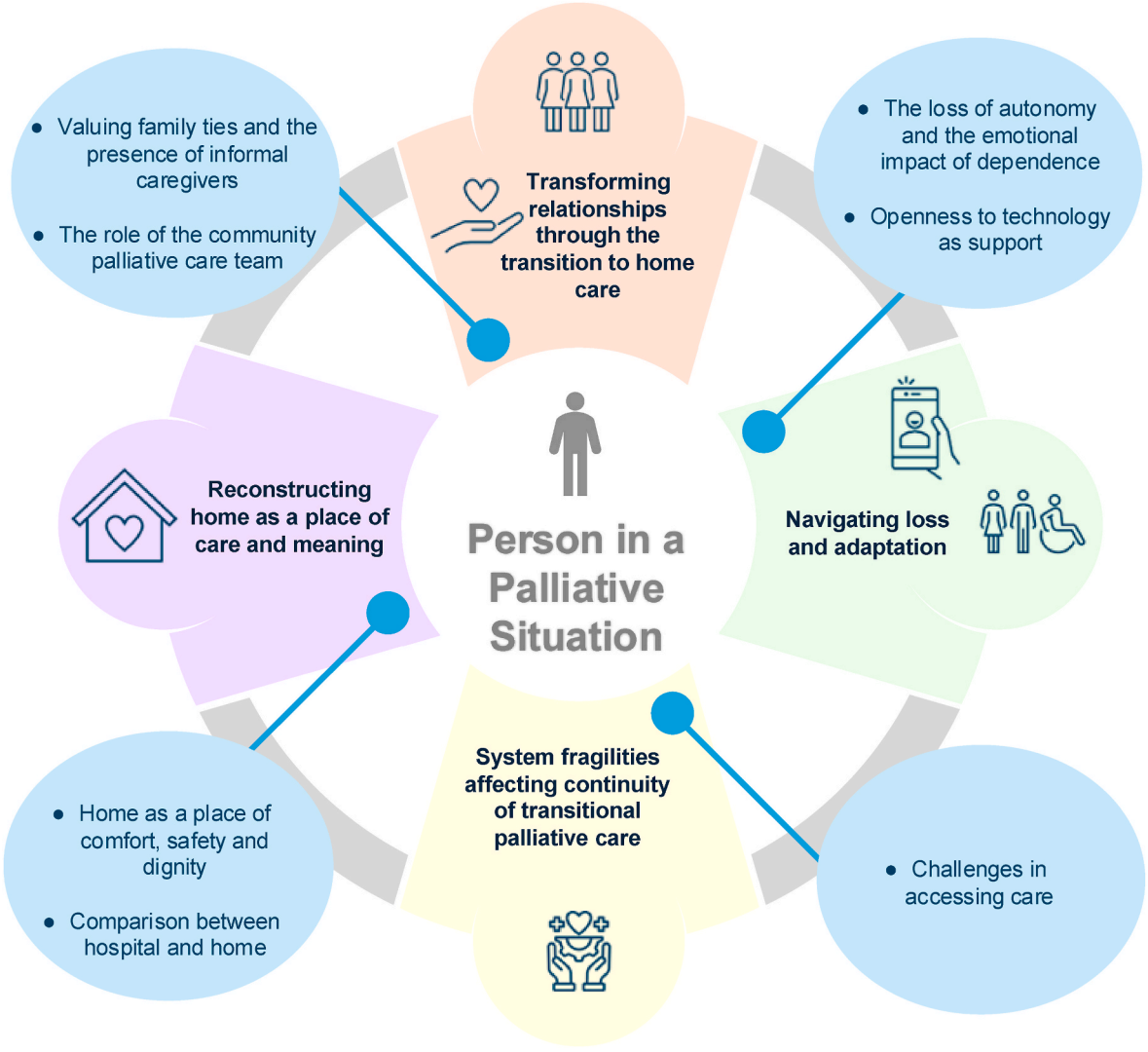

Fig. 1. Essential thematic structure of patients' experience of transition from hospital to home in palliative care.

balance. For many, the home regained its role as a space where care and affection coexist naturally, in contrast to the technical and impersonal atmosphere of the hospital.

Being at home was also described as preserving dignity and intimacy, allowing patients to make small choices that reaffirmed their identity and autonomy within the limits imposed by illness. One participant said, *"Here at home I feel freer, I can sleep better, eat what I like … it's my space"* (P2). Another shared, *"Here at home, I sleep in my bedroom, the bedroom I've had for 40 years … when it's sunny, I go to the window to see my neighbors and we talk … when my sister is cooking, I go to the kitchen and we stay there together"* (P19). Another participant emphasized the relational dimension of this comfort: "*It's essentially the proximity to my family, and that's fundamental because I was treated very well in both hospitals. I have absolutely no reason to complain. Being with my family is completely different*" (P10).

These accounts illustrate how the transition home is experienced not only as physical relocation but as a reappropriation of daily life, where routines, relationships, and spaces regain personal and existential meaning.

3.2.2. *Comparison between hospital and home*

Participants made sense of their transition experience by comparing the hospital and home care environments. This contrast served as a way of interpreting the process of change they had undergone. The hospital was often described as a space of constant observation and immediate access to professional help, yet characterized by impersonality, rigid routines, and a sense of depersonalization. In contrast, home represented a return to familiarity, emotional warmth, and the reestablishment of daily rhythms and personal autonomy.

However, this comparison also revealed the ambivalence inherent in the transition. While the home was experienced as more humane and dignified, participants acknowledged the insecurities associated with the absence of continuous clinical surveillance. As one participant explained, *"In the hospital, even though there was no availability, there were professional people, right? People who are trained and therefore qualified. That's why I missed that professionalism here at home. But the comfort makes up for the lack of professionalism"* (P1).

Others emphasized that the home allowed a more natural pace of living and greater respect for individuality: *"Here at home with my wife, with permanent* support*, all I have to do is call and she is right there to help me … I'm very comfortable at home. Take the example of three patients going to take a shower in a chair … I was always the last one and took a shower very late … at home it's calmer, there's no rush like in the hospital"* (P7).

These narratives illustrate how the transition is experienced through comparison, where participants re-evaluate both spaces and their meanings. The home becomes a place where the absence of professional control gives rise to both freedom and vulnerability, encapsulating the emotional and existential tension of living the transition.

3.3. Theme 2: transforming relationships through the transition to home care

The transition from hospital to home was experienced as a process of relational transformation. Participants described changes in how they related to family members, informal caregivers, and professionals, emphasizing that the quality of these relationships shaped their experience of safety, comfort, and continuity of care. Returning home made dependence and interdependence more visible: family members became central figures in care, while the presence or absence of community palliative care teams deeply influenced the sense of security and accompaniment. Thus, the transition was not only a change of place but also a reconfiguration of relational bonds and care dynamics.

3.3.1. Valuing family ties and the presence of informal caregivers

The presence and involvement of family members and informal caregivers were described as essential sources of comfort, protection, and emotional stability throughout the transition. Sharing the domestic space with loved ones allowed participants to preserve a sense of belonging and continuity in daily life, even as physical limitations increased. Being "at home with their loved ones" was experienced as a condition for maintaining dignity and emotional balance in the face of illness.

Yet, this dependence also awakened feelings of guilt and concern for family members who were visibly exhausted by caregiving. This dual awareness of receiving care and witnessing the suffering of those who provided it was part of the ambivalence that marked the transition experience. As one participant shared, *"Do you think I don't know that this is very hard for my mother? She is much thinner, it's because of her nerves. She spends all her time here with me … it's very hard"* (P17). Another participant described how his wife's presence brought comfort: *"Here at home with my wife, with her constant* support*, all I have to do is call and she is right there to help me … that's why I am very happy at home"* (P7).

These narratives show that returning home deepens family intimacy but also exposes its fragility. The transition makes visible both the closeness and the vulnerability inherent in family care.

While some participants described family care as naturally integrated into daily life, others highlighted the emotional and physical toll placed on relatives, reinforcing the relational complexity of home-based care.

3.3.2. The role of the community palliative care team

The relationship with the community palliative care team was described as a vital extension of the care previously provided in the hospital, yet transformed by proximity and personalization. Participants experienced this team as a reassuring and trustworthy presence, offering not only clinical expertise but also emotional and relational support. Home visits and follow-up calls were interpreted as gestures of continuity that bridged the gap between institutional and home-based care.

As one participant explained, *"Everyone on the palliative care team who comes here is so good, so calm … they are always calling to see how I am … since last week, they've come three times, and my wife feels very* supported *by them"* (P17). Another participant reflected, *"After a week at home, I immediately felt a different way of being … I feel more cheerful, more willing"* (P7).

Through these relationships, the transition becomes relationally sustained a shared space between professional care and family life that enables the person to feel accompanied rather than abandoned.

3.4. Theme 3: navigating loss and adaptation

The transition from hospital to home made the experience of physical decline and dependence more tangible. At home, participants became more aware of their bodily limitations and of how these affected their ability to manage daily life. The loss of autonomy was lived not only as a clinical condition but as an existential process, revealing the vulnerability of the body and the need to renegotiate one's role within the family and the world of care. Moving home therefore confronted participants with the dual challenge of accepting dependence while striving to preserve dignity and a sense of self.

3.4.1. The loss of autonomy and the emotional impact of dependence

Participants described the progressive loss of autonomy as one of the most difficult dimensions of their lived experience at home. This process was marked by frustration, sadness, and, at times, indignation—particularly when ordinary tasks suddenly required the help of others. The confrontation with physical deterioration and the awareness of being dependent on close family members triggered ambivalent emotions: gratitude for the support received, but also discomfort and shame for feeling like a burden.

As one participant expressed, *"I accept my situation, but I am afraid of getting worse and being a burden"* (P20). Another reflected, *"I know I need my wife's help a lot; I would like to give her less work. I am sad to feel the disease progressing and taking away my strength"* (P9).

These narratives show that the transition home exposes patients to a new intimacy with their own fragility, transforming the domestic space into a place where loss and care coexist. The meaning of dependence evolves from a sense of defeat to a learning process of acceptance and trust in others.

3.4.2. Openness to technology as support

In this process of adaptation, technology emerged as an unexpected ally, facilitating continuity of care and offering a renewed sense of control in moments of vulnerability. Although not all participants were initially familiar with or comfortable using technology, its gradual introduction was experienced as a form of reassurance and safety. Devices enabling communication with healthcare professionals or emergency response were perceived as extending the reach of care into the home.

For some, technology represented a means of regaining limited autonomy, allowing them to remain connected and feel secure even when physically fragile. *"My son is good with computers and cell phones … he knows some things about my illness from reading on the internet … he looks for supplements for me and submits social security papers online"* (P19). Another participant added, *"If there were an app with videos or* support *on how to do things, it would help my wife more"* (P20).

These accounts suggest that openness to technology reflects not a fascination with devices, but a search for relational security a way of maintaining continuity of care and symbolic closeness with professionals after hospital discharge.

3.5. Theme 4: system fragilities affecting continuity of transitional palliative care

The transition from hospital to home made visible to participants not only the personal and familial challenges of living with illness but also the limitations of the healthcare system in sustaining continuity of care. Returning home often exposed a gap between institutional care and community resources, where the flow of information, coordination between services, and responsiveness were inconsistent. For participants, these system fragilities transformed moments of clinical uncertainty into experiences of insecurity and isolation, undermining the sense of stability they sought after leaving the hospital.

3.5.1. Challenges in accessing care

Several participants described difficulties in accessing professional support outside regular hours of the community palliative care teams, especially during acute symptom exacerbations or emergencies. The absence of timely responses was experienced with anxiety, helplessness, and frustration, reinforcing the feeling that home care was fragile and that safety was conditional on systemic responsiveness.

Bureaucratic and organizational barriers such as delays in activating

home support services, difficulties in inter-institutional communication, or administrative requirements incompatible with urgent needs were also perceived as burdensome. In the context of physical and emotional vulnerability, these procedures amplified the sense of being abandoned by the system.

As one participant expressed, *"It's very bad to go to the hospital by ambulance, the ambulance bounces around and it's uncomfortable … then to spend all that time in the emergency room corridor … I have no cure, I shouldn't be in an emergency room corridor. I think it would be ideal not to have to make these trips, which are torture"* (P7). Another reflected, *"Sometimes the worst thing is something that deviates from the norm … I would need some information on how to proceed. And this happened outside the team's hours of operation … I had to go to the emergency room. It would make sense for this team to be connected to the hospital team, so that someone would respond when this one isn't available"* (P6).

These accounts reveal that the transition home is not only a personal or relational process but also a test of the system's capacity for continuity. Participants experienced the lack of coordination and accessibility as a rupture in care an abrupt contrast to the immediacy of the hospital environment. The transition thus emerged as both a movement toward autonomy and an exposure to structural vulnerability, where the ideals of comfort and dignity at home were conditioned by the responsiveness of the healthcare system.

The phenomenological synthesis of the participants' narratives revealed that the transition from hospital to home in palliative care is lived as a multidimensional process of reconstruction of space, relationships, self, and trust. This transition marks the passage from an institutional world of technical security to a domestic world where meaning, care, and vulnerability coexist. Patients experience the homecoming as both a return to familiarity and an encounter with fragility: while the home restores identity, intimacy, and dignity, it also exposes dependence, relational ambivalence, and systemic fragilities that threaten the continuity of care.

Across all themes, the transition emerged as a lived tension between autonomy and vulnerability, proximity and absence, comfort and uncertainty. It is through navigating this tension that patients reconstruct their sense of being-in-the-world while facing finitude. The essence of this experience lies not in the success or failure of the transition, but in the way individuals reconfigure their everyday existence reclaiming meaning, relationships, and a sense of continuity within the limits imposed by illness and by the healthcare system itself.

4. Discussion

The present study aimed to describe the lived experience of people in palliative care during the transition and integration process from hospital to home care, in light of a phenomenological approach inspired by Giorgi's method. Data analysis identified four central themes that reflect the meanings attributed by participants to their experience of this process: reconstructing home as a place of care and meaning, transforming relationships through the transition to home care, navigating loss and adaptation, and system fragilities affecting continuity of transitional palliative care.

These themes reveal that the transition from hospital to home is not just a physical displacement, but a deeply felt phenomenon that involves emotional, relational, and existential dimensions. Phenomenology allowed us to access the way in which these people attribute meaning to their experiences at a time of great vulnerability, and to show that end-of-life care, beyond being technical, is inevitably human, situated, and relational.

The first essential theme, reconstructing home as a place of care and meaning, reflects how returning home was experienced as a reunion with what is familiar and meaningful, restoring a sense of belonging and identity. This perception confirms the centrality of the home as a therapeutic space in palliative care, already highlighted by other authors (Pinto et al., 2024; Pollock et al., 2024), who identify the home as the preferred place for the end of life for many people. The home was described as a space where dignity is preserved, control is regained as far as possible, and affection is reinforced. It was experienced not only as the physical space where care takes place but as the place where the person feels recognized, integrated, and protected in their identity and history, which is in line with what is described in the literature (Osberg Ferm et al., 2025).

The comparison with the hospital environment, often perceived as impersonal and institutional, highlights the importance of environments that respect the subjectivity and daily life of people at the end of life. This experiential difference has already been noted in other studies (Miller et al., 2022), which emphasize the need to make clinical environments more humanized and responsive to the experience of people at the end of life. This perception of home as a space for reconnecting with oneself contrasts with the hospital experience, which is often associated with institutionalization and impersonality. At home, participants were able to resume simple decisions such as choosing where to be, maintaining daily rituals, and staying close to their belongings and loved ones, which gave them back a sense of control and dignity (Morey et al., 2021).

The second theme, transforming relationships through the transition to home care, highlights the importance of relational dynamics as central to the lived experience of this process. Family relationships and the presence of informal caregivers emerged as structuring dimensions of home care, described as essential for emotional balance, a sense of belonging, and a feeling of security. The bond with family members and informal caregivers constitutes a matrix of meaning in which the person feels welcomed, protected, and validated. The presence of the other is not only functional but constitutes the main pillar of staying at home, which aligns with the literature that recognizes the informal caregiver as a central element of the home support network (Fringer et al., 2017; Guo et al., 2022; Hirakawa et al., 2017; Salifu et al., 2021a).

At the same time, the presence and role of the community palliative care team were experienced in an ambivalent way, providing a source of security when effective and present, but also a cause of distress when absent. These findings reinforce the importance of skilled and integrated interdisciplinary teams, capable of ensuring continuity and personalization of care, which is supported by the literature (Feliciano and Reis-Pina, 2024; Hughes et al., 2023; Janke et al., 2024).

The third theme, navigating loss and adaptation, captures the emotional and existential work involved in living with progressive dependence. The loss of autonomy was experienced as an emotionally difficult reality, associated with frustration, moral pain, and a sense of loss of functional identity. This experience echoes the findings of several authors (Bovero et al., 2023; Fringer et al., 2017), who point to dependence as one of the main factors of suffering in palliative care. However, adaptation processes also emerged, in which acceptance of help was described as an expression of trust and bonding with those who replace them in carrying out the tasks on which they depend.

The openness to technology as a support for staying at home was experienced as a facilitator, especially when it ensured safety. In this sense, technology was integrated as an extension of human care, which is in line with recent studies (Cruz et al., 2023; May et al., 2023), which propose the incorporation of technological solutions into home palliative care models as a way to promote continuity of care. Technology, in turn, is described in the literature as functional and emotional support (Maguraushe and Ndlovu, 2024). Simple technological devices were perceived as facilitators of staying at home. This data is consistent with studies that show the growing role of support technologies in the context of palliative care (Oelschlägel et al., 2023). When humanized, technology is experienced as an extension of care and not as a threat to the relationship.

Finally, system fragilities affecting continuity of transitional palliative care were experienced by participants as lived interruptions in the continuum of support. The limitations of the healthcare system were identified as structural and organizational and were experienced as

failures in continuous care, mainly in situations of lack of response outside team hours and excessive bureaucracy, which coincide with findings in the literature (da Silva et al., 2024). These challenges generated feelings of insecurity, frustration, and helplessness, and were experienced as breaks in the support network. Some authors also highlight the importance of integrated transition models, with coordinated teams and accessible responses to needs in real time (Couchman et al., 2022). Phenomenological analysis revealed that these failures are not perceived merely as technical, but as ruptures that compromise the perception of continuity and the lived sense of safety.

Across the board, the results of this study reveal that the lived experience of people in palliative care during the transition from hospital to home is marked by a profound articulation between space, relationships, and identity. Home is experienced as a place of comfort, dignity, and reconnection with everyday life; family relationships and community team support emerge as pillars of lived care; the loss of autonomy, although painful, is gradually incorporated through acceptance and adaptation; and the limitations of the healthcare system are felt os breaks in the continuity of care, compromising safety and well-being. The phenomenological approach allowed access to how these elements are experienced and felt in the first person, revealing the complexity of the experience of being at home at the end of life. These findings reinforce the need to reorganize palliative care models, focusing on continuity, proximity, and listening to people's experiences as an essential condition for ensuring truly person-centered care.

4.1. Strengths and limitations

One of the main strengths of this study lies in its descriptive phenomenological approach, grounded in Giorgi's method, which enabled in-depth access to the meanings experienced by people in palliative care during the transition from hospital to home. This methodological framework supported a rigorous and systematic exploration of lived experience, remaining faithful to participants' narratives while allowing the articulation of essential meanings.

The study contributes to addressing an important gap in the literature by giving direct voice to people in palliative care, a group often underrepresented in qualitative research on care transitions. By focusing on lived experience rather than solely on the perspectives of professionals or caregivers, the findings offer a unique and patient-centered understanding of the challenges, meanings, and needs associated with this critical phase of illness.

The diversity of experiences reported, collected across different home contexts and involving participants with varied diagnoses and family arrangements, enabled a broad understanding of the phenomenon. This diversity highlighted not only the potential of home-based palliative care but also the structural fragilities of healthcare systems in ensuring continuity and support during transitions. The systematic application of Giorgi's method further reinforces the credibility and analytical rigor of the findings.

Despite these contributions, several limitations should be acknowledged. First, the phenomenological nature of the study, while appropriate for exploring subjective experience in depth, limits the transferability of the findings. The meanings identified are contextually grounded in the experiences of participants receiving palliative care within three community teams in northern Portugal and reflect a specific sociocultural and organizational context. Readers are therefore encouraged to consider contextual similarities when assessing applicability to other settings.

Second, data collection involved individuals in clinically fragile situations, which may have influenced the length and depth of some interviews. Ethical considerations required sensitivity to participants' physical and emotional condition, potentially constraining prolonged exploration of certain topics.

Third, although participant validation is often recommended in qualitative research, returning transcripts or full findings to participants was not considered ethically appropriate in this palliative context due to illness progression and potential burden. Credibility was instead supported through in-interview clarifications, reflexive practices, team-based analysis, and an internal audit process.

Finally, participants were initially identified by liaison nurses within community palliative care teams, which may raise concerns about potential influence. To mitigate this risk, liaison nurses had no role in consent procedures, data collection, or analysis, and participation was clearly presented as voluntary and independent of care provision.

5. Conclusion

These results highlight that the lived experience of the transition from hospital to home care is a complex process of reconfiguration of space, relationships, and identity. Recognizing this transition as a lived phenomenon rather than a logistical transfer emphasizes the urgent need to reorganize palliative care models, strengthening coordination between care contexts, ensuring continuity, and valuing the voice of patients as an essential dimension of quality. A deeper understanding of these experiences supports the development of more humanized, context-sensitive, and person-centered nursing practices that uphold dignity until the end of life.

For clinical practice, these findings reinforce the importance of early, coordinated discharge planning and sustained community follow-up. At the policy level, they highlight the need for integrated transition frameworks and accessible palliative home care pathways. Although this study focused on the experience of people in palliative care, complementary qualitative studies with professionals and family members within the same project contribute to a more comprehensive understanding of the transition process. Future research should explore longitudinal and interventional approaches to assess how organizational models and technological tools can strengthen continuity and safety of care at home.

CRediT authorship contribution statement

Sara Cruz: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Bruno Magalhães:** Writing – review & editing, Visualization, Validation, Supervision, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Carla Fernandes:** Writing – review & editing, Validation, Supervision, Project administration, Methodology, Investigation, Formal analysis, Data curation.

Declaration of competing interest

No conflict statement.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2026.103139.

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