Palliative Care for the Ageing Group in China

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Abstract

Since the end of the 20th Century, China has become an ageing society, with numerous elderly people facing both healthy and mental sufferings in their last days of life. Under such circumstances, Palliative Care appeared in China and has been developing with more and more concerns from the society. This paper mainly demonstrates the Palliative Care for the Ageing Group in China, in terms of its social background, the status in quo and development, the experiences of western countries, the challenges China faces as well as the suggested solutions, with a special focus on the role everyone could play in their devotion for the Palliative Care.

Since 1988 with the first Palliative Care Center set up in China, plenty of Palliative Care Hospitals appeared in many big cities and are growing in strength. Though the experiences of western countries have set up good models for future development, Palliative Care in China still has a long way to go—the insufficient economical input, the traditional cognition about life and death, the lack of professional nursing workers, and the immature mode and system are all big challenges. To solve these problems, on the one hand, the strong support from the government on both the policy and financial input is quite necessary, combing with the completion of medical security system; on the other hand, a mind revolution on the conventional ideas of death, enhancing the education of respecting life and the elderly, and calling attention of the whole society to the Palliative Care are other effective and sustainable ways confronting the challenges. Only with the effort of the government, every individual and every family, can Palliative Care in China really improve the quality of life of elderly patients physically and spiritually, and help establish an all-age-friendly society everyone shares.

Key words: Palliative care, the aged, China
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“You matter because you are. You matter until the very last moment of your life. And we will do all we can. Not only to help you die peacefully. But to live until you die.”

— Dame Cicely Saunders “Founder of the Modern Day Hospice Movement”

1. Introduction of Palliative Care

1.1 WHO Definition

According to the WHO Definition of Palliative Care, Palliative Care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

In other words, People in their late stage of their life should be surrounded with love and help, have less pain, less suffering, so that they could walk through their last journey with dignity. At the same time family members should also get social and
psychological support in order to pass smoothly through bereavement.

1.2 Goal of Palliative Care

The goal is not to cure, but to relieve suffering and provide the best possible quality of life for patients and their families. Well-rounded palliative care programs also address mental health and spiritual needs. The focus is not on death, but on compassionate specialized care for the living.

1.3 How the Care Is Provided — by a Team

Palliative care is typically carried out by a team of professionals who are committed to working together to provide the patient and their family comprehensive care. This team may include palliative care doctors, nurses and social workers. Chaplains, massage therapists, pharmacists, nutritionists and others might also be part of the team. The team helps the patient and their family navigate through the health care process, and assist in making health care choices that are right for them.

1.4 What Care Is Provided

The palliative care team provides caring for the physical, emotional, and spiritual needs of patients and their families.

- Physical: Pain and symptom control (relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping.)
- Emotional and spiritual support for you and your family (a comfortable and supportive atmosphere that reduces anxiety and stress, fear to the coming death.)

1.5 Palliative Care & Hospice

Palliative care is NOT the same as hospice care. Palliative care may be provided at any time during a person’s illness, even from the time of diagnosis. And, it may be given at the same time as curative treatment.

Hospice care always provides palliative care. However, it is focused on terminally ill patients — people who no longer seek treatments to cure them and who are expected to live for about six months or less.
1.6 History of Palliative Care

Palliative care began in the hospice movement in Britain. In 1967, Dr. Cicely Saunders, a British physician began the modern hospice movement by establishing St. Christopher's Hospice near London.

Since then, with national differences in focus and application, Hospice has rapidly expanded throughout the world. After 4 decades, palliative care is well established and delivered in developed countries like America, UK and Australia. Now there are more than 60 countries and regions worldwide which have opened hospice care services. The well known global network is the International Association for Hospice & Palliative Care (IAHPC) which aims to promote Hospice & Palliative Care worldwide.

2. Palliative Care Development for the Ageing Group in China

2.1 Social Background

According to the UN definition of an ageing society, since 2000 China has become an aging society when a national census showed people aged 65 and above made up 7 per cent of the population. Now the number of people aged 60 and older has reached 160 millions, and the annual increasing rate for people aged 80 and older is 5%.

<table>
<thead>
<tr>
<th>Year</th>
<th>Population over 60 years old (million)</th>
<th>Percentage of the total population(%)</th>
<th>Population over 65 years old (million)</th>
<th>Percentage of the total population(%)</th>
<th>Number of death (million)</th>
<th>Death rate(%)</th>
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Table1
Table 1 clearly shows that the population over 60 and 65 years old has always been increasing, and it is estimated that the number will continue increase in the future. By 2050, one quarter of the total population in China will be the people over 65 years old. Moreover, the death rate is also increasing annually.

Therefore, the needs for medical care and support for daily living among the elderly have been increasing. Both physically and psychologically, more and more elderly people are suffering from chronic illness and their physical functions are getting worse. There are great demands for psychological consultation, health promotion and disease prevention and control. It also becomes an increasingly important problem concerning all society how to make the old feel happy and comfortable in their remaining years, especially in the extreme hours of their lives, how to let them leave the world with dignity, and how to make their relatives and friends have less sadness. Thus the need emerged to set up and develop palliative care for the ageing group in China.

2.2 Palliative Care Development in (Mainland) China

In China Palliative care for the elderly is translated into Lin Zhong Guan Huai (临终关怀)—Caring for a Person Approaching Death. At the beginning of 1990s Palliative care is introduced into China. Since then, Palliative care has taken root in China and has made remarkable progress as trainings have been carried out by the government and organizations, more and more people are coming to understand and accept the idea, and more than 200 multiform hospice care organizations in 24 provinces and regions have been set up nationwide.

2.2.1 Forms of Palliative Care in China

There are three forms of palliative care services in China:

• A small number of palliative care hospitals;

• About 200 end-of-life wards in medical institutions, the main form of service;

• Home-based hospice service, like the 30 hospice “Ning Yang Yuan”（“宁养院”）
established by the Li Ka Shing Foundation (LKSF).

2.2.2 Progress and Achievements

- In 1987 the first hospice in China was founded — Beijing Song Tang Hospice.

The mission statement of Song Tang Hospice is: “To love everyone from the bottom of our hearts.”

In China, when all adult family members are employed outside the home, there is no one to care for the terminally ill; therefore, out-of-home care becomes necessary. Beijing Song Tang Hospice, an inpatient facility in China, has a nursing assistant’s bed in the room with the patient in order to attend to a patient’s needs twenty-four hours per day. The program survives on charitable contributions and the periodic assistance of foreigners who come to China to help provide care.

- In 1988 the first hospice care research center was set up in China — Hospice Research Center in Tianjin Medical College.

It symbolizes the embarking of hospice research and practice in China. With clinical ward established later in 1990, the center actively shoulders the tasks of publicizing the benefits of hospice care and training staff. The public media’s reports about the center aroused a strong social reaction to hospice care. Various hospice programs gradually appeared in big cities.

At the beginning of 1990s, Tianjin Research Center held a series of training classes, lectures and seminars over the country with two thousands of medical, nursing, and psychological workers attended, which facilitated the formation and development of the care-giver team.

- In May 1992, the First Eastern and Western International Hospice Conference was held in Tianjin.

The Ministry of Public Health decided to bring hospice care into the national medical and health development plans. In the opening ceremony Professor Chen Minzhang, the former Minister of Health said: “Take care of the patients in their late
stage of life, not only to maintain the person's dignity, but also to alleviate the burden on their family and institution, it is also a part of developing social productivity, is a philanthropic act without negative result.” After the conference, more and more hospice programs emerged over the country, indicating the blossom of hospice care development.

• In 1993 Palliative Care Committee was set up in Chinese Association of Mental Health

• In 1994 The Committee of Rehabilitation and Palliative Care (CRPC, China) was first established, which focuses on the academic and theory research and investigation.

• In 1996 Chinese Journal of Hospice started publication.

• In 1998 the Li Ka Shing Foundation (LKSF) set up China's first free hospice “Ning Yang Yuan” (“宁养院”).

Hong Kong entrepreneur Li Ka-shing pioneered free hospice care services in the mainland. In 1998, the Li Ka Shing Foundation (LKSF) set up China's first free hospice “Ning Yang Yuan” (“宁养院”) at the First Affiliated Hospital of the Shantou University Medical College. It is a home-based care program which provides free service for impoverished cancer patients.

• In 2001 the LKSF Foundation extended the service nationwide by The National Hospice Service Program.

Adopting this similar model, in 2001 the Foundation extended the service nationwide by The National Hospice Service Program. The annual funding of this Program is 25 million RMB. Each Hospice Unit receives 1.2 million RMB per year. Until now the service has been further expanded to 30 hospices throughout 30 cities of 24 provinces, benefiting more than 70,000 patients. The programs promote volunteers to support the service. Presently, more than 8,000 volunteers have participated in the program and 78% of the volunteers are university students.
In 2006 the Chinese Association for Life Care was set up—a nationwide regulatory organization.

Set up in 2006, the Chinese Association for Life Care would act as a nationwide regulatory organization in the field of end-of-life care. The mission of the association was to regulate services across the nation, organizing academic communication and domestic and international exchanges to improve the quality of care in China. The association, composed of medical workers, psychological consultants, legal workers, religious workers, volunteers, public media, and the respective government section would engage in the development of end-of-life care, palliative care, gerontology research and healthcare for the elderly.

In 2007 Emperor Foundation funded the establishment of Hubei Hong Kong Emperor Elderly Care Center.

Hubei Hong Kong Emperor Elderly Care Center was established in 2007, funded by the Emperor Foundation of Hong Kong Emperor Group, to provide hospice care for the lonely elderly people. Up till early 2009, the foundation has funded over RMB 10 million to the project and will continue to subsidize the operation expenses of the Centre on a yearly basis. A total of 475 dying senior citizens have received special care at the center since its operation.

In April 2009 Albert Yeung Sau Shing Charity Foundation (Shunping) Elderly Care Centre was established.

Hong Kong Entrepreneur Albert Yeung founded Albert Yeung Sau Shing Charity Foundation in 2008. In April 2009, the foundation has donated RMB 1.2 million to establish "Albert Yeung Sau Shing Charity Foundation (Shunping) Elderly Care Centre" joint with Civil Affairs Bureau of Shun Ping, Hebei Province. The centre provides accommodation and hospice care services.

Today, the palliative care has been carried out widely in China, with totally more than 200 multiform hospices. In addition, many medical schools and nursing undergraduate education programs have offered elective courses on palliative care,
and textbooks on hospice palliative care and a mass of academic papers and literature have also been published.

Admittedly, China's palliative care development is regionally uncoordinated, with services still rare and located only in major cities like Tianjin, Beijing, Shanghai, Chengdu, and Guangzhou.

3. Experiences of the United States

The first hospice in the United States was established in New Haven, Connecticut in 1974. Hospice in the United States has grown from a volunteer-led movement to improve care for people dying alone, isolated, or in hospitals, to a significant part of the health care system. Hospice is the only Medicare benefit that includes pharmaceuticals, medical equipment, twenty-four hour/seven day a week access to care and support for loved ones following a death. Hospice care is also covered by Medicaid and most private insurance plans. Moreover, charity donations are widely used in the hospice programs. Most hospice care is delivered at home. Hospice care is also available to people in home-like hospice residences, nursing homes, assisted living facilities, veterans' facilities, hospitals, and prisons. Today there are more than 4,700 hospice programs in the United States. Hospice programs cared for 965,000 people enrolled in Medicare in 2006, and nearly 1.4 million people in the United States in 2007, with more than one-third of dying Americans utilizing the service.

To the palliative care development in China, the highlight of the experiences of America lies in its expense mode covered under Medicare and Medicaid, which is funded by the United States government. Since this benefit covers all services, medications and equipment related to the illness, patients eligible for Medicare or Medicaid will pay few out of pocket expenses related to their hospice care. The same expense mode can also be applied to the palliative care in China, combining with the implementing of China Social Insurance Legislative Update.
4. The Challenges China Faces in Promoting Palliative Care

Though the experiences of western countries have set up good models for future development, Palliative Care in China still has a long way to go— the insufficient economical input, the traditional cognition about life and death, the lack of professional nurses and specialists, and the immature mode and system are all big challenges.

4.1 Insufficient Economic Input & Immature Health Care System

Some experts believe a lack of funding is the main obstacle to hospices thriving over the country. The economical fund from the government input and society donation is quite limited, which directly lowers the quality and quantity of palliative care service. Many hospices have to raise money from the society; some hospices even could hardly support itself for the normal run. Besides, current medical insurance only covers treatment and medicine costs, but for a hospice included in the insurance system, much expenditure is incurred in the care of the elderly and such palliative care expense is not covered by medical insurance. In the less developed areas, many hospices are not included in the medical care system. Furthermore, many elderly persons are not even covered by medical insurance, and they have no or very low pensions.

Overall, a mature mode for the palliative care development has not been established in China, which is the root of the insufficient fund.

4.2 Traditional Cognition about Life and Death

Traditional cognition about life and death has impeded the development of palliative care. In China, the term Palliative Care is still very new for the concept has not been widely accepted that terminal patients need special care in their last days. Patients and families also consider hospice or palliative wards as places to wait to die, so they are unwilling to go for palliative care because it makes them desperate. Until now, not many people understand that palliative care can be helpful for terminal patients just diagnosed with cancer, especially the elderly.
China has been regarded as a **death-denying** society. The pursuit of longevity is inherent in Chinese culture, and people avoid mentioning death. For example, since 1987, when Song Tang Hospice was established in a corner of the Fragrance Hills in the western suburb of Beijing, it has moved 11 times. Some moves were prompted by strong protests from local residents who complained that there were often coffins outside the hospice. The family members usually try to hide the truth from the terminally ill patient in order to avoid any fear or anxiety. This is in keeping with the Confucian practice of benevolence and compassion.

Moreover, Chinese values **filial piety** very much, and proper care of one’s parents is the most fundamental duty. In most regions, elderly Chinese prefer to die in their homes with their children beside them. Children who send their parents to hospices to wait for death are widely seen as lacking in filial piety.

Therefore, the rooted idea about life and death has been an influential obstacle in promoting the palliative care in China.

### 4.3 Lack of Professionalism

- **Lack of knowledge and skills**

  In some surveys concerning health professionals’ self-evaluation about their knowledge and skills in palliative medicine, a majority of participants showed unfavorable confidence and expressed their need for more training. Clinicians are more skilled in dealing with common symptoms such as pain, but feel incompetent in dealing with less common ones like depression and anorexia. Apart from medical skills, **communication** is also a big problem. Let alone communication with specific tasks such as truth telling, decision making, or breaking bad news, general communication skills of average physicians are very poor as a result of “the illness-centered” medical education.

- **Lack of registered nurses and specialists**

  Another obstacle in providing hospice care is the lack of registered nurses and specialists. According to a speech made by Vice-Health Minister Ma Xiaowei in late
2005, the ratio between wards and nurses even in first-level hospitals in China is only 0.26 to 1 while in developed countries, it is often 1 to 1. Given this shortage, elders in the hospices could only be tended by their family members or by unprofessional nursing workers who are mostly from the rural areas who has little knowledge about palliative care as well as professional trainings. At Song Tang Hospice, in 2006 the number of registered nurses is 25 and of nursing workers, 90. “We have no choice but to train nursing workers to provide all non-medical services to the patients and the elders, ranging from washing clothes to chatting with them to ease their pain,” said Zhu Lin, the vice-president of Song Tang. "We do not have enough psychiatrists in the Western sense, but in our own way, every nurse or nursing worker plays such a role," he added.

5. Solutions to the Problems

5.1 Policy and Financial Support from the Government

The essential and ultimate solution to promote the rapid development of palliative care in China is the policy and financial support form government.

On the one hand, the government should establish related policy and law to ensure the standardization and regulation of palliative care, and carry out them accordingly. Moreover, palliative care is a systematically social project, which should be a part of Social Security System. Thus, using for reference the western experiences especially the American mode would be an effective solution to the currently immature situation of palliative care for the elderly. The Chinese government is currently implementing a massive and ongoing upgrade of citizen access to social security and quality healthcare. This analysis suggests that it would be logical to include hospice services in this upgrade of the Medical Care System so that more and more elderly patients can benefit from it.

On the other hand, the central and local government should constantly assign a specialized fund to assist the development of hospice care, while calling on and encouraging social groups and individuals for donation.
5.2 Public Education

5.2.1 Mind Revolution on Ideas of Death

Mind revolution on ideas of death through the education and public media is necessary to clear the unique cultural obstacles in the path of hospice care development.

We're born, we live, and we die. Life and death together consist of a full cycle for everyone. Like it or not, death is a normal part of life. Facing death is actually embracing the whole life. The great philosopher Confucius said: “Not knowing about life, how could one know about death?” (“未知生，焉知死?”) While in the sense of Palliative Care for the elderly, it also seems wise to say “Not knowing about death, how could one know about life?” (“未知死，焉知生?”) Such understanding about life and death positively enables people to live toward death, inspires them to pursue the real meaning of their life (like the real happiness, true love, and fulfillment of dreams etc.), and urges them to value and make the best of their remaining life.

Moreover, the real filial piety offered by children to their parents should be providing comfort and maintaining the highest possible quality of life for as long as life remains. Observed by the medical director of Song Tang hospice, “It takes nine months for a baby to grow in the womb. When we know we are going to die, it takes nine months for us to do our last growing up. We want to make the last 280 days of our patients’ lives the best in dignity, without any regret.” Thus, the essential aims of death education are not to over-treat the terminal patients meaninglessly to extend their tortured time, but to promote the quality of the end of their life, and to assist in creating and maintaining the conditions to bring this about. Respecting and satisfying the individual emotion and needs of the elderly patients (including their choices on the ways of death) reflects the real humanistic and civilized spirit in contemporary society.

5.2.2 Education of Respecting the Elderly

Education of respecting the elderly should be advocated to the society, especially
to the youth, which will accumulates to a potentially tremendous power accelerating the future development of Palliative Care and Hospice in China.

Elder respect and filial piety has been the notable Chinese tradition for thousands of years, with the old saying “Honor the aged of other family as we honor our own”. However, due to the market economics and China’s one child policy, there has been a cultural shift from a society oriented towards the respect of elders to one that celebrates youth. The older generation is being more silent in the family and more silent in society. With China stepping into an ageing society since 2000, rates of elderly living alone or suffering from depression are rising.

Under such circumstances, education of respecting and loving the elderly is very significant. Elder respect is not the superficial form of polite, but one’s inner appreciation and esteem to the life and soul of the aged, which is related to empathy and philanthropy. One’s humanistic consciousness, which can only be achieved by education, decides his ability to truly love and respect others. Thus family education, school education, and self-education through publications, media and volunteer service should all be encouraged to the youth as well as adults in a society-level environment.

Particularly, encouraging the youth to be the volunteers in the hospice is not only rich social resources supporting the palliative care development, but also a live and invaluable lesson of respecting elder and treasuring the value of life. A high school volunteer in Beijing once wrote: “One Monday afternoon when I arrived in the hospice, many elders were enjoying the sunshine in the yard. To my surprise, on seeing me they applauded for a long time. For the first time in my life, I got to understand that it is more blessed to give than to receive. My parents gradually discovered my patience to their naggings and saw the disappearance of my revolt to their advices. I have changed because I know the meaning of life, and I know that one day my parents would also become as weak as the elders in Song Tang. From now on, I would let them know that I love them, and I will treasure every moment spent with them.”
5.3 Professional Training and Academic Communication

To further improve the Palliative Care service quality, related training and academic communication is indispensable.

Professional training on theories, practices and ethics should focus on the specialization of the physicians, nurses, and nursing workers, as well as the psychiatrist, psychologist, pharmacists, and nutritionists, who are usually neglected in the care service in China. In other words, to better and expand the service-provider team in both quality and quantity is needed.

In addition, for the caregivers, both local and international academic communication should be enhanced by literature publications, workshop, seminars, forums and international conferences, so that the advanced theories and information can be spread locally and globally.

6. What Can We Help in Promoting Elder Palliative Care?

— A loving heart is a hospice for the world.

• Be there with our family members at the end of their life.

Consider such a question: What means most to someone who is lingering for the departure? It’s his family being at his side.

Personally, I always believe that the best spiritual care to terminal patients is their family members’ love. Having a strong desire for family love at the end of life, what they want most is their beloved’s accompanying, which can never be equally replaced by the nurses’ comfort in the care center.

For your parents and grandparents, you matter more than the whole world. So be sure to be there, at the side of your beloved ones, so that when they open their eyes searching your faces, they can see you and carve you into their memory, eternally. No matter how busy your work is during that period, drop it immediately and just be there, or you’ll never erase the biggest regret for the rest of your life. Be sure to remember to hold both of their hands, for your warm hands pass them not only the reassurance
and peace, but also the power and courage to face death—an lonely and unpredictable path ahead of them. On their last moments of life, they need your love and help to face the end.

When you accompany them on the end of their journey, you are also sharing part of the burden of the society. If every family takes their own responsibility on the palliative care for the old, the hospice quality in China would be greatly improved and developed.

• Be a volunteer in a hospice near our place.

As the old Chinese saying goes, “Honor the aged of other family as we honor our own” (“老吾老以及人之老”), being a volunteer may be the most direct way to support the palliative care for the elderly.

What terminal patients need is more than medicine — they are hopeless, helpless and lonely, so they need someone to listen to them, to talk to them and to help them achieve their uncompleted hopes, so that they can leave the world without regrets. The elderly patients are more like the children rather than adults, eager for sincere love and easy to be satisfied. Behind those faces having been through life’s roughness and those hands spread with deep wrinkles there lies a lonely soul longing for your smile and touch. Removing the solitude and grief, your smile and listening warms their heart; bringing them happiness and laughter, you are spiritually benefited and purified in such a soul-to-soul relationship. Every aged man is a profound book; reading them with humbleness you will definitely receive more than you give.

How we treat the aged today is how we will be treated tomorrow. How a nation treats her aged citizens today decides the nation’s destiny tomorrow, prosperous or declining. With a loving heart to the aged people, let’s help them embrace the end of life surrounded with love!

Only with the effort of government, every individual and every family, can Palliative Care in China really improve the life quality of aged patients physically and spiritually, and help establish an all-age-friendly society everyone shares.
Reference


