Hospice and Palliative Care in China: Development and Challenges

Yuhan Lu¹, Youhui Gu¹, Wenhua Yu²

¹Department of Nursing, Key Laboratory of Carcinogenesis and Translational Research (Ministry of Education), Peking University Cancer Hospital and Institute; ²Peking University School of Nursing, Beijing, China

Corresponding author: Yuhan Lu, MSN, RN
Department of Nursing, Key Laboratory of Carcinogenesis and Translational Research (Ministry of Education), Peking University Cancer Hospital and Institute, Beijing, China
Tel: 86-010-88196184; Fax: 86-010-88122437
E-mail: lu_yuhan@sina.com
Received: October 12, 2017, Accepted: November 28, 2017

ABSTRACT

Hospice and palliative care have been demonstrated to improve quality of life, shorten hospital stays, and save costs. As a developing country, faced with a rapidly aging population and an increasing number of patients with life-threatening illnesses such as cancer, China has made great progress in promoting hospice and palliative care during the past few decades. A trained nurse can play a significant role in promoting quality hospice and palliative care by providing care, coordinating a multidisciplinary team, calling for policy support, and raising public awareness. It is critical for nurses to clearly understand the development and challenges that currently exist in the country. With this awareness, nurses will improve their ability to recognize and address patients’ and families’ needs, resulting in quality, dignified, and individualized end-of-life care.

Key words: Challenge, China, development, hospice and palliative care, nurses

Introduction

The aging population and the increasing number of patients with cancer in China have led to the increasing need for hospice and palliative care service. This article presents a review of the context of care, the progress China has made during the past decades, and the challenges that will be confronted in the future.

Hospice care is end-of-life care provided by health professionals and volunteers who give medical, psychological, and spiritual support to dying patients and their families. The goal of the care is to help people who are dying die in peace, comfort, and dignity.¹ Palliative care is a caring approach through prevention, assessment, and treatment of pain and other physical, psychological, or spiritual problems,² which improves the quality of life of patients and their families facing life-threatening illness. Thus, palliative care can be applied during the whole disease process while hospice is considered one form of palliative care.
care applied at the end of life. Hospice and palliative care have been demonstrated to improve quality of life, reduce costs, and shorten hospital stays.

**Context of Care in China**

China is a large country with a population of approximately 1.38 billion in 2016. Moreover, it is the third largest in the world in regard to landmass, with more than 9.6 million km². In the past decade, tremendous changes have been seen in many aspects of Chinese society, such as health-care needs, the population curve, and other aspects. While the average age of people is rising, the disease spectrum is changing, and chronic diseases are increasing. The population group aged 65 years and older reached nearly 144 million in 2015. According to a report from the International Agency for Research on Cancer, the estimates of new cancer cases and cancer deaths in 2012 were 3.065 million and 2.206 million, respectively. These estimates show the significantly increased need for hospice and palliative care.

The hospice concept was introduced in China in the 1980s. The first hospice, named Beijing Songtang Care Hospital, was founded in 1987 in Beijing, followed by the establishment of another hospice, named Nanhui Nursing Home, in 1988 in Shanghai. The patients in these facilities could no longer receive life-prolonging treatment and received hospice and palliative care instead.

The beginning of hospice and palliative care as a specialty in China was carried out by experts from medical facilities and academic associations. In some specialized cancer hospitals, teams composed of medical professionals began working in inpatient and outpatient services. In 1994, the Committee of Rehabilitation and Palliative Care of China Anti-cancer Association (CRPC) was founded. The CRPC has been the national voice for hospice palliative care in China. It achieves its mission by supporting research, promoting education and training, and improving public awareness. Experts in the association, such as physicians, nurses, and psychotherapists from different hospitals have led the implementation of hospice and palliative care services within medical facilities where there is the most urgent need for hospice and palliative care.

Hospice and palliative care services are provided in various forms in China: inpatient specialized units, inpatient specialized beds, outpatient units, and home care. The inpatient specialized unit takes one of the hospital units as a hospice or palliative care unit. Inpatient specialized beds involve assigning several independent beds in a unit as specialized hospice care beds. However, in both units, the provision of care is often carried out by interdisciplinary teams composed of specially trained professionals working in their hospitals. In outpatient services, consultation about and support for symptom management and emergency conditions are provided. Home care is usually provided by primary medical facilities such as community hospitals and health clinics.

**Development of Hospice and Palliative Care**

**Government policy and approach**

With the promotion by CRPC, in 2011, the National Health and Family Planning Commission of the People's Republic of China (NHFPC) initiated a national program to establish pilot units for standard management for cancer patients with pain in general and specialized hospitals. More than 735 pilot units were established as models providing a conceptual framework to facilitate consistency in the development and distribution of palliative care services for pain management across China by October 2015, and the number had reached 913 in 2017.

In February 2017, the NHFPC released three documents on hospice care. These documents stipulate the standards of structure, human resource, and environment of the hospice care service with quality monitoring standards and practice guidelines for health caregivers. The presence of these documents further accelerated the development of the hospice care service in China. At the same time, the government also initiated a plan to establish five national pilot hospice and palliative care programs in big cities such as Beijing, Shanghai, Changchun, and others. One of the pilot centers in Shanghai aims to develop the model of community-based hospice care service that will serve as a model across China.

**Medication availability**

Thirty years ago, a major obstacle in providing efficient pain management was the limited availability of and access to opioids and other essential medicines for the care of dying patients. However, in the past two decades, important improvements have been made.

Owing to the leadership of the director and the dedication of the CRPC, the most widely used medication for pain relief and many other essential palliative medicines began to be covered by medical insurance in accordance with the WHO list of essential palliative medicine. To ensure enough opioids for medical use for patients with pain, the State Council of China issued the Regulations on Narcotic Drugs and Psychotropic Substances in 2005. As a result of a mandate that NHFPC released, detailed rules and administrative measures for prescription of analgesics were released to ensure the medication was available for the
These efforts have promoted opioid availability for patients suffering from cancer pain.

**Education for health providers**

Since the establishment of the CRPC in 1994, various educational opportunities such as seminars, workshops, and conferences, have emerged across China. These educational offerings effectively advance the specialization of palliative care in different provinces and cities throughout China. In some specialized hospitals, palliative care became a part of continuing education courses that are easily available for doctors and nurses.

Palliative care had been the historical “missing piece” in nursing textbooks. Juying Lin was the first author to introduce the concept of palliative care in her community-nursing textbook, followed by other textbooks. Certainly, many of the critical content pertaining to the palliative care, such as symptom management, was integrated within the specific disease information rather than in the care of patients with life-threatening illness. Although the content related to communicating bad news and the alleviation of suffering was included in a few textbooks, there was a lack of depth.

In addition, the school of nursing’s content-laden curriculum allowed only limited time for the palliative care and hospice content. As a result, only a handful of academic faculties in schools of nursing included hospice and palliative care content in their courses. Thus, the students graduate with limited knowledge and skills related to the care of patients and their families who are facing life-limiting illnesses.
As noted by Pam Malloy, the director of the End-of-Life Nursing Education Consortium (ELNEC), nurses cannot practice what they do not know. In 2009, the Chinese Nurses Association recognized the apparent need and began to offer educational opportunities in hospice and palliative care in their certification course for oncology nurses. The content consisted of 14 class hours divided into six modules, namely, nursing care at the end of life, pain and other symptoms management, communication, ethical issues, spiritual care, and grief and bereavement. In the past 9 years, 1,797 nurses have attended the education course “Certificated Oncology Nurse” that included the end-of-life content.

In 2010, to further assess the nurses working in hospice and palliative care, Lu et al. from Beijing Cancer Hospital investigated 463 nurses representing 19 hospitals in different provinces and cities. Lu et al. found that the nurse-participants in their study demonstrated a low level of recognition and ability to provide psychological support for dying patients and their families. In a follow-up study, Lu et al. found that nurses have a high level of negative attitudes toward caring for dying patients. To further increase Chinese nurses’ awareness, skills, and knowledge of palliative and end-of-life care, their attitude toward caring for those with life-threatening illnesses needs to be changed. In 2014, the ELNEC was translated from English to Chinese, which was sponsored by the Oncology Nursing Committee of the Chinese Nurses Association. Then between April 6 and 8 2015, the first ELNEC course was held in Beijing with 56 nurse participants, representing 16 provinces and cities throughout China. These 56 trainees returned to their hospitals and trained more nurses about the knowledge and skills in end-of-life care across the country. To date, more than 1000 oncology nurses have received the ELNEC training course in the past 2 years.

Recently, the Oncology Nursing Committee of the Chinese Nurses Association developed an education program using the NHFPC guidelines for hospice care practice. Through a collaborative relationship with the Cancer Education Network, live courses using audio-video teleconferencing (Oncology Nurses OnLine) was created. This resulted in increased educational access to more remote provinces of the country. Through the online courses, over 3100 nurses had participated, and this has, undoubtedly, impacted the quality of care for dying patients and their families in China.

As nurses show increasing demand for hospice and palliative care, the Chinese nurses still lack a textbook on evidence-based skills and principles that are required for quality palliative care. Lu and Chen and 33 other professionals from hospitals spent about 18 months completing the book “Palliative Nursing: a guide for oncology nurses.” This book is the first textbook to provide evidence-based practice on hospice and palliative care for oncology nurses in China and was published by Peking University Medical Press in April 2017.

**Patient education and public advocacy**

There are many public education programs in different provinces and cities across China. In the past 5 years, nurses at Beijing Cancer Hospital taught an education program called “The Pain Education Program” for patients suffering from cancer pain. Patients learn to take the pain relief medication accurately and clarify their concerns about opioids. Within the same period, over 1600 patients and family members attended various health education programs in the hospital. In 2016, a caregiver education program for family members called “Warmth with You” was implemented. This program educates family members about how to care for their loved ones, deals with emotions,
talk about dying and death, respect the patients’ right of knowing the truth, and making decisions.

In China, there are many nonprofit organizations devoted to public advocacy for hospice care. The Chinese Association for Life Care, which was founded in 2006, focuses on caring for the elderly, public welfare, volunteer training, and so on. The Beijing Living Will Promotion Association was founded in 2013, calling for death with dignity by promoting living wills. These organizations have done a lot of work in promoting the public education for hospice care through websites, journals, activities, training courses, and so on.

**Current Issues and Challenges**

While significant progress has been made in China, ensuring that more and more people can benefit from hospice and palliative care service, China’s health-care system still faces many challenges that need to be addressed.

**Limited Facilities to Offer Hospice and Palliative Care**

Although there have been many facilities providing various forms of hospice and palliative care services in many provinces during the past decades, none of these forms are widespread or integrated into the mainstream health-care system. The number of facilities is far from meeting the growing demand for hospice and palliative care services, as the population is aging and the number of patients with life-threatening diseases is increasing in China. For now, most of the hospice and palliative care services are still provided in secondary and tertiary hospitals where high-quality care is provided, while beds for hospice and palliative care are in great shortage. Many people’s preference of dying at home needs to be taken into account, and more hospice and palliative care services should take place outside formal hospice or hospital settings. Now with the support of the government, community-based hospice and palliative care services are also the focus of development in the next decade. At the same time, it is necessary to explore appropriate service models to ensure that patients can receive continuous care service in different facilities.

**Essential Medicines for Palliative Care**

As for the medication availability, pain relief medication in large hospitals and specialized hospitals, such as cancer hospitals are easily available, while many patients who live in rural and remote communities have limited or no access to opioids. Although a government policy about increasing access to palliative care has ensured that the medication can be available, the operating mechanism and monitoring regulations need to be put in place to achieve this goal.

**Educational Challenges**

The rising demand for hospice and palliative care requires more skilled and knowledgeable medical professionals. Thus, training and education needs to be continuously supported. Although efforts to improve educational opportunities are in place, implementation of training and education varies between schools of nursing and hospitals, creating inconsistencies in training outcomes. In some nursing schools, the concepts of palliative and hospice care are still integrated into other established courses such as geriatrics nursing and community nursing. In some specialized hospitals, the courses on palliative care are provided through institutional education for all nurses, but this practice is not pervasive in Chinese hospitals, especially in the remote, rural areas.

Efforts to improve palliative and hospice care training should be supported and promoted by governmental and professional regulatory boards. It is an urgent task to promote specialty certification programs for both general and specialized hospice and palliative care nurses in China to meet the increasing demand. To date, there is still no certification program for hospice and palliative care nurses in China. Credentialing through certifications will help nurses to be well positioned in the team to provide integrated care, education, and research related to the care of the dying and their families.

Advance care planning (ACP) is the process of communication to make advance directives when individuals are still competent to provide direction for medical decisions. Although it has been proven to effectively promote good death in some countries, in China, it is still not being addressed comprehensively. Educating the
health-care providers to initiate the conversation, integrate it into the plan of care, and advocate it for policy changes is a perennial challenge.

Cultural Challenges

Although death is believed to be a natural part of life, the Chinese find it hard to think and talk about death and dying, as it may create imbalance in the inner harmony. Further, in China, there is a misunderstanding about the role of palliative and hospice care. Many people have a misconception that once they are offered palliative and hospice care, it means that the health-care providers are giving up on them and that they are just waiting for death. They do not want to be regarded as dying persons. As a result, many terminally ill patients refuse the service. Second, diseases and death are inevitable, and they are necessities of life, but most people are reluctant to face them. In some situations when cure is impossible, active treatments, including life-sustaining measures, are still given, which not only increases the patient’s suffering but also potentially leads to an undignified death.

Further, in most instances, it is the family members, rather than patients, who usually make decisions; and often, the patients are not included in discussions related to their care. This practice creates patient confusion and misunderstanding about their illness and prognosis. Many patients have no time to say goodbye, and leave the world with regrets, which does not serve the best interest of the patients or their families.

Therefore, more education of the patients and the public needs to be done to make the end-of-life experience as peaceful as possible. On the one hand, it is important to improve the quality of hospice and palliative care service to show more positive outcomes to the public. On the other hand, it is needed to support patients to receive proper care at the right time, guide people to face death, and allow them to decide their care with all the information they need.

Implications for Nursing

Although China has made great strides in providing affordable access to hospice and palliative care, there remain a number of current challenges that need to be attended to. There are still issues relating to policy approaches, availability of palliative care, and professional training and public advocacy, which are essential when delivering high-quality care. Cultural beliefs need to be honored and integrated while these challenges are being resolved.

Nurses are critically positioned throughout the health-care system, and they can be the appropriate drivers for hospice and palliative care in China. As a result, Chinese nurses should understand the current issues, gaps, directions, and goals. Nurses need to increase the knowledge, skill, and research to be able to respond to changing disease patterns, promote advanced practice in hospice and palliative care nursing, and engage in enhancing the communities’ capabilities to provide compassionate and effective hospice and palliative care service. Further development of better nursing education in specialized certification, evidence-based practice, measurable outcomes, initiating conversations about ACP, and speaking up in collaborative teams will be essential in the future.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

1. Medlineplus. Hospice Care. Available from: http://www.nlm.nih.gov/medlineplus/hospicecare.html. [Last accessed on 2017 Oct 09].
2. World Health Organization. WHO Definition of Palliative Care. Available from: http://www.who.int/cancer/palliative/definition/en/. [Last accessed on 2017 Oct 09].
3. United Nations Population Fund. World Population Dashboard. Available from: http://www.unfpa.org/data/world-population-dashboard. [Last accessed on 2017 Oct 09].
4. National Bureau of Statistics of China. Total Population of China. Available from: http://www.data.stats.gov.cn/easyquery.htm?cn=C01. [Last accessed on 2017 Oct 09].
5. International Agency for Research on Cancer. GLOBOCAN 2012: Estimated Cancer Incidence, Mortality and Prevalence Worldwide in 2012. International Agency for Research on Cancer; 2015. Available from: http://globocan.iarc.fr/Pages/fact_sheets_population.aspx. [Last accessed on 2017 Oct 09].
6. Beijing Songtang Care Hospital. Available from: http://www.sghyy.com/. [Last accessed on 2017 Oct 09].
7. Cheng Y. Through thick and thin, more responsibilities would be carried for rehabilitation and palliative care. Chin Ger J Clin Oncol 2010;9:430-1.
8. Ministry of Health. Notice of the General Office of the Ministry of Health on the Establishment of a Standardized Treatment Demonstration Ward for Cancer Pain. Available from: http://www.nhfpc.gov.cn/zwgkzt/wsbysj/201104/51234.shtml. [Last accessed on 2017 Oct 09].
9. Xiao X. The Market of Analgesic in China. Available from: http://finance.sina.com.cn/chanjing/gsnews/20151021/061923531286.shtml. [Last accessed on 2017 Oct 09].
10. National Health and Family Planning Commission of the People’s Republic of China. Basic Standards and Management Specification of Palliative Care Centers (trial). Available from: http://www.nhfpc.gov.cn/yzygj/s3593/201702/2f506d62faa4cd9d9a09d5162a661f.shtml.[Last accessed on 2017 Oct 09].
11. National Health and Family Planning Commission of the People’s Republic of China. Palliative Care Practice Guidelines (trial). Available from: http://www.nhfpc.gov.cn/yzygj/s3593/201702/83797c0261a94781b158d8d76666b717.shtml.[Last accessed on 2017 Oct 09].
12. Ministry of Health. Narcotic Drugs and Psychotropic Substances Prescription Act. Available from: http://www.nhfpc.gov.cn/zwgk/glgf/201306/977a1bbde574cc5bf26e5c77b15c1.shtml. [Last accessed on 2017 Oct 09].

13. Pamela M. Nursing education. In: Ferrel BR, Coyle N, Paice JA, editors. Oxford Textbook of Palliative Nursing. 4th ed. New York: Oxford University Press; 2015. p. 1009-10.

14. Lu Y. Palliative Care. In: X Bo, editor. Cancer Nursing. 1st ed. Beijing: Peking University Medical Press; 2008. p. 161-76.

15. Lu Y, Guo R, Liu L. Oncology nurses' identification with their responsibilities and negative experience in caring for dying cancer patients. Chin Nurs Manag 2011;11:84-6.

16. Lu Y, Yang H, Zhao Y, Zeng C. Survey of attitude of nurses in oncology department to terminal care and its influencing factors. Chin Nurs Res 2016;30:2647-50.

17. Lu Y, Chen F, editors. Palliative Nursing: A Practical Guide for Oncology Nurses. 1st ed. Beijing: Peking University Medical Press; 2017.