

Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

# Asia-Pacific Journal of Oncology Nursing

journal homepage: [www.apjon.org](http://www.apjon.org)

## Original Article

# Experiences and barriers in downward referral decision-making for palliative care patient caregivers under China's three-tiered linkage model: A qualitative study



Yahui Liu<sup>a</sup>, Yanan Xu<sup>a</sup>, Yubiao Kang<sup>b</sup>, Ligui Wu<sup>a</sup>, Yujie Zhou<sup>b,\*</sup>, Ling Yuan<sup>a,\*</sup>

<sup>a</sup> Department of Oncology, Nanjing Drum Tower Hospital, Affiliated Hospital of Medical School, Nanjing University, Nanjing, China

<sup>b</sup> School of Nursing, Nanjing University of Chinese Medicine, Nanjing, China

## ARTICLE INFO

### Keywords:

Hospice  
Referral  
Decision aid  
Qualitative study

## ABSTRACT

**Objective:** This study aimed to explore hospice caregivers' downward referral decision-making experiences and barriers under the triadic linkage model in China and to analyze the deeper social dynamics of hospice referral choices.

**Methods:** Semi-structured interviews were conducted with caregivers handling hospice referrals from two primary hospice agencies in Nanjing, China. The themes were analyzed and summarized using the Colaizzi 7-step analysis.

**Results:** Four themes and nine subthemes were extracted: multidimensional caregiver psychological experience (Dilemma and Guilt, Emotional Support and Psychological Adaptation), perceived disparities between referral organizations (convenience and affordability in the home community, perceived lack of primary health care resources), limitations of caregiver decision-making (cognitive comprehension bias, difficulty in information seeking, and passive acceptance of decision making), and limitations of health care referral support (lack of health care referral guidance, inadequate referral handoffs).

**Conclusions:** Feedback from caregivers of hospice-referred patients reveals many barriers to hospice referral decision making and referral implementation. Overcoming these barriers entails efforts to change the cognitive misunderstandings regarding hospice referrals from patients' perspective, clarify the distribution of responsibilities among hospice agencies, and provide information support and decision-making assistance. These measures must be employed to improve the implementation of hospice referral, realize the multiple benefits of hierarchical diagnosis and treatment, boost patients' satisfaction with the referrals, and ensure the rational and efficient distribution of hospice resources.

## Introduction

According to the World Health Organization, 40 million people worldwide require hospice care each year, but only 14% of them receive it.<sup>1</sup> The global demand for hospice care will continue to grow as the population ages, and society will place a premium on quality end-of-life care.<sup>2</sup> To address this growing demand and balance it with the scarcity of hospice resources, many countries have adopted a tiered care system to match hospice services to the need. For example, the hospice system in the United States is divided into primary, secondary, and tertiary services. The primary hospice model is based on home care, secondary hospice provides general inpatient care and multidisciplinary team support, and tertiary hospice's professional care model is mainly for difficult

case consultations.<sup>3</sup> Similarly, the health care delivery system in the United Kingdom is organized into primary, local, and central health care providers to ensure that hospice services are delivered effectively from primary to critical care.<sup>4</sup>

Meanwhile, China's hierarchical diagnosis and treatment system divides hospice services into three categories: hospitals, communities, and homes. Tertiary hospitals provide hospice services to seriously ill patients requiring hospitalization and are responsible for hospice technical support, professional training, and other tasks. Lower-tier hospitals and communities provide institutional hospice services to hospice patients with less severe symptoms who require hospitalization. For hospice patients with stable symptoms who do not require hospitalization, the community provides home hospice services. The national document

\* Corresponding authors.

E-mail addresses: [2310054542@qq.com](mailto:2310054542@qq.com) (Y. Zhou), [yuanling@njgly.com](mailto:yuanling@njgly.com) (L. Yuan).

<https://doi.org/10.1016/j.apjon.2024.100578>

Received 24 June 2024; Accepted 16 August 2024

2347-5625/© 2024 The Authors. Published by Elsevier Inc. on behalf of Asian Oncology Nursing Society. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

emphasizes the need to explore the establishment of a working mechanism that combines institutional, community, and home hospice care and to form a seamless and reasonable referral system.<sup>5</sup> In recent years, many places in China have implemented the hospital–community–home hospice model, which is an effective linkage of hospitals, communities, and homes through health care consortiums and Internet-based service platforms. Regional health care alliances have also been formed among different levels of institutions for resource sharing and division of labor to realize the rational allocation of health care resources and personalized care for patients.

Some studies have confirmed that transitions of patients with terminal illnesses between different institutions are common; however, the lack of coordination between different institutions leads to the fragmentation of care, which prevents patients from receiving consistent, high-quality care.<sup>6</sup> The two-way referral system under the triadic model facilitates patients' coordinated, flexible, and efficient transfer between different levels of care and their families according to their objective physical condition, disease progression, and subjective personal wishes. Patient preference and prognosis and the resources required for care influence patient choice.<sup>7</sup> However, caregivers are often the primary decision makers in hospice care because of the severity of their patients' conditions and diminished decision-making ability.<sup>8</sup> In this process, patients and caregivers often do not receive adequate decision-making support, such as communication and information exchange, emotional support, and social support from professionals.<sup>9</sup> At the same time, owing to a lack of public trust in the ability of primary care organizations to provide hospice services in the community and other primary care settings, transferring patients from specialized hospices to primary care settings, such as community and nursing homes, is particularly difficult while primary care resources are not adequately utilized.<sup>10</sup> Stiel et al.<sup>11</sup> demonstrated that the tensions and decision-making complexities involved in the transfer of patients with hospice needs to nursing homes are associated with feelings of abandonment and guilt for both patients and caregivers. Decision-making experiences and barriers for patients and their caregivers have emerged as important variables influencing the effectiveness of referrals. The purpose of this study is to explore and describe the decision-making process and rationale for hospice referrals in patients' homes from the perspective of patients who have experienced referrals to different levels of hospice care. In addition, this study aims to analyze the underlying social dynamics of hospice referral choices to further optimize the referral mechanism and maximize the service capacity of health care organizations at all levels.

## Methods

### Design

A descriptive phenomenological approach was used to examine hospice caregivers' downward referral decision-making experiences and barriers in a three-tiered linkage model. Face-to-face, semi-structured, in-depth interviews were conducted with eligible caregivers to gather information on their referral experiences and feelings.

### Participants and setting

Hospice patients are more symptomatic, making it difficult to obtain their cooperation during prolonged interviews. Given that caregivers play an important role in their patients' medical decision making, life care, and emotional support, the interviews were adapted to caregivers. In this study, caregivers of hospice patients referred by two primary care organizations in Nanjing, China, from January to March 2024 were selected using purposive sampling. These two primary care organizations have established a close ternary health care alliance with one or two tertiary care hospitals to achieve mutual referrals between tertiary care–primary care–at-home care. All their downstream referrals are patients from the original tertiary care hospitals. The inclusion criteria for

caregivers were as follows: (1) the primary caregivers of the hospice patients included in this study and had participated in hospice referral decision making and the complete referral process and (2) those who voluntarily participated in this study and agreed to share their hospice referral experience. The exclusion criteria were as follows: (1) those in an employment relationship in which they received payment for their labor and (2) caregivers who had recently experienced other major stressful events or had a mental illness. The sample size was used until no new themes emerged from the data analysis and the data were saturated.

### Interview topic guide

With the population–capacity–process (PCP) model<sup>12</sup> as a theoretical guide, the model in this study was derived from existing research showing that failures in interagency patient referral (e.g., vaguely defined referral populations, service capabilities of health care organizations that do not fit patients' needs, and a poorly flowing referral process) are often attributed to the neglect of one or more of the three PCP domains. On the basis of a literature review, this study developed an interview outline that incorporated the three areas of the PCP model to systematically analyze hospice referral decision-making experiences and barriers. The first draft of the interview outline was guided by two experts in the hospice field. Two caregivers were selected for pre-interviews, the results of which served as basis in modifying the interview outline. The interview outline was as follows: (1) How much do you know about hospice care and the referral system? (2) Did you initiate the referral? Who recommended the downward referral to you? Why did you accept it? (3) Where do you most expect hospice care to be and what factors do you think will influence your choice? (4) What advice did health care professionals give you as they helped you make your choice of referral organization and what else would you have liked them to have done to assist you? (5) What is the impact of receiving a hospice referral on you and your family (illness, death, meaning of life, finances, caregivers)? (6) Did you experience any difficulties during the referral process? If so, what were the specific difficulties?

### Data collection

A semi-structured in-depth interview method was used to collect data. The interviewees were postgraduate hospice care students and were registered in the hospice unit in advance to ensure their familiarization with the work. The patients and caregivers were initially screened according to the nativity criteria prior to the start of the interview. Under the guidance of a charge nurse, the interviewer approached each caregiver for a brief introduction and trust building. The purpose and significance of the study were explained to the interviewees before they signed an informed consent form, and a general information questionnaire was distributed to collect information on their age, sex, relationship with the patient, education level, number of days of referral, and participation in the referral process. The interviewees had completed learning and training modules on qualitative research methods before the interviews to ensure that the interview process was reasonable and standardized. The interviews were conducted in a quiet and private consultation room. The interviews were recorded with the interviewees' consent. By using various techniques such as careful listening and feedback and raising appropriate follow-up questions, the interviewees proceeded with the in-depth interviews and encouraged the interviewees to express their thoughts and feelings freely. The interviewees' facial expressions and body movements were recorded in a timely manner without using guiding or suggestive language. Each interview lasted for 30–60 min.

### Rigor

The interviewees arrived early at the lower-level hospital to build trusting relationships with the patients and caregivers. To ensure the accuracy and adequacy of the caregivers' memory and experience with regard to the downward referral process and decision making, this study

limited the referral of a patient to the institution where he or she is currently located to a period between 2 weeks and 1 month. The interviewers remained neutral throughout the interviews and did not express their personal opinions or judgments. When unclear statements or feelings arose, the interviewers sought clarification from the participants during the interview. In the data analysis process, the original statements of the interviewees were acknowledged without personal interpretations or opinion. After the data analysis, the textual data were given to the interviewees for validation to ensure the stability of the results.

**Data analysis**

A researcher transcribed the acquired audio-recorded data into textual data within 24 h after the end of each interview. Upon completing the transcription, the researcher checked the data again, coded the interviewees sequentially, and finally imported all data into NVivo 11.0 software for data management. Using the Colaizzi 7-step analysis method<sup>13</sup> for data analysis, two researchers performed textual analysis and integration independently and then compared and summarized the results; any disagreement was discussed and resolved by the members of the subject group.

**Ethical considerations**

The study was reviewed by the Hospital Ethics Committee (IRB No. 2024-090-03), and the subjects provided informed consent and voluntarily participated in the study.

**Results**

**Participants' characteristics**

Twelve caregivers (coded as F1–F12) were ultimately included in this study. General information about the caregivers is presented in Table 1. The caregivers' experiences in decision making for the downward hospice transfer of patients and the barriers they faced were categorized into four themes and nine subthemes based on the PCP theory.<sup>12</sup>

**Theme 1: caregivers' multidimensional psychological experience**

**Dilemma and guilt**

Under the advocacy of the "patient-centered" concept, caregivers gradually develop a value system that prioritizes the needs and well-being of patients. Caregivers often worry that their decisions might cause further harm to the patients. F1: "I am really torn. I'm very worried that if we transfer him to another facility, their infrastructure might not

be adequate, and the staff may not understand his symptoms, thus failing to provide proper care." F7: "My mom's cancer has metastasized throughout her body, and she is aware of her condition. We have considered transferring her to a smaller hospital for more convenient care, but we are uncertain whether the new hospital can handle all of her medical needs." Additionally, transferring patients to nursing homes or community facilities presents an emotional burden for caregivers, as they fear the patients might feel abandoned to some extent. To alleviate these concerns, caregivers often reassure the patients. F7: "We will not leave you; we will stay with you. Moving to a nursing home will allow us to take better care of you."

**Emotional support and psychological adaptation**

Influenced by the traditional Chinese concept of "returning to one's roots," many terminally ill patients wish to return home. Transferring palliative care patients to community or home settings aligns with some patients' attachment to their families and desire for a familiar environment. Caregivers also express an understanding and support for the emotional needs of patients. F1: "He knows he doesn't have much time left, so he wants to stay at home." F2: "She wants to die at home, and we plan to take her back when she feels a bit better." Some respondents also recognize that a community environment may bring positive experiences to patients and their families. F4: "He is quite satisfied with transitioning to community care because they feel it allows for a more normal life." F12: "For us, there is a sense of hope, that transferring her down might be a good sign, or at least she will be in less pain."

**Theme 2: perceived interagency gaps in referrals**

**Convenience and economy of home communities**

Although primary care is not an option prioritized in previous studies, the patients and caregivers referred to primary care services in this study generally reported that these services exceeded expectations. F5 offered the following response: "Because dad is already in the end stage, there is not much point in fighting against the tumor anymore. He originally had many other chronic illnesses, so he wanted to have an integrated and comprehensive treatment over here. There is no need to transfer him to other departments to address individual diseases." As for F10, "My father is old and has multiple metastases, and it's not easy for him to move around at home, so it's more convenient for us to go back and forth to take care of him because we can provide this kind of comprehensive and all-inclusive medical service here." F6 said, "So I want a single room as it makes offering care easier." F8 mentioned, "There is less waiting time in the queue for registration and checkups, and there is no need to transfer to different departments for individual diseases." Meanwhile, the high cost of treatment for end-stage diseases puts a huge financial burden on

**Table 1**  
General information of respondents (N = 12).

Code	Primary caregiver				Patient			Referral pathway
	Sex	Age (years)	Educational attainment	Relationship with patients	Age (years)	Type of disease	Self-care ability	
F1	Female	38	Junior High School	Adult children	67	Lung cancer	Unable to self-care	3A Hospital - Home - Community
F2	Female	40	Bachelor's Degree	Adult children	63	Colorectal cancer	Unable to self-care	3A Hospital - Home - Community
F3	Female	43	Bachelor's Degree	Spouse	49	Pancreatic cancer	Partially self-care	3A Hospital - Community
F4	Male	49	Junior High School	Spouse	55	Lung cancer	Partially self-care	3A Hospital - Home - Community
F5	Male	35	Bachelor's Degree	Adult children	67	Lung cancer	Unable to self-care	3A Hospital - Community
F6	Female	42	Junior High School	Adult children	70	Cerebral infarction	Unable to self-care	3A Hospital - Community
F7	Male	43	Senior High School	Adult children	81	Pancreatic cancer	Partially self-care	3A Hospital - Home - Nursing Home
F8	Female	48	Junior High School	Adult children	76	Heart failure	Unable to self-care	3A Hospital - Nursing Home
F9	Female	30	Bachelor's Degree	Adult children	62	Liver cancer	Partially self-care	3A Hospital - 2A Hospital - Nursing Home
F10	Female	45	Junior High School	Adult children	76	Lung cancer	Partially self-care	3A Hospital - 2A Hospital - Nursing Home
F11	Female	67	Junior High School	Spouse	62	Liver cancer	Partially self-care	3A Hospital - Home - Nursing Home
F12	Male	38	Junior High School	Adult children	66	Pancreatic cancer	Partially self-care	3A Hospital - Nursing Home

3A Hospital: Grade III, Class A hospital in China.

2A Hospital: Grade II, Class A hospital in China.

patients' families, and some patients' caregivers are using economic factors as one of their considerations. F3 responded, "Because there is no hope for a cure, I thought about transferring to this side (the community). The pressure on us has been minimized."

#### *Perceived inadequacy of primary health care resources*

China is increasing its support for primary hospice services, but the existing primary care system is not highly trusted and accepted by patients and caregivers because of limited resources, inadequate policies, and insufficient training. F1 said, "We are also coming from tertiary hospitals, which are more complete in terms of medical facilities, security, medicines, and so on." F6 responded, "I think the main problem was because we didn't have enough resources when we transferred over here." Especially for hospice patients requiring a wide variety of medications, their symptom control requirements are high. F6 added, "We have to take a picture of the medication in the tertiary hospital and send it to this side to make sure he has his medicine before the transfer; only this drug is very effective for him."

#### *Theme 3: limitations of caregiver decision-making*

##### *Cognitive understanding bias*

Owing to a lack of publicity about MCH and the tertiary referral system, the respondents were less aware of hospice referrals. They had social biases and misunderstandings about downward hospice referrals. Specifically, they believed that referral to primary care was equivalent to abandoning treatment and that referring patients from a high-level hospital to a primary care facility was irresponsible and thankless. This perception seriously impeded the acceptance of referrals. F5 said, "We resisted going to a community hospital as soon as we heard the doctor's suggestion that we needed to go there." F3 responded, "Other people say that moving to hospice is done only when there is no hope and that referral to a community facility creates a negative impression for others."

##### *Difficulty in seeking information*

Access to hospice referral information and advice is critical for patient and caregiver decision making. Patients and caregivers often lack adequate information during the referral process, resulting in an inability to fully understand the hospice referral organization. F1 responded, "It's hard for me to know who's responsible for what (hospital, primary, community hospice), and the doctors don't have very clear guidance." The caregivers reported that referral information was mostly obtained online and through acquaintances and that they lacked access to objective and authoritative information. For example, F4 said, "We learned about this service (hospice) through a friend." F9 responded, "From the little red book or something, and I've checked on Baidu, the internet says there's still a big demand for this." When faced with a large amount of information, caregivers have difficulty sifting through and judging the correctness and reliability of the information, and they are easily misled. F11 described the same: "There is so much information on the internet, and we don't know which is true and which is false."

##### *Passive acceptance of decision making*

In many cases, hospice patients and caregivers are unable to fully recognize what is at stake because of a lack of professional knowledge and decision-making support, and they can only passively accept the advice of health care professionals. This limitation makes communication and discussion with physicians on an equal footing particularly difficult. Consequently, patients and caregivers lack the ability to make decisions on their own. This passive acceptance of decision making tends to undermine caregivers' initiative to participate in the referral process. F3 described the following scenario: "Oftentimes, we just have to do what the doctor says, and we don't know what to do ourselves." F8 said, "We don't always fully grasp the doctor's words, and we can only understand the arrangements." Faced with complex medical decisions, caregivers often tend to rely on the professional judgment of health care

professionals and ignore their own judgment and wishes. F12 responded, "I think the doctors are more professional so we just listen to them."

#### *Theme 4: limitations of health care referral support*

##### *Lack of health care referral guidance*

In this study, the caregivers expressed a desire for more advice and guidance from professionals during the referral process to facilitate decision making. "It might have been easier for me if my doctor had given me advice to come here," F7 said. Meanwhile, F11 responded, "I think it would have been easier for the doctors in the hospitals to give advice on referrals." Additionally, demanding health care work can affect the exchange of information between health care providers and patients, with caregivers feeling inadequately guided. As F5 said, "But that doctor is also busy and doesn't have time to give you a very detailed explanation. So communication is not very easy."

##### *Discharge referral system to be improved*

The lack of development in the discharge referral system causes a gap in palliative care services. This erodes caregiver confidence and interferes with patients' ongoing care. F5: "We are completely unfamiliar with the new palliative care facility, and there was no detailed introduction during the referral." F3: "We were also unaware of the services provided by the new facility at the time of referral, and we were reluctant to transfer." After a patient is referred, the system for their continued care and assistance is still in its infancy. After being sent to primary hospitals, patients and caregivers anticipate assistance from higher-level hospitals. Nevertheless, there is a lack of proper implementation of homogeneity management between medical facilities of varying levels. F12: "Initially, I was very reluctant to come, but the doctor informed us that it was a collaborative relationship with our previous hospital, with direct communication and cooperation between doctors, which is why we came." F10: "I hope the doctors from the previous higher-level hospital could come for consultations, but it hasn't happened yet. So, I believe there are communication issues between the doctors at the two hospitals."

## **Discussion**

### *Main findings*

End-of-life health care is a major practical concern for everyone. Hierarchical hospice care aims to fully utilize all levels of health care and societal resources to meet the growing demand, promote the rational triage of patients, and balance the relationship between supply and demand for hospice care. Appropriate hospice care settings are an important part of ensuring quality of life at the end of life. The results of this study showed that strong emotional stress and lack of decision-making support for caregivers involved in the decision-making process for the downward referral of patients to hospice care cause some patients to develop complex emotions such as helplessness and indecisiveness, which lead to decision-making barriers. Okimura et al.<sup>14</sup> confirmed that owing to the sense of uncertainty about the referral process between hospice sites, about 70% of caregivers regret their choice of hospice care facility. Influenced by traditional views of filial piety and death, caregivers also face a complex decision-making process in referring patients to primary care.<sup>15</sup> In the current study, some of the caregivers attributed their complex psychological experiences to the lack of knowledge about the hospice and referral system and the uncertainty in decision making; this result is consistent with the findings of Yamamoto et al.<sup>16</sup> Hence, the hierarchical hospice care system should be fully explained to patients and caregivers, they should be provided with informational support to expand their knowledge base and thereby reduce the sense of uncertainty about decision making. Advanced care planning can also be employed to improve patient and caregiver congruence in future health care decisions and promote shared decision making.<sup>17</sup>

The interviews in this study revealed the caregivers' inadequate knowledge of primary hospice care and the discrepancies between the expected and actual experiences of interagency referrals, which may be attributed to the lack of clear guidance on hospice site selection. Previous research has focused on the quantitative study of factors influencing patients' choice of end-of-life location,<sup>18</sup> but the expected and actual end-of-life locations are not always aligned.<sup>19</sup> Furthermore, the end-of-life process is characterized by a lengthy course of illness and complex symptomatic changes; therefore, a single end-of-life location cannot satisfy actual situations. Community and home hospice services have several advantages, such as keeping patients in their living environment, increasing patient satisfaction, and saving medical and health resources.<sup>20</sup> Hence, primary hospice care may be the final destination for most patients. Owing to information asymmetry between doctors and patients, patients' choice of referral largely depends on their doctors' recommendations,<sup>21</sup> as confirmed in this study. Accordingly, the current level of knowledge, attitudes, and behaviors of health care professionals toward medical associations and hospice referrals must be improved.<sup>22</sup> Therefore, the referral system must be clarified and promoted among health care professionals to encourage them to actively introduce the advantages of the referral system to patients and caregivers and eliminate the influence of stereotypes on the decision-making process for hospice referrals of affected patients. These measures will increase the rate of downstream referrals.

The caregivers interviewed in this study identified the need for communication and information support. Moreover, the analysis revealed barriers to communication, including the lack of communication opportunities because of health care staff shortages and heavy workload, lack of communication methods as result of the existing organizational structure and work patterns in hospitals, and lack of information provided because of inadequate improvements in hospice services; these findings are similar to those of Adriana et al.<sup>23</sup> Timely and effective communication between hospice professionals, patients, and caregivers can reduce negative emotions such as pain and sadness and assist patients and families in preparing for and facilitating a smooth transition to referrals.<sup>24</sup> Despite differences in national contexts, the content and needs of hospice communication share commonalities.<sup>25</sup> To understand the willingness of end-stage patients to choose treatment and care, other countries have constructed communication models such as the REMAP care goal communication framework,<sup>26</sup> COMFORT communication program,<sup>27</sup> and THREE-TALK communication model,<sup>28</sup> all of which mobilize the autonomous decision-making power of patients and caregivers to improve communication efficiency. In the future, we can learn from relevant communication frameworks and shared decision-making models of patients and caregivers in different countries, conduct localized research and improvements, and construct communication models suitable for the clinical environment of China to promote communication and decision-making support.

Owing to a lack of clarity in the admission and exit criteria for each level of hospice care, referral channels between health care organizations are not standardized, and patients suffer from delayed downward referrals and a lack of clarity in the target referral organization. Currently, no gold standard has been established for hierarchical hospice referrals, and most referrals are based on the clinical experience of health care providers, who are susceptible to individual decision-making differences and implicit bias in the absence of a systematic approach. Scotland's NHS Quality Improvement clinical standards for hospice care suggest the desirability of using a validated assessment tool to assess referral needs and prioritization.<sup>29</sup> However, limited research has been conducted on the referral criteria between different levels of care in hospice services.<sup>30</sup> Although a great deal of work has been done to identify potential hospice clients or develop criteria for referral to hospice services,<sup>31,32</sup> only a handful of studies from abroad have investigated how hospices direct patients to appropriate agencies. The fulfillment of the needs of patients with terminal illnesses is one of the most important indicators for evaluating quality of death and is key to developing hospice practice.<sup>33</sup> For example, the referral

classification tool RUN-PC developed by Russell et al.<sup>34</sup> and the inpatient hospice admission triage tool IPAT developed by Philip et al.<sup>35</sup> improve the distribution of hospice services by assessing the urgency and prioritization of patients' needs to ensure their access to the appropriate resources. These studies suggest that hospice referral is a complex process that requires collaborative and negotiated decisions based on local hospice resource availability, patients and caregivers, and clinical care specifics. Therefore, in the future, scholars should further develop multi-attribute decision aids in hospice referral organization selection and referrals so that patients can participate in the referral decision-making process, choose the appropriate hospitals based on the assessment of multiple indicators, and improve patient satisfaction with referrals while facilitating the rational and efficient allocation of hospice resources.

#### *Implications for nursing practice and research*

Future research and practice should further investigate how to optimize the triadic linkage model to more effectively support patients and caregivers in their decision-making process. Psychosocial support should be enhanced by providing more comprehensive and transparent information to facilitate their understanding of and ability to cope with the complexity of downward transfer decisions. Further research should investigate how to improve the balance of quality of care in health care alliances and the provision of improved information sharing and transitional care services. In addition, nurses, as the core force of doctor-patient communication, should develop locally-appropriate communication models, considering the specific circumstances in China, to improve the efficiency of communication and decision-making support for patients and caregivers during the referral process.

#### *Limitations*

This study is the first to explore downward referral decision-making experiences and barriers using the current hierarchical referral model for hospice care in China. Barriers to hospice referral can be better analyzed by surveying patients and caregivers who have personally experienced the referral process. However, this study only interviewed caregivers from hospice organizations in Nanjing, China. Future research could expand the survey population and gain a deeper understanding of the current status of hospice referral services in rural and remote areas to promote hospice care in remote grassroots areas.

#### **Conclusions**

This study provides an in-depth analysis of the downward referral decision-making experience and barriers for caregivers of hospice-referred patients through a semi-structured interview methodology. The results are important for constructing a hospice referral assessment program and promoting interagency referrals for hospice care. When implementing the three-tiered hospital–community–home hospice model, site-specific and demand-driven principles should be followed to facilitate the implementation of hospice referrals, improve the referral experience of patients and their caregivers, and fully utilize the service capabilities of health care organizations at all levels.

#### **CRedit authorship contribution statement**

**Yahui Liu:** Conceptualization, Methodology, data collection, transcription and summarization, Writing – Original draft. **Yanan Xu:** Conceptualization, data collection, transcription and summarization. **Yubiao Kang:** Conceptualization, Methodology, data collection. **Ligui Wu:** Funding acquisition, Writing – Review and editing. **Yujie Zhou:** Conceptualization, Methodology, Writing – Review and editing. **Ling Yuan:** Conceptualization, Methodology, Funding acquisition, Writing – Review and editing. All authors had full access to all the data in the study, and the corresponding author had final responsibility for the

decision to submit for publication. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

### Ethics statement

The study was approved by the Institutional Review Board of the Nanjing Drum Tower Hospital (IRB No. 2024-090-03). All participants provided written informed consent.

### Funding

This study was supported by the Jiangsu Provincial Geriatric Health Research Project (LKZ2022014) and the Nursing Research Key Project of Nanjing Gulou Hospital (2024-A705). The funders had no role in considering the study design or in the collection, analysis, interpretation of data, writing of the report, or decision to submit the article for publication.

### Data availability statement

The data that support the findings of this study are available on request from the corresponding author. Data are not made public due to privacy and ethical restrictions.

### Declaration of generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

### Declaration of competing interest

The authors declare no conflict of interest.

### Acknowledgments

We sincerely express our gratitude to the hospice patients and caregivers who participated in this study and generously shared their experiences and thoughts with us. We also extend our appreciation to the hospice health care workers who provided us with invaluable assistance and guidance.

### References

- Organization WH. *Global Atlas of Palliative Care*. 2nd ed.; 2020. <https://news.un.org/zh/story/2014/01/208332/>. Accessed March 20, 2024.
- Currow DC, Nightingale EM. "A planning guide": developing a consensus document for palliative care service provision[J]. *Med J Aust*. 2003;179(S6):S23–S25. <https://doi.org/10.5694/j.1326-5377.2003.tb05572.x>.
- Von Gunten CF. Secondary and tertiary palliative care in US hospitals[J]. *JAMA*. 2002;287(7):875–881. <https://doi.org/10.1001/jama.287.7.875>.
- Smets T, Onwuteaka-Philipsen BBD, Miranda R, et al. Integrating palliative care in long-term care facilities across Europe (PACE): protocol of a cluster randomized controlled trial of the 'PACE Steps to Success' intervention in seven countries[J]. *BMC Palliat Care*. 2018;17(1):47. <https://doi.org/10.1186/s12904-018-0297-1>.
- Department of Aging and Health. Guiding opinions on establishing and improving the elderly health service system. <http://www.nhc.gov.cn/cms-search/xxgk/getManuscriptXxgk.htm?id=cf0ad12cb0ec4c96b87704fbb5bbde/>; 2019. Accessed March 20, 2024.
- 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[J]. *Eur J Publ Health*. 2015; 25(4):569–575. <https://doi.org/10.1093/eurpub/ckv039>.
- Salifu Y, Bayuo J. Transfer and transitioning between palliative care settings[J]. *Ann Palliat Med*. 2022;11(10):3035–3039. <https://doi.org/10.21037/apm-22-1057>.
- Moon F, Mooney C, Mcdermott F, et al. Bereaved families' experiences of end-of-life decision making for general medicine patients[J]. *BMJ Support Palliat Care*. 2021. <https://doi.org/10.1136/bmjspcare-2020-002743>.
- 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[J]. *Palliat Med*. 2021; 36(1):124–134. <https://doi.org/10.1177/02692163211043371>.
- Zhou Yujie, Yuan Ling, Wu Ligui, et al. Construction of hierarchical referral service system for hospice care and evaluation of application effect[J]. *China Nursing Management*. 2024;24(5):675–680. <https://doi.org/10.3969/j.issn.1672-1756.2024.05.007>.
- Stiel H, Nagarajan SV, Forster BC, et al. Palliative care physicians' perspectives on transferring patients to nursing homes and communication strategies to facilitate this transition: a qualitative study[J]. *Palliat Med*. 2019;33(3):323–331. <https://doi.org/10.1177/0269216319827803>.
- Kreindler SA, Struthers A, Star N, et al. Can facility-based transitional care improve patient flow? lessons from four Canadian regions[J]. *Health Manage Forum*. 2021; 34(3):181–185. <https://doi.org/10.1177/0840470421995934>.
- P C. *Psychological Research as the Phenomenologists Views it*. New York: Oxford Univ Press; 1978.
- Okimura A, Hayashi N. Relationships between bereaved families' decision-making regret about end-of-life care place for patients with cancer and relevant factors[J]. *Asia Pac J Oncol Nurs*. 2023;10(1):100167. <https://doi.org/10.1016/j.apjon.2022.100167>.
- Li WW, Singh S, Keerthigha C. A cross-cultural study of filial piety and palliative care knowledge: moderating the effect of culture and universality of filial piety[J]. *Front Psychol*. 2021;12:787724. <https://doi.org/10.3389/fpsyg.2021.787724>.
- Yamamoto S, Arao H, Masutani E, et al. Decision making regarding the place of end-of-life cancer care: the burden on bereaved families and related factors[J]. *J Pain Symptom Manage*. 2017;53(5):862–870. <https://doi.org/10.1016/j.jpainsymman.2016.12.348>.
- Chan CWH, Wong MMH, Choi KC, et al. What patients, families, health professionals and hospital volunteers told us about advance directives[J]. *Asia Pac J Oncol Nurs*. 2019;6(1):72–77. <https://doi.org/10.4103/apjon.apjon.38.18>.
- Hanari K, Moody SY, Sugiyama T, et al. Preferred place of end-of-life care based on clinical scenario: a cross-sectional study of a general Japanese population[J]. *Healthcare (Basel)*. 2023;11(3). <https://doi.org/10.3390/healthcare11030406>.
- Smith S, Brick A, Johnston B, et al. Place of death for adults receiving specialist palliative care in their last 3 months of life: factors associated with preferred place, actual place, and place of death congruence[J]. *J Palliat Care*, 0(0): 08258597241231042. <https://doi.org/10.1177/08258597241231042>.
- Cotton A, Sayers J, Green H, et al. Older persons' perceptions and experiences of community palliative care: a systematic review of qualitative evidence[J]. *JBI Evidence Synthesis*. 2024;22(2):234–272. <https://doi.org/10.1111/JBIES-22-00353>.
- Wang Y, Xiang L, Chen J, et al. The downward referral experiences of stroke caregivers in the regional medical alliance in China: a phenomenological study[J]. *Medicine (Baltim)*. 2022;101(42):e31151. <https://doi.org/10.1097/MD.00000000000031151>.
- Zhang Qinghui, Chen Yongyi, Chen Evening, et al. A survey on the knowledge, belief and behavior of hospice graded services among healthcare workers[J]. *Contemporary Nurses (Zhongdian)*. 2021;28(4):83–87. <https://doi.org/10.19792/j.cnki.1006-6411.2021.11.030>.
- Ventura AD, Burney S, Brooker J, et al. Home-based palliative care: a systematic literature review of the self-reported unmet needs of patients and carers[J]. *Palliat Med*. 2014;28(5):391–402. <https://doi.org/10.1177/0269216313511141>.
- Hatcher I, Harms L, Walker B, et al. Rural palliative care transitions from home to hospital: carers' experiences[J]. *Aust J Rural Health*. 2014;22(4):160–164. <https://doi.org/10.1111/ajr.12105>.
- Nicholson CJ, Combes S, Mold F, et al. Addressing inequity in palliative care provision for older people living with multimorbidity: perspectives of community-dwelling older people on their palliative care needs: a scoping review[J]. *Palliat Med*. 2023;37(4):475–497. <https://doi.org/10.1177/0269216322118230>.
- Childers JW, Back AL, Tulsy JA, et al. REMAP: a framework for goals of care conversations[J]. *J Oncol Pract*. 2017;13(10):e844–e850. <https://doi.org/10.1200/JOP.2016.018796>.
- Wittenberg-Lyles E, Goldsmith J, Richardson B, et al. The practical nurse: a case for COMFORT communication training[J]. *Am J Hosp Palliat Care*. 2013;30(2):162–166. <https://doi.org/10.1177/1049909112446848>.
- Goossens B, Sevenants A, Declercq A, et al. Shared decision-making in advance care planning for persons with dementia in nursing homes: a cross-sectional study[J]. *BMC Geriatr*. 2020;20(1):381. <https://doi.org/10.1186/s12877-020-01797-0>.
- Fergus CJ, Nicol JS, Russell PB. Is a STAS-based tool valid to triage patients at a specialist palliative care inpatient unit?[J]. *Int J Palliat Nurs*. 2008;14(1):24–29. <https://doi.org/10.12968/ijpn.2008.14.1.28151>.
- Cole CS, Bennett CR, Carpenter JG, et al. Palliative care in nursing homes: a qualitative study on referral criteria and implications for research and practice[J]. *J Am Geriatr Soc*. 2024. <https://doi.org/10.1111/jgs.18938>.
- Pigni A, Alfieri S, Caraceni AT, et al. Development of the palliative care referral system: proposal of a tool for the referral of cancer patients to specialized palliative care[J]. *BMC Palliat Care*. 2022;21(1):209. <https://doi.org/10.1186/s12904-022-01094-0>.
- Hui D, Mori M, Watanabe SM, et al. Referral criteria for outpatient specialty palliative cancer care: an international consensus[J]. *Lancet Oncol*. 2016;17(12): e552–e559. [https://doi.org/10.1016/S1470-2045\(16\):30577-0](https://doi.org/10.1016/S1470-2045(16):30577-0).
- Finkelstein EA, Bhadelia A, Goh C, et al. Cross country comparison of expert assessments of the quality of death and dying 2021[J]. *J Pain Symptom Manage*. 2022;63(4):e419–e429. <https://doi.org/10.1016/j.jpainsymman.2021.12.015>.
- Russell B, Philip J, Phillips J, et al. Pilot implementation of the responding to urgency of need in palliative care (RUN-PC) triage tool[J]. *J Pain Symptom Manage*. 2023. <https://doi.org/10.1016/j.jpainsymman.2023.12.012>.
- Philip JA, Le BH, Whittall D, et al. The development and evaluation of an inpatient palliative care admission triage tool[J]. *J Palliat Med*. 2010;13(8):965–972. <https://doi.org/10.1089/jpm.2009.0374>.