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Experiences of family caregivers of patients with end-of-life cancer during the transition from hospital to home palliative care: a qualitative study

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Abstract

Background The transition of family caregivers of patients with end-of-Life cancer receiving palliative care from hospital to home is a complex and challenging process. This phase of care involves not only the physical and psychological health of the patient but also the role adaptation and emotional support of the family caregivers. To gain a deeper understanding of the various experiences and feelings during this process, we conducted a qualitative study.

Methods This study employed a descriptive phenomenological research method. The interviews focused on the specific experiences, challenges faced, support received, and coping strategies of family caregivers of patients with end-of-life cancer during the transition from hospital to home palliative care. All data were treated with strict confidentiality, and recordings and transcriptions were made with the participants' consent.

Results A total of 15 family caregivers participated. Four main themes and nine sub-themes were identified: complex transition process (anxiety about uncertainty, resistance to transition), discontinuity in care (insufficient discharge guidance, lack of continuous communication mechanisms), post-discharge continuous care needs (need for home care knowledge and skills, social and emotional support, grief counselling and death education), and personal growth and gains (enhanced coping ability, increased psychological resilience).

Conclusion Family caregivers face numerous emotional, cognitive, practical, and social support challenges during the transition from hospital to home care. To improve the caregiving experience and quality of life, appropriate training and support should be provided to better meet the caregivers' needs.

Keywords End-of-life cancer, Family caregivers, Transitional care, Palliative care, Experience, Qualitative study

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Background

In recent years, the global burden of cancer has continued to increase, with cancer-related mortality rising annually. According to data from the International Agency for Research on Cancer, there were 20 million new cancer cases and 9.7 million cancer deaths worldwide in 2022 [1]. This trend poses a significant threat to global health. With the evolution of medical paradigms and the increasing emphasis on dignity and end-of-life care, palliative care has garnered widespread attention and recognition as a novel medical service model globally [2]. Palliative care typically encompasses the entire course of an illness and is further enhanced during the end-of-life stage through hospice care. Hospice care is generally considered a specific form of palliative care that is applied at the final stages of life. Palliative care typically involves a patient-centred, multidisciplinary team providing comprehensive care in China. This team is composed of doctors, nurses, volunteers, social workers, physiotherapists, and psychologists, focusing on the patient's comfort and dignity. Rather than aiming to treat the disease, the care acknowledges the inevitability of death, neither hastening nor delaying it. The goal is to offer holistic support, addressing the physical, psychological, and spiritual needs of patients and their families, while also providing humanistic care [3, 4].

In China, approximately 7.5 million people require palliative care annually, with patients with end-of-life cancer accounting for about one-third of this population [5, 6]. Influenced by the deep-rooted Chinese tradition of "falling leaves returning to their roots" patients with end-oflife cancer often prefer to spend their final days at home. Approximately 53.64% of cancer patients reportedly prefer home care services during the end-of-life stage, making home-based palliative care an essential component of end-of-life care for cancer patients [7]. In China, hospice and palliative care services are provided in various forms, including inpatient care, community-based care, homebased care, outpatient care, and the "Internet +" model. Home-based palliative care systems are primarily delivered through two models: one is hospital-led home palliative care, and the other is community health centre-based palliative care [8]. The hospital-led model is supported by internet service platforms, allowing patients and caregivers to make appointments through online hospital platforms, with the palliative care team providing home care services offline. The community health centre-based model, on the other hand, requires close coordination with local healthcare institutions.After the family or patient registers and fills out an appointment application form at a relevant palliative care facility (such as a hospital, hospice, or community health service center), the palliative care team will conduct a home visit. During this visit, they will inquire about the patient's medical history, perform a physical examination, conduct various assessments, manage the patient's symptoms, and provide psychological and social support to the family. However, the transition between care environments can be a significant burden for family caregivers, especially for those managing complex illnesses at the end of life. These caregivers face a series of new challenges and adaptation processes [9, 10]. Meleis and colleagues in the United States have developed transition theory [11], which is widely applied to continuity of care, transitional care, and discharge planning services [12, 13]. Transitional palliative care refers to the support provided to patients as they move from hospitals or other healthcare institutions to home or long-term care facilities, ensuring a smooth transition between different environments [14]. Patients receiving palliative care frequently experience multiple transitions between hospital and home [15, 16]. Wang et al. reported that, on average, patients transition between care environments 2.9 times in the last six months of life [17]. During the shift from a hospital's intensive medical environment to home palliative care, family caregivers become the primary force in the patient's daily and medical care. Research by Morey et al. [18] indicates that family caregivers experience significant psychological stress during this period, including anxiety, depression, helplessness, and grief. Recent studies have shown that support for family caregivers during the transition period is relatively scarce [19]. Family caregivers need support and assistance from professional institutions, healthcare providers, and other social resources during home palliative care.

In 2023, the Chinese National Health Commission responded to public demands for improved healthcare services by introducing a series of policies aimed at continuously enhancing the patient care experience. These policies ensure that patients receive coordinated and continuous medical services across different healthcare settings [20]. In this context, ensuring smooth transitions between care environments is crucial to reducing the physiological and psychological stress caused by environmental changes, and providing continuous, consistent, and high-quality palliative care [21]. Despite the increasing research on cancer patient care, there remains a lack of studies focusing on the challenges, confusions, and coping strategies of family caregivers during the transition from hospital to home care. This gap not only affects the quality and efficiency of family caregiving but may also indirectly impact the quality of life and psychological state of patients. Research indicates that effective transitional care can alleviate caregivers' anxiety and stress during care environment changes and lay a solid foundation for successful home palliative care [22]. By studying the transitional care experiences of family caregivers of patients with end-of-life cancer from hospital to home palliative care, we can identify existing issues and gaps in the current healthcare system. Additionally, this study provides empirical evidence for the development of relevant policies and the improvement of palliative care services, better meeting the needs of late-stage cancer patients and their families, reducing their fear and anxiety about death, and ensuring a dignified end of life. Therefore, this study aims to: (1) Explore the psychological changes and emotional experiences of family caregivers during transitional care, (2) Identify the challenges and difficulties faced by family caregivers during transitional care and how they cope with these challenges, (3) Understand the interaction and cooperation between family caregivers, healthcare professionals, and community resources.

Methods

Ethical considerations

This study was approved by the Ethics Committee of Nanjing Drum Tower Hospital, affiliated with Nanjing University Medical School (Ethics Approval No.: 2024-048-03). The research was conducted in accordance with the principles of the Declaration of Helsinki, adhering to relevant guidelines and regulations. Informed consent was obtained from all participants prior to their involvement in the study.

Study design

Formation of the research team

The research team comprised eight members: one chief nurse, one chief physician, one head nurse, two senior nurses, and three nursing postgraduates. All members underwent systematic training in qualitative research methods and were familiar with the needs of oncology patients and their family caregivers. This study utilised a descriptive phenomenological approach, conducting indepth, semi-structured, face-to-face interviews between December 2023 and March 2024. The study followed the standards for reporting qualitative research (SRQR) [23].

Table 1 Semi-structured interview questions

No	Interview questions
1	What were your biggest challenges and concerns dur- ing the transition from hospital to home care?
2	What do you think are the main reasons for the difficul- ties you experience in transitional care after discharge?
3	What preparations did you undertake after the patient was discharged, and how did you address the ensuing difficulties and challenges?
4	What kind of support and help would you like from the health system, community, or otherwise?
5	What supports do you think can help you navigate the transition care difficulties? What other needs and suggestions do you have?

Development of semi-structured interview outline

The interview script was developed based on relevant literature [24] and discussions with an expert team in the fields of oncology nursing and palliative care. A pilot version was created and pre-tested by two participants to evaluate the appropriateness and comprehension of the questions. The interview outline was then discussed and revised under the guidance of an expert in oncology nursing. Table 1 presents the final scripted questions.

Participant recruitment

The first author conducted purposive sampling of family caregivers of end-of-life cancer patients at a tertiary cancer hospital in China, facilitated through gatekeepers (the head of the oncology department and the head nurse). The inclusion criteria for participants were: (1) providing care to the patient for an average of more than 4 h per day, (2) being aware that the patient has end-oflife cancer, (3) the patient is receiving inpatient palliative care, (4) experiencing or having experienced the transition from hospital to home care, (5) willingness to sign an informed consent form. Family members with significant organic diseases or language and cognitive impairments were excluded from the study.

Data collection

Semi-structured face-to-face interviews were conducted in the patient-doctor communication room at the hospital, at times chosen by the participants. Each interview lasted between 20 and 35 min and was recorded with the participant's consent. Before the formal interview began, the researcher provided a brief self-introduction to establish rapport with the participants and explained the study's purpose, significance, and methodology. During the interview, it was ensured that the interviewees felt comfortable and free to express their views and experiences. In-depth questions were asked based on the participants' responses to encourage them to share their true feelings. The researchers carefully observed and promptly recorded the participants' body language, facial expressions, and emotional reactions to ensure useful information was collected. The order of questions was adjusted as necessary based on the actual situation. Participants were informed that they had the right to withdraw from the study at any stage. Data collection continued until information saturation was achieved, with no new themes or information emerging during the interviews.

Data analysis

Data collection and analysis were conducted simultaneously. The researchers, along with a second research member, listened to the recordings and transcribed the interviews within 24 h after they ended. The transcripts were anonymised and archived as N1–N15, and analysed

Variables	Categories	N (%)
Gender	Male	5
	Female	10
Age	18~39	4
	40~60	8
	>60	3
Relationship with patient	Spouse	6
	Son or daughter	8
	Brother or sister	1
Work status	Full-time	8
	Freelancer	4
	Retired	1
	Unemployed	2
Educational background	Primary school or below	4
	Junior high school	3
	Senior high school	2
	College or above	6
Length of caring (month)	2–8	3
	9–20	6
	22–38	6
Number of transitions(n)	2–5	10
	6–9	5

Table 2 Characteristics of participants

using Colaizzi's method [25]. Utilising open coding methods, the interview data were systematically coded and categorised. First, the transcribed texts were imported into NVivo11.0 software. By repeatedly reading the interview records, statements related to the research questions were extracted and coded. Important statements were then given specific meanings and categorised into themes. The results were integrated into a comprehensive description of the caregiving experiences and validated through participant feedback. To ensure the credibility of the research, the team held regular meetings to discuss and refine the data analysis. Throughout this process, the researchers regularly documented self-reflections, identifying and addressing potential biases. For instance, when dealing with sensitive topics, the researchers took special care to avoid imposing personal views on the participants' narratives. By meticulously recording the analysis steps and decision-making processes, we ensured the transparency and traceability of the research.

Quality control

The study employed the "triangulation" method [26], considering the general information of the interviewees during sampling and selecting participants with diverse characteristics to ensure sample diversity. Interviews were conducted by a primary interviewer who asked questions and made observations, while a second researcher monitored the interviewer for neutrality. After each interview, the researchers identified any observed issues, for example, the interviewer was

Table 3	Summary of all primary and sub-themes extracted from
the inter	views

Theme	Sub-theme	
complex transition process	anxiety about uncertainty	
	resistance to transition	
discontinuity in care	insufficient discharge guidance	
	lack of continuous communication mechanisms	
post-discharge continuous	need for home care knowledge and skills	
care needs	social and emotional support	
	grief counselling and death education	
personal growth and gains	enhanced coping ability	
	increased psychological resilience	

advised to remain proactive and adhere to the interview guide. When participants deviated from the topic, the researcher guided them back to the interview scope, then integrated data recorded by both researchers.

When compiling the interview records, the interviewer and all researchers confirmed that the text data included diary reflections and analyses, which mainly addressed issues and unclear data points from the interviews as reference points. Data analysis was independently performed by the primary interviewer and another researcher, who, after verifying the accuracy of the transcriptions, repeated the analysis process to refine the research themes and independently coded the themes. Finally, an interdisciplinary expert team was invited to discuss the research findings to establish the final themes.

Results

A total of 15 family caregivers participated in the study, achieving a 100% interview completion rate. Table 2 presents the characteristics of the participants. Thematic analysis identified four main themes and nine sub-themes: (1) complex transition process, (2) discontinuity in care, (3) post-discharge continuous care needs, (4) personal growth and gains. (Table 3)

Theme 1: Complex transition process Sub-theme 1: Anxiety about uncertainty

Family caregivers experienced emotional fluctuations during the transition of patients from the stable environment of the hospital to the uncertainties of the home setting.

"I don't feel comfortable letting her go home. Since she fell ill, we've been in the hospital where the doctors and nurses are familiar with her condition. It would be too troublesome if something happens at home" (Participant 5).

"I am very scared that her condition might change once she's discharged. Everything we need is at the hospital, and we're not prepared at home. I wouldn't know how to handle an emergency situation..." (Participant 6).

Sub-theme 2: Resistance to transition

Family caregivers may resist the transition due to their fear of facing the patient's impending death. They may prefer the patient to receive extended hospital care to delay the inevitable outcome.

"The whole family doesn't want her to come home! We are not ready for her to die. I don't even know if she can survive this time at home" (Participant 6).

"His body is very weak, and there are many stairs at home. I'm already scared now, not knowing what will happen. What if I can't handle it alone?" (Participant 2).

Theme 2: Discontinuity in care

Sub-theme 3:Insufficient discharge guidance

Hospitals may fail to provide comprehensive home palliative care instructions upon patient discharge, including specific recommendations on symptom management, medication use, and nutritional support. This inadequacy leaves family caregivers feeling confused and unprepared for home care.

Lack of discharge plans

The absence of a detailed discharge plan is one of the primary challenges during the transition period. Participants expressed a desire for healthcare professionals to develop personalised discharge plans to guide home care.

"The doctor didn't give me a detailed discharge plan. I wasn't prepared to take care of my spouse alone at home. They only gave me a pamphlet, but I couldn't understand its content" (Participant 9).

"I understand that he doesn't have much time left, but I still want him to be pain-free at home. If the doctors and nurses could provide us with a detailed post-discharge plan, I would feel much more reassured." (Participant 4).

Caregivers' inadequate preparation for discharge care

Family caregivers transitioning from hospital to home palliative care often face challenges due to the lack of effective care guidance and access to professional information and knowledge about home care. Participants indicated they were not fully prepared to care for the patient independently.

"After coming home, I realised I hadn"t prepared many things. Firstly, I wasn"t mentally prepared to face the difficulties of caring for her alone" (Participant 13).

"I understand the potential issues you mentioned, but I am the only one at home. I can't handle all these tasks by myself" (Participant 10).

Sub-theme 4: Lack of continuous communication mechanisms

Family caregivers may struggle to maintain effective and ongoing communication with the hospital or professional

healthcare providers, hindering their ability to seek timely professional help when problems arise.

"I was really happy when the doctor said he could go home, but I also realised I had to care for him alone. If there's an issue, how can I seek your help?" (Participant 4).

"I am a farmer with limited education. I haven't mastered many of the techniques. After going home, are we just supposed to stay in that one room? How can I keep in touch with you?" (Participant 1).

Theme 3: Post-discharge continuous care needs Sub-theme 5: Need for home care knowledge and skills

Family caregivers need to possess not only professional medical knowledge but also a range of home care skills to meet the diverse needs of patients.

"Can you continue to help us after we go home? There are many things I don't understand, like changing his stoma bag and cleaning his catheter... I need your assistance with all these tasks" (Participant 7).

Wound care

Participants expressed a lack of information regarding wound care for the patient and sought guidance on how to dress wounds and change dressings.

"Taking care of her daily needs isn't difficult, but I don't know how to do some of the professional tasks, like dressing her wounds. I constantly need to ask the nurse when to change the dressing and how to handle any complications" (Participant 13).

Symptom management

Two participants mentioned their need for techniques to manage the patient's symptoms, such as dealing with vomiting and constipation.

"He has diabetes, hypertension, and many other conditions, with lots of tubes in his body. I need some home care skills, like how to clean him and how to alleviate his vomiting" (Participant 12).

"Her constipation is severe, sometimes she doesn't have a bowel movement for several days. At the hospital, the nurse can give an enema, but I don't know how to handle it at home" (Participant 14).

Sub-theme 6: Social and emotional support

Family caregivers generally expressed a desire for increased social support, such as volunteer services and neighbourhood assistance, to alleviate their burden and enhance their coping abilities.

Desire for volunteer and social worker support.

The demanding caregiving responsibilities place significant psychological stress on family caregivers, who seek social support to provide them with opportunities for respite. "They mentioned that we could go to the palliative care ward, where we could receive excellent care and have volunteers and social workers to help us. I really need such support" (Participant 15).

Emotional support

In order to care for the patient, family caregivers may need to reduce their social activities and spend extended periods in a confined environment. This reduction in social interaction can lead to feelings of loneliness and helplessness, creating emotional needs.

"I feel very lonely. Over these years of taking care of him, I have lost almost all my friends. My focus is entirely on him, and it's overwhelming. Sometimes, I even think about going with him (crying)" (Participant 4).

Economic support

Participants indicated that economic considerations were a factor in choosing palliative care, and they hoped for government and societal support to alleviate financial burdens.

"Treating her illness has cost a lot of money. When we heard from the hospital nurse that we could receive care at home and save a lot of money, we decided to go home. I hope you can help us more (sigh)" (Participant 3).

Sub-theme 7: Grief counseling and death education

Grief counseling and death education is a critical service for family caregivers of patients with end-of-life cancer, some caregivers said:

"I am really afraid of facing his death. I can hardly imagine that scenario, and the pressure of dealing with it alone is immense... Your comfort means a lot to me, and I hope you can support me until the very end" (Participant 2).

"I would like to receive education about death. It's fine, I can handle it. It's better than suffering alone after his death" (Participant 7).

Theme 4: Personal growth and gains *Sub-theme 8: Enhanced coping ability*

Participants reported experiencing a deep sense of satisfaction and accomplishment when their caregiving efforts were recognised as important by others. This recognition enhanced their ability to cope with various caregiving challenges.

"I've had a few such experiences. Initially, I felt like a novice, completely lost, but now I can handle these situations. I even know how to manage some simple emergencies" (Participant 8).

"These experiences have helped me grow. I have to admit the changes brought by these experiences. After coming home, I actively face these difficulties. Even though I am *in great pain, I must be strong to accompany him through the last stage of his life" (Participant 9).*

"He believes that my care is of significant value and importance. He trusts and depends on me a lot. My children also look up to me, and my family sees me as a good wife and mother. Now I am capable of doing even more" (Participant 12).

Sub-theme 9: Increased psychological resilience

The prolonged caregiving experience not only changed family caregivers' perspectives on life and death, enhancing their respect and appreciation for life, but also made them more resilient and confident through enduring hardships and challenges.

"When I realised my situation, I cried many times, but now I have a new perspective. I should live in the moment and cherish the present" (Participant 11).

"Although it pains me to see him go through this, I know that life and death are natural laws. I must learn to grow and accept reality" (Participant 14).

"I can now accept death; suddenly, it doesn't seem so frightening. It's a normal part of life, and I should also teach my children about death and dying" (Participant 7).

Discussion

This study utilised qualitative methods to gain an indepth understanding of the real experiences and feelings of family caregivers of end-of-life cancer patients during the transition from hospital to home palliative care. End-of-life patients and their family caregivers face multifaceted challenges during this transition period [15]. Research indicates that approximately 46% of family caregivers report a decline in their own physical health, often neglecting their own well-being [27]. The findings of this study reveal that during the transition period, family caregivers often experience emotional fluctuations and psychological stress, feeling anxious, uneasy, and sorrowful, and thus require emotional support and psychological comfort [28]. Research indicates that providing psychological counselling services, support groups, and community resources is crucial [29]. The transition from hospital to home means that family caregivers must take on more caregiving responsibilities. Studies have found that caregivers in home palliative care often desire more training and guidance on home care [30], which aligns with the results of this study. To help family caregivers better adapt to the tasks and demands of home palliative care, relevant training and support can be enhanced. For instance, training courses or online learning resources could be offered to help family caregivers acquire necessary caregiving knowledge and skills. Tailored to the caregivers' needs, training in areas such as wound care, pain management, and nutritional support can be provided. Employing nurse-led ENABLE model to

gudie patients and caregivers problem-solving, coping, decision-making, advance care planning, symptom management, self-care, and communication, in turn reduce the burden on family caregivers [31, 32].

Continuity of care is crucial in transitional palliative care, as it not only enhances patient satisfaction and reduces hospitalisation rates [33] but also helps caregivers better understand the pace and focus of care, minimising unnecessary interventions and conflicts, improving care efficiency, and enhancing caregiver capabilities [18]. Research shows that caregivers bear significant caregiving burdens and psychological stress during transitions, and these burdens can be exacerbated by a lack of continuity in care. Patients with end-of-life cancer, their family caregivers, and healthcare professionals often perceive a lack of coordination and continuity in care during discharge or transition periods [34]. This finding aligns with our study results, where participants frequently faced substantial psychological burdens during the transition to a new care environment, primarily due to the lack of continuity in care. McCoy et al. demonstrated that collaboratively designing and implementing interventions for palliative care patients during the transition period can effectively improve the experiences of patients and family caregivers [35]. The study found that interdisciplinary collaboration is essential to ensure continuous and consistent care, necessitating close cooperation among medical teams, family caregivers, and community resources to develop personalised care plans [36]. However, our study identified several challenges in interdisciplinary collaboration, such as poor information communication and insufficient discharge guidance. Research highlights that communication and information transfer across care settings are critical for promoting continuity of care [37]. Family caregivers need to maintain close communication with the medical team to ensure continuous support for the patient. Enhancing communication and collaboration between different healthcare institutions and family caregivers can optimise information transfer and team cooperation, thereby improving the continuity and quality of care [38]. Dillen et al. [39] emphasise the importance of establishing effective communication mechanisms and collaborative relationships. To assist family caregivers in better accessing medical information and addressing changes in the patient's condition, a support system for obtaining and managing medical information can be established. During the patient's discharge or transfer process, healthcare professionals should promptly provide detailed information to both the patient and the caregiver, including treatment plans, care plans, and potential risks. Furthermore, it is crucial to ensure accurate information transfer across different care settings. For example, providing patient handbooks, online medical consultation platforms, and other resources can help caregivers better understand the patient's condition and treatment plans, enabling them to make informed care decisions. The medical team should offer clear guidance and advice, promptly responding to the caregivers' questions and needs.

Family caregivers generally believe that through the process of caring for their loved ones, they not only achieve personal growth but also become more optimistic and confident, thereby deepening their understanding of self-worth [40]. This study corroborates these observations, clearly demonstrating the positive impact of caregiving on caregivers' personalities. Additionally, the mutual support and encouragement between caregivers and patients can help caregivers better adapt to their caregiving roles [41]. The study reveals that family caregivers of end-of-life cancer patients employ various coping strategies during the caregiving process, such as active coping and seeking support. These strategies help family caregivers better manage the challenges of caregiving and improve their quality of life. Through interaction and caregiving, family caregivers may discover their potential and capabilities, leading to greater appreciation and recognition of themselves.

This study has several limitations. Firstly, it was conducted in a single healthcare institution, which limits the ability to provide information on coordination and cooperation between different institutions. This is a significant gap in understanding the comprehensive process of care transitions. Secondly, although 15 family caregivers were interviewed, this sample size is not sufficient to fully capture the experiences and feelings of all family caregivers of end-of-life cancer patients. Thirdly, the varied definitions and understandings of the concept of "transition" may have led to interpretive biases in participants' descriptions and explanations.Future research should involve multicentre studies and utilise various research methods to gain a more comprehensive understanding of the experiences and challenges faced by family caregivers in different care settings. Additionally, it is important to explore the experiences and coping strategies of family caregivers from diverse cultural and social backgrounds to provide targeted support and interventions.

Conclusion

This study utilised a descriptive phenomenological research method to explore the experiences of family caregivers of end-of-life cancer patients during the transition from hospital to home palliative care. The findings reveal that this particular phase is filled with challenges and stress for family caregivers. To better support family caregivers, we propose the following recommendations: Firstly, provide comprehensive psychological support to family caregivers, including counselling and emotional support services, to help them develop a positive mindset and coping strategies. Secondly, enhance the skills training for family caregivers. As patients transition from hospital to home, caregiving tasks and responsibilities increasingly fall on family caregivers, who need to acquire a range of skills, such as pain management, medication administration, and daily care.Future research should further explore how to optimise the processes and service models for home transition care. For example, improving the connection between hospitals and communities, establishing support networks for family caregivers, and promoting telemedicine services can enhance the continuity and coordination of home transition care, thereby reducing the burden on family caregivers.

Supplementary Information

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Supplementary Material 1

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Author contributions

YX, YL: Writing – original draft, Writing – review & editing, Formal analysis, Data curation. YK, DW: Conceptualization, Supervision, Formal analysis, Data curation, Validation. YZ, LW: Formal analysis, Project administration. LY: Methodology, Conceptualization, Supervision. All authors read and approved the final manuscript.

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Data availability

The data used during this study are available from the corresponding authors on reasonable request.

Declarations

Ethics approval and consent to participate

This study was approved by the Ethics Committee of Gulou Hospital, Nanjing University School of Medicine (Ethics Approval No. 2024-048-03). Our research adhered strictly to the ethical principles outlined in the Declaration of Helsinki, ensuring compliance with all pertinent guidelines and regulations. Prior to their participation, all individuals involved in the study provided their informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

 Bray F, Laversanne M, Sung H, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin. 2024;74(3):229–63.

- Alnajar M, Darawad M, Khater W, et al. Exploring Palliative Care Needs Among Patients With Cancer and Non-Cancer Serious Chronic Diseases: A Comparison Study. Am J Hosp Palliat Care. 2024; Vol. 0(0) 1–12.
- Ning XH. Hospice and Palliative Care in Mainland China: history, current Status and challenges. Chin Med Sci J. 2018;33(4):199–203.
- 4. Wu Y, Li L, Su H, Yao X, Wen M. Hospice and Palliative Care: Development and challenges in China. Clin J Oncol Nurs. 2016;20(1):E16–9.
- Lu Y, Yu W, Zhang J, Li R. Advancements in hospice and palliative care in China: a five-year review. Asia Pac J Oncol Nurs. 2024;11(3):100385.
- Li X, Wang XS, Huang H, et al. National survey on the availability of oncology palliative care services at tertiary general and cancer hospitals in China. BMC Palliat Care. 2023;22(1):144.
- Guo J, Dai Y, Gong Y, Xu X, Chen Y. Exploring the telehealth readiness and its related factors among palliative care specialist nurses: a cross-sectional study in China. BMC Palliat Care. 2023;22(1):82.
- Zhou Y, Wang S, Zhi X. Status quo of home palliative care of patients with cancer pain. Chin Nurs Rev. 2017;31(06):641–3.
- Rocío L, Rojas EA, González MC, Carreño S, Diana C, Gómez O. Experiences of patient-family caregiver dyads in palliative care during hospital-to-home transition process. Int J Palliat Nurs. 2017;23(7):332–9.
- Dionne-Odom JN, Lyons KD, Akyar I, Bakitas MA. Coaching Family caregivers to become Better Problem solvers when caring for persons with Advanced Cancer. J Soc Work End Life Palliat Care. 2016;12(1–2):63–81.
- 11. Meleis Al. Role insufficiency and role supplementation: a conceptual framework. Nurs Res. 1975;24(4):264–71.
- Orr E, Ballantyne M, Gonzalez A, Jack SM. The complexity of the NICU-tohome experience for adolescent mothers: Meleis' transitions Theory Applied. ANS Adv Nurs Sci. 2020;43(4):349–59.
- Chen J, Chen J, Wang Y, et al. Transition experiences of patients with post stroke dysphagia and family caregivers: a longitudinal, qualitative study. PLoS ONE. 2024;19(6):e0304325.
- 14. Salifu Y, Bayuo J. Transfer and transitioning between palliative care settings. Ann Palliat Med. 2022;11(10):3035–9.
- Guo P, Pinto C, Edwards B, et al. Experiences of transitioning between settings of care from the perspectives of patients with advanced illness receiving specialist palliative care and their family caregivers: a qualitative interview study. Palliat Med. 2022;36(1):124–34.
- Van den Block L, Pivodic L, Pardon K, et al. Transitions between health care settings in the final three months of life in four EU countries. Eur J Public Health. 2015;25:569–75.
- Wang SY, Aldridge MD, Gross CP, et al. Transitions between Healthcare Settings of Hospice Enrollees at the end of life. J Am Geriatr Soc. 2016;64(2):314–22.
- Morey T, Scott M, Saunders S, et al. Transitioning from hospital to Palliative Care at Home: patient and caregiver perceptions of continuity of Care. J Pain Symptom Manage. 2021;62(2):233–41.
- Tietbohl CK, Dafoe A, Jordan SR, et al. Palliative Care across settings: perspectives from Inpatient, Primary Care, and Home Health Care providers and Staff. Am J Hosp Palliat Care. 2023;40(12):1371–8.
- National Health Commission.State Administration of Traditional Chinese Medicine. Further improvement of nursing care services dynamic plan (2023–2025). 2023. Retrieved from https://www.gov.cn/zhengce/ zhengceku/202306/content_6887303.htm
- Mertens F, Sercu M, Derycke A, et al. Patients' experiences of transfers between care settings in palliative care: an interview study. Ann Palliat Med. 2022;11(9):2830–43.
- 22. Marston C, Morgan DD, Philip J, Agar M. Supporting carers as patients move between Hospital and Home: a systematic review of interventions to support these transitions in Care. J Palliat Med. 2023;26(2):270–98.
- O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245–51.
- Mertens F, Vanderstichelen S, Deveugele M, Deliens L, Pype P. Family carers' experiences regarding patient transfers between care settings in palliative care: an interview study. Ann Palliat Med. 2023;12(4):767–82.
- Wirihana L, Welch A, Williamson M, Christensen M, Bakon S, Craft J. Using Colaizzi's method of data analysis to explore the experiences of nurse academics teaching on satellite campuses. Nurse Res. 2018;25(4):30–4.
- Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. Oncol Nurs Forum. 2014;41(5):545–7.

- Koçak N, Şenel G, Oğuz G, Karaca Ş, Gökse F. Quality of life and burden in family caregivers of patients with advanced cancer receiving specialized palliative care. Indian J Cancer. 2022;59(2):187–93.
- Özdemir F, Doğan S, Timuçin Atayoğlu A. Psychosocial problems of family caregivers of palliative care patients and their spiritual coping styles. Perspect Psychiatr Care. 2020;56(3):636–41.
- 29. Fernandes JB, Domingos J, Castro C, et al. Needs and expectations of family caregivers of cancer patients in palliative care: a study protocol. Front Psychol. 2023;13:1071711.
- Nysaeter TM, Olsson C, Sandsdalen T, Hov R, Larsson M. Family caregivers' preferences for support when caring for a family member with cancer in late palliative phase who wish to die at home - a grounded theory study. BMC Palliat Care. 2024;23(1):15.
- Yang GM, Dionne-Odom JN, Foo YH, et al. Adapting ENABLE for patients with advanced cancer and their family caregivers in Singapore: a qualitative formative evaluation. BMC Palliat Care. 2021;20(1):86.
- Bakitas MA, Dionne-Odom JN, Ejem DB, et al. Effect of an early Palliative Care Telehealth intervention vs Usual Care on patients with Heart failure: the ENABLE CHF-PC Randomized Clinical Trial. JAMA Intern Med. 2020;180(9):1203–13.
- Hamar B, Rula EY, Wells AR, Coberley C, Pope JE, Varga D. Impact of a scalable care transitions program for readmission avoidance. Am J Manag Care. 2016;22(1):28–34.
- den Herder M, Hasselaar J, Payne S, Varey S, Schwabe S, Radbruch L, Van Beek K, Menten J, Busa C, Csikos A, et al. How continuity of care is experienced within the context of integrated palliative care: a qualitative study with patients and family caregivers in five European countries. Palliat Med. 2017;31:946–55.

- 35. McCoy M, Shorting T, Mysore VK, et al. Advancing the Care experience for patients receiving palliative care as they transition from hospital to Home (ACEPATH): codesigning an intervention to improve patient and family caregiver experiences. Health Expect. 2024;27(2):e14002.
- Lundereng ED, Dihle A, Steindal SA. Nurses' experiences and perspectives on collaborative discharge planning when patients receiving palliative care for cancer are discharged home from hospitals. J Clin Nurs. 2020;29:3382–91.
- Bucknall TK, Hutchinson AM, Botti M, et al. Engaging patients and families in communication across transitions of care: an integrative review. Patient Educ Couns. 2020;103(6):1104–17.
- Ullrich A, Goldbach S, Hollburg W, et al. Specialist palliative care until the very end of life - reports of family caregivers and the multiprofessional team. BMC Palliat Care. 2023;22(1):153.
- Dillen K, Joshi M, Krumm N, et al. Availability as key determinant in the palliative home care setting from the patients' and family caregivers' perspectives: a quantitative-qualitative-content analysis approach. Palliat Support Care. 2021;19(5):570–9.
- Teo I, Paramasivam K, Chee WY, Ng C, Neo PSH, Lee GL. Deathbed experiences and meaning-making: perspectives of family caregivers of patients who received cancer palliative care. Palliat Support Care. 2024;22(3):444–50.
- McCauley R, Ryan K, McQuillan R, Foley G. Mutual support between patients and family caregivers in palliative care: a qualitative study. Palliat Med. 2023;37(10):1520–8.

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