

Care Issues at the End-of-Life in China*

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With changes in population structure, more Chinese live into old or even oldest-old age. Older Chinese, as the elderly in other countries, are more likely to have chronic diseases and die of them. The causes of death and place of death among the elder Chinese have brought up an issue of how to die, or end-of-life care. According to our research, Chinese start to think and talk about death preparation. Living will has become a recent target of promotion among various forces in society, which makes more Chinese understand the concept of living will and gives individuals more choices to decide how they will die. On the part of Chinese society, we have seen a gradual increase in providing hospice care services, a type of end-of-life care. However, comparing with the need of the care and services available, China still has a long way to go to build a better end-of-life care service system for Chinese population.

Keywords: *living will, hospice, aging, China*

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Introduction

China has been an aging society since year of 2000. She encountered many new demographic and social issues. Among them, the size of the population is not as crucial as the age structure¹. Although China has the tradition to take care of the elderly, changes in age structure as well as social changes as a result of economic reform and open policy generated challenges dealing with the care of the growing old-age population and forced the government and the society as a whole to develop new approaches and new policies to reduce the potential burden for individual families or society. How much care exactly the aging population on the average need is one of the major concerns. Earlier researches found out that among elderly population the higher the ADL score, the more hours needed for care per week. On the average, the elderly based on a survey in 2011-12 received 23.1 hours of care a week; however, the elderly had severe limitation in ADL needed about 115 hours of care, which was 69% of total hours a week (Zhou and Feng 2015). The elderly over 80 years, on the average, needed 92 days of care towards the end of their life, while the oldest-old with poor health usually needed 124.5 days of care (surveys in 1998 and 2000; Zhan 2004). Among general old population (65+, a survey in 2005), on the average, 11 days of full care were needed within the last month of their life, 33 days needed within the last six months and 47 days needed within the last year of their life (Gu et al. 2007). The care that the elderly need toward the end of life is part of long-term care, or should be called the end-of-life care.

In 2012, the Chinese government, for the above concern, redefined and promoted “new 24 filial piety,”² in hoping to encourage younger generations keeping the old-age care tradition. However, the reality is that the older people today under such spectacular social and economic changes are very different from the elderly in the past in terms of financial, health and family status. Our society should well prepare for balancing the need of care and search for and generating available sources of care. However, the needs and the available sources are always difficult to be matched and balanced. Therefore, under this general background, an important alternative needs to be considered and discussed is the end-of-life issue since life expectancy is

¹ For example, “No Worry of the Impact of Second Birth.” November 14, 2013. Retrieved July 8, 2015 (http://news.xinhuanet.com/politics/2013-11/14/c_125701790.htm).

² “Announcement of the Standard of New 24 Filial Piety.” August 14, 2012. Retrieved July 8, 2015 (<http://news.sina.com.cn/c/2012-08-14/023924961026.shtml>).

improved significantly in China but not necessarily healthy one. More people die at older or oldest age with long-term chronic diseases. Being able to live to old age is a blessing, but also a burden with certain long-term diseases. Thus, both the elderly and their families more likely need to deal with the issue of peaceful death.

Following a general discussion of mortality among Chinese population, this article examines how Chinese, individuals and the society as a whole, prepare for the care needs of the elderly towards the end of life. The care ranges from emotional to physical care of the elderly. We will discuss individual awareness of the end of life issue and the social preparations to deal with the issue, especially living will. The article also explores the development of the societal preparations or programs on palliative care (called by different Chinese names) and hospice with an emphasis on the latter. All these issues are rather new to Chinese, however, are gaining more attention in the society today.

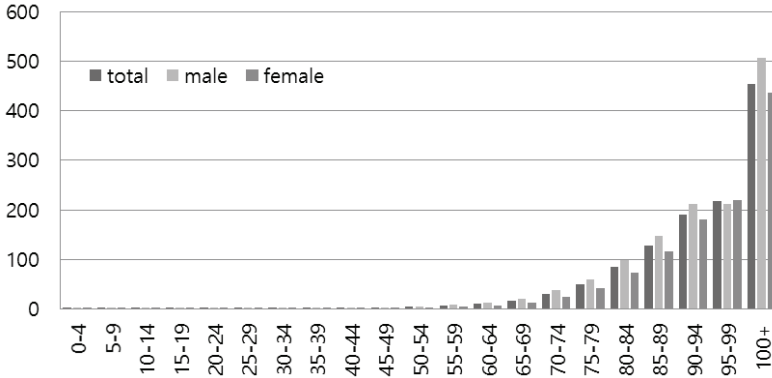
Mortality in China

Chinese are living longer today. According to the statistics by the National Health and Family Planning Commission, life expectancy before 1949 (the establishment of the People's Republic of China) was as low as 35 years (Table 1). It has been increased gradually and dramatically and reached to 74.8 in 2010, which was about 2.1 times that of earlier years. In 2010, Chinese males lived 8.8 years and females lived 11.1 years longer compared to males and females in 1970s respectively. Female Chinese benefited more from the improvement of life expectancy than male Chinese. In 2010, females on

TABLE 1
LIFE EXPECTANCY BY GENDER IN CHINA, IN YEAR

Year	Total	Male	Female
Before 1949	35	--	--
1973-75	--	63.6	66.3
1981	67.9	66.4	69.3
1990	--	68.6	66.9
2000	71.4	69.6	73.3
2010	74.8	72.4	77.4

SOURCE.—National Health and Family Planning Commission 2013, p.239.



SOURCE.—Population Census Office under the State Council/Department of Population and Employment Statistics National Bureau of Statistics 2012, p.441.

FIG. 1.—Age/Gender-specific Mortality Rate, China (%)

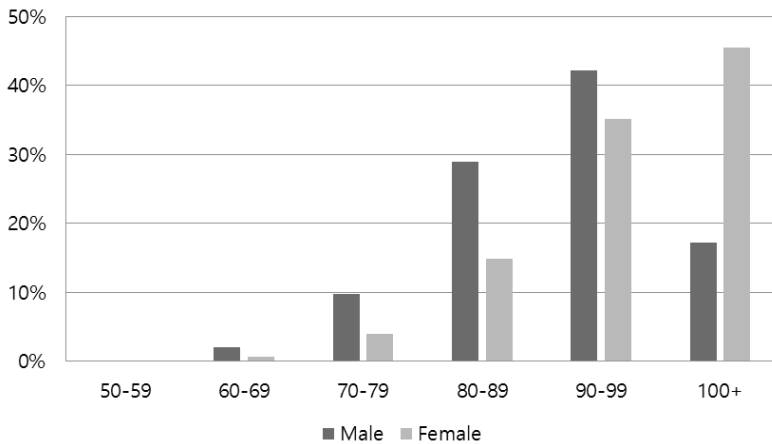


FIG. 2.—Age at Death by Gender

average lived 5 years longer than males while that was only 2.7 years in 1970s.

Since people are living longer, mortality occurred more towards old age, according to the 6th census of China. A little over 1% of people in age group 60-64 died between 2009-2010; by age 70-74, 10 years older in the year, the death rate reached 3.1%, and by the oldest-old age group (100+), 45.4% of the older people died, which was almost half of the people in the age group. Males' mortality rate at each age group was always higher than that of

females, except the age group of 95-99 (Figure 1). The difference in death rates between males and females was getting wider towards older ages. Male and female Chinese are dying by different age patterns.

Figure 2 shows age at death among older people by gender from China Longitudinal Healthy Longevity Survey (CLHLS, 2011-2012)³. The survey provided supporting information on gender difference of death by age among older Chinese. The death information was reported by the relatives of 5,642 subjects who were alive at the time of 2008-2009 survey but died before the 2011-2012 follow-up survey. By this follow-up survey, over the years, average age at death among the elder females was 97.2 years old, about 5.6 years longer than the males' average age. Females in general lived longer than males. Between the two surveys, in three years, percentage of males died increased with age, from about 10% in 70-79 age group to about 42% in 90-99 age group. For the oldest-old age group that is over 100 years, fewer of them died compared with males in younger age group. Females also died more with age. However, age 90-99 for males and age over 100 years for females were the time that the elderly experienced most loss of life.

People die by different causes. The latest report on "Chinese nutrition and chronic disease" in 2015 indicated that 86.6% death among general Chinese population in 2012 was due to chronic diseases and the death rate was 533 per 100,000 population. Cardia-cerebrovascular disease, cancer and chronic respiratory disease were responsible of 79.4% of deaths in 2012⁴. There were gender differences in the rank of the diseases. For example, among urban Chinese, cancer was the number one killer for men and heart disease was for women (Table 2). Due to current mortality pattern (people die at older age) and types of causes of death in China (chronic and degenerative diseases), at least 4 out of the top 5 causes of death may relate to deaths of the elderly. That is excluding the causes of injury/ toxicosis.

The five leading causes of death among the Chinese elderly were provided by their family members in the survey of CLHLS⁵; Figure 3 and Figure 4 presented results from the calculation based on CLHLS data. While hypertension, heart disease, stroke/CVD, and bronchitis/emphysema/pneumonia were the common causes for all the elder Chinese, the type and

³ Data for Figure 2 comes from "Chinese Longitudinal Healthy Longevity Survey Projects." Retrieved September 17, 2015 (<http://web5.pku.edu.cn/ageing/english/projects.htm>).

⁴ "Chronic Disease on Rise in China: health survey." June 30, 2015. Retrieved September 17, 2015 (http://news.xinhuanet.com/english/2015-06/30/c_134369371.htm).

⁵ "Chinese Longitudinal Healthy Longevity Survey Projects." Retrieved September 17, 2015 (<http://web5.pku.edu.cn/ageing/english/projects.htm>).

TABLE 2
MORTALITY RATES AND RANK OF CAUSES OF DEATH BY GENDER IN URBAN
CHINA 2010

Causes of Death	Male		Female	
	Mortality rate (in 100,000 population)	Rank	Mortality rate (in 100,000 population)	Rank
Cancer	201.99	1	122.35	2
Cerebra Vascular Disease	137.30	2	112.56	3
Heart Disease	135.15	3	123.02	1
Diseases of Respiratory System	78.06	4	58.22	4
Injury/toxicosis/ other external cause	48.43	5	27.38	5

SOURCE.—Arranged based on data from National Health and Family Planning Commission 2013, p.295.

rank of the causes of death represented a gender different. The fifth reported cause of death for male elderly was prostate cancer, a special type of cancer only for males; that for females was glaucoma, a special type of eye diseases not necessarily only affecting females. However, all the top 5 causes relate to chronic diseases. Some of them may cause sudden death, or a direct cause of death; some leads to gradual loss of physical function of daily life and functions as indirect causes of the elderly's death. Chronic diseases have become common causes of death among the older Chinese.

With the characteristics of causes of death, according to the same survey (CLHLS, 2011-2012), most people died at home today. We have analyzed patterns of place of death by residency, gender and bedridden status among those who were alive at the time of 2008-2009 survey but died before the 2011-2012 follow-up survey (CLHLS). Majority rural and urban elderly died at home (Figure 5). The percentage was higher for rural residents where more urban residents died at hospital; very few people died at institutions. If we examine place of death by gender and place of death (Figure 6), over 80% of the deaths happened at home for both male and female elderly. However, deaths at hospital constituted 11.4% and 6.1% of deaths for males and females respectively. Less than 2% of deaths occurred in institutions for both genders.

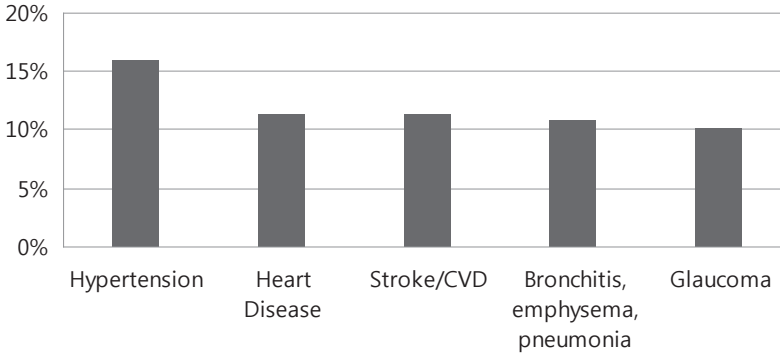


FIG. 3.—Prevalence of top 5 diseases among female (reported)

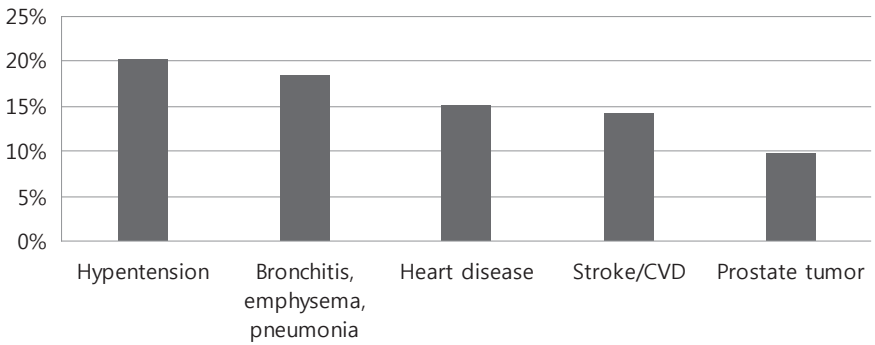


FIG. 4.—Prevalence of top 5 diseases among male (reported)

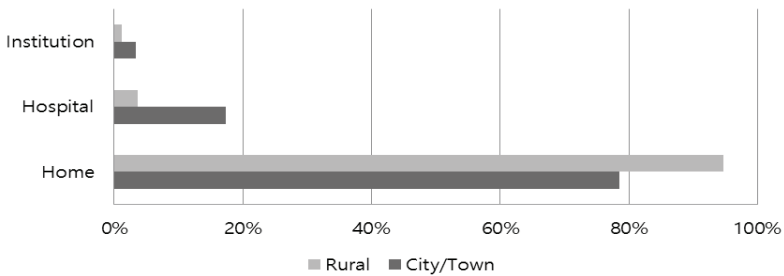


FIG. 5.—Place of Death by Residency

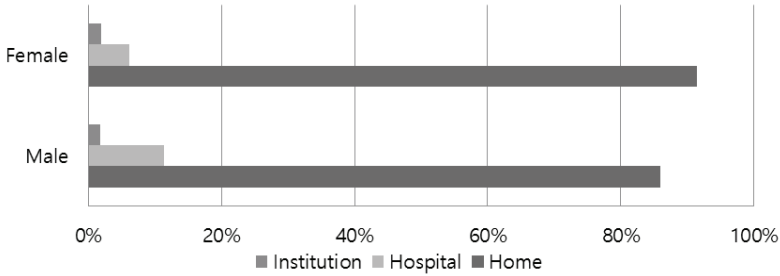


FIG. 6.—Place of Death by Gender

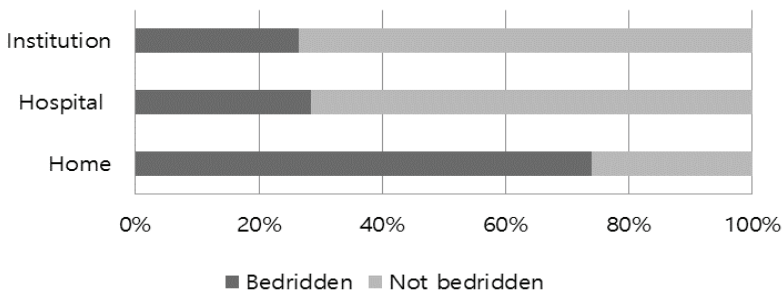


FIG. 7.—Place of Death by Bedridden Status

It seems that hospital was a place of death more for urban and male elderly. We further explored the difference in place of death in terms of bedridden status (Figure 7). It is clear that 74% of subjects who died at home were bedridden, whereas for those who died in hospitals and institutions, the numbers are 28.5% and 26.4% respectively. Reasons behind this pattern are worth of further investigation. The mortality pattern, leading causes of death and place of death among the elder Chinese have brought another issue that is how people prepare to die.

Living will

Due to the aging of Chinese population and causes of death among the elderly (chronic diseases), dying becomes an issue in China. According to the Chinese traditional culture, care of the aged or even the disabled parents is the responsibility for their children generation. The traditional practice is that

parents raise their growing children and children take care of their elderly parents. This means that at old age, the elderly will not have to make major decisions regarding their daily living and household matters. However, as age structure changes as a consequence of fertility decline, younger and working population size are declining, care resources within and outside of a family are becoming major concern to the elderly about their life voluntarily or involuntarily. For example, they have to consider or plan place to live when they are unable to live independently and people to rely upon for both physical and medical care when they need, including seriously illness, and ultimately place to die at the end of life. Type and degree of medical care for one's life gradually have been discussed in China. Living will is a topic which gives individuals a right to make full decision about how they go about to live toward the last stage of life.

Individual awareness and preparation of the end-of-life

Death with dignity is considered as a decent way to leave the world in China recently. Based on a survey by internet conducted in Qingdao (in 2013), a medium-size city of China, 93% of the respondents agreed that a determined step to prevent the provision of unwanted and unnecessary life-sustaining medical technology are used to patients should be taken. Reasons included that death with dignity will 1) make the patients no longer suffering pain anymore (85%), 2) release financial burden of family members (43%), 3) save medical resources and provide more opportunities of medical treatment for other patients (18%) and 4) other reason (3%)⁶. Another survey launched by Sina China in 2012 asked people “do you think we should promote ‘dying without tube?’” Out of 39,862 respondents nationwide, 92% of them choose “yes; the right to die should be given to the individual; should promote death with dignity.”⁷ “Dying without tube” means leaving this world with more dignity but not with tubes all over the body. Survey carried out by “The Beijing News Survey” in 2013 revealed that 60% of people surveyed accepted the type of death and only 13% of them disagreed with it⁸. However, due to

⁶ “Do You Support ‘Death with Dignity’ When One’s Life Depends on Machine?” August 1, 2013. Retrieved April 24, 2015 (http://news.bandao.cn/news_html/201308/20130801/news_20130801_2231943.shtml).

⁷ “Do You Think We Should Promote ‘Dying without Tube?’” November 21, 2012. Retrieved June 26, 2015 (<http://survey.news.sina.com.cn/result/74343.html>).

⁸ “Legalization of ‘Death with Dignity’ Needs Consensus in Society.” August 17, 2013. Retrieved July 27, 2015 (<http://www.bjnews.com.cn/opinion/2013/08/17/278849.html>).

the newly introduced concepts of “dying without tube” and death with dignity or recent promotion of the concept, still 30% of the respondents were uncertain and they preferred the answer of “it depends”.

How to achieve the ideal of death with dignity? Signing a living will is still a most popular approach for ordinary people. A living will is close to or equal to an advance directive which leads to a death with dignity but not euthanasia. Living will is a new concept and is not a familiar one in China yet. A survey of 2,484 individuals on internet in 2012 by “Choice and Dignity” website,⁹ 61% of the respondents had never heard about living will, but 67% of them were willing to file a “five wishes” living will. In the same survey, 68% expressed their willingness to make their own decision for their medical care at the end of their live, 18% will depend on their family, 7% will rely on doctors, and 6% had no opinion on the issue.

Among those who are willing to make plan for their life after illness, Mrs. Tian Guiyun is one example. With two sons as medical doctors, Mrs. Tian suffers nephrotic syndrome for 10 years. As a frequent hospital visitor, she witnessed patients suffered pain with tubes all over their bodies. Furthermore, patients spent all their savings in order to postpone their life which is almost impossible by current medical technologies and their children are exhausted mentally and physically. Given whatever she experienced and observed, Tian signed a living with the concern of legality.¹⁰

Societal preparations and programs for individual's living will

In China, no laws or regulations support or prohibit living will (or an advance health care directive) and the promotion of it relies on society and

⁹ “Research on Knowledge and Acknowledgement of Living Will among Urban Residents.” September 11, 2013. Retrieved April 24, 2015 (<http://www.xzyzy.com/Pub/s/69/327.shtml>). About the respondents of the survey, 63% of them were under 30 years old, 30% were between 31-60, and 7% of them were over age of 60 years.

¹⁰ “When I Die, I Will in Charge of My Death.” March 19, 2015. Retrieved April 24, 2015 (http://news.my399.com/local/content/2015-03/19/content_1480057.htm). “I worried that the living will does not have legal power and went to notarial office. However, staff work in the office does not accept this type of notarization. I want the media to help me to achieve my goal”. Her way of achieving the goal was to bring her living will, already signed by 6 witnesses (her sons and daughter-in-laws, her younger brother and her husband's younger brother), to the Harbin Daily newspaper office and requested the newspaper to publicize her living will on the newspaper. As a result of her effort, everyone may read an article regarding Mrs. Tian's will with a picture of her and her husband holding the living will together. By this way, she feels that her living will will be acknowledged and put into practice in the future. “We have arranged our life of the last stage and feel peaceful now. It is good for us and for you [her sons]”.

common people¹¹. Different levels of government only regulate and monitor organizations which initiate activities related to living will. In the year of 2013, Beijing Living Will Promotion Association (LWPA) was established, the first of the kind in China and it is an NGO registered at Bureau of Civil Affairs of Beijing. The goal of the LWPA is to promote the acceptance and to draft individual's "living will" among Chinese as well as to propagate the idea of death with dignity.¹² People considered "a good death" in a survey as a death respecting individual's choice and with dignity (51%), a death one has completed his or her wishes in this world without any regret (25%), or a death without pain and comfortable (23%).¹³ Signing a living will lead to a death with dignity, since a living will provides individual power to determine how they leave this world themselves or actions should or should not be taken if their life cannot be saved anymore and they are no longer able to make decisions for themselves due to illness or incapacity.

A living will in China include five wishes: wish for wanting or do not wanting related medical treatment(s); wish for wanting or do not wanting life-support treatment; wish for how I want people to treat me; wish for what I want my family members and friends to know; and wish for the person who will help me. Under each wish there are detailed questions or 42 choices¹⁴ for individuals to consider. The five wishes developed in China are based on the popular "five wishes" in the United States. Individuals living will is signed and effective only when the person is physical healthy and mentally competent. Once they lose the ability to make their own decision due to illness or accident, relatives or friends could follow the signed living will to act. Individual is able to change or even terminate their living will as they wish.¹⁵ A living will with notarization or witnesses will have better legal power. Since notarization for living will is still not available in China today, according to the explanation of LWPA, a living will signed by an individual with clear consciousness as well as witnessed and signed also by two

¹¹ "We Must Sign a Living Will if We Choose 'Death with Dignity.'" July 30, 2013. Retrieved April 15, 2015 (http://news.xinhuanet.com/fortune/2013-07/30/c_125085592.htm).

¹² "LWPA's Statutes." Retrieved April 15, 2015 (<http://www.xzyzy.com/XZYZY/NewsIndex.aspx?queryStr=p0w7x08q7x15x15o3w8w1vZ8w7x08q7x15x15o3w8w1v1v5z8p4x2X12x01w1u9>).

¹³ "Research on Knowledge and Acknowledgement of Living Will among Urban Residents." September 11, 2013. Retrieved April 24, 2015 (<http://www.xzyzy.com/Pub/s/69/327.shtml>).

¹⁴ "An Introduction to 'Death with Dignity.'" August 1, 2013. Retrieved April 23, 2015 (<http://news.eastday.com/whyauto/2013-08-01/500699.html>).

¹⁵ "We Must Sign a Living Will if We Choose 'Death with Dignity.'" July 30, 2013. Retrieved April 15, 2015 (http://news.xinhuanet.com/fortune/2013-07/30/c_125085592.htm).

witnesses is considered as a document with legal power.¹⁶

Promotion of living will in China is operating only in large cities but not available in rural area yet. Format of the promotion is to disseminate information of living will in a booklet and leave the booklets at shopping centers, in hospitals, or at public places for people to read¹⁷. Most influential leading figures to promote living will in China so far include Luo Diandian, daughter of the late General Luo Ruiqing and Chen Xiaolu, son of the late General Chen Yi and others. They promote the idea of living will in many different ways, including advocating the idea on TV¹⁸, through other media channels, articles based on interviews published in newspapers,¹⁹ or even by books such as “Who Will Make Decision for My Death,”²⁰

Medical doctors also make enormous efforts to encourage living will at hospitals. For example, at Beijing Union Medical College Hospital, living will is a serious topic for both medical doctors and the patients. By their daily work, doctors disseminate the idea of living will among doctors and patients that a living will is not only a choice, but also a right for their patients.²¹ At Beijing Geriatric Hospital, doctors even elaborate a procedure to implement a living will, including drafting a suitable living will for geriatric hospitals and implementing it within the hospital. When patients are admitted to the hospital as an inpatient, a counselor at the reception desk will introduce the living will to the patients and help them to fill out the will²². Many medical

¹⁶ For an example of Chinese version of living will, please see the following link. “For a Living Will, What Should We Do?” June 16, 2015. Retrieved April 15, 2015 (http://mp.weixin.qq.com/s?__biz=MzA3NDE5MjYzNw==&mid=209343279&idx=1&sn=6c48c8dddc99ec56dc39fd5d4ecec4de#rd).

¹⁷ “Chen Xiaolu and Ding Xueliang on ‘Living Will.’” January 24, 2014. Retrieved April 23, 2015 (http://news.ifeng.com/shendu/nfzm/detail_2014_01/24/33321982_1.shtml).

¹⁸ For TV, e.g., an interview with Luo Diandian on “Cui’s Talk” of CCTV. May 25, 2011. Retrieved August 1, 2015 (<http://blog.cntv.cn/13933599-2081631.html>); another interview with Luo Diandian on “Horizon” of CCTV 1. March 25, 2013. Retrieved August 1, 2015 (<http://tv.cntv.cn/video/C29837/1b185eabb1bf435fbadc4c32c7656571>).

¹⁹ For example, “Last Dignity of Life” on Chinese Youth Daily. November 21, 2012 page 12. Retrieved August 1, 2015 (http://zqb.cyol.com/html/2012-11/21/nw.D110000zgzqnb_20121121_1-12.htm); “Why Does Luo Diandian Promote ‘Dignity of Death?’” on China Philanthropist. March 2, 2015. Retrieved August 1, 2015 (<http://school.hexun.com/2015-03-02/173650473.html>).

²⁰ “Who Will Make Decision for My Death.” March 6, 2011. Retrieved April 23, 2015 (<http://www.chinawriter.com.cn/book/2011-03-06/2235.html>).

²¹ “At the End of Life, Choose Dignity.” April 18, 2012. Retrieved April 24, 2015 (<http://www.pumch.cn/Item/7495.aspx>).

²² “Beijing Geriatric Hospital First Introduced ‘Living Will’ Program.” August 1, 2013. Retrieved April 24, 2015 (http://finance.ifeng.com/a/20130801/10319550_0.shtml).

doctors have brought the issue to the National People's Congress (NPC) and the National Committee of the Chinese People's Political Consultative Conference (CPPCC) in the past and continuously do so. For example, in 2010, Hu Dingxu (as a member of CPPCC) made a proposal of promoting living will to the NPC and CPPCC. He again in 2015 (as a member of CPPCC Standing Committee) proposed to start palliative care as soon as possible in China.²³ Doctor Gu Jin proposed a bill of death with dignity and legal power of living will for 2012's NPC meeting.²⁴ And medical doctor Ling Feng recommended to ratify Natural Death Act in 2013 NPC and CPPCC's meeting.²⁵

Issues brought up by living will include legal power of the will, ways to monitor the practice, the rights and responsibilities of doctors as well as who's will should be acknowledged if the wills by will writer and his or her family members are different. At present, several laws and regulations provide guidelines for doctors to perform their duties. According to Article 56 of the Tort Law of the People's Republic of China (2009)²⁶ and article 33 of the Management Regulations of Medical Facilities (1994),²⁷ other than principle of respecting patients' and family members' wills, under circumstances, if patients life is at high risk of life threat or critical emergent situation that doctors are unable to reach patient's family members for treatment endorsement, then they have the rights to immediately perform suitable medical procedures and treatment under their supervisor's approval.

Regarding living will, different survey results and sporadic examples imply that many Chinese, both young and old, consider and concern death issues recently, especially the most suitable way to die when they face incurable diseases or unsuccessful medical treatment. Many citizens wish to direct their own life even toward the end of their life. Living will become a possible way to fulfill one's own will for death. Behind this trend is a substantial societal change to encourage individuals accepting the idea of

²³ "Pioneer for Palliative Care—Hu Dingxu." April 14, 2015. Retrieved July 28, 2015 (http://www.chinatoday.com.cn/chinese/tgaq/ga/201504/t20150414_800032756.html).

²⁴ "It Is Necessary to Promote 'Death with Dignity.'" March 20, 2013. Retrieved July 28, 2015. (<http://bynew.bjmu.edu.cn/ztxw/2013nlkzt/97108.htm>).

²⁵ "Ling Feng, Member of CPPCC, Proposed for Natural Death Act But Was Rejected." March 11, 2013. Retrieved July 28, 2015 (<http://finance.china.com.cn/industry/medicine/yyyyw/20130311/1322780.shtml>).

²⁶ "Order of the Chairman of the People's Republic of China." December 26, 2009. Retrieved July 15, 2015 (http://www.gov.cn/flfg/2009-12/26/content_1497435.htm).

²⁷ "Management Regulations of Medical Facilities." August 1, 2005. Retrieved July 15, 2015 (http://www.gov.cn/banshi/2005-08/01/content_19113_2.htm).

living will as well as to develop a procedure enabling individuals to fulfill their wills. The change includes public promotion of the idea, establishing NGOs to carry out related activities, making and submitting public proposals to the National People's Congress and National Committee of the Chinese People's Political Consultative Conference, and testing procedures to practice individual's living will in hospital environment. With all of these efforts and activities, we expect more Chinese will understand the concept of living will, not only in large cities, but gradually in the entire country, hopefully with legal system to be established. Living will provide choices for people to decide their life by signing a piece of paper or document. In the next session, one type of practical care towards the end of life, relevant to living will, hospice will be discussed.

The end-of-life care: hospice care

Unlike living will, hospice is a genuine practice or service for those with terminal ill. It is not a medical treatment but a type of medical care. Hospice provides last care to the individuals with need in this world; it is the last stage of palliative care, or end of long-term care in general. Demands of the care are affected by age structure of the population, by the type of diseases widely spread in a population, and also by locations of a death usually occur. That is, if a population is aging and suffers chronic disease, especially cancer with the pain generated, then more people may need hospice at end of their life either at home or at hospital. The term "palliative care" should not be confused with "hospice care." Hospice care is a form of palliative care that delivers comfort care to those at the end of life. Both hospice and palliative care share the same goal of alleviating pain and suffering and improving quality of life for patients. However, hospice focuses on terminally ill patients, who no longer seek curative medical treatment, and who, generally, are expected to live for about six months or less. Hospice provides a patient-centered approach to care that involves both the patient and family in decision making about care at the end of life." (Colello et al. 2009, p.6). It has been estimated that about 7.5 million Chinese need hospice care each year (Li and Liu 2012, p.106).

Definition of "hospice care" in China

Hospice care depends on the definition of end-of-life. Unfortunately, there is no unified definition for the term in China and in the world. In China there

is even no definition for “period of end-of-life”. Chinese medical professionals consider “a patient is entering into end-of-life period if the person does not response to radical medical treatment, whose illness continues to deteriorate, and whose life is getting short. Furthermore, if the patients is living at home or community, ≤ 90 days is defined as the period of end-of-life; if the patients is living in medical facility, then ≤ 60 days is considered as the period of end-of-life” (Shi and Wang 2010, pp.5-6). This specification of time period may lead to the initiation of hospice care proposed by the WHO. According to the WHO, palliative care, including hospice 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”.²⁸ Although WHO does not specify time point that the care should/can start under this definition, it states clearly the purpose, means and target population of the palliative/hospice care.

Individual awareness of hospice care

In China, individuals have not paid much attention to hospice care because of traditional conservative norms on death (i.e., the fear of talking about “death and dying” and preference of dying at home) and lack of choices or shortage of services for hospice care. Only a small segment of population is aware of hospice care. For example, in a survey of the elderly living in urban community, only 33.5% (out of 429 respondents) had knowledge on service provided by hospice. For location of hospice services provided, among 1,279 respondents under same survey mentioned above, community health service center was responded as the most popular place for hospice care, followed by comprehensive hospice ward within a hospital, geriatric hospitals, and independent hospice (Shi and Wang 2010, p.42). Given current limited number of hospice in China and the lack of services for the end-of-life, not too many Chinese realize that for those with need, hospice may be the best choice for the individual and family members.

²⁸ “WHO Definition of Palliative Care.” Retrieved July 30, 2015 (www.who.int/cancer/palliative/definition/en/).

Societal preparations for and programs of hospice care

China started to use the word “hospice” when Xie Mei-e (from Taiwan) wrote an article about hospice as early as in 1982 and Zhang Xie-quan translated an article on hospice in 1986. In 1988, with the help and support from overseas Chinese Huang Tian-zhong and Cui Yi-tai (“the father of Chinese hospice care” [Chen 2013]), Tianjin Medical School established a research center of end-of-life. In the same year, the first hospice care home in mainland China was established in Shanghai, named Retiree’s Nanhui Huliuyan. In Taiwan, the first center of the kind was in the Makai Memorial Hospital Danshui branch, named palliative ward in 1990; and in Hong Kong, the first hospice was the Hospital for Hospice Care in 1992. (Li 1998, pp. 22-5). By 2003 about over 100 hospice facilities and several thousands of professional personnel were working in the field (Cui and Meng 2004, p. 6). However, based on incomplete statistics (Shi and Wang 2010, pp. 3-4), only about 26 hospices still operated in 10 years since 1988. They were mostly in large cities and almost none in small cities and town and rural areas. Most hospice were part of medical schools, belong to health service system; few of them operated by community health service centers. Later, one third of the 26 more or less hospice has transferred to other facilities or closed (Su 2013, pp. 58-9).

There are at least three types of hospice in mainland China: the one operates within hospitals or hospital based hospice care (i.e. special wards for the patients), the one operates independently, especially by private organizations (e.g. Song Tang hospice), and the one provides home or community based hospice care operated by private or government organizations (Li and Liu 2012, pp.102-3). Therefore, the general characteristics of Chinese hospice are: 1) few numbers and majority of them operated by private organizations. 2) Those affiliated with medical facilities underdeveloped with financial restraint (Su 2013, p.6). In general, the development of hospice in China were rapidly in 1990s, but stagnated since then after experiencing a further market economy and the increased cost of running hospice and declined effectiveness.

In the process of societal preparation for hospice care, Chinese government, NOGs and private hospices have played important roles. Three types of social efforts to improve hospice care are discussed here.

Type 1 Government efforts: Due to aging of Chinese population and growing size of the elder Chinese, Chinese government is speeding up the

improvement of the existing facilities and plans for new types of facilities for the elderly. To provide better end-of-life care services, in the hospice related field of nursing, China Nursing Career Development 12th Five-Year-Plan (2011-2015) stated that one of the major goals during the five years was to develop a nursing service model for the elderly, persons with chronic disease(s) and *hospice patients* [author's italic] as well as to accelerate the development of elderly care and *hospice services* [author's italic]²⁹. For the first time, hospice care became a concern for nursing services in the government development plan. In the past, scattered policies on the end-of-life care existed. The related policies first came from the ministry of health. They were on the status of hospice services in the medial service system, care models, and function of some medical institutions. Since 2006, the State Council involved more in the hospice issue, including to develop and release policies supporting and encouraging various types of institution to provide the end-of-life services in 2006³⁰, to build new institutions or to transform the existing facilities better serving the elderly with need of hospice care (2013) and to improve national health care service system including hospice care. In 1999, the State Council established the China National Working Commission on Aging (CNWCA). It is an advisory and coordinating organization of the State Council, working on aging issues nationwide.³¹ With works developed and expanded by this commission, Chinese government has developed white paper on the development of Chinese aging career (2006), five-year plan on Chinese aging career (2011) and other aging related government policies and regulations. Hospice became a popular word used more frequently in the government development plans, policies and documents.

Type 2 NGOs' and private foundation's involvement: "Care with Love Project" (CLP) is a project supported by the Chinese government and managed and monitored by the NGO of China Aging Development Foundation.³² CLP was

²⁹ "Notice on Printing and Distributing the 'Outline of China Nursing Career Development Plan (2011-2015)' by the Ministry of Health." January 6, 2012. Retrieved September 17, 2015 (<http://www.nhfpc.gov.cn/yzygi/s3593/201201/5d494a1dd2104029878f01dc2568be04.shtml>).

³⁰ "Notice on Distributing 'Opinion on Accelerating Development of Old-age Care Service Industry' by National Aging Commission and Nation Development and Reform Commission, General Office of the State Council." February 17, 2006. Retrieved September 17, 2015 (http://www.gov.cn/zwqk/2006-02/17/content_202553.htm).

³¹ "China National Working Commission on Aging." June 1, 2013. Retrieved July 20, 2015 (<http://www.cncaprc.gov.cn/contents/47/22770.html>).

³² "Introduction of 'Care with Love' Project." September 17, 2013. Retrieved April 30, 2015 (<http://www.cadf.org.cn/html/hxyw/aixinhuligongcheng/huodongjianjie/534.html>).

proposed by 46 members of the Committee of the Chinese People's Political Consultative Conference in 2005. The project was endorsed by the Chinese government and some of the goals of the project had been written in the government's 11th Five-Year Plan (2006-2010): to start the Care with Love project and to strengthen the development of service facilities for the elderly, including care services, medical rescue, and family beds facilities.³³

CLP intendeds to and has helped to develop institutions of care with love in urban China for the oldest old Chinese and to provide professional care and *hospice services* [author's italic]. Other service goals are to improve and assist children to fulfill filial piety for their parents, to solve problems for the aged parents, and to share certain burden of aging society for the government. Institutions of care with love built or on the way under the CLP's plan are operated by social forces under self-management and self-financing principle but supported by the government. The entire project of CLP is managed and monitored by China Aging Development Foundation (CADF). Li Baoku, the Chair of CADF, in a work meeting in 2012, indicated that China should build over 600 facilities for the elderly with service of hospice by the end of 2015 to deal with aging population needs and care of the disabled elderly.³⁴ By the end of November 2014, there were 487 institutions of care with love were established in over 200 cities of 31 provinces, autonomous regions and municipalities in China. The institutions provide 250,000 beds for the elderly. More than 500,000 Chinese families and the elderly have been benefited from the services.³⁵

The "Heart of Gold" National Hospice Service Program is supported by private foundation Li Ka Shing Foundation, started in 1998. Its brief Chinese name is Ning-yang-yuan, meaning a sanatorium filled with peace and serenity. This is a mainstream community-based hospice program. The program provides free home-based holistic care for economically disadvantaged patients with advanced cancer as well as out-patient and counseling services. Services cover "pain relief, nursing care, psycho-socio-spiritual and bereavement support-provide continuous care for the patient

³³ "11th Five-Year Plan of Chinese Aging Career." December 12, 2006. Retrieved July 20, 2015 (http://www.china.com.cn/policy/txt/2006-12/12/content_7493038_2.htm).

³⁴ "China Will Build 600 Old-age Care Facilities with Hospice Care By the End of 2015." November 26, 2012. Retrieved June 7, 2015 (<http://shfl.mca.gov.cn/article/xjyy/201212/20121200388521.shtml>).

³⁵ "Work Report of China Ageing Development Foundation for 2014 and Major Work Goals for 2015." July 2, 2015. Retrieved September 17, 2015 (<http://www.cadf.org.cn/html/news/meitibaodao/821.html>).

and family.”³⁶

The service started at Shantou University Medical College-affiliated First Hospital where a special Hospice Unit was set up. This unit served as a model to provide hospice care and stimulated more hospitals have joined the program nationwide.³⁷ The entire program is managed electronically at the Program Office at the medical college. Hospitals interesting to be part of this program need to submit application first and agree to be under the program leadership and financial support. In the application, the potential hospice unit needs to provide following information: general status of the hospital (# of out-patients, # of staff, # of hospital beds), general information on oncology department in the hospital (# of staff, # of medical beds and medical facilities available in the department; cancer patients served in the hospital and their needs; plan for future medical service to cancer patients), cancer prevalence in the area, and general status of the city that the hospital locates (medical insurance coverage and degree of the coverage, average annual income, major industries, and minimum social security standard set by the local civil affair department).

A hospital interesting to join the hospice service program has to guarantee to support the hospice unit. Each hospice unit should have a hospice team, containing 2-3 nurses, 1 psychosocial worker, 1-2 driver(s), 1 clerk with 1-2 special cars. The unit also should have special space for the services, e.g. a separate section with sitting/waiting area, doctor's area, nurse's area, consultation room, office, and a few day-patient beds³⁸. The hospital is required to pay salary and bonus to the working staff of the unit and to pay water and electricity bills used by the office. Also the hospital should agree to monitor the work of the unit collectively with the Program Office in Shantou University Medical College, e.g. on patient data, medications used, services provided and expenses incurred. Other evaluation system is also recommended by the program office. For example, it recommends to use quantitative evaluating indicators (such as “awareness rate of hospice home, # of beneficiary of the service, times of services, # of volunteers, research articles, research achievement”) and qualitative evaluating indicators (such as patient's satisfaction, improvement in life quality, knowledge on hospice care among medical and general staff, media's reports, research conference,

³⁶ “Program Features.” Retrieved June 7, 2015 (<http://www.hospice.com.cn/en/#A3>).

³⁷ “‘Heart of Gold’ National Hospice Service Program.” Retrieved July 26, 2015 (<http://www.hospice.com.cn/en/>).

³⁸ “Our Services.” Retrieved July 26, 2015 (<http://www.hospice.com.cn/en/>).

training workshop, social acceptance of doctors/nurses' professional ranks and titles, support of hospice programs from the society)".³⁹

The "Heart of Gold" program accepts an application with all required documents and an evaluation team will come to the hospital to complete a thorough assessment. After approved from the provincial administrative department, the foundation signs a written cooperative agreement with the hospice unit. With the financial support from the Li Ka Shing Foundation, the local hospice unit starts to operate service to the patients.

To get services from the hospice unit within a hospital, cancer patients needs to provide their medical records, poverty status certificate, ID card and household register as well as ID of individuals who will get medicine from the program for the patients.⁴⁰ And the following procedure is used to serve the patients: "Phone enquiry → sign up at a local Hospice Unit → submit required documents → make home visit appointment → initial assessment → establish medical records and proceed to treatment plan → follow-up by phone calls or home visits at the regular basis → patients pass away, bereavement supports → close case files → case discussions."⁴¹

According to the information from the foundation, in June 2016, there were 37 hospice units were founded by the foundation in mainland China and a total of 160,000 patients had been served.⁴² The program also provides training/education on medical care for the patients (e.g. medication usage, possible side-effects and its management, and nursing care) and public education on attitude towards death and suitable way to chat about death and dying without fear.⁴³ Since 2013, the program has strengthened its monitor system by performing on-site assurance evaluation once in every two years for all hospice units under the program.

Type 3 Private hospice's practice: China has very few private hospices. Among the operating hospices, one of the most important ones is Beijing Song Tang Hospice (STH). It is an inpatient facility and first hospice hospital in China. The hospice was established in 1987, under the leadership of China Aging

³⁹ "Project Introduction of Heart for Gold." Retrieved July 26, 2015 (http://www.hospice.com.cn/project_intro.aspx?pid=12).

⁴⁰ "How to Apply for Services." Retrieved July 26, 2015 (http://www.hospice.com.cn/project_intro.aspx?pid=11).

⁴¹ "Our Services." Retrieved July 26, 2015 (<http://www.hospice.com.cn/en/#A4>).

⁴² "A New Page for Hospice Service in Mainland China." Retrieved September 17, 2016 (<http://www.hospice.com.cn/en/#A4>).

⁴³ "Training and Education." Retrieved July 26, 2015 (<http://www.hospice.com.cn/en/#A4>).

Development Foundation (CADF).⁴⁴ As an exemplar institute of “Care with Love Project”, STH functions as a grade 1 first class hospital (mainly as a geriatric hospital), senior home and welfare center. With 400 beds today, 2-3 patients (usually the elderly) die each day on average at the hospice and with an average in-patient care of 31 days.⁴⁵

The founder of the hospice Li Wei was a barefoot doctor in rural Inner-Mongolia when he was sent there as an educated urban youth in 1968 two years after Cultural Revolution, and returned to Beijing in 1979. With profits from investment in stamps at the early stage of economic development, Li started his hospice career.⁴⁶ Devoted his time and efforts to study and research on 10,713 hospice patients over 10 years, he developed a theory of “Social Mother” to indicate that the end of life period is 288 days which is almost identical to the period of pregnancy (about 280)⁴⁷ and published a book titled “Embracing Death Everyday”, based on 16,000 cases of death he experienced over 17 years.

Doctors and nurses are serving the patients in 3 shifts in 24 hours in the hospital. Each ward has a care-giver(s) to be with patients in 24 hours. Family members do not need to stay in the hospital to provide daily care like in other types of hospital but are able to visit their loved ones in 365 days. Other than palliative care, the hospice provides various kinds of religious services for people with needs toward the end of life. Up to 2015, in less than 30 years, over 30,000 elderly died at Song Tang Hospice peacefully and 500,000 person-time volunteers provided services for the elderly at the hospice.⁴⁸

Song Tang Hospice (STH) is planning to expand its services nationwide. In an undated document (at least after August 2013, according to citation in the document), STH plans to establish one Song Tang Hospice branch in cities with 5 million population in 3 years, and one branch in cities with 1 million population in 5 years. In the next 5 years, STH Management Company will become the Listed Company and in 10 years, there will be at least 100 STH branches. Other than this expansion plan, the STH

⁴⁴ “Songtang Yiyuan Official Blog.” Retrieved June 20, 2015 (<http://songtangyiyuan.blog.sohu.com/>).

⁴⁵ “A Visit to the First Hospice Hospital in China.” April 6, 2015. Retrieved June 7, 2015 (http://news.xinhuanet.com/fortune/2015-04/06/c_1114879015.htm).

⁴⁶ “Hospice.” March 22, 2006. Retrieved June 20, 2015 (<http://blog.ifeng.com/article/31654.html>).

⁴⁷ “A Brief Introduction of Songtang.” Retrieved June 20, 2015 (<http://www.stghyy.com/a/songtangjianjie/>).

⁴⁸ “A Visit to the First Hospice Hospital in China.” April 6, 2015. Retrieved June 7, 2015 (http://news.xinhuanet.com/fortune/2015-04/06/c_1114879015.htm).

Management Company is preparing to establish “China Song Tang Nursing College”. The college will be the leading and largest training institute for caring of the elderly and will send professional old-age caregivers to Song Tong Hospice, nursing homes and individual families.⁴⁹ Therefore, more Song Tong type and Song Tang quality of hospice care in China will be available in the near future.

General Conclusion

With social development, improvement in economic condition and more importantly the significant change in demographic age structure, Chinese have paid attention to the end-of-life issue gradually. More people, especially the elderly in urban China, accept the idea of living will and intend to make their own decision about their medical treatment and even death. Living will has laid a foundation to encourage Chinese talking and preparing death more easily, openly and logically. Not only living will, hospice has become a choice for individuals with terminal illness in some Chinese cities. Under the government, NGOs and private/individual efforts, China works hard to build a better society for all including the terminal ill individuals.

However, in order to have a better hospice care system China still has a long way to go. We need to identify difficulties or obstacles on the journey. At present, hospice care in China faces difficulties including the lack of funding and trained staff, short of regulations to standardize hospice operations, as well as poor perception and understanding of death for general population⁵⁰. It also includes the shortage of policy support, low standard of service facilities and service quality, insufficiency of care providers and care workers, tensed and stressful relationship between doctors and patients, and less utilization of resources of religion (Li and Liu 2012, pp.107-116). In addition, service fees from hospice care are still not included in the health care reimbursement system yet.

Without social institutional changes, hospice in China will not be able to develop based on the gradually increased needs of Chinese, especially the elderly population who suffer terminated illness, and their family members. China opens her mind and is willing to learn the lessons of the end-of-life

⁴⁹ “Business Plan of Beijing Songtang Guanhuai Hospital.” May 5, 2014. Retrieved July 25, 2015 (<http://www.stghyy.com/a/ziliaoku/ziliaoxiazai/2014/0211/58.html>).

⁵⁰ “Families lament lack of palliative care centers.” March 29, 2011. Retrieved July 25, 2015 (http://www.chinadaily.com.cn/cndy/2011-03/29/content_12240782.htm).

care from other countries with successful experience. With gradual but firm changes of Chinese society under the suitable and correct direction, all people will have a life with excellent start and respectable end.

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