EDITORIAL

Hospice and Palliative Care in Mainland China: History, Current Status and Challenges

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Key words: palliative care; hospice; China; history; current status

Abstract The concept of End-of-Life Care (EOLC) came into China in the late 1980s. However, hospice and palliative care in medical practice developed slowly. In recent years, professionals, patients and their families, as well as government began to attach importance to it. There is a hospice and palliative care movement now in China. This article gives an overview of the progress and the current status in multiple aspects of hospice and palliative care in mainland China, and points out the barriers and challenges for its further development in the future.

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PALLIATIVE care is to give comprehensive treatment and care to patients with limited survival time for severe diseases (including malignant and non-malignant diseases, such as advanced malignancies, advanced chronic congestive heart failure, end-stage chronic obstructive pulmonary disease, etc.) in an effort to help end-stage patients for the best quality of life, and help their families to get through this hard time. It achieves this goal by controlling symptoms including pain and reducing mental, psychological and spiritual suffering.

Palliative medicine is a subject aiming at alleviating pain and pursuing the peace and dignity of dying. It is also a subject combining medical technology with humanities. Palliative care is a basic concept of clinical care. It is the basic skill of medical staff in departments where medical care is provided to end-stage patients (e.g. ICU, emergency room, geriatric and oncology department). In fact, all clinical staff should understand the concept and knowledge of palliative care so that they could help the terminal patients and their family in a better way.

Hospice refers to the care of people at the end stage of life (usually the last half year of life). As patient care in this stage is different from that of acute medical situation in term of patients' needs, treatment measures, place of care, so it is proposed separately. In China, translation of the term "hospice" has been officially determined as "Anning Liaohu" in Chinese in 2016.

The quality of death has gained more and more attention around the world. *The Economist* 2010 survey in the quality of deaths of 40 countries has triggered a policy debate on the provision of palliative care. Since then, Italy, Japan, Russia, Singapore, Sweden and other countries have formulated or updated their guidelines, laws or national plans.¹ An international resolution issued by the World Health Assembly in 2014 called on countries to integrate palliative care into their health care systems.² The 2015 Quality of Death Index published by *The Economist* assessed the death quality of 80 countries using 20 qualitative and quantitative indicators. The survey showed that the death quality of China ranked the 71 th out of 80 countries, behind Britain, Singapore, Mongolia, South Africa, Malaysia, Thailand, Vietnam, India, South Korea, Japan. Chinese Taiwan ranked the sixth, while Chinese Hong Kong ranked the twenty-second.³ The quality of death in mainland China is worth worrying.

EARLY STAGE OF PALLIATIVE CARE IN CHINA

The development of hospice and palliative care (HPC) in China had been slow in its early stage. To cure the disease was the dominated strategy in clinical practice, and the end-stage patients care was of very low quality. The concept of HPC emerged and just started to be accepted at the end of last century in China.

In the late 1980s, the end-stage patient care arised as a nascent concept in China. Tianjin Medical College, currently named as Tianjin Medical University, set up a hospice care research center early in July 1988. Then the first hospice care institution, Shanghai Nanhui Nursing Institute, was established for retired workers in the same year. In 1989, Mr. Wei Li founded the Beijing Songtang Care Hospital.

Subsequently, the concept of cancer pain control has been gradually accepted. In 1990, the Ministry of Health held the first training class on promoting and implementing the WHO principles of cancer pain controlling in Guangzhou China, where some Chinese oncologists such as Prof. Tongdu Li and Prof. Yan Sun participated. Since then, the WHO three ladders principle for control of cancer pain has been gradually adopted and practiced by oncologists around mainland China.

The hospice care was incorporated into the national development plan of medical and health work in 1990s. The First National Symposium and Workshop on Hospice Care was held by the Hospice Care Research Center of Tianjin Medical College in 1991, and in 1992, the First International Symposium on Eastern Hospice Care was held by Tianjin Medical College in cooperation with the American Society of Eastern and Western Death Education and Research. At this symposium, Prof. Minzhang Chen, the Health Minister of China then, attended the symposium and strongly advocated hospice care.

The Committee of Rehabilitation and Palliative Care (CRPC) in China was established in 1994. Prof. Tongdu Li served as the first chief chairman. The establishment of professional societies has laid the foundation for further promotion of this concept in Chinese academic community.

After that, The regional clinical practice of palliative care started under leaderships of some local doctors. The Fourth Hospital of West China University Medical Sciences established a hospice care ward

in 1995, and the Third People's Hospital of Kunming in Yunnan province established its hospice care ward in 1996. However, most of these wards encountered great difficulties, did not sustain and closed shortly.

In 2001, the National Hospice Medical Service Plan sponsored by Li Ka Shing Foundation was carried out in China. There have been more than thirty service sites all over the country. Although this has been a success for the end-stage cancer patient care focusing on pain control, it is irreproducible in mainland China, because it is financially supported by outside charitable funding. Later on, some hospice care wards/departments were established in academic hospitals such as Shanghai Fudan University Affiliated Cancer Hospital in 2006 and Shenyang Shengjing Hospital in 2008. Wards in these two hospitals are still the benchmark for EOLC in China. Beijing Desheng Community Health Service Center opened their hospice care clinic in 2011, and set up hospice care ward in 2012; Zhengzhou Ninth Hospital set up hospice care center in 2011. In 2012, Peking Union Medical College Hospital (PUMCH) began to develop their HPC practice.

Through the implementation of palliative care projects by Shanghai municipal government in 2012 and 2014, 76 pilot facilities for end stage patient care have been built in 17 districts of Shanghai. The local government in Shanghai initiated this project and gave continuous supports for the selected community care provider, which attributed to the rapid development of end-stage care in Shanghai. Although the community based service of end-stage care may be a general trend in the future in China, quite a lot of patients are still willing to spend their last days in large hospitals instead of these community care facilities, and doctors in large hospitals seldom transfer their terminal patients to community hospice wards. The Shanghai's experience showed that the impact of high reputed hospitals on development of palliative care should be emphasized, for their strong educational system and great influence in both academics and publics.

DEVELOPMENT AND CURRENT STATUS

In the past decade, HPC in China has gained much attentions from professionals, societies, government and publics. There has been a great progress nationwide.

Policy from the government

Chinese government has been involved in the hospice

care and provides policy and administrative supports for the end of life care (EOLC). Fortnight Symposium of The National Committee of the Chinese People's Political Consultative Conference (CPPCC) on "Promoting hospice Care" was held in 2016. In 2017, the National Health and Family Planning Commission issued series documents on palliative care, including "the Basic Standards for Hospice Care (Trial)", "the Management Standards for Hospice Care Centers (Trial)" and "the Practice Guidelines for Hospice Care".⁴ Subsequently, five pilot sites on hospice care across the country were launched in Haidian district in Beijing, Changchun city in Jilin province, Putuo district in Shanghai, Luoyang city in Henan province, and Deyang city in Sichuan province. A national training project as the backbone for these pilot hospice care sites was launched in the meantime.

Centers and hospice wards growing

Since the publication of the national guidelines, medical facilities in areas other than the five pilot regions also started to open their hospice care wards, but the staff were not so well trained and were lack of experiences. These facts indicate a broad need for hospice care in China and an extremely arduous burden of training for professionals nationwide on hospice care. It is happy to see a training center for hospice care was established in the Shengjing Hospital affiliated to China Medical University, which is the best hospital in Liaoning province. Besides, Sichuan Hospice Education Center was just born in 2018.

Education and training

Medical education on palliative medicine has developed in recent year. Some universities have opened courses of palliative medicine, such as Peking Union Medical College, Medical school of Peking University, China Medical University and West China University of Medical Sciences. These courses are basically optional courses for undergraduates or postgraduates. Teachers are from various disciplines, mostly oncology. Given the large number of medical schools in China, the proportion of schools offering palliative medicine course is relatively low. Compared with the United States, Britain, Japan, and Chinese Taiwan, where palliative care has been well developed, there is a big gap regarding education in this field.⁵

The needs for continuing medical education (CME) courses on palliative medicine are urgent.⁶ Thus there

have been many CME programs on hospice running in some departments, hospitals, and academic societies as well. Some of them receive support from government.^{7,8}

Academic organizations

Committee of Rehabilitation and Palliative Care (CRPC) was established in 1994, and to date it has more than 20,000 members, mainly oncologists.⁹ In recent years, many professional associations focusing on palliative care have been established, such as the Chinese Association for Life Care,¹⁰ the Subcommittee of Palliative Care in Chinese Association of Geriatric Research,¹¹ the Subcommittee of Hospice care in Chinese Nursing Association, the subcommittee of Cancer Palliative Care and Humanistic Care in China International Exchange and Promotion Association for Medical and Health Care,¹² Chinese Geriatrics Society,¹³ etc. In 2016, the Chinese Children's Palliative Care Cooperative Group was established. These committees or associations have greatly promoted the cognition or acceptance of HPC in Chinese medical professionals.

Public society involvement

In recent years, some non-profit social organizations have been engaged in promotion of hospice care, such as the Beijing Living Will Promotion Association,¹⁴ the China Hospice and Palliative Care Development Foundation,¹⁵ Ren-Ai Charity Foundation¹⁶ and the Life Zen non-profit Cultural Foundation.¹⁷ These non-governmental organizations have greatly enriched the movement of HPC in Chinese publics. Besides, many volunteer groups have also actively committed to the EOLC, such as the palliative care volunteer teams of the Shifang Yuan,¹⁸ the Colorful Leaf and the volunteer team at PUMCH.

PROBLEMS AND PROSPECTIVES

Insufficient education and training resources

The education for professionals is the most important power for continuous development of palliative care in China. The curriculum of training courses on palliative medicine need to be carefully developed. The contents related to death, end-of-life, and the terminal care should be added in school teaching system early and delivered more generally to medical students. Dedicated training courses should be designed for clinicians

who are practicing medicine, as well as for those funeral workers, spiritual care givers, physiotherapists, social workers, and volunteers.

Extensive and profound researches needed

There has no official data that address the demand and quality of terminal care in the country. We need to generate more clinical practice guidelines for HPC in China. Besides, we need to explore what Chinese people believe about the "good death", and what Chinese doctors and nurses need indeed when they provide medical service to dying patients. Apart from the above, extensive researches are needed urgently to ensure the effective intervention can be carried out.

Lack of law and policy support

Law and policy support from the government are indispensable. The social medical insurance system in China need to establish insurance plan that cover hospice care for all terminal patients. Apart from the guidelines issued in 2017, more specific policy proposals for EOLC and laws that provide legitimacy for "allowing citizens to die naturally" and "patients have the power to do their own decision about their death" are needed.

Insufficient medicine for symptom control

Medicine is the basic tool to help patients to relieve their physical and psychological suffering. There are still areas in China where morphine is in shortage. Even in big hospitals, some medicines for symptom control are not accessible, e.g. haloperidol. It is urgent to include these symptom control medicines in the National Essential Drug List to make these medicines accessible to health care facilities at all levels throughout the country for the end-stage patients.

Transformation of attitude towards death

Openly discussing the death is rare in circumstance of Chinese cultural. People believe that maintaining hope and pleasure, keeping good relationship with medical staff and families, being independent, being respected, dying in a favorite place with comfort environment, not being a burden to others are symbols of "good death".¹⁹ Ideas about "life", "death" and "good death" needed to be constantly publicized and discussed. Education about life cycle, quality of life, as well as EOLC are needed, which is important to both professionals and the publics.

To conclude, the aging population in China and the huge annual death toll raise a serious issue of "make people die better". There is an urgent need for the development of HPC in China. Although HPC in China started late and developed slowly, there has been a leap in demand and a rapid progress in recent years. With governmental involvement and policy supports, and in joint efforts from both professionals and publics, HPC in China can have a promising prospect in the future. Reaching the goal of making people die comfortably with dignity will be a bright interpretation for the progress of Chinese civilization.

Conflict of interests statement

The author has no conflict of interests disclosed.

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