An Exploration of the Challenges for Oncology Nurses in Providing Hospice Care in Mainland China: A Qualitative Study

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ABSTRACT

Objective: Although there has been an increasing emphasis on assisting nurses with providing quality hospice care to patients and family members, few studies have explored the challenges that oncology nurses face when delivering hospice care in the Chinese cultural context. The objective of this study was to elucidate the challenges for oncology nurses in providing hospice care for terminally ill cancer patients in mainland China. **Methods:** A descriptive qualitative study with purposive sampling using audio-recorded fact-to-face interviews. A total of 13 hospice nurses from four hospitals in Beijing, mainland China, participated in this study. Data collection was from April to June 2019, and thematic analysis method was used to analyze the data. **Results:** Challenges identified by hospice nurses in providing hospice care for terminally ill cancer patients included: (1) public misperception on hospice

care, (2) lack of financial support, (3) fear of medical disputes and legal action, (4) shortage of human resources, (5) insufficient specialization and lack of "hierarchy" training on hospice care, (6) inexperience in communication skills, and (7) lack of self-care and stress management skills. **Conclusions:** It is imperative and critical for the government, health-care institutions, and hospice care providers to clearly understand the challenges that currently exist in providing hospice nursing. Joint efforts are needed to overcome those challenges, which might result in qualified hospice nurses and provide evidence for further development of hospice care in mainland China.

Key words: Challenges, China, hospice care, oncology, nurses, qualitative study

Introduction

With the largest population in the world, China is witnessing an increasing number of aging people with cancer and other chronic illnesses; these people have led to a great need for hospice care.^[1] Hospice care has emerged as integrated services in the oncology setting in mainland China for three decades. However, the development of hospice care in mainland China still lags far behind,

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especially compared to that of developed countries;^[2] it is far from being able to meet needs of the aging population and the increasing number of cancer patients in mainland China.^[1]

To promote the development of hospice care in mainland China, in 2015, the Chinese government issued 17 hospice

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care-related policies, guidelines and documents, and part of them were crucial to the development of hospice care in mainland China.^[1] In 2017, several more vital guidelines on hospice care were released by the Chinese government, which stipulated the standards of structure, environment, and human resources of hospice service and practical guideline for health professionals,^[3] and five cities across mainland China, including Beijing, Shanghai, Changchun, Luoyang, and Deyang, were designated by the government as the first five hospice care pilot cities to implement hospice care. To universalize hospice care in mainland China, in 2019, the government further issued a policy, recommending 71 more regions to provide hospice care,^[4] which further accelerated the development of hospice care in mainland China.^[5]

An increasing number of hospices have been operated across mainland China.^[1] These hospices are mainly dedicated to providing compassionate care to terminal cancer patients. To achieve this goal, health-care providers, including physicians, nurses, and social workers, are supposed to be competent in meeting hospice patients' needs and eliciting their concerns,^[6] and as well to assist with completing advanced directives.^[7,8] Meanwhile, educational initiatives have been launched. Plenty of training initiated by various organizations across mainland China have been focusing on improving hospice care competence for nurses and physicians.^[2] The training is mainly continuing education programs, including workshops, seminars or conferences. However, they did not significantly change clinical practice because of the barriers of traditional Chinese culture and ethics and the lack of support from the government.^[1,2]

Among the health professionals, oncology nurses take a crucial role in hospice care provision. Literature have shown that competent oncology nurses are more likely to provide hospice care and facilitate good death for dying patients,^[6] and they are supposed to possess a set of various competencies to deliver high-quality hospice care.^[7,9,10] However, oncology nurses in mainland China found it uncomfortable or difficult to establish hospice care goals and initiate hospice services, partially due to the profound influence of traditional Chinese culture.^[11,12] In mainland China, the majority of Chinese citizens demonstrate an unfavorable attitudes toward hospice care, [13,14] as they think hospice care is equal to giving up on treatment, which goes against Chinese traditional virtue of "filial piety";^[2,14,15] the latter is rooted in traditional Confucian values that have pervaded Chinese culture for thousands of years. Another reason is that it is difficult for Chinese nurses to deliver hospice services as most of Chinese avoid talking about death, even when their relatives' death is imminent.^[13,15,16]

A number of hospitals in mainland China have attempted to construct hospice care unit, most of which were integrated into oncology wards, and hospice services were delivered to terminally ill cancer patients.^[17-19] However, the literature suggested that oncology nurses were underprepared to provide hospice care, leading to their incompetency to meet hospice patients' demands.^[20,21] Oncology nurses in mainland China exhibited negative attitudes toward hospice care,^[20,21] as they had limited knowledge and skills related to the care of terminally ill cancer patients, even though numerous continuing education and training programs have been launched across the country.^[2]

Oncology nurses in mainland China are not yet competent to provide quality hospice care to cancer patients.^[20,21] Understanding the challenges oncology nurses encounter during providing hospice care is vital, given that they are the core multidisciplinary team members who have the most frequent contacts with terminally ill cancer patients and family members. In addition, identification of challenges for oncology nurses in providing hospice care is key to advance hospice care practice in mainland China. However, to our knowledge, few empirical studies have been done to explore the challenges that oncology nurses face when delivering hospice cancer care in the Chinese cultural context. Hence, the purpose of this study was to explore the challenges for nurses in providing hospice care from the perspectives of oncology nurses who provide hospice services for terminally ill cancer patients.

Methods

Aims

To explore Chinese nurses' perceptions of the challenges they encountered when delivering hospice services in the oncology settings.

Design

A descriptive qualitative study was conducted with oncology nurses. The method of this study and its reporting followed the Consolidated Criteria for Reporting Qualitative Research. This study was conducted on either a hospice ward or a day care center integrated in the oncology settings in four tertiary hospitals in Beijing, China. Among the four participating hospitals, three were general hospitals and one was a nation-wide cancer hospital, and their beds for hospice care ranged from 4 to 14.

Sample/Participants

Participants were approached individually and recruited using purposive sampling by the corresponding author. To be eligible, participants had to be aged 18 years older; be full-time registered nurses working on the inpatient hospice ward or day care center where hospice services were provided to terminally ill cancer patients; be willing to participate and be able to speak Mandarin.

Data collection

Data were collected face-to-face using semi-structured interview guide between April and June, 2019 by the corresponding author who is a PhD-prepared nursing scholar with expertise on qualitative research. Written consents and demographic information were obtained from all participants prior to formal interviews. All interviews were conducted in the meeting room on each ward and were audio recorded.

The interview guide was developed based on the purpose of the study and literature review, and was pilot tested with two nurses. Interview questions included: (1) What are the challenges working as an oncology nurse providing hospice services for terminally ill cancer patients? (2) What challenges have you encountered when providing hospice care? (3) How do you think about the training and education you have received for providing quality hospice care? (4) How do you think about your competency on providing quality hospice care? Additional questions were developed based on themes emerging from the first several interviews and were asked in subsequent interviews until reaching data saturation when no new information appeared, and no new themes emerged.

A total of 13 interviews were conducted, and the lengths of interviews were between 20 and 30 minutes, with an average length of 25 minutes. Field notes were taken for informal conversations with the nurses after the interviews.

Ethical approval

Ethics approval was granted by the institutional review board at the Capital Medical University (Approval No. Z2019SY040). All participants signed informed consent form, and they were informed that they could refuse to participate or withdraw from the study at any time, and they could refuse to answer any questions or stop the interview whenever they wanted.

Statistical analysis

All recorded interviews were transcribed verbatim. Data analysis was performed in conjunct with data collection using Word and Excel. Thematic analysis^[22] method was utilized to analyze the data, which mainly includes six steps: (1) Repeatedly reading through the transcripts and getting familiar with them, and taking initial notes; (2) Using phases or sentences to code the potential interesting texts and gain a condensed overview of main points that recur throughout the data; (3) Identifying patterns among the codes and combining and generating themes; (4) Reviewing themes, comparing the themes against the data set; (5) Defining each theme with an exact concept and coming up with succinct and easily understandable names for themes; and (6) Writing up the analysis of data.

Rigor

Several techniques were used to ensure the rigor of this study. Data saturation was strictly followed to guarantee the trustworthiness of the study. Investigator triangulation was assured by having two authors independently analyzed the data and compared their findings. All authors reviewed the resultant themes and a consensus was reached. Member checks were conducted using face-to-face discussion with two participants to ensure that the findings were clear, understandable, and resonated with their experience.

Results

Demographic characteristics

A total of 13 oncology nurses were approached and all of them took part in this study. All participants were women, with no religious belief. Three (23.08%) were single and 10 (76.92%) were married, and they were aged from 23 to 49 years (mean age 34.23 years). Besides one nurse (7.69%) with diploma certificate, all others had either a bachelor's degree (n = 10, 76.92%) or a master's degree (n = 2, 15.38%). The range of their experience in healthcare and in hospice care varied from 3 to 30 years (mean 11.85 years) and 2 to 9 years (mean 2.85 years), respectively. Table 1 shows the demographic characteristics.

Themes of findings

Challenges identified by nurses in providing hospice care included: (1) public misperception on hospice care, (2) lack of financial support, (3) fear of medical disputes and legal action, (4) shortage of human resources, (5) insufficient specialization and lack of "hierarchy" training on hospice care, (6) inexperience in communication skills, and (7) lack of self-care and stress management skills. Detailed reports on the seven themes with supportive descriptive exemplars are as follows:

Public misperception on hospice care

Nurses stated that one of the biggest challenges in providing hospice care was the public's misperception on hospice care. In mainland China, most people perceive hospice care as offering no treatment and giving up the patient, which is contrary to the Chinese culture of "filial piety" and the traditional view of "to live is better than to die." As one nurse said:

"Even the illness is incurable, patients and family members still want to cure the disease and prolong life. They (family members) were reluctant to be hospitalized on a hospice care ward as they believed that hospice meant letting the patient die, which was conflict with their responsibilities as family members." (N13)

Zheng, et al.: Challenges for Oncology Nurses in Providing Hospice Care

Participant	Age (year)	Gender	Marital status	Education	Department	Professional rank	Years of being a nurse	Years of working on hospice
N1	35	Female	Married	Bachelor	Day care ward	Senior nurse	16	2
N2	30	Female	Married	Bachelor	Day care ward	Senior nurse	9	2
13	37	Female	Married	Bachelor	Hospice care	Senior nurse	16	3
N4	35	Female	Married	Bachelor	Hospice care	Nurse-in-charge	13	2
15	32	Female	Single	Bachelor	Hospice care	Junior nurse	9	2
16	27	Female	Married	Bachelor	Hospice care	Senior nurse	4	2
17	23	Female	Single	Diploma	Hospice care	Junior nurse	3	2
18	32	Female	Single	Bachelor	Hospice care	Senior nurse	6	2
19	40	Female	Married	Master	Day care ward	Nurse-in-charge	12	9
10	49	Female	Married	Bachelor	Hospice care	Nurse-in-charge	30	2
111	37	Female	Married	Bachelor	Hospice care	Nurse-in-charge	16	2
12	31	Female	Married	Bachelor	Hospice care	Senior nurse	6	2
N13	37	Female	Married	Master	Hospice care	Nurse-in-charge	14	5

Nurses also mentioned that even for those patients who were on a hospice care ward, their goal of care was symptoms control, rather than preparing dying patients for a peaceful death. This practice further impeded the provision of "true" hospice care to terminally ill patients. As one nurse stated:

"Many patients came to us because they wished to find a place to control their physical suffering, and some of them might never think about their dignity, meaning in life, quality of life or their wishes and needs at the end of their life, as they never talked about or asked for help regarding those things." (N12)

Despite the public misperception about hospice care, the oncology nurses addressed the importance of hospice care by citing the need of continuity of care throughout all stages of disease, which begins with diagnosis and proceeds through to death, to fill in the gap that care for people at the end stage of life is missing. Thus, to universalize hospice care, public education on death and dying as well as scopes of hospice care is urgently needed.

Lack of financial support

Nurses pointed out that lack of financial support from the government and health institutions has indirectly prevented them from providing hospice care. The Chinese health-care system does not have adequate funding for hospice staff employment, and additionally, insufficient insurance coverage of hospice services resulted in poor affordability among patients. As one nurse said:

"An issue is lack of financial support. Many hospice services are not covered by health insurance, patients do not have money to pay for those services, and we do not have the money to hire more people (nurses) to do this (hospice care)." (N3)

In addition, nurses mentioned the importance of physical environment in hospice care. However, without adequate financial support, the ward infrastructure even could not meet the basic care needs of dying patients, let alone building a welcoming, home-like environment.

"We know that spiritual support is important, but we even do not have a place for patients or family members to pray or grieve. We need more money to improve infrastructure development on our ward." (N13)

Fear of medical disputes and legal action

Fear of medical disputes and legal actions was another challenge identified by the nurses during providing hospice care. As hospice services have not been integrated into the Chinese health-care system, some types of care were not listed as essential nursing care, and nurses hesitated to provide the care to avoid possible medical disputes. As one nurses said:

"We have some good resources, for example, the aromatherapy, I think it's great. However, it is not required in our work. We worry that whether the patient and family members could accept it, and we also fear that the family might accuse the worsening condition of patient to this (aromatherapy)." (N3)

Nurses were vigilante at work as legal actions could easily happen due to conflicts between patients/family members and hospice care providers or conflicts between the patients and their family members in terms of treatment decision-making. As one nurse said:

"Sometimes patients wanted to stay comfort when dying (without doing resuscitation), and they believed improving quality of life was more important than prolonging life. However, family members mostly insisted on resuscitating a dying patient, to prolong even only 1-h life of the patient. If we respected the patient's choice, the family members might bring us to court for refusing to resuscitate the dying patient." (N10)

Shortage of human resources

Nurses in this study addressed that shortage of human resources, especially hospice care providers from different

disciplines, was a critical challenge in providing hospice care. On one hand, there were insufficient job positions for social workers or psychologists on the hospice care ward; on the other hand, well-trained hospice staff were scarce. The nurses in this study stated that they were incapable to handle dying patients' complex psychological and spiritual issues, leading to unmeet care needs of dying patients. One nurse stated:

"If you (nurses) want to provide quality hospice care, healthcare professionals, such as social workers, psychologists and spiritual counselors who can provide specialized psychological and spiritual care, are indispensable; however, those staff are scarce. We can perform some psychological and spiritual care, but they are far from meeting the patients' demand." (N13)

Shortage of human resources led to increased workload of nurses, which prevented them from providing compassionate care due to lack of time. As one nurse said:

"We are required to provide holistic care, to talk to the patients and show our concern, but we have too much work to do ... I even don't have the time to listen to them patiently." (N10)

Insufficient specialization and lack of "hierarchy" training on hospice care

Some nurses in this study stated that although they did provide holistic care for patients, they perceived the services they provided were not specialized hospice care as they felt that they did not have enough in-depth knowledge. As one nurse mentioned:

"We could do a little bit of all kinds of services for the patients, including physical, psychological, and spiritual care, but what we did were too superficial to reach a specialty-level of hospice care." (N13)

Lack of systematic, comprehensive training imposed a challenge on nurses as they needed basic to advanced education to be able to deal with different problems that patients might have. As one nurse said: "We need more comprehensive, systematic training on hospice care knowledge and skills" (N11). Nurses preferred "hierarchy training," covering knowledge from general to specialized hospice care. As one nurse stated:

"I think we need different levels of training, from primary, intermediate to advanced levels. For instance, beginners receive primary training to learn basic hospice care knowledge, and experienced hospice nurses attend more advanced training for specialized hospice care, so that we can deal with both simple and complicated issues." (N4)

Specifically, nurses stated that the training they had attended was not needs-tailored, so the training was not much helpful in clinical practice. They perceived that they provided insufficient psychosocial and spiritual care to patients due to lack of care skills. Therefore, compared to symptoms control techniques, nurses thought that they needed more training on psychosocial-spiritual supports to patients and family members. Particularly, they stated those supports to bereaved family members were nearly nonexistent in the current hospice practice. As one nurse stated:

"I think we didn't provide enough psychological and spiritual supports for the patients, largely because we were not competent to do this. I also realized that we paid very little attention to family members who also needed this kind of service, especially those whose loved one had passed away." (N8)

In addition, compared to support to patients, nurses indicated that they were less skilled in providing support for family members, which was much less addressed in current hospice training. As one nurse said: "Not only the patient but also the family are the unit of hospice care, so we need to learn about their needs and support them" (N9). Other nurses mentioned that another issue they needed to address was to teach family members to provide informal care for the patient during hospitalization or at home. One nurse said:

"Family members are major caregivers for the patient, so we need to teach them basic care-giving knowledge and skills, so that they would be more engaged in caregiving." (N2)

Inexperience in communication skills

One of the biggest challenges nurses encountered in providing hospice care was lack of skills in communication with patients and their family members. Nurses perceived that they had insufficient communication with patients and family members in terms of disclosure of diagnosis and prognosis, patients' feelings toward dying and death and their last wishes and wills, due to inexperience in communication. As one nurse said:

"A patient once told me she felt very painful and tired of living, but I didn't know how to respond to her, and just said 'we would do our best to treat you and it was normal to experience some sufferings caused by the treatment'. I knew that this response was not the one the patient needed." (N3)

Another nurse said: "We wanted to know the patients' feelings and wishes, but we neither knew how to communicate with them, and nor knew how to let them talk to us" (N2). Therefore, communication skills were urgently needed: "We need to learn more communication skills, so that the patients would want to share their stories with us" (N1).

Lack of self-care and stress management skills

Lack of self-care skills was another challenge for nurses providing hospice care. The oncology nurses mentioned

that they could be negatively impacted and became down in spirits while caring for dying patients. As one nurse said, "We need to know how to avoid being affected too much by negative emotions of patients and how to maintain a strong mind" (N2). However, they reported that they were rarely taught how to adjust and support themselves during work.

Some nurses managed stress by acknowledging and accepting self-limitation, so that they could feel better in the face of their patients' suffering: "We are not the God, in face of death, we have done as much as we can, and we need to acknowledge and accept our limitations" (N11). Others used more negative management strategies to avoid negative impacts on them. As one nurse said:

"He (a patient) sometimes complained to me and talked about negative things. I couldn't help him and felt perplexed and depressive when I was with him, so I tried not to go into his room." (N5)

Discussion

There is a growing need of hospice care in mainland China due to the ageing population and people's requirement for good death. Despite a number of years of development, hospice care in mainland China is still much less than expected and demanded.^[15] The major challenges that impeded provision of hospice care identified in this study included public misperception on hospice care, lack of financial support and shortage of human resources, which were also identified in previous studies,^[1,14,15,23] suggesting that to universalize hospice care in mainland China, we need to overcome the cultural barriers by educating the public to change their perceptions toward hospice care. Meanwhile the government is advised to support hospice care by covering hospice services in national health-care insurance system, and train more competent hospice professionals.^[2,14,15]

One unique challenge prevented nurses from practicing hospice care proposed in this study is their fear of medical disputes and legal actions. One reason is that there is no law or regulation to ensure occupational safety of hospice professionals and to regulate standards of hospice practice.^[24] Furthermore, due to the profound influence of the traditional Chinese cultural values,^[13,14] hospice care is not welcomed by patients and family members, and the majority of physicians and nurses in mainland China are hesitated to provide "pure" hospice services to terminally ill patients. Because of misperceptions on hospice care among patients and family members, the oncology nurses might be easily accused of killing the patients due to failure to fulfill the obligation of treating the patient and saving life.^[14]

Since when the practical guideline for hospice care was released in 2017 by the National Health and Family

Planning Commission of the People's Republic of China, an increasing number of regional and national programs and training on hospice care have been delivered. Nevertheless, hospice care training for nurses is still limited, and the training effectiveness is inconclusive,^[1,14] which is also evident in this study. As hospice care is at the initial stage of development in mainland China, both clinical practice and professional education on hospice care are immature and not well designed,^[1] so there are insufficient hospice care experts to serve as trainers,^[16] resulting in low quality of training programs with nonsystematic, superficial information and poor training effects as identified by the nurses in this study.

Similar to findings of previous studies,^[25,26] lack of communication skills and inadequacy in psychosocial and spiritual care were identified by nurses in this study as challenges in providing hospice care. The oncology nurses reported that they needed to learn more about how to support family members, as insufficient supports were offered to family members in hospice care; this was reflected in many studies that addressed the importance of recognizing family needs and the importance of families.^[27] Our findings reflected the educational needs of hospice nurses, which could offer insights into the development of needs-tailored training programs. In addition, nurses in this study reported that they felt inadequate to manage job stress and there were few resources available to support them, although providing hospice care negatively impacted them. This result indicated that it is also imperative for healthcare institutions to assist hospice nurses to deal with stress and manage the negative impacts, which might in turn promote the competency of hospice nurses.

This study identified that oncology nurses took various roles in caring for hospice cancer patients as multidisciplinary team members were scarce, which is consistent with the findings of previous studies.^[28] Hospice care provides multidisciplinary care, which requires healthcare professionals from different disciplines to work together to address the demands of hospice patients as a whole person.^[29,30] In mainland China, although some hospitals have attempted to establish multidisciplinary care teams and delivered multidisciplinary care to terminally ill cancer patients,^[19,31] the development of multidisciplinary hospice care teams is still in its initial stage. The delivery of multidisciplinary care for hospice cancer patients is impeded by the shortage of qualified multidisciplinary team and the lack of mature hospice training programs tailored to team members.^[28,32] Therefore, it is imperative to develop more effective, culturally-sensitive training programs with a purpose of training competent multidisciplinary team members, which in turn could advance the development of hospice care in mainland China.

Implications for research and practice

This is one of the very few original studies that reported challenges for Chinese oncology nurses in providing hospice care in mainland China. Our findings indicated that to develop hospice cancer care in mainland China, public death education is needed to overcome cultural impacts on the public's perceptions on death and dying as well as hospice care. Governmental supports, including financial support, legal protection, and regulation of standards of hospice practice, would be helpful to authorize nurses to practice hospice care. Our findings also suggested that systematic, comprehensive training programs tailored to needs of hospice nurses, including psychosocial-spiritual care, support to family, end-of-life communication skills, and self-care techniques, would be helpful to improve hospice nurses' specialization and professional competence; this would also provide valuable insights into the development of hospice care education initiatives suitable for nurses in China or other countries.

Limitations

This study has limitations. Participants were recruited from hospice care wards in the oncology settings in tertiary hospitals in Northern China; nurses working in lower levels of hospitals, different care settings, and different areas of China may give different answers. Thus, this might be a nongeneralizable sample. All participants were female, although this is representative of the sample of hospice nurses, their views might be different from that of male nurses. Several oncology nurses in this study had more than 10 years of working experience, and some have worked as a hospice nurse for a longer time than others, which might to some extent impact their perceptions of challenges while providing hospice care and also their responses to the interview questions. However, we did not find any differences regarding the responses of young nurses and senior nurses, and those with different years of working experience at hospice or having different levels of education. Nevertheless, it is suggested that future research could focus on nurses with different characteristics, especially those young, inexperienced hospice nurses, to explore their perspectives of challenges in providing hospice care.

Conclusions

There are plenty of challenges that prevent Chinese oncology nurses from providing quality hospice care. Collaborative efforts from the government, health institutions, medical universities and hospice care providers are needed to overcome those challenges to advance the development of hospice care in mainland China. Public education on death education and systematic, professional educational programs on hospice care are also needed, and tailored training on how to equip hospice nurses with self-care strategies should be provided.

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Conflicts of interest

There are no conflicts of interest.

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