

Development of Palliative Care in China: A Tale of Three Cities

ZHENYU YIN,^{a,b} JINXIANG LI,^c KE MA,^d XIAOHONG NING,^e HUIPING CHEN,^c HAIYAN FU,^d HAIBO ZHANG,^{a,f} CHUN WANG,^b
EDUARDO BRUERA,^a DAVID HUI^a

^aDepartment of Palliative Care and Rehabilitation Medicine, MD Anderson Cancer Center, Houston, Texas, USA; ^bDepartment of Geriatric Oncology, Nanjing Drum Tower Hospital, The Affiliated Hospital of Nanjing University Medical School, Nanjing, Jiangsu, People's Republic of China; ^cWest China Fourth Hospital of Sichuan University, Chengdu, Sichuan, People's Republic of China; ^dThe Third People's Hospital of Kunming, Kunming, Yunnan, People's Republic of China; ^ePeking Union Medical College Hospital, Beijing, People's Republic of China; ^fGuangdong Provincial Hospital of Chinese Medicine, Guangzhou, Guangdong, People's Republic of China

Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. China • Health Services • Neoplasms • Palliative Care • Program Development

ABSTRACT

Background. China is the most populous country in the world, but access to palliative care is extremely limited. A better understanding of the development of palliative care programs in China and how they overcome the barriers to provide services would inform how we can further integrate palliative care into oncology practices in China. Here, we describe the program development and infrastructure of the palliative care programs at three Chinese institutions, using these as examples to discuss strategies to accelerate palliative care access for cancer patients in China.

Methods. Case study of three palliative care programs in Chengdu, Kunming, and Beijing.

Results. The three examples of palliative care delivery in China ranged from a comprehensive program that includes all major branches of palliative care in Chengdu, a program that is

predominantly inpatient-based in Kunming, and a smaller program at an earlier stage of development in Beijing. Despite the numerous challenges related to the limited training opportunities, stigma on death and dying, and lack of resources and policies to support clinical practice, these programs were able to overcome many barriers to offer palliative care services to patients with advanced diseases and to advance this discipline in China through visionary leadership, collaboration with other countries to acquire palliative care expertise, committed staff members, and persistence.

Conclusion. Palliative care is limited in China, although a few comprehensive programs exist. Our findings may inform palliative care program development in other Chinese hospitals. *The Oncologist* 2017;22:1362–1367

Implications for Practice: With a population of 1.3 billion, China is the most populous country in the world, and cancer is the leading cause of death. However, only 0.7% of hospitals offer palliative care services, which significantly limits palliative care access for Chinese cancer patients. Here, we describe the program development and infrastructure of three palliative care programs in China, using these as examples to discuss how they were able to overcome various barriers to implement palliative care. Lessons from these programs may help to accelerate the progress of palliative cancer care in China.

INTRODUCTION

With a population of more than 1.3 billion, China has one fifth of the world's population, and cancer is the leading cause of death. In 2015, there were approximately 4.3 million patients with newly diagnosed cancer and more than 2.8 million cancer deaths [1]. Many cancer patients already have an advanced disease at the time of diagnosis, which is associated with significant physical symptoms, psychological distress, and existential concerns throughout their disease journey [2, 3]. Many of these care needs are not adequately addressed for a vast majority of cancer patients [4, 5].

Over the past few decades, palliative care has evolved as a specialty that addresses the care needs of patients living with advanced illnesses. Specifically, palliative care is defined as “an

approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual” [6]. Numerous studies have demonstrated enhanced outcomes associated with palliative care, ranging from improvements in physical and psychosocial symptoms, quality of life, quality of end-of-life care, satisfaction, costs of care, and survival [7–9]. Importantly, palliative care should be provided early and throughout the disease trajectory [10].

Although palliative care is now widely available in Western countries, it is extremely limited in mainland China [11–14].

Correspondence: David Hui, M.D., Department of Palliative Care and Rehabilitation Medicine Unit 1414, University of Texas MD Anderson Cancer Center, 1515 Holcombe Boulevard, Houston, Texas 77030, USA. Telephone: 713-745-7082; e-mail: dhui@mdanderson.org Received March 13, 2017; accepted for publication June 8, 2017; published Online First on July 24, 2017. <http://dx.doi.org/10.1634/theoncologist.2017-0128>

According to a 2016 report, only 0.7% (146/22,000) of hospitals offered palliative care [15]. This is consistent with our search of the International Association for Hospice and Palliative Care Global Directory, in which fewer than 10 palliative care programs were listed. A survey by the Chinese Association for Life Care (CALC) revealed that among the 15,300 cancer deaths in Beijing each year, 9 of 10 patients had no access to palliative care [16]. This partly explains why mainland China ranked 71st among 80 nations in the 2015 Quality of Death Index [17].

To date, there are only a handful of palliative care programs operating successfully in China [14, 18, 19]. A better understanding of the level of palliative care services offered at these programs and how they overcome the barriers to provide care would inform how we can further integrate palliative care into oncology practices in China. Here, we describe the program development and infrastructure at the palliative care programs of three institutions, using these as examples to discuss how to accelerate palliative care access in the most populous country in the world. After extensive consultation with palliative care practitioners in China and review of the Global Directory of Palliative Care Services by the International Association for Hospice and Palliative Care, we identified three programs to showcase because they represent a few of the most reputable centers of palliative care development in China and may serve as models of care to support further growth of palliative care in China.

WEST CHINA FOURTH HOSPITAL OF SICHUAN UNIVERSITY

The palliative care department in West China Fourth Hospital of Sichuan University is currently the only such program in the province, which has a population of 81 million. It represents one of the most established and comprehensive palliative care programs in China. It was first started by an internist, Dr. Jinxiang Li, in 1996 after he studied palliative medicine in the U.K. under Professor Dame Cicely Saunders between 1994 and 1995. Between 2005 and 2008, Dr. Li furthered his study under Dr. Robert Twycross, a pioneer of the hospice movement, and obtained his master's degree in Palliative Medicine from the University of Oxford and another master's degree in Palliative Medicine from Cardiff University.

Initially, the program consisted of two inpatient beds under the Geriatrics Department. Over the years, he and his colleagues established institutional guidelines for opioid prescribing [14] and optimized clinical pathways in acute palliative care and home care settings for patients with advanced cancer and noncancer diseases. Sponsored by the Li Ka Shing Foundation's National Palliative and Hospice Care Project and Cyrus Tang Foundation, the Palliative Care Department was formally founded in 2004.

By 2016, this program was staffed by 12 palliative care physicians and 24 nurses. The acute palliative care unit has grown to 48 beds with more than 600 inpatient admissions per year (Table 1). An outpatient clinic was also started in 1996 and has more than 4,800 visits annually. Since 2007, a home palliative care service also became available with a daily census of 10 patients. The palliative care team offers home care services and delivers pain medications for patients in the last days of life. This program is supported by the Li Ka Shing Foundation and is free for low-income individuals. This program also provides pediatric palliative care to more than 100 patients per year. It is currently a member institution of the International Association

for Hospice and Palliative Care and the Asia Pacific Hospice Palliative Care Network (APHN).

A new initiative was started in 2016 by creating a palliative care network with 18 community medical facilities in Chengdu. Supported by video conferencing technology, these centers offer palliative care outpatient consultations and home palliative care services. In addition to pain and symptom management, the palliative care service offers bereavement counseling at home.

Apart from clinical service, Dr. Li and his team also devoted many efforts to the education for health care practitioners and medical students. More than 20,000 medical providers from different regions of China have received training from this program since 2005. Dr. Li contributed to several textbooks and teaching materials, such as *Palliative Medicine* [20], and introduced master's and doctoral education programs in Sichuan University.

THE THIRD PEOPLE'S HOSPITAL OF KUNMING CITY

The Third People's Hospital of Kunming City is the most established palliative care department in Yunnan Province and has one of the largest palliative care units in China. Under the leadership of Dr. Ke Ma, it started with 20 beds, 3 physicians, and 6 nurses in 1996, expanding to include 70 beds, 9 physicians, and 28 nurses by 2016. It has more than 700 admissions per year with an in-hospital mortality rate of 80% and a median length of stay of 26 days (Table 1).

This program has a strong expertise in pain management, offering various pain interventions for refractory cancer pain, such as percutaneous kyphoplasty, image-guided tumor ablation, and endogenous field hyperthermia technology [21–23]. In addition to pain management, this program also provides symptom management (e.g., dyspnea, cachexia), psychosocial care, and spiritual care for patients and families, along with bereavement care. More than 120 volunteers provide psychosocial support.

Dr. Ke Ma, a surgeon by training, studied palliative medicine at Flinders University in Australia in 1998 for 1 month and decided to dedicate his career to palliative care. Since then, he and his colleagues have continued to expand their palliative care knowledge by site visits at various institutions in Taiwan.

In 2006, the Palliative Care Department of Third People's Hospital of Kunming became one of the first member units of CALC. Later, in 2011, they joined APHN. Because Yunnan is a minority enclave with 52 different ethnic groups, this palliative care program has a strong multicultural component.

The Palliative Care Program also takes on the responsibility of educating and training medical students and health care providers. From 1999–2004, it offered elective courses in palliative care for undergraduate students in Kunming Medical University. Dr. Ma's book, *Palliative Therapy*, was used as the textbook for this course. Continuing education courses have also been provided since 2010, with more than 200 health care practitioners trained from all over the country each year. This program has also collaborated with other universities on several research studies.

In 2009, the Palliative Care Program undertook a research project to study the state of urban palliative care service in Kunming, which provided the National Ministry of Health with information for its decision making related to end-of-life care delivery. In 2015, they participated in an international collaboration project with Lund University in Sweden entitled "Palliative Care of the Elderly: A Comparative Study of China and Sweden."

Table 1. Characteristics of palliative care clinical programs

Hospital name	West China Fourth Hospital of Sichuan University	The Third People's Hospital of Kunming City	Peking Union Medical College Hospital
Location	Chengdu, Sichuan	Kunming, Yunnan	Beijing
Hospital type	Tertiary care general hospital with 600 beds	Tertiary care general hospital with 750 beds	Tertiary care general hospital with 1,800 beds
Year palliative care program started	1996	1996	2012
Palliative care program staffing (full-time equivalent)			
Physicians	12	9	1
Nurses	24	28	1
Social workers	1	0	0.5
Volunteers	110	120	60
Palliative care unit			
Number of beds	33	70	NA
Duration (yr)	21	21	NA
Average number of discharges/month	50	60	NA
Medium duration of inpatient stay (days)	20	26	NA
Median survival from admission (days)	30	18	NA
Inpatient mortality rate	90%	80%	NA
Inpatient consultation team			
Availability	24 hours/ 7 days per wk	24 hours/ 7 days per wk	Working hours from Monday to Friday
Numbers of referrals/month	20	4	3–4
Median survival from inpatient referral to death (days)	15	18	NA
Outpatient clinic			
Availability (days/wk)	5	NA	3
Average number of new patient consultations/month	240	NA	19
Average total number of patient visits/month	400	NA	50
Median survival from referral to death (days)	110	NA	76
Hospice or home palliative care program			
Daily census	10	NA	NA
Median survival from referral to death (days)	55	NA	NA

Abbreviation: NA, not available.

PEKING UNION MEDICAL COLLEGE HOSPITAL

Peking Union Medical College Hospital is one of the leading hospitals in China. Its palliative care service started in 2012 by oncologist Dr. Xiaohong Ning. Initially, this service was under the Oncology Department, and in 2014 Dr. Ning transferred into the Geriatrics Department. As a relatively young program, it currently consists of seven physicians (the equivalent of one full-time physician) and five nurses (the equivalent of one full-time nurse) (Table 1). The outpatient clinic has 50 visits for palliative care per month, averaging 30 minutes for consultations and 20 minutes for follow-up visits. The inpatient consultation service sees approximately 50 patients per year. The main symptom for palliative care referral was pain.

Early in her career, Dr. Ning was concerned about the suffering cancer patients experienced and was eager to learn how to alleviate their distress. After visiting several palliative care programs in Taiwan in 2012, she was inspired to dedicate her career to palliative care. She completed a course at St. Christopher Education Center in the U.K. and was certified as a trainer

of the St. Christopher's Quality End of Life Care for All program. After completion of the Training the Trainer Program, Dr. Ning was identified by the St. Christopher Education Center and Living Will Promotion Association as a key coordinator for development of palliative care in mainland China. She spent additional time seeking training in Taiwan and Hong Kong before returning to Beijing to start the palliative care program at her institution.

The Beijing program has been active in providing teachings to health care professionals in China. In 2014, it introduced the postgraduate course in palliative care in Peking Union Medical College. The number of students has increased from 20 to more than 100 over the past 3 years. Dr. Ning has also expanded the palliative care training with the platform of the Chinese Association Geriatric Research Palliative Care Branch, as well as the Ubiquitous Massive Open Online Course system, to more medical students and health care providers. The training program for health care providers in Beijing is supported by APHN.

In addition to program development, patient care, and education, Dr. Ning and her colleagues have been very active in advocacy and educating the public about various palliative care issues, such as euthanasia, end-of-life care, and prognostic disclosure, through the mass media, such as China Central Television, China National Radio, and Beijing Television.

DISCUSSION

We provided three different examples of palliative care delivery in China, ranging from a comprehensive program that includes all major branches of palliative care in Chengdu, a program that is predominantly inpatient-based in Kunming, and a smaller program at an earlier stage of development in Beijing. Despite the numerous challenges related to the limited training opportunities, stigma on death and dying, and lack of resources and policies to support clinical practice, these programs were able to overcome many barriers to offer palliative care services for patients with advanced diseases. It is important to point out that the examples above represent some of the most respected palliative care programs in China, suggesting that there is tremendous opportunity for further development of palliative care in China.

One of the major barriers to palliative care delivery is the stigma associated with the end of life. Death and dying is a major taboo in Chinese culture. For example, Chinese often avoid saying the number four because its pronunciation is similar to death. Indeed, patients are often referred to palliative care late in the disease trajectory in the three centers (Table 1). When “palliative care” was first introduced in China, the name “Lin Zhong Guan Huai (临终关怀)” was used, which translates to “terminal care.” Understandably, this term is regarded by both the general public and health care professionals as unlucky and presents as a major impediment to referral. Recognizing this challenge, Dr. Jinxiang Li adopted the term “Gu Xi Guan Huai (姑息关怀)” in 1996 for his department, which means “care to alleviate suffering.” This name is now widely used in China along with another name, “Huan He Yi Liao (缓和医疗),” which has a similar meaning. This rebranding effort is similar to the name change from “palliative care” to “supportive care” in many Western countries [24, 25].

Another major barrier that hinders the development of palliative care in China relates to the shortage of professionally trained health care providers. Courses in palliative care are rarely included in the medical school curricula [26]. Indeed, less than 15% of medical interns felt that they were adequately trained in basic pain and symptom management [16]. A recent survey also found that most oncologists (69%) reported that they had never received formal education in palliative care [27]. This major deficiency in education has contributed to the vacuum in the number of palliative care specialists, the absence of qualified teachers and role models, and the unfamiliarity to palliative care among oncologists and other clinicians. Importantly, a recent study found that oncologists who were less comfortable with end-of-life care were also less likely to refer patients to specialist palliative care [28]. This explains why only 32.6% of Chinese oncologists stated in a survey that they were willing to refer cancer patients to palliative care at the time of diagnosis [27]. Taking a bottom-up approach, the leaders and core members of the three programs above have all studied palliative medicine in Western countries and the regions of

Taiwan and Hong Kong. Furthermore, these three centers are now involved in the training and dissemination of knowledge regarding palliative care regionally. For example, Peking Union Medical College and Sichuan University both offer elective postgraduate courses in palliative care [11]. In addition to training abroad and local educational conferences and workshops, other educational initiatives, such as Education in Palliative and End-of-Life Care [29] and Prepare, Embrace, Attend, Communicate, and Empower [30], that can be provided online in a modular format may be translated into Chinese to facilitate mass education. The National Comprehensive Cancer Center Network (NCCN) cancer treatment guidelines have been translated into Chinese and are often used by Chinese oncologists; however, the NCCN Palliative Care Guideline has not yet been translated [31]. Finally, it may be helpful to establish centers of excellence in palliative care to facilitate and standardize the training of clinicians throughout China.

One of the major reasons for lack of trained professionals is that palliative care is not yet an accredited specialty in China. Until this is established, it is difficult to encourage medical students to pursue this as a career, and it is challenging to ask hospital administrators for resources. The Committee of Rehabilitation and Palliative Care, the largest national organization of palliative care in China, has been collaborating with the National People's Congress to actively apply for the establishment of cancer palliative care subspecialty. This top-down approach could significantly stimulate the growth of palliative care in China.

In addition to a lack of health professionals trained in palliative care, there is limited awareness of the concept of palliative care among the general public in China [16]. A survey conducted in Wuhan, one of the biggest cities in central China, found that 36.9% had never heard of palliative care and 49.5% had a very limited understanding of this discipline [32]. This lack of awareness means few advocacy groups are available and translates to a low level of interest among public officials and hospital executives to support these programs. Encouragingly, some leaders in palliative care are taking active steps to educate the public. For example, Dr. Ning from Beijing Union Hospital is actively engaged in education campaigns and national television programs to help raise the awareness on palliative care-related issues.

Governmental policies also have a critical role in the development of palliative care. Despite the rapidly aging population, there are no national policies to guide end-of-life care to our knowledge. Unfortunately, many services under palliative care are not covered by the national health insurance [2]. This lack of coverage creates a major barrier for the development of this field because many hospital executives believe that palliative care programs are financially not sustainable. The three programs described above were able to thrive locally because of the support of hospital leadership and the persistence of the palliative care program leaders to advocate for resources. At the same time, philanthropic support, such as the Li Ka Shing Foundation and the Cyrus Tang Foundation, represents another major source of funding. Although indigent patients at Chengdu were able to receive free palliative care through foundation support, this is more of an exception than the rule in China, and patients at the other two institutions could only access palliative care if they were able to pay. Policy makers of

the health care system may also be made aware of the growing body of literature to support that palliative care could result in improved health care value by improving quality of life while decreasing the cost of care, predominantly through cost-avoidance measures [7, 33, 34]. Indeed, palliative care is a highly sustainable discipline in many countries worldwide.

Access to opioids has been increasing in China, but it remains low. According to 2011–2013 data, the defined daily dose for statistical purposes was 91 per million people per day for China compared to 43,879 for the U.S. [35]. Although many strong opioids have been approved and marketed in China [36], their use outside of palliative care programs remains uncommon because of limited training in opioid prescribing, state policies (e.g., duration of opioid prescriptions is often restricted to 7 days), and apprehensions about the risk of addiction, diversion, and opioid-related adverse effects. In contrast, patients seen by the three palliative care programs had greater access to opioids. These programs utilize a combination of strategies to improve opioid access, including routine symptom screening, pain management guidelines and pathways (e.g., World Health Organization Analgesic ladder), clinician training, patient and family education, strict monitoring policies (e.g., identity card recording, double lock and key), and opioid disposal programs.

Given the vast unmet patient care needs in China and the growing evidence to support the benefits associated with palliative care, this discipline will likely grow exponentially over the next few decades. Unique to the Chinese culture is the widespread use of traditional Chinese medicine. Upon further research, some of these therapies, such as acupuncture, may offer innovative approaches for symptom management [37]. Of note, the number of hospitals with more than 50 beds in the U.S. that have a palliative care program increased rapidly from

25% in 2000 to 65% in 2010 [38]. Furthermore, a vast majority of cancer centers in the U.S. now provide palliative care in the U.S. [39]. This kind of “great leap forward” for palliative care can also happen in China, but it will require fundamental policy changes, investment into clinical programs, emphasis in education, and stimulation for research.

CONCLUSION

Despite the clinical, educational, societal, and financial challenges, the three programs examined here took a bottom-up approach to overcome many barriers to provide a sustainable model of care at each institution. Common to all three programs were the visionary leadership, the committed staff members, the collaboration with other countries to acquire palliative care expertise, and persistence. Our findings may inform palliative care program development in other Chinese hospitals. Further work is needed to standardize the clinical care delivery and education of palliative care in China, and to promote national policy and public education through advocacy and research.

AUTHOR CONTRIBUTIONS

Conception/design: Zhenyu Yin, David Hui, Chun Wang, Eduardo Bruera
Provision of study material or patients: Zhenyu Yin, David Hui, Jinxiang Li, Ke Ma, Xiaohong Ning, Huiping Chen, Haiyan Fu
Collection and/or assembly of data: Zhenyu Yin, David Hui, Haibo Zhang
Data analysis and interpretation: Zhenyu Yin, David Hui
Manuscript writing: Zhenyu Yin, David Hui
Final approval of manuscript: Zhenyu Yin, David Hui, Jinxiang Li, Ke Ma, Xiaohong Ning, Huiping Chen, Haiyan Fu, Haibo Zhang, Chun Wang, Eduardo Bruera

DISCLOSURES

The authors indicated no financial relationships.

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For Further Reading:

Julia Berendt, Stephanie Stiel, Steffen T. Simon et al. Integrating Palliative Care Into Comprehensive Cancer Centers: Consensus-Based Development of Best Practice Recommendations. *The Oncologist* 2016;21:1241–1249; first published on July 20, 2016.

Implications for Practice:

General and specialized palliative care (SPC) is an integral part of comprehensive cancer care. However, significant diversity concerning the design of SPC in the German Comprehensive Cancer Center (CCC) Network led to the establishment of consensual best practice recommendations for integration of SPC into the clinical structures, processes, research, and education throughout the CCC network. The recommendations contribute to a greater awareness relating to the strategic direction and development of SPC in CCCs. The access to information about SPC and access to offers regarding SPC shall be facilitated by implementing the recommendations in the course of treatment of patients with cancer.