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End-of-life care in China: ecology of hope

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End-of-life Care in China:

Ecology of Hope

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ABSTRACT

In this thesis I explore the current end-of-life care provision as experienced by older people with advanced cancer in three distinct care settings in Yunnan China: a hospice, an inpatient palliative care ward and a self-help organisation. In particular, I focus on the role of "hope" at the end of life, hope having emerged as a significant aspect of participant's experiences. I took a "multiple-embedded case study" approach, employing mainly qualitative interviewing and observation to capture the richness and complexity of the experience of end-of-life care in different settings.

The findings show that mainstream health care for advanced cancer in China focused on curative western medicine and failed to alleviate prevalent pain and symptoms. Specialised palliative/end-of-life care services adapted from the western palliative care model contributed mainly to relieving cancer pain and symptoms. "Total care for the whole person" – the core of the palliative care philosophy, was an aggregate of the resources located in the family, health care and the broader sociocultural environment.

The study revealed the nature of hope as essentially affirming life in all circumstances and as situated and fostered in a "hierarchical social and cultural ecology of hope" (Feudtner 2005, p. S23) comprising an individual, his or her family, care providers and other physical, social and cultural elements. The fostering of hope, as a resource at the end of life, has implications for improving care and support at multiple levels – personal, interpersonal and social and cultural.

Hence, it is suitable to take the public health approach proposed by Kellehear (2005) to advance palliative care development in China because it endorses a compassionate approach to death and dying and loss and proposes that care for people at the end of life is a fundamental responsibility of not just health professionals, but also communities, governments and societies.

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This thesis is dedicated to the participants of my research, especially the older people who lived with advanced or terminal cancer. Had they not courageously and generously shared their intimate experiences with me, this thesis would not have been possible. I am truly indebted to them for their contribution to my study and my personal growth.

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TABLE OF CONTENTS

LIST OF FIGURES AND TABLES

Chapter One
Introduction

The purpose of this thesis is to explore the lived experiences of palliative/end-of-life care and hope in older people with advanced cancer in the Chinese context. In this introductory chapter, I provide some background to the study and outline the structure of the thesis.

First of all, it was my professional and academic background that led me to choosing this research project that the Open University and an external charitable organisation have jointly funded to study the current situation of palliative/end-of-life care in China. From 2004 to 2006, I worked as a project officer for ORBIS International[1], an international charitable organisation committed to eliminating avoidable blindness and restoring sight in the developing world. Through that work, I acquired hands-on knowledge about a public health approach to health and illness: community capacity building; partnership and collaboration between sectors; health promotion and education; raising public awareness and advocacy; and influencing policy. I also worked closely with some local hospitals in the projects I managed and, in the process became quite familiar with the health care structure and settings in China.

My experience in ORBIS International also kindled my desire to pursue public health as a career, beginning with the academic study of the field. I was fortunate to gain the opportunity through a full scholarship to undertake The European Public Health

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[1] http://www.orbis.org/

Master[2], which is a two-year masters course provided by two European universities, in my case, these being the University of Sheffield in Britain and the Jagiellonian University, in Krakow, Poland. My first-year (2006-2007) curriculum covered the basic issues of public health and the second-year curriculum (2007-2008) covered the specific health and social issues related to fertility and maternity, mental illness, chronic disease, disability, ageing and health and safety in the workplace.

By the end of the masters' study, I became particularly interested in care for older people and mental health. In addition, my initial introduction to palliative care was during my practical placement in a skilled nursing home in Krakow in early 2008. These professional and academic prerequisites eventually led me to, and prepared me for taking on this research project about the experiences of older people with advanced cancer. More importantly, from the outset, I believed that caring for older people living with cancer was a public health issue, particularly in the sense that it is not just about providing health care, but also a concern for the underlying social, cultural, economic and wider determinants; about collective responsibility and organised efforts of society; and about government leadership and intersectoral cooperation and partnership.

In addition to my professional and academic background, I was suited to the cross-cultural nature of the research. Having been born and brought up in China, it was expected that my "insider" status would afford me many advantages that an "outsider" researcher would not have (Liamputtong, 2010). Indeed, as it turned out, I did not encounter any significant social, cultural or linguistic barriers in conducting this research. Furthermore, my Chinese origin placed me in a position to be able to offer

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[2] http://www.europubhealth.org/us/accueil/

new angles and a depth of understanding that an "outsider" might not have had access to. However, I would argue that I was less of an "indigenous insider", and more of an "indigenous outsider" (Banks, 1998), in the sense that I had adapted to and was assimilated into outside cultures, having lived, worked, studied and travelled in South Africa, Cambodia, the UK, Poland and other countries. More importantly, my scientific "thinking framework" related to the topic areas – theoretical, conceptual and methodological, was purely "western", acquired through my work with ORBIS and my Masters' study. Before then, I had no scientific knowledge about health and illness except for my lay knowledge[3]. As such, I believe that my very diverse experiences before taking on the research project would have a bearing on my research conduct and findings, and I would argue that what I will offer in this thesis is a mixture of both insider and outsider accounts, which cannot be separated.

Moreover, I was also an outsider in the sense that I had never had any personal experience of relating to people with cancer or who were dying. I had only experienced my grandfather's death when I was a teenager, at a time when I was too occupied with other concerns to be aware of his dying and death. Indeed, for a long time, I was confused and could not answer the question: "what is it that you are really interested in about these people's experience?" I was only sure that it was not death that I was interested in. In searching for the focus of the study, it was half way through my research that I eventually understood that what I was really interested in was what it was like to "live" with such an appalling condition as advanced cancer, how these people persevered, what supported and anchored them and what could be done for them. In this sense, my thesis is biased towards "living with" rather than "dying of"

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[3] My first degree in China was enterprise management and my jobs before ORBIS were accountancy and management in different business lines.

3

advanced cancer, although many of the older people I studied believed that they were dying even without a terminal diagnosis.

My interest in hope was initially inspired by the experiences of the older people with advanced/terminal cancer whom I interviewed in the pilot study. The pilot interviews revealed that they suffered not just from relentless symptoms, but also from inappropriate or insufficient medical and social support in coping. Their situation seemed totally hopeless to me at that time, as it was my first experience of being exposed to and witnessing such intense human suffering under the shadow of impending death. In the aftermath of shock, sadness and hopelessness, a question kept occurring to me: "Is there any hope at all?" Yet, as my emotional turmoil subsided, I realised that all of the terminally ill people I had interviewed had somehow endured their experience however dire their situation appeared to be, something which suggested to me that they must have been capable of drawing on hope to sustain them. But I kept wondering: "how do they sustain such hope to enable them to continue living day by day?" Also, for me to endure the process of carrying out this study, I also needed hope to be able to bear witness to their suffering.

Following my initial inspiration described above, I conducted a literature review on hope in terminal illness, which reinforced my idea of exploring hope in the main study. I wanted to find out the source of hope and how hope could be brought to life or rekindled, if it was hope that enabled people to rebound and sustain themselves regardless of adversity. And I hoped that my study of hope in this seemingly hopeless situation would contribute to identifying sources of support and the ways support could be best provided for patients in palliative/end-of-life care.

As such this thesis has two interlinked key themes: palliative/end-of-life care approach in China and hope in older people with advanced cancer. These two themes will be addressed through the following structure. Chapter Two introduces and explicates some key features of the sociocultural context of care for older people in a Chinese setting. Chapter Three reviews literature on palliative/end-of-life care and hope in terminal illness. Chapter Four outlines my methodological approach to achieving the aims of the research and how this has been derived from theoretical, ethical and practical imperatives, and reports in detail on the process of data collection and analysis.

Following Chapter Four are five analytic chapters. In Chapter Five I illuminate the current situation of care (in its broadest sense) for older people with advanced cancer in China to identify the sources both of support and suffering in their lives, with reference to the three key areas of health care, community life and perceptions of cancer. Chapter Six reports on the case study of two distinct models of specialised palliative/end-of-life care – a hospice and an inpatient palliative care ward; and I discuss to what extent, the two models had adopted the western palliative care philosophy of total care responding to their local contexts, and to what extent they had met their patients' complex needs at the end of life. Chapter Seven discusses patients' two common strategies of coping using hope, explores the implied or explicit meanings of hope in their accounts and reveals the nature of hope at the individual level. In Chapter Eight I explore the key external sources of patients' hope encompassed in their sociocultural ecology of hope and represent some of the ways in which these sources influenced the nature of their hope. Finally, in Chapter Nine, I explore the contribution to knowledge of this thesis, evaluate the research process,

summarise and synthesise the research findings in terms of the themes that this study

has aimed to explore, and make some policy recommendations.

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Chapter Two
Sociocultural Context of Eldercare

Introduction

Having explained my research interest and perspective relating to the research problems in Chapter One, in this chapter I will introduce and explicate some key features of the sociocultural context of care for older people in a Chinese setting. However, it is beyond the scope of this chapter to provide more than a snapshot of this context as represented by the findings of my research. Therefore, it cannot fully capture the enormous, heterogeneous and fast-changing nature of Chinese society, which I have come to experience through my research. In Section 1, I introduce the currently available data on China's demographic and epidemiological transition to an ageing society and the factors that underpin and shape this transition. Section 2 outlines the social context of eldercare in China in terms of social security, social welfare and social assistance, health care and long-term care. In the final section (3), I discuss the most influential cultural values and traditions in eldercare in China, that is, familism, filial piety and widely-held attitudes towards death and dying.

1. China's demographic and epidemiological transition to an ageing society

"The Law of the People's Republic of China on the Protection of the Rights and Interests of Older People", promulgated in 1996, stipulates that "older people" refers to citizens aged 60 years and above (Zhang et al, 2009). On October 31st, 2000, this population of older people reached 10.2% of the total population, signifying that China was already an ageing society[4] (UNFPA, 2006; Flaherty et al, 2007; CNCA, 2008a; Zhang et al, 2009). By 2008, the percentage of older people reached 12% (Zhang et al, 2009). With 1.5989 billion older people (accounting for over one-fifth of the world's older population and equating to the total number in the whole of Europe), China was ranked number one in the world. However, it is not just the absolute number that is unprecedented but also the speed and duration of ageing. The proportion of older people in China is projected to triple from 11% to 32.73% between 2005 and 2050, to a total of 450 million (Kaneda, 2006; CNCA, 2008a).

Ageing is an inevitable mathematical consequence of two underlying demographic trends, namely, fertility decline and improved longevity (Kaneda, 2006; UNFPA, 2006). From the mid-1950s onwards, the Chinese Government implemented three consecutive national birth control campaigns (Flaherty et al, 2007). Together, these campaigns brought about a remarkable reduction in the fertility rate, from around six children per woman in the early 1950s to less than three children per woman by the end of the 1970s. Then came the most stringent birth control policy: the One-Child

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[4] According to the United Nations, a population is generally considered to be 'aged' if persons over 60 account for more than 10 per cent.

8

policy in 1979, which sustained this achievement in fertility reduction. Consequently, the fertility level has remained below 2 children per woman since the early 1990s. Meanwhile, China has made remarkable gains in health over the past five decades, with life expectancy at birth rising by two-thirds from 43.5 in 1949 to 71.5 in 2005, attributable to the advances in medical care, successes in public health programmes and improvements in the general standard of living (England, 2005; Kaneda, 2006). As the result of these two demographic trends, China's population is now ageing at one of the fastest rates ever recorded (Kaneda, 2006; UNFPA, 2006).

However, an ageing population usually leads to a shift towards a disease pattern dominated by more chronic diseases and disabilities, as ageing is inevitably accompanied by biological changes which increase the risk of illness and disability (Huang, 2005; Zhang and Chen, 2006; WHO, 2008). Indeed, the disease profile of China now resembles that of a developed country, with some 85% to 90% of deaths attributed to noncommunicable diseases and injuries (WHO, 2008). According to Ministry of Health (2008), the five leading causes of death in urban areas in 2007 were: first, cancer (accounting for 28.53% of the total deaths); second, cerebrovascular diseases (18.04%); third, heart diseases (16.29%); fourth, diseases of the respiratory system (13.01%), and fifth, injury and poisoning (6.09%). This is slightly different in rural areas where 24.8% of deaths were attributed to cancer, 20.59% to cerebrovascular diseases, 17.24% to diseases of the respiratory system, 14.8% to heart diseases, and 8.96% to injury and poisoning. Altogether, these five leading causes were responsible for 85% of the total deaths in China in 2007.

In particular, mortality from cancer has increased by 83.1% over the past three decades and cancer has become the number one killer disease (Huang, 2005; Zhang

and Chen, 2006). The top five most common malignancies in China are lung, liver, gastric, oesophageal and colorectal; notably, the incidence of lung cancer among both sexes and of breast cancer among females are on the rise (Ma et al, 2008). What is more, cancer predominantly affects older people, so the increase in the numbers of older people will inevitably lead to more cases of cancer (Cancer Research UK, 2005).

2. The social context of care for older people

China has made impressive gains in improving living standards, reducing poverty and maintaining strong economic growth since initiating market reforms in 1979 (WHO 2011). However, China has aged before becoming rich (Zhang et al, 2009). In other words, the Chinese population is ageing rapidly while China is not yet economically and socially prepared to provide for and support such a large older population. For example, social security, social welfare and social assistance systems are underway, but not yet established; and they are still very basic and not yet sufficient. With ongoing socioeconomic development, life expectancy will continue to increase. This will exert greater pressure on the current, already stretched health care and long-term care provision. In what follows, I outline the social context of eldercare in terms of social security, social welfare and social assistance, health care and long-term care.

2.1 Social security, social welfare, and social assistance

In China, the social security system differs between rural and urban areas (Zhang et al, 2009). In urban areas, a social security system comprising basic old-age insurance, basic medical insurance, unemployment insurance, industrial injury insurance and childbirth insurance, has basically taken shape and coverage is expanding. In rural areas, the government is exploring a viable way of providing old-age insurance and is setting up the New Rural Cooperative Medical Insurance System. Nonetheless, despite the remarkable progress, the overall coverage of the two systems is fragmented and far from sufficient. The differentiated systems also provide far more benefits for urban residents than rural ones. Take the old-age insurance as an example: only 21% of the 1.3 billion Chinese were insured in 2008. In the urban system, 56% of the employed urban residents and 6% of the migrant workers from rural areas were covered. In the rural system, only 22% of rural residents were covered. As a result, in urban areas, income in old-age was mainly from the social security system and supplemented by families (76% of older people were pensioners in 2005), whereas, it was mainly from families in rural areas (only 3.1% of older people were pensioners in 2005).

Social welfare in China does not cover social security, health care, domestic and social services and other areas of improving living standards. Rather, it is narrowly based on the target of guaranteeing the basic livelihood of people. In other words, it is not intended to benefit the whole population; the target population are the vulnerable groups such as older people, disabled people, orphans, disabled veterans and the "three-without people" [5]. "The Law of the People's Republic of China on the Protection of the Rights and Interests of Older People", promulgated in 1996, outlines the social welfare system for older people. The system is aimed at meeting older people's needs for 1) livelihood and safety (e.g. housing, daily care, health care), 2)

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[5] Without capability to work, without any provider, and without any income.

respect and entertainment (e.g. cultural, sports and entertaining activities, infrastructure for such activities, preferential treatment in public services), and 3) development (e.g. continued education). But variety, coverage and payment level differ between regions, subject to the local government's financial situation.

Social assistance is provided by the government and the society for individuals and families who cannot maintain minimal living standards due to natural disasters and other causes. It basically involves poverty relief and disaster relief. The established systems include: 1) the system for ensuring a minimum standard of living for urban residents, 2) the disaster relief system, 3) the system of "five guarantees" [6] for the "three-without" older people, disabled people or young people in rural areas, 4) the aid system for extremely impoverished families in rural areas, and 5) the aid system for vagabonds and beggars. The new systems being established are medical, educational, housing and legal aid systems. These social aid systems benefit a great number of extremely needy older people.

2.2 Health care

The health care system in China was regarded as exemplary for low-income agrarian societies during the period between 1949, when the People's Republic of China was founded, and the early 1980s (Hsiao, 1995; Hesketh and Zhu, 1997; Liu and Yi, 2004; Blumenthal and Hsiao, 2005; Kaneda, 2006; Zhang and Chen, 2006; Flaherty et al, 2007; Gao et al, 2007; Wong, 2007). At that time, it was renowned as a publicly-owned health care delivery system with established health financing schemes that covered most of the population and enabled excellent health across the country.

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[6] Guarantee of food, clothing, housing, medicine and burial.

However, since the early 1980s, the system that relied heavily on public subsidies and provided universal access to basic health care has shifted to a market-oriented system that relies heavily on private funding and features excessive usage fees. Within this market orientated system, some major flaws have emerged:

a. The contribution of the government to health care financing is low (only 24.7% of the total health expenditure in 2009) (Du et al, 2009; Theory Bureau of the Propaganda Department of the Central Committee of the Chinese Communist Party, 2010);

b. public hospitals (accounting for 71% of the hospitals in China and undertaking over 80% of the total service load of all hospitals) are profit driven;

c. over-prescription of costly drugs and over-use of high-tech services are rampant, incentivised by price regulation;

d. health care costs are escalating rapidly compared to the cost of living;

e. while medical insurance coverage is increasing, many people are underinsured and continue to face high out-of-pocket costs (accounting for half of total health expenditure in 2009);

f. the health care delivery system is inequitable and inefficient; particularly, there is a lack of primary health care facilities and services;

g. allocation of scarce health care resources is irrational; resources have not been shared equally across geographic regions, rich and poor households, urban and rural residents, and migrant and resident populations within cities;

h. the price of medicine is inflated;

i. poor performance and lack of professional ethics and ethos are common among health care professionals;

j. public health policies may be considered less important than encouraging consumption; public health institutions and programmes are underfunded (WHO, 2011);

k. regulations relating to public health and health care delivery systems are underdeveloped and poorly enforced, and monitoring capacity is weak.

As a result, it is generally very hard to access and afford health care in China (Theory Bureau of the Propaganda Department of the Central Committee of the Chinese Communist Party, 2010). First, in large hospitals particularly, it takes many hours and numerous queues to register, pay, receive tests, medicine and treatment, and wait to be seen by a doctor. But a medical consultation lasts for only 10 minutes or so. Seeking medical help is therefore a physically exhausting and mentally disturbing process. Second, Chinese patients are free to choose between hospitals and between doctors in a hospital. To receive better treatment (for even minor problems), they tend to choose specialists and senior doctors in large hospitals.[7] Consequently, some doctors are extremely popular; patients have to queue for a long time, find "guanxi"[8], or pay extra to register for them. Third, the burden of medical expenses falls heavily on individuals and families. In 2009, it cost an inpatient RMB 5952 (around £590) per hospitalisation on average, which is one third of the average annual income of an urban resident, and 1.12 times the average annual income of a rural resident. Fourth,

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[7] Today's health care delivery system is highly inefficient, with both resources and patients concentrated in larger (tertiary) hospitals in urban areas. These hospitals treat all types of patients with all levels of severity, and have a large number of operations and outpatients, and a disproportionate number of patients. This has resulted in a situation where large hospitals are growing rapidly providing general as well as specialist services, while smaller community hospitals (secondary hospitals) and health centres (primary hospitals) are caught in a vicious cycle where the lack of patients and income make it difficult for these service providers to upgrade their medical infrastructure, which, in turn, further reduces their attractiveness to patients (IBM Corporation, 2006).

[8] The term "guanxi" has been created to describe and reveal social connection and social relationship in China (Lu and Chen, 2011). Nowadays, it often implies a special connection between people, a connection which brings along exchange or reciprocity of special rights and obligations; or an informal, unofficial relationship utilised to get things done, from simple tasks to major life choices.

14

among different social groups, it is most difficult for rural residents to get health care. Generally speaking, China is facing severe problems arising from what is called "One China, four worlds" (Theory Bureau of the Propaganda Department of the Central Committee of the Chinese Communist Party, 2010, p. 5), that is, the uneven economic, political and social development, particularly between rural and urban areas, and between the east and the west. In terms of public services such as health care, urban areas enjoy 70% of the scarce health resources while rural areas struggle with the remaining 30%. Health expenditure on rural residents is only one quarter of that of urban residents. These problems impact on older people deeply because they suffer more chronic health problems and often live with one or more long-term conditions, and therefore, in general have a greater need for health care than younger people in general.

To tackle these problems, in 2009, the Chinese Government announced a new round of the national health reform (Du et al, 2009; WHO, 2011). The main objective was to provide universal health care coverage by 2020. Reforms are proposed in five areas: the public health system, the medical care delivery system, the medical insurance system, the pharmaceutical system and the public hospitals. Measures will be taken to improve the following aspects of the five areas: management, operation, investment, pricing, monitoring, science, technology and talents, information and legislation. The initial three-year implementation plan for 2009-2011 emphasises several programmes, including: 1) improving the three medical insurance systems (for urban employees, urban residents, and rural residents respectively) and medical assistance programmes; 2) establishing an essential-medicine system; 3) strengthening primary health care facilities; 4) reducing disparities in public health services between regions; and 5)

piloting reforms in public hospital financing by reducing the reliance on drug sales for operational costs and salaries.

2.3 Long-term care

At present, 99% of older people in China still live in their own home, with only 1% in long-term care facilities (Zhang et al, 2009). However, the traditional model of long-term care provision will be compromised in the light of the One-Child policy (Huang, 2005, WHO 2011). In other words, informal care traditionally provided at home for older people by adult children, especially by daughters-in-law, will become increasingly unfeasible in the near future, when the parents of the first generation since the introduction of the One-Child policy start reaching old age and retiring. This is because these single children will face the need to care for two parents and often four grandparents without siblings with whom to share the responsibility, a problem sometimes referred to as the "4-2-1 problem" in China (Flaherty et al, 2007).

In addition to the "4-2-1 problem", trends in both the female labour force participation and the sex ratio of young Chinese people may well create additional challenges for a society which traditionally has left the care of its older people to women, especially daughters-in-law (Kaneda, 2006). The female labour force participation in China is quite high: 71% in 2000 (Maurer-Fazio et al, 2005); and this could affect the informal provision of long-term care in the coming decades (Kaneda, 2006). Emerging from the One-Child policy is another problem, that of gender imbalance (England, 2005). The sex ratio at birth for the young cohorts, who were born after China's One-Child policy, is highly skewed toward boys, the estimated sex ratio for all births in 2000 being 120,

the highest in the world (Riley, 2004); and this may well lead to a shrinking pool of daughters and daughters-in-law as the caregivers for older people (Kaneda, 2006).

What is more, 62% of Chinese people are currently living in rural areas (Kaneda, 2006). Rural older people account for 65.82% of the country's total older population (Xin, 2008). The gap in the proportion of older people between urban and rural areas is expected to widen with continuing rural-to-urban migration which leaves increasingly more rural older people alone in their "empty nests" (UNFPA, 2006; Zhou, 2006 p.27; CNCA, 2008b). As rural areas have not yet benefited as much from the economic growth and social development as the urban areas, rural residents are disadvantaged in many ways, such as much lower levels of income, living standards, education, health status & health care, insurance coverage and other social security benefits (Blumenthal and Hsiao, 2005; England, 2005; Flaherty et al, 2007; Zhang et al, 2009). Hence, it will be even harder to support rural older people since they may have greater needs compared to urban dwellers but less means to meet these needs.

On the other hand, long-term care facilities and community services for older people are currently sparse and patchy across the country and are often too expensive for many older people and their families to access (Kaneda, 2006). For example, according to Information Office of the State Council of the People's Republic of China (2006), at the end of 2005, there were 39,546 long-term care facilities providing care for older people, which included social welfare institutions for the aged, older people's homes, senior residents' lodging houses and nursing homes for the aged. The number of beds available in these facilities totalled to 1.5 million including 895,000 beds in 29,681 rural older people's homes. On the whole, the existing facilities can only accommodate 0.8% of China's total ageing population, far fewer than are needed.

3. The cultural context of care for older people

In addition to the social environment discussed above, the cultural milieus also have a bearing on the eldercare in China. There are three main religious/philosophical tenets in China, namely, Confucianism, Taoism and Buddhism. These are the foundation of Chinese society, each playing a vital role in community and family life (Yick, 2002; Lu and Chen, 2011). Grounded in these three religions and philosophies are complex traditional Chinese cultural values and norms such as the privileging of collectivity over individuality, familism, hierarchy, male-dominancy, face-saving, harmony and conformity of behaviour, emphasis on paternal lineage, significance of filial piety and restrained and indirect communication styles. Of great influence in the care for older people, particularly at the end of life, are familism, filial piety and attitudes towards life and death.

In traditional Chinese society, interdependence and harmonious coexistence fostered in an extended family denotes that the autonomy of an individual must surrender to family determination (Tse et al, 2003; Xu, 2007). Chinese culture is therefore a collectivistic one, in which the concept of self is relational. The notion that an individual exists independently of the family is foreign to Chinese people. As an individual is always part of the family, the western concept of autonomy is unfamiliar to the Chinese and even conflicts with their values and beliefs. As such, for the Chinese, important personal decisions, such as marriage or job seeking, are often

made in consultation, if not in conjunction, with family members. Likewise, medical decisions are also family decisions. This not only applies to mentally ill people who might not be competent enough to make rational decisions, but is also common practice, enshrined in hospital policy, as with, for example, consent for surgery (Yick, 2002; Tse et al, 2003; Wang et al, 2004; Cheng et al, 2008).

The tradition of filial piety denotes the responsibilities of children for their parents, these responsibilities reflecting the high social standing of older people in Chinese society (Chen, 2009). First, it is children's responsibility to provide for their parents. Second, children should look after their parents considerately and make them happy in their day-to-day domestic life. Particularly, when parents are ill, children should care for them, and share their worries, concerns and pains. Third, when parents die, children should control their own grief and put their energies into arranging the funeral. Only afterwards, should they mourn for their parents and hold rituals to commemorate them. Fourth, children should treat their parents respectfully. In addition, children should cherish their bodies because they are bestowed by their parents. One's body is treated as the continuity of the bodies of one's parents, but exists in another life form; therefore to hurt one's body is to hurt that of their parents. Filial piety also requires that one cherish one's life because it is the basis for fulfilling filial piety. As the moral foundation of the traditional long-term care model for older people, filial piety is reinforced by Chinese laws, such as the Constitution of the People's Republic of China and "Law of the People's Republic of China on the Protection of the Rights and Interests of Older People" (Zhang et al, 2009).

The ancient Chinese philosophers' attitudes towards life and death are to respect life seriously and accept death peacefully (Chan and Chow, 2006). On the other hand,

both Taoism and Buddhism have elaborate and horrifying portraits of punishments in hell for the various crimes that humans may commit, in order to deter the living from violating social rules and norms. Interacting with Confucianism, Taoism, and Buddhism, co-existing local folklores and superstitions also play a big role in shaping Chinese peoples' attitudes towards death and dying, contributing in particular to negative meanings associated with death and dying (Yick, 2002). After all, greater importance has been attached to life in Chinese culture, and death is almost always perceived as a negative life event (Xu, 2007; Wang and Wang, 2011). Because a life is lost forever when death occurs, heroic measures to sustain and prolong life should be implemented and sustained at all cost, as a popular Chinese saying advocates: "it is better to struggle to live on than die a good death".

Consequently, death as a subject is one of the taboos in Chinese culture and perhaps the number one on the list. It arouses negative and evasive attitudes among the public, who try not to touch on this topic in daily life (Yick, 2002; Bian and He, 2004; Qiu, 2008). However, as such, it is a taboo that affects the fabric of everyday life (Xu, 2007). For instance, it is culturally taboo to give a clock as a present since the phonetic sound of "clock" in Chinese is the same as "death". Chinese words that sound like "death" are avoided as far as possible, for example, the number "4", which pronounces the same as "death" and the number "9413", which sounds like a Chinese idiom that means nine (9) out of ten will die (4) and only one (1) out of ten will live (3) (Chan and Chow, 2006). The places where people die or are buried are perceived to be contaminated, inauspicious and surrounded by bad spells (for example graveyards, private houses if people die at home and even hospices), and therefore should be avoided (Yick, 2002; ChinaCulture 2008). In addition, bereaved people are not invited to happy celebrations such as weddings and birthday parties for fear of the spread of

the bad luck or evil spirits they may carry with them (Chan and Chow, 2006; Seymour et al, 2007).

These cultural values and norms have had a profound influence on the eldercare in Chinese society. Here I have only mentioned in passing the link between this cultural context and current health care practices. I will elaborate on this in relation to palliative/end-of-life health care in Chapter Three.

Summary

This chapter has provided a succinct description of the sociocultural context of care for older people in China at the time of my research. Due to the dramatic fertility decline and the improved longevity, China's population is ageing rapidly. This has led to a shift towards chronic diseases and disabilities among an ageing population. However, while the magnitude, speed and duration of ageing in China are unprecedented, China is not yet economically and socially prepared to provide for and support such a huge ageing population.

First, despite recent and remarkable progress, the social security, social welfare and social assistance systems are still fragmented in their coverage and insufficient, providing only basic protection. Besides, rural residents are particularly underinsured and underserved. Second, the shift towards chronic diseases and disabilities puts greater demands on health care and long term care provision. Currently, there are

constraints in the existing systems to meeting the rising needs of older people, and it is generally hard to access and afford health care in China. The traditional model of long-term care provided at home by adult children is also undermined by the socioeconomic changes in Chinese society and will become increasingly unfeasible in the near future. Meanwhile, long-term care facilities and community services for older people are sparse and patchy across the country and are often too expensive for many older people and their families to access.

What is more, the underpinning cultural values, traditions and attitudes also have implications for an appropriate approach to caring for older people in China. Familism determines that, as with other personal decisions, medical decisions are the whole family's concern. The western concept of personal autonomy is inconsonant with this cultural value, and therefore alien to the Chinese. Filial piety constitutes a moral obligation for children to provide for, look after, and respect parents, and cherish one's own body and life. This tradition is preserved and reinforced by Chinese laws. With greater importance attached to life in the Chinese culture, the predominant attitudes towards death and dying are rather negative, prone to denial and avoidance. The Chinese therefore believe "it is better to struggle to live on than die a good death", while death, as one of the most deeply held taboos in China, affects the fabric of everyday life. Inevitably, these cultural values and norms have had a profound influence on the eldercare in Chinese society, as I will discuss in more detail in relation to palliative/end-of-life health care in the next chapter. The next chapter places this study into the context of the existing knowledge of the two key themes: palliative/end-of-life care and hope in terminal illness.

Chapter Three
Literature Review

Introduction

Following an explanation of how I came to identify the focus of my research in Chapter One and an introduction of the sociocultural context of eldercare in China in Chapter Two, in this chapter I review the literature on palliative/end-of-life care and hope in terminal illness, the two key themes of my research. In so doing, I harness the existing knowledge to explore the nature and essence of the two subject areas. I then go on to conceptualise these two areas in relation to my data, and finally to extend the existing knowledge about them in my findings and conclusions. In Section 1, I begin by introducing the foundation of the modern palliative/end-of-life care approach, that is often enshrined in the modern hospice movement, followed by a discussion of trends in the development of palliative/end-of-life care worldwide and the evolving definitions of such care that reflect its development. In Section 2, I present the literature on hope from different disciplinary backgrounds (mainly philosophy, psychology, nursing, palliative care and sociology) whereby I explain the significance, complexity, depth and breadth of hope and conceptualise it in relation to my data. Section 3 describes the situation of palliative/end-of-life care in mainland China in terms of the contemporary developments, the predominant medical approach to care for people with advanced cancer and the status quo of the research into such care. I conclude this chapter with an assessment of where I position my own research in relation to existing knowledge in the two subject areas.

1. Palliative/end-of-life care worldwide

In this section, first, I introduce the foundation of the modern palliative/end-of-life care approach associated with the modern hospice movement. I present the rationale, the most important contributors and the major limitations and controversies of this movement. I then discuss the trends in the development of palliative/end-of-life care worldwide in terms of extending its benefit to other countries (cultures) and all people at the end of life, as well as extending its resource to mainstream health care and beyond. In the final part, I represent the evolving definitions of such care that reflect its development. This section sets the scene for my study of the Chinese situation in this field of care. My findings will be contrasted and compared against this body of existing knowledge and will contribute to understandings in this area.

1.1 Modern hospice movement

Within western societies, contemporary approaches to palliative care are usually identified as having emerged in the 1950s and 1960s, through the development of the modern hospice movement (Stevens and Raftery, 1997). The rapid growth of western medical science in a sociocultural context that was paradoxically denying the inevitability of death set the backdrop for the movement to develop (Forman et al, 2003). This, coupled with the belief of a few pioneers that dying patients need not suffer alone and without relief, engendered a movement towards humanising death,

which found expression in the modern hospice movement. Among these pioneers, the contributions of Dame Cicely Saunders (in particular), Glaser and Strauss, and Elisabeth Kübler-Ross are particularly notable and have profoundly influenced the way society and health professionals perceive terminal illness, death and dying and end-of-life care (Forman et al, 2003; Armstrong-Coster, 2004).

In Britain, in the 1950s and 1960s, through her work as a nurse, a social worker, then her medical studies and later her work as a physician, Dame Cicely Saunders came to understand the complex needs of cancer patients that arose from their "total pain" which incorporated physical, psychological, social, emotional and spiritual elements (Forman et al, 2003; Saunders, 2006 p.87). She then developed the principles of a new approach to the care of dying people, that is, palliative care (Clark and Seymour, 1999; Saunders, 2006). This approach would not only draw on the medical advances in pain and symptom management, but also address wider concerns for the practical and social needs of patients and families and respond to their spiritual needs. The principles on which palliative care was to be based included: 1) acceptance of death as a normal part of life; 2) patient's total care managed by a skilled and well-coordinated interdisciplinary team; 3) effective symptom control and pain relief; 4) recognition of the patient and family as a single unit of care; 5) implementation of a home-care programme; 6) provision of bereavement care for the family following the death of patients; and 7) ongoing research and education (Forman et al, 2003; Saunders, 2006). At the time, this more holistic approach to death was revolutionary in a health care system that focused almost exclusively on curative medicine with death seen as a failure.

During the same period as Saunders' work in Great Britain, in the United States, Glaser and Strauss published their seminal work entitled "Awareness of Dying" (1965), in which they described four contexts of awareness of dying between hospital staff and patients (i.e. closed, suspicion, mutual pretence and open). The findings of Glaser and Strauss, which drew attention to the importance of open communication between dying patients, professionals and their families, have had a profound influence on the treatment of dying patients, particularly in relation to disclosure of a terminal condition (Armstrong-Coster, 2004). In 1969, Elisabeth Kübler-Ross published a book entitled "On Death and Dying", in which a theoretical framework was created to describe the psychological stages of dying (i.e. denial, anger, bargaining, depression and acceptance), based on her interviews with dying patients (Kübler-Ross, 2009). Her book challenged the taboos and silence on death and dying prevailing in the nineteenth and twentieth centuries, which made it possible for palliative care to be considered (Forman et al, 2003). Her theoretical framework proved to be an important underpinning of the practical and supportive work that hospices continued to do (Calman and Hine, 1995; Doyle, 1997).

This notwithstanding, the hospice movement has often been criticised for being limited on three grounds. First, it has tended to focus solely on those with cancer (Field and Addington-Hall, 2000) and failed to extend palliative care to all. Second, referrals to hospice services from minority ethnic groups have been poor, even in areas with a comparatively large minority ethnic population (Ahmed et al., 2004). This questions whether the western model of palliative care and hospice care services are applicable elsewhere. Third, it has tended to over-medicalise the process of dying (Conway, 2007), for example, through continuing to institutionalise those who are

dying (Kellehear, 2007). (Further critique of the hospice movement is provided in the next section.)

Furthermore, the modern hospice movement offers a radical alternative to hospital death and has become synonymous with the notion of a "good death", as Clark and Seymour (1999) put it:

> Hospice and palliative care has, it might be argued, become synonymous with "good death", which stands now not only as a symbolic critique of medicalized, institutionalised death, but has also become a central point of reference for popular expectations of dying and of standards of care at the time of death.

(p. 79)

The features of how people define what constitutes a good death have been explored in various studies. Karen (2006) analysed 42 articles published in English between 1995 and 2004 about the concept of a good death. He found that medical, nursing, and patient perspectives, as well as literature in sociology, agreed on a number of attributes of a good death. They were: 1) being in control, 2) being comfortable, 3) sense of closure, 4) affirmation/value of the dying person recognised, 5) trust in care providers, 6) recognition of impending death, 7) beliefs and values honoured, 8) burden minimised, 9) relationships optimised, 10) appropriateness of death, 11) leaving a legacy, and 12) family care (Karen 2006, p.281). Therefore, what has emerged is a prevailing good death ideology, a western (North American/European/Australian) perspective that "upholds the ideals of dying with dignity, peacefulness, preparedness, awareness, adjustment and acceptance" (Hart et al 1998, p.72).

However, a good death is a contested concept. The work of many scholars (see Kellehear, 1994; Bradbury, 2000; Lawton, 2000; McNamara, 2001; Clark, 2003; Walter, 2003; Komaromy, 2005a; Sandman, 2005; Karen, 2006; Kellehear, 2007) has demonstrated that enormous diversity and difference exist in the way people view and approach death and dying, which may vary according to individuals' biographies, psychological and social status, the context in which the death occurs, as well as broader historical, social and cultural contexts. In the context of postmodern western societies, characterised by increasing individualism (Walter, 1994)[9] , many people are given opportunities to explore different options for living and dying and the emphasis is now on the individuality of dying and of death (Walter, 1994; McNamara, 2001). For example, regardless of the availability of palliative care, "supporters of assisted dying have invoked the rights of patients to self-determination as a reason for promoting the 'ultimate' choice: that of choosing the timing of one's death" (Seymour 2012, p.12). As such, examining and making decisions about how one might categorise different deaths as either "good" or "bad" is morally fraught and difficult.

Nonetheless, as the good death ideology has underpinned the modern hospice movement (Hart et al, 1998), ideas about a good death have come to play a significant role in palliative care, to the extent that palliative care has an essential goal to provide dying people with help in arriving at what a good death amounts to for them (Sandman, 2005). As Sandman (2005) argues:

The only route to the good death is that chosen (explicitly or implicitly) by the individual dying person and promoting the "good death" is therefore about

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[9] That is, a decline in traditional forms of authority such as religion and kinship networks leading to both uncertainty and to an increasing array of personal choices for the individual (Giddens, 1991).

respecting autonomy and the goals of the patient – however engaged or disinterested they may be in details.

<div align="right">(p.viii)</div>

In reality, however, recognising and working with difference and diversity can be especially difficult with regard to death and dying, which raises complex social, moral, existential and emotional issues and where working environments can be "emotion-rich yet time-scarce" (Gunaratnam 2008, p. 34). According to McNamara et al (1994; 1995), there can be conflicts between the hospice ideal of the good death and the maintenance of the organisation's vested interests of cost effectiveness, administrative imperatives and the routinization of care. The concern is that the dying person's preferences and needs may be sidelined by the organisational imperative of efficient service delivery. Furthermore, caregivers on the one hand can enable patient choice, yet on the other hand can shape the lives of dying people to the prevailing ideal (Hart et al, 1998). Walter (1996) observed a process of negotiation and legitimation taking place between dying people and those involved in their care. He argues that the expectations of dying people and caregivers interact to constrain and/or enable individualised dying processes. There are also those whose dying and death cannot be good not only because of disadvantage but also because of very real practical, physical and physiological differences in how people die (Lawton, 2000; McNamara, 2001).

1.2 Palliative/end-of-life care reaching out

Apart from the limitations and controversies discussed above, cultural issues arise with the import and spread of care models from one culture to another (Clark, 2007). Bowman et al (2004) argue that:

<div align="right">29</div>

Western health care is grounded in patient autonomy. It promotes individual determination, informed consent and disclosure of illness as ideal. Yet in many cultures family duties and obligations take precedence over patient autonomy.

(p.406)

Indeed, there remain major differences across cultures, for example, regarding communication of "bad news" (disclosure versus concealment), the locus of decisions (patient's autonomy versus collective, family-centred decisions), and traditional and societal expectations of who provides end-of-life care {family or institutions} (Davis et al, 2002; Blank, 2011). As such, there are no universally accepted standards of end-of-life care that can be transferred from one country to another (Higginson, 2005). Clark (2012) thus contends:

Although palliative care makes universal and global cultural claims on behalf of all people with life-limiting conditions, there has long been a recognition that it must be rooted in specific cultural contexts if it is to thrive and be effective...Putting culture at the centre of palliative care will be a key determinant of efficacy and sustainability.

(p.195-196)

Despite the challenges in adapting to different cultures, the western model of the hospice movement has continued to extend across the world. Since Dame Cicely Saunders founded the world's first modern hospice – St Christopher's Hospice in 1967, a global spread of hospices has followed, featuring rapid expansion and diversification (Stevens and Raftery, 1997; Clark and Seymour, 1999; Saunders,

2006). Different countries and continents have begun to adapt aspects of the palliative care philosophy that are most acceptable to their specific contexts and cultures (Clark et al, 1997; Clark and Seymour, 1999; Saunders, 2006; Seymour, 2012). The timing and rate of growth, and particularly the forms and settings in which this type of care is delivered vary greatly from country to country. The development of palliative care worldwide has not been a case of transporting and introducing a "one-size-fits-all" model of care. Rather, it has been shaped by the local social, cultural, political and economic conditions (Clark and Seymour, 1999).

Considering that palliative care is still a young discipline, it is remarkable that palliative care services have become established in half of the world's countries (115) and capacity-building activity (but no service) is evident in a further 40 countries (Wright et al, 2006). Nonetheless, even with this rapid growth in hospice services the worldwide need for this type of care remains far greater than the actual provision (Clark, 2007), particularly as a gradual transformation of the rhetoric of "palliative" care for cancer patients to "end-of-life" care for all is occurring internationally (Seymour, 2012). As a result, death and dying in the developing world often remain distressing, humiliating and dehumanising experiences for the dying person, their family and the health workers associated with their care (Clark, 2007). Even in the UK, which is commonly seen as the founder of modern palliative care and the exemplar of good practice (Economist Intelligence Unit, 2010), the policy rhetoric of providing good quality end-of-life care to all who need it is not matched by the reality of the provision (Seymour, 2012). Worldwide, while more than 100m people would benefit from hospice and palliative care annually (including family and carers who need help and assistance in caring), less than eight per cent of those in need access it (Economist Intelligence Unit, 2010).

Central to the current debate surrounding the direction of the specialty is the trend towards medicalisation within palliative care (Corner and Dunlop, 1997; Clark and Seymour, 1999). Palliative care is now practised in two different contexts: as a specialty by the hospice and palliative care services and in a general sense by health professionals who work in mainstream health care services (McNamara, 2001); and "a distinction is drawn between the delivery of palliative care and the philosophy of palliative care" (Clark and Seymour 1999, p.86). The growth of the professional discipline and the integration of palliative care into mainstream medical and nursing practice indicate a movement to reinstate the medical focus of terminal care within the hospice/palliative care domain (McNamara, 2001). As medicine is organised in such a manner that precedence is given to physical causes and treatments, within the holistic framework of "total care", psychological, social and spiritual components, while considered important, are accorded a lesser priority within the hierarchy of care. Thus, the original ideals of the hospice movement have been watered down to emphasising physical care, and palliative care has moved its emphasis from dying people to issues of symptom control and palliation. There is the danger that palliative care increasingly looks like traditional health care service with hospice overtones.

With the trends in palliative care indicating a greater level of medical intervention and hierarchical organisation, the original hospice vision of reorienting society to a greater acceptance of death could well be undermined by the strong philosophical themes of "denial of death" and "power over death" entrenched in medical discourses (McNamara, 2001). While palliative care continues to have a commitment to improving the care of dying people, the acceptance of death is pushed into the background while practitioners attend to the physical needs of the patient. Dying and

death are still "managed" within the context of medicine though they are essentially social processes and social problems (Kellehear, 2007).

What is now evident is an imbalance between medicine and care which "directs attention from paternalism to participation, from linearity to holism, and most importantly, from patient to person" (Clark and Seymour 1999, p. 81). Moreover, Kellehear and O'Connor (2008) note that quality of life for people with a life-threatening illness is influenced by medical as well as social support. Although symptom control is crucial to the management of life threatening illness, strong community support throughout the course of the illness are equally important to well-being. However, as Kellehear (2005) points out:

The idea of the life of a citizen − that a dying person may have needs more complex and beyond health services for the majority of his or her time whilst living with a life-limiting illness − is rarely considered a time or experience for palliative care to make a contribution.

(p.21)

Hence, the need for and challenges in reaching everyone in need and the encroaching medicalisation of care, demand that palliative care should adopt a public health approach and be recognised as a human right. The maturing of palliative care as a clinical specialty and academic discipline has coincided with the development of a public health approach to global and community-wide health problems (Gwyther, 2009). Given that death and loss are both inevitable and universal, the care of people who are dying or have a life-limiting illness and their families stands equal to all other public health issues. WHO recommends a public health strategy to assist governments

33

in integrating palliative care into the country's health care system (Stjernsward et al, 2007). The main elements of this strategy are: 1) policy development; 2) drug availability; 3) education of policy makers and health care workers and improving community awareness of palliative care services; and 4) implementation of palliative care at primary, secondary, and tertiary care levels.

Kellehear (2005) proposes a public health vision that expands the WHO's strategy to involve whole communities, arguing that health is everyone's business, and that communities can work in partnership with professional groups to offer inclusive care and support that is underpinned by the recognition that death and loss are part of the life of any community. This broader public health approach is also a recognition of the limits to service provision outside of "acute" episodes of professional care and in remote areas where medical and social care services are few or overstretched (Kellehear and O' Connor, 2008). It thus revolves around the need to complement direct service provision before, during and after death and bereavement and build community resilience in the face of ageing, dying and death. Central to this approach are community development, health promotion and partnership (Kellehear, 2005). Strategies that derive from these concepts stress the traditional public health practices of prevention, policy development, government leadership and intersectoral cooperation. These strategies resonate with the human rights approach to advancing palliative care development, which serves to coalesce a broad medical, moral, and legal imperative that the care of patients with life-threatening illness is a fundamental responsibility of governments, societies and health professionals (Gwyther, 2009). The international palliative care community has articulated a simple but challenging proposition that palliative care is an international human right.

1.3 Definitions of palliative/end-of-life care

Despite the substantial and important breakthroughs, there is no single, universal agreement as to what palliative care actually constitutes. This reflects "what might be termed an identity crisis in this field of care, as it struggles to evolve and transform" (Seymour 2012, p.3). However, all of the differing interpretations that are in circulation are based to some degree on the definition set out by the World Health Organisation, whereby:

> 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 counselling, 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.

(WHO, 2002)

Further confusion about palliative care comes from uncertainty over what constitutes end-of-life care and how this relates to palliative medicine. The National Council for Palliative Care (2007) defined it as:

Care that helps all those with advanced, progressive, incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

(p.3)

The NCPC's definition and principles of "end-of-life care" basically reflect those of palliative care (WHO, 2002), but are extended to meet the needs of people with cancer, organ failure and dementia and those who are elderly and frail, and to encompass other elements such as partnership in care, needs assessment, advance care planning, patient choice for place of care and death, and coordination of care. In terms of time, "end-of-life care" usually refers to the care of a person during the last stage of his/her

life, from the point at which it has become clear that the person is in a progressive state of decline. In other words, end-of-life care is specifically concerned with the care of people who are diagnosed as dying.

In its report "The quality of death: ranking end-of-life care across the world", the Economist Intelligence Unit (2010) defines "end-of-life care" as including palliative care but also referring to broader social, legal and spiritual elements of care relevant to quality of death. According to Seymour (2012), worldwide, there occurs a gradual and as yet incomplete transformation of the rhetoric of "palliative" care for cancer patients to "end-of-life" care for all, although, in reality, the terms "end-of-life care" and "palliative care" are used interchangeably particularly in current professional practice.

Hospice (care) is another term which has been often used interchangeably with palliative care. According to Hawthorne and Yurkovich (2004), today, hospice refers to a program of care for the dying, a type of care synonymous with palliative care, or a location of care in the community, and a reflection of scientific thinking regarding the end of life. Hospice care is usually referred to as specialist palliative care (NICE, 2004). While using the principles of palliative care, it typically focuses on people who have moderate to complex needs and who require expert help from professionals trained in palliative care. Or "hospice care" refers to care in specialist institutions (Economist Intelligence Unit, 2010).

2. Hope

The existing theoretical and empirical work on hope draws on different disciplinary perspectives such as those from philosophy, theology, psychology, psychiatry, nursing, palliative care, and sociology. For my study, I mainly draw on literature from psychology, nursing, palliative care and sociology, as presented in this review. I start this section by establishing the significance of hope for people as individuals and as collectives. I then focus on hope in terminal illness in terms of its major roles, meanings and controversies in relation to death and dying. In the final part, I present the conceptual models of hope that I draw on in analysing and interpreting my data. The literature I have selected and present in this section serves at least two purposes: first, as a whole, it provides me with a framework for thinking about and understanding the depth and breadth of hope; second, the separate sources provide conceptual tools for interpreting my data and developing my findings.

2.1 The significance of hope

The natural flights of the human mind are not from pleasure to pleasure, but from hope to hope.

Samuel Johnson: The Rambler (March 24, 1750)

Frankl (1959), a survivor of Hitler's concentration camps, believed that hope is so vital to life that its loss is equal to the loss of life itself. Fromm (1968) also states that hope is so integral to human life that understanding it is like a fish trying to understand the meaning of water – water might be the last thing a fish is concerned about until it is taken out of it. Hawthorne and Yurkovich (2004) and Johnson (2007) argue that hope is such an essential component of life that people retain the capacity to

have hope throughout life. They note that hope is what energises people, drives them forward and keeps them going; and that hope enables and strengthens people to endure suffering and transcend difficult situations, and gives them courage to face the uncertain and explore the unknown and wisdom to find meaning in life and dying.

There are varied definitions of hope in the literature (drawn from philosophy, theology, psychology, psychiatry, nursing, palliative medicine and sociology), which appear to cause confusion. However, hope is generally understood as multidimensional rather than trait-oriented and one-dimensional, and as a fragile but dynamic state (Dufault and Martocchio, 1985; Watson, 2009). As such, a universal definition of hope might simply reduce the complexity and richness of hope and fail to take account of the fullness of the range of actual experience of hope. That is to say, while different definitions may well capture different essential attributes of hope, together, they present a fuller picture of what hope is. The following definitions of hope are demonstrative of the essential attributes and significance of hope and are particularly pertinent to my study.

Hope is a multidimensional dynamic life force characterised by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant.

(Dufault and Martocchio 1985, p.380)

Hope is the multidimensional, dynamic, and future-oriented expectation of achieving a positive outcome that has experiential, spiritual, rational, and relational attributes that energise and provide a sense of freedom and resilience.

(Felder 2004, p.321)

Hope is a process of anticipation that involves the interaction of thinking, acting, feeling and relating, and is directed toward a future fulfilment that is personally meaningful.

(Stephenson 1991, p.1459)

Hope is able to facilitate action even when the likelihood of positive outcomes may seem distinctly remote, and thus enables agency through the concomitant existence of a positive vision alongside mistrust and probable failure.

(Brown and Flores 2011, p.64)

Hope is entrenched in meaning, an experience tied to socially constructed meaning.

(Parker-Oliver, 2002)

Whilst a multiplicity of values is reflected in individual expressions of optimism (hope), a kind of meta-value is expressed in its common, cognitive form: of energy over entropy, of living over dying.

(Bennett 2011a, p.317)

Bennett (2011a) argues from a cultural sociology perspective that hope, as a tendency to hold positive expectations of the future, manifests in all human cultures, and has been central to the process of human evolution and ultimately human existence. According to him, this widely distributed "optimism of everyday life" takes effect even when people are living under the most adverse conditions. It performs significant psychological, social and cultural functions; for example, it is closely associated with

both psychological and physical health, is necessary for the proper functioning of family and social relationships and underpins achievement in many different domains. Indeed, Bennett goes on to argue that the social function of hope is so important that, without it, a society or civilisation would be unable to sustain itself.

Sociologists Brown and Flores (2011) further explain the social functions of collective hope. For example, in hoping, members of society shift their interests towards a future where the hardship and inequalities of the present are addressed and ameliorated. Hope can therefore act as a potent resource for dispelling social unease and friction. Hope has the potential to bring about solidarity across society in that shared hopes of what a better society would look like create bonds based on a shared recognition of and concern with the present situation of dysfunction or despair, as well as "a unifying utopia emblematic of shared norms and values" (p54). Hope also has an ideological function of translating ideas and values into practical action. It enables the initial vision in which the willingness to act is rooted, and then enables agency through the concomitant existence of a positive vision alongside uncertainty, complexity, risk, mistrust and probable failure. The prospects offered through hope compel action based on the promise of a better set of circumstances which can be "proactively" brought about. Thus, hope can be a valuable means of bringing about emancipation and change and thus a better future.

According to Bennett (2011a), the necessity of hope has given rise to "a complex" of hope promoters/manufacturers which "function as agents of implicit cultural policy" (p.317). The family, religious institutions, the medical profession, psychotherapists and counsellors, businesses and political leaders are, among others, all part of this complex, deeply engaged in the reproduction of cultures of hope. For example,

Bennett (2011b) notes that all religions (Hinduism, Buddhism, Christianity and Islam) contribute to the manufacture of hope through the production of meaning, models of divine justice and theories of ultimate destiny. Medicine, too, is underpinned by a culture of hope (Bennett, 2011a). Despite the scale of the problem it faces including those arising from its own successes, such as iatrogenesis, resistance to drugs, and unprecedented human longevity, and despite the pharmaceutical industry's economic interests being integral to the development of medicine itself, medical research is nevertheless also strongly driven by hope and its clinical applications promote it. In other words, in both research and clinical practice, medical science continues to subscribe to a narrative of progress, which sustains the hope that the treatment of disease and the alleviation of suffering will become ever more effective. Seale (1998) argues that medicine and systems of social security then provide people with many of the comforts previously only available through religious belief since they help to contain anxieties about the future, just like religion.

The creation of and function of the complex of hope promoters/manufacturers can be best explained through Berger and Luckmann's (1967) theory of the social construction of reality, that is, the basic societal dialectic whereby subjective social reality gives rise to an objective social world which, in turn, is internalised back into subjectivity. For example, drawing on this theory, Brown and Flores (2011) use the NHS and hospice movement as exemplars to propose that a dialectical process exists whereby compassion and hope spur the creation of, and are embedded within, health care and hospice institutions; and in turn, these institutions encourage and give rise to the practice of these emotions across society by virtue of making normative structures more visible. Therefore, they contend that there is much about the role of the welfare state, and health care systems in particular, which goes beyond instrumental service

provision. Health care provision, however limited in its ability to redress deeper inequalities can nonetheless contribute to the flourishing of society through its role in symbolising hope and compassion. That is, it stands as a symbol of the potential for society to cultivate care and social justice through compassion, as well as to transform itself for the better via hope. In this way, it impacts on those who do not use it, as well as those who are its patients, so much so that its goals remain to cure some, improve many and comfort all.

Furthermore, Bennett (2011b) points out that in a postmodern era, ironically, the advance of science, which allows people to know far more about the universe they inhabit, has come at the cost of reducing human significance, thus tending to marginalise even trivialise human beings. Such challenges to the status of human life (as centre of the universe), and the belief that human life and history are possessed of special meaning or significance, come not only from within science, but also from the arbitrary annihilation of thousands of people through natural disasters. As a consequence, there are widespread anxieties around human purpose and significance. Moreover, modern societies are exposed to risks that are the result of the modernisation process itself (Beck, 1992). Risk and uncertainty and their unequal distribution are increasingly visible and problematic; this may cause almost anyone to feel threatened, trapped and desperate (Scioli, 2007). Therefore, in the light of this age of anxiety, the utility of hope as a coping mechanism is of heightened salience (Brown and Flores, 2011). Indeed, there is a growing search for hope spreading through society (Scioli, 2007). However, the role of hope (or lack of it) in local, national and international events is still vastly underappreciated; the public is in need of hard data as well as inspiring exemplars of hope that can empower, unify and reassure (Scioli et al, 2011).

2.2 Hope in terminal illness

Kübler-Ross (2009) contends that even the terminally ill person must maintain hope for a future life, and hope for cure even during the end-stage of dying is normal and functional to existence. Empirical evidence (from nursing, psychology, psychiatry, and palliative medicine) has highlighted the significant role hope plays in terminal illness. First, hope has been found to be an indispensable resource for adapting to illness and coping with the anticipation of separation and death (Coward and Reed, 1996). Second, it facilitates effective coping (Herth, 1989; Gum and Snyder, 2002; Felder, 2004; Duggleby and Wright, 2005; Johnson, 2007; Alidina and Tettero, 2010) and holistic healing (Herth, 1989; Feudtner, 2005), thus its presence can improve both physical and mental well-being (Herth, 1989). Third, most terminally-ill patients require hope to maintain their dignity and enhance their quality of life (Herth, 1989; Owen, 1989; Duggleby and Wright, 2005; Johnson, 2007; Alidina and Tettero, 2010), so maintaining hope is an essential element for achieving a good death (Mak, 2007). In contrast, hopelessness is commonly associated with depression (Beck et al, 1974), suicidal intent (Beck et al, 1985) and negative changes in physical health (Schmale, 1958).

In order to develop hope-fostering strategies or interventions to improve care for terminally ill patients, scholars and practitioners from different disciplinary backgrounds in health care (i.e. nursing, psychology and palliative medicine) have sought to understand the meaning of hope in terminally ill patients. Common themes that emerge from this body of literature revolve around cure, comfort, self-determination, caring interpersonal relationships, short-term goals, spirituality, leaving

behind a legacy, life review, and a positive outlook on life (Dufault and Martocchio, 1985; Owen, 1989; Hall, 1990; Herth, 1990; Hockley,1993; Post-White et al,1996; Fanslow-Brunjes et al, 1997; Koopmeiners et al, 1997; Benzein et al, 2001; Gum and Snyder, 2002; Parker-Oliver, 2002; Sullivan, 2003; Felder, 2004; Eliott and Olver, 2007; Johnson; 2007; Eliott and Olver, 2009; Garrard and Wrigley, 2009; Maxfield, 2010; Nolan, 2011). These themes, with their individualised expressions, demonstrate that while hope for cure or remission may still be paramount in terminal illness, there is large scope beyond this hope, for patients to engage in other matters that are meaningful, significant and achievable by them.

Although empirical studies have found that hope for cure or remission is quite common among terminally ill patients, its legitimacy is not yet widely endorsed, particularly by health professionals. The question of whether it is an unrealistic or false hope to be dismantled in the case of a terminal illness is debatable. Corr (1991) differentiates between "hope" which is grounded in reality and "wish", which is not, and argues that only hope has therapeutic effect in terminal illness. McGee (1984) and Stoner (1988) question the unrealistic hopefulness of patients who ignore the reality of their grim diagnosis. However, Jones (2005) explains that what each person considers hopeful will conceivably depend on many and varied factors, such as their psychological make-up and subjective views of human existence. Similarly, Watson (2009) argues that hope implies an expectation that the desired thing might be achieved; this expectation may itself be realistic or unrealistic, but assessment of what might or might not be realistic depends on one's perception of reality. Therefore, Hall (1990) and Gum and Snyder (2002) suggest that it is best left to the dying person to judge if their hope is realistic or not.

Moreover, Eliott and Olver (2009), drawing on discourse analysis of patients' talk about hope, argue that clinical efforts to dismantle this hope may be misplaced and irrelevant. This is because the significance of patients' hope for cure or remission rests precisely on how it functions to value all parties and relationships involved, not on whether the goal itself is attainable. In other words, patients' hope for cure or remission, thus (more) life, is rendered a moral requirement, because it expresses a desire for continued engagement with intimate/significant others, conveying appreciation and respect for their relationships. In contrast, hope that signals a patient's surrender to death may be interpreted as depreciating the value of all parties and the relationships between them.

In addition, according to Stoner (1988), hope is an emotion, the purpose of which is to maintain emotional well-being in the face of both ordinary and dire circumstances and thus has definite and positive value at all time. In fact, Back et al (2003) found that hoping for a cure and preparing for potential death need not be mutually exclusive. Although it may seem contradictory, hoping for the best (cure or remission) while at the same time preparing for the worst (death) is found to be a useful coping strategy for some patients. By allowing themselves to conceive and acknowledge all the possible outcomes, patients and their physicians can then expand their medical focus to include disease modifying and symptomatic treatments and also to attend to underlying psychological, social, spiritual and existential issues.

Nonetheless, it remains questionable whether health professionals should encourage a terminally ill patient to hope for cure or remission by deceiving the patient about the full nature or prospects of their condition or by exaggerating the chance of miracle cures or the effectiveness of treatments. Garrard and Wrigley (2009) argue against this

approach on the ground that the beneficent desire to improve patient welfare through sustaining hope conflicts with the imperative to respect patient autonomy and is therefore morally objectionable. In addition to this, Randall and Downie (2006) have argued that the truth must be told to maintain meaningful communication between patient and carer and demonstrate respect towards a person. By not telling the truth health professionals risk eroding trust that is central to a good relationship with a patient.

2.3 Conceptualisation of hope

Snyder's (1991, 1994, 2000, 2002) classic hope theory conceptualises hope as a multifaceted concept that involves complex, dynamic cognitive appraisals of one's desired goals, position in relation to those goals, abilities to develop and initiate behaviours to make progress toward goals, and the requisite motivation to move toward goals. Thus, individuals experience hope when they have an expectation that a desired goal can be achieved. This psychologically grounded theory, although illuminating, focuses exclusively on the inner process of hope in individuals, artificially isolating them from their external environment.

Farran et al (1995) conceptualise hope as "a rational thought process that grounds hope in reality with goals and needed resources (physical, emotional, and social)" (p.5). Morse and Doberneck (1995) conceptualise hope as involving seven components: 1) a realistic initial assessment of the predicament or threat; 2) the envisioning of alternatives and the setting of goals; 3) a bracing for negative outcomes; 4) a realistic assessment of personal resources and of external conditions and resources; 5) the solicitation of mutually supportive relationships; 6) the continuous

evaluation for signs that reinforce the selected goals; and 7) a determination to endure. According to Dufault and Martocchio (1985), hope consists of two spheres having six common dimensions. First, they make a distinction between particularised hope and generalised hope: the former has a predominantly action-oriented or goal-setting focus, while the latter represents the intangible inner experience of hope that is not linked to any particular concrete or abstract object of hope. Second, the six dimensions of hope are: 1) affective (dealing with emotions and feeling of hope); 2) cognitive (having to do with imagination, interpretation, and judgement); 3) behavioural (relating to decisions to act to ameliorate possibilities); 4) affiliative (an optimism generated through relations with others or with God); 5) temporal (embedded in experiences of past, present, and future); and 6) contextual (in the form of "circumstances that activate or test hope"). These conceptualisations, developed through empirical nursing research, expand on Snyder's theory to illuminate dimensions or sources of hope that are external to individuals (e.g. interpersonal and social), in addition to those internal to them.

With regard to the interpersonal dimension of hope, Hockley (1993) claims that "hope is as much a dependence on others for help as something generated from within" (p.182). Farran et al (1995) regard hope as a relational process in that hope occurs between persons and is influenced by another's hope, presence, communications, and strength. Hawthorne and Yurkovich (2004) emphasise an element of reciprocity in hope. For them, hope can be renewed through the hope of another, and "it is in relationship, a profound experience shared by humans as they join together on the journey through life, that a new meaning of hope is found" (p.415).

Perakyla (1991), in his ethnographic study, explored this interpersonal dimension of hope in a clinical setting and termed it "hope work" (p. 408). He defines hope work as recurrent interactional patterns among caregivers, patients and family members that either enhance or diminish hope in the management of the end of illness trajectories. He argues that a particular hope narrative is co-constructed by patients together with health professionals. He notes that in what he describes as curative hope work, hope is closely connected to the biomedical model, as indicators of physical improvement and the ultimate goal of a cure are used as markers of hope. In palliative hope work, hope is associated with making the patient feel more comfortable or better, without focusing on a cure. In work to dismantle hope, caregivers attempt to undo previous hope work. For example, caregivers dismantle curative hope work when a terminal illness is diagnosed, and they dismantle palliative hope work when death is imminent.

Eliott and Olver (2002, 2007, 2009), in their study of patients' talk about hope, went further to place the interpersonal dimension of hope into the context of social action/practice, that is, the social dimension of hope. Their theoretical positioning of social constructionism and their analytical approach based on conversational analysis and Foucauldian discourse analysis are premised upon two key assumptions about language. First, individuals' everyday speech is shaped by the socially and culturally derived ideologies and assumptions that constitute their own particular cultural milieu. Second, the language employed in discussing and understanding experience is not a neutral, transparent description of an objective world. Rather, it is used for a variety of purposes related to the intention of the speaker. Moreover, there are multiple available sets of meanings pertaining to any phenomenon, and therefore accounts produced will vary dependent on the context within which they emerge. Thus, they view hope as situationally specific, negotiated and purposeful social action and that its deployment

in talk achieves certain interpersonal and social objectives. They examined patients'
hope "talk" in terms of its function within the immediate conversational context (e.g.
to signal what is valued in patients' lives and simultaneously to value all entities
involved in the hope). They specifically considered how medical discourses of hope
impacted on patients, what other discourses were employed by patients in their talk
about hope, and the clinical implications of discrepancies between different versions.

Encompassing the dimensions of hope discussed so far, the model of hope proposed
by Feudtner (2005) is the most holistic and comprehensive. Feudtner (2005)
acknowledges that hope is "a set of goal-directed cognitive processes that influence
and are influenced by emotion, and a potent cognitive/affective heuristic that
influences how individuals consider and select goals" (p. S23). More importantly, he
locates the individual experience of hope in a "hierarchical social and cultural ecology
of hope" (Feudtner 2005, p. S23). What he means by this is that hope does not exist in
social isolation or in a cultural vacuum. He uses paediatric patients as an example to
illustrate that the social network of relationships in which one is located is highly
pertinent to one's goal formulation and hope construction. That is, a child and his/her
parents constitute the most intimate level of this network, but their individual hope
will be influenced substantially by the conduct of health care staff, social workers,
pastoral care workers, other members of the family, community and the like. In
addition, via this social network, the policies and decisions of third-party players, the
precedents of legal decisions, or the belief and values of a culture and its ethics will all
influence the hope of patients and families. As such, "this network of social influences
on hope, concatenating outward from an intimate to a macro level, suggests that the
individual experience of hope can be situated—and perhaps best understood—within
an encompassing ecology of hope" (Feudtner 2005, p.S26).

Feudtner (2005) dissects this ecology of hope and illustrates that it exists in a hierarchy of six possible levels (See Figure 1). At level one, patients and family members exist as individuals. At level two, they can wield a strong influence on each other's cognitive and affective mechanics of how they hope, as a family unit. At level three, the family unit is influenced by a doctor (or nurse, child life specialist, social worker, or pastoral care worker), who in his/her conduct, encourages that hope in the context of illness be addressed in a particular way. In the setting of hospital care, these multifamily/health-care-provider units cohabitate on particular wards of the hospital and thus aggregate into level four of the ecology. At this level, shared features of the physical environment (e.g. cheerful or gloomy atmosphere, domestic or clinical setting, private space etc.), approach to care (e.g. biomedical or whole-person), information processing/decision making approach (e.g. family-centred or patient-centred) and so on will potentially influence all individuals living or working within. These hospital wards (or, with a different scheme of aggregation, specialty services such as medicine, surgery, or any of the subspecialties) compose level five, that is, the hospital or health care institution. Each hospital or institution, with its own history, charitable origins, religious affiliations, research commitments, economic realities, managerial priorities, administrative techniques and leadership styles, shapes how health care professionals and other staffs conceive of themselves and behave in each of the wards or specialty services. Finally, these hospitals/institutions and all the levels contained therein including the individual patients and family members, exist in the broadest level of the ecology of hope, that is, society and its culture. Feudtner (2005) concludes:

> To the degree that an environment—comprising the patient, family, care providers, and other physical, social, and cultural elements—can prevent, correct, or

51

counteract these cognitive and affective biases, that environment moves closer to being an optimal healing environment.

<div align="right">(p.S27)</div>

Figure 1 Multilevel Model of Ecology of Hope

Individual patients or family members ...

P

... interacting in families ...

P — P

Hospital

Hospital

Hospital

Media
Religious Communities
Economic Realities
Cultural Values
Social Structures

... existing in a broader social and cultural environment

... cared for by physicians with different styles ...

P   P
  MD
P   P

... in a hospital or health care institution ...

... in a clinic, ward, or specialty service ...

Surgical Service

Medical
Service

Ward

P MD P   P MD P
P   P   P   P

RNs

P
MD
P

Staff

Technology

Attributes of
Physical Space

FIG. 5.   Multilevel model of an ecology of hope.

52

3. Palliative/end-of-life care in mainland China

This section describes the current situation of palliative/end-of-life care in mainland China, as revealed in the existing literature in Chinese (mainly) and English languages. I first introduce the contemporary developments of specialised palliative/end-of-life care that somewhat resemble those of the West. I then examine the predominant medical approach to care for people with advanced cancer. Finally, I describe the status quo of the research into palliative/end-of-life care in mainland China to identify the niche of my research.

3.1 Contemporary developments

It was not until 1988 that the first end-of-life care research centre was founded in Tianjin Medical University, heralding the emergence of end-of-life care as a specialty in its own right in China (Li et al, 2005). Two years later in 1990, palliative care wards were established in this centre, followed by the opening of specialised end-of-life-care hospitals such as the (now well-known) Beijing Songtang End-of-Life Care Hospital and Shanghai Nanhui Huliyuan. Over the following years, similar facilities were established in Xi'an, Shenyang and other major cities across China.

Meanwhile, WHO's three-tier analgesic protocol [10] was officially introduced to Chinese professionals in 1991(Wang et al, 2002). In 1992, China adopted a national

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[10] According to WHO (http://www.who.int/cancer/palliative/painladder/en/). "if pain occurs, there should be prompt oral administration of drugs in the following order: nonopioids (aspirin and paracetamol); then, as necessary, mild opioids (codeine); then strong opioids such as morphine, until the patient is free of pain. To calm fears and anxiety, additional drugs – "adjuvants" – should be used. To maintain freedom from pain, drugs should be given "by the clock", that is every 3-6 hours,

cancer pain relief policy, easing restrictions on morphine and other opioids, increasing the manufacture, sale and distribution of new opioid analgesics and making it easier for hospitals to obtain analgesics (Economist Intelligence Unit, 2010; Li et al, 2011). In 1996, the Chinese version of the Brief Pain Inventory (BPI-C) was validated and recommended as a standard pain assessment scale in government-published national guidelines for cancer pain management (Wang et al, 2002). Since 2000, certification training on opioid prescription for clinicians caring for cancer patients has been a government requirement (State Drug Administration, PRC) and administered nationwide (Wang et al, 2002; Li et al; 2011). "The Guiding Principle of Clinical Application of Narcotic Analgesic Medications" published in 2007 by Ministry of Health permits a physician to prescribe controlled/slow-release opioids, or transdermal fentanyl patches for 15 days per prescription time according to patient's requirements. As a result, opioid consumption has increased from 10 kg (morphine equivalents) in 1989 to 906 kg in 2008, and accounts for 2.33% of the global consumption of morphine equivalents (Li et al, 2011).

In November 1998, the Li Ka Shing Foundation established the "Heart of Gold" Hospice Service Program (http://www.hospice.com.cn/) and set up China's first hospice at the First Affiliated Hospital of the Shantou University Medical College (Li Ka Shing Foundation, 2009). Responding to a pressing need to serve patients with terminal cancer, by 2009 the Foundation had extended its service nationwide through establishing hospices at 32 major hospitals. As a result, 20,000 cancer patients benefit from this programme annually. At present, this is the only charitable programme in China that provides free hospice care for impoverished cancer patients (at home). It

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rather than "on demand". This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80-90% effective. Surgical intervention on appropriate nerves may provide further pain relief if drugs are not wholly effective."

has been well recognised by the communities who benefit from the services and is highly acclaimed by government officials.

To date, palliative/end-of-life care in China is organised and delivered on a localised basis. Scattered and uncoordinated, services are typically found only in or near major cities such as Tianjin, Beijing, Shanghai, Guangzhou and Chengdu (Xinhua News Agency, 2006; Zhou, 2006; You, 2008; Zhao et al, 2009). These existing services take three forms: a small number of specialised end-of-life care hospitals; around 200 palliative care wards in medical institutions; and 32 hospices affiliated to medical institutions (Bian and He, 2004; Xinhua News Agency, 2006; Li et al, 2011). As a whole, palliative/end-of-life care has yet to establish its niche in China despite the need for it increasing rapidly as the result of the increase in mortality from cancer and other long-term conditions (see Chapter Two). This situation leaves a vast population with end-of-life coverage extending to only a fraction of those in need.

3.2 Medical care for people with advanced cancer

Anticancer treatment, with minimal positive effect on patients at a late stage of cancer, is costly (Zhou, 2006; Li et al, 2011). It not only puts enormous economic pressure on both the state and families but also causes patients extra physical pain, disability and even premature death. The cost of palliative care, however, is only one tenth of that of anticancer treatment. Thus palliative care may well help to save health care costs for families and the state alike, while preventing or alleviating unnecessary suffering of patients and families (Hua et al, 2008; Qiu, 2008; Qiu and Shi, 2008; Yu, 2008). Nevertheless, the reality is that not only is palliative care an inaccessible option, but also excessive anticancer treatment is rampant in advanced cancer care in China.

Conventional curative methods (e.g. surgery, chemotherapy, radiotherapy and maintenance therapy) and interventional approaches (e.g. tracheotomy, respirators, blood transfusions and dialysis) are continued until the patient is no longer able to endure the side effects, or at the end of the disease trajectory and dying. When patients are close to death, resuscitative intracardiac injections and CPR are persistently used in response to cardiopulmonary system failure (Li et al, 2011). On the other hand, physicians fail to take advantage of the accessible analgesics to relieve pain in patients because of their opioid phobia and ignorance. Consequently, cancer suffering is extensive in China.

The cause of the current adverse situation in advanced cancer care is manifold. First, a strong objection of families towards patients knowing their diagnosis and prognosis and entering palliative/end-of-life care persists, despite the fact that doctors and/or patients themselves may opt for these choices (Wang et al, 2004; Chen and Huang, 2010). Chinese doctors give far greater weight to families' preferences than patients' own preferences, and involvement of patients in decision making appears to be rare. This situation is due in part to filial piety and familism (as discussed in Chapter Two). Filial piety holds adult children responsible for looking after their parents, especially at the end of life (You, 2008), placing enormous moral pressure on them to provide the best care possible (as far as they know and can afford) (Qiu et al, 2006; Zhang, 2007). As in other cultures that feature familism as the core of their value systems, medical decisions are seen as family decisions in China (Yick, 2002; Tse et al, 2003; Wang et al, 2004; Cheng et al, 2008).

Second, the Chinese medical tradition still requires health professionals to save and prolong life at all cost (Zeng et al, 2008). There are also financial incentives to

prescribe anticancer or interventional treatments as these are much more profitable to both individual doctors and hospitals compared to palliative treatments, which are determined by the current health care system (Li et al, 2011).

Third, there is low awareness of palliative care and lack of public discussions about end-of-life care issues in China (Guo et al, 1994; Zhang and Cao, 2003; Li et al, 2005; You, 2008). The public still has little knowledge of the existence of palliative/end-of-life care or little understanding of what it provides (Economist Intelligence Unit, 2010; Chen and Huang, 2010). Even in medical circles, many doctors and other health professionals remain unaware of what it entails. As a consequence, there is often much misunderstanding about palliative care. As withdrawing life-sustaining treatment is regarded as "passive euthanasia", palliative care services are perceived to be providing euthanasia in a disguised form, which raises moral and ethical concerns (Tse and Pang, 2006; Zhang, 2007; Xiao, 2008; Li et al, 2011). An end-of-life care facility is perceived as a place for patients to wait to die and to die, and this dissuades people from using the service (Guo et al, 1994; Li et al, 2011). To consider the choice of giving a patient palliative care is perceived to be an abandonment of hope and "giving up" on the patient, which is against filial piety and the health professionals' ethos of "saving life at all cost" (Li et al; 2011).

Even when people know about palliative/end-of-life care, the culture of death-denial in China that upholds "it is better to struggle to live on than die a good death" and thus the cultural taboo against engaging in serious discussions about death-related issues (see Chapter Two) inhibit people from talking about it (Li et al, 2011). Responding to this, organisations or units engaging in hospice or palliative care refuse to use the term "hospice" or "end-of-life" in their titles. Instead, these terms are translated into

Chinese words that do not reflect their associations with death and dying. Health professionals are reluctant to engage in palliative work because the kind of practical rewards and sense of achievement which they find in curative work are not available in palliative work, not to mention the emotional, social and spiritual challenges in constantly dealing with issues related to death and dying (Wang et al, 2004; Li, et al, 2011; Chen and Huang, 2010).

3.3 Research into palliative/end-of-life care

According to Pastrana et al (2010), palliative care research is fundamental to identifying needs, informing stakeholders and the public, allocating resources, and implementing evidence-based measures with consequent health improvement. As palliative care is a culturally sensitive issue, it also requires culturally sensitive research that reflects the diverse realities. Such research should seek to describe the situation, identify gaps, and help focus on country-related differences in priorities concerning palliative care. Besides, not only can non-western societies benefit from learning about western palliative care; the reverse may also be the case, as much can be learnt in western societies about how non-western societies care for dying people (Higginson, 2005). Either way, learning about diversity and difference can introduce ideas that challenge and improve existing policy and practice. However, at present, there is a scarcity of such research in low and middle-income countries (LMIC), where the need for palliative care to prevent unnecessary pain and suffering is especially pronounced (Pastrana et al, 2010).

The paucity of research is also the case in mainland China (Li et al, 2005). A literature review conducted by Chen and Bai (2011) identified and analysed all the research

literature on palliative/end-of-life care published in Chinese periodical full-text databases of mainland China. There were only 471 relevant papers by March 2010, with the first such paper appearing in 1998. The majority of these summarised the lessons learnt in clinical practice. Only a few reported on interventional/ comparative studies, or studies of the current situation. The majority of authors were medical/nursing professionals or students, with only a few from a social science background. Further, most studies were conducted in eastern and southern provinces, with only a few from the western region. The research participants included mainly tumour patients, with non-tumour patients, families, health professionals, communities, and end-of-life care service providers less represented. The focus of this body of literature was on the theoretical principles of palliative/end-of-life care and their application in Chinese clinical settings. There were few empirical studies concerning education/training, social support, funding, policy, ethical issues, patients' quality of life and needs. This review demonstrates that overall little research has been undertaken in the field of palliative/end-of-life care in mainland China and little is known about either the overall situation or the particular aspects of palliative/end-of-life care.

When I searched the largest and the most important Chinese database- National Knowledge Infrastructure (http://www.global.cnki.net/) for qualitative research on cancer patients, terminally ill patients or dying patients, only 12 empirical studies were identified between 1988 (when end-of-life care first emerged in China) and 2011. Almost all of them (11) adopted a phenomenological approach and all studies employed qualitative interviewing method (semi-structured or in-depth). Eight studies explored a particular aspect of cancer experience from the patients' own perspectives (Wang, 2006; Wang et al, 2007; Zhang et al, 2008; Li et al, 2009; Yao et al, 2009;

Wang, 2010; Ye et al, 2010; Zhao et al, 2010), with one study (Zhao et al, 2010) concerning breast cancer patients' experience of hope in the process of diagnosis and treatment. A further search for research on hope in terminal illness and dying identified another seven empirical studies (Gao et al, 2004; Zhang, 2006; Zhang et al, 2007; Sun et al, 2009;Wang et al, 2010; Zhang et al, 2010; Wang, 2010). Herth Hope Index (Herth, 1992), a psychosocial clinical care tool, was either the tool or the focus of these studies on cancer patients' hope level – a measurable quantitative construct. The literature searches I have undertaken have therefore revealed that qualitative research, research into hope, and research from patients' perspectives in the area of palliative care are not only new and rare in China but also limited in their approach.

Conclusion

In Section 1, I began with an introduction to the foundation of the contemporary western approaches to palliative/end-of-life care, that is, the modern hospice movement. The literature I presented suggests that as the result of the movement which was a reaction against the medicalisation of death, palliative care was initially committed to an essential goal of providing cancer patients with "total care" to prevent and alleviate their "total pain". Nevertheless, the movement has been criticised for failing to extend palliative care to all those who need it, for not being suitable for minority ethnic groups (other cultures), and for promoting an over-medicalisation of the process of dying.

Moreover, offering a radical alternative to hospital death, the movement has become synonymous with the "good death", which is a contested notion due to the enormous diversity and difference that exists in the way people view and approach death and dying. Examining and making decisions about how one might categorise different deaths as either "good" or "bad" is morally fraught and difficult. Though recognising and working with difference and diversity may be the answer, it can feel especially difficult with regard to death and dying, which raises complex social, moral, existential and emotional issues and where working environments can be "emotion-rich yet time-scarce". There is also concern that the dying person's preferences and needs may be sidelined in the need for efficient and organised services. Moreover, there are people whose dying and death cannot be good not only because of disadvantage but also because of very real practical, physical and physiological differences in how people die.

Further, cultural issues arise with the import and spread of care models from one culture to another. There remain major differences across cultures, for example, regarding communication of "bad news" (truth telling versus concealing), the locus of decisions (patient's autonomy versus collective, family-centred decisions), and traditional and societal expectations of who provides end-of-life care (family or institutions). As such, there has long been a recognition that palliative/end-of-life care provision must be rooted in specific cultural contexts if it is to thrive and be effective.

The hospice movement has indeed succeeded in reaching out to other cultures adaptively, considering it is still a young discipline (with a history of just over 40 years). Nonetheless, even with the rapid growth in hospice services the worldwide need for this type of care remains far greater than the actual provision, particularly as

a gradual transformation of the rhetoric of "palliative" care for cancer patients to "end-of-life" care for all is occurring internationally. In scaling up to meet the rising need, the future direction of this specialty sees a trend of medicalisation in the process of mainstreaming. Subsequently, as some argue, the original ideals of the hospice movement have become watered down to an emphasis on physical care, and palliative/end-of-life care has moved its emphasis from dying people to issues of symptom control and palliation. With the trends in palliative care indicating a greater level of medical intervention and hierarchical organisation, the original hospice vision of reorienting society to a greater acceptance of death could well be undermined.

Not only is there an imbalance between medicine and care, but also a dying person's complex needs that may go beyond health services are rarely taken into consideration in palliative care. As such, I argue for the appropriateness of public health and the human rights approaches to advancing palliative care development in that they endorse a compassionate approach to dying, death and loss, and propose that care for people at the end of life is a fundamental responsibility of not just health professionals, but also communities, governments and societies.

In Section 1, I also demonstrated that there is an identity crisis in this field of care, as it struggles to evolve and transform. There is no single, universal agreement as to what palliative care actually constitutes. The three terms: palliative care, end-of-life care and hospice care are often used interchangeably in spite of their nuanced differences and shifting ground. It is for this reason that, in this thesis, I use "palliative/end-of-life care", a combination. In addition, I use "hospice care" to refer to the services provided by one of the organisations that I studied which was named "a hospice" (see Chapter Four).

In Section 2, I have argued that hope is absolutely essential to human life. It has been central to the process of human evolution and ultimately human existence. It performs significant psychological, social and cultural functions. The necessity of hope has given rise to a complex of hope promoters/manufacturers that deeply engage in the reproduction of cultures of hope, for example, religion, medicine and the hospice movement. It has been endorsed by the practitioners of every healing art, even in the context of terminal illness, where there is large scope beyond hope for cure or remission – though still paramount and vital – for patients to engage in those aspects of life that are meaningful, significant and reachable by them.

Although hope is common to all, its meaning is unique to each person. I have argued that no single definition can suffice to convey the plethora of meanings of hope, and a universal definition of hope would reduce the complexity and richness of hope and fail to take account of the fullness of the actual range of practical experience of hope. For the same reason, it is the whole body of literature presented in this review that provides me with a thinking framework to apprehend the significance, complexity, depth and breadth of hope. Accordingly, there are varied conceptualisations of hope. Those that I have chosen and presented in this review reveal that the source of hope lies both within the individual, between them and in their social and cultural environments. I draw on these conceptual models to analyse and interpret my data. In this way, I aim to contribute to a sociological understanding of hope as situated in the end-of-life care culture in China, or rather, an understanding of how individual patients' biographies, their present life situation and external resources located in health care, families, communities and broader social and cultural environments,

contribute to the construction of their hope thus their illness experiences in "living" with advanced/terminal cancer (see Chapters Seven and Eight).

The literature I presented in Section 3 demonstrates that in China, palliative/end-of-life care has yet to establish its niche despite the rapidly increasing need for such care as the result of the increase in mortality from cancer and other long-term conditions. This leaves a vast population with end-of-life coverage extending to only a fraction of those in need. As a result, not only is palliative care an inaccessible option, but also excessive anticancer treatment is rampant in advanced cancer care in China, which has caused enormous and staggering cancer suffering. The ethical and practical dilemmas that contribute to this reality lie within the Chinese cultural framework most significantly, the taboo status of death, familism and filial piety, and the social and structural constraints of the current health care system, for example, insurance, funding and entrenched attitudes within the medical profession.

Meanwhile, the evidence presented in this section suggests that there is a scarcity of research in China that seeks to describe the situation, identify gaps, and help focus on country-related differences in priorities concerning palliative/end-of-life care. There is much need and scope for rigorously designed research into palliative/end-of-life care to be conducted in China, and particular attention should be given to such issues as patients' quality of life and needs, ethics, social support, education/training, funding and policy. In this thesis, I will explore these issues to varying degrees from a sociological perspective. In addition, my research will contribute to the Chinese knowledge base of qualitative research, hope research and research from patients' own perspectives in the area of palliative care, all of which are novel and under-explored, but vital to understanding patients' experiences and needs of and the process and

outcomes of palliative/end-of-life care. Furthermore, there is also a need to find out how current practices of palliative/end-of-life care in China have learnt from the western models of such care and how China's own practices can contribute to such care in other cultures.

In the next chapter, I will explain the rationale of my methodological approach to this study and report in detail on the process of data collection and analysis.

Chapter Four
Methodology

Introduction

In Chapter One, I reflected on my decision to study palliative/end-of-life care in China, drawing attention to the advantages of my academic and professional experience in public health and my cultural background for conducting such cross-cultural research. I also explained that, in approaching the original research topic, the other central theme that I explore in this thesis was developed through the pilot study. As a result, the focus of my study has evolved into both end-of-life care provision and hope in terminal illness, which I have chosen to approach from a sociological perspective. My research therefore aims to: 1) represent the current palliative/end-of-life care provision as experienced (defined) by older people with advanced cancer (hereinafter called patients[11]), in three distinct care settings (organisations); 2) and explore what hopes were present and how these hopes were fostered in patients at the end of life. As such, this research takes a cross-cultural approach to exploring sensitive topics in complex situations, highlighting the need for a qualitative methodology that is sensitive to: 1) the cultural issues in both the social phenomena studied and the process of conducting research; 2) the ethical issues in sensitive research that are culture specific and context related (Liamputtong, 2010); and 3) the complexity in both my research interest and

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[11] The main reason I use this medicalized term is to distinguish this group of participants of my study from other groups such as doctors, nurses, nursing workers, and family members.

the field work. It is within this basic framework that my decisions about theory, methodology and methods were shaped.

In this chapter, I outline my methodological approach to achieving the research aims and how this has been derived from theoretical, ethical and practical imperatives, and report in detail on the process of data collection and analysis. In Section 1, I introduce my philosophical position of critical realism that underpins my research, explaining what it is, the main features of it that are relevant to my study and their methodological implications. In Section 2, I outline the case study approach that I took, of which the main elements are multiple methods and sources of evidence, and multiple embedded cases. Particularly, I justify my choice of the main methods (qualitative interviewing and observation), and the embedded cases (the hospice, the committee and the ward). I also describe the background information of the three embedded cases. I dedicate Section 3 to my field work. I report on the major achievements of the pilot study including gaining access, developing culturally appropriate ethical conduct and informing the case study approach. Then I present the main feature of each case study: qualitative interviewing in the study of the committee, adaptation to the practical constraints in the study of the hospice and participant observation in the study of the ward. Finally, in Section 4, I report on how the data were analysed following the completion of the main study, including data transcription/translation and framework analysis.

1. Critical realism

Traditionally, sociological and biological explanations for health and illness have often assumed polarised positions (Bird and Rieker, 1999). Particularly, "personal tragedy" and "social oppression" are two extreme models supported by medical naturalism and social constructionism respectively (Williams, 1999). My study challenges these polarised positions or extreme models. Instead, I draw on Williams' (1999) disability model and propose that cancer suffering, like disability, is best seen as "a dynamic, dialectically unfolding process between body and society, located within a temporal frame of reference both historical and biographical" (p. 813). In line with this proposal, my study is based on three assumptions: 1) the biological reality of cancer suffering; 2) the reality of the structural constraints that are often placed on people with cancer; and 3) the wider reality of cultural attitudes towards cancer in which these structures are embedded. As such, I take a critical realist position as the most appropriate frame of reference for my study. In the following sections, I explain in more detail this theoretical position and its methodological implications, informed by the published literature in the area.

1.1 Overview of critical realism

The philosophical basis of critical realism has been largely associated with the British philosophers Roy Bhaskar and his mentor Rom Harré (Bergin and Owen, 2008). Critical realism is a philosophical perspective that combines a realist ontological perspective (theory of being) with a relativist epistemology (theory of knowledge) in subscribing to a form of "robust" relativism (McEvoy and Richards, 2003). It redresses what it sees as the "epistemic fallacy" in constructionism, that is, "what is"

(the question of ontology) is reduced to the question of "how we know what is" (Bhaskar, 1989). It also challenges the positivists' view that the scientific conceptualisation of reality directly reflects that reality. Rather it argues that there is a distinction between reality and its conceptualisation, which is simply a way of knowing that reality. Thus claims to truth are conceived as making provisional and fallible statements about the real (Bryman, 2008).

Critical realism has the capacity to contain the insights of other meta-theoretical perspectives, without limiting an understanding to one or other of these positions (Bhaskar and Danermark, 2006). According to Busfield (2001), the philosophical principles of critical realism facilitate an understanding of "illness [that] varies across time and place, but does not suggest any denial of the material reality of the phenomena that come to be constituted as disease or disorder... whilst also recognising the importance of the social processes ..." (p. 5). Carpenter (2000) suggests that the critical realist framework is suitable for achieving a balance between ". . . structure and process, and analysis of biology and culture . . ." (p. 47), and that it facilitates this process of amalgamation of knowledge because it makes no basic distinctions between the importance of medicine and sociology.

1.2 Features of critical realism

Bhaskar's critical realist philosophy features the importance attached to the stratified character of the real world, generative mechanisms, and the dialectical interplay between social structures and human agency. The last two are particularly pertinent to my study in that 1) the aim of my research was to identify the generative mechanisms;

69

and 2) the underlying assumption of my study was that there exists a dialectical interplay between social structures and human agency. I will explain these features in more detail below.

The stratified character of the real world

Critical realism has a stratified rather than flat ontology (Bhaskar, 1978). The strata are the empirical, the actual and the real. The empirical domain is where people experience and make observations. However, events occur in the actual domain and may not be observed at all or may be understood quite differently. There is a process of interpretation that intervenes between the two domains. Events occur as a result of generative mechanisms that operate in the real domain. The real domain is all that exists (natural or social) whether we experience it or not, or have knowledge of its disposition (Sayer, 2000). A feature of reality is that "there is an ontological gap between what we experience and understand, what really happens, and – most important – the deep dimension where the mechanisms are [real domain] which produce the events" (Danermark et al 2002, p. 39).

Generative mechanisms

The real domain is the realm of objects, structures, powers and relations – the generative mechanisms that explain how things work beneath a surface (observable) appearance (Sayer, 2000). It is the transitive aspect of science to identify this realm:

We will only be able to understand – and so change – the social world if we identify the structures at work that generate those events and discourses... These structures are not spontaneously apparent in the observable pattern of events; they

can only be identified through the practical and theoretical work of the social sciences.

(Bhaskar 1989, p.2)

The questions to ask about a social phenomenon, therefore, are "what makes it happen", what "produces", "generates", "creates" or "determines" it, or, more weakly, what "enables" or "leads to" it? (Sayer 1992, p.104)

The dialectical interplay between social structures and human agency

According to Bhaskar (1989), social structure and human agency are:

Existentially interdependent but essentially distinct. Society is both an ever-present condition and a continually reproduced outcome of human agency: this is the duality of structure. And human agency is both work (generically conceived), that is, (normally conscious) production, and (normally unconscious) reproduction of the conditions of production, including society: this is the duality of praxis.

(p. 92)

People do not have control over the social situations into which they are born, but they do have the capacity to affect social situations and contexts through their own agency (Bhaskar, 1979), which possesses a critical reflexivity and creativity towards the world in which they live (Archer, 1995). However, while human agency plays a key role in shaping the creation, maintenance and alteration of social structures, it should not be viewed as totally autonomous, but rather conditioned by the social context in which actions are taken (Bhaskar, 1979). The mutual interplay between social structure and human agency across time, can result both in stable reproduction and

change through the emergence of new properties or powers (Williams, 1999). Critical realist research seeks to understand the web of multidirectional and interdependent relationships between social structures and human agency (Ewing and Rajaratnam, 2010).

1.3 Critical realist methodology

Critical realism acknowledges that social phenomena are intrinsically meaningful, and hence that meaning is not only externally descriptive of them but constitutive of them (though of course there are usually material constituents too). Meaning has to be understood, it cannot be measured or counted, and hence there is always an interpretative or hermeneutic element in social science.

(Sayer 2000, p.17)

Easton (2010) proposes critical realism as "a coherent, rigorous and novel philosophical position that not only substantiates case study research but also provides helpful implications for both theoretical development and research process" (p.118).

From a realist perspective, science aims to understand this intransitive dimension of reality through socially produced theories (transitive) that are potentially fallible and limited. Such theories, models and paradigms may compete and challenge each other; however, the world that they reflect (intransitive) remains constant (Sayer, 2000). Since it is unlikely to reveal completely any social situation and lead to a full understanding of it, and since there can be no definitive criteria to judge the "truth" of a particular version, critical realism relies on the researcher to collect further data that helps to distinguish among alternative explanations (Sayer, 1992, 2000) and on the

community of researchers to debate different versions thoroughly. The latter is called "judgemental rationality" which means:

We can publically discuss our claims about reality as we think it is, and marshal better or worse arguments on behalf of those claims. By comparatively evaluating existing arguments, we can arrive at reasoned, though provisional, judgements about what reality is objectively like; about what belongs to that reality and what does not.

(Archer et al 2004, p.2)

To facilitate this judgemental rationality, it is helpful that a researcher is reflexive, as Brewer (2000) contends that:

Reflexivity on the part of the researcher assists in identifying the contingencies that produced his or her portrayal of it [social world], so we should claim no more for the account than what it is, a partial, selective and personal vision.

(p. 48)

As such, in reporting my field work, I follow what Altheide and Johnson (1994) suggest:

Researchers should report how they gained access to the research setting, how they presented themselves within it, including details of the roles taken, the degree to which researchers believe that trust and rapport were achieved and an account of any 'mistakes', misconceptions, surprises. Ways in which data were collected

and recorded should also be included, as well as lists of the various types of data available to researchers and coding and any other analytic procedures.

(p. 494)

In addition, in this thesis, I also distinguish claims from evidence, provide the strongest evidence for more important claims, and expose my own judgments and assumptions for readers to scrutinise, as suggested by Seale (1999).

2. A case study approach

Palliative/end-of-life care research is generally sensitive, challenging and complex (Addington-Hall, 2007). The practical and ethical challenges identified in the pilot study (as shall be discussed in Section 3) call for a research approach that is: 1) sensitive to the complex ethical issues embedded in palliative/end-of-life care research; and 2) flexible in design to accommodate the many practical constraints in researching a sensitive topic at multiple sites (care settings) within a short period of time. To meet these needs, I took a loose "multiple embedded-case study" approach to understanding both the care settings (organisations) and the individual patients within these settings, focusing not on biomedical matters, but on people and social issues. By "loose" I mean that I have only adopted some but not all of the key elements of case study research as prescribed by Yin (2002) and Stake (1995). The main elements that define the case study approach in my study are multiple embedded cases, and multiple

methods and sources of evidence. I will explain these elements in more detail below, after justifying the choice of case study design.

2.1 The use of case study in palliative care research

Yin (2002) states that:

> A case study is an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between the phenomenon and context are not clearly evident.

> (p.13)

Stake (1995) stresses that it is "the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances" (p. xi). Case studies can be used for many purposes: exploring (new areas), describing (complex events or interventions), and explaining (complex phenomena) (Kohn, 1997; Yin 2003). Within these purposes it is possible to adapt the design of the case study to meet different practical, ethical and theoretical considerations (Kohn, 1997).

Case studies have been found to shed detailed light on problems in palliative/end-of-life research (Payne et al, 2007). They are suitable for exploring practically and ethically complex situations involving a variety of perspectives. The ability of case studies to deal with complex situations is often identified as key to the choice of this approach, both because of the complexity of provision and the multifaceted consequences of complex services in palliative care (Cowley et al, 2001; Skilbeck et al, 2002). Recruitment, attrition, timing and ethics can all be problematic in palliative

care research. Case study researchers often have the flexibility within a rigorous approach to work effectively within these constraints and still produce high quality, relevant work (Walshe et al, 2004). Using case study strategies rigorously and appropriately can contribute to knowledge in a way which is sensitive to the complex, context-dependent and multi-professional nature of palliative care (Walshe et al, 2004).

Walshe et al (2004) have summarised those situations when a case study strategy is appropriate to use in palliative care research. They are: 1) when complex situations need to be addressed; 2) when context is central to the study; 3) when multiple perspectives need to be recognised; 4) when the design needs to be flexible; 5) when the research needs to be congruent with clinical practice; 6) when there is no strong theory to which to appeal; and 7) when other methodologies could be difficult to conduct. To varying degrees, all of these seven situations pertain to my research project. I will touch on these situations in my study in the following part of this section and in Section 3.

2.2 Multiple methods and sources of evidence

A distinctive feature of case study research is the use of multiple methods and sources of evidence with the aim of ensuring the comprehensiveness of findings as well as potentially strengthening their validity (Yin, 2002). Using a range of data collection methods within case studies appears to be the key to capturing complexity (Cowley et al, 2001; Skilbeck et al, 2002). Much case study literature emphasises the strength of using different sources of evidence to corroborate a phenomenon (Yin, 2002). Triangulation between different sources and methods within case studies is a good

way to generate more comprehensive data and encourages a more reflexive analysis of the data as the researcher can expect to find elements of convergence, divergence and contradiction in data that are drawn from different sources and methods (Keen, 2006).

In this study, I mainly used qualitative interviewing and observation to collect data about the three organisations and the selected patients within these organisations. Data were collected from multiple sources of evidence, that is, from patients, their families, and the staff (director, doctor, nurse, nursing worker or other relevant staff). However, due to the ethical and practical constraints reported in Section 3, the weight, quality, duration, interval of each method, and the combination of sources of evidence varied among the settings (see Table 1). Mainly, I conducted formal, semi-structured interviews with patients from the committee and the hospice. I explored their experiences of end-of-life care (as defined by them) and their experiences of hope in living with a terminal diagnosis. I also interviewed one family member and the doctor-in-charge of each selected patient in the ward to study the patients' experiences (most of them were not suitable for interviewing). Besides, I observed the organisational contexts of the three settings, focusing on how palliative/end-of-life "health care" was provided in the case of the ward and the hospice, and how patients undertook community-based rehabilitative activities in the case of the committee. I also observed the daily lives of the selected patients in the ward. In addition, I used documents to supplement the main methods and the main sources. Those documents were the media reports about the organisations, and the internal documents of each organisation, such as administrative manuals, newsletters, publications, information and education materials for clients, and patients' medical records. The process of generating data drawing on these methods and sources of evidence will be reported in more detail in

Section 3. Next, I justify the selection of qualitative interviewing and observation as appropriate methods for this study.

Qualitative interviewing

Qualitative interviewing is one of the most widely used methods of generating data in qualitative health research (Green and Thorogood, 2004; Pope and Mays, 2006). It has also been widely used in researching sensitive topics (Liamputtong, 2007). It is regarded as a suitable method in palliative/end-of-life care research (Payne, 2007). Gysels et al (2008) found that qualitative interviewing could be a positive experience that caused minimal distress to palliative care patients and carers.

According to Rubin and Rubin (2005), although varying in aim, style, and design etc., all forms of qualitative interviews share key features. First, research using qualitative interviews builds on a naturalistic, interpretive philosophy. Second, qualitative interviews are extensions of ordinary conversations. Third, the interviewees are "partners in the research enterprise rather than subjects to be tested or examined" (p.12). Qualitative interviewing has the capacity to generate very large amounts of data; and it is more interactive with opportunities to develop or deepen the discussion in particular areas, according to the material which arises and the interests and judgement of the researcher (Clark, 2001). In addition, it can be adjusted to patients' levels of understanding, reformulating questions into more familiar language, or introducing sensitive topics and checking their appropriateness for discussion (Gysels et al, 2008). Each interview is unique, as researchers match their questions to what each interviewee knows and is willing to share (Rubin and Rubin, 2005). Qualitative interviewing is therefore "responsive interviewing" (Rubin and Rubin 2005, p. vii).

A commonly cited shortcoming of interviews is that they only provide access to what people say, not what they do; and it does less well in producing information about how people interact or behave in contexts other than interviews (Green and Thorogood, 2004). In my study, there were also practical and ethical challenges in arranging and conducting interviews with people living with a terminal illness, which will be discussed in Section 3.

Participant observation

Participant observation is a method of research in which the researcher:

participates, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is being said, asking questions; in fact collecting whatever data are available to throw light on the issues with which he or she is concerned.

(Hammersley and Atkinson 1983, p. 2).

It is particularly appropriate for studying how organisations work, the roles played by different staff and the interaction between staff and clients (Pope and Mays, 2006). It has been widely applied in health research for addressing a range of research questions within health professions (Reeves et al, 2008). Particularly, it can generate rich and detailed accounts of clinicians' professional and inter-professional relationships, their interactions with patients, and their approaches to delivering care, as well as in-depth accounts of patients' care experiences. It is also common in health research to use observation to corroborate or nuance accounts given by interviewees (Pope and Mays, 2006).

Participant observation also gives researchers opportunities to gather empirical insights into social practices that are normally "hidden" from the public gaze (Reeves et al, 2008). It is used for accessing the experiences and views of physically and emotionally vulnerable patients in the final stages approaching death, as a potentially non-invasive and unobtrusive method of data collection (Lawton, 2001). The emphasis given to observational methods rather than to interviews also affords unique and important opportunities to include directly in a study patients who would otherwise have to be excluded, for example, those too weak and lethargic to be interviewed (Lawton, 2001; Payne, 2007). But it can also be laden with practical and ethical challenges as I will report in Section 3.

2.3 Multiple embedded cases

"In social sciences and human services, the case has working parts; it is purposive; it often has a self. It is an integrated system... Its behaviour is patterned" (Stake 2000, p.436). Therefore, boundedness and behaviour patterns are useful concepts for specifying the case (Stake, 1988). When a case (unit of analysis) is examined mainly to provide insight into an issue, it is an instrumental case (Stake, 2000). In other words, the case is of secondary interest, it plays a supportive role, and it facilitates an understanding of something else. In my study, all cases, either organisations or patients, were instrumental. The cases were looked at in depth, their contexts scrutinised, their ordinary activities detailed, but all because they helped to understand the social phenomena under scrutiny, that is, end-of-life care provision in China and hope in terminal illness. My expectation was that the phenomena of interest observable in these cases would potentially represent the phenomena writ large. The cases were therefore opportunities to study the phenomena.

An "embedded case study" is a case study containing more than one sub-unit of analysis (Yin, 2002). Within a single case, attention is given to a sub-unit or sub-units. What Yin (1994) considers as a possible problem in the embedded case study design occurs when the case study focuses only on the sub-unit level and fails to return to the larger unit of analysis (Yin, 1994). This can be avoided by using the multiple embedded-case design, which contains a number of embedded cases wherein each embedded case includes multiple sub-units of analysis. In my study, each organisation was an embedded case within which selected patients were sub-units. Conducting the research in the three organisations allowed for multiple analyses (Yin, 1994). The conclusions drawn from the findings of each organisation were studied in relation to the organisation as well as in comparison to other organisations. In such a design, I was able to study end-of-life care from both the providers' and the users' perspectives, and to explore the interplay of the internal and external mechanisms of hope in terminally ill people.

Organisations were selected on a convenient (opportunistic) and purposive basis (Bryman, 2008; Reeves et al, 2008). First, I selected the three organisations because I had some confidence that I could gain access to them. Second, and equally important, was their particular relevance to the social phenomena I aimed to study. Third, via these organisations, I could access and thus study those people whom the researched social phenomena really concerned. The rationale was that "balance and variety are important; opportunity to learn is of primary importance" (Stake 1995, p.6). The three organisations I chose (the committee, the hospice and the ward) differed markedly in the care and support they provided for people with advanced cancer. Inevitably, the people whom each organisation served revealed distinct features. Thus, they presented

the opportunity to learn about varieties of experiences of end-of-life care and hope among older patients, thus facilitating data corroboration.

The selection of individual patients in each organisation mainly depended on the gatekeepers' preliminary choices, followed by the chosen candidates' health status and willingness to participate, and in this sense was limited and opportunistic. As a result, the patients chosen by the gatekeepers were mostly representative of their organisational culture (particularly in the case of the committee) or demonstrative of their success in delivering care (particularly in the case of the hospice and the ward), and therefore hardly any "deviant" cases were presented to me. In terms of hope, patients who agreed to participate tended to be more hopeful, and it was hard to recruit those who were depressed and hopeless. There are also limitations to the diversity of the "sample", for example, this study does not represent the experiences of those people from an ethnic background other than the Han majority, those who are from different religious backgrounds, people who do not use the services provided by the three organisations I studied, or who are from different geographical regions of Yunnan province.

The details of gaining access to organisations and individual participants will be reported separately in Section 3. Next, I present the background information of the three embedded cases: the committee, the hospice, and the ward.

The committee (See Appendix 1 for the images that illustrate the care setting of this organisation as described below)

The committee was a self-help patients' organisation. It was established by and for cancer patients 20 years ago, responding to their need for mutual and social support, against the backdrop that they (and their families) were left with nothing but medical treatment. It was a legally registered Non-Governmental Organisation (NGO), affiliated to the Red Cross Yunnan Branch. By 2010, the number of registered members (adult cancer patients of all ages) from Kunming (the capital of Yunnan Province) had reached 5000. It was run entirely by cancer patients on a volunteer/unpaid basis. It was funded mainly through membership fees and occasionally through donations from both the public and private sector.

The committee was headquartered in the biggest specialised tumour hospital of Yunnan province (in Kunming). Patients usually went to register as a member of the committee after a diagnosis was made and following recommendation by doctors or fellow-patients in the same hospital. All members knew they had cancer due to the procedure of registration, which required presentation of a patient's medical records, particularly a diagnostic test report. Most members benefited from the basic medical insurance tied to their previous or present employment. Some had a "special disease certificate" for cancer treatment, with which they could be reimbursed more for their medical cost than with the basic medical insurance. Members had free access to public buses and all the public parks, where they usually did daily exercises, which was the preferential treatment offered by the local government.

The most popular and trusted approach to cancer rehabilitation among the members, regardless of age and the stage of cancer, was the so called "comprehensive rehabilitation", which encompasses:

a. western medicine (WM), that is, active cancer treatment mainly including surgery, chemotherapy, radiotherapy and biological immunisation therapy;

b. traditional Chinese medicine (TCM), aimed to counteract the side and toxic effect of WM active cancer treatment, and enhance "self-defence" and "self-restoration" of the body, based on a holistic and dialectical philosophy;

c. a range of physical exercises of patients' choosing (e.g. Taiji, swords, dancing), the most recommended Guolin Qigong – popular and accepted nation-wide among cancer patients, has nation-wide training networks, and is the central rehabilitative activity for the 16 groups of the cancer patients who exercised daily in the parks of Kunming;

d. "food therapy", that is, proper diet for cancer patients with dos and don'ts;

e. healthy living and pursuit of hobbies;

f. psycho-social therapy, which they referred to as "collective anti-cancer spirit", or mutual support, of which the featured activity among these members was "chat therapy";

g. health education lectures given by medical specialists;

h. publicity and advocacy (e.g. art festivals, sports meetings, and commendation meetings for the elected "anti-caner fighter", "anti-cancer hero" and "anti-cancer god of longevity");

i. fundraising art performances;

j. and charitable work for other vulnerable groups (e.g. drug-addicts, older people, prisoners).

In addition to the "comprehensive rehabilitation", a mentality of not giving up on life, that is, maintaining a strong sense of hope for cure and prolonging life, was vital for the members of the committee. As a result, some (e.g. anti-cancer heroes) had indeed

survived for quite a long time despite their terminal diagnosis (e.g. for over ten years). However, the vast majority eventually died in mainstream hospitals.

The hospice (See Appendix 2 for the images that illustrate the care setting of this organisation as described below)

The Hospice was established in September 2007 as the 24th hospice of the "National Hospice Service Program", which was founded by Li Ka Shing Foundation to provide free home-based palliative/end-of-life care for people with advanced cancer who are impoverished (see Chapter Three for more information about this national programme). Among a total of 32 hospices set up under this programme, it was the only one located in the remote rural areas in the southwestern region of China (in Yunnan Province), where residents were predominantly minority ethnic groups and its service covered hard-to-reach mountainous areas and border towns on the Burma-China border.

The hospice was affiliated to and headquartered in the People's Hospital of Dehong Prefecture in Manshi city (the capital of Dehong Prefecture). It was jointly funded by the hospital and the foundation. Each year, the hospice received limited funding from the foundation mainly to cover the cost of medicine, vehicle, travel, training, advocacy and publicity, while the hospital provided staff salaries, an office building and its maintenance. The foundation played a leading role in managing the hospice. It provided the staff with ongoing specialist training on hospice care, delivered by the palliative care specialists invited from western countries, Hong Kong or Taiwan. It also determined the model of palliative care implemented, in terms of staffing,

facilities, coverage, target, procedure, standards, delivery mode, admission criteria, quality control, monitoring and evaluation.

The staff included two doctors, two nurses, a driver, a social worker and an IT technician. Some junior nurses from the hospital worked as volunteers. The hospice had served more than 800 patients since 2008, with roughly 190 still alive by 2009. The capacity of service provision by this small team peaked at 210 patients at any one time. The aim was to provide total care for the whole person throughout the last phase of their life, as well as to support their family. The services included pain relief, symptom control, guidance on daily home care, psychological and spiritual care, social support and a bereavement service. These services were delivered totally free of charge through the outpatient service, home visits, phone follow-ups, and volunteers' work (only in Manshi city). The targeted population was those who had advanced cancer, had severe pain, were living under the poverty line, and lived within 150 km of the hospice. As a result, a majority of people the hospice served lived in the hard-to-reach mountainous areas that were in many respects disadvantaged. This made it extra hard for this small team to reach the dispersed targeted population.

The hospice conducted campaigns at the initial stage to raise public awareness of palliative/end-of-life care, publicise the national hospice programme and promote hospice services, through the mass media and working with local (community) government sectors particularly health bureaus, and multi-tier health care delivery systems (hospitals, clinics, health care centers, community health care workers etc.). As a result, patients were usually referred to the hospice by their relatives or by hospitals. At registration, a diagnostic test report and a poverty certificate issued by the local government had to be presented for a person to qualify for the free service.

Often, families registered patients for hospice services. A great number of patients did not know they had cancer at registration. The maximum survival time of these rural patients was usually no more than two years.

The ward (See Appendix 3 for the images that illustrate the care setting of this organisation as described below)

The ward was established in 1996 as an inpatient palliative care ward, with 20 beds, three doctors, six nurses and four nursing workers. It was an independent department of the 3rd People's Hospital of Kunming – one of the municipal general hospitals in Kunming. In 2006, it became the Palliative Care Center of Kunming City. It was the first and remained the only specialised inpatient palliative care ward in Yunnan province. It had treated some 4000 patients by 2010, in the 15 years since its inception. Meanwhile, the ward had expanded, now with 70 beds, nine doctors, 18 nurses, and 29 nursing workers (normal inpatient wards were not staffed with nursing workers).

The director was the founder of the ward. He graduated at Kunming Medical College and then worked as a neurosurgeon. He then studied palliative care through reading medical magazines and attending short training courses in Beijing organised by an Australian palliative care specialist. He also visited serveral palliative care practices in Taiwan and Australia, to learn how to lead his own team. Between 1999 and 2004, he initiated and taught a palliative care course in Kunming Medical College and some 2000 medical students and nurses attended his lectures. In 2000, he compiled and published the textbook he used. All the other doctors in the ward were licensed internists. Their initial training in palliative care was given by the director, as there was no formal education or training available in the medical colleges or in

professional circles. There were a handful of published textbooks to which they could refer including the one compiled by the director. Only one doctor was sent to Singapore to do a part-time Bachelor's course in palliative care. Nurses and nursing workers received even less training in palliative care than the doctors.

Since its inception, the ward aimed to provide palliative/end-of-life care for patients with advanced cancer or geriatric problems. On average, only 30 per cent were cancer patients; others had cardiovascular diseases, cerebrovascular diseases, or chronic bronchitis; and a few were frail older people. Ninety per cent of patients were aged over 60. Most of the admitted patients died in the ward. The scope of palliative care provided in the ward was subject to the basic medical insurance scheme, among other factors. That was, the ward only provided those items either the insurance or the patients themselves could pay for. Pain relief with narcotic drugs and symptom control were covered by the insurance, therefore were guaranteed in the ward. Other items of palliative care, such as home-based care, counselling and other therapies were not covered by insurance and therefore were not provided in the ward.

The average stay of a patient in the ward was 45 days, but it was possbile for a patient to stay as long as he or she needed. This was unlike other inpatient wards in mainstraim hospitals, where there was pressure to lower "average hospitalisation days" and "mortality" – indicators of quality, efficiency and the technical level of a hospital, as the health care system is oriented towards curing disease and saving life. This was also the reason why at least half of the patients admitted were referred to the ward by other hospitals. Consequently, the demand for its service has been always greater than the supply.

The ward resembled a commercial enterprise which assumed sole responsibility for its own profits or losses and for sustaining itself financially, with minimal state financial subsidies. The ward had managed to be the most profitable department in the hospital and its staff were paid better than those in other departments in the hospital. As a business partner, a local funeral company had stationed its staff in the ward for over five years, to provide funeral services for the convenience of families as well as to secure business.

3. Field work

This section reports on the process of data collection in the field, that is, the process of studying the three embedded cases, preceded by a pilot study. The pilot study was conducted between November 2009 and January 2010 and the main study between May and September, 2010. Data from the pilot study informed one of the two research foci I address in this thesis (as reported in Chapter One) but were not included in this thesis. In section 3.1 I report on how the pilot study practically, ethically and methodologically prepared me for the main study. In Section 3.2 I report on the main study which consisted of three embedded-case studies. While the methodological and theoretical imperatives must be kept in mind in the field work, I particularly stress the need to be sensitive to the ethical and practical constraints specific to each site, each method, and even each participant and each situation. Researching such a complex, sensitive and distressing topic in such complex situations thus afforded me the

opportunity to learn the art of equilibrium amidst the "mess" of the reality on the ground.

3.1 Pilot study

In August 2009, having passed the probation assessment, and before applying for ethical approval from Human Participants and Materials Ethics Committee (HPMEC) of the university, I returned to China to confirm the settings for my field work and find out about the procedures for gaining ethical approval from each setting. The trip was successful. Back in the UK, I gained ethical approval from the OU HPMEC, which equipped me with second-hand knowledge about ethical research that would not only "do no harm", but also have the potential "to do good" (Liamputtong, 2010). However, this second-hand knowledge that I obtained by reading the literature was derived from the research experience in the UK. Therefore, it was unclear whether it could be readily applied to research in the Chinese context. In the light of this and other uncertainties that concerned the research aims, the research strategy, and the method that I proposed in the probation report, I conducted a pilot study between November 2009 and January 2010. Through this pilot study, I methodologically, ethically and practically prepared myself for the main study between May and September, 2010. In Chapter One, I reflected on how the pilot study, particularly the 12 pilot interviews, informed one of the two research foci I address in this thesis. Below I report other major achievements made in relation to the pilot study.

Access to the field work sites

Gaining access depended on both serendipity and joint efforts. The key was to access an organisation through a "gatekeeper", that is, someone in a position to allow and

90

facilitate the research (Pope and Mays, 2006). In my study, there were three gatekeepers who were directors of the organisations. I was fortunate that my friends used their "guanxi" [12] and found someone of prestige to introduce me to the gatekeepers of the committee and the hospice. Being introduced by someone prestigious was key to establishing my credibility. However, I did not find anyone who could help me to gain access to the ward. Media reports convinced me of the ward director's devotion to and enthusiasm for promoting palliative care. With this shared enthusiasm (I assumed), I was confident and bold enough to visit him as a total stranger, taking along my CV, my supervisors' CVs and the brochures about The Open University.

What followed were the official meetings between the gatekeepers and my supervisors, who visited Kunming to help me negotiate access at a perfect timing. My supervisors also arranged for the Faculty to send an official letter to the gatekeepers confirming my identity. By then, I could rest assured that I was really accepted by the gatekeepers as a trustworthy researcher from an authentic UK university with a sincere intention of conducting research that shared their concerns, rather than being suspected of being a swindler with suspicious intentions. So the key was also to establish my authenticity in the context of rampant fraudulence and a crisis of trust in China.

In addition, I offered to reciprocate the favour of having been granted access, as I know as a Chinese person that to establish my "guanxi" (Lu and Chen, 2011) with the gatekeepers to "get things done", reciprocity is key. The director of the committee (a cancer patient himself) firmly rejected my offer, making it clear that he would support me simply because of my real concern over the fate of cancer patients. The favours I

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[12] A special connection between people which brings along exchange or reciprocity of special rights and obligations; or an informal, unofficial relationship utilised to get things done, from simple tasks to major life choices (Lu and Chen, 2011) (see also Chapter Two).

returned to the directors of the hospice and the ward concerned their professional work, which indirectly would benefit patients (see the case studies below for more details). Having made the necessary efforts, in the end, it was also the gatekeepers' need for their voice to be heard that motivated them to permit and facilitate my research in their organisations since, in a death-denying society (as argued in Chapter Two), both the voices of people at the end of life and those of the professionals who care for these people are silenced.

During the process of gaining access, I also collected contextual data about the organisations through: 1) informal conversations and formal interviews with the key informants (the gatekeepers), 2) collecting relevant organisational documents from the key informants, and 3) collecting media reports about the organisations from the internet.

Culturally and practically appropriate informed consent

According to "The Probationary Guidelines for the Ethical Approval of the Biomedical Research that Concerns Human Participants" promulgated by the Chinese Ministry of Health in 2007, non-interventional, qualitative studies were not subject to ethical approval from the hospital's ethics committee (Cao et al, 2004; Ministry of Health, 2007). Therefore institutional approval was not required from the three organisations. However, the gatekeepers were made fully aware of my research aims, methods, potential risks to patients, what was expected of them and the like, before allowing me to proceed. Also, my initial contacts and all the pilot interviews with patients were observed by the gatekeepers. Therefore, I passed their informal "ethical scrutiny", that is, they were convinced that my research would do no harm to the

patients nor threaten the interest of the gatekeepers, other staff and the organisations as a whole.

My common sense (or my cultural knowledge as a Chinese person), backed up by other similar studies (e.g. Mak, 2007; Gysels et al, 2008; Payne et al, 2008) had alerted me to the possible reluctance, resistance, even refusal of the Chinese participants to sign the consent form. My suspicion was proved right – this happened with those who verbally agreed willingly to participate and who were very open during the interviews. Although eventually some participants signed under pressure from the gatekeepers or persuaded by me, it became evident that the most culturally and practically appropriate approach to informed consent was verbal consent.

There were several reasons for this. First, the participants did not perceive signing the form as a way to protect their own rights. Rather, it was something to be suspicious of, thus worrisome and threatening. It created fears about signing away their rights or losing confidentiality (anonymity of participation). This was particularly true with farmers and older people who were mostly illiterate or with low level of education and thus could not check the content of the form. Second, between Chinese people, using a formal approach, such as requiring a written guarantee of their verbal consent only demonstrated mistrust, and was thus counterproductive to rapport, as demonstrated by the responses of those participants who had verbally agreed to participate. Also, it could have compromised my rapport with the gatekeepers who had already received verbal consent on my behalf from the participants (the gatekeeper of the hospice had to do so before taking the trouble to drive me to the patients' homes). Indeed, the gatekeeper of the hospice complained that I did not trust them when I insisted on obtaining the participants' signatures in front of them.

In the case of the hospice, it was not possible for me to visit those patients living in remote and hard-to-reach mountainous areas on my own, neither was it possible to visit them twice: firstly to gain consent and secondly to conduct the interviews. Under such circumstances, I only had one chance to meet and interview a patient, within a limited time slot, which could fit into the hospice's home-visit schedule. This constitutes the third reason: written consent was not always practically favourable. Getting a signature from a hospice patient compromised the time available for the interview, as it took considerable time to convince him or her to sign, and when he or she could not read, another trustworthy person had to be found to check the form. Also, an illiterate participant could not possibly sign his or her name.

Flexible and adaptable research design

In my original proposal, I opted for qualitative interviewing with patients among data collection methods and sources of evidence. However, after arranging, conducting and analyzing the 12 pilot interviews (with five patients, their family members and/or doctors) and making observations all the way, I came to the conclusion that qualitative interviewing was not always an appropriate and sufficient method for studying in depth a patient's experience of living with advanced cancer. It well suited patients from the committee, but not those from the hospice and the ward. What determined this situation were the distinct characteristics of each organisation and the patients in it, and consequently the inherent ethical and practical constraints unique to each organisation.

The committee encouraged its members to collectively fight cancer and survive as long as possible. Therefore, when requested to select patients for informal

conversations and then formal interviews, the gatekeeper opted for those who did this well, particularly those "cancer heroes" or "cancer fighters", to best represent the organisation. As the selected patients were all long-term cancer survivors (e.g. more than ten years) and retirees, they were mostly pain and symptom free, living independently, and had free time at their disposal. Also, due to their organisational traditions, such as "chat therapy" (healing through sharing narratives), mutual support, helping vulnerable people, and making contributions to society, they were more than happy to be interviewed and were very articulate. With these patients, it was practically and ethically feasible to conduct individual, in-depth qualitative interviews within sufficient time and in privacy.

However, the hospice patients I hoped to interview were very poor rural residents with advanced cancer who were suffering from severe pain and other symptoms. As such, most of them were bedbound, living in the geographically isolated and socioeconomically disadvantaged mountainous areas. Although this has presented me with the best opportunity to study rural/urban discrepancies in palliative/end-of-life care, it also placed a number of constraints on my field work. First, I had to rely on the hospice to reach the patients. The hospice staff had a vehicle at their disposal; they took me with them when they paid home visits. But there was usually a two-month interval between home visits to a patient, over which time he or she could have died. Therefore, it was better that I would interview him or her at the initial meeting. Second, because of their workload and extra travel cost, the hospice staff could not afford to visit a patient just to enable me to conduct an interview. My interviews had to fit into their home-visit schedules. They took the trouble to arrange their home visits – usually around eight patients per day, so that I could interview a patient while they went to visit another one living nearby. This meant that it was possible to have

more than one eligible patient to interview during a day, but I could only have 40 minutes maximum for each interview. Worse still, when the hospice staff came back to pick me up, I was always pressured to end an interview hastily without a proper ending. Third, the rural patients still lived with their extended families and their living space was humble. Therefore, there was no privacy at all for my interviews. Both family members and the hospice staff were around. They either cut in on the interviews or made loud noise by conversing or doing housework. The quality of my work in the interviews was thus compromised, as I felt distracted and disturbed. Also, there was so much background noise in the recordings that some words were not audible. Fourth, among the Han patients I interviewed or observed, some spoke Chinese with local accents (most older people do not speak Mandarin) or used local slang that sometimes I could not understand, let alone the local minority ethnic groups who spoke different languages. Some could not understand my accent or expressions. Under such circumstances, families or hospice staff had to interpret for us. Some patients could not express themselves well because of illiteracy, reduced listening, pain, or symptoms. Given sufficient time, it was not impossible to overcome some of these practical difficulties. But under the time pressure, they could significantly compromise the breadth and depth and thus the quality of the interviews. On the other hand, an advantage was that on a day trip with the staff, I could observe many home visits, have lots of conversations with the staff in between the visits, and have opportunities to ask the families questions about the patients.

In the ward, it took me many fruitless visits and long waits to find an eligible interviewee. The ward served those patients who were regarded as "hopeless" cases by other hospitals, of which only 40 per cent were cancer patients. A patient could be sitting upright and alert in bed one day but in a coma the next. A few patients died a

couple of days after admission. Other patients slept for long periods of time and only experienced rare and unpredictable moments of lucidity. Even when I found some patients awake, they were too frail or reluctant to talk. Struck by these patients' situations, I felt that to exclude them from the study would be as unethical as forcing an interview on them and that I needed a method that could embrace opportunities to observe and listen to these patients as and when they happened (Lawton, 2001; Payne, 2007).

In the light of the complex situations described above, I realised that a flexible design would be necessary to include the views and experiences of the broadest possible range of patients. This design should employ mixed methods – interview, observation and documentation, to obtain data from different sources (patients, families and health professionals), which could be adapted to the unique ethical and practical constraints in each setting. This constituted a major reason for using a case study design (see also discussion in Section 2).

3.2 Main study

Having methodologically, ethically and practically prepared myself through the pilot study, I conducted the main study, that is, the three case studies, between May and September, 2010. As reported above, each embedded case was unique, presenting distinct ethical and practical constraints; adapted to which, the weight and nature of each method, and my role were different in each case study. In the following sections, I present the main feature of each case study: qualitative interviewing in the study of the committee, adaptation to the practical constraints in the study of the hospice, and participant observation in the study of the ward.

Qualitative interviewing

In the study of the committee and its patients, the main method I used was qualitative interviewing. Observation – with me as a "complete observer" (Gold, 1958), was limited to observing the interviewees' community-based rehabilitative activities before or after the interviews. The focus of this section is on these qualitative interviews.

The gatekeeper provided me with a list of 15 eligible patients, based on the following selection criteria: 1) with advanced cancer (at least stage III); 2) aged 60 years or above; and 3) being well enough to talk. The initial contacts were made by phone to introduce myself and my research, seek consent, and arrange interviews. I introduced myself as "a research student from a UK university" and my research as "investigating older people's illness experiences". Not all of these patients had heard of me, and a few suspected that I was a saleswoman from a drug company, like those who had approached them before. Upon their request, a recommendation letter to prove my authenticity was issued by the director of the committee and presented at the interview.

Eight patients happily agreed to be interviewed on the grounds that 1) potentially they would help other patients through my research; and 2) they would help me, someone they perceived as being like their own children and a poor student who would face lots of challenges in life ahead, particularly career wise. I could not reach three patients because their phone numbers were incorrect. One person declined because he was suffering from uncontrolled pain due to bone metastases. Another one declined saying that my kind of research was not useful and meaningful as it would not change anything. In the end, I interviewed 10 patients in May and July, 2010 (see Table 1).

At the patients' request, all the interviews took place in the parks or community centres where they engaged in their daily exercises, except one that was conducted in the patient's home. I interviewed them in either Mandarin or Kunming dialect, as they chose. Interviews lasted between 40 minutes to one hour and a half. A demographic information sheet (see Appendix 4) was completed before the interview. Formally, a script (see Appendix 5) was read to inform the patients (again) of my research interest, aims, methods, benefits, risks, anonymity and confidentiality, and the supervision contacts (the gatekeepers). Then, at the beginning of the interview I obtained verbal consent, which was confirmed again at the end of the interview, both were audio-recorded. Field notes were also audio-recorded after each interview to describe the context of the interview (e.g. time, place and environment), my reflections, and my observations of their rehabilitative activities. Interviews were spaced out: one a day with at least a one-day interval. This allowed me time for evaluating and analysing the previous interview and preparing for the next one (Rubin and Rubin, 2005).

Interviews were structured around two main related topics: illness experience and hope. I started an interview with some casual chatting to relax both the patient and myself (Rubin and Rubin, 2005). The opening question was: "Please feel free to tell me about your illness experience". If asked to clarify, I would explain that I was interested in their health status, disease history, health care and daily life. This offered them a broad framework for narration. During the first half of an interview, I took an active-listener role (Rubin and Rubin, 2005) listening attentively and empathetically, and encouraged them to explore whatever issues were salient to them within the broad framework. During the second half, I focused on further exploring their hopes (often these naturally arose in the first half), care and support, and burdens and difficulties, with follow-up questions and probes. More difficult, sensitive or provocative

questions were asked during this half (Rubin and Rubin, 2005), but I encouraged them to refuse to answer and to stop whenever they wanted. Towards the end, the questions I asked were slanted to invite positive responses in order to close the interview on a more positive note, as "no interview should end abruptly after an interviewer has asked the most searching questions or when the participant is distressed" (Charmaz 2006, p. 30). In closing an interview, I expressed gratitude, offered to maintain contact, answered questions, reassured confidentiality, asked them to evaluate the interview process, and also stayed alert to additional and often important information delivered by them (Legard et al, 2003; Rubin and Rubin, 2005).

Bearing in mind that some of these patients may be inherently vulnerable (Addington-Hall, 2007; Liamputtong, 2007; Koffman et al, 2009), I took extra caution to make the interview a positive experience that caused minimal distress to them, such as: 1) I followed their agenda, used empathy and understanding and remained unhurried and non-judgemental (Green and Thorogood, 2004; Gysels et al, 2008); 2) I dealt with my own unease with asking difficult questions and asked in a matter-of-fact way (Legard et al, 2003); 3) I did not initiate using such terms as "cancer", "dying," "death" or "end of life", but always paid attention to how they referred to their illness and then followed their lead (Koenig et al, 2003); 4) I maintained "a sense of emotional balance" (Watts 2008, p.9); I achieved empathy without becoming over-involved, remained detached and calm when the subject matter became emotional or shocking (Legard et al, 2003); 5) I gave them time to cry, pause or express significant emotions, and acknowledged their pain and loss (Heather et al, 2001); 6) I made them more comfortable about revelations by sharing some of my own feelings, views, and experience at the end of the interview (Rubin and Rubin, 2005); I tried not to do so during the interview for fear of influencing their answers (Legard et al, 2003).

Generally, the interviewees evaluated the interviewing process as meaningful, rewarding, enjoyable, or therapeutic. With these interviewees, the pain and frustration I felt in response to the vicarious experience of living with advanced cancer was somewhat eased by their "quest narratives" (Frank 1995, p.115), through which they searched for alternative ways of being well in illness and suffering – the possibilities they found in the context of such a fate – the gains through their losses: closer relationships, more poignant appreciations, and clarified values.

Adaptation to practical constraints

In the study of the hospice and its patients, I encountered some unusual practical constraints in relation to qualitative interviewing (as described in Section 3.1); to adapt to which, I used observation to make up for the compromised quality of the interviews. Although neither of the methods could be used to its full potential, together they made up a relatively fuller picture of the work of the hospice and the lives it touched. The focus of this section is on the adaptation to the practical constraints in collecting data.

The criteria for selecting interviewees were: 1) with advanced cancer; 2) aged 60 years or above; 3) being well enough to talk; and 4) speaking Chinese (Mandarin or dialect). My original plan was that I would visit the hospice three times and work with participants for five working days, each time interviewing 3-5 patients. I explained to the gatekeeper that I would need reasonable intervals between interviews and between visits to analyse and prepare for interviews and recover (from stress). The gatekeeper agreed initially.

My first visit was arranged in the second week of June, 2010. I had requested four patients this time. My intention was to conduct one interview a day during four day-trips for home-visits. Then one day I would observe their outpatient service in the office. When I got there, however, the gatekeeper first hinted then pointed out that my original plan was inefficient and it would be too much trouble for them to arrange. Instead, she suggested that the 10-15 interviews I aimed for could be done in one week. The reason was: 1) that they would visit eight patients (ten maximum) each day, and in five days, they would visit around 40 patients, half of which would be eligible; and 2) they were all trained to counsel each other, so they would help me with my stress to enable me to do the interviews as they conducted the home-visits.

At the beginning, I tried to defend my plan. Then I realised that I was in no position to negotiate because they facilitated my research on a voluntary basis. The only favour I could return was that the gatekeeper and the head nurse asked me to help them with some paper work (e.g. field trip reports, academic papers). Therefore, I should not ask them for more than they were willing to offer, and instead, should appreciate and make good use of what they offered. I was also humbled by their efforts to reach those poor rural patients who otherwise would be totally left alone shouldering their intense suffering. A day trip could last for more than 12 hours: they left home at dawn and returned in the dark. During one trip, they ran around to serve as many patients as possible due to insufficient funding and staffing. Driving along narrow, muddy, winding or bumpy roads in the mountains, they were exposed to dangers, particularly in bad weather conditions. By contrast, I felt ashamed to have asked for time to recover from the tiredness of trips and the stress from listening to patients frequently.

Eventually, I had no choice but to seize this opportunity – I completed my field work in one week. Indeed, this was the most intense week during my field work. I took as many opportunities as I could adapt to and "bear with" to collect as much data as possible. I did four-day observation of 25 homes visits as a complete observer (Gold, 1958), during which I interviewed 11 patients (see Table 1). In between, I had many conversations with the staff and families. Although to varying degrees, these interviews were limited by time constraints, lack of privacy, patients' health status, and communication barriers (as described in Section 3.1), opportunities to observe my interviewees' (before the interviews) and other patients' home visits, to some extent, made up for the shortcomings of interviews. I also observed the outpatient service for one day. During the final day, I interviewed the director and the head nurse, and helped them with some office work. Before the interviews, I completed the demographic information sheet, based on a patient's record, which I was also allowed to see. Interviews were audio-recorded. Field notes were audio-recorded (in private) or written (often in front of people), about interview contexts, my reflections and my observations (e.g. home visits, outpatient service, conversations). I had some time in the evenings to write notes and reflect. Also, more field notes were made retrospectively after the trip.

I encountered several new ethical challenges in this study. First, quite a few patients did not know their diagnosis and families insisted on concealing the truth. Having been alerted to this possible situation in the pilot study, I found out what the patients knew about their diseases beforehand. During the interviews, I was very careful not to ask questions or respond in ways that would hint at the truth to the unknowing patients or confirm their suspicion. Second, a few patients, in desperation, kept asking me questions such as "Will I die soon?", "Can I be cured?", or "How long can I live?" I

tried to be honest but avoid giving absolute answers to either foster false hope or distress them. Third, consent for observing home visits was given by the gatekeeper. Patients' families had all signed consent forms to allow the hospice to collect data on the patients for the purpose of research, education or training. The gatekeeper therefore granted my observation, and consent was not formally sought from the patients and their families. Fourth, most of the interviewees were new to the hospice, thus their pain and other symptoms were still acute. At the time of the interviews, which followed the hospice staff's lengthy initial assessment and care instruction, the patients were already tired. Because I had observed and taken notes about the work of the staff, during which they had asked questions highly relevant to my research interest, I refrained from probing too much with these new patients.

On my part, I was deeply affected by the intensity of the field work, and "the chaos narratives" (Frank 1995, p.97) that I heard and observed of this group of patients, who were mostly overwhelmed by the intensity of their illness. Their narratives were often disjointed and without sequence, conveying an underlying message that life would not get better. Their experiences revealed to me human frailty and vulnerability and how easily each of us could be "toppled". All of this had a deep effect on me. After this trip, I was unable to proceed with my field work until after some counselling was offered by my UK counsellor and my supervisors, and a short holiday was taken. In addition, I also suffered strong feelings of guilt from utilising the patients for the purpose of my research during the intensity of their suffering without being able to return the favour. What is more, due to the time constraints, I could not even close an interview properly, as I did with the patients from the committee in order to make it a more positive experience. To relieve this guilt, I donated to the hospice a meagre amount of money and requested that they spent it helping patients.

Participant observation

In the study of the ward and its patients, the main method that I used was participant observation. Qualitative interviewing was supplementary. In this section, I focus on the experience of being a participant observer in this setting.

During the pilot study, I had gained access to the organisation. However, I still needed to secure access to the organisation and also gain access to people, which was ongoing (Bryman, 2008). During the preparation visits, I became aware that my conversations with patients were monitored by the doctors (patients told me so); and I suspected and worried that the staff would perceive me as either monitoring them for senior management or evaluating (making value judgments about) their work. But I was lucky that the situation developed in my favour. Two things that I did particularly helped smooth the path of ongoing access. First, during the pilot study, I had offered to reciprocate the favour of having been granted access. In late June, I helped organise the National Seminar on Geriatric Diseases and Palliative medicine, which was sponsored by the ward and held in Kunming. I had opportunities to work with the ward staff and sympathise with them. I also met the senior management of the hospital, who acknowledged my contribution to the success of the seminar and granted me access to the ward in the name of the hospital. Most doctors and several nurses had become quite comfortable and relaxed with me. During the seminar, I interpreted for an American palliative care specialist and co-presented with him a talk on communication in end-of-life care, through which I demonstrated my competency and credibility as a researcher. By the end of the seminar, the level of acceptance, rapport and trust I felt with them was enough for me to initiate field work. Second, at my request, on the first day of my observation, the director formally announced my field

work in the routine morning meeting of doctors and nurses. He also requested that they cooperate with me and learn from my work. In addition, I made a poster to inform them of my research interest, aims and methods, and who would be involved in which methods (see Appendix 6). It was put on the wall in their office throughout my field work. I particularly hoped to allay their suspicions that I would be monitoring or evaluating their work, by stressing that my interest was in older peoples' experiences, which concerned many aspects of their life, not just their work.

Access to nursing workers, patients and families, however, was ongoing, informal and sought individually. Although I intended to seek access through an overt route, it was not practical in all situations. As the ward is a semi-public space, it was impossible to inform the visitors fleetingly passing by. Neither was it possible with the patients, who could be extremely anxious, confused, sedated, or experiencing very distressing symptoms, or who died within a matter of hours or days of their admission.

Nonetheless, empathy, understanding and being non-judgemental were the key to gaining access. However, this attitude was not always possible and it took conscious effort. Especially at the beginning, I could not help judging people based on my own values and assumptions; therefore I was more likely to be "performing" empathy and understanding. As I entered deeper into their world, seeking to understand them from their perspectives and exploring the external forces (objective reality to them) that impinged on their subjectivity and behaviours, I became truly able to empathise and understand them. It was also helpful to assure them of confidentiality, that is, information given to me did not get back to others. At the end of the field work, I reported back my evaluation of the ward to the director, at his request and as a favour

(I hoped my work would help him improve the service), but it was generalised feedback without individual names or identifying features.

Obtaining informed consent from dying patients was particularly difficult and problematic (Lawton, 2001). Instead, I gained proxy consent from families for observing the five cases (patients) I followed up, as it was a common practice in Chinese hospitals to use proxy consent from a close relative, which had formal legal and ethical status (Lin et al, 2011). Verbal consent for formal interviews and observing the five cases was audio-recorded. Verbal consent from others that I observed and conversed with was either given in advance or retrospectively, and again, was not always possible. A typical situation where consent was particularly problematic was when deaths occurred. At that time families were extremely distressed and the staff were preoccupied with their work. Retrospective consent was obtained from the staff, but some families never returned.

My role was observer-as-participant (Gold, 1958). I participated in care work as a volunteer in a limited way. This is due to the potential risk of me harming the vulnerable dying patients – I had no previous experience in caring for such people. I mainly fed them water, fetched things for them, notified the staff when they were in need, and chatted with them. My participation was mainly in the rooms of the patients that I studied as cases. At other times, I could take the role of a detached observer, unobtrusively watching what went on, as the ward was a semi-public space.

My presence may have stimulated modifications in behaviour or action – the so-called Hawthorne effect (Holden and Bower, 1998), but this effect seemed to reduce over time as people got used to me being there. At the organisational level, things such as

routines, roles, rules and physical layout, as objectively existed reality to me, were unlikely to be amenable to my immersion. Therefore, I doubt that during my field work, my presence had affected the broader dynamics taking place. However, my interpretation of events could have been affected by my own beliefs and values. Therefore I maintained a research diary with reflective notes, as the use of reflexivity could assist in managing my influence on the situation studied (Byrne, 2000). These reflective notes helped to promote rigour during data collection and analysis but were not analysed as data.

I interviewed a family member of each patient whom I studied as a case (see Table 1). I explored the patients' illness experiences and expressed hopes, and their families' hopes for them. I also interviewed the doctors-in-charge of these patients to explore the care they provided for them, and their understandings, intentions and practices in relation to the patients' hopes. The three directors were interviewed to provide data on the organisation as a whole. All these formal interviews were audio-recorded.

Observation took place between the end of July and the end of August, 2010. Although it was a rather short period of time for participant observation, during which I could only collect a relatively limited amount of data, it compensated for the lack of opportunities for interviewing patients and thus the potential to exclude them (as discussed in Section 3.1). I had planned on studying all the seven patients with advanced cancer, aged 60 years and above, and who were there at the beginning of my observation. However, on the second day of my observation, two of these patients died. Therefore, I studied five patients until they died (two patients) or till the end of my observation. Episodes of five-hour-per-day observation incorporated different times of a day, days of a week, to ensure maximisation of the range of behaviours and

people observed and as much time as possible spent with the patients being studied (see Table 1). However, "the ordinary is too complicated to be mastered in the time available" (Stake 2000, p. 445). It was impossible to study every aspect of the case from every angle. Through the analytical process which was entwined with the data collection, I made choices about the phenomena that were most likely to yield answers to the main research inquiries (Hammersley and Atkinson, 1995). Therefore, the focus of observation was on: 1) the five patients' daily lives in the ward; 2) patterns of care provision to patients by different actors involved (doctors, nurses, nursing workers and families); and 3) hope work – what hopes were fostered in patients and in which ways.

I tried to remember events and conversations with the aid of the jotted notes, made in a small notebook where possible during observation. Then, the initial jottings of key events, quotes and impressions served as a prompt to full field notes that I typed up on my laptop as soon as possible after the observation. I used six files to record field notes: a separate file for each patient and one for the organisation. Field notes only recorded concrete and thick descriptions of conversations, encounters, nonverbal communication, spatial arrangements and the physical environment observed. In the notes, different types of observation, such as verbatim quotes from conversations, summaries of conversations, non-verbal behaviours and gestures were denoted by different colours. Separately, I recorded in my reflexive diary my impressions, feelings and reactions to those observations, my intuitive hunches, my questions, and my plan for the next day or days – what next and what more to observe. Particularly, in the diary, I reflected on challenging assumptions about why certain things were done or said, as I had to be ever vigilant to assuming shared understanding especially

in the areas of hope, and I needed to be careful that I was not just seeing or hearing what suited my enquiry and the conclusions that arose during the process of field work.

In this study, my guilt for utilising the patients for the sake of my research was mediated by my volunteer work. I coped with the emotional effects on me of spending sustained periods of time with patients in distressing circumstances and frequently witnessing deaths by talking to my UK counsellor and keeping a reflexive diary.

Table 1 Participants in Case Studies

	The committee	The hospice	The ward
Interviewees	The director (a patient) and 10 patients	11 patients, 2 doctors (one was the director) and 2 nurses	5 family members of the 5 patients I studied as cases, the director (a doctor), two vice directors (also doctors), 4 junior doctors, the head nurse, 4 nurses, 2 nursing workers (individual interviews), 5 nursing workers (group interview),and a funeral service worker stationed in the ward
Observations	9 of the 10 interviewed patients and other members of the committee who were doing rehabilitative activities with these patients before or after interviews	2 doctors, 2 nurses, the driver, the social worker and 25 patients and their families present at home visits	5 patients I studied as cases and their families, 8 doctors, 9 nurses, 11 nursing workers, 2 funeral service workers, and some families whose relatives died when I was observing

4. Data analysis

Analysis occurs throughout the research process (Rubin and Rubin, 2005). During the field work (including both the pilot study and the main study), as much as practically possible, I took an iterative approach to data collection and analysis so that the results of previous analysis could direct further investigation. In between the pilot study and the main study, the pilot data were analysed to inform the main study. Following the completion of the main study, I devoted a half year to the systematic and comprehensive data analysis consisting of data transcription and framework analysis. In this section, I report on this stage of concentrated data analysis. This is not to say that the analysis ended at this stage, but rather it continued while writing up this thesis. In addition, data collected on individual patients during the pilot study were excluded from this stage of analysis. But I must acknowledge the contributions of all the patients and their families, whom I either interviewed or had informal contact with, to setting the scene for the main study, and broadening and deepening my understanding.

4.1 Data preparation

All the formal interviews and the audio-recorded field notes (in Chinese) were directly transcribed into English, that is, transcription and translation were carried out simultaneously (see Appendix 7 for an example of an interview transcript). This was due to: 1) the need for data analysis in English so my supervisors could support me; and 2) the considerable amount of time and work required for transcribing them in Chinese and then translating the scripts into English. According to Rubin and Rubin (2005), we should "put into the transcript only the level of detail we are likely to analyse and include any information that might influence the interpretation" (p.204). Therefore, in the transcripts, I included laughter, tears, exclamations, stalling words (e.g. um and ah), silences, pauses, hesitations etc. to facilitate interpretation. The

handwritten field notes were also translated into English. The full field notes of the observational study in the ward were already typed up in English on the same day as the observation, based on the hand written jottings in Chinese. The data preparation yielded a set of English data in electronic format, to be analysed with the aid of NVivo software.

Birbili (2000) points out that:

> Collecting data in one language and presenting the findings in another involves researchers taking translation-related decisions that have a direct impact on the validity of the research and its report.
>
> (p.1)

This applies to my study. The grammatical and syntactical structures of Chinese do not match those of English. I found it impossible to translate Chinese sentences literally (verbatim) into English. Neither do the two languages offer direct lexical equivalence. For instance, some Chinese terms have no linguistic equivalence in English, but some have more than one. Under such circumstances, it is recommended that one's efforts should be directed "towards obtaining conceptual equivalence without concern for lexical comparability" (Temple 1997, p.610). However, as Temple and Edwards (2002) contend:

> Language is "an important part of conceptualisation....It speaks of a particular social reality that may not necessarily have a conceptual equivalence in the language into which it is to be translated.
>
> (p.5)

In this sense, the process of translation in my study is also a process of transforming the particular fragment of the Chinese social reality that I captured into an English one. I view it as another dimension of "data interpretation", which is subject to my knowledge of both cultures, my proficiency in both languages as well as my autobiography (Birbili, 2000). Although I aimed to grasp the full implications that a term carried for my Chinese participants and ensure that the cultural connotations of a word were made explicit to English readers, this process inevitably involved "the introduction of pseudo-information or the loss of information" (Ervin and Bower 1952, p. 597-598).

According to Woodby et al (2011), qualitative researchers who explore an individual's experience of health, illness, death and dying often experience emotional stress in their work, which is not limited to the research arena. In my experience, the emotional challenges that I had to handle impacted on me differently at different stages. For example, as an interviewer, I was more resistant to emotional stress as I attempted to balance my scientific stance with my personal instincts, being careful not to allow interviewees to penetrate my boundaries in ways that would compromise my professional roles (see Section 3.2 for more discussion). Data analysis and writing up the thesis entailed levels of abstraction or theorisation which mediated my stress by creating distance from the concrete reality; and seeking out the actionable causes could temper my sense of guilt and powerlessness, and foster hope. However, during the three-month transcription, I listened to the tapes repeatedly until I was sure I had grasped the meanings of my participants, and I thought through alternatives before translating. Although this did not guarantee that there was no introduction of pseudo-information and loss of information, it did immerse me into the participants' worlds,

to the extent that I experienced the most intense emotional stress. I believe it was what Malacrida (2007) refers to as "research student syndrome" (p. 1334), that is, I over-identified emotionally with participants' plights, seeing myself at risk of similar life events, and I experienced physical and emotional responses that paralleled those of participants (e.g. sadness, anger, guilt, hopelessness) as well as "compassion stress" (Rager 2005, p. 426). During this stage, except for counseling and peer debriefing, I found journal writing particular helpful as a self-care strategy.

4.2 Framework analysis

It is required that my research meets the specific information needs of the external funder and my own interest is in its potential for actionable outcomes. Framework analysis is explicitly geared towards generating policy and practice-oriented findings (Ritchie and Spencer, 1994). It has proved flexible for a range of different types of studies, including in-depth interviewing, case studies, and projects involving different groups or subpopulations of participants. It is grounded, systematic and comprehensive. It is also dynamic, relying on the creative and conceptual ability of the analyst to determine meanings, salience and connections. It enables easy retrieval and allows between- and within-case analysis. By following a well-defined procedure, it is possible to reconsider and rework ideas because the analytical process has been documented and is therefore accessible. It involves five distinct though highly interconnected stages, which I will describe in relation to my study below.

Familiarisation

My immersion in the data was through transcription and reading observational field notes. As a result, I became very familiar with the range and diversity of data. I also

114

took notes of salient or recurrent issues and my analytical ideas emerging from the data.

Identifying thematic frameworks

I set up three thematic frameworks, one for each embedded case, within which the data would be sifted. I drew on three sources: 1) a priori issues – those introduced into the interviews or translated into the foci of the observation informed by the research aims; 2) ideas for important themes and concepts "borrowed" from the published literature in my field; and 3) concepts and themes emerging from the data – those recorded in my research notes as the result of ongoing analysis or identified through the open coding of the first few transcripts. The multi-level thematic frameworks, when inputted into NVivo software, became hierarchical "tree nodes". They provided a mechanism for labelling data in manageable bits for subsequent retrieval and exploration. The three frameworks shared common main themes, but differed in some of the sub-themes (see Appendix 8), thus capturing both the convergent and divergent across cases.

Indexing

The three thematic frameworks (tree nodes) were systematically applied to the three data sets (of the committee, the hospice and the ward) respectively, with the aid of NVivo software. This process involved making numerous judgements as to the meaning and significance of the data. A "data unit" (Rubin and Rubin 2005, p. 202) was determined then coded in one theme or multiple ones, depending on its meaning, both as it stood and in the context of the interview as a whole.

Charting

Charts were drawn up for each key theme or issue, and entries made on each chart for all the participants from the same organisation (see Appendix 9). In other words, for each key theme, there was a separate chart for each embedded case (see Appendix 10 for an example of a data analysis chart). In this way, comparison within and between both individual participants and organisations was facilitated. The headings (key themes) and subheadings (sub-themes) of charts were drawn from the thematic frameworks, but rearranged and developed, as I took into consideration how best to present and write up the findings. Charting helped to develop a picture of the data as a whole, by considering the range of attitudes and experiences for each theme or issue.

Mapping and interpretation

At this stage, I aimed to pull together key characteristics of the data, and map and interpret the data sets as a whole. Although I had noted and recorded some emergent categories, associations and patterns during the indexing and charting phases, the serious and systematic process of "detection" now began. I reviewed the charts and research notes, compared and contrasted the perceptions, accounts, or experiences; searched for patterns and connections and sought explanations for these internally within the data. This process was "not simply a question of aggregating patterns, but of weighing up the salience and dynamics of issues, and searching for a structure rather than a multiplicity of evidence" (Ritchie and Spencer 1994, p. 186). This final stage moves framework analysis beyond a sophisticated thematic analysis (Green and Thorogood, 2004).

Summary

In this chapter, I explained the philosophical position I took as the basis for my study – critical realism. Critical realism combines a realist ontological perspective with a relativist epistemology in subscribing to a form of "robust" relativism. It has the capacity to contain the insights of other meta-theoretical perspectives, without limiting an understanding to one or other of these positions.

I outlined how my methodology was responsive to the cross-cultural, sensitive and complex nature of my research. I took a "multiple embedded-case study" approach to understanding both the care settings (organisations) and the individual patients within, focusing not on biomedical matters, but on people and social issues. The main elements of my case study approach include multiple embedded cases, and multiple methods and sources of evidence. I mainly used qualitative interviewing and observation to collect data about the three embedded cases – the three organisations (the committee, the hospice and the ward) and the selected patients within. Data were collected from multiple sources of evidence, that is, from patients, their families, and the staff (director, doctor, nurse, nursing worker or other relevant staff).

I reported the process of data collection in the field, that is, the process of studying the three embedded cases, preceded by a pilot study. The pilot study was particularly fruitful for the main study in terms of gaining access to organisations, developing culturally appropriate ethical conduct and informing a case study approach. While the methodological and theoretical imperatives must be kept in mind in the field work, it was also imperative to remain sensitive to the ethical and practical constraints specific to each site, each method, and even each participant and each situation. As a result, the weight, quality, duration and interval of each method, and the combination of

sources of evidence varied among the organisations. Each embedded case study turned out to be unique. I therefore presented the main feature of each case study: qualitative interviewing in the study of the committee, adaptation to the practical constraints in the study of the hospice, and participant observation in the study of the ward.

Finally, I reported on how I analysed the data following the completion of the main study, which included data transcription/translation and framework analysis. Transcription and translation were carried out simultaneously, a process that I experienced as another dimension of "data interpretation", which was subject to my knowledge of both cultures, my proficiency in both languages as well as my autobiography. This process inevitably involved "the introduction of pseudo-information or the loss of information". Framework analysis is explicitly geared towards generating policy and practice-oriented findings. It involved five distinct though highly interconnected stages, that is, familiarisation, identifying thematic frameworks, indexing, charting, and mapping and interpretation.

So far, I have discussed the layered context of my study in terms of: some background to the study in Chapter One, the broader social and cultural context of my study in Chapter Two, the existing knowledge on the key themes of my study in Chapter Three, and the research rationale and process of my study in this chapter. In the next four chapters, I will present the findings, which can be best understood against this layered context. First, in Chapter Five, I report findings about the mainstream palliative/end-of-life care approach in China in its broadest sense and as experienced by the older people with advanced cancer.

Chapter Five
Mainstream End-of-life Care

Introduction

As discussed in Chapter Three, palliative/end-of-life care as defined in western societies has yet to establish its niche in the Chinese health care system, and thus it is not yet an available and accessible option for the majority of people who need it. Also, there is not much evidence to illustrate how a handful of the existing palliative/end-of-life care services have adopted the western philosophy of palliative care to meet local needs. Under such circumstances, I adopt a loose definition of palliative/end-of-life care to encompass all forms of care and support that do the work of "palliation" that are available in China to those people who need it.

In this chapter, I present a picture of the lives of a group of older people with advanced cancer in China, based mainly on data generated from qualitative interviewing. In so doing, I illuminate the current situation of care for this group of people to identify the sources of both support and suffering in their lives. This will be achieved with reference to the three key areas of health care, community life and perceptions of cancer. In terms of health care for this group of people, I will examine the practices of disclosing diagnosis and prognosis, the mainstream medical treatment that cancer patients usually receive, and their financial situation in relation to medical treatment (in Section 1). As far as community life is concerned, I will describe their

practices of self care beyond the medical regimen, and how their family situations, their relationships with fellow cancer patients and with the wider community may impact on their illness experience (in Section 2). Then I will summarise the predominant perceptions of cancer among this group of people (in Section 3). Finally, in Section 4, I will discuss the implications of these findings for a care approach that encompasses all the potential resources that lie in family, health care and the broader sociocultural environment.

1. Health care

For the older people with advanced cancer in this study (patients), health care had made up a big part of their daily lives; and many aspects of which had profoundly influenced their illness experiences. In this section, I present my findings on the three aspects of health care that were particularly influential: 1) the practices of disclosing diagnosis and prognosis, 2) the mainstream medical treatment that cancer patients usually received, and 3) their financial situation in relation to medical treatment. Preceding these findings, I first describe patients' demographic profile, disease status and general health status.

1.1 Patients' health Status

Across the three settings of care (organisations), patients who participated in my study did not comprise a homogeneous group. They differed in many respects relating to

both their demographic profile and cancer status, as shown in Table 2 and Table 3. What is more, their self-reported, general health status differed as well.

Nonetheless, patients from the same organisation tended to share a similar health status. For example, those from the committee told me they were "feeling fine" or felt "balanced"; by which they meant that they had "recovered from cancer", they had "no reoccurrence or metastases", their "lump totally disappeared", they "hadn't got a relapse yet", or they had felt "fitter than before". However, at least half of them reported having also lived with other health problems, diseases or post-operative sequela from cancer. Nonetheless, this group of patients were not only capable of undertaking Activities of Daily Living (ADL) – eating, bathing, dressing, toileting, transferring (walking) and continence, but also were living a relatively "normal life". Like other older people in China, they shared house chores with their spouse and children, some helped to look after grandchildren, some even worked as volunteers in the committee, and the majority of them actively participated in a variety of social activities organised by the committee.

By contrast, the situation of patients from the hospice was much worse. Except for one patient who "got better generally", all the others complained that they were suffering greatly from sever cancer-related pain and symptoms. They described their pain, general health status and bodily functions in the following ways: "I was paralysed by pain", "my health went downhill day by day", "my health broke down", "I felt unbearably uncomfortable", "nowhere is good", "now I don't even chase and kill a fly", "I am just skin and bones", "it is pain, pain, pain ......", "this pain – stinging pain, I really cannot stand it". Three patients also suffered from other chronic diseases. However, none became totally bed-bound although they relied on their children for

day-to-day needs. All could sit up, walk around a little, and perform some ADLs on their own; a few were able to help with simple house chores such as cooking.

Unlike those from the hospice, the patients I observed in the ward had their pain and other symptoms under control. But three of them also had other health problems (cardiovascular diseases or cerebrovascular diseases). Over the period of my observation, two died from terminal cancer not long after admission (20 days and one month and eight days respectively); one had significant improvement in his health status although having been admitted for not only advanced cancer but also other geriatric problems; another two did not improve significantly nor did they become much worse. Except for one patient who could perform ADLs and was mobile, all others were totally bed-bound. Two patients could communicate, one was unable to speak because of throat cancer, and the other two were unconscious most of the time and could only utter simple words on the few occasions that they were awake.

Table 2 Demographic Profile of the Patients

	%	(n)
Age		
50-59	12%	3
60-69	40%	10
70-79	40%	10
80-89	8%	2
Sex		
Male	44%	11
Female	56%	14
Ethnicity		
Han	92%	23
Bai	4%	1
Xi Bo	4%	1
Religion		
Non-religious	88%	22
Buddhism	8%	2
Christianity	4%	1
Marital Status		
Married	72%	18
Widowed	24%	6
Divorced	4%	1

Education		
Illiterate	16%	4
Primary school	24%	6
Middle school	24%	6
High school/secondary technical school	20%	5
Junior college	8%	2
Undergraduate	8%	2
Occupation		
Retired peasant	24%	6
Retired officer	28%	7
Retired teacher	8%	2
Retired doctor	4%	1
Retired worker	28%	7
Retired engineer	8%	2
Residency		
Urban	60%	15
Rural	40%	10

Table 3 Diagnosis of the Patients

	%	(n)
Primary site		
Endometrial cancer	4%	1
Ovary cancer	4%	1
Prostate cancer	8%	2
Rectal cancer	20%	5
Breast cancer	12%	3
Lung cancer	16%	4
Bone cancer	4%	1
Bladder cancer	8%	2
Brain cancer	4%	1
Throat cancer	4%	1
Rhinitis cancer and lymphoma	4%	1
Renal pelvis and ureter cancer	4%	1
Squamous cell cancer	4%	1
Colon cancer	4%	1
Survival time		
< 5 years	40%	10
5-9 years	32%	8
10-15 years	16%	4
16-20 years	8%	2
> 20 years	4%	1

1.2 Disclosing diagnosis and prognosis

My data show that full disclosure of diagnosis and prognosis was often not the case in

this group of patients. Although the majority (14 out of 20 patients) reported that they

knew that they had cancer, I found out during the interviews with them and their families and/or doctors that cancer in fact meant different things to different patients. Specifically, to varying degrees, they understood what type of cancer they had, the stage of cancer progression and what it meant in terms of disease trajectory, treatment options, treatment outcomes and prognosis. For example, a few were fully informed and could be described as lay experts in their diseases. Some did not know at exactly what stage their cancer was, nonetheless believed that they were dying from it. Some knew the initial diagnosis, but did not know the extent and severity of the metastasis. Some did not understand the implications of having cancer to the extent of not being aware of its common association with death, incurability, and the toxic/side effects of curative treatment. Some knew what a tumour was but did not associate it with cancer, perceiving tumours to relate to a less severe type of disease. Among the three patients from the hospice who did not know they had cancer, one believed that he had another disease, whereas, the other two perceived or suspected they had serious, even incurable diseases from which they would die. Three patients from the ward were never told or had confirmation that they had cancer; nonetheless their families suspected that they must have known about it.

In addition to partial awareness, the interviews also reveal that the way patients found out about their diagnosis and prognosis differed as well. Only eight patients reported having been told the truth directly by their doctors, and all of them attended medical check-ups on their own. Indeed, when families were present, doctors almost always disclosed the truth to families and left it for them to decide whether or not to inform patients. Most families tried hard to hide the truth initially or persistently. In some cases, particularly in the case of the ward where patients had frequent contact with doctors, doctors were pressured by families to collude in constantly lying about

patients' conditions and treatment. However, families were not always successful in hiding the truth no matter how hard they tried. In the end, some families were obliged to confirm patients' speculations, or tell the truth to justify the curative treatment they arranged for them. Sometimes, the truth was disclosed by accident, for example, patients happened to see the medical report or overheard conversations about them. Sometimes they picked up cues from the care setting, such as all the other patients having cancer or the type of treatment being for cancer. Those who had never been told the truth or whose speculation had never been confirmed became aware of the truth in the end or came to believe that they had very serious diseases because their physical deterioration was self-evident.

1.3 Medical treatment

Although 15 out of the 25 patients I studied as cases were being looked after by the specialised palliative/end-of-life health services (i.e. the hospice and the ward), I would argue from my data that these services were the last resort after other health resources in mainstream health care had been exhausted (see also Chapter Six). In other words, the patients relied solely or mainly on the available cancer treatments in mainstream health care; whereas, the hospice and the ward, although located in mainstream health care, were exceptional and marginal. I present my findings on the mainstream cancer treatments in this section, and report the case studies of the hospice and the ward separately in Chapter 6.

In terms of treatment decision making, almost half (13) of the patients reported having made independent decisions regarding their treatment at some point or persistently, often in consultation with families, after they had gathered information from doctors

and other sources. In other cases, families, mainly adult children and spouses, became the gatekeepers of patients' medical care, playing a dominant role in treatment decision making. Particularly, if at the beginning, diagnosis and prognosis were concealed from patients by families, families made all the decisions together with doctors, without consulting with patients. Sometimes, even when patients knew the truth, treatment was arranged for them despite their objection or reluctance. When patients lost the capability to make conscious decisions, for example being unable to talk or unconscious, again, treatment would be arranged by families.

Most patients' lives appeared to revolve around seeking medical treatment and adhering to treatment regimen(s). First, the majority of patients (23) reported having used at least one, though often more than one of the following curative treatments: surgery, chemotherapy, radiotherapy and biological immunisation therapy. They appeared to be standard treatments and the core medical care available to cancer patients. Second, the overall tendency was that those patients who lived in urban areas received more of these treatments than those living in rural areas. Indeed, two patients from more remote rural areas of Dehong Prefecture did not receive any curative treatment but entered hospice care directly or shortly after diagnosis. Third, the majority reported having suffered from surgery, chemotherapy and radiotherapy, but in different ways: 1) side or toxic effects (of surgery, chemotherapy and radiotherapy), 2) post-operative sequela (hernia), 3) post-operative body deformation (artificial excretory opening), or 4) medical accidents in the process of treatments. Some reported having had to get more or ongoing treatment including surgery to fix or mitigate the problem caused by curative cancer treatment. None of the patients reported negative effects from biological immunisation therapy. In addition, some patients had other geriatric diseases that were treated alongside cancer. On the other

hand, cancer pain relief was lacking in hospitals. Although two thirds of the patients reported moderate to severe cancer pain, only two reported having got prescriptions for morphine from hospitals.

Other complaints of the patients concerned the process of getting medical help, which reflected the overall unfavourable condition of the whole health care system (as discussed in Chapter Two). Their complaints included: 1) unfavourable physical environment of the hospital setting, 2) health professionals' improper attitude and communication styles, 3) insufficient, inaccurate, or misleading information provision, 4) lack of education or support before and after treatment, 5) over-subdivision in a hospital thus inconvenience for patients to seek medical help, 6) lack of cooperation in and between hospitals thus lack of coherence of treatment, 7) the profit-driven nature of prescription, 8) scarcity of health-care resources for rural patients, and 9) lack of quality assurance of medical care in hospitals.

In comparison, patients generally spoke highly of traditional Chinese medicine (TCM) in cancer care. More than half of the patients talked about taking TCM prescribed by TCM doctors from policlinics or specialised TCM hospitals, alongside and/or after curative cancer treatment. Except for one patient who commented that it did not work for him, others reported positive effects of TCM in cancer treatment; particularly, seven out of ten patients from the committee relied on it for recovery or remission. According to these patients, TCM cured some of the symptoms (e.g. swelling, cough, ulcer, cold, pain, inflammation), and counteracted the side effects of chemotherapy thus helping them to endure it; it strengthened the body's self-defence and resistance to disease, and self restoration of health, so they relied on their own immunisation to inhibit the growth of cancer cells; it also helped the body to gain balance in adjusting

to cancer, so as to maintain and prolong life. The patients also compared TCM with western medicine (WM), and they reported that its advantages over WM include: 1) that it was cheaper; 2) it was easier and quicker to obtain reimbursement for its cost with a medical insurance card; 3) it caused minimal side effect; 4) it was a "more dialectical" and "patient-centred" approach as the combination of ingredients was adjusted to patients' individual differences and changing health status; 5) it was slower in taking effect but more effective for chronic health problems; and 6) it adopted a more holistic approach, targeting not only disease/symptoms but also sleep, diet, mood and overall balance etc. Patients also mentioned many varieties of ways in which TCM could be administered, for example, TCM soups, injections of herbal abstracts, ready-made TCM capsules/syrups, acupuncture, hot packs, machines that massage or stimulate acupoints, fuming acupoints and massage.

1.4 Financing medical treatment

Overall, from my data, I would argue that medical care for cancer patients, particularly WM appeared to be an enormous financial burden for patients and families; and, therefore, patients' ability to finance and balance different financial demands in their lives had consequences for their medical treatment. My data also show that among other factors, pension and/or income, insurance scheme(s), and family situation were the three main determinants in cancer care.

A patient's own pension or income determined his or her ability to pay for the part of the medical cost which was not covered by insurance. His or her insurance scheme(s) determined how much of the medical cost was covered and thus how much was left for himself or herself to pay with out-of-pocket money. Unfortunately, insurance is

128

positively associated with pension and income level, and both depend on occupation and residency – urban or rural (as discussed in Chapter Two). Usually, occupational advantage or urban residency translates into a higher pension, higher insurance reimbursement rate and thus more out-of-pocket money but less medical cost to bear. Conversely, occupational disadvantage or rural residence translates into lower pension; lower insurance reimbursement rate, thus less out-of-pocket money but more medical cost borne by individuals. As such, among the patients, retired government officers, engineers, teachers, and bank staff had little complaint about financial burden; their favourable financial situation also allowed them a greater choice of treatment in terms of type, length and quality. Retired workers were financially burdened to varying degrees. The worst-case scenario was that of the peasants': not only did they have no pension and a meagre and unstable income, but also the insurance reimbursement rate was very low.

Further, patients' family situation either cushioned or exaggerated the impact of pension and insurance on their financial situation in relation to medical care, which also had implications for their treatment. For example, a few patients were indeed better off, but felt a heavier weight of financial burden because while seeking medical help, they also had to provide for children or grandchildren. Some impoverished peasants relied entirely on their children for medical care and daily living. But the type of treatment they could get, the length of it and when and where to get it were all dependent on their children's financial status and will to provide for older people. These older people were passive recipients of care that was arranged for them because of their financial disadvantage and subsequent dependence. Indeed, two peasants never received any curative cancer treatment because their children did not have the financial means to arrange that for them. Similarly, in the city, some low-paid workers

also had their care arranged and paid for by their children or spouses. But as their children or spouse were more affluent, they received more medical care for a longer period of time. In extreme cases, this actually led to excessive curative treatment. However, not all low-paid workers in the city were fortunate enough to have support from their children or spouse. Some of them, having lost their jobs or some financial benefits because of their cancer diagnosis, had to borrow money from other people or take up part-time work to continue treatment. In the end, they fell into debt because of medical costs. For others who also had to provide for children while coping with their own illness, the struggle to get financial resources was even more ruthless. As the result of the financial constraint, quite a few patients withdrew from effective treatment (including more affordable TCM) when they could not cope financially.

2. Community life

Beyond health care, patients' lives were intertwined with the lives of all kinds of others who they interacted with in their communities and the broader social milieus: their families, fellow patients, people in their social networks and the public. In this section, I present my findings on how patients' relationships with the above-mentioned others and the broader social environment had impacted on their illness experiences – both positively and negatively, following a description of the forms of "self care" that patients engaged in to restore health and improve quality of life.

2.1 Self care

Patients who had survived cancer for over 5 years, particularly those from the committee, talked about different ways of "self-care" to improve their general health status and quality of life. First, regular physical exercise was highly rated for enhancing overall fitness and mental health, boosting the body's natural defence system and self-restoring capacities, mitigating some symptoms and pain, improving microcirculation, and recovering or maintaining physiological functions. The most popular exercise was Guolin Qigong among the patients from the committee (as discussed in Chapter Four); some of them even regarded it as a complementary or even alternative cure for cancer. Other patients played Taiji or other forms of martial art, danced, walked or hiked in the mountains regularly. Second, proper diet was also recommended by these patients. A "healthy" or "balanced" diet (usually pro-vegetarian diet) was generally thought to be health-enhancing and optimising treatment effect. Besides, some food was believed to have therapeutic effects, e.g. replenishing blood, eliminating toxins in the body, uplifting mood, alleviating some symptoms or pain, and even preventing or curing specific diseases. Whereas, some food was believed to provoke symptoms or pain, even cause diseases, and thus was to be avoided. In addition, pursuing hobbies was believed to be important for living their lives fully and well while fighting cancer. In short, in addition to seeking medical care and adhering to medical regimen(s), it was believed that a healthy life style entailing regular exercise, proper diet, quality sleep, healthy hobbies and some form of work (either it is volunteer work, housework or paid work) was beneficial to patients' physical and mental well-being and contributive to their recovery or remission from cancer. Self-care also involves mental adjustment to the illness and impending death, which will be discussed in Section 3 of this chapter and in Chapter Seven.

2.2 Relating to families

In this study, "families" refers to patients' immediate families including their children and spouse. My data show that the burden of care fell most heavily upon families in China, and therefore, patients' overall well-being, quality of life, and survival time was as much to do with family care as medical care. Nonetheless, patients' accounts in the interviews also reveal that families could be both a source of support and a source of burden to the patients. On the positive side, families provided the patients with the essential support, such as practical, material, financial, emotional and psychological support. For example, they urged the patients to seek medical help. They accompanied the patients throughout the course of their illness from diagnosis, through to treatment and dying and death. They made critical decisions on behalf of the patients – decisions concerning both disclosure and treatment, and other important matters in daily life. They shouldered the burden of daily care day and night, provided for the patients, and gave them emotional and psychological support to cope with the dire situation. When they found it hard to juggle their work, their own family life and care for the patients, at least, they hired a "carer" to look after the patients.

On the negative side, however, families added to patients' pain – physical, financial, practical, psychological, emotional and spiritual. For instance, some patients fell into debt or had to work part-time while coping with the illness because they had to provide for their children or spouse. Broken relationships between a patient and his/her family or among his/her family members, family members' plights and ill health, loss of a beloved family member, and family's absence all added to patients' emotional and psychological pain. Some families required the patients' practical support, for example, housework, farming and child care, which worsened the

132

patients' physical fatigue and symptoms and pain (when overdone), or caused them to delay seeking medical help. Absence of families resulted in some patients' delay in seeking medical help and difficulty in coping with the daily activities of living, housework or farming (which also exacerbated their pain and symptoms). Over-treatment and improper care due to families' over-protection or over-reaction (however good-intentioned), also led to the patients' unnecessary suffering (from symptoms, treatment, loss of control and autonomy etc.). Spiritually, at times, families were the very reason that the patients held on to life, whereas at other times, guilt of burdening families (financially, emotionally, practically) eroded the patients' will to fight cancer and live on.

2.3 Relating to fellow patients

My data reveal that sharing experiences with fellow patients had a profound impact on the patients' lives. This is particularly evident in the case of the committee, which was perceived by the patients to be like "a big family" or "second home", offering an arena for the patients to relate to each other, sustaining a culture of mutual support and "collectively fighting against cancer" while living fully and living well, and promoting a more holistic approach to recovering from cancer (as discussed in Chapter Three). The majority of the patients commented in the interviews that involvement in the committee was a mostly positive experience, and demonstrated that it provided major social support for them. For example, patients provided role models to each other and encouraged and accompanied each other in "the battle with cancer". They taught each other Qigong, Tai Chi or other physical exercises and practised collectively and regularly to enhance overall well-being and facilitate recovery from disease. They engaged in "chat therapy" which was a form of counselling that gave psychological,

emotional and spiritual support. They also undertook other collective activities (e.g. social gatherings, outings, fundraising performances, sports meetings, art festivals, annual meetings to nominate "anti-cancer fighters", "strong man in life", and "anti-cancer stars"); these activities enriched their lives, lifted their spirits, and united them. They shared lessons leant about self-care and medical care, and consulted with each other in decision making. Occasionally they looked after each other when their family members were not available to help. Some devoted themselves to volunteer work in the committee. Others contributed to the committee's public welfare work – to show compassion to and to care for other socially marginalised people or vulnerable people (e.g. drug addicts, prisoners, and older people). The committee also organised a few lectures each month, free of charge, given by invited medical experts in the major hospitals, on prevention of diseases, healthy living and treatment of cancer etc., and published bimonthly newsletters to promote a holistic approach to recovery from cancer.

Nonetheless, I argue that, while the committee had done tremendous good for the involved patients, it also had created a culture of survivorship and denial of death. My data show that death was openly discussed among the patients, and acceptance of impending death was vital for them in coming to terms with cancer. Nonetheless, the end-of-life stage of a fellow patient often triggered the patients' fear for their own death and dying. They told me that they dreaded the process of dying, which, as they had witnessed in fellow patients, was typified by enormous and agonising suffering (from pain and other symptoms), and a deformed body with no self and no dignity. As they were all certain that they would die in the mainstream hospitals as other patients in the committee had died, having little awareness of palliative/end-of-life health care and the idea of "good" dying associated with it, the only choice left for them was to

keep fighting. Subsequently, as they also told me, in the committee, when patients entered relapse or the end-of-life stage, they tended to become silent and even withdraw from social life, feeling that they had lost the battle.

Similarly, in the other two care settings, some patients also talked about how sharing and witnessing other patients' experiences either strengthened them or rendered them more fragile or desperate. Particularly, in the ward, constant exposure to and awareness of other patients' deaths or suffering triggered, for those patients who were conscious, a fear of death and dying, and thus a hope to die to end the fear.

2.4 Relating to the wider community

Patients' social networks usually involved families, friends, schoolmates, colleagues, neighbours, or acquaintances. However, these networks had been built up throughout patients' lives, that is, their life experience or biography before the illness determined what kind of social networks were there for them when they got cancer. My data show that for some patients, people in these networks were sources of medical, practical, financial, emotional or social support. For example, some patients told me they consulted with them for medical decisions. Some borrowed money from them to sustain their daily life and medical treatment. Some took comfort from spending time with them. For other patients, at times, these people influenced them in deleterious ways; for example, when they avoided the patients, treated them with no compassion, or totally disappeared from their lives.

Beyond social networks, the social environment in which patients lived and worked also had an impact on them, both positively and negatively. Patients from rural areas

reported that it was also important to stay in their own neighbourhood or community, that is, in an environment they were familiar with and felt they belonged to. This meant that they could have their usual social involvement and normal daily activities and they believed that without this, their diseases would worsen. In the city, many patients had work-related issues and concerns after a diagnosis of cancer. Some were unfairly or improperly treated at work, some were deprived of entitlement to a salary increase, some lost their jobs, and some did not get due reimbursement for medical costs due to the workplace's financial plight. All this adversely affected the patients' access to medical care, or added to their financial difficulty as well as psychological stress. Conversely, the patients who had jobs (part-time, voluntary or within the home) and had good relationships with colleagues said that they could reinvigorate their spirit in work, enjoy a sense of achievement, self-worth and belonging, and reduce the financial burden for themselves or their families.

The public's attitudes towards the patients also mattered. Many patients from the committee told me that they were shunned by "healthy people" as if they were "floods and beasts" or "plague" when they performed singing or dancing in public. Some told me they were treated as if they were already dying. Some complained: "I felt we were despised as if we had got HIV/AIDS". Some felt treated as "pandas", in other words, overly-protected. All this hurt their feelings and some patients withdrew from socialising with "healthy people" or even from social life. On the other hand, some "healthy people" enjoyed singing and going on outings with the patients and felt positively affected by them. This inspired the patients and made them feel "normal". Some patients felt a need for and enjoyed connecting to their peers, for example, other older people or retirees, but not just other patients, as this reminded them of their other identities rather than their identity as a cancer patient.

In addition, many patients commented that Chinese society nowadays created an environment that also caused them much unease. They complained that the society was "too dark", being overly competitive and materialistic; that it was predominantly money-driven and traditional virtues were not promoted and therefore lost; and that people's morality was low, there was too much falsity around, and corruption was rampant. In sum, according to them, despite the rapid and outstanding economic development, Chinese society lacked spirituality, morality, virtue, love, kindness, compassion and humanity that were essential for reducing social inequality, promoting social justice, and nurturing a social environment that embraced the vulnerable groups including cancer patients. This society, therefore, made the vulnerable more vulnerable.

3. Perceptions of cancer

In the interviews with the patients from the committee and the hospice, both divergent views and shared perceptions about cancer were expressed; and it appeared that how patients understood the nature of their cancer had implications for how they would come to terms with it.

Some patients viewed cancer as a "normal" disease, believing that it was nature's rule or plan for human beings to be infected with a disease at some stage (particularly in an old age), and to die from it. They believed that, as one of those normal diseases

created by nature, cancer had existed since ancient times but with different names. Similarly, some patients viewed it as a "common" disease, as they had seen too many patients with cancer. Some patients had fatalistic views about it, they thought that it was a punishment from or unfair treatment by God, or the will of heaven, so it could not be defied and nothing could be done about it. Some patients viewed it as a "real disease", by that they meant: "cancer doesn't involve moral causes like HIV/AIDs, it is clean and one shouldn't be ashamed of it". On the contrary, some patients viewed it as "strange" or "rare". They couldn't understand why they got it – "it came like a bolt from the blue", they asked if there were other people who got it and if they survived. Some patients were not upset at all because they were unaware of what cancer was about.

Nonetheless, cancer was invariably perceived as "a death sentence" regardless of the stage. Therefore, coming to terms with death or coming to accept death became a must, a prerequisite for mentally adjusting to cancer so as to live with it. However, there seemed to be a paradox in making sense of death among the patients. On the one hand, they were convinced that cancer meant inevitable, impending death, and survival was just a bonus. So they came to accept death from cancer by reasoning that death was nature's rule and plan, it was everyone's fate and final destination which no one could ever escape from. However, they also convinced themselves that, although death was certain to all, it was uncertain when and how one would die even with a cancer diagnosis as there were mystical forces like Hades to decide this. As such, they concluded that, in the light of the certainty and uncertainty of death, one should just focus on living a life until and unless they had already died. On the other hand, they were also influenced by the traditional belief that "it is better to struggle to live on than to die a good death" (as discussed in Chapter Two and frequently quoted by the

patients). Consequently, the paradox seemed to be that they accepted death in order to have peace, so they could focus on living while they were still alive, whereas, they also denied it in struggling to live on.

Cancer was also perceived by most patients as a psychosomatic disease to the extent that their state of mind affected their illness. Some patients believed that their psychological and emotional stress from traumatic life crises had caused their cancer. Some believed that they had a typical "cancer personality" that tended to give themselves excessive stress which then led to cancer. Some believed that their disease was off and on because of the "mental stimulus" (mainly the adverse events concerning themselves or their families). Conversely, it was believed that psychological and emotional balance could facilitate recovery or remission, that is, "the mind does 70% of the curative work and treatment does 30% of the work", "with a good mental attitude and being careful in all respects, one could still fight it off and survive"; or "cancer could be fought off with perseverance". Some patients reported having endured severe physical pain through managing their thoughts, for example, avoiding thinking of it or distracting themselves from it. Conversely, some believed that if their attention was focused on the felt pain, the pain could intensify and even kill them. Some thought that "if one always thinks about cancer, one will get it quickly even if one didn't have it" and "if one gets cancer then fears everyday that he will die, he may really die very soon". This was echoed in a popular saying quoted by a few patients: "one third of cancer patients died from being scared, one third died from being overly treated and only one third survived". As such, patients were aware that negative thoughts and emotions (e.g. anxiety, fear, worry, despair, depression, insecurity, uncertainty etc.), as they could exacerbate cancer, were to be managed and controlled, which appeared to be a big task in the cancer experience. At times, this

became a heavy burden for patients as they could not always manage to be optimistic and stay in a good mood, after all, as they told me, there were many things in their lives that they were not in control of and that were worrisome and troubling. Consequently, some patients seemed to fret not only about the disease itself but also about their worries about the disease.

In addition to death, cancer was perceived as frightening by many because of the intensity and multiplicity of suffering it may entail – the total pain. My data show that, although all of the patients desired life and struggled to live on and push death away, when pain took over, they hoped to die and end it. For almost all of the patients from the hospice, their fear of death was overridden by their fear of physical pain. They told me that when the physical pain was so agonising, all they wanted was to die and nothing else mattered. Most patients also suffered from the side and toxic effects caused by curative treatment, the most unbearable of which was from chemotherapy. Moreover, patients were constantly confronted by uncertainties of all sorts, e.g. uncertainty of relapse, reoccurrence or metastasis of cancer and uncertainty of when they would die and how. They told me that they felt a sense of losing control of their body and their life, and of being trapped forever in the illness, as cancer would never disappear and would always be with them, and as it was no good not to treat it, neither was it good to treat it. As the whole meaning of life was also questioned at this time, they were afflicted by all sorts of negative thoughts and feelings that were heightened under the shadow of death, so much so that some believed that it was anxiety and fear that killed cancer patients. On the other hand, palliative care with the potential to ease their suffering was not conceived of at all, and a good or better death and dying was not something they expressed. Therefore, fear of a living or dying process dominated by suffering was common to all; they were uncertain about continuing to live when

they thought it would entail prolonged suffering. Either living or dying with cancer, or death itself, was dreaded; it seemed like a deadlock to the patients.

4. Discussion

These findings have shown that living with advanced cancer is not a homogeneous experience determined solely by the diagnosis and prognosis of cancer. The patients lived not only with cancer but also chronic or co-morbid conditions. They also had to cope with other difficult life situations such as financial plights, familial problems or social isolation and discrimination, the impact of which may well have been equally detrimental. As described by WHO Europe (2011), contemporary cohorts of older people frequently experience serious and life threatening illness against a backdrop of social isolation, physical or mental impairment, and economic hardship, producing cumulative disadvantage. Cicely Saunders coined the term "total pain" to capture the multi-dimensional suffering cancer patients may experience over their cancer trajectories – emotionally, spiritually and socially – rather than just the body and its manifestations of disease (Clark, 1999). On the other hand, if one understands health from Ewles and Simnett's (1992) perspective, which conceives the concept of health as multi-dimensional – physical, mental, emotional, spiritual, sexual, societal, environmental and social, one comes to understand that the patients differed in their "health resources", regardless of their disease status. Nettleton (1995) sums up something of the complexity of the contributing factors to how illness is experienced as follows:

... responses to illness are not simply determined by either the nature of

biophysical symptoms or individual motivations, but rather are shaped and imbued

by the social, cultural and ideological context of a person's biography. Thus illness

is at once both a very personal and a very public phenomenon.

(p.69)

As such, older people with advanced cancer (even with the same diagnosis and

prognosis) may experience cancer differently, with differing survivorship and dying

trajectories, as shown in this study. Hence, the scale of complexity inherent in the

matter of caring for them, a result of the above-mentioned contributing factors, points

to the need to reconsider palliative/end-of-life care in a broad sense that involves but

is not confined to medical care; that is, to consider all that can be mobilised and

utilised to meet their complex needs and bring about positive changes over the course

of their illness, in order to alleviate their all-inclusive suffering. In the case of China,

as palliative/end-of-life has yet to be established as a medical specialty and become a

viable option in cancer care, palliative/end-of-life care in a broad sense appears to be

an aggregate of the resources that lie in family, health care and the broader

sociocultural milieus, as I will discuss below.

4.1 Family

My data reveal that in China, it is still common for families to act as the gatekeepers

of patients' medical care, playing a dominant role in decision making relating to both

disclosure of diagnosis and prognosis and treatment. In this study, disclosing

diagnosis and prognosis was often not a straightforward matter between doctors and

patients. As long as patients were accompanied by families, doctors would always

disclose the truth to families. Then it was left to families to decide whether or not the truth should be disclosed to patients. Doctors often could not disclose the truth directly to patients without families' agreement. They even had to collude with families in concealing the truth upon families' request. As the result of this disclosure practice, patients' access to information was often indirect or blocked and thus their knowledge of their cancer status was often partial, fuzzy or even non-existent. These findings accord with what is revealed in Zeng et al's (2011) survey of Chinese health professionals' attitude towards information disclosure to cancer patients.

The current practice of disclosure may be attributed to a number of factors, according to Zeng et al (2011). First, the reason that the majority of families strongly object to patients knowing their diagnosis and prognosis is paternalistic. This proved to be true in this study. Zeng et al (2011) argue that family members who insist on non-disclosure are frequently worried that the cancer diagnosis will upset patients and place an unnecessary burden on them at a vulnerable time; and that families will be unable to manage patients' strong emotional responses. Second, Chinese health professionals lack training and therefore skills in communicating bad news. For example, they do not know how to initiate the conversation, how to manage their own and patients' emotions, how to find out how much information a patient already has, and how much information he or she is willing to receive and able to digest. Third, unlike western cultures, where respect for individual autonomy is a central doctrine, in China the principle of beneficence seems to predominate. Like families, health professionals consider it their obligation to promote patients' well-being by maintaining patients' hope even in terminal illness. Finally, some health professionals would rather not tell the truth in order to prevent themselves from being involved in lawsuits, when they judge that it will cause harmful consequences for patients.

What followed is that in this study, medical treatment was often arranged for patients by families regardless of their awareness of diagnosis and prognosis and their capability of making conscious decisions. My data reveal the same trend as found in previous studies (Wang et al, 2004; Chen and Huang, 2010; Zeng et al, 2011) that Chinese doctors give far greater weight to families' preferences than patients'. Therefore, despite the fact that the patient's right to information and autonomous decision-making is protected by law (Ministry of Health, 2002), in reality, this right is not a primary concern in medical practice. On the contrary, my data show that medical care for cancer patients in China is family-centred rather than patient-centred. This is partly due to familism in that Chinese culture still features familism as the core of its value system; legitimately, medical decisions are seen as family decisions in China (as discussed in Chapter Two and Chapter Three). This situation is also likely to be a matter of administrative convenience to secure payment from the patients (Zeng et al, 2011). Obtaining consent for treatment decisions from family members helps to ensure that someone will be responsible for the patient's fees, which is crucial in the current health care system where out-of-pocket payment of medical fees is normal practice. Health professionals protect patients' interests as well as their own, by giving precedence to the wishes of the family. Moreover, my data indicate that loss of independence among patients resulted in their loss of the right to decision-making, particularly under the circumstances in which they were financially dependent on children or their spouse. In addition, health professionals nowadays are under great pressure to avoid medical disputes that may lead to lawsuits with families, as shown in this and Zeng et al' s (2011) study.

It appears that family is an indispensable and inseparable part of a Chinese person's life. Thus, family may also play a decisive role in other aspects of a patient's illness experience as in his or her experience of medical care. As shown in my data, this may work both ways: as a source of support and a source of burden or pain to patients. For the most part, the burden of day-to-day care fell most heavily upon families, in addition to their dominant role in arranging medical care for patients. Families usually undertook the responsibilities of providing personal care and other essential support, such as psychological, emotional, financial and practical support on a daily basis. They also provided meaning for which patients strove to endure their suffering and live on – they were the patients' "spiritual anchors". On the other hand, however, they added to patients' total pain, as patients' lives were inextricably interlinked with theirs. Consequently, I argue that patients' overall well-being, quality of life and survival time is as much to do with their family situation as the medical care they receive. Lack of family support, improper support from family, or family burden can all lead to a patient's unnecessary suffering and potentially even shortened survival time.

4.2 Health care

There is a trend among Chinese cancer patients to undergo excessive curative cancer treatment (western medicine), and for it to be continued until the patient is no longer able to endure the side effects, or is dying at the end of the disease trajectory, as Zhou (2006) and Li et al (2011) revealed. In this study, this phenomenon appeared to be more obvious in the urban areas where medical resources were relatively abundant and individuals had more financial means to access these resources. By contrast, in the rural areas, some patients could not even benefit from necessary and potentially effective curative treatment because medical care was either unavailable or

inaccessible. I argue that the reason for this trend is in part due to a lack of service and awareness of palliative/end-of-life care as an alternative (as I shall discuss in Chapter Six). In addition, it is attributable to families' insistence on "providing the best care possible", which aligns with health professionals' medical tradition of saving and prolonging life at all cost (Zeng et al, 2008), and with their need to generate profit for themselves and for hospitals as in the current health care system, curative treatment is more lucrative than palliative treatment (Li et al, 2011).

According to Zhou (2006) and Li et al (2011), curative cancer treatment, with a minimal positive effect on patients at a late stage of cancer, can cause them extra physical pain, disability and even premature death while putting enormous economic pressure on both the state and families. This also proved to be the case in my study. Most patients reported having suffered from curative treatment. Meanwhile, patients and families shouldered the enormous financial burden incurred by curative treatment, which caused them much "financial pain", particularly when they already lived with other financial disadvantages as the result of their occupation, residency and family situation. Inevitably, this had implications for the medical care patients could receive in terms of quality, quantity and duration, and thus the extent to which they suffered from the disease. Although, in the case of some rural patients, their financial disadvantages actually protected them from the damage of excessive curative treatment and led to them taking up the hospice service, it had, on the other hand, stopped them from taking up potentially effective curative treatment, and had negatively influenced their physical, emotional and psychological status and thus compromising on their positive health. In addition, generally speaking, patients' experiences of seeking medical care were adversely affected by those drawbacks existing in the current health care system (as discussed in Chapter Two). As such,

medical care drawing on western medicine, presents an unfavourable prospect for cancer patients as a predominant approach to cancer care.

My study agrees with other studies that traditional Chinese medicine (TCM) may provide a complementary approach to relieving cancer suffering. The fundamental theoretical framework of TCM was established over 2000 years ago, so it is a long-standing, traditional approach to healing and health in China (NG, 2006). There are two core theories that characterise TCM: holistic perspective and "syndromatic diagnosis" as the basis for treatment formulation (p.196). It is well-acknowledged among the Chinese public that it is better at curing the root of the problem. It has been and will continue to be an essential part of the mainstream health care in China (Xu et al, 2006; WHO, 2011). Also, the government has put it on their agenda to further develop TCM, foster a modern TCM industry, and promote a culture of TCM (WHO, 2008, 2011). The experiences of the patients in this study demonstrate that TCM may generally contribute to enhancing patients' positive health, counteracting the adverse effect of WM curative treatment, as well as mitigating symptoms of the disease. It also has other advantages over WM: 1) it causes little side effect and is safer; 2) it is much cheaper and more affordable; and 3) it is more "dialectic", "holistic", and person-centred. In fact, the clinical practice of cancer care has generated some evidence that the combination of WM and TCM works better than WM or TCM alone in cancer care throughout early stage to advanced stage (Xu and Chen, 2004 ; NG, 2006; Xu et al, 2006 ; Ji et al, 2008). When combined with conventional cancer treatment, it improves efficacy of the treatment, reduces side effects and toxicity, and prevents metastasis. When used for late-stage cancer, it relieves physical pain and symptoms, enhances physical and mental health, and provides a sense of control and continuity of treatment when conventional treatments stop. However, there is limited high-quality

scientific evidence on TCM's effectiveness in cancer care, and hardly any formal documentation of personal experience regarding TCM cancer therapy (Xu et al, 2006). As such, conducting both medical and social research would be crucial for the recognition and dissemination of TCM inside and outside China.

4.3 Sociocultural milieus

As Kellehear (2005) points out, the person that we call "patient" is also a citizen and community member, and therefore has needs more complex and beyond health services for the majority of his or her time over the course of his or her illness. On the other hand, as he puts it:

> As citizens, people are capable of self-help and as, in other stages of life aside from death, are able to call upon and use the resources of support, information and power in their communities.
>
> (p. 21)

Yen and Syme (1999) argue that the social environment we live in, encompassing the groups to which we belong, the neighbourhoods in which we live, the organisations of our workplaces, and the policies we create to order our lives, is associated with disease and mortality risks, independent of individual risk factors, and thus it influences disease pathways. My data is in tune with the arguments of Kellehear, and Yen and Syme, demonstrating that in addition to family and medical care, many other factors located in patients' sociocultural environment can impact on patients' physical and mental well-being, as I shall elaborate below.

It appears that there were at least four basic categories of support that patients got from others in their social networks, that is, emotional support, material support (money, service and goods), information, and companionship. This finding is echoed in Fiori et al's (2006) study. Further, the extent and quality of the support provided by others proved to be critical for patients' coming to terms with cancer and making adjustments physically, mentally, socially and practically, for example, in the case of family members as discussed above. In this study, patients mainly depended on the social networks that had been built up throughout their lives, in other words, their life experiences or biographies before the illness determined what kind of social networks were there for them when they got cancer. Subsequently, how people in their social networks responded to and adapted to their illness had an important impact on how well they coped with the illness. Lawton (2000) and Armstrong-Coster (2004) found in their studies that major life events such as health deterioration could affect people's ability to sustain relationships thus affecting their social networks. As a direct result of their illness, the established social networks could be subject to shifts of power. Lifetime relationships could be suddenly proving difficult and the close relationships with families and friends might prove especially testing. Although my study did not reveal much about how patients' social networks changed or suffered as the result of their illness, it does indicate that patients' relationships with others and their significant others' life circumstances do yield a profound impact on patients' illness experience to the extent that others in their social networks can be both sources of support and sources of pain.

In addition, resources for a healthy life style entailing regular exercise, proper diet, good-quality sleep, the pursuit of hobbies and some form of work (volunteer work, housework or paid work) were also thought to be contributive to patients' recovery or

remission from cancer and their improvement in quality of life (this is when patients are living with cancer but not dying). Conversely, when patients had work-related issues and concerns after a diagnosis of cancer, this adversely affected their access to medical care, added to their financial plight and psychological stress, and reduced their sense of self-worth. Many patients also experienced a stigma attached to cancer, and felt a need to be treated as a "normal" human being, but not to be reduced to nothing but a "cancer patient". They wanted to be included in social life, but not to be avoided, shunned, discriminated, isolated, or overly-protected in the public places. Some patients were very concerned that, with its rapid economic development, Chinese society was in the process of losing the spirituality, morality, virtue, love, kindness, compassion, humanity etc. that were crucial for creating a compassionate social environment wherein social justice was promoted and the vulnerable groups including cancer patients were embraced by society. As such, they felt that they were living in a generally unfavourable society where the vulnerable were made more vulnerable.

Sociocultural discourses relating to cancer may also have a profound impact on cancer patients' illness experiences. In this study, it is evident that how patients came to terms with cancer and how they coped were linked with how they perceived the nature of cancer. Typically, cancer was invariably perceived as "a death sentence" regardless of its stage; thus coming to terms with death became a prerequisite for adapting to the illness, and patients found themselves living in a state of limbo between acceptance and denial of death. It was perceived as a psychosomatic disease with psychological and emotional causation, thus patients were held morally responsible for both causing and curing cancer through their mentality, and this worked both ways: it strengthened them as well as burdened them. It was mystified as a punishment by god, the will of

heaven, or being caused by natural forces, thus patients subscribed to a fatalistic view – to surrender to it. It was also perceived as a ruthless, evil, abominable "enemy" that corrupted a patient's body and thus took away his/her control over life, so knowing the diagnosis might prove to be paralysing to some while stimulating fighting and conquering spirits in others. These findings in my study are similar to those discussed as a mythology of cancer by Sontag (1991), who claims that this mythology of cancer has been developed to cope with it; nonetheless, it often distorts the truth about the illness and isolates patients. Because only negative metaphors and connotations have been ascribed to cancer, it not only creates a stigma, but also materially hinders people from seeking the necessary support. Sontag (1991) is convinced that these metaphors and myths kill. In attempting to demystify the disease and dismantle such myths which exert profoundly damaging consequences for those troubled by the disease, she reduces illness to what it is at its most essential level – nothing more than a disease – in the case of cancer, a malignant tumour caused by the abnormal multiplication of cells. She suggests that disease and illness should not fundamentally define one's identity nor should they ascribe an inner sense of guilt or shame. In the face of such prejudice, society's and each individual's understanding of the disease can indeed combat such metaphors of blame and fear. She concludes:

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

(p.3)

In my study, I also found that in coming to terms with cancer-related death, patients typically drew on contradictory discourses embedded in the most significant religious

151

and philosophical traditions in Chinese culture, such as Confucianism, Buddhism, Taoism and local folklore, as discussed in Chapter Two. The two contradictory views are affirming death as a natural event that is invincible and inescapable so as to be accepted, and pursuing longevity as reflected in a popular Chinese saying: "it is better to struggle to live on than to die a good death". As a consequence, patients lived in a paradox whereby they accepted death in order to have the peace they needed to live on, while denying death in struggling to live on. As patients usually perceived cancer as a psychosomatic disease, they also drew on a predominant discourse among cancer patients that assumes that the mind can influence the body. This discourse is identified by Delvecchio-Good et al (1990) as a discourse of will. It incorporates western concepts of the individual as responsible for his or her own life and the relationship between psyche and soma, suggesting that "if one has enough hope, one may will a change in the course of the disease in the body" (p. 61). As such, it became a moral imperative for patients to be mentally strong or think positively. While this could be beneficial, as shown in my data, it could equally be detrimental when it became a moral oppression (De Raeve, 1997).

In addition to the death metaphor, cancer appeared to be frightening to patients because of the intensity and multiplicity of suffering it entailed – "the total pain" (Saunders 2006, p.87). Fear of a dying process typified or stereotyped by agonising and multifaceted suffering was common to all the patients; this fear even overrode their fear of death: they were not so certain about living on when they thought it would mean prolonged suffering. As such, both living (dying) with cancer and the eventual realisation of death were feared, which was experienced as a deadlock to the patients. This situation demonstrates a desperate need among cancer sufferers for finding relief for their total pain. It also shows a lack of knowledge and awareness of

palliative care, a resort that may help them feel somewhat hopeful and fearless. More importantly, it represents a call for a holistic approach to care that is capable of addressing the complex needs of cancer patients that arise from their "total pain", as "sadly, that are not so easily or readily addressed by palliative systems of health care delivery" (Lawton, 2000).

Summary

In this chapter, I portrayed a picture of the lives of older people with advanced cancer in China. I presented the current situation of care for this group of people to identify both sources of support and sources of suffering in their lives, framing their lived experience in three broad aspects including health care, community life and perceptions of cancer. My findings demonstrate that living with advanced cancer is not a homogeneous experience determined solely by the diagnosis and prognosis of cancer. These older people with advanced cancer lived with "total pain" as the result of their cancer as well as other cumulative disadvantages embedded in their social, cultural and economic circumstances. On the other hand, the same set of the milieus that have bred their suffering also provided sources of support that enabled them to cope with and endure the adversity of living and dying with cancer. Consequently, older people with advanced cancer (even with the same diagnosis and prognosis) may experience cancer differently, and thus may have different survivorship and a dying process, as individuals. In sum, care for this group of people appears to involve an aggregate of the resources that are located in family, health care, and the broader

153

sociocultural environment, against a backdrop of the adverse conditions that are shaped by the same set of milieus. Considering the scale of this complexity inherent in the matter of caring for these people, it is important to reconsider palliative/end-of-life care in a broader sense that includes but is not confined to medical care, and consider everything that can be mobilised and utilised to meet their complex needs and bring about positive changes over the course of their illness in order to alleviate their all-inclusive suffering.

Chapter Six
Specialised End-of-life Health Care

Introduction

In Chapter Five, I explored the status quo of care for older people with advanced cancer in China to identify both sources of support and sources of suffering in their lives. In sum, care for this group of people appeared to involve an aggregate of the resources that were located in family, health care and the broader sociocultural environment. In terms of resources from the health care sector, Chinese cancer patients relied solely, mainly or even excessively on the curative treatments available in mainstream health care. The specialised palliative/end-of-life care, as provided by the hospice and the ward, appeared to be exceptional and marginal, entirely alien from mainstream health care. In this chapter, I present the two distinct models of specialised palliative/end-of-life care (those of the hospice and the ward), focusing on the following aspects: reasons for admission, scope of care, organisation and delivery of care, perceptions about the care, and constraints on the care (in Sections 1 and 2). In the final section (3), I discuss to what extent, the hospice and the ward had adopted the western palliative care philosophy of total care, responding to their local contexts; and to what extent they had met their patients' complex needs at end of life by providing such palliative/end-of-life care.

1. The hospice

The hospice was one of the 32 hospices established under the "National Hospice Service Program" by the Li Ka Shing Foundation, to provide free home-based palliative/end-of-life care for people with advanced cancer who have severe pain and who are impoverished (see Chapter Three). It was affiliated to a prefectural hospital and the only one of its kind in the whole Yunnan Province. In this section, I present my findings from the case study of the hospice, including the following aspects: reasons for admission, scope of care, delivery of care, and constraints on care.

1.1 Reasons for admission

The main reasons for admission to the hospice were uncontrolled cancer pain and poverty (see Chapter Four). According to the director's accounts, cancer in rural patients was usually diagnosed at a late stage when metastasis was already present. Some rural patients even died without their cancer diagnosed. This was due mainly to two factors. First, rural patients usually received medical care in county, township, or village-level health facilities. But these facilities were only capable of treating minor diseases and a lack of necessary equipment and competent staff meant that cancer was often left undiagnosed. Second, most rural patients were poor and thus could hardly afford quality care in cities (see Chapter Five). As a result, it was common among rural patients that the diagnosis was delayed and by the time of diagnosis, life expectancy was short (two years at most among patients served by the hospice).

Subsequently, the patients' pressing need was to relieve their pain that could be overwhelming. The director told me that patients were scared of nothing but living in pain, not even death. But effective pain relief for cancer patients was not available in the local hospitals (See also Chapter Five), nor was it affordable to patients. Indeed, the hospice staff were treated as angels and saviours mainly because they effectively relieved patients' agonising pain.

1.2 Home-based hospice care

My data demonstrate that the hospice aimed to provide family-based hospice care that was person-centred total care for a whole person (see also Chapter Four). This total care included pain relief and symptom control for patients, psychological, spiritual and social support to patients and families, promotion and education of end-of-life care for the public, and bereavement care for families.

According to doctors' accounts and official documents, pain relief followed WHO's three-tier analgesic protocol, involving evaluation of pain status before and after treatment, personalised treatment, and prevention and treatment of side effects. The five patients I studied, who had used the hospice service for varying periods (2 years maximum), reported that they were offered a sufficient amount of narcotic drugs free of charge and their pain was usually under control. But they experienced pain sometimes when they failed to take the drugs on time or at the right dose. For example, illiterate patients could not read the instructions thus more often took the wrong dose or took the medication at the wrong time. Some reduced the dose for fear of drug-resistance. Sometimes they forgot to take it when pain was absent. Some did not get the prescribed drugs on time (see Section 1.3 below).They also suffered from various

side effects of the drugs although their pain was relieved. Nonetheless, the directors claimed that in 80-90 per cent of patients, pain was well controlled.

The responsibilities of day-to-day nursing and personal care for patients totally fell on family members. However, medical staff gave family carers ongoing guidance on the following issues: 1) how to help patients adhere to the medical regimen, 2) how to look after patients, attending to their diet, sleep, turn-over in bed, bed sore, phlegm, safety etc., and 3) how to deal with some minor symptoms and side effects. In this regard, my data indicate that these families were given much more support compared to those who looked after the patients from the committee and the ward. Nonetheless, patients' complicated symptoms or emergent conditions – beyond the hospice's service scope and capability, had to be dealt with in other local health facilities, which were not always possible because the services needed might not be affordable or accessible.

Psychological care (counselling) was offered to both patients and families during home visits or on the phone. As I observed, it was done in a rather informal way, as if it was a chat between friends or relatives, and during which, the staff listened to and tried to address patients' or families' concerns and worries. Particularly, a lot of effort was made in disclosing diagnosis and prognosis, and helping patients come to terms with and prepare for their impending death. The interview data show that families usually insisted on non-disclosure, while patients differed in the extent of awareness, willingness to know and acceptance (see Chapter Five for more discussion). The staff told me that they tried to balance between families' and patients' needs, aiming eventually to disclose the truth. So they took one step at a time and acted with caution and tactically. In principle, disclosure was never done without families' consent, to

avoid lawsuits. This often entailed persistent persuasion to families prior to disclosure to patients. With patients, they always found out first how much patients already knew, whether they wanted to know, if they could accept the truth and if knowing the truth could do them any good. Then they told or implied the truth when patients were prepared, which was followed by a discussion of concerns and worries (e.g. post-mortem arrangements, families affairs etc.). As such, it appears that disclosure was never a one-off business, but was not impossible to the staff either.

According to the director's accounts, the staff also tried to give bad news while sustaining patients' hope (see Chapter Eight). But the staff consciously avoided giving false hope for a cure: they always told patients honestly that they would not cure their cancer, but that they would mainly relieve pain. Instead, they focused on fostering hope beyond cure- for such things as quality of life, freedom from pain, quality of relationships and spiritual elevation. Following disclosure, spiritual care was also provided by attending to patients' religious beliefs, facilitating life review and seeking the meaning of life.

According to the vice director's accounts, social work was provided to meet patients' and families' needs beyond medical care. First, the staff helped patients sustain supportive relationships or mend broken relationships with (particularly) families and other people in their social networks, or in their communities. For example, the staff sometimes held family meetings in the community to help reconcile patients with their families and help them communicate effectively. Second, the hospice organised educative or support-group activities for families. Third, the staff sought out social resources for financial aid and practical support that were available to patients or families. For example, they persuaded a few local governments to subsidise patients

for daily necessities and transportation for fetching medicine. They found for patients or families the information that they needed regarding medical services, job centres or other social services that they might benefit from. In the city where the hospice was headquartered, volunteers offered practical help such as fetching medicine for the patients when their family members were not available to do so, or simply being patients' company when they were alone.

1.3 Service delivery

The above-described hospice care was delivered through outpatient services, home visits and follow-up phone calls. According to official documents, the initial home visits were made within ten working days of patients' registration with the hospice, during which a pair of medical staff – a doctor and a nurse, conducted the initial assessment and prescribed treatment. As I observed, the initial assessment was fairly thorough, compared to that of a medical institution. It was to find out, through physical check-ups and enquiries, about the patient's 1) disease history, 2) pain status and other physical symptoms, 3) impairment of senses and motor function, 4) ability to conduct daily activities of living, 5) condition of diet, urine, faeces, skin, sleep etc., 6) psychological, emotional and spiritual status (particularly awareness and acceptance of diagnosis and death), and 7) social support (this referring mainly to their close kinships). It usually lasted for 30 minutes or longer. It was then followed by the initial treatment: prescription, guidance to families and some counselling.

The staff told me that a follow-up home visit was made once or twice per month to a patient, depending on whether the patient needed it and how far away he or she lived from the hospice. It was shorter, usually for 20 minutes or so, entailing physical

check-ups, evaluation, prescription, guidance and counselling, as I observed. In addition to home visits, a follow-up phone call was made to a patient at least every two weeks, as the staff told me. Also, patients and families called the staff whenever they needed and they also visited the hospice sometimes to get help. Two pairs of medical staff took turns to conduct home visits from Monday to Thursday. In other words, there was always a pair staying in the office for outpatient services while the other pair was conducting home visits. Each Friday, all of the staff worked in the office to provide outpatient services.

1.4 Constraints on service provision

My data reveal that poverty counteracted the hospice's work. First, according to the directors' accounts, narcotic drugs were strictly controlled in the hospice as elsewhere in China. At the beginning, doctors were only allowed to give a prescription for seven days maximum. Also, patients or their families had to go to the prefectural hospital to obtain medication. Although medication was provided free of charge, many patients were so poor that they could not afford to travel frequently to collect the medication. Consequently, some patients did not get prescribed drugs in time, which compromised the effect of pain relief. After negotiation with the hospital, doctors were allowed to give prescriptions for a maximum of 15 days, which meant that families could collect the medication less frequently. Nonetheless, this did not help all of the patients. The hospice had been trying to solve this problem; for example, they convinced a county government to subsidise the poor patients the hospice served (i.e. 1000 yuan- £98 per person per year). But not all local governments attached importance to and supported the hospice's work. In some extremely difficult cases where patients lived too far away from the prefectural hospital and their families were very poor, doctors collected

medication from the hospital on behalf of patients and delivered it to them during home visits. As this was against the rules and potentially doctors would be punished if caught by the national hospice programme, an agreement was made between doctors and families to keep this practice a secret.

Second, some patients could not afford basic food for sustenance, not to mention special diet for cancer patients. A doctor told me that some patients' monthly living cost was 100 yuan (£9.8 approximately), and sometimes a family of 8-9 people had only 200 yuan or so at their disposal. Some families became debt-ridden after patients' treatment; for example, a surgery cost a patient 7000 yuan, while the annual income of the whole family was 2000 – 3000 yuan. The hospice was persuading some local governments to provide subsidies for these patients, as well as trying to get personal donations for them, but efforts were often painstaking and in vain.

Also, the service volume of the hospice was limited by its small scale, particularly in terms of the number of staff. According to official documents, it was required by the national hospice programme that the hospice treat 500-600 patients per year. The staff told me that at the beginning, they served patients living as far as they could reach, even beyond 150 km from the hospice. Then they were exhausted by the workload and travel involved in serving those patients. In the end, they started turning down some patients living beyond 150km, particularly, if the patient was the only one in that area that they could serve. The director defended this by saying that if they focused on serving patients living nearer, giving up on far-away ones, they could guarantee quality and quantity of home visits. On the other hand, she said, it was not possible to recruit more staff in order to serve more patients. This is because, as a department of the prefectural hospital, the hospice was the only one that did not generate any profit

for either the individuals or the hospital, while other departments were all self-sustainable financially. In other words, the hospital invested in the hospice without any return, so the hospice was indeed a financial burden to the hospital. As such, the hospital was not willing to provide more staff due to more costs incurred.

In addition, it appears that the social work provision was weak although it was deemed essential in meeting patients' and families' complex needs beyond medical care. According to the official documents, the social worker should: 1) evaluate and attend to patients' and families' psychological and spiritual pain, 2) help patients build harmonious family and social relationships, 3) organise educative or support-group activities for families, 4) seek out social resources for patients and families to solve their financial and practical problems, 5) recruit, train and manage volunteers, 6) provide support for staff to relief their stress, 7) provide bereavement care for families, and 8) engage in public education and propaganda. Although there was a designated social worker in the hospice, in reality, as my data reveal, the above-mentioned work was shared among the staff including the driver. The problem lies in that the national hospice programme took the lead in developing the social work profession in the hospices it established at a time when social work as an occupation was still new to China. As such, in most hospices, social workers had a background of nursing, medicine or psychology, but no specialised training in social work. Although the programme provided training in social work, generally, social workers lacked competence and experience. Particularly in this hospice, the social worker was too young and inexperienced, not even a licensed nurse. She actually worked as an assistant for doctors and nurses, an apprentice who could not work independently.

What is more, volunteer work was not something people were familiar with and willing to do either. It was hardly possible for the hospice to recruit volunteers among the public, so the head nurse – the vice director, asked for help from the prefectural hospital: volunteers were all newly-hired young nurses working there. At the time of my investigation, there were only eight volunteer nurses, who only served those patients living in the city where the hospice was located.

2. The ward

The ward was an inpatient palliative care ward, a department of a municipal general hospital in the capital city of Yunnan Province – Kunming. It was the first and still the only one of its kind in Yunnan province, which served only the patients who had financial means to pay for its services. In this section, I present my findings from the case study of the ward including reasons for admission, organisation of care and perceptions of end-of-life care.

2.1 Reasons for admission

My interviews with families and doctors reveal a couple of reasons for which patients were hospitalised in the ward. The foremost reason was that they were welcomed and allowed to stay there continuously as long as they wanted, which is not possible in other hospitals. Most patients were taken there by their family members only after they had tried all kinds of treatments in other hospitals, and other hospitals could do

164

no more because they were so ill (they had co-morbidities, terminal illness, multiple-organ failures, dementia etc.) that they were considered to be not treatable – some were directly turned down by other hospitals. Moreover, even if they were accepted and hospitalised in other hospitals, they could only stay for 10 days or so each time, subject to the medical insurance which stipulated the maximum length of a hospital stay (see Chapter Four). As these patients needed continuous medical treatment, they moved frequently between home and hospital, which added to their suffering and their families' care burden.

The second reason was that family caregivers needed respite. These patients had been looked after by their children or spouse for years throughout their disease trajectories. Family caregivers were drained or eventually unable to juggle care for patients, their own family life and their work. Particularly, when patients had messy medical conditions such as cancer, or had a disability that required constant supervision, family caregivers felt inadequate at times falling short of means to help, and thus overly stressed when looking after them at home. Under such circumstances, hospitalising the patients in the ward provided respite care for family caregivers since medical care, nursing care and personal care were all provided by professionals.

The third reason was that patients had pain and symptoms that required timely medical attention, which could not be managed in a nursing home. Families usually sent the patients to the ward in the hope that their pain would be relieved, symptoms controlled, quality of life improved, life prolonged or maintained if possible, and they would not suffer much while dying. In addition, most patients in the ward could be categorised as low or middle income, even with their family members' financial support; and they had become impoverished because of the health care expenditure,

having lived with the disease for a long time. Therefore, some patients and families also expected to save money in the ward. The ward was cost-saving in two main ways. First, the medical treatment focused on palliation and cardiopulmonary resuscitation (CPR), both were cheaper than curative methods. Second, personal care provided by nursing workers was covered by medical insurance whereas, in nursing homes, it was borne by the patients.

2.2 Care organisation

My interview and observational data reveal that the kind of palliative/end-of-life care provided by the ward featured medical treatment, personal care, reduced medical cost and an on-site funeral service. For each patient in the ward, their care team mainly included doctors, nurses, nursing workers (ward-employed or privately-hired), and family members. The ward was staffed with 8 internists, 19 nurses and 22 ward-nursing workers, to serve 45-60 patients. Patients' family members participated in care to varying degrees and in different ways, working with the staff. The staff undertook their tasks of caring for patients basically according to their hierarchical roles and routines defined by the organisation. Families' care usually fit in with the staff's routines. Therefore, these routines also framed and shaped patients' daily routines. Otherwise, how each patient was cared for varied as the result of the ongoing negotiation between formal and informal caregivers and patients themselves. But in the end, it was the families who played a dominant part in care arrangements regardless of patients' capability to articulate needs. In addition, a local funeral company was stationed in the ward to provide post-mortem services which constituted part of the care for both patients and families.

In terms of medial care, according to doctors' accounts and my own observation, usually there were six doctors in the morning, one from 12am to 2pm, five in the afternoon, and one after 5.30pm; but on weekends, there were fewer doctors as the three directors did not work. Each patient had a "doctor in charge" (usually a junior doctor), who was supported by any of the three senior doctors (one director and two vice directors). Every day, at 8.30am, doctors made ward rounds to check patients' situations and then left medical instructions. In addition, they were notified by families or nursing workers at other times to treat patients' sudden onsets of symptoms or give resuscitation. Doctors mainly attended to patients' physical symptoms (palliation and nutrition); other aspects of patient's needs, for example, psychological, emotional, social and spiritual, were only occasionally addressed. When a patient was near death, the standard resuscitation was CPR although some doctors offered families other options, for example, transferring a patient to the ICU (intensive care unit) of the hospital to be resuscitated, or maintaining a patient's life in the ward in addition to CPR. The two vice directors, rather than nurses, were also responsible for treating patients' bedsores. Both patients and families complained that generally, they did not see doctors very often unless patients had a medical condition that needed intensive supervision and treatment. However, as I observed and families commented, doctors did interact with patients and families during their visits, and some of them even provided some forms of emotional and psychological support for them. Their communication style varied, but most of them were kind to patients and families.

Nurses' responsibilities differed depending on what type of work they were assigned to on a particular day by the head nurse, according to the nurses' accounts. "Chief work" included taking doctors' advice, mastering the overall situation of a patient, and

dividing and allocating work to other nurses or nursing workers (it was done in the doctors' office). "Computer work" included recording doctors' advice etc. into the computer system (it was also done in the doctors' office). "Bedside work" included administering intravenous drips and injections, suctioning phlegm, and dispensing drugs etc. in patients' rooms. "Treatment work" included preparing drugs, injection, and drips etc. in the "Treatment Room". Generally, there were eight nurses working every day. Among them, five nurses undertook "bedside work", one undertook "computer work", one undertook "chief work", and another one undertook "treatment work". Therefore, only the five nurses who undertook "bedside work" had direct contact with patients each day. Nurses were also responsible for supervising nursing workers. However, according to my own observation and my conversations with doctors, families and patients, it was not uncommon that nurses made nursing workers help with their "bedside work"; also, they hardly interacted with patients and families when doing "bedside work", not to mention explaining to them what the treatment was for, or spending extra time listening to patients and offering psychological support. Nurses in the ward therefore were perceived to be "invisible nurses" by patients and families.

Ward nursing workers worked under the guidance and supervision of nurses. According to my observation, they mainly provided personal care for patients including tube-feeding or feeding them food and liquid, dealing with their urine and faeces, cleaning and making beds for them, helping them turn over every two hours to prevent bedsores, bathing and dressing them at least twice a day and so on. They also cleaned the whole ward twice a day at 7am and 2pm. In addition, they assisted nurses in doing "bedside work" such as changing drips or oxygen for patients, pulling out the needle after intravenous medication was given, and suctioning phlegm for patients.

After a patient died, they cleaned and dressed up the corpse upon the request of families (families had to pay extra for this service). They also called for nurses or doctors' help when they noticed something unusual about patients. One nursing worker was responsible for cooking for all the nursing workers and patients, and then dispensing food at mealtimes[13]. These nursing workers interacted with patients and families far more frequently than doctors and nurses did. Most of the time while they were doing something for patients, they talked to them or at least called them (if patients were not conscious). They also took time to chat with patients and families, or watched TV or relaxed in patients' rooms when they did not have work to do. My interview data show that some nursing workers were very close to the patients they looked after and provided lots of psychological and emotional support for them.

According to the night-shift workers' accounts, although nursing workers had the same routines regardless of shift, the night shift was more demanding than the day shift. First, many patients slept during the day and were awake thus more active and demanding at night. Night-shift workers therefore, did the same work but more frequently at night, and they also talked more with patients because some patients were scared or lonely and needed comfort or company. Second, there were only four workers each night, working for 50 patients on average, compared to eight workers during the day. Third, during the day, some families also looked after patients, thus they shared the workload of the day-shift nursing workers. Then, most families would leave the ward at 10pm and instruct night-shift nursing workers what to do and what to watch out for before they went home. From my observations I noted that most nursing workers were very kind and close to patients; and they were trusted and appreciated by families as they were families' main support in looking after patients.

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[13] The ward charged patients 200 yuan per month for three dinners per day, which was very cheap, but many families complained that the ward food was not nutritious enough, so they usually brought home-made food to supplement it.

169

Indeed, when patients were abandoned by their families, nursing workers were their main "saviours". Nonetheless, some families told me that some nursing workers prioritised care for the patients whose family members paid them tips secretly. There were also complaints about them being rough in handing patients or ignoring patients when they called for their help, particularly when families were not around. Also, some families were not satisfied with the quality and quantity of care provided by the ward nursing workers, as after all, only a few nursing workers were available to look after many patients. In this case they sometimes hired private nursing workers to look after and stay with the patients day and night.

According to doctors' accounts, patients in the ward usually survived for a maximum of three months on average, although a few had lived here for years and a few died shortly after admission; and more than 90% of patients could not articulate their thoughts and feelings because they were unconscious, frail, or in pain. My data show that level and content of care needed for patients were changing with their disease trajectories, and were dependant on their physical and mental health status, and their ability to do ADLs. Nonetheless, patients' direct involvement in arranging their own care was very rare and limited. Most of them appeared to be passive recipients of care. However, I noted that the very simple or subtle way they reacted to care given to them and any change of their disease and health status might feed back to caregivers' decision making loop. As such, the extent to which they had control over their body (e.g. responding by body-language or utterances) determined the extent to which they could feed back on the care they received and thus potentially influence any care negotiation. Notwithstanding, at times, even when some patients were able to articulate needs, families had the final say and patients' preferences could be totally

ignored. At this stage, these older people were treated as if they were children and therefore deprived of autonomy in the name of protection.

My observational data show that families provided personal care for patients to varying degrees and in different ways, and that such care was negotiated between families, ward nursing workers and/or private nursing workers. Some families relied entirely on private nursing workers to look after patients on a daily basis, and they only paid a visit occasionally. Some children took turns to visit patients; and they shared personal care with the ward nursing workers to the extent that care for patients could be fit into their schedule for work and family life. In this case, families and the ward nursing workers worked as a team. Some families visited patients frequently but provided little personal care for patients; care for patients was left to the ward nursing workers. Some families stayed in the ward with patients all the time and provided all the personal care required with a little support from the ward nursing workers.

Family members of newly-admitted patients had to sign an agreement with doctors about the content of palliative care and resuscitation, according to both doctors' and families' accounts. However, decisions regarding medical treatment on a daily basis were negotiated between families and doctors. I noted that often there were competing interests among families and doctors. Most families would ask for unnecessary treatment as they were keen to fulfil their duties of filial piety. A few would ask for little or no treatment or tests possibly hoping to let the patient (a burden) die as soon as possible. Or they would ask for the cheapest treatment regardless of its effect hoping to save medical costs. But the doctors were often keen to provide the right medical treatment and keep patients alive at least for some time (to feel a sense of achievement). Moreover, according to doctors' complaints, there were trust issues

generally between health professionals and lay people for all sorts of reasons (see Chapter Two); and thus families were either suspicious of doctors' competencies or their motives. For instance, when the effect of a treatment was not up to their expectation, they blamed doctors for "cashing in on them" by dragging the treatment on. Therefore, in the end, despite the doctors' belief that they knew best how to treat patients as medics and their advice should prevail over patients' and families' as in other hospitals, they often compromised and catered to families' preferences for patients' treatment, even when families' requests were unreasonable (e.g. families could reject necessary tests and treatments, ask for insufficient or excessive doses, ask for particular treatments, or change preference for resuscitation). Doctors told me that this compromise was mainly to avoid conflicts and medical disputes with families. Consequently, as my data show, care for patients in the ward seemed to be "family-centred" rather than "patient-centred".

My observational and interview data show that the external funeral company stationed in the ward provided traditional funeral services which were lengthy and complex, including services in the ward and in the cemetery or crematorium. However, I was only able to observe its services in the ward, which included: 1) that funeral workers approached families before or after patients' death to persuade families to use their services and strike a bargain; 2) immediately after patients died and then were cleaned by the nursing workers, they applied all kinds of artefacts (e.g. shroud, accessories, token belongings) to the corpses, and 3) they performed rituals in the ritual room before patients were taken out of the ward. My data indicate that these funeral services had sophisticated cultural underpinnings and served to help families fulfil filial piety (see Chapter Two), build post-mortem bonds, and grieve and cope with death. However, it appears that it was quite unusual that such funeral services were arranged

and provided in a hospital ward. First, the hospital had its own mortuary (as in all the Chinese hospitals) which was for the use of all the departments in the hospital; normally, patients that died in the hospital would be sent to the mortuary, where they were kept until families arranged funerals and then took them to the cemetery or crematory. Second, mortuaries in Chinese hospitals were typically hidden and out of sight; but in the ward, the office and the ritual room of this company were located at the most obvious and central point in the ward. Because of its location, it was impossible to hide deaths from other patients and families in the ward. Besides, as two patients shared a room, it was unavoidable that patients would experience one or more deaths before their own. I argue that death being so highly visible, it served to desensitise people's responses to what was happening, and raised questions about the emotional and spiritual consequences of patients' frequent witnessing or sensing of their fellow patients' deaths before their own (see Chapter Eight for further discussion).

The physical environment of the ward appeared to be no different from a regular ward in a hospital, except that the setting was more basic and frugal. In addition to the problem of death being highly noticeable, the consequence of the ward's spatial arrangement, it was also common that patients and families complained about the physical surroundings and the facilities of the ward not being up to the standard of a normal hospital. For example, pipes were broken in patients' bathroom; therefore bed-bound patients were bathed in bed by nursing workers or families while mobile patients had to go home to take a bath. There was no alarm on the wall beside patients' beds for them to call for help, so patients had to shout at the staff passing by their rooms to get help when alone. Most rooms accommodated two patients (see Appendix 3). In a shared room, patients, families or nursing workers did not always

get along well with each other; this also influenced the quality of patients' lives. The ward was actually inside the outpatient building occupying the whole third floor, which was unusual. The hospital's location was central and thus noisy; while all the other inpatient wards were in the backyard of the hospital which was away from the main street and thus quieter, the ward faced the noisy main street and at the time of my observation, there was also construction work nearby going on day and night that added to the noise level.

2.3 Patients' and families' perceptions of end-of-life care

Patients' family members talked to me about their ambivalent views of end-of-life care. All of them felt strongly that the patients had suffered tremendously and had been living a life that was not meaningful and thus not worth living. By that, they meant that the patients lived passively having lost control of their body and life, were unable to work and contribute to society, and were unable to enjoy life; and that they were a burden to both self and their children as "a living dead man". Therefore, families thought that to prolong their lives was to prolong their suffering, and if they were the patients, they would prefer euthanasia. However, patients' existence was deemed meaningful to families, they were families' psychological and spiritual anchors, and as children, they were also morally held responsible for looking after their parents in all possible ways. As such, they didn't want the patients to die. They felt they could not set free the patients by any means but to "let nature take its course". They also felt that they had to do something to maintain the patients' lives and it was not right to do nothing at all (e.g. withholding artificial hydration and nutrition was thought to be leaving patients to starve to death, and thus a cruelty). As a result, these families all preferred CPR, artificial hydration and nutrition.

The ward was not preferred by any of these families or patients; instead, it was a last resort. Families told me that they felt that they were given up on and rejected by mainstream hospitals. Meanwhile, nursing homes were not capable of handling patients' medical problems, nor were families at home. Families, therefore, were left with no choice but to send the patients here. But what they really had hoped was for the patients to be continuously treated in mainstream hospitals and doctors to do whatever possible and use all available means to treat the patients. As this had become impossible, all the families only expected that the patients' physical pain would be relieved in the ward, and that they would die without much suffering here, or they would get better and their lives would be maintained or prolonged as long as possible. Families commented that by relieving the patients' suffering, the ward was helping them as well. Otherwise, families would be tormented by witnessing the patients' suffering without being able to help.

The ward was perceived to be associated with death. The patients and families commented that it was a hopeless place for patients to "wait to die" or "to be cared for to die" but not to live. The patients and families who had newly moved into the ward, expressed that "it was bloodcurdling" because they were aware that many older people had died in the ward and the patients were staying in the beds where lots of older people had died. So they had to try to "put this fear in the back of their minds". The patients did not appreciate being kept in the ward although they could stay as long as they wanted. They complained that it was a penalty, or that they felt "confined" or abandoned. One of the patients I studied moaned everyday until his death, once he said: "I am moaning everyday as long as I am here. I did not commit any crimes, why am I confined here? I want to go home, please."

2.4 Doctors' perceptions of end-of-life care

Doctors told me that the duty of the ward was to provide palliative/end-of-life care, and their common goals were to: 1) relieve the pain, manage the symptoms and improve the quality of life of patients; 2) to share the families' burden of care thus providing them with respite care; 3) to help families fulfil filial piety, as otherwise, families could only leave patients at home suffering and waiting to die, unable to help much. They commented that the advantages of the ward over other hospitals were the provision of personal care and medical cost saving. My observation reveals that they tended to focus on relieving physical pain and managing physical symptoms, and that they stressed the importance of the personal care provided by nursing workers in improving quality of life for patients.

Although these doctors aimed to provide palliative care, they told me that they felt frustrated when they failed to provide effective treatment to maintain, prolong, or save life. After all, they were trained to "save life at all cost", their sense of self-worth and competency as a doctor was compromised when they failed to do so. As one of the vice directors explained, "the Chinese word for 'doctor' literally means 'treat' and 'live'; it means that if one is treated by a doctor, there is hope for one to live. Most doctors hope their patients can survive at least for some time". I noticed that when the mortality rate was unusually high in the ward, the first thing they did was to check if it was due to their own failures. It seemed acceptable if it was due to patients' extreme conditions or superstitious reasons[14].

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[14] Some doctors said around Ghosts' Festival or Qinmin Festival, there seemed to be more patients dying every year.

It appears from doctors' accounts that disclosure was an awkward matter for them. They told me that they usually found the patients who did not know or understand their terminal diagnosis and prognosis hard to deal with. These patients often had high or unrealistic expectation of treatment hoping for a cure. Initially, their pain and other symptoms were alleviated and they felt better, so they were grateful, but after some time, when they realised that their diseases were not being cured but still progressing, they became frustrated and dissatisfied with doctors. They said that they believed that patients wanted to know the truth so that they could decide what to do themselves; and that they wished that patients had known and accepted the truth, so they could honestly and directly discuss with them what they could expect from treatment realistically: to relieve pain, slow down cancer growth, or prolong life. But in reality, most families did not allow them to tell the truth, so they usually cooperated with families in hiding the truth by telling lies or giving partial information, about which they said they felt "very uncomfortable". On the other hand, they told me that they also did not want to risk hastening a patient's death by telling the truth because, as they had witnessed, some patients did collapse immediately and died much sooner than expected once told the truth, some even committed suicide; whereas some who did not know the truth lived out the dim prognosis. A doctor argued that disclosure was not suitable for all patients by saying the following:

> If one knows about his prognosis but cannot accept it, over the last phase of his life, instead of living to the full and fulfilling his wishes, he would be obsessed with thoughts about his death – how and when etc. – waiting to die. This kind of patient would be hurt the most, would be scared the most – the process of waiting to die is the most unbearable. These patients normally want to die because of unbearable pain.

In terms of hope, what doctors told me about their beliefs and practices appeared to be focused on fostering in patients the hope of living on (see Chapter Eight for further discussion). First, they said that they believed that regardless of knowing the truth or not, everyone hoped for cure and life; that those who had terminal illness could still hope to live for longer, even for just one day more; and that no one really wanted to die unless they had suffered from unbearable pain and could not adjust mentally, so if there was one more day to live, it had to be pain free. Second, they believed that patients usually built their hope on doctors' expertise and entrusted doctors with their lives; that when doctors said to patients: "your disease won't be cured and you won't survive for long", they risked destroying their last hope totally, thus hastening their death. So they thought that doctors should never easily tell a patient this, instead, they should try to give patients hope or strengthen their hope of living on and living well. Third, they believed that they could instil hope in patients by showing them they really cared about them and would try their best to give them the most appropriate and beneficial treatment, or by reminding them of the meaning of life. In practice, this was mostly achieved by directly telling patients, for example: "I will try my best to treat you", "it is not necessary to think of death, you should live one day at a time and try to live well, if you have any pain or discomfort, tell me and I will relieve it for you" ; "we try our best to treat you, rest assured, after some time, you will get better" ; "you live not just for yourself, you live for others too, think about your family members' feelings, they love you, that is why they send you here to be helped"; "you should not be thinking of death, your families come to see you and they are so nice to you, if you die, they will be devastated".

My interview data also show that to varying degrees, these doctors believed that a patient's pain, more or less, was the result of a mixture of problems: physical, relational, financial etc.; and that humans were psychosomatic: one's psychological or emotional status could have effect on his or her physical status and thus treatment outcome including life expectancy. However, as I noted, although most doctors were kind to patients and families in daily interactions, the level of psychological, emotional and spiritual support they provided was inadequate and the scope was limited to issues relating to awareness and acceptance of diagnosis and prognosis, treatment and death. On the other hand, based on my observation, it appeared that doctors who gave more emotional support to patients and families felt less frustrated and more rewarded, whereas doctors who focused mostly on relieving physical pain felt more frustrated, when they failed to provide effective treatment and keep patients alive.

A vice director commented: "it is easier to be a doctor in the ward because patients come with clear diagnosis confirmed by other hospitals, so we only need to give treatment accordingly". On the other hand, the doctors I talked to complained that it was harder to be a doctor there because they had patients with all sorts of diseases which were normally treated in specialised departments or hospitals, thus their work could involve internal medicine, surgery, gynaecology, even paediatrics – basically, they had to be general practitioners. In addition, they also needed to be loving, responsible, caring, patient and empathetic, which they felt was more demanding compared to working in a normal hospital ward. They admitted to me that they still felt emotional pain when the patients they were close to, familiar with, or liked died, and that they could be affected by the families' grief as well, despite the fact that all of them had "been through a lot and had been used to it". The younger doctors told me

that gradually they had learnt to consciously keep emotionally distant from patients in order to protect themselves from having intense feelings of loss, parting and thus grief, and they had decided to "just focus on my role as a doctor".

Nonetheless, in addition to monetary reward (the ward was the most profitable department in the hospital, and therefore the staff's salaries were much higher than those in other departments), most doctors also found their work rewarding in spiritual terms. One doctor said that she had learnt to believe in Buddhism in terms of karma. She thought that she was doing charitable work and good deeds, so she would have good karma, which would also bring good luck to her significant others, so she felt content and secure and peaceful. One said working in the ward to face death and dying of older people had made him grow and mature. Another one felt privileged to be able to care for older people: according to Buddhism or Chinese tradition, she was doing good deeds, so she expected to have good karma – to have a baby soon. Finally, one doctor felt that as a palliative care doctor, it was a reward that he could help reduce patients' and families' pain.

3. Discussion

Over 40 years ago, Dame Cicely Saunders developed the principles of a new clinical approach – palliative care (see Chapter Three); following which, in the global expansion, different countries and continents have begun to adapt aspects of the original palliative philosophy that are most acceptable to their specific contexts and

cultures (Clark et al, 1997; Clark and Seymour, 1999; Saunders, 2006). My study shows that the palliative/end-of-life care provided by the hospice and the ward is the result of such adaptive adoption of the western palliative care philosophy subject to its local contexts.

According to the Economist Intelligence Unit (2010), in many countries, hospice and palliative care movements were founded on a charitable basis. Institutions that specialise in giving palliative/ end-of-life care are often not part of national health care systems, and many rely on volunteer or charitable status. Worldwide, there is a trend or process of integration of palliative care services into mainstream health care services (McNamara, 2001; Economist Intelligence Unit, 2010). However, this is not true in the case of China. The existing specialised palliative/end-of-life care services, such as the hospice and the ward, have emerged initially as part of the Chinese national health care system (see also Chapters Three and Four), although the hospices are partially funded by a charitable organisation – Li Ka Sheng Foundation. As such, both the ward and the hospice were surviving under the constraints imposed by the health care system, although in different ways and to different extents. Other constraints that the hospice and the ward were faced with in service provision were located in the broader sociocultural environment of China (such as those discussed in Chapter Two). Overall, my study suggests that the development of palliative/end-of-life care in China is faced with the same kind of challenges as elsewhere in the world (see Chapter Three), as I shall demonstrate below.

3.1 The hospice

The National Hospice Service Programme [15] set up its model of home-based palliative/end-of-life care based on a western (English) model while taking into consideration the Chinese context. The hospice, as one of the hospices established by the programme, aimed to attend to not just patients' physical needs but also their psychological, spiritual and social needs; and by providing free narcotic drugs, they also satisfied patients' practical and financial needs to some extent. My data demonstrate that the palliative care philosophy of total care (as discussed in Chapter Three) was embraced and enthusiastically practised by those staff who had been well trained by palliative care experts from western countries, Hong Kong and Taiwan. Moreover, though a department of the prefectural hospital, the hospice's funding was of charitable origin (including the part invested by the hospital), and all the services it provided were free of charge for users. This means that unlike other hospital departments, the hospice was not under the pressure to self-finance and generate a profit, and thus the staff's enthusiasm and effort was dedicated to alleviating suffering, as shown in my data. Therefore, I argue that the hospice, with quite a small number of staff and limited funding, but admirably, with the staff's zealous devotion to the cause of relieving total pain, had done its best to serve those extremely vulnerable rural patients in the region.

Despite this, my data reveal two obvious limitations that lie in this model of hospice care. The first limitation concerns the hospice's service coverage. As shown in my study, in rural patients, cancer was usually diagnosed at a late stage when metastasis was already present and pain was overwhelming, mainly due to a lack of health services that were capable, affordable and accessible. Sun (2009) also noted that in rural areas, over 70 per cent of patients had already missed the chance for cure when

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[15] http://www.hospice.com.cn/

182

cancer was diagnosed; and then, due to poverty, most could only "sit there and wait for death". This situation points to a more pressing need for relieving cancer suffering in rural areas. However, the hospice was the only one of its kind in the entire Yunnan Province. My data show that only a handful of extremely poor patients in and around Dehong prefecture could benefit from it (such as those patients in my study); and that in that region alone, the demand for care had far exceeded the supply. Nonetheless, it appears that the current hospice team had reached its full potential; and meanwhile, there was little hope of expansion, mainly due to its fundraising limitations, among other factors. First, there was only one source of charitable funding- from Li Ka Sheng Foundation, which provided limited and fixed funding each year (a million Yuan for each hospice per year). Second, the hospice was a financial burden for the hospital as the only department that was not financially self-sustainable, and thus the hospital was not willing to invest more either. As such, I argue that the current model has little potential in expanding its service coverage; and that in the long run, it even may not be sustainable, lest the hospital or the foundation ceased funding it.

The second limitation is that the quality of the total care that the hospice aimed for was inconsistent among the patients. In terms of medical care, despite the staff's dedication, poverty and geographical isolation stood in the way, compromising the effect of pain relief and hindering the improvement of quality of life because they led to delay in obtaining prescribed medication and lack of basic food for sustenance, among other things. I noted that the hospice's home-based medical care was isolated – not integrated into or backed up by other local health facilities. This meant that, when more serious conditions and emergent situations occurred which were beyond the capabilities of the hospice, patients could still be left to "sit there and wait for death", which was also counteractive to the hospice's efforts. As day-to-day care for patients

(e.g. adherence to medical regimen, personal care, nursing care) totally fell on families with medical staff providing only guidance, the quality of hospice care depended greatly on family support. However, it appears from my data that care for families was insufficient or even rare particularly in areas such as social support and bereavement care (which was hardly mentioned by the staff). Geographical isolation, and staff and funding shortages also made it impossible to pay home-visits at an optimal level, which also had implications for quality and quantity of care. With regard to non-medical care, for example, psychological, social and spiritual support, provision appeared to be patchy. This is mainly attributable to the fact that the social work provision was poor and shared among the staff. Psychological, spiritual and social care became the sideline of the medical staff, competing for time and energy with their main work – medical care. Under the circumstances of high demand and staff shortages, the medical staff were overly-burdened, and thus there was not much room for improvement in the quality of any aspect of total care. Volunteer work was also limited with a small number of volunteer nurses, benefiting only a few people in the city. In the end, the hospice's major contribution appeared to be the provision of free narcotic drugs to relieve severe cancer pain and some counselling for rural patients who, otherwise, would have had little resources for alleviating their suffering. My data therefore point to the fact that the hospice care was insufficient in meeting these rural patients' complex needs at end of life.

These limitations are not surprising considering the current socioeconomic situation in the rural China. The hospice worked against a backdrop of poverty, lack of social welfare (i.e. medical insurance, retirement insurance) and patchy public services (i.e. health care, transportation) (see Chapter Two). Meanwhile, philanthropy (i.e. NGOs, fundraising, donation, volunteer work) and social work were all in their infancy, just

like palliative/end-of-life care itself (Feng, 2009; Sun, 2009; Liu et al, 2011); and therefore, from which hardly any social resources were available for both the hospice and the individual patients. As such, I argue that for the complex needs of these extremely vulnerable rural patients to be met, the hospice care must go hand in hand with poverty relief, development of social welfare, public services and philanthropy.

3.2 The ward

By contrast to the principles of palliative care discussed in Chapter Three, the service of the ward featured: 1) a clinical setting for the terminally ill, chronically ill and dying older people; 2) "a dumping ground" of older people abandoned by the mainstream curative services; 3) medical interventions focused on palliation, nutrition, and CPR, provided by internists; 4) personal care provided by nursing workers and thus respite for families; 5) lower medical cost compared to the mainstream curative services; 6) indifferent and minimal nursing care provided by nurses; 7) family-centred care arrangements leaving patients with little choice or control; and 8) on-site post-mortem services provided by an external funeral company, constituting part of care for both patients and families.

My findings show that the palliative/end-of-life care in the ward was practised within a structural framework of the national health care and the medical insurance systems and in this way, its work was framed and subject to the mainstream curative biomedical model of care. The scope of palliative/end-of-life care provided in the ward was subject to the basic medical insurance scheme (which covered mainly basic medical treatment, nursing care and personal care), and the staff's competency (who generally lacked specialised training in palliative care philosophy), among other

factors (see Chapter Four). The less medical aspects of total care – emotional, psychological, social and spiritual care were not routinized and prioritised, although doctors were aware of how these aspects of care could positively influence patients' physical and mental well-being, treatment outcome and life expectancy. Doctors were still attached to the traditional ethos of "saving life at all cost", which, according to McNamara (2001), underpins the strong philosophical themes of "denial of death" and 'power over death' in medical discourses. They subscribed to a medical discourse of cure and a cultural discourse of familism (e.g. "one lives not just for oneself but also for families") in instilling hope in patients (see Chapter Eight). As in elsewhere in the Chinese health care system, care for patients in the ward appeared to be "family-centred" rather than "patient-centred (see Chapters two, Three and Five). Health professionals were faced with the same kind of structural constraints as prevalent in the whole health care system (as discussed in Chapter Two). Additionally, they encountered new challenges both professionally, psychologically, emotionally and spiritually, working with patients whose impending future was death. But there was no support system for them and they had to cope alone.

I also found that among those who knew about or used the ward's services, it was not uncommon that they regarded the ward as a hopeless place for patients to "wait to die" or "to be cared for to die" but not to live. This finding also supports other studies (Wang et al, 2004; Chen and Huang, 2010). As such, it is not surprising that the patients entering palliative/end-of-life was not a preferred choice but a last resort when other options such as mainstream curative treatment or nursing home care became impossible, as demonstrated in my data. You (2008), Qiu et al (2006) and Zhang (2007) point out that the tradition of filial piety (see Chapters Two and Three) places enormous moral pressure on children to provide the best care possible (as far as

they know and can afford). When palliative/end-of-life care is perceived as giving up on patients and leaving them to wait to die, families are likely to regard it as unfilial and irresponsible to offer their parents this care (Guo et al, 1994; Zhou, 2006). The strong influence of filial piety on families in choosing medical care for patients was also manifested in families' ambivalent views about euthanasia in my study. All families who I interviewed in the ward told me that they would prefer euthanasia for themselves if they were in their parents' shoes; nonetheless, most of them felt a need to do everything possible to at least maintain or prolong their parents' lives when cure was not possible, conforming to filial piety. My study thus highlights how, apparently, this tendency among families to provide for patients as much curative treatment as possible was also attributable to the reality that palliative/end-of-life care has yet to establish its niche in China and subsequently, there was little awareness but much misunderstanding among Chinese people of what palliative care really could do for patients, as supported in other studies (See Wang et al, 2004; Chen and Huang, 2010; Li et al, 2011).

My data indicate that what underpins this unique model of care is, to a great extent, an economic drive: cost saving (for patients and the ward) and more importantly, maximising profit (for both the staff and the ward). Though for patients and families, it was cost-saving in the ward compared to using curative services, extra cost could be incurred: first, for the post-mortem services (e.g. nursing workers cleaning the corpse, and funeral services provided by the external company), and second, for personal care (e.g. tipping ward nursing workers or hiring private nursing workers). Prices for these services were negotiable, and there was also negotiation between families and doctors in treatment decision making that concerned the cost of care. As for the ward, it resembled a business enterprise, which assumed sole responsibility for its own profits

or losses and for sustaining itself financially, with minimal state financial subsidies (see Chapters Two and Four). It was not clear exactly what deals were made between the ward and the funeral company, the medical insurance administrators, the nursing workers, the pharmaceutical companies, and the hospital (the staff and families mentioned these deals, but did not tell me the details), and what other mechanisms were used to control cost and maximise income (these were sensitive issues that I did not manage to uncover). However, the fact is that the ward had managed to be the most profitable department in the hospital and its staff were paid far better than those in other departments (see also Chapter Four). I argue that the ward resembled an economic-marketplace where products of medical and personal care and funeral (cultural) practices were traded between families, health professionals, nursing workers and the funeral company and then consumed by dying and deceased people; and thus it was a microcosm of Chinese society that featured material civilisation and consumerism, and prioritised economic growth more than anything else (Lu and Chen, 2011). Hence, the underpinning economic drive, I argue, must have had implications for the scope, quantity, and quality of care that the ward could provide.

Although my study focused on patients' experiences, it is also obvious from my data that families were in great need of support and care. But the ward's service was not meant to care for families – families were yet included in the unit of palliative care, although providing patients with personal care, attending to their physical pain and relieving their financial burden from medical care provided families with some respite, and some psychological, emotional and financial support. Since its inception over 40 years ago in the UK, palliative care has aimed to care for both patients and families as a unit of care (Forman et al, 2003; Saunders, 2006). However, my study indicates that in the context of China, families have yet to be included in this unit of care (the

hospice meant to do so, but failed). I argue that to provide better care for Chinese patients at the end of life, palliative/end-of-life care in China needs to expand the existing model of care to caring for and supporting families, and to involve families in a constructive way in all aspects of care, as they have the strongest and the most profound influence on patients' illness experience as discussed in Chapter Five.

Summary

In this chapter, I explored two distinct cases of specialised palliative/end-of-life care – the hospice and the ward. I presented the following aspects of the two models of care: reasons for admission, scope of care, organisation and delivery of care, perceptions about the care, and constraints on care. I argue from my data that these services were the last resort after other health resources in mainstream health care had been exhausted; and that they were insufficient in meeting their patients' complex needs at the end of life.

My findings indicate that the hospice, although located in the health care system, of charitable origin and nature, and with a small number of well trained and dedicated staff, had done its utmost to provide the total care for those extremely vulnerable rural patients in the region. Despite this, its service capacity was limited and the quality of its total care was inconsistent. This is mainly attributable to: 1) its organisational context, such as lack of charitable funding sources and collaboration with other local health services, 2) the socioeconomic circumstances in rural China, such as prevalent

poverty, lack of social welfare and patchy public services, and 3) the broader sociocultural context of China, wherein philanthropy, social work and the like were all budding and alien and, therefore, from which hardly any social resources were available for both the hospice and the individual patients.

By contrast with the principles of palliative care discussed in Chapter Three, the features of the ward's services appear to be somewhat odd and irrelevant. A department of an ordinary Chinese hospital, the ward's services were subject to the structural framework of the national health care system and the medical insurance system. Besides, the staff generally lacked specialised training in the western philosophy of palliative care. As a result, my findings show that its work fits in with the mainstream biomedical model of care in the sense that it prioritised and routinized only care for the body, whereas, the concept of total care for a whole person was irrelevant. What is more, what underpins this unique model of care was, to a great extent, an economic drive: cost saving and more importantly, maximising profit, which I argue, must have had implications for the scope, quantity and quality of care that the ward could provide.

In this and the last chapter, I have presented my findings on the current situation of palliative/end-of-life care provision in China. In the next chapter, I turn to the other key theme of my study: hope in terminal illness.

Chapter Seven
Hope in Older People with Advanced Cancer

Introduction

Fromm (1968), Hawthorne and Yurkovich (2004) and Johnson (2007) contend that hope is as essential for human life as water for fish. In western societies, scholars and practitioners from different disciplinary backgrounds have theorised the meaning of hope in terminal illness, as discussed in Chapter Three. Empirical studies highlight the significant role hope plays in terminal illness; for example, it is an indispensable resource for adapting to illness and coping with the anticipation of separation and death (Coward and Reed, 1996). Common themes relating to the meaning of hope have been identified across the existing literature (e.g. Dufault and Martocchio, 1985; Herth, 1990; Hall, 1990; Koopmeiners et al, 1997; Gum and Snyder, 2002; Parker-Oliver, 2002; Felder, 2004; Johnson; 2007), which are used to develop hope-fostering strategies or interventions to improve care for terminally ill patients. However, research into hope in the field of palliative/end-of-life care is a new departure in China as I have demonstrated in Chapter Three. As such, I make sense of hope in the older Chinese people with advanced cancer (patients) in my study by harnessing the relevant hope theories described in Chapter Three and contrasting my findings with those in the existing western literature. In this chapter, first, I discuss two common coping strategies used by the patients: "hope for the best and prepare for the worst"

and "hope to live in the present (live one day at a time), and hope to live each day to the full and happily". Then I explore meanings of hope implied or explicit in patients' accounts that echo those found in the western literature and reflect the specific Chinese context wherein they were located. Finally, I reveal the nature of hope through depicting how patients' hopes – the future implications embedded within these, were linked to their past (biography) and their present life (particularly their illness).

1. Common strategies of coping

All the patients I interviewed either explicitly expressed or else implied a common coping strategy using hope, that is, "hope for the best and prepare for the worst". They spoke about hope in the context of cure, remission and the possibility of prolonging their life, while at the same time acknowledging that they could die at anytime. They went on to talk about making the best of what they had now, which constituted the second common strategy of coping: they hoped to live in the present (live one day at a time), to live each day happily and to the full. The two strategies were complementary to each other and worked hand in hand in helping patients cope proactively with living with dying, as I shall elaborate below.

1.1 Hope for the best and prepare for the worst

Patients explicitly expressed their hope for cure or remission as "the best" they hoped for. This was despite the extent of their awareness of their diagnosis and prognosis and of their suffering. By hoping for cure or remission, they really hoped to go on living (a reprieve from a death otherwise prognosticated or felt), a hope that reflects a finding from studies that were discussed in Chapter Three, that is, that despite a terminal diagnosis, everyone hoped for cure or remission. However, the length of time for which they hoped to survive differed. Some said that they hoped to live for "two years more"; "a few years more"; "as long as possible" or even "a long life" (longevity). Some told me they hoped to live until an important life event had taken place or when they had fulfilled certain responsibilities, as demonstrated by the following quotes:

Guo: I hoped to live to at least Hua Jia [花甲] which means 60 years old at which one becomes an older person and is not a short-lived ghost if one dies...Now I hope to live to when my grandson goes to middle school.

Shui: I hope to live on to see my daughter have a baby.

Lin: I cannot close my eyes unless my youngest daughter is married.

Bin: I really hope that I won't die so I can finish my unfinished business. I have my older and younger generations to care for – my mum and grandchildren.

Li: My strongest hope was to survive in order to bring up my daughter.

As such, these patients were not striving to prolong their physical existence alone, but rather to continue their "life" as a "social experience" or to delay "social death" (Kellehear 2007, p. 237). It appears to me that as long as they could still find meaning in this life, they would not want to end it in spite of the suffering. Their hope for life conveyed their desire to continue meaningful and valued social engagement with

significant others, particularly their families. In other words, they hoped for continued "interpersonal connectedness". My findings also echo those of Eliott and Olver's (2009) study that for the majority of patients, the hope to live longer was tied to specific conditions, typically to be free from pain or at least for any pain to be bearable and to have an acceptable quality of life. Such conditions reflected their desire to be able to engage in meaningful interaction with family, or realise goals that had positive consequences for their family (see also Section 2 of this chapter).

Without exception, patients made it explicit that "the worst" that they were preparing for was death, despite the fact that not all of them had received a prognosis of impending death. This is mainly because cancer was invariably perceived as "a death sentence" regardless of the stage they had reached (see also Chapter Five). Mostly, patients focused on their mental and emotional preparations for death, while some also reported making practical preparations, such as preparing a will, planning the funeral and burial, putting their affairs in order and making other arrangements concerning families and friends. Mental preparation appeared to involve coming to "accept" (or indeed, confront) the prospect of death (as shown in the following quotes), which is the primary task of their mental adjustment to the illness as discussed in Chapter Five.

Guo: At that time [when I just got to know my diagnosis], I just felt that nothing could be done about it. Here I have to talk about my personal views of the life and death issues. In the past, I went to Bai Ma temple to do what the Buddhism calls Zen, which is basically the same as Christianity. It was on the Qian Hu Mountain; the couplet said: "it is to return to be born – it is to die to be born". In Christianity, it is like this as well, it says that it is like this to be born.

Ze: The world consists of all kinds of materials, human beings, plants and animals. There must be a rule. It is the nature's rule to control human population during its reproduction process, no one can defy it. If no one dies, no one gets ill, in the end, there will be no foothold on this earth. Since it is a rule, it is contradictory – life versus death; there must be something that causes death, it is a matter of what, cancer or something else. As it is a rule, no one can defy it, so you have to just accept it, and adapt to it... Yes, there was [high risk of me dying in the surgery], so I had imagined the worst scenario and arranged the things to do with my families. [He laughed] To be honest, since medical examination, then surgery till now, I have been always calm. One should be calm, that one gets ill and eventually dies, is a rule, which no one can defy; it is only a matter of when and how, which you don't know; you should understand this.

In patients' narratives, "acceptance" of death usually came after and in response to their initial reactions towards the cancer diagnosis. These reactions reflect Kübler-Ross' (2009) stages of grief for people facing death (which I discussed in Chapter Three) insofar as denial (no, it cannot be), anger (why me?), and depression (as a result of a past loss and in preparation for impending losses). For example:

Li: I thought that it could not have happened to me. I had never thought it would be me who got this. (Denial)

Shui: At the beginning, I didn't feel and didn't always think it was cancer in my heart. I thought I was not like I would die right away like a typical cancer patient. (Denial)

Yue: I thought that I didn't deserve this at all because I had done many good deeds. (Angry)

Guo: I felt unfairly treated by God. I had lived through so many political movements and had just started to have an easier life. (Angry)

Li: I felt really sad thinking my daughter would be left alone without my care if I had died. (Depression resulting from anticipating forthcoming loss)

Jia (from the committee): I was upset that the artificial excretory broke my normal/intact body my parents gave me. (Depression resulting from a past loss)

Mei: I am in a good mood when I am sleeping because I know nothing. (Depression)

Nonetheless, "acceptance" for these patients differed from Kübler-Ross's (2009) final stage of acceptance of death, in which the dying patient no longer shows fear and despair, or takes interest in worldly affairs, or struggles to survive and clings to hope. On the contrary, they feel peaceful and restful, and in anticipating and welcoming death, they gradually detach from the world and all that they have valued. In contrast, my data reveal a more nuanced negotiation in that patients' acceptance of death was tied to and aligned with "hope for the best", and this hope was indeed their drive: it was active and goal oriented with the intention to struggle and strive to live on. A good example is Li's heroic story of survival. Although she was told that she had less than one year to live, her strong hope to live on had maintained her for 19 years. Her hope to survive in order to bring up her young daughter had driven her to try her

utmost to seek a cure and maintain health, to deal with ongoing financial crises and even to change her "cancer personality", which she believed had caused her cancer. Like Li, many patients were motivated by the hope to act (psychological, physical, social and religious) and directly effect the hoped-for outcome. Indeed, they were energised by their hope to take action directed towards attending to the daily demands of living, expanding or revitalising interests, extending themselves to others, caring for others and altering their personal outlook, which Dufault and Martocchio (1985) define as the behavioural dimension of hope. Therefore, in essence, patients were in the stage of what Kübler-Ross (2009) called "bargaining" in the sense that:

It is really an attempt to postpone; it has to include a prize offered 'for good behaviour,' it also sets a self-imposed 'deadline' (e.g. one more performance, the son's wedding), and it includes an implicit promise that the patient will not ask for more if this one postponement is granted.

(p. 67)

Like those patients in Kübler-Ross' (2009) study, many patients in my study set self-imposed deadlines marked with a life event that they would like to see happening or achieve, such as "I hope to live to when my grandson goes to middle school"; "I hope to live on to see my daughter have a baby"; or "I cannot close my eyes unless my youngest daughter is married". However, the way the patients in my study bargained differed from Kübler-Ross's finding that most bargains were made with God. In bargaining, the patients typically drew on the discourse of will as discussed in Chapter Five. In hoping to buy more time, many of them made conscious efforts to maintain "a good mental attitude", or "a balanced mental attitude", like Ce concluded: "as long as

you have a good mental attitude and you are being careful in all respects, you can still fight it off; it is not uncommon that people with cancer survive".

By a "good" or "balanced" mental attitude patients meant that they tried to maintain both "fighting spirits" (let's hope for the best) and an attitude of acceptance (let's prepare for the worst), that is, they tried to stay simultaneously optimistic and realistic, as Yue, Ce and Ming explained below.

Yue: I deeply feel that it doesn't matter one is ill; the key is how to face it. Are you going to bow down or lift up your head in front of it? I think I should lift up my head when I am confronted with it. I should conquer it. I said [to myself] the worst thing was I could not get better and would die, but it doesn't matter as everyone has to walk this path, it is just a matter of time; so I must keep my mental attitude balanced.

Ce: I thought that once it was diagnosed, I would go and get treatment; I would take it lightly: if it worked that was fine, if it didn't work out, I would take it lightly. As a human being, we are bound to be born and to die sooner or later. If nothing worked, I would calmly accept it.

Ming: Gradually I got to know that if you didn't fight against it, it came to erode you and you just went downhill... you should take things as they come, but must bear in mind you should fight against the disease.

The above quotes reveal that it was not uncommon for patients to vacillate between two mental attitudes that seemed to be cognitively and emotionally dissonant. I would

argue that what kept them going was exactly the fragile balance between the attitude of "holding on to hope" and "accepting the inevitable". While they fought against the current to move on, at times, they also tried to relax into going with the flow, just to regain some momentum because the effort to fight was so exhausting. They tried to maintain control over things within their capabilities, but also learnt to let go of control over what was uncontrollable, in that they were inevitable, uncertain and unexpected aspects of life. In all, "hope for the best and prepare for the worst" was a powerful bargaining strategy, which was geared towards living, not death. It was the way patients coped with living with dying.

Similarly, Back et al (2003) conclude that living with a terminal illness is often marked by profound ambivalence about being a dying person, or vacillation between living and dying, in which patients vacillate between the state of continuing to live and plan and the state of preparing for death. I argue that in the case of the patients in my study, this ambivalence and vacillation could have been further strengthened by the contradicting discourses of death that affirm death as an invincible, and inescapable natural event so as to be accepted calmly, while promoting the pursuit of longevity (as discussed in Chapter Five). As such, Back et al (2003) suggest that although it may seem contradictory, hoping for the best while at the same time preparing for the worst is a useful strategy for conversing with patients with potentially life-limiting illness in clinical consultations, in that using this strategy frames the discussion to include both living and dying. By acknowledging all the possible outcomes, patients and their physicians can expand their medical focus to include disease modifying and symptomatic treatments and attend to underlying psychological, spiritual and existential issues. Thus the physician-patient communication strategies that are based on this approach of hope and preparation can

199

effectively support patients in coping with living with dying. Back et al (2003) also pointed out that there were few data linking hope and preparation to other outcomes; and that although descriptive data indicated the importance of both of these approaches, no studies had examined how supporting hope and preparing for death might affect medical outcomes such as survival, quality of life, symptom management, and quality of death. In my study, patients' narratives suggest that this coping strategy might have contributed to their survival, quality of life and symptom management.

1.2 Hope to live in the present, and to live each day to the full and happily

As discussed in Section 1.1, the strategy of "hope for the best and prepare for the worst" is future-oriented despite terminal illness signalling to patients the potential loss of all future possibilities. This strategy provided them with a sense of purpose or direction, as well as a sense of control when they could still do something towards what they hoped for. In contrast, the second strategy of "hope to live in the present (live one day at a time), and hope to live each day to the full and happily" is relatively present-focused. The employment of the first strategy brought to the fore an awareness of death and thus entailed an acceptance that life could be brought to an end at any time, despite all their efforts to survive. This motivated patients to cherish each moment and each remaining day, in other words, to appreciate life. In essence, what this strategy aimed to achieve was conveyed by the following motto (of the Society for the Promotion of Hospice Care in Hong Kong):

When days cannot be added to life, add life to days.

(Chan and Chow 2006, p. xv)

200

In this sense, living in the present and living to the full was also a way to prepare for the worst, as shown in Yun and Ming's quotes.

Yun: We have got this disease, how can we make long-term plans, we only think as long as we have one day to live, we will live it happily.

Ming: My colleagues, my cadres and my friends all came to visit me and encourage me... they said I should take things as they come and live well even if I have only one minute or one second to live, and should not be unhappy about it. I thought they made sense, then gradually my thoughts changed and my mental attitude was well-adjusted... my biggest hope is to lead well my life in the old age, after all I was sentenced to death already.

In addition to cherishing time still available in preparation for the worst, this strategy also served to help them cope with day-to-day suffering, including anxiety and fear resulting from contemplating the uncertain future. In trying to live to the full or live happily, they did things that they enjoyed doing or found meaningful, things that contributed to their health or recovery, or at least things that temporarily diverted their attention away from pain or other problems on their mind. In this way, they improved the quality of their life and made it somewhat bearable to live in the midst of adversity, as they could take a break and have moments of peace or comfort (as demonstrated in the quotes below). As Dufault and Martocchio (1985) point out, some particular hopes serve as a diversion or respite from stress generated by threats to other particular hopes. The second hope strategy indeed served as a diversion or respite from stress generated by threats to the first strategy. Ultimately, this strategy of living their daily

life to the full and happily also contributed to materialising the best that they hoped for.

> *Guo:* I don't think about tomorrow today. Today, I get up at dawn, I go somewhere to play for fun, and have some nice food; at night I go to bed. By the next morning, I say to myself: "don't think of tomorrow today".

> *Yun:* sometimes I looked around and saw others having more serious disease still fighting against the devil of disease, so mine seemed to be nothing. Therefore in addition to persistent treatment, check-ups, medicine and qigong, as long as I live one day, I will live this day happily – to cast off mental burdens.

> *Dong:* Normally, I am just thinking of eating well, having fun and sleeping well.

> *Shui:* If you want to live on, just let it be and live one day at a time, just like my husband said: "let it be. Live one day at a time, day by day one month passes by, month by month, one year passes by, and you are one year older."[She laughed].

In all, the two strategies fulfil and complement each other. One is aimed at maximising the quantity of one's life while the other at maximising the quality of one's life. My data indicate that it is the first strategy that drives the second one. On the other hand, it is through the concrete realisation of the second strategy in patients' day-to-day living that the first one becomes a reality. Hall (1990) argues that "a large part of living is having a future orientation. In our culture, the present and the future are so interrelated that if one dies, so does the other." (p. 182). This argument is also supported by Randall and Downie (2006). As such, both hoping strategies were

202

indispensable in the patients' lives. Together they give life meaning, direction and an optimistic focus, and, as Duggleby and Wright (2005) state, constitute what is needed to stay engaged in living while shouldering the burden of an uncertain future. Hall (1990) proposes that if people who are terminally ill are given a chance of hope for the future through a relationship with a supportive person or through discovering their own potential for living, they can feel happy, fulfilled and useful. This is true even with the patients whose suffering was very severe, as shown in the case of Shui below.

Shui: My children and my husband counselled me. My son in law was nice to me too, he said: "mum, don't you worry! As long as your disease can be treated, we will sell our house to treat it. But now the problem is that there is no way to treat it, since it is now advanced cancer. Please try to take it lightly! If you want to eat anything, tell me and I will buy it for you. If you feel any pain, don't keep it to yourself and deal with it yourself." I did tell them. Children are nice, as long as I tell them what I want to eat, they buy it for me. Even when the meal was ready but I did not want to eat it, they went to buy what I felt like eating. As my children are so nice to me, I feel it also meaningful to stay alive like this. If I had died, there would be no any meaning at all, so I tried to take it lightly. Sometimes when I had such agonising pain that pain-relief drug would not help, I sat on the floor suffering [She laughed]. I cannot explain clearly, after all, people who have got this kind of disease suffer. In order to stay alive, what else to do except to take it lightly? I thought about some people who had got the kind of disease that they became bed-ridden and needed someone else to look after them. Although I have pain and suffer from it, I can still get up, which is a good thing. Now worrying that my blood vessels might be broken which might cause haemorrhage, I dare not go out to walk. If I really want, I go out for a little while and come back; I dare not

make myself tired. I used to go everywhere before I had broken blood vessels: in the evening, I went out to dance with them; sometimes I went to (…) twice a week and I could climb it up. Now it is not right anymore. I cannot make it to just climb up the stairs; when I go upstairs, I feel out of breath, I just can not bear with it. I think if there is one day to live, I live for one day, if there is one month to live, I live for one month, and what else could I do if I cannot take it lightly? Just to live one day at a time, like others said, if I think of it everyday, I could not even manage to live for one day.

2. Meanings of hope

The two strategies discussed in the previous section are overarching hopes, from which many particular hopes ensued that were rich in meanings unique to each patient that I studied. According to Dufault and Martocchio (1985), "particularised hope" (p. 380), as opposed to "generalised hope" (see Section 3. for detailed discussion), "clarifies, prioritises, and affirms what a hoping person perceives is most important in life" (p. 381). As such, the patients' particular hopes were personalised, as shown in my data. Notwithstanding, their particular hopes share some common themes that reflect their needs for freedom from suffering, improved health services, and support from families and communities. Simultaneously these hopes signal what patients cherished the most, that is, interpersonal connectedness particularly with their families, and what they valued, that is, their social networks or the communities to which they belonged. In the following sections, I explore these hopes in four broad categories.

2.1 Hope for freedom from suffering (see also Section 1.)

Although hope for life was strong and persistent among these patients, they stated that at times they also hoped to die. This was usually when the magnitude of suffering contested their capability to endure it and they felt that they could not find their way out of it. Then they experienced despair or hopelessness. The kind of suffering they referred to in their talks was from physical, psychological, emotional, social and spiritual pain (as discussed in Chapter Five). My data indicated that very often these dimensions of suffering were intertwined. Nonetheless, the most prominent among the patients from the hospice was physical suffering from pain and symptoms, particularly cancer pain. Almost all of them expressed hope to end their lives as a means to end their physical suffering, as shown in the following quotes:

Shui: I hope to be freed from suffering from pain. I am not scared of death or cancer, but the pain.

Mei: When it hurts so much that I cannot stand it, I want to die. If it doesn't hurt, I want to live on.

Jia (from the hospice): Let me die soon, don't let me suffer! If I die sooner, I can be freed. It feels so unbearable, really! It is so hard to live like this.

Gang: I hoped to die right away, it was hard to treat it. I feared that the pain couldn't be controlled which was too much suffering.

Hope to die was also linked to psychological distress, for example, when the patients had the following feelings or thoughts:

Jia (from the committee): I felt so ashamed of the excretory opening.

Liu: I am fretful in my heart all the time about my disease.

Bin: It is extremely hard not to fret about many unfavourable things in my life.

Xi: I will not leave this place [the ward] alive either. I am just waiting to go to the crematorium like others ...... I am not scared of death, but of living to suffer. I hope to die quickly but not to suffer slowly.

In sum, this hope of ending life arose when the hope for comfort and freedom from suffering was no longer conceivable or seriously frustrated. Other studies (e.g. Sullivan, 2003; Johnson, 2007; Maxfield, 2010) also found that hope for comfort, freedom from pain and that one's symptoms would be well managed were salient among terminally ill patients. In my study, a few patients expressed this hope directly, whereas, most of them expressed it (stressed it) in an extreme way by saying that they hoped to die to end suffering, as discussed above. Typically, among those patients whose pain and symptoms were well managed, their hopes became focused on the maintenance of the health status (as the following patients stated). This further demonstrated their firm hope for comfort and freedom from suffering.

Ding: I hope to take good care of myself and maintain health.

Li: I hoped that it wouldn't reoccur after 5-year survival and I would stay well.

Yun: I hope that there will be no more relapses of cancer and related health problems.

Wu: I hope that my physical health won't be influenced and my disease won't be triggered off and on again by my psychological stress.

2.2 Hopes that reflect need for better health services

Most patients expressed the hope that their financial burden would be relieved, and that they would get more financial support to pay for their medical expenses, particularly in terms of medical insurance coverage and reimbursement. Some expressed the hope that doctors would never "give up" on them. By this, they meant that they hoped that doctors would strive to cure their diseases and help them survive if possible, if not possible, at least they would help them get better physically, feel better mentally, and cope better practically. This hope was also reflected in their hopes for improvement in the specific aspects of the health services. For example, some hoped to get adequate information regarding diagnosis, prognosis, coping in daily life, and alternatives of treatment and care. Some expressed hope for types of care currently lacking or inaccessible in the mainstream health care system but for which they felt great need, such as psychological care, postoperative care (for the patients with excretory openings), and general practice. Many expressed or implied a generalised hope that it would be an easier and more convenient process to seek medical help including getting diagnosis and treatment. This was in response to the flaws existing in the whole health care system and infrastructure (as discussed in

Chapter Two). Dong, a retired doctor now a patient himself, reflected on this as follows:

I: The last thing you said is that you felt it inconvenient to get treatment and it was different from the way it worked in your day, could you please explain what exactly you meant by this?

Dong: A couple of days ago, it was reported in the news that in the national health care conference, the central government required to train general practitioners. In our day, doctor-patient relationship was nothing to do with market economy; whereas now, it is involved in market economy. If you look at newspapers, there are lots of ads about medical treatment and how people's health problems can be solved; but it is hard to say to what extent they really can do so; there is no purpose in this but for clinics' and doctors' income, so it has become like this…what I have is one of the so-called "special and chronic diseases" – cancer is classified as a special disease; so we should pay only 20% of the cost of the medicine for it. But, I give you an example, yesterday I went to the 2nd Hospital of Yunnan Province, from which I was just discharged; I gave him the bills for a photo and medicine, but he could not debit my insurance card. It just differs so much! I still have the prescription as I did not get the medicine yesterday; so I have to find someone I know, my acquaintance, to get all these done. It takes so much trouble and it tires me. On the contrary, yesterday, I got TCM prescription, which was worth 100 yuan or so; my insurance card was debited only 20 yuan. There are regulations regarding "special and chronic diseases", but they don't really implement them.

Some current or previous inpatients expressed a firm hope to die at home but not in a hospital ward, when they perceived or were worried that they would die soon. This was attributable to both poor quality care they felt they received in the hospital and their preference for dying at home. For example, a night-shift nursing worker who looked after Fu (in the ward), told me that over the last few days before he died, Fu kept begging everyone who saw to let him go home. But, as Fu's younger son told me after Fu's death, his family had ignored him and at last he died in the ward, having maintained silence without giving his last words to his sons, although he was conscious. The nursing worker and his younger son also told me their speculation that Fu probably had had an intuition that he would die soon and had hoped to go home to die, but that they had all overlooked his need, so he died in resentment. Liu (from the hospice, but was interviewed in a county hospital where she was temporally admitted for treatment) told me that she hoped to stay at home and not to be hospitalised no matter what. She said: "I don't care if I will die at home with no treatment". Xi (in the ward) complained many times to me that he was treated unfairly by the nursing workers, who ignored him when he called them for help with urination, defecation, drinking and the like. So he said: "if I don't go home soon, I will die from being mistreated by nursing workers". He told me he really wanted to go home and die "naturally", without treatment.

2.3 Hopes that concern families (see also Section 1.)

Most patients expressed a firm hope that they would not be too much of a burden to their families. This hope was often translated into their concrete actions and efforts in day-to-day living and materialised in different ways, depending on what they meant

by "burden". The burden could be material, financial, emotional and practical, as demonstrated in the quotes below:

Mei: I have to eat, have to wear clothes, so it will not do if I don't work hard. I have to economise on food and clothes. I have to think of my children.

Lin: If I am sad every day, they will feel uncomfortable at home too. Sometimes, I had pain, but I didn't tell them – I didn't want them to know…I don't tell them for fear that they will be anxious. My older daughter got so anxious. She used to weigh over 45kg, she got so anxious that she lost weight to 40kg these days, so I said how I could tell them?

Lu: Of course we have difficulties as I have been ill for so long. How come they asked me to stay in the hospital but I was not willing to? It is because I had caused my children big financial burden; so I don't ask for anything.

Yue: I cook and wash vegetables etc. I do everything by myself. As long as it is within my ability, I do it by myself… I could not take care of them, I could only look after myself; and if they don't have to worry about me, that is the best thing I can do for them and to show my love for them… now during the holidays, I look after my grandson. As long as I am healthy, I will look after them; if I am not healthy, they have to look after me which will add to their burden.

In addition, in making up for being a burden and in appreciation of families' support, some patients said that they hoped to fulfil their families' wishes. What follows is, as they told me, that they tried to be "cooperative" or "not to disappoint families".

Indeed, McPherson et al's (2007) systematic review has found a growing body of evidence from different countries and cultures to suggest that worry about creating burden to others is a common and troubling concern for people at the end of life. It also suggests that contextual and cultural differences may shape how individuals perceive and deal with the self-perceived burden. According to Lu and Chen (2011), western influence came to China and facilitated the culture change in China at the turn of the 20th century, with the launch of economic reform and open-door policy. As a consequence, the value of "filial piety" is challenged by the increasing sense of individualism and independence. My data reflects this tension in that although filial piety makes it a social norm and morally legitimate for older parents to be totally dependent on their children (see Chapter Two), none of the patients took it for granted, instead, they worried about being burdensome to their families and hoped to relieve this burden for their families one way or another.

For some patients the hope to live on was linked to hoping to fulfil their responsibilities for caring for their families. For example, Li was diagnosed as having terminal renal pelvis and ureter cancer as well as squamous cell cancer in1992, and was told that she would not live out one year. At that time, her daughter was very young; therefore, all that she had hoped for was to survive as long as possible in order to bring up her daughter. Her hope was so single-minded that it had sustained her for 19 years, during which time she fought against cancer, poverty and other difficulties whilst bringing up her daughter. Li told me proudly that she was nominated as "Anti-cancer Star" in the committee and her heroic story inspired many other cancer patients.

Bonding with families enabled some patients to maintain the hope to survive in spite of experiencing extreme physical pain. Shui's physical suffering was the most staggering of all, having had advanced ovarian cancer and multiple metastasises including in her kidney. Over the past six years, as she described to me, she had been suffering from many kinds of bodily pain and discomforts induced by tumours and related treatment (3 surgeries, 19 sessions of chemotherapy and frequent treatment to relieve severe symptoms). She told me that she was horrified by some of her symptoms (see her account below). However, she conveyed how she still hoped to stay alive because her children were very nice to her in both words and deeds, and her families wanted her to live on – "I feel it also meaningful to stay alive like this", she said.

Shui: There is something breaking off which is frightening to me! Because it is cancer, the tumour inside rots and something breaks off and comes out. What breaks off and comes out is scary for me to see: blood, purulence, something rotten and the like; some comes out from my vagina, some from my anus. Those things have to come out, they cannot stay inside anyways, when it was time, they break off...

Some patients hoped to live on to be able to participate in particular meaningful activities with families. For example, Kang's daughter told me she strongly believed that Kang had survived a fatal onset earlier in 2010 and had held on to his life for so long because of his strong hope to see his granddaughter once more. His granddaughter was doing a Master's Degree in Australia and a family reunion was scheduled for later that year to welcome her back and celebrate her success in completing the course.

Some patients' hopes are directed towards their families – for favourable future outcomes to happen to them. For example, Shui said she hoped that her children would take good care of her husband as he never cooked or enjoyed cooking. Wu hoped that his grandson would get a post in the Civil Service and his wife would recover from her ill health. Lin hoped that her third child would marry soon as she had passed the age when most village girls marry. Gang hoped that his children would treat their mother well after he died and his oldest son would have his own house. Similarly, some patients expressed hope for the general well-being of their families, using terms such as "safe and sound", and "a better and smoother life".

Most patients also expressed hope for families' company, attention and love. Liu and Xi told me that they were not afraid of death, but they really hoped that they would not die alone when none of their children were around. Jia (from the hospice) said she hoped that she would not be left alone at home because she felt worse, that is, more lonely and less able to endure the pain. She also hoped that her oldest son, who was working in another city and being treated for many diseases, could come back to accompany her for a few days, so she could set her heart at ease if she were to die.

2.4 Hopes that involve communities

Many patients also expressed hopes of either making a contribution to their communities or getting support from their communities. Most patients from the committee said that they hoped to make a contribution to fellow patients' or other vulnerable or marginalised people's well-being in their remaining years. Specifically, some hoped to work or continue working voluntarily in the committee as

administrative staff or group leaders. Some hoped to continue participating in the committee's charitable undertakings or fundraising activities. Some hoped to reciprocate and support other patients in and through their daily interactions. On the other hand, some patients from the committee said that they hoped to receive or continue to receive support from other patients in the committee through, for example, counselling each other, pursuing hobbies and doing exercise together, and offering each other advice on treatment options.

In addition, some patients from the committee hoped that people who did not have cancer in their communities could really understand cancer patients and treat them in an appropriate way, instead of discriminating against and isolating them, as shown in Ze and Yun's quotes below:

Yun: Some people don't know about this disease and think the disease is terrible: like when we used to practise Qigong here – we walked together in a line, now we walk alone, there was a woman who spit at us; she may have thought we were the most terrible and we were like HIV/AIDS patients... They think that we are terrible and dare not stay with us, even dare not hold our hands worrying we may get them infected. That is why some people keep it private and don't let others know about it... I will feel better if they can treat us properly and understand us. For example, if we go somewhere, they don't avoid us; if we sit together, they don't move away; just treat us a normal way, I will feel better. If they see us and treat us as if we were hornets and walk away immediately, or if they see us standing somewhere, they avoid us, we will feel bad.

Ze: In the art group, we have people who are good at dancing or playing musical instrument. Once we went to a company to perform; at the beginning, we introduced ourselves: "we are from the Luzhou Art Group of Yunnan Red Cross Cancer Rehabilitation Committee; all of the players today are cancer patients." If it were a loving country, with loving people, they would have been moved by us. On the contrary, some people just stood up and left the arena; they said: "oh, they have got cancer!" At that moment, I felt really upset! They treated us cancer patients as if we were floods and beasts; this is their mental attitude... many so-called normal people radiated repulsion, I have met many people like that; not to mention HIV/AIDS, you could imagine how hard it must be for those patients to survive in our country... We did poetry recitation "when I walk toward tomorrow". When we – cancer patients, did this, we were filled with the aspiration for future and for life; but they were not touched at all; on the contrary they just left. Would you feel sad for this? Why are they like this?

Some patients from the hospice had left their own home in a village to stay with their children in a county or city, in order to have easier access to more effective health services. Both these patients and those staying in their home in a village conveyed a firm hope to either return to or remain in their neighbourhood in the countryside, so they could lead a "normal life" in their remaining days in a familiar physical and social environment. Lu even believed that her health would deteriorate without such a familiar environment. Lu had lived in a village that was far beyond the hospice's service coverage. Therefore, to get hospice care, she moved to the city where the hospice was based and stayed at her son's house. Her daughter in law said that Lu felt unsettled at their place and wanted badly to go back home in the countryside. Lu explained that "it is not that I don't want to be here with you. I am just worried if I

stay here, my illness will get worse. I really want to go back home. As an older person, it is better for me to be home."

Thus, as discussed above, the meanings the patients gave to hope echo those that have been found across the existing (mostly nursing) literature in the sense that there is large scope beyond the hope for cure or remission, for patients to engage in life's matters that are meaningful, significant and reachable to them (see Chapter Three). My data also extend that literature in that they reflect the unique Chinese context, for example, in terms of the current health care system, the family relationships of this generation of older people, and their community settings in urban and rural areas. Moreover, they point to the potential sources of hope for patients – those external to them and in their environment, which I will further discuss in Chapter Eight.

3. The nature of hope

According to Dufault and Martocchio (1985), "hope is not a single act but a complex of many thoughts, feelings and actions that change with time. Hope is multidimensional and process-oriented" (p. 380). Moreover, although hope is directed towards a future good, past and present are also involved in the hoping process, and in this sense, hope bridges past, present and the future. In relation to the patients in my study, the capacity to remain hopeful regardless of the intensified suffering, was grounded in their past life experience (their biography), while their specific and variable hopes (that is, their particularised hope as discussed in Section 2) were

216

occasioned by their present life situation, particularly their illness. In the following sections, I will explain how their past and present circumstances came to shape their hoping process.

3.1 Past (Biography) and hope

In their narratives, patients frequently directly or indirectly related their survivorship to their experience of overcoming the plights that they had encountered during the political upheavals (e.g. The Cultural Revolution), in the countryside, or generally in their lives, which were shaped by the particular political context wherein they were born and grew up. They demonstrated that in the many life crises they had lived through, they had gained inner strength and had become extremely resilient and optimistic; and this had enabled them to maintain hopeful and hold on to life over the course of their illness (see the quotes below).

Guo: My personal view is that my own mindset matters. I was a teenager when China was liberated...During the old society, we had had provincial and municipal officers in the family, so [after liberation] we were affected by the political movements very badly, which you cannot understand as you are so young. Since the agrarian reform, I had been affected by the political movements, after which, I felt like a thief who was used to stealing – as I was mistreated many times I became fearless and insensible...... About my spirit, I have to tell you that I am really broad-minded. I have endured so many political movements, during which I was persecuted again and again and ruthlessly, to the point that they worried I would kill myself. But I told them to go to sleep and not to worry about me and

that I would live well and absolutely wouldn't die... So this is my mental attitude, which is determined by the sufferings I went through since young.

Ze: [I never felt despair] Because I treat life like this. I have always been like this. It is to do with my experience, my experience in the face of difficulties or dangers when I was a soldier...I have been always optimistic in my whole life, even before I got cancer. Therefore, by the time I got ill, I was still calm. If you have been always indecisive and just cannot let go of anything, once you are ill, you can feel worse. I have been always so optimistic.

In addition, some of them recounted memories of hopes that had been fulfilled as reasons to be hopeful about new hopes or as reasons not to be hopeless, even if the present hope was not fulfilled in exactly the manner or time frame desired. Some described memories of successful coping that gave them courage to remain hopeful, even if specific hopes seemed unpromising at the time. All in all, my data convey a sense of hopefulness in patients regardless. Such a state in the patients resembles what Dufault and Martocchio (1985) termed "generalised hope" (p. 380), which:

protets against despair when a person is deprived of particular hopes, and preserves or restores the meaningfulness of life – past, present and future – in circumstances of all kinds. It imparts an overall motivation to carry on with life's responsibilities and gives a broad perspective for life and thought that includes flexibility and openness to changing events... Generalised hope is like an intangible umbrella that protects hoping persons by casting a positive glow on life.

(p. 380)

Yedidia and MacGregor (2001) revealed in their study that outlooks on dying among terminally ill patients were thoroughly grounded in patients' frames of reference for giving meaning and consistency to other major events in their lives. They found that their patients demonstrated a striking capacity for coherence, integrating their responses to dying with broader motifs in their life stories. They stressed the importance of the context, that is, the patient's broader biography or narrative, born of a lifetime of experience, in shaping patients' perceptions of dying and giving them authenticity. In my study, it would appear that the specific historical context of this generation of older people (as they described themselves) predisposed them to living with dying in ways Yedidia and MacGregor (2001) termed as endurance motif (triumph of inner strength), coping motif (finding a new balance), and quest motif (seeking meaning in death). I would argue that generations growing up in a different historical context in China would have different ways of coping when confronted with cancer and death. My data also resonate with Hockley's (1993) argument that the futuristic implications of hope are embedded in previous life experiences not only of self but also of others.

3.2 Present (illness) and hope

Patients portrayed their journey through the illness as a journey through multidimensional changes, and subsequently a journey through change in hope. In terms of physical well-being, they described the change they went through as deterioration (even "in the jaws of death"), remission, recovery, relapse, reoccurrence, or spread. In adapting to these physical changes their hope changed too, as in Shui's case. Over her 6-year survival, her physical well-being had changed mainly as the result of disease progression, 3 surgeries and 11 chemotherapies, other medical

219

emergency treatment, and the hospice service. In the meantime, her hope changed from single-minded hope for cure before her 1st surgery, to hope to remove all the metastasis before the 2nd surgery, then to hope to cope better with the shame, inconvenience and embarrassment of using excretory opening, and relieve agonising pain after the 3rd surgery, and in the end, to hope to relieve suffering from all kinds of symptoms particularly frequent haemorrhages from her vagina and anus.

At the time of my investigation, patients from the same setting (organisation) were usually in a similar state of the illness, whereas patients from the different settings were in a contrasting state of the illness. Subsequently, this overall trend was markedly manifested in their hope. For example, nine of the ten patients from the committee were in a state of remission or recovery and had longer survival (7-22 years), so their hopes were focused on enriching life in day-to-day living, maintaining health, and making a contribution to other's lives. By contrast, nine out of ten from the hospice were in a state of deterioration, relapse, reoccurrence, or spread that their hopes were focused on comfort, pain and symptom relief. Three out of the five patients whom I observed in the ward were nearer to death; consequently, their hopes were focused on the company of their family or going home to die.

Following change in their physical well-being, patients also reported living through changes in their close relationships, their financial situation, and their living situation (environment) as well as changes in their functional abilities and independence, their ability to fulfil role expectations, and their ability to be creative and to enjoy or participate in preferred aesthetic recreational and intellectual activities. These changes were also reflected in their particular hopes, as discussed in Section 2.

The nature of hope as variable is well explained by Dufault and Martocchio (1985). They contend that in general, people are able to maintain a hope until they can no longer ground it in reality. At this point they may choose to abandon the hope either temporarily or permanently, revise or modify the original hope, or substitute a new hope. Individuals may retain some weakly grounded hopes as they wait for new evidence to support these hopes; and in the meantime, they may focus on other hopes. In common with my data, Eliott and Olver's (2009) study found that the things that patients hoped for changed throughout the course of their life, over the course of their illness, or even day to day. Particularly, the hope of dying patients shifted from hope centred on cure to one which valued an acceptable death for oneself and the well-being of others. They conclude that hope both reflects and constitutes different stages in life, and hope functions at each stage to maintain engagement with and activity in life, often involving others.

As such, people's hope is bound to change over time, tied to and occasioned by their ever-changing "present life situation". However, among the patients I studied, their present life situation comprised not just their illness, but also other aspects of mundane life that every one has to live with. Also, a diagnosis of cancer does not erase their previous problems; neither does it prevent new problems from occurring in daily life. Indeed, for some patients, cancer was not the predominant problem in their lives. Alongside living with cancer, they went through other life crises, such as loss of a life partner, divorce, witnessing or being involved in their children's plights, and suffering other conditions (e.g. depression), which they perceived to be as traumatic and challenging as (if not more than) their cancer (as Ce, Dong and Jia stated below). This situation implies that in addition to one's biography and the illness, there are

many and varied factors in one's life (both internal and external) that can potentially shape one's hopes, as will be further discussed in Chapter Eight.

Ce: Actually, what I felt the most difficult to get over was my husband's death [he died when Ce was recovering from cancer]. I could say that was the biggest plight in my whole life, although in the past, we went through many political movements... Now my worries are all about my children. I just have to take it lightly. I have three children; none of them is leading a good and smooth life.

Jia (from the committee): While I was recovering [from cancer], my husband had an affair with someone else, so we divorced. This had hurt me so badly that I got depression. I was hospitalised in a mental hospital for three months, over which I had a life as if I was a prisoner. In order to prevent me from committing suicide, they cautiously watched over me. I was feeling like in hell, only wanting to die, but had no any means/tools to kill myself. Later, a psychiatrist in Yunda hospital cured my depression over a five-year period...I felt the experience of depression was more painful than that of cancer.

Dong: The most difficult situation is: there were all sorts of things; and as I am getting older, now I feel myself old, frail, ill and disabled; so I gradually see some real disadvantages.

Summary

In this chapter, I have discussed two common strategies of coping using hope that fulfil and complement each other among the patients I studied. The strategy of "hope for the best and prepare for the worst" aims at maximising the quantity of one's life while the strategy of "hope to live in the present (live one day at a time), and hope to live each day to the full and happily" at maximising the quality of one's life. Both strategies appeared to be indispensable in patients' lives, with one orientated towards the future and another focused on the present. Together they gave life meaning, direction and an optimistic focus, and provided what was needed to stay engaged in living whilst shouldering the burden of an uncertain future.

Ensuing from these two overarching hoping strategies are particular hopes that are rich in meanings unique to each of the patients. The common themes that I found in the patients' particular hopes centred on hope for freedom from suffering and interpersonal connectedness. They echo those that have been found in the existing literature in the sense that there is large scope beyond the hope for cure or remission, for patients to engage in life's matters that are meaningful, significant and reachable to them. Meanwhile, they reflect the unique Chinese context in terms of the current health care system, family relationship of this generation of older people, and their community settings in urban and rural areas.

Hope in its nature is a complex and ever-changing process that bridges one's past, present and the future. The patients being particularly hopeful regardless of the intensified suffering was grounded in their past life experience (their biography), while their variable objects of hope were occasioned by their present life situation, particularly their illness. However, some patients perceived that other life crises were

as traumatic and challenging as (if not more than) living with cancer. This perception implies that in addition to biography and the illness, there are many and varied factors in one's life (both internal and external) that can potentially shape one's hopes. In Chapter Eight, I will explore the complex web of influences of hope or sources of hope external to patients, which are embedded in the particular sociocultural environment – at micro and macro levels or in between, wherein the patients were positioned.

Chapter Eight
Ecology of Hope

Introduction

In Chapter Seven, I explored patients' hope at the end of life in terms of their shared coping strategies through hope, the common themes of the meaning of their specific hopes and the nature of their hope. These findings point to their hope originating from sources residing both inside and outside of them. In this chapter, I go on to analyse key external sources of their hope that emerged from my data, drawing on the theoretical model of the "hierarchical social and cultural ecology of hope", proposed by Feudtner (2005, p. S23). This model portrays the sociocultural ecology of hope originating from someone's inner sources, extending outward to interpersonal relationships, organisations, institutions, industries and to society as a whole, and thus comprising a highly complex system of sources of hope (see Chapter Three). I argue from my data that the key external sources of patients' hope are encompassed in their sociocultural ecology of hope, and I represent some of the ways in which these sources influenced their hoping process. First, I represent some of the ways in which others who were in a relationship with the patients served as sources of hope for them. Second, I reveal how, to a great extent, the specific organisational context (of the ward and the hospice) influenced patients' hope through shaping the type of "hope work" (Perakyla 1991, p. 409) and how it was achieved in the organisation. Finally, I demonstrate other ways in which the macro sociocultural environment might

potentially impact on individual patients' hopes; particularly I analyse how it impacted on patients' hopes directly through normative sociocultural discourses.

1. Others as sources of hope

In Chapter Seven, I explored the meanings of hope in those patients I studied, which highlighted how the objects of their hope were often concerned with others (families, health professionals, fellow patients, friends, and other people in their social networks). Indeed, all-pervasive in what patients told me was the consistent reference to others, and ubiquitous in what I observed was the involvement of others. I argue from my data that this interpersonal relatedness played an essential role and was indispensable to patients' hope. In this section, I will demonstrate some of the ways in which others served as sources of hope for the patients in my study.

According to Dufault and Martocchio (1985), by providing cues or information, others contribute to the hoping persons' reality scanning and understanding of their situations. These contributions shed light not only upon what can be hoped for, but also upon how the hope may be realised. For example, when the hospice staff gave Jia (from the hospice) the initial assessment, she expressed her strong hope to continue with chemotherapies in order to recover. Later, her son and daughter-in-law explained to the hospice staff that she did not know how severe her condition was: she knew it had metastasized to her lung, but she did not know it also reached her bones and because it was at such an advanced stage, chemotherapy would not do her any good. They said

that they dared not tell her the extent of the metastasis for fear that her hope would be completely destroyed. What is more, the interview with Jia revealed that her doctor encouraged her to hope for cure through chemotherapy by exaggerating the effectiveness of the therapy, as the following quote shows:

Jia: The doctor said it would be beyond redemption if cancer cells went into the brain; by then the chemotherapy wouldn't work, nothing would. But as long as cancer cells don't go into the brain, there can be a remedy.

Indeed, my data show that doctors and families were all particularly aware that what they would say to patients would have profound consequences on them, although not all of them were aware of its influence on patients' hope. This is why providing information about diagnosis and prognosis, and treatment options and outcomes, appeared to be challenging and contentious. Take disclosure as an example, almost all families I spoke to preferred non-disclosure, while doctors expressed differing, ambiguous or mixed views (see Chapter Five and Six); and my data neither argue for nor against open disclosure. The crux of the uncertainty around disclosure, I argue, lies in not just information giving but also how the recipient takes in the information, as Jones (2005) explains that what each person considers hopeful will conceivably depend on many and varied factors, such as their psychological make-up and subjective views of human existence.

Other people as potential or actual resources, also contributed to what the patients could hope for and how they might realise their hope. For the most part, patients were dependent on their families and health professionals for physical, practical, financial, emotional, or psychological support. Or they relied on others' actions or responses to

realise their particular hopes or remain hopeful. As such, their hoping process was also influenced by their evaluation or perception of others' capability, willingness, or motivation to give needed support and to facilitate their hope. In other words, their hope was dependent on others' situations, actions, responses, attitudes and so on. For example, Rou had foregone her hope to go to a large hospital in Kunming to get treatment for uterus cancer (which was suggested by the local doctor who diagnosed her cancer) because her two sons were working in Burma and nobody was at home to support her. But when she was introduced to the hospice, her hope for treatment was rekindled, she said:

> Now the policies [of the hospice] are really good, so I also want to give it a go — try to treat my disease. If it works, I can live for two more years; if it doesn't work, there is nothing else to do.

Lu perceived that her children would have no more money to get her curative cancer treatment, and therefore she told the hospice that she only hoped to be freed from the suffering from the pain. Wu strongly hoped that he would be able to maintain his psychological balance so that his cancer would not be triggered again by any "psychological stimulus". But, as he stressed, this depended as much on others as his self-adjustment. He gave many examples in the interview of how others (his wife, grandson, siblings, old friends, students, and other older people who spent leisure time with) had influenced his psychological status. Xi (in the ward) told me how frustrated he was because he really wanted to go home (he meant his fourth daughter's place where he used to live) to spend the last of his days and die naturally without treatment, but that his five children did not agree on this. His fourth daughter explained to me why they could not take him home:

228

His health status is not as bad as other patients here; mainly he cannot walk now...

But if he comes back to my place, my sisters and brothers have to come to my place to look after him when I go to work; then I will look after him when I don't work. I discussed with others about this arrangement, but they said they cannot always come to my place to look after him when I am gone for work for all sorts of reasons, which means he will be left alone sometimes. After all, now he cannot walk anymore, so we cannot decide to let him come home. Deep down, I really want to take him home, but I cannot be with him all the time. He cannot get treatment at home either, not even taking oxygen.

Generally, as my data demonstrate, the presence of caring and loving relationships with others was fundamental to hope in patients. Their hope was fostered and maintained in their love and care for others as well as love and care they received from others. Li is a good example. She told me the following in the interview:

How come I am still alive? Everyone said it is a miracle. I first had symptoms when I was 44. My daughter was very young – she was still in the primary school. I said to myself: "If I die, it is going to be so bad for my daughter, so I must be alive" [She was emotional and sobbed]. This is the hope that has supported me. In addition, my superiors in the factory, workers, and other cadres etc., some of whom I knew, some I did not know at all, all came to visit me. I was most touched by a worker in my workshop, who lived across the street from the hospital... they had given me blood transfusion again; but this time my situation did not improve at all. That was when I started to wonder if I was really doomed, and if so, what about my daughter. [That night] I felt really sad... I was alone feeling really sad

and thinking I must be doomed. At this moment, a child from the room opposite to mine came in with a bowl of soup in her hand. She asked me to drink the fish soup, saying that her mum cooked it just for me. I did not know who her parents were at all. I was so touched! And she started to chat with me, which diverted my attention away. So the two hours before she came was the only time when I felt really sad, then she came to chat; and after she left, two people from my factory came to chat till 11pm that night. Then I decided that as so many people cared about me, both acquaintances and strangers like the child and her parents, I must manage to live, even if it is just for these people who cared about me.

Ming's experience with her husband is another typical example of hope being sustained in mutual care and love. When I asked her to tell me how her husband looked after her, she told me:

His own health status was no good. Like I said, he had heart disease, had surgery and also had high-blood pressure. Under such circumstance, he gave me the best care possible. People say: "a spouse when you are young and a companion when you are old". Our children were too busy at work, so it was only my husband who looked after me. He made me better through daily care. He learnt to look after me: he read about dos and don'ts of cancer patients' diet, and then he did his best to buy the food I could eat and cook it. Like frog, seafood etc., I could hardly smell it when I was receiving chemotherapies... but he made a lot of efforts. He made "three bits" for me – a bit of rice, a bit of soup and a bit of vegetables. At the beginning, I said to him I really could not eat any [because of the smell]. Then I saw he was very sad, as if he was saying: "I worked so hard on this, but you did not accept my affection" [She laughed]. I suddenly realised how hard it must be

for him. He was ill himself, but he went to buy and then cooked the food for me, but I did not want to eat it. I felt I must have let him down, so I closed my eyes, opened my mouth and forced myself to drink the soup…I felt I should not let him down and I must live on.

As such, in relationships with others, it is both giving and taking that give hope. This supports Morse and Doberneck's (1995) claim that hope involves solicitation of mutually supportive relationships. Likewise, Hawthorne and Yurkovich (2004) emphasise an element of reciprocity in hope. According to Cialdini (2001), the norm of reciprocity is a powerful social norm that dictates that we treat others as they have treated us; that is, we should reciprocate in kind the good things done for us, whether it is returning benefits for benefits or concessions for concessions. Indeed, Gouldner (1960) argue that a norm of reciprocity is universal and an important element of culture, although its concrete formulations may vary with time and place. As Westermarck (1908) stated, "to requite a benefit, or to be grateful to him who bestows it, is probably everywhere, at least under certain circumstances, regarded as a duty." (p. 154.)

Specifically, in a caring relationship, others influence the continuation of hope by their affirmation, encouragement and loving support, as well as by their willingness to listen, and to share hopes, associated thoughts and feelings, according to Dufault and Martocchio (1985). My data support this argument, for example, Guo told me:

My daughter kowtowed several times to press me to go to hospital. It was my fault that I had not told her clearly that I would be 60 in one month. In China we have this traditional notion that when one lives to 60 years old, it is a "Hua Jia"[花甲];

231

and that if one lives to Hua Jia and dies, one is not a short-lived ghost – ghosts do not exist, of course. When I told her this, she said that it was fine and I should do things as I hoped to. So I had had the hospitalisation certificate for one month before I went there on May 25th, which was my birthday. We had birthday dinner on the evening of May 24th...the whole family – three children and their spouses and my son's two schoolmates, altogether 8 people. had a dinner together at Xue Cheng restaurant. The next morning, I went to hospital at 6am and stayed.

On the other hand, according to Farran et al (1995), hope is also influenced by another's hope, presence, communications and strength, as shown in Ze and Lin's stories below.

Ze: My son told me it was rectal cancer and it was confirmed. But he said that the likelihood of a cure for rectal cancer was high, owing to the current clinical conditions and the surgical technology. He said the surgery was very likely to succeed, so I must be courageous. What he said was very supportive to me. They were very strong! Of course he was a doctor. Of course they must have felt upset. But in front of me he appeared to be very strong and did not show his anxiety or fear. When everyone in my family accompanied me to outings during the May-day holidays before the surgery, none of them showed their worries or fears about future, they all looked happy. But I knew that in their hearts, they must have felt sad. My family condition was very important to me, the way they affected me was important; I am only one of the factors. When knowing the truth, if I did not fall apart but they already did, it would be all over with me... later, when I met other patients' families in the hospital, I told them: "you must be strong! If you are in

low spirits, you are killing him. At this time, your being strong is more important than him being strong."

Lin: Ah, my disease status, the pain, I really didn't want to live on. When I just came back, I really thought of buying some pills to kill myself [She started to cry]. But thinking of my children, I cooperated with them to get treatment. Let it be! Just live to whatever extent, I don't want to think of it... Then I just thought and thought, ate every day, then at home (...), there was nothing to do. I took TCM, WM and got injection every day, my injection was brought here from Kunming... I had thought that it was really meaningless to live like this. But I went to the hospital, saw lots of people there and they seemed really happy! There was someone who also went to Kunming for treatment like me. She had a huge tumour on her waist; two months after surgery she still couldn't move around. We lived in the same room. We chatted and laughed a lot together; her husband was so funny... [She gave examples of his jokes].

In all, my data demonstrate that hope can be fostered in relationships in many ways, of which I have only represented a few in this section. Hence, I argue that the social network of relationships that a patient is located in is highly pertinent to his or her goal formulation and hope construction. This echoes others' findings (e.g. Dufault and Martocchio, 1985; Herth, 1990; Farran et al, 1995; Hawthorne and Yurkovich, 2004; Johnson, 2007; Eliott and Olver, 2009).

Nonetheless, a relationship does not exist in social isolation or in a cultural vacuum, nor does hope subsequently. For example, reciprocity in relationship is a universal social norm and rooted in all cultures (Westermarck, 1908; Gouldner, 1960; Cialdini,

2001). Filial piety and familism in Chinese culture play a significant role in shaping relationships in Chinese society (see Chapters Two, Three, Five and Six). This is one way that sociocultural environment shapes relationships and thus frames the way hope is constructed. In the next section, I build on this section to explore how the micro sociocultural environment, that is, the organisational context could influence patients' hope, for example, by influencing relationships within the organisation.

2. Organisational hope work

Perakyla (1991) defines "hope work" (p. 409) as a particular type of medical work that leads to either the establishment of hope or its dismantling in a clinical setting. It is usually implicit, nevertheless essential and pervasive in hospital life (Perakyla, 1991; Feudtner, 2005). In this section, I mainly draw on Perakyla's work to explore hope work performed in the ward. Specifically, I represent the type of hope work and some of the ways in which it was achieved in the ward (as opposed to that of Perakyla's), based on my observational data. More importantly, I want to reveal how, to a great extent, the specific organisational context (of the ward and the hospice) I discussed in Chapters Four and Six influenced patients' hope through shaping hope work. To achieve this, I will focus on analysing the relationship between hope work (thus patients' hope) and two main aspects of the complex and multifaceted organisational context, that is, 1) defined and negotiated roles and routines of carers, and 2) the ways the space was used in the management of death and dying.

2.1 Roles and routines and hope work

As I have described in Chapters Four and Six, in the ward, a patient's care team usually comprised doctors, nurses, nursing workers and family members, which became the patient's social network in the ward. The ward had its unique leadership and management style, and had its own mission statement that set the priorities and the major tasks for professionals to achieve. Accordingly, it defined the particular hierarchical roles and routines of professionals for "getting the job done" cooperatively. It also allowed families a certain degree of power to negotiate roles and routines in collaborating with professionals to care for a patient. As a result of this, in this specific organisational context of the ward, patients were located in a particular social network predetermined by the organisation, in which there appeared patterned ways of relating to each other, thus patterned ways of talking and doing things, despite the individual differences and complexity. Particularly, each carer group (doctors, nurses, nursing workers or family members) had its unique and distinct pattern of talking and doing/being with patients informed roughly by its defined and negotiated role and routines; and it was through which that hope work was done, as I will elaborate below.

Doctors' hope work

It appears that doctors tended to engage in hope work more explicitly, and hope work was achieved mainly through verbal communication during their routine and formal presence – when they were doing ward rounds in the morning or handling emergencies at other times. First, they usually colluded with families in hiding the truth by telling lies or giving partial information, in order to maintain patients' hope for cure thus life. Second, they tried to instil hope for life in their patients by showing

them they really cared about them and would try their best to give them the most appropriate and beneficial treatment, or by reminding them of the meaning of life (see Chapter Six). My data show that in practice, this was more often achieved by directly telling patients the following:

Deng (a senior doctor): I will try my best to treat you… it is not necessary to think of death. You should live one day at a time and try to live well. If you have any pain or discomfort, tell me and I will relieve it for you.

Wang (a junior doctor): We try our best to treat you, so rest assured. After some time, you will get better.

Xu (a junior doctor): You live not just for yourself, you live for others too. Think about your family members' feelings. They love you; that is why they send you here to be helped.

Wan (a junior doctor): You should not be thinking of death. Your families come to see you and they are so nice to you. If you die, they will be devastated.

While doctors intentionally tried to instil hope for life in patients, sometimes unintentionally, they dismantled this hope by talking to patients in certain ways – usually in an insensitive or unsympathetic way; for example, when they blamed patients for their own misery. An extreme example is that of a middle-aged female cancer patient who complained to me that when she told a doctor she had vaginal infection, the doctor blamed her for causing the problem herself by failing to wash it on a regular basis. The patient felt very upset because first of all, she had so much

pain that she could hardly move, second, the ward had no bath or shower for patients, and third, she felt it too private for anyone to do it for her.

Doctors also had opportunities to achieve hope work through their professional conduct when administering treatment. For example, the two vice directors (senior doctors) were responsible for treating patients' bedsores (see Chapter Six). The way they did it for patients, as I observed, was very gentle and careful. The message conveyed in this conduct seems that "I understand it hurts, I care, and I really want to help you feel more comfortable, and I am doing it". In this way, they were giving hope for quality of life, and thus hope for life. However, although most doctors were very gentle, careful and skilful when performing check-ups or administering treatment, patients and families complained to me that doctors did not visit patients except for morning ward rounds and emergencies, and that sometimes they could not find the doctors in their office when they needed them. As such, by their rare presence and their focus on physical palliation, they could be seen as dismantling the hope, as some patients complained that they felt insignificant, unsupported and ignored (or even abandoned) in the ward.

The following extract from my field notes described an ideal situation of hope work where a doctor gave hope through both his deeds and words:

> *Hou has throat cancer (he cannot speak at all). His throat was cut open and an iron tube was inserted in the hole to help him breathe, as he could not breathe through nose or mouth. Yesterday, Ma (a senior doctor) found that Hou could not breathe well because the iron tube was not inserted properly into his throat, and the oxygen tube was not properly connected to the iron tube. In addition, Hou's*

wife had asked him to replace the old iron tube with a new one of bigger size. Hou's wife and daughter permitted me to take photos during the treatment. I recorded the interactions between Hou and Ma: Ma would tell Hou what he would do next, how Hou might feel about it, and then comfort Hou before he made the move. Ma handled Hou very carefully, gently and accurately. The treatment was done in ten minutes or so. Once in a while, Hou did "thumbs up" [see Appendix 11 for the image of this gesture] ... When the treatment just started, Hou's daughter stayed in the room; whereas, his wife left the room. Before she left the room, she had said: "I cannot bear to see him suffer from this. Last time in No. 43 Hospital, the doctor cut him open and inserted the tube forcefully and he suffered a lot." Here Ma used local gas. Later his wife came back and stayed to observe the treatment. Ma also explained to his wife how to absorb phlegm using the machine while doing this. When everything was done, Hou struggled to get up. Ma and his wife helped him. He sat for a while and made a few deep breaths to try the new device Ma just fixed for him. Then he stood up and held Ma's hands, tears welling up in his eyes. His wife also went up to hold Ma's hands. Ma reassured them by saying: "don't worry about a thing here. Let me know if you have any problem, I will handle it properly for you." He was trying to leave the room while Hou and his wife were standing there and gesturing "thank you" in a traditional way – palms together and tilt up and down [see Appendix 11 for the image of this gesture]. On the way back to office, he said to Dr. Wang: "you see, this is a minor treatment; but you can solve a big problem for the patient and families, and make their lives much easier."

(Extract from my field notes dated July 28th, 2010)

Nurses' hope work

My data show that nurses in the ward were mostly invisible and when rarely visible, they appeared indifferent, rough and hasty. As described in Chapter Six, every day, there were five nurses who did bedside work thus had direct contact with patients. However, these nurses hardly interacted with patients or families when doing bedside work, nor did they explain to them what the treatment was for, or spend extra time listening to patients and offering psychological and emotional support. There were also complaints from families and patients themselves that when nurses administered treatment, they physically treated patients roughly, in addition to being emotionally distant. What is worse, they shirked their duties by asking nursing workers to do part of their bedside work.

One vice director explained that it was to do with the head nurse (Li)'s management style. Li did not really want to improve nurses' abilities because she felt her position would be threatened if other nurses became better than her; as a result, nurses were lazy and incapable. One junior doctor said it was mainly because nurses were incompetent in communicating with patients and families. Doctors used to tell families and patients something, but then nurses gave contradictory accounts which caused misunderstanding and conflict. An intern nurse told me the main reason was that there were only a few nurses looking after 50 patients on average and also nurses had to do a lot of paper work required by the hospital. Whatever the reason, nurses' physical, interactional and emotional disengagement with patients had left patients neglected and disregarded. Therefore, I argue that paradoxically, while administering medical treatment to save or maintain life, nurses also did the hope work that threatened to dismantle hope in patients.

What is more, according to Hochschild (1983), "emotional labour" is an aspect of caring which can have profound implications for performers of caring roles. This labour requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others. In relation to nursing, it usually requires nurses to care for patients by calming them and appearing reassuring and positive, and to make patients feel cared for and safe (Smith, 1992; Henderson, 2001). Nonetheless, it is obvious that the ward was an unusual case in that this presentation of caring in nurses had been sacrificed. Subsequently, the opportunity of fostering hope in patients in a caring relationship (as discussed in Section 1) was dismissed.

Nursing workers' hope work

As described in Chapter Six, nursing workers (ward employed or privately hired) interacted with patients frequently on a daily basis. My data show that for some patients, nursing workers were more present and available than anyone else including their own families. Their hope work, which I argue is giving hope for life, permeated through their deeds, words and simply, their "being" with patients. For example, when providing personal care, they physically handled patients gently and carefully and talked to them amiably (whether they were conscious or not). When not working, they did not shun patients, instead, they took time to listen to and chat with patients, or simply stayed in patients' rooms watching TV or unwinding.

Some nursing workers were indeed very close to the patients they looked after and had actually provided lots of psychological and emotional support for them (see Chapter Six), for example Zhang, who mostly worked on the night shift, looking after 12 patients or so. One day, when I was talking to Zhang about her work, Fu (a patient she

cared for) cut in and commented: "Doctor Zhang is the nicest. She took good care of me. Every time when I had a problem, she saved me." Zhang corrected: "he meant that I always gave him water at nights, he drank a lot." Zhang reflected on her work and told me the following:

Some patients became very dependent on me. They kept calling me for help; some said "I will be saved, as long as you are on duty". This is because I really walked around and checked on patients on time (every two hours) and changed their diapers or turned them over etc. I got along very well with the patients, particularly conscious ones. If patients are not conscious, I tried my best to look after them. I also talked to unconscious ones; some responded a bit, some didn't at all. Every two hours on night shift, I walked around to deal with urinary and faecal discharges, turn over patients, give water and check on patients etc. In between, some patients called me for help as well. It can be exhausting but I am used to it. I have worked here for three years… Sometimes at night, some older people couldn't fall asleep, so I stayed in their rooms to chat with them till they fell asleep… Patients sometimes told me they wanted to die. I tried to counsel them. For example, one patient said she didn't want to be a burden, and she suffered so much, so she wanted to die. I said to her: "Don't think this way. To struggle to live on is still better than a good death. Other patients suffer more, but they still hold on. Your children are so nice to you; they come to feed you while they are busy with work. If you are alive, it is worthwhile for them because they have someone to call mum". Then the patient cried and said she wouldn't say that again. These patients became dependent on me.

In fact, some patients entirely depended on nursing workers because their own families were mostly or totally absent. For these patients, nursing workers became their families; and it was with them that the patients had their last caring relationship with another human being in this world. For example, when Kang was just admitted to the ward, he was agitated and upset by the severe pain caused by his rectal cancer and metastases. He also had problems swallowing food (was tube fed) and could hardly respond to anything or anyone. Kang's daughter only visited occasionally in the evening. Kang entirely relied on his private nursing worker – Zhao. Beyond everyone's expectation, he had survived for quite long. During my observation, his pain was under control, he could swallow even solid food when he was conscious, and he started to respond to people in simple words. Indeed, he was the only one who got much better, out of the five patients I studied. People who knew about him told me that this was, for the greatest part, attributable to Zhao, who attentively looked after and accompanied him all the time. She even managed to improve Kang's quality of life, with her limited personal resources in the ward. For example, as Kang's condition was improving, he was hungry for normal food. But his daughter hardly came. Zhao therefore got food from other patients' families, such as Xi's family, to feed Kang. The extract below conveys the bond developing between Zhao and Kang:

Around 10.20am, Kang was awake. Zhao was sitting in her chair beside him – at the front of the bed... I asked him if he felt ok today. He nodded immediately. I asked him: "do you have any discomfort?" He said determinedly and loudly with a hoarse voice: "I do". But when I asked him: "where?" He did not respond. He seemed to be thinking; after a while, he closed his eyes. Worker Zhao told me that he was lying in the bed like this for so long that he must be having aches all over. Zhao touched his forehead gently to test his temperature. His eyes were tracing

her again. It is obvious to me that there seemed always something very gentle and warm in his eyes when he fixed his eyes on her while she was doing things for him. ... He slept with his face facing her and head leaned towards her. Every time he looked into her eyes, I felt he had feelings for her, but what were those feelings about? From 1.30pm to 3.30pm, Zhao was sleeping in her chair, so was he in his bed. At 3.30pm, she was bathing him – his lower body exposed.

(Extract from my field notes dated August 9th, 2010))

As demonstrated above, it appears that it is these nursing workers that really treated patients as a whole and living person. In their low-paid, low-ranked and seemingly humble work, they met not just patients' basic physical needs (although basic but essential for life) but also their needs to be accompanied, noticed, heard, helped, understood, respected, remembered, cared about and loved – the essentials of life. Hence, I argue that among all the professional carers in the ward, these nursing workers gave patients the greatest hope for life (in ways discussed in Section 1).

However, according to families and the director, a few nursing workers prioritized care for the patients whose family members paid them secret tips. There were also complaints about them being rough in handing patients or ignoring patients when they called for their help, particularly when families were not around. I argue that behaviours such as these worked to dismantle hope, for example, in Xi's case (see below the extract from my field notes and Xi's daughter's comments).

As I went in, Xi complained that the nursing workers were very bad and mean. He called them many times for help but they ignored him pretending that they did not hear him. He wanted to pee and reached out for the urinal but it fell off the chair.

As he could not get anyone's help, he got off bed himself and picked it up and peed. He thought that they ignored him because he did not pay them tips as others did here. But he did not tell me how he found out that other people paid workers tips when I asked him... In the end, I asked him if he wanted to pee; and he asked me to hand him the urinal, which I did. But I was not sure that he could do that on his own, so I went to look for a nursing worker who could help him. I searched in several rooms and did not find anyone. When I went back to his room, he said he was done. I asked him how to deal with the urine in the urinal; he said that I could pour it into the plastic bucket under the bed, so I did it. Then I noticed that his bed was soaked by urine; I asked him what to do; he asked me to leave it as it is. I did not know what to do, but I know he would feel bad sleeping on wet bedding, so I went to look for a nursing worker again. Eventually I found one just in the room opposite, who was dozing. She came to take away the wet paper under his bottom; the bedding under the paper was wet also. She then wiped the part around his penis and put new paper above the wet bedding and under his bottom. While she was doing this, Xi asked her why they did not come to help him when he called them. She said that she did not hear him. Later in the dining room, I was chatting with a vice director when the nursing worker came in to get water. So I asked her if Xi scolded her a while ago. She said he did not, even if he did, she would not take it seriously. ...The vice director then said to the nursing worker that she should go check on him more often in case he would fall and get hurt (Xi couldn't walk), and admitted to me that Xi was a bit bad-tempered. After the nursing worker left, he told me that Xi was troublesome but the nursing workers can also be lazy and slippery.

(Extract from my field notes dated August 23rd, 2010)

Xi's youngest daughter: We cannot trust nursing workers here. I found that nursing workers didn't even feed him water for a few days... A nursing worker connected urine tube to his penis, but they tied it so tight that his penis swelled, so we took it away and bought him diapers. But nursing workers didn't change diapers as often as needed, so he had to wear soaked ones for quite long. My sister once found the diapers stank and leaked because he had worn it for too long... Xi cried that if he didn't go home soon, he would die from being mistreated by nursing workers. Although Xi is fussy himself, I have seen that patients whose families paid nursing workers tips were also treated roughly when the families were absent – but when families were about to come, they did some face-work to show families that they were taking good care of the patients.

Families' hope work

Families directly or indirectly (e.g. through doctors) controlled the information given to patients regarding diagnosis and prognosis (see Chapter Five and Six). In this way, hope work was done to maintain patients' hope for cure thus life. Families shared personal care with nursing workers to varying degrees along the continuum between doing nothing (e.g. Xian's four children) and doing everything (e.g. Hou's wife). Therefore, their hope work was done in ways similar to those of nursing workers – through words, deeds and "being" with patients (as discussed above). In addition, families did hope work through: 1) decision making, 2) frequency and length of visit, and 3) food serving.

As families were usually decision makers regarding patients' medical care and other aspects of their lives (see Chapters Two, Three, Five and Six), I argue that their decisions had potential either to validate, maintain and facilitate the realisation of

patients' hope or to frustrate, dismantle and nullify patients' hope. For example, Fu's son and Zhang (the ward nursing worker who looked after Fu) reflected after Fu's death that Fu probably had had intuition that he would die soon, so he had kept asking everyone he saw to take him home over the last few days before his death; and that as this strong and last hope of his was denied by his family, Fu died in the ward in resentful silence. Xi also hoped to go home, but his children could not manage care at home and therefore his hope was not going to be realised either. Hou's wife always had her own ideas regarding his treatment, even doctors had to compromise sometimes. When she made decisions against Hou's hopes, Hou struggled to negotiate with her with body language and through strong emotional responses (he could not talk), but he did not always succeed.

Frequency and length of families' visits did matter. For example, even though Xian's four children did not actually provide much personal care, by their frequent and long visits, they wanted to show their love for and care about Xian, as Xiang's daughter told me in the interview. In this way, they also instilled hope for life in Xian (who was mostly conscious) by their loving presence and company. Conversely, there were patients in the ward who hardly had any family visitors; these patients felt abandoned, lonely, humiliated, and thus hopeless and dead, according to some nursing workers.

In addition to information control, personal care, decision-making and accompaniment, serving food and drink appeared to be a very important way, sometimes the only way (when patients could not express themselves for whatever reason), to communicate and instil hope for life in patients. Komaromy (2005b) argues that food and drink not only sustain the "natural" living body but also are cultural symbols of life. In her study of care homes for older people, she found that food and drink were media through

which residents could acquire membership to "living" status; taking part in meals, through eating or being fed, brought together the biological and symbolic act of "living". In my study, by taking food and drink, patients both communicated and realised their hope to stay alive, and by giving food and drink, families communicated, reinforced and facilitated the realisation of that hope. This is demonstrated in the following quotes from a senior doctor and Xian' daughter:

Xian's daughter: I believe that she has had strong desire to keep alive because when family members told her: "you should eat, so you can have strength to survive", she would eat. Every time if she didn't want to eat, the family would say so, then she would eat.

Deng (a senior doctor): some patients suffered from the most agonising pain but still hoped to live on. You could tell if someone wants to live – if they try to eat even when suffering from eating – no appetite, vomiting, constipation etc. They keep eating because they want to live on – that is basic desire for life.

Davies (2011) also contends that "at its most pragmatic level, hope as a mood of survival is often symbolised in and through food, the quintessential symbol of survival." (p. 197) Indeed, serving food was so important for families who wanted to show their love and care, and their hope for patients to linger on that sometimes it was overdone and became counteractive, for example, in Xian's case (see below the extract from my field notes).

Ao (a private nursing worker) and his wife together complained that Xian's oldest daughter did not believe that they had fed Xian the nutritious liquid food (provided

by the ward) even after they showed her the emptied packages they threw into the

rubbish bin. Every time she came, she brought for Xian two extra meals after they

had fed her the liquid food. After that, Xian had diarrhoea and outflow of food

from her mouth. Ao thought that if Xian kept having diarrhoea like this, her

bottom will be corrupted. Xian's son explained that his sister felt greatly that their

mother should be fed enough and fed well, so she could get better; and it was the

way she showed Xiang her love for her.

<div align="right">(Extract from my field notes dated August 14th, 2010)</div>

2.2 Space utilisation and hope work

Death was highly noticeable in the ward although measures were taken to protect patients from witnessing other patients' deaths. This is mainly due to the ways in which the space was used. First, two patients shared a room; second, the funeral company's ritual room was located at a central point; both of which were, in great part, out of the economic considerations of saving cost and maximising profit (see Chapter Five). But the unintended consequence is that for patients who were conscious, frequent witnessing or sensing of fellow patients' deaths defeated their hope for life. In this sense, I argue that the ward also did hope work (unintendedly) through its particular way of using its physical space, in addition to the patterned relationships discussed above. A good example is on my second day of observation, when five patients died – an unprecedented number of deaths. The following extracts and quotes show the influence these multiple deaths had on patients' hope.

Fu lived next door to the patient in Bed 53 who died in the morning. He was

moaning even louder today. He said anxiously: "I am a patient of the 3rd People's

Hospital. I am 77 years old. I am moaning everyday as long as I am here. I did not commit any crimes, why am I confined here? I want to go home, please." ...Xi's room was just opposite to the ritual room. When I stopped by his room, the door was wide open, he opened his tightly closed eyes and said to me: "I should go now, I am too old............ ".

(Extract from my field notes dated July 28th, 2010)

Xi said that his disease could not be cured and he would not leave this place alive (But Xi had bladder cancer with no metastases, so he actually had quite a good prognosis). I asked him how he knew this. He said most people here came in and died here. I asked him how he found out about this. He said he overheard people talking about it. He gave an example of what happened on July 28, he said: "that day, at least two people died. The mortuary was just opposite to my room." I was confused about "mortuary", I wondered whereabouts it was in the hospital; later I realised that he meant the funeral company's ritual room in the ward. He said that one of his colleagues also died here. He sighed: "my disease could not be cured; I will not be able to leave this place alive either."

(Extract from my field notes dated August 1st, 2010)

Zhang *(a ward nursing worker):* Some patients were really hurt by other patients' deaths, for example, a patient lived in Bed A53. Eight or nine patients died in the other bed in the same room; later, she was so traumatised that she stopped talking but kept staring at the other bed in her room. Gradually, she became totally mute until her death. Sometimes I found her crying alone – she must have been scared a lot.

As demonstrated above, generally, the type of hope work intentionally done in the ward was to establish "hope for life" in patients. However, some carers' deeds, words and ways of "being" with patients, and the ways in which the space was used were counteractive and had dismantling effects on hope. In addition, among all the carers, it is nursing workers whose hope work was the most intense, followed by some families.

My findings are in contrast to Perakyla's (1991) findings in his ethnographic study in several ways. First, he contends: "what is particular to hope work is that it is accomplished solely through conversation." (p430) I argue that there are other ways that are equally important, if not more important, through which hope work can be achieved. For example, in my study, it was done in relationships through carers' deeds, words and simply "being" with patients, and through the ways in which the physical environment was set up. Feudtner (2005) also points out that shared features of the physical environment and shared features of how decisions tend to be made in a ward can influence everyone within this niche of an ecology of hope (see Chapter Three). Second, Perakyla (1991) defined three types of hope work in a clinical setting, namely: curative hope work, palliative hope work, and hope work to dismantle curative or palliative hope work (as discussed in Chapter Three). In my study, in the hope work through conversation to instil hope for life, there appeared to be a mix of curative and palliative hope work (as defined by Perakyla (1991), which is not clear-cut but overlapping. Hope work to dismantle hope, either curative or palliative, was never done in conversation. But the dismantling of hope for life was done, often unintentionally, through carers' deeds and ways of being with patients, as well as through the ways in which the physical space was used, as discussed above. Third, unlike my study, Perakyla's study did not analyse the differences in hope work performed by different professional (or carer) groups.

Nevertheless, both Perakyla (1991) and Feudtner (2005) suggest that there may be marked differences in hope work in different clinical settings, depending on the organisational context. In Chapter Four and Six, I also described the organisational context of the hospice, which is markedly different from that of the ward. As a result, the type of hope work and how it was achieved in the hospice also differ from the ward in some aspects despite the similarities. For example, although the care team for each patient consisted of doctors, nurses and family members, the care burden fell heavily on families. Therefore families' hope work to give (or dismantle) hope for life was the most intense. Doctors and nurses always consciously, determinedly but tactfully engaged in palliative hope work in conversation with patients, despite that sometimes families stubbornly insisted on and engaged in curative hope work (see Chapter Six). Deaths of patients usually took place in a private space – their own homes or their children's homes, so patients would not be affected by other patients' deaths. The hospice's physical environment had no effect on patients' hope either because most patients never had to go there. On the whole, for the patients who received free hospice care, the existence of and accessibility to such a hospice gave them the biggest hope for life, whereas, the ward was perceived as a hopeless place for patients to wait for death (see Chapter Six). As such, I argue that palliative/end-of-life care organisations potentially can influence individual patients' hope by providing a certain micro "ecology of hope" (Feudtner 2005, p. S23) wherein certain type of hope work is done in certain ways.

The ward and the hospice differed in many aspects of the organisational context due to the interplay of a complex range of factors, both internal and external to them (as shown in Chapter Four and Six). For example, externally, at the most intimate level,

they were subject to the ethos of the hospital to which they were affiliated: hospitals differed in many aspects such as location (rural or urban), rankings (in the health care system), charitable origins, economic realities and leadership styles. Further, these hospitals and all that contained therein, including the ward (or the hospice) and the individuals, were subject to a broader sociocultural environment wherein they existed, which encompasses such elements as media, religious communities, economic realities, cultural values, social structures and the like (Feudtner, 2005). As such, hope work of an organisation such as the ward and the hospice, may well be influenced, directly or indirectly, by the organisation's external sociocultural environment from local to macro level. In the next section, I demonstrate how the macro sociocultural environment may influence an individual's hope, for example, through popular sociocultural discourses.

3. Macro sociocultural environment and hope

In the previous section, I pointed out that the sociocultural environment may indirectly influence individuals' hope through organisations in which they receive care. In this section, I demonstrate other ways in which the macro sociocultural environment may potentially impact on individual patients' hope. I focus on analysing how it impacted on patients' hope directly through normative sociocultural discourses; that is, how patients drew upon the dominant cultural understandings (often current in the media) of death, terminal diagnosis, medical science, and willpower to legitimise and assess the hope of cure/remission thus living longer as within the bounds of the real.

In my study, the majority of patients argued that death was certainly coming to all of us, not just cancer patients; but it was not certain when and how we would die, even with a diagnosis of terminal illness. They cited in the interviews unexpected sudden deaths from natural disasters or man-made accidents and people who died at all ages for all sorts of reasons, even mysterious ones. On the other hand, they recounted tales in the media that related instances of long-term survivors among those who had been told that they would have but a short time to live. Some also gave examples of themselves or other cancer patients outliving "healthy people" or even the doctors who had told them to prepare for death. As such, patients reasoned that the chance of them living or dying might well be the same as others who did not have cancer, and this gave them hope. This finding reflects that of Hall (1990), who suggests that human beings are not privileged to know when they are going to die but live with the constant awareness that death is eventually coming to all people, and that this should not differ between cancer and non-cancer victims. But, as he points out, medical science calculates aggregate predictions and applies them to an individual, and thus creating the illusion that the time of death can be predicted with accuracy.

However, there appeared to be growing acknowledgement in the media and in the medical circle of the inaccuracy and uncertainty of the prediction of life expectancy in terminal illness, as shown in the extract from my field notes below. As Hall (1990) has pointed out, medical technology aggressively numbers the stages of diseases in an attempt to predict the time of death as nearly as possible. However, the prediction is very often not accurate as such predictions are based almost exclusively on physical findings, ignoring social, contextual and psychological facets that are inextricably connected with longevity. Nowadays, due to the growing awareness of the limitations

of medical prediction of life expectancy, some patients may instead view it as a potential cause for hope (of living longer than predicted), as found in my study and that of Johnson's (2007).

The director said: "although doctors could predict a patient's remaining days, it can never be accurate. There are other factors that may influence when a patient may die, which are beyond the clinical criteria of predicting death, for example, a patient's will to live or his/her spiritual or psychological status. It could be even unknown/mysterious factors. For example, on July 28th, five patients died; one of them shouldn't have died – no one could believe that he died that day. I had expected him to live much longer because his condition had been perfectly fine. I had checked on him at 11am, but he died after 4 deaths at 1pm or so." The director was talking about his uncle; he was not ready for his death at all. He said that when he told his colleagues in other departments what happened that day, they told him that July 28th was a day on which three planes had crashed in history, and it was the 34th anniversary of Tangshan earthquake which killed nearly 250,000 Chinese people. CCTV news also announced several strange disasters which killed quite a number of people across China on that day.

(Extract from my field notes dated August 1st, 2010)

Bennett (2011a) contends that medicine is underpinned by a culture of hope. In both research and clinical practice, medical science continues to subscribe to a narrative of progress, which sustains the hope that the treatment of disease and the alleviation of suffering become ever more effective. In China, this culture of hope in medicine extends to traditional Chinese medicine (TCM) (WHO, 2011). The media supports and promotes this culture; specific to cancer, they call it "a comprehensive approach

to cancer care, combining western medicine (WM) with TCM". So among Chinese patients, it is common that they build their hope not only upon WM but also upon TCM and even other alternative approaches such as qigong (see Chapter Four). Indeed, in my study, when WM failed to work, some of the patients from the committee resorted to and solely relied on TCM and/or qigong to sustain their hope thus their life. As a whole, the health care system gives hope through its promises to care for the sick (Bennett, 2011a), thus contributing to the flourishing of society through its role in symbolising hope and compassion (Brown and Flores, 2011), although, as my study suggests, it can also take away hope from people due to its limited ability to redress deeper inequalities.

As discussed in Chapter Five, the patients in my study drew on the same discourse that is prevalent among cancer patients in the West, and that assumes that the mind can influence the body, or positive thinking can facilitate recovery (De Raeve, 1997). This discourse is identified by Delvecchio-Good et al (1990) as a discourse of will, which incorporates western concepts of the individual as responsible for his or her own life and the relationship between psyche and soma. My data indicate that it was enthusiastically promoted in the Chinese media regarding cancer rehabilitation. Thus, it sustained patients' hope in that they were persuaded to believe that through taking care of their own psychological, spiritual and emotional well-being, they could enhance and maintain their physical well-being, as one patient cited: "the mind does 70 per cent of the curative work and treatment does 30% of the work".

In addition to the sociocultural discourses discussed above, on the whole, Chinese society with its particular sociocultural environment, constituting the broadest level of

the ecology of hope (Feudtner, 2005) for the patients in this study, shaped their hope in certain ways, as Ze's quote demonstrates below:

To be honest, all these years, I have been reflecting upon our country. There are a lot of things indeed that you cannot take pride in. Even if you are rich now, your spirituality is poor. They [two colleagues he had really liked and had invited to his "farewell" dinner before his surgery] had worked with me for so many years – I had been their superior and friend, and we had got along so well; but they just did not show up – hasn't visited me till now. So you see, these things must have had influence on me. But now I have learnt to take it lightly. It is nothing strange – the society is just like this... What is love? So now I have a deeper perception of love. What I am talking about is not the kind of love between couples; it is love of a nation, love of humanity, it is reflected in all respects. If a nation is caring, it can support a lot of people to go on living sturdily and to stand up sturdily. If a nation is not caring, you are forcing these people to head for the road to destruction. This is my view.

Ze's quote suggests that the way in which the community responded to his problem of living with advanced cancer and potentially dying from it involved social and moral choices about care. Indeed, Kellehear (2007) contends that:

The human problem of dying has always been a set of social and moral choices about care, and about how those choices are negotiated between dying persons and their community – whatever form that community has taken in the past. In this precise way the study of dying is like gazing into a reflecting pool. The waters

there reflect back to us the kinds of people we have become. More than ever before then, it is timely to ask the question: what kinds of people have we become?

(p. 250)

Summary

This chapter has explored some of the external sources of patients' hope encompassed in the "Hierarchical social and cultural ecology of hope" (Feudtner 2005, p. S23) wherein they existed, and has represented some of the ways in which these sources influenced patients' hope.

First, my findings demonstrate that the social network of relationships that a patient is located in is highly pertinent to his or her goal formulation and hope construction. In this study, others in the patients' network served as sources of hope in a variety of ways, for example, by providing information, as patients' potential or actual resources, and through their loving relationships with the patients.

Moreover, the organisational context may influence patients' hope through shaping the type of "hope work" (Perakyla 1991, p. 409) and how it is done to the patients in an organisation. For example, two main aspects of the complex and multifaceted organisational context of the ward were: 1) defined and negotiated roles and routines of carers; and 2) the ways the space was used in the management of death and dying. These two aspects shaped the type of hope work that was intentionally and

257

unintentionally carried out in the ward, as the result of which, the patients' hope was facilitated in certain directions. As the organisational context differed, the organisational hope work differed accordingly. For example, the hope work of the ward differed markedly from that of the hospice due to their differing organisational contexts. As a consequence, for the patients who received the free hospice care, the existence of and accessibility to such a hospice gave them the biggest hope for life, whereas, the ward was perceived as a hopeless place for patients to wait for death. The reason that the ward and the hospice differed in many aspects of the organisational context is because of the interplay of a complex range of factors, both internal and external to them. As such, the hope work of an organisation such as the ward and the hospice, may well be influenced, directly or indirectly, by the organisation's external sociocultural environment from local to macro level.

Furthermore, the macro sociocultural environment may wield a broad and profound impact on individuals' hope in a myriad of ways, in addition to the more immediate organisational influences. For example, patients drew upon dominant sociocultural discourses regarding death, terminal diagnosis, medical science, and willpower to legitimise and assess the hope for cure/remission thus living longer as within the bounds of the real. Constituting the broadest level of the ecology of hope, Chinese society with its particular sociocultural environment, facilitated the hope of the patients in culture-specific ways.

Chapter Nine
Conclusion

Introduction

I begin this concluding chapter by summarising the contribution to knowledge this study makes (in Section 1). I then evaluate the research process, highlighting its strengths and limitations in Section 2. In Section 3 I bring together the research findings and synthesise them in terms of the two central themes that this study has aimed to illuminate; following which, I discuss the broad policy implications of these findings in Section 4. I will conclude this chapter and the thesis with my final reflection on this study.

1. Contribution to knowledge

In this thesis, I have reported on a sociological study of the current Chinese approach to end-of-life care and the role of hope in terminal illness. As such, this study contributes to the scarce knowledge, both in China and in western countries, of the current palliative/end-of-life care provision in China. It represents the overall situation and to varying degrees, touches on a variety of specific aspects of such care, such as

patients' quality of life and needs, ethical and cultural issues, health resources and social support, funding and policy. I have explored mainstream palliative/end-of-life care as experienced by the patients I studied in its broadest sense. I have illuminated all forms of care and support that did the work of "palliation" and were available to patients, including but not limited to medical care. I have studied two unique models of specialised palliative/end-of-life health care as adapted from the western model. Thereby, I have identified those aspects of the western philosophy of palliative care that were adapted to Chinese practices and the way that China's own priorities arising from its social, cultural and economic contexts shaped those aspects .

Also, I have presented a sociological explanation of hope in terminal illness as situated in end-of-life care culture in China, that is, how individual patients' biographies, their present life situation and external resources located in health care, families, communities and broader social and cultural environments, have contributed to the construction of their hope thus their illness experiences in "living" with advanced/terminal cancer. In this way, the study contributes to a more holistic understanding of hope, building on the existing empirical work in the "care professions" that has focused on the different dimensions of hope – psychological, relational or social, and drawing on the conceptual model of "hierarchical social and cultural ecology of hope" proposed by Feudtner (2005, p. S23) that encompasses the aforementioned dimensions of hope. I have revealed the nature of hope, demonstrated the role of hope in terminal illness and identified sources of hope internal and external to patients. Hence, the findings about hope, which complement the findings about palliative/end-of-life care provision, have contributed to identifying actual and potential resources for end-of-life care in China at multiple levels – personal, interpersonal, organisational and social and cultural.

In addition, adopting a cross-cultural perspective to exploring sensitive topics in diverse and complex situations in China, this research has implications for overcoming challenges in conducting cross-cultural, qualitative, palliative care research, particularly in terms of theory, methodology and ethics. I have demonstrated how I selected and adapted western methodological and ethical approaches and imperatives to suit diverse Chinese settings. I have highlighted the need to balance among scientific enquiry, ethical and moral duties and practicalities, and among the needs of all those involved in the field work, prioritising those of dying people. The findings also contribute to the Chinese knowledge base of qualitative research, research into hope and research from patients' own perspectives in this area of care, all of which are novel and under-utilised. In the next section, I summarise the methodological strengths of this study.

2. Ethical cross-cultural research into sensitive issues

The aim of this study was: first, to represent the current palliative/end-of-life care provision as experienced and defined by older people with advanced cancer (patients[16]), in three distinct care settings (organisations), and second, to explore what hopes were present and how those hopes were fostered in these patients at the end of

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[16] I use this medicalized term to distinguish this group of participants of this study from other groups such as doctors, nurses, nursing workers, and family members.

life. In this section I evaluate the research process through which I have addressed these questions.

I chose a critical realist position as the most appropriate frame of reference for this study because it retains an ontological realism while accepting a form of epistemological constructivism and relativism (Maxwell, 2012). In the study of health, illness and disability, it facilitates a process of amalgamation of knowledge and thus a more holistic approach to understanding people's real-life experiences, making no basic distinctions between the importance of medicine and sociology (Carpenter, 2000). In relation to this study, a critical realist view means that the biological basis of cancer suffering, the structural constraints that are often placed on people with cancer and the cultural attitudes towards cancer, in which these structures are embedded, are all treated as real and as having a tangible effect on people, which places limits on their exercise of agency. Cancer suffering is then seen as "a dynamic, dialectically unfolding process between body and society, located within a temporal frame of reference both historical and biographical" (Williams 1999, p.813). Therefore, by focusing on social issues, structural constraints and cultural attitudes while acknowledging the importance of biomedical matters and the personalised and diverse nature of cancer experience, this study has the potential to suggest changes that may bring about positive outcomes. However, my understanding of these phenomena is a construction from my own world view. Therefore, in the thesis, I have aimed to provide a valid account of the phenomena that I have witnessed by providing layers of contextual information, being reflexive and acknowledging that my account is inevitably partial, incomplete and fallible.

The strength of my approach also lies in the qualitative methodology that I chose: the "multiple embedded-case study", which was responsive to the cross-cultural, sensitive, complex and context-dependent nature of my research. As much as possible, I addressed the cultural issues in both the social phenomena studied and the process of conducting research. Bearing in mind that it was sensitive research involving vulnerable people (including myself), I dealt with the ethical and moral challenges I encountered in culturally and situationally appropriate ways, harnessing the ethical principles of research conduct that I had studied in the UK. I also embraced the diversity and complexity in both my research interest and the field work, trying my best to maintain a flexible and open-minded mindset.

In actual terms, the strengths of my methodological approach resulted in me using mainly qualitative interviewing and observation to collect data about the three embedded cases (the committee, the hospice and the ward) and the selected patients within, from multiple sources of evidence, that is, from patients, their families and the staff (director, doctor, nurse, nursing worker or other relevant staff). The weight, quality, duration and interval of each method and the combination of sources of evidence varied among the organisations as the result of the adaptation to the ethical and practical constraints specific to each site, individual participants and their situation. Although this meant that neither method was used to its full potential, which limited the breadth and depth of the data collected from an individual participant or an individual organisation, the combination of different cases, methods and sources of evidence has resulted in sufficient and appropriate data having been collected to achieve the research aims. This provides a basis on which future research into palliative/end-of-life care in China or experience of health and illness can be developed.

Nonetheless, there are several major limitations to this study. To represent the overall situation of palliative/end-of-life care in China, this study explored, to varying degrees, a wide variety of issues relating to such care, such as patients' quality of life and needs, ethical and cultural issues, health resources and social support, funding and policy. In so doing, although it achieved the breadth of the issues covered, it sacrificed the depth that each specific issue deserves. Another limitation is selection bias in the case of individual patients. The patients chosen by the gatekeepers were mostly representative of their organisational culture (particularly in the case of the committee) or demonstrative of their success in delivering care (particularly in the case of the hospice and the ward), and therefore hardly any "deviant" cases were presented to me. There are also limitations to the diversity of the "sample", for example, this study does not represent the experiences of those people from an ethnic background other than the Han majority, those who are from different religious backgrounds, people who do not use the services provided by the three organisations I studied, or who are from different geographical regions of Yunnan province. In terms of hope, patients who agreed to participate tended to be more hopeful, and it was hard to recruit those who were depressed and might have been feeling hopeless. Therefore, experiences of those who were depressed and without hope might not have been represented. Also, I chose to focus exclusively on exploring how the external sources of hope could impact on patients' hope construction, although I was informed by literature and my data and thus aware of patients' active role in influencing their external environment and hence the two-way interaction between patients' internal and external sources of hope.

3. End-of-life care in China and hope in terminal illness

In this section, I integrate the findings with the focus of the study, that is, the current end-of-life care approach in China and hope in terminal illness.

3.1 Current end-of-life care approach in China

My data show that in terms of medical care, Chinese cancer patients relied solely, mainly or even excessively on the curative western medicine (WM) available in mainstream health care, while the pressing need for pain relief was poorly resolved in advanced cancer care. What is more, it is generally very hard to access and afford health care in China due to many flaws of the current health care system, as discussed in Chapters Two and Five. Consequently, medical care for cancer patients in terms of WM presented a predominantly unfavorable prospect as it indeed exacerbated the cancer suffering: 1) it caused patients excessive physical suffering (e.g. side and toxic effect, disability) while cancer pain was left unrelieved; 2) it put enormous financial burden on patients, families and the state alike, adding to patients' financial pain; and 3) the process of seeking medical care itself was painstaking for patients, physically fatiguing and emotionally stressful.

What cushioned this adverse impact of medical care on advanced cancer patients was traditional Chinese medicine (TCM). The experiences of the patients in this study demonstrate that TCM generally contributed to enhancing patients' positive health,

counteracting the adverse effect of curative WM treatment as well as mitigating symptoms of the disease. It also had other advantages over WM: 1) it caused little side effect and was safer; 2) it was much cheaper and more affordable; and 3) it was more "dialectic", "holistic", and person-centred. This study thus agrees with other studies that TCM may provide a complementary approach to relieving cancer suffering (Xu and Chen, 2004; NG, 2006; Xu et al, 2006; Ji et al, 2008).

I also studied two unique cases of specialised palliative/end-of-life care services (the hospice and the ward) which followed the lead of the western palliative care principles. My data reveal that these services were not preferred by patients and their families, but were the last resort after other mainstream health resources had been exhausted. This was mainly because palliative/end-of-life care was an unavailable and inaccessible option to most people and people hardly knew of its existence and understood what it really does, and also, due to the death taboo in Chinese culture (see further discussion below).

As newcomers to the Chinese national health care system, both services were surviving under the constraints imposed by the health care system although in different ways and to different extents, and in addition to this, under other constraints located in their specific local contexts as well as the broader sociocultural environment of China. Subsequently, their adoption of western palliative care philosophy has resulted in the uniqueness of their models of palliative/end-of-life care.

I have argued from my data that the hospice, although located in the health care system, due to its charitable origin and nature and small number of well trained and dedicated staff, has done its utmost to provide the total care as promoted by the

hospice movement for those extremely vulnerable rural patients in the region. Despite this, its service capacity was limited and the quality of its total care was inconsistent. Ultimately, what they really met was patients' physical need for pain relief; despite their effort, these rural patients' other pressing needs – physical, psychological, social, financial and spiritual, were far from being met. This was mainly attributable to: 1) its organisational context, such as lack of alternative charitable funding sources, staff and collaboration with other local health services, 2) the socioeconomic circumstances in rural China, such as prevalent poverty, lack of social welfare and patchy public services, and 3) the broader sociocultural context of China, wherein philanthropy, social work and the like were all budding and alien, and therefore, few social resources were available for either the hospice or individual patients.

In contrast to western principles of palliative care, some features of the ward's services appeared to be somewhat odd and irrelevant. A department of an ordinary Chinese hospital, the ward's services were subject to the structural framework of the national health care system and the medical insurance system. Besides, the staff generally lacked specialised training in the western philosophy and practice of palliative care. As a result, my findings show that its work fit in with the mainstream biomedical model of care in the sense that it prioritised and routinized only physical care, focusing on pain relief, symptom control, artificial nutrition and hydration and personal care. The principle of "total care for the whole person" was not the underpinning precept for this unique model of care; rather, it was, to a great extent, driven by the economic concerns of cost saving and more importantly, maximising profit, which, I argue, have had implications for the scope, quantity and quality of care that the ward could provide.

This study thus demonstrates that what the hospice and the ward had met, for the most part, was the need of their patients for alleviating physical pain. This was certainly a significant contribution as pain relief was far from adequate in mainstream cancer care. However, I argue that the services were insufficient in meeting their patients' complex needs at the end of life – emotional, psychological, social, spiritual and financial.

My data also highlight that in China, it was not uncommon for families to act as the gatekeepers of patients' medical care, playing a dominant role in decision-making relating to both disclosure of diagnosis and prognosis and treatment. Chinese doctors gave far greater weight to families' preferences than patients', and subsequently, medical care for patients was family-centred rather than patient-centred. Besides, the burden of day-to-day care usually fell most heavily upon families. In most cases, families undertook the responsibilities of providing personal care and other essential support, such as psychological, emotional, financial and practical support on a daily basis. Consequently, patients' overall well-being, quality of life and survival time was as much to do with their family situation as the medical care they received. This reality was upheld by Chinese cultural values such as familism and filial piety, which determine that an individual is always part of the family – not independent of it, and family is the traditional care provider. However, there is no evidence from my data suggesting that families were supported in any way either in mainstream health care system or beyond. Indeed, in the case of the ward, families were yet included in the unit of palliative care as advocated by the hospice movement, while the hospice meant to care for carers but failed due to all kinds of constraints. My study thus points to a great need for supporting and caring for carers considering their central role in meeting patients' complex needs and the heavy care burden they shoulder as socially expected and accepted care providers.

Apart from medical and family care, patients were capable of self-help and able to call upon and use their social networks for emotional support, material support (e.g. money, service and goods), information and companionship, as demonstrated particularly by the experiences of the patients from the committee. Besides, the neighborhoods in which patients lived, the organisations of their workplaces and the public's attitudes and response to their illness were thought to be contributive to their illness experiences.

Predominant sociocultural discourses also had profound impact on patients' illness experiences. My data suggest that how patients came to terms with cancer and how they coped were linked with how they perceived the nature of cancer. Typically, cancer was invariably perceived as "a death sentence" regardless of the stage and as a psychosomatic disease with psychological and emotional causation, in addition to other myths that surrounded it. This mythology of cancer distorted the truth about the illness and isolated patients; it not only created a stigma, but also materially hindered them and their families from seeking the necessary support (Sontag, 1991).

Subsequently, the Chinese cultural orientation of denying death and pursuing longevity was drawn upon in coping with dying. This death-as-a-taboo culture underpins the health care professionals' ethos of "saving life at all cost", families' preference for curative medicine over palliative medicine, patients' coping strategy of "hoping for the best while preparing for the worst" (see more discussion of this in the next section) and a lack of public discussions about end-of-life care issues. In order to fight off cancer and thus death, patients also drew on a predominant discourse among cancer patients that assumed that the mind can influence the body – a discourse of will

(Delvecchio-Good et al, 1990). As such, it became a moral imperative for patients to be mentally strong or think positively. While this could be beneficial, as shown in my data, it could equally be detrimental when it became a moral oppression (De Raeve, 1997).

To summarise, the findings demonstrate that living with advanced cancer is not a homogeneous experience determined solely by the diagnosis and prognosis of cancer and thus the provision of medical care. These older people with advanced cancer lived with "total pain" as the result of their cancer as well as other cumulative disadvantages embedded in their social, cultural and economic circumstances. As such, as Kellehear (2005) contends, as a citizen and community member, the person that we call "patient" also has needs more complex and beyond health services for the majority of his or her time over the course of his or her illness. On the other hand, "… people are capable of self-help and as, in other stages of life aside from death, are able to call upon and use the resources of support, information and power in their communities" (Kellehear 2005, p.21). Hence, as revealed in this study, the total care (physical, psychological, social, financial, practical and emotional) for this group of people appears to be an aggregate of the resources that are located in family, health care and the broader sociocultural environment, against a backdrop of the adverse conditions that are shaped by the same set of milieus. The findings of this analysis are echoed in the analysis of patients' hope in the following section.

3.2 Hope in terminal illness

I have argued in this thesis that hope is absolutely essential to human life. It performs significant psychological, social and cultural functions. The source of it lies within

and between individuals and in their social and cultural environments. So resilient and resourceful, it indeed persists in all circumstances and at all stages of our life, even in the context of terminal illness. My findings and those of others (e.g. Dufault and Martocchio, 1985; Hall, 1990; Gum and Snyder, 2002; Johnson; 2007; Eliott and Olver, 2009) have shown that at the end of life, there remains much scope beyond hope for cure or remission – though it is still paramount and vital, for patients to engage in matters that are meaningful, significant and still achievable by them.

I have discussed two common strategies of coping using hope among the patients I studied that fulfil and complement each other. The strategy of "hope for the best and prepare for the worst" aims at maximising the quantity of one's life while the strategy of "hope to live in the present (live one day at a time), and hope to live each day to the full and happily" at maximising the quality of one's life. Both strategies appeared to be indispensable in patients' lives, with one orientated towards the future and the other focused on the present. Together they gave life meaning, direction and an optimistic focus, and provided what was needed to stay engaged in living whilst shouldering the burden of an uncertain future.

Apart from these two overarching hope strategies, the common themes that I found in their particular hopes reflect their most pressing needs for freedom from suffering and interpersonal connectedness that have to be met in the current health care system, family relationships, their community settings in urban and rural areas, and in Chinese society as a whole.

My findings point to how the social network of relationships in which a patient was located was highly pertinent to his or her goal formulation and hope construction. In

271

this study, others in the patients' network served as sources of hope in a variety of ways, for example, by providing information, as patients' potential or actual resources, and through their loving and reciprocal relationships with the patients.

Moreover, organisations may influence patients' hope through their "hope work" (Perakyla 1991, p. 409), the implicit but an essential aspect of professional care in clinical settings or generally in care professions. This hope work, could be done in two ways among others, as shown in this study: first, through carers' relationships with patients, that is, their words, deeds and being (particularly emotionally) with patients as informed by their negotiated roles and routines (in addition to their personality), and second, through the physical environment, that is, how the space was used in the matter of care. As the organisational context differed, so too did organisational hope work. As a result, some organisations appeared to be more "hopeful" such as the hospice in this study and some more "hopeless" such as the ward.

Furthermore, the organisational context differs because the organisation's sociocultural environment from local to macro level, which is heterogeneous, has a bearing on it. This means that the sociocultural environment can impact on individuals' hope by shaping the structural, physical and ideological facets and thus the hope work of an organisation wherein individuals receive care. Indeed, as my findings show, the macro sociocultural environment may wield a broad and profound impact on individuals' hope in a myriad of ways, including doing so through individuals' social networks or organisations where they receive care. For example, the dominant sociocultural discourses on death, terminal diagnosis, medical science and willpower provided resources for patients to legitimise their hope for cure/remission thus living longer and to assess it as realistic. In the case of the health

care provision in China, its narrative of progress in both western medicine and traditional Chinese medicine and thus its promise that the treatment of disease and the alleviation of suffering become ever more effective sustained hope, and yet its limitations in redressing inequalities eroded hope. Nonetheless, health care provision can contribute to the flourishing of society through its role in symbolising hope and compassion (Brown and Flores, 2011).

Constituting the broadest level of the ecology of hope, Chinese society with its particular sociocultural environment could facilitate the hope of the patients in culture-specific ways. My findings show that currently, it contributed to a sense of hopelessness, with its overall sociocultural hue of too much competition and too little compassion.

To summarise, my data have revealed the nature of hope as essentially affirming life in all circumstances and as situated and fostered in a "hierarchical social and cultural ecology of hope" (Feudtner 2005, p. S23). I have demonstrated the significant and vital role of hope in terminal illness, that is, through hope, patients in my study engaged in searching for alternative ways of being well in illness and suffering, seeking out gains from losses and exploring possibilities rather than dwelling on lost opportunities. As such, my data have shown how hope helped patients adapt to, cope with and thus "live with" the experience of "dying". Their hope was constructed in and through their relationships with other people and the broader physical, cultural and social environments. Hence, the fostering of hope, as a resource, has implications for improving care and support for people at the end of life at multiple levels – personal, interpersonal and social and cultural in China.

4. Fostering an end-of-life care culture that provides a benign ecology of hope

Clark and Seymour (1999) concede that "palliative care as a set of activities and an emergent specialty is currently beset by status ambiguity, imprecise definition and uncertainty of mission" (p. 180). Meanwhile, in scaling up to meet the rising need of all people at the end of life, the future direction of this specialty has seen a trend of medicalisation in the process of mainstreaming worldwide. Subsequently, the original ideals of the hospice movement have become watered down to emphasise physical care and palliative/end-of-life care has shifted its focus from dying people to issues of symptom control and palliation (McNamara, 2001). In the case of China, palliative/end-of-life care services, as newcomers to the Chinese health care system, have mainly adopted the physical aspect of the total care so far, fitting into the biomedical curative model of health care. As such, the vision of total care advocated in the hospice movement appears to be waning in health care settings.

Nonetheless, I would argue against blaming the palliative care specialists or other health professionals or the health care sector as a whole for having not performed well enough to meet people's needs. As I have shown in this study, patients mobilised and utilised a broad range of resources – not just medical but also social and cultural, to bring about positive changes over the course of their illness, to alleviate their all-inclusive suffering, to meet their complex needs, and to build their hope at the end of

life. This is not just about their need for total care (physical, psychological, spiritual and social) not being attended to in health care settings, but more about the "total care" they needed being more complex and demanding than what health services alone could promise. It is also shaped by the reality that "the distinction between end-of-life medical issues and end-of-life social issues are subtle" (Kellehear 2005, p. 52). Thus, it raises important questions such as: how to care for these people in institutional settings, how to care for them outside of institutional settings, and how to address their social care issues in non-clinical ways. These are all challenges and skill gaps that I argue, cannot and should not be tackled by the palliative care specialty alone.

Although the health care sector would definitely benefit from mainstreaming palliative care philosophy as well as developing specialist palliative care services to provide quality care for people, dying or not, the humanitarian, compassionate and noble ideal of "total care for the whole person" of the original hospice movement should not be situated narrowly in health care as the health care sector alone cannot undertake this huge task because "death, dying and loss are essentially social issues" (Kellehear, 2005, p. 52). As Kellehear (2005) argues, the holistic approach of palliative care has only emphasised the whole person as individual, but sidelined the fundamental crux of caring for these people, that is, to treat the whole person as individual-in-community.

As such, I support the public health approach to advancing palliative care development proposed by Kellehear (2005) in that it endorses a compassionate approach to death and loss and proposes that care for people at the end of life is a fundamental responsibility of not just health professionals, but also communities, governments and societies. My sociological understanding of hope also endorses this

approach in that people at the end of life must have hope to live with dying and loss, and hope is fostered in their ecology of hope comprising themselves, family, care providers and other physical, social and cultural elements. Hope work is thus a responsibility of not just patients and carers but also communities, governments and societies. Hence, the implications of my findings for broad policy orientation basically point to a spread of the holism of palliative care – social, physical, psychological and spiritual, to the holism of public health: "the nomenclature of ecology, politics, community, settings and environments" (Kellehear 2005, p. 50). Within this broad framework, the key findings of this study have the following implications for the policies that may contribute to an end-of-life care culture that has potential to be a benign ecology of hope.

Health care

Although I argue that it is unrealistic to expect the newly developed specialised palliative care services and other conventional medical specialties in the current Chinese health care sector to meet every need of people at the end of life, it is nonetheless their responsibility to continue striving to improve the quality of their services that are currently focused on physical care. This includes overcoming the existing flaws of health care provision to make medical care generally more available, accessible, affordable, equitable and sustainable. The problem of excessive anti-cancer treatment but insufficient cancer pain relief should also be redressed to ensure that medical care itself would not contribute to the total pain of people living with advanced cancer. It is also possible for health professionals to learn to provide some psychological, spiritual and social support alongside their work on the body, within all sorts of constraints discussed in this thesis. These tasks may be approached in a number of ways. First, as China continues reforming its health care sector, it would be

beneficial to introduce the original hospice ideals of "total care for the whole person" into the ideological and ethical principles of the sector to shift it from an overly biomedical and curative emphasis and a consumerism orientation to a more holistic and compassionate approach to health and illness and death and dying. Second, while continuing developing specialist palliative care services that focus on palliative medicine for symptom control and palliation, it is important to establish partnership and cooperation between these new services and other services such as primary health care services in the communities, specialist curative cancer treatment services, mental health services and rehabilitation services to provide as much "total care" as possible in the health care settings. Third, as the Chinese government has put it on their agenda to further develop traditional Chinese medicine (TCM), foster a modern TCM industry and promote a culture of TCM, this should be extended to palliative medicine but not just focus on curative medicine.

Community capacity building

As shown in this thesis, the complex needs of people at the end of life cannot be totally met by and in the health care sector alone; some of these needs concern community and thus call for community resources. As such, there is need for building community capacity and solidarity. An essential aspect of community support in the Chinese context should be to support the families of people at the end of life because of the critical role they play in looking after these people and the heavy burden they shoulder as dedicated care givers. This can be financial support, information provision, training in required skills in caring for patients, respite care, counselling, bereavement care, support groups and flexible working hours etc. The aim should also be to raise people's awareness of their own abilities, knowledge and skills that permit them to employ available support systems, solve problems, take decisions and communicate

and act more effectively. It is also important to build social capital in a community, that is, helping dying people maintain the continuity of social relations with family, friends and others, and creating opportunities for community members to come together, establish networks and develop trusting and caring relationships with one another so that they are better able to support themselves in death and loss. It is not just about addition of more health and social services as the government has planned, but also encouraging communities and organisations to use what they have more effectively to meet more needs.

Public education and awareness campaigns

To facilitate positive changes such as those suggested above, there is also a great need to engage in public education, raising public awareness and influencing public discussions to influence and transform the culture and thus the experience of illness, death and loss. Palliative care education should be an integral part of clinical education. Public education programmes and public awareness campaigns through the media should focus on the following areas: 1) demystifying a disease such as cancer – dismantling the myths around it, to combat the metaphors of blame and fear, so that ill people and their families are not stigmatised and isolated and thus are more confident in seeking the necessary support; 2) challenging the predominantly negative attitudes towards death and dying and the public view that death and loss are abnormal social experiences in the community; 3) reminding and remembering the presence and diverse experiences of death and loss to maintain the continual sense of fragility and thus a sense of compassionate purpose for any community; 4) raising public awareness about the existence and nature of palliative care services, and facilitating mainstreaming of these services; 5) disseminating knowledge and skills of identifying and responding to the special needs of people who are dying in the community; 6)

fostering and supporting positive ageing, positive aspects of chronic illness and death and loss and positive contribution to self and community in such experiences; 7) engaging the public in debates about how to harness the underpinning cultural values and traditions such as familism and filial piety in caring for people at the end of life.

Research

As pointed out in Chapter Four, this study represented a partial picture of end-of-life care experiences, exclusively involving older people with advanced cancer, who are mostly Han majority without religious belief and from the south-western region of China. Future research is needed to explore the diverse experiences of different groups who need end-of-life care, reflecting the range of health problems, ethnicities, social classes, religious beliefs, ages, genders, geographical locations and life styles within Chinese society, so as to develop palliative/end-of-life care with greater sensitivity, openness and flexibility. There is also a need to collect much high-quality scientific evidence on TCM's effectiveness in general and in relation to palliative medicine. Conducting both medical and social research would be crucial for the recognition and dissemination of TCM inside and outside China. As shown in this study, Chinese families play a critical role in caring for people at the end of life. If the government is to continue relying on families to look after its sick, disabled and older population, there needs to be research on families' needs and how to involve and support families in end-of-life care in the light of many social issues that weaken the traditional model of long-term care by families, such as One-Child policy, 4-2-1 problem, rural-to-urban, in-country and international migration and the shrinking pool of female caregivers. In terms of hope, the selection of participants and other methodological constraints meant that experiences of those who were depressed and hopeless were not represented. Therefore, further research should involve these people to deepen insight

of the impact of hope and the lack of it and its implications for end-of-life care. Also, in this study, I focused on exploring how the external sources of hope could impact on patients' hope construction. Future research could explore how patients could impact on their ecology of hope including their families, health professionals and organisations etc. and the implications of this reversed impact for designing interventions to empower patients.

Lastly, my findings suggest that to provide better care for people at the end of life, there are wider social and economic issues that have to be considered and addressed, for example, as reflected in this study: large gaps in providing social services, the rural/urban discrepancies and debased social morality in a highly competitive society. In other words, there is need for the Chinese government to continue striving to build a compassionate society. As Clark and Seymour (1999) point out:

How a society cares for its dying and bereaved is indeed a measure of its compassion and worth. There is need to marshal evidence, to lobby, to organise and to influence governments at the highest level.

(p.187)

My final reflection

I have learnt from this study that in any situation, however hopeless it may seem, such as living with a terminal illness, there is always hope; and most important of all, there

is always hope to create and foster an ecology of hope that supports and enables individuals to remain hopeful: the key is to promote social connection and responsibility towards each other and this should be what underpins end-of-life care. This is because, as Kellehear (2007) argues:

Across our entire human history we have provided that support to our dying through the social offerings of recognition, presence, giving and receiving, and ritual. Sadly, those deep-seated responses towards our dying now increasingly seem endangered. And if they are at risk, if we dare abandon these reciprocities at the end of life, then we need to recognise one further, serious possibility. We should understand that the reasons we choose to live at all often reside in this precious handful of human intimacies, and as companions, may take to the same wind and eventually disappear with them.

(p. 256)

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290

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APPENDICES

Appendix 1: The care setting of The Committee

Cancer patients were practising Guolin Qi Gong in Kunming Zoo Garden

An interview was conducted here in a public place close to the community centre where the patient just finished his morning exercise

Appendix 2: The care setting of The Hospice

The hospice's car was stuck in the mud on the way to visiting a patient

Home visit

Just arrived a patient's home in the mountains

Home visit

Appendix 3: The care setting of The Ward

The layout of the ward
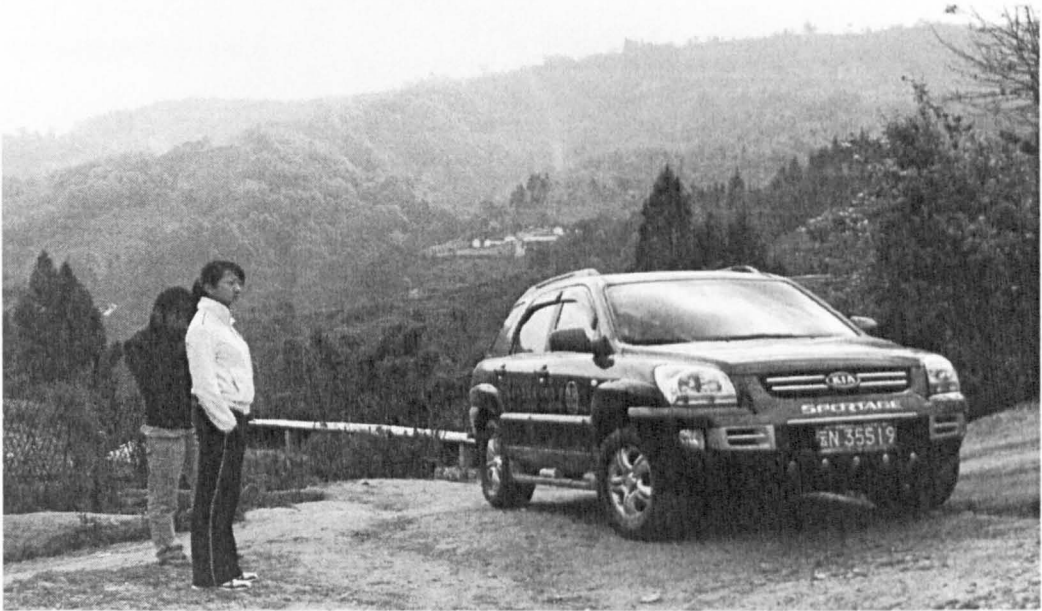
The corridor of the ward

A patient just died and a nurse and a nursing worker were looking after his roommate
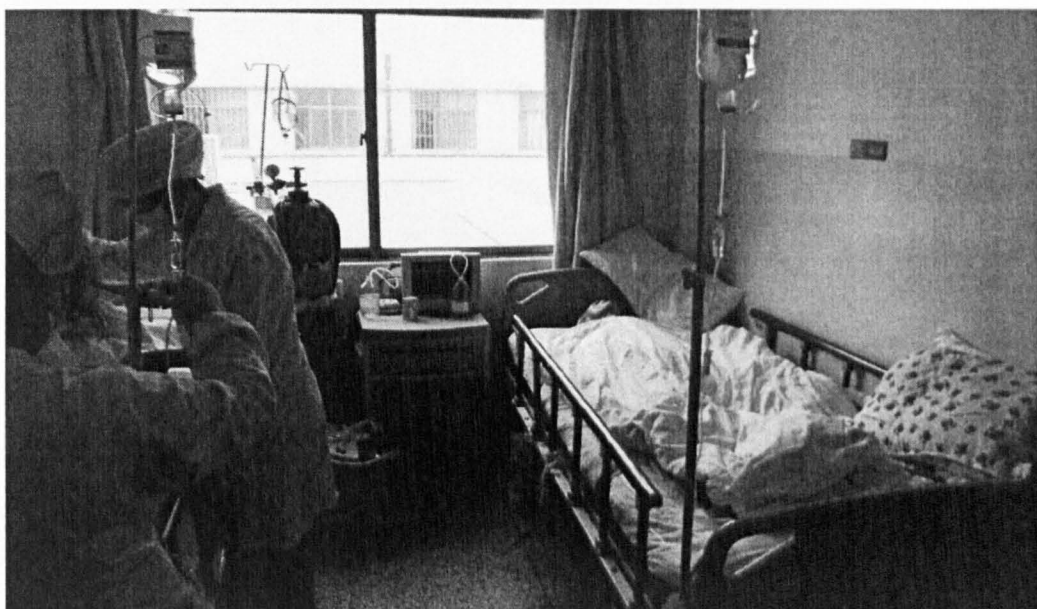
The funeral company's ritual room
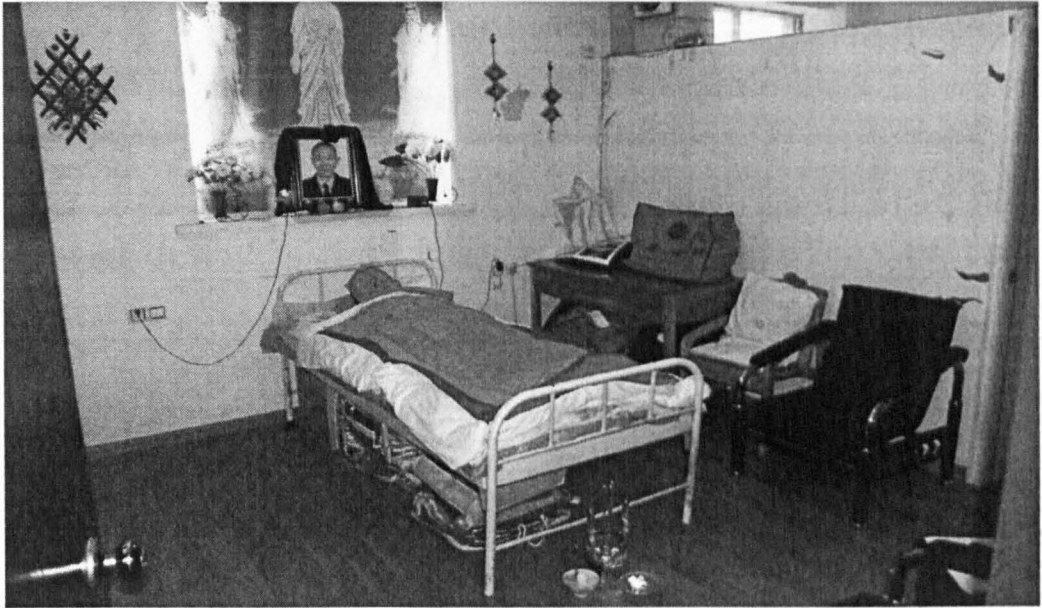
Appendix 4: Demographic information sheet

Demographic Info Questionnaire
基本信息表

Time and Place **时间和地点**	
Sex **性别**	
Age **年龄**	
Ethnicity **民族**	
Religion **宗教信仰**	
Marital status **婚姻状况**	
Educational level **教育水平**	
Occupation **职业**	
Place of living **长期居住地**	
Diagnosis and time of diagnosis (the most recent) **诊断时间及结果（最后一次）**	
When did the current health service start? **现在接受服务的起始时间**	
Remark 备注:	

Code	P	R	H
Pseudonym			
Note: *P- Kunming Palliative Care Ward; R- Cancer Rehabilitation Committee; H- Dehong Hospice*			

Appendix 5: Script for informed consent

Participant Information Sheet
(English version approved by the OU Human Participants and Materials Ethics
Committee)

Introduction

I am Hong CHEN, originally from Kunming, Yunnan Province. Currently, I am a registered PhD student in the Faculty of Health and Social Care, at The Open University, UK. My research interests concern the need for care and support of older people with a diagnosed health problem. You are invited to participate in this study either because you are 60 years or older and have been diagnosed with a health problem, or you are the principal family carer of the invited older people.

Purpose of this research study

The aim of this study is to find out what care and support is needed by ill older people during the course of an illness starting from its diagnosis.

Procedures

You are invited to have a talk with me at a time convenient for you and at a venue of your choosing. During our conversation, I will ask you some questions about your experience in living with a diagnosed health problem (if you are 60 years or older with a health problem), or about your experience of looking after an ill older person (if you are the principal carer of such a person). This will take about 40-60 minutes of your time. I will be using a tape recorder so that I do not miss anything that is said. But if you feel uncomfortable with it at any time, I can turn it off.

Possible risks or benefits

In generating a better understanding of the needs of ill older, by participating you may be benefiting ill older people and their families in the future. Although the aim of the research is to find out about your needs and what might be done in the future to help others in a similar position, you need to be aware that some of the questions might be potentially upsetting. You will be provided with full details of support services available.

Right of refusal to participate and withdrawal

You are free to choose to participate in the study. You may refuse to participate without any adverse consequences or loss of benefits from your care providers who refer you to this study. During the interview, you may decline to answer some or all the questions if you don't feel comfortable. You may also withdraw at any time from the study for any reason. If you decide to withdraw, your contribution up to that point will not be used in the final analysis and will be destroyed if you so request.

Confidentiality

You may be assured that your identity and the data you provide will be kept confidential and anonymised in any publications following this research. This means that when reporting the data, pseudonyms will be used as well as minor editing to change identifiable details.

Script for verbal informed consent before interviews
(Translated and adapted from the English version)

我叫陈宏,是英国开放大学医疗及社会服务学院的博士研究生.大学和一个慈善组织资助我在国内调查了解老年病人的医疗护理和日常生活情况.

调查的方法是同您交谈,也就是听您讲述您的经历,然后问您一些相关的问题.

您可以自由选择是否参与调查,谈话期间您可以拒绝回答问题,也可以随时要求结束谈话.

谈话将被录音,以免遗漏您提供的重要信息.但录音仅限于我本人使用.

您提供的重要信息,将被间接用于我的论文和其它出版物中,如果需要直接引用您所说的话,将使用假名.总之,我保证在任何情况下,不会暴露您的真实身份,并且对您所提供的信息保密,以保证您的利益不受侵害.

英国开放大学
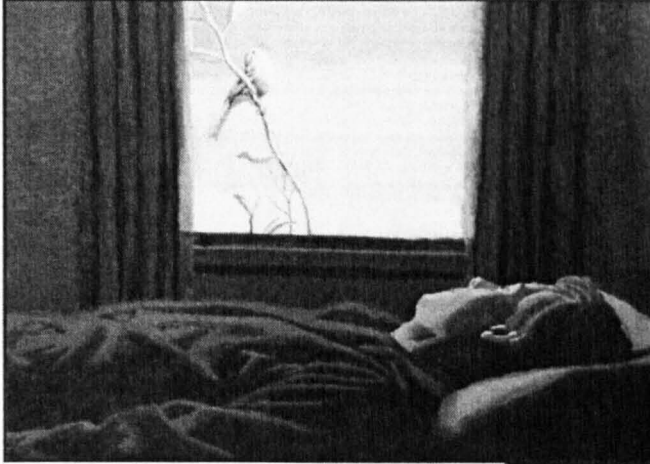The Open University
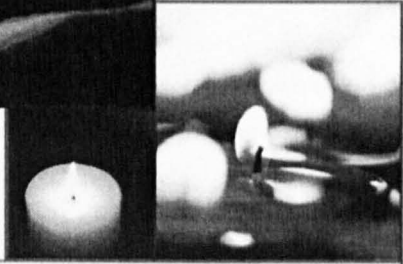
绝境中的希望

-医学社会学研究

顾问：马克主任

导师：
Dr Carol Komaromy
Dr Jackie Watts

研究员：陈宏
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研究目的: 从社会学的角度理解老年癌症病人带病生活的经历

研究对象: 老年癌症病人（60岁以上）

主要研究方法:
- 向病人的主治医生以及其他相关医护人员了解病人的情况
- 对家属进行正式访谈
- 对病人的生活环境进行绘图和拍照
- 对病人进行观察
- 观察地点：纳入研究的病人的病房
- 观察时间：7月26日至8月26日，5个小时/天
- 观察时段：7点－12点，12点－17点，或17点－22点

其它事宜: 有时难免打扰医护人员的日常工作，请多多原谅！并感谢你们的参与和支持！

Appendix 7: An example of an interview transcript

Code	R2
Pseudonym	Guo
Sex	Male
Age	75
Ethnicity	Han
Religion	Christianity
Marital status	Married
Educational level	Technical secondary school
Occupation	Retired worker
Place of living	Kunming
Diagnosis and time of diagnosis	Lung cancer, Mar. 20th, 1996
Time that the current health service started	(From Cancer Rehabilitation Committee)

Interview context:

The interview took place at 9am, May 21st, on the corner of a quieter side street in Dong Hua Community. During the interview, there were noises from passing cars, from the older people exercising in the park and from the children playing in the kindergarten nearby. He often confused and surprised me by giving answers out of my expectation and with lengthy description of all sorts of things. He talked a lot about his biography, background and family situation, later I gradually realized all these have actually shaped his mental attitude toward his illness, which is why it was necessary for him to tell these stories. As I was confused, at times I did not really know what to ask further, I felt myself clumsy over the interview, not sure if he has given me the material that could reveal his hopes and what to ask further to explore his hopes. At times, I felt impatient as he talked randomly about all sorts of things that seemed to me irrelevant, but I remembered that during the first interview, I constantly interrupted the interviewee to pursue my own agenda, so I decided that this time I would try to do it differently and let him ramble on. As a result, most of the time, what he said did make sense, but at times I lost patience and interrupted him. As I reflected on the interview afterwards, I felt that he did surprise me and confuse me with unexpected but indeed very important and interesting data.

I

Now please tell me about your illness experience, freely and as much as you like.

Guo

Since I started working, I had hardly got ill. (I) relied on exercise; I was very good at sports - at 50s I was still able to play football. But unexpectedly, maybe it was some of my hobbies- drinking and

309

smoking and the like, that caused this. But till now, 14 years after I got cancer, I am still smoking and sometimes drink a bit- as a hobby, and it is pretty good. Once when I was on a business trip in Shanghai, I suddenly had hemoptysis. Then I got medical check-ups in Shanghai and (the doctor) gave me injection to subdue the inflammation. In the end, I left Shanghai and went to Hangzhou to work. I had many acquaintances in Hangzhou, so those acquaintances took me to the doctor they knew for check-up. During the check-up, (he/she) listened; as there might be some problem, he/she asked me not to take (X-ray) photograph, then he/she did fluoroscopy of chest for me; then a lump was shown on the top right of my lung, so he/she told my colleague- a factory manager: "you should ask him to go back to Kunming soon, (ask him) not to get further check-ups for his problem, if he does so, he may not be able to come to terms with it". At that time, he/she did not tell me (the diagnosis); he only told me that he would give me an injection if I would go back that day. At that time although I got the check-up in Hangzhou, I was living in Yiyao, so I went back to Yiyao after the injection. Back to Yiyao, he told me this, I said it was fine, but I am not afraid [我说也行，但是不怕]. My wife went there with me; because it was my last business trip and I was about to retire, I took her to Mountain Putuo to travel around. So when he told me about it, I said it was fine. I had already noticed that when I wanted to go from Hangzhou to climb Mountain Huang with my wife, I did not have any strength, which was why I went to see the doctor. (I said:) "it is not a problem at all whether to go back or to stay for a few more days". But he requested me to go back soon. The day before he asked my son to drive there to buy the air ticket; then the next day, they sent me off at Ningbo airport and I came back. After I came back, it took a half year to confirm the diagnosis through check-ups. It was at the end of 1995 when I was on a business trip in Hangzhou that (my problem) was discovered. After an X-ray in Yunda Hospital, it was said to be (…) pathological changes. I was a bit anxious, but my schoolmates working in Yunda Hospital- several directors or vice directors said: "from the location [of the lump], it looks like you cannot get a surgery as it is middlemost; if it is opened, in case the surgery cannot be done, it has to be sealed, in case the surgery can be done, you may not survive the surgery." As we went to school together when we were very young- they knew about my character, they told me not to have a surgery done but to stay calm. I asked Director Yang from Yan An Hospital, who is the director of the radiological department and an excellent doctor I know, he also said that I absolutely should not have the surgery, even if I was (dying of it) [不行了]， I should not have the surgery, it was better to have medicine than to have myself cut open just to find nothing could be done. Therefore, I decided to adopt conservative treatment. But they put forward a plan to eliminate the possibility of TB first before dealing with my malignant tumour- to confirm first if the lump was a TB lump. As a result, the possibility of me having TB was eliminated [he stopped to cough], then they did (…) [he described the details of the biopsy]. I was hospitalized and waited for a month to get the result of the biopsy- cancer cells were found. But I felt a bit strange: my lump was as big as 2.5 * 3 (cm), but I did not feel any pain except for Hemoptysis; several patients who were with me in the hospital died after a month or so, even though their lumps were really small; how come I have survived for so long; I am not sure how but I am still pondering this now. Recently I was thinking

that it was not that the doctor estimated that the lump was malignant, but that they actually took the tissue of the lump for testing so the diagnosis was absolutely no mistake. I was hospitalized in Yan An Hospital but the tissue was tested in another hospital- a higher level research institute. So I was analysing this question; I also asked the doctors about it, but they could not tell me the right reasons. I think that it is because the doctor was very responsible. Why is that? My cousin works in Yan An hospital, so I asked her to get my original record and make a copy of it. On the biopsy report, the doctor wrote: "cancer cells found." So I think that the doctor was very responsible in treating my disease. But the doctor who gave me the treatment died of liver cancer two years later in his 40s. Now I feel balanced, and my lump totally disappeared. I got 7-week "Tan Chun Hua Juan" and "Shun Bai" treatment; the treatment reduced my red cells to the extent that I felt so cold that I had no strength to have on clothes. I felt it was all over with me [不行了]; I thought and thought, but just felt it was all over with me. But in the end, I got better gradually, when (the bleeding was stopped). My personal view is that my own mindset matters. I was a teenager when China was liberated. I was pressured to attend entrance exams to the school during the agrarian reform. During the old society, we had provincial and municipal officers in the family, so we were affected by the political movements very badly, which you cannot understand as you are so young. Since the agrarian reform, I had been affected by the political movements, after which, I felt like a thief who was used to stealing - as I was mistreated many times I became fearless and careless. So when I got the disease, I felt regretful: I had lived through so many political movements, how come at 60, I got cancer? God is so unfair to me. Right? [I: Hmm] I had such a thought, but only this thought of regret but nothing else, so my mental attitude is very balanced. Among cancer patients, there were ones who were hospitalized, who did not want to eat, who did not want to sleep, or who did not want to have chemotherapies; I went to persuade them in person wherever they were hospitalized; as long as the families requested, I was more than happy to go, which shows that my mental attitude is like this. As regard to the political movements, it is hard to say, it is because of the societal change, I was nothing but in charge of the labour union, but they kept mistreating me- excessive criticism and merciless attacks, till the Cultural Revolution, till May 16th [when the notice regarding the Cultural Revolution was promulgated]. I am not a communist because I was not able to be; in 1959 I wanted to join in the communist party, but I could not. I already decided that I should have belief, but it should not be communism, because as long as I applied for the membership, I had to disclose my father and older generations, so I decided not to join. So I had been working like this, but just could not escape the political movements. I recalled that when just graduated from the primary school, I was made to fill out the land certificates only because I was good at calligraphy, and I was locked up, a board hung around my neck which read "landowner"; at that time, I was so bold that I went to see the secretary of the district committee and said I would not fill out the certificates any more and then smashed the board. (...) I was not given the graduate certificate, so I went to the principal's and kowtowed. I got the certificate, and then I was accepted by the school after passing the exams. I studied till 1958; of course I had some benefits- subsidies in the middle school, provided for totally by the country in the vocational secondary school. The problem is that I did not accept the job assigned to me after graduation from the

vocational secondary school. Why? It is impossible to eliminate the brand of a class. Premier Zhou once said we could not choose our origin, but it is only my origin that was no good, how come you mistreated me every time. I was only allowed to work in agriculture, but not industry; you assigned me a job in the mountain, then my whole life would be ruined. So I had to take other measures- like an ant, if you step on me, I would run away quickly; I used me being injured when playing basketball as an excuse to elude the graduation exams- I found a doctor and begged him to give me an disease certificate to prove that I was unable to continue my study and needed suspension; I thanked him for saving my whole life. So I suspended for one year; later, the school asked me to go back to (...); then I came out to look for jobs on my own, eventually found one in the factory. In the factory, in 1958 or 1959, I was well-educated, and the municipality had to invite me to write the Big- character Posters for them; in the end, I dared not look for a partner, those primary school teachers in Wuhua District, we all knew that they had love affairs and that caused them troubles, so I could not look for a partner, I did not marry till when I was nearly 30 years; I am 75 this year but my oldest child is only in his 40s, who is now in America; the second child is almost 40; the third is in her/his 30s. ... [He talked a bit about the sensitivity in talking about political movements, especially with foreigners.] So my mental attitude is like this. Why have I survived? I thought it was due to this. I did not do bad things, so I don't have to hide from and avoid other people; what I got is a real disease. Even if I made some mistakes, I would let others know; maybe some nice people really care about me; so if they criticize me, it would be good to me. So these are my thoughts. I regretted not having gone to the university, fortunately, I made my oldest child graduate from the university. ... [He talked about how he managed to find the right middle school for his oldest child, as the result of which, he passed the entrance exams to the university.] I was really satisfied with him, I told him so. Because he passed the exams and could go to university, my own regret could be totally let go off. I wanted to come to Kunming because I wanted to go to university; it was better in Kunming than in the countryside where I stayed; but it was during the Great Leap Forward in 1958, so they persuaded me to work, but not to study, then they arranged for me the jobs; in the countryside, every time when I filled out the application, they were picky about my father, my grandpa, so I was not allowed to go to university at all; but it was quite another story in Kunming, so I agreed that they arranged for me a job; they first let me work in a renovation company to do some construction work, but I thought I needed to learn some skills, so I went to a machine tool factory first then came to my present factory. This is my personal (experience). With regard to my wife, a relative knew her and made a match between us. She is 11 years younger than me. She went to the middle school, but it was during the Cultural Revolution; as she is 11 years younger, she studied during the Cultural Revolution, it was impossible to learn much during that time. We don't have problems arising from our age difference, but she is less educated plus that she lost her mother as a child and was brought up by her father (her father likes me much too), so I would accommodate her on some matters and let her be, whatever she likes, it is ok with me; right? [I:Hmm] (...) [the horn of a passing car made it impossible to hear him.] My whole family- Zhangs, is doing great now; there were two sisters and 10 brothers, now 7 are still alive; we have houses in the countryside, houses built up in Chuxiong, more than what the old landowners had, so we are

very satisfied. I fall short of the best, but am better than the worst, so I am content, and that is enough. It is meaningless to have the surplus; it is no use at all to have more money but no health, right? [I: Hmm] ...[He said, in the old society, his parents, his aunts etc. were very close to a very nice English priest and learnt virtues from her, so were good at educating children; so his families are good]...[He talked about how come his whole family have come to choose to believe in Christianity and he disagreed that his son join in the communist party]. These are nonsense. My mental attitude is good. Someone asked me about my disease: how come your have recovered so well- now the lump is totally gone. I had my own ideas about injection- you just cannot overdo it; I know about the chemotherapy, in fact, the country produced the chemotherapy medicine just to do trials on us cancer patents and the price is awfully high; 7 therapies of "Shun Bai etc." cost several 10000, my whole families and all relatives in Kunming or in Chuxiong were mobilized to collect the money to treat my disease, as I could only claim it back after discharged from the hospital. So I made up my own mind, after the discharge, the doctors asked me to get CT etc. but I told them it was impossible the lump would have changed much over two months and better not waste money on that. I went to get the check-up 8 months after the discharge; there was some change, so I chose the medicine for myself based on my schoolmate's advice. That was the second time I got chemotherapy and I used "Tai Su"- yew exported from China to America to be extracted- also called paclitaxel. I know that the medicine produced abroad is more standardized than that produced in China- I know Russian and my son knows English; our domestic chemotherapy medicine was only tried on several patients, but according to the instruction, the medicine produced abroad, such as the German medicine- Tan Chun Hua Juan, was tried on several thousands of patients- they are very serious therefore coefficient of safety is high; so I decided to use Tai Su. But it was too expensive; it cost 15000 yuan per time- 200 cc.; and it was self-borne by myself, which is ok with me. The children suggested buying it in America, but I said it would cost 15000 dollars in America if it costs 15000 yuan here, so I rejected them and decided to buy it in Kunming. I persuaded the big boss and the managers of the pharmaceutical company to offer me the price for wholesale, (...) then because I was a cancer patient and they happened to be promoting the medicine, they also offered me a 7% discount; as such, I spent a total of 15000 yuan on it including the hospitalization. After the injection, at 8th month, I went to get check-up again, my lump shrunk a bit. Chemotherapy guaranteed the lump was removed; a surgery should have been done according to the experience abroad, as it is the main treatment; chemotherapy kills both the good and the bad, like extreme left-wing views- good or bad, as long as you think it not right, you kill it. Since that time I got Tai Su, I never had chemotherapy again till now. [I: Hmm] Now I get some "Kang Lai Te" injection made in Hangzhou, it is extracted from semen coicis; it also costs 1000 yuan to get several injections; it can be imported from Europe, although it is produced in Hangzhou; it works well on me, so I mainly get this with no chemotherapy and I keep it up. Since discharged from the hospital, I also take herbal medicine, till now. But my herbal medicine was also very expensive, such as "Jia Zhu" when the lump was still there, and scorpion- 4 scorpions in each dose. Of course, the doctor was my schoolmate; he was grandson and so was I, and we went to school together- he went to study medicine and I studied too; after graduation from the high

school, he stayed home to learn Traditional Chinese Medicine (TCM) from his grandpa; my grandpa was friend to his grandpa, the two families had three-generation contact; his grandpa is still alive-over 90, he could not treat my disease so he asked him to treat my disease; since the discharge, I have been always having his medicine, even now if I have any problem, I would take his herbal medicine; since I got cancer, I never had fever, and I made sure to keep it up. So I am doing great, and this is my mental attitude toward the disease. This is all that I have to say about it! Anything else you want to know?

I

I have got a few questions to ask you.

Guo

That is fine.

I

I did not get you: when were you discharged from the hospital? You were diagnosed in 1995.

Guo

In 1995, it was found; in January, I came back from Hangzhou and started the process of diagnosis, and it was not confirmed till May 20th that it was cancer. Then I was admitted to Yan An Hospital on May 25th.

I

How long did the treatment last?

Guo

I was hospitalized from May 20th to sometime in July, for more than two months-over 70 days.

I

What treatment did you get at that time?

Guo

Chemotherapy.

I

You said that later, you bought something worth over 10000 yuan, is it yew?

Guo

Right, yew. In 1996, I was discharged in July, I stopped the treatment and started to take Chinese herbal medicine; then in 1998, they informed me to get chemotherapy, then I chose for myself yew, so in 1998, I got the injection of yew. Since the yew in 1998, I have never got any chemotherapy again.

I

Is yew herbal injection?

Guo

Right. It is called paclitaxel. It is made in America, but now our country also produces it, in Chengdu. Now it costs only a thousand or so.

I

Now you are getting the injection of the extract of semen coicis.

Guo

Hmm, I got only these types of injections, but nothing else. Now I don't get these injections, if I have fever, I have normal injection.

I

How did you know how to use this herbal medicine?

Guo

Semen coicis was prescribed by my doctors in Yan An Hospitals ...[He talked about the doctors' family situation and fame]

I

So the herbal medicine was prescribed by the doctors in the formal hospitals?

Guo

The herbal medicine is from the formal hospitals and the doctor who gave me treatment is a real TCM doctor...[He talked about the doctor's qualification and close relationship with him, as mentioned above].

I

Is he a Western Medicine (WM) doctor or TCM doctor?

Guo

TCM. I have been always taking his medicine. [I: Oh!] Now I still use several of his prescriptions. So what I have got is WM and TCM combined treatment.

I

Earlier on, you said that you saw the diagnosis report read "cancer cells found", then you commented that the doctor was very responsible. How come?

Guo

I just thought of saying this. In the past when I did not get the report, they said that I had got wrong diagnosis, but I thought it was not wrong diagnosis because my diagnosis did not depend on blood test but ... [He repeated the details of the biopsy]; so I didn't realize this till now. The test report says that cancer cells were found and the doctor signed her name, which shows the doctor was responsible. But if at that time, the doctor was ridiculous and said that my problem was no big deal without taking further measures, my cancer would not have been diagnosed and I could have been gone. [I: Hmm], so it was my good luck. I had this thought in my heart that the doctor was responsible. I mean, my disease was new occurrence, as my lymph nodes did not come out yet· I did not have any on my body but on my lung, several ones, 1cm or so[in diameter]; otherwise, it meant I had metastasis. So I thought that probably the timely diagnosis and treatment was appropriate; now my lump totally disappeared.

I

How did you find out it was degree-three cancer?

Guo

It was written on the discharge certificate. I just noticed it this time when preparing the documents about my disease for my oldest son... [He talked about why his oldest son, now living in America, needed from him these documents about his disease].

I

Did you just recently know it was degree-three cancer?

Guo

No. I knew it before.

I

Who told you this?

Guo

It was written on the first page of the discharge certificate.

I

How did you feel about it at that time?

Guo

At that time, I just felt that nothing could be done about it. Here I have to talk about my personal views of the life and death issues. In the past, I went to Bai Ma temple to do what the Buddhism calls Zen, which is basically the same as Christianity; it was on the Qian Hu Mountain, the couplet said it is to return to be born- it is to die to be borne; in Christianity, it is like this as well, it says that it is like this to be born. What do you get in the sun? It is work; but now they believe in worshiping someone, but I understand it as looking after parents and caring for children. [He answered the phone and told his wife he was about to go back.]

I

Could I talk to you for a little longer? Or do you have to go now?

Guo

Don't worry. We could talk for a bit longer. I could show you the documents about my disease, if you want, but at another time... [He explained the documents were not with him and where they were and why].

I

Don't worry. I don't have to see that since you have told me about your disease. I mainly want to know about your mental attitude and what has been your spiritual support during the process, particularly when it was the most difficult.

Guo

About my spirit, I have to tell you that I am really broad-minded. I have endured so many political movements, during which I was persecuted again and again and ruthlessly, to the point that they worried I would kill myself; but I told them to go to sleep and not to worry about me and that I would live well and absolutely wouldn't die....[He gave an example of why he was persecuted- he was good at using both hands to write]. So this is my mental attitude, which is determined by the sufferings I went through since young. If you want to have a good life, you have to work hard; and I am not afraid of hardness and tiredness. I studied for more than a decade, during which I did not have any shoes to wear, which caused my foot problem thus hospital admission... [He explained his foot problem in detail.] Later I thought that as a human, I always think that I want to have longevity, I cannot (...) Once born, how could I know myself when I will die. So on Qian Hu Mountain, it says that it is to return to be born, it says something else in Bai Ma Temple. When we went to travel, we dropped by these famous places; in Kunming, I went to the temples on West

316

Mountain with them. Everyday, I listen to the bible when I am free; my child recorded the bible in mp3, I could listen to any part of the whole bible; so when I am free, I sit quietly and turn on the bible. Since the Cultural Revolution, I have never read newspapers, I only watch news. Of course I cannot talk (…) now the falsity is way out of line.

I

What is way out of line?

Guo

In our country [He laughed]- of course, you are also Chinese, there is too much falsity, now it has been-it is really hard to say. We can only have this much salary, according to the bible, when you have, you should be content and try not to think of more; all that I want to eat, which is delicious, are all good things, I can only think that way. Of course, you have to consume and play, but I am not willing to be luxurious; I educated my children to be the same, but the younger two were not content; but the oldest knows better, so he is very economical. But we don't want their money; I told them we have enough… [He talked about his oldest son had hoped to go to the UK but did not manage to]

I

Before, when you were the head of the office in the Cancer Rehabilitation Committee, how did you persuade other patients?

Guo

Oh! First, whatever disease you have got, particularly cancer, don't be afraid, don't get anxious; but I told them, in your heart, deep in your thoughts, you must really truly set it aside; it is about life and death, as long as there is life then there is bound to be death; some may live longer, some may live shorter, it is not that one can decide it himself; if you are ill, you have to face it. Some people get cancer and say that "it is all over with me". Over or not, but as long as I can eat and I still have one breath, how can I die? If you are like this, there are several advantages: I am ill, first, I am not anxious, deep down, I am truly not anxious, then I want to eat, drink, sleep, which is good for myself; then when a doctor gives you medicine, the medicine would work better. This is how I persuaded them. Some people, I went to persuade several times. But I am too frank; some people said I was right that they would listen to me; I said to them: "how would you listen to me? Once I leave, you will be like: Ah! I am done [完蛋了]." When one is feeling painful or whatever, you have to have ability to endure it; you have to be sane; for example… [He described how he used to have server headache since young- overwhelming, for no reason and untreatable], the doctors in the end gave me some general advice- they asked me to be sane, when I felt headache, I should use other methods to divert [my attention]. When I got cancer, it started from headache; my teeth was all knocked off, when the doctor saw me, he said he was sorry; I said that he should not feel sorry as it was me who asked him to know off my teeth- I could not bear with the pain anymore; then I had to get false teeth. Now I remember, before I got cancer, I had had toothache besides Hemoptysis; I had had tears when having headache; I insisted that the doctor knock off my teeth although the X-ray showed that my teeth was great; but after the teeth knocked off, I still felt painful in the root of the teeth. In the end, I got cancer and after the chemotherapy, the pain was

317

gone; I regretted a bit, but it was my own choice to have the teeth knocked off, so I should not blame it on the doctor. Then I had to eat softer food, or after I got false teeth, if I want to eat something but could not swallow it, I chew it then spit it out; it is just a waste of food, I spit more at home, when visiting others, I try to take less food. So this is how I persuaded others. But there are many aspects in this, like personal characters, you just have to be a bit sane. Either you have money or not, you should treat your life the same. Theoretically speaking, there should be room left, but the room is left by you. Even if I cannot use it up, why should I be luxurious? You cannot do that; I don't know how to play like that. If I cannot eat that much, it does not make sense to get that much... [He talked randomly about his extended family- assets, persecution, education problems, grandchildren etc.] So this is about mental attitude- it will be great as long as one is content. Well, I cannot tell more details as my memory is no good now.

I

When you knew the diagnosis, what hopes did you have?

Guo

When I recovered, after the discharge from the hospital, I took herbal medicine, I had no cold at all, so I felt recovering day by day; my weight once increased to over 70 kg, so I thought that my disease was very well treated.

I

What about before chemotherapy when you just knew the diagnosis?

Guo

Hmm. I knew it, I was aware of everything. So I agreed with whatever they wanted to do.

I

What hopes did you have at that time?

Guo

I had some selfish thoughts, to be honest. I thought that all my children had got jobs and I just started to have an easier life, but God did not let me have a good life. I only had a little bit of this kind of thought. But on the other hand, I thought that if it was meant to be all over with me and I would die, then I just had to die. When alive, you have thoughts etc. but once you die, you are like sleeping and you know nothing. This is what I thought. ... [He explained how his oldest child and her husband were going through the procedures to go to American, but had to make special arrangements for her to go later because he was ill] When I got ill, my daughter kowtowed several times to press me to go to hospital, but it was one month before my 60th birthday... [He described again how the decision to give up surgery was made, as above-mentioned] She kowtowed and begged me to go to hospital. It was my fault that I did not tell her clearly: I would be 60 after one month; in china we have this traditional notion that when one lives to 60 years, it is a "Hua Jia"[化 甲], if one lives to Hua Jia and dies, one is not a short-lived ghost; in fact there does not exist ghost, of course. Then she said that it was fine and I could do things as I wished. I had got the hospitalization certificate for one month, but I did not go till May 25th which was my birthday; we had birthday dinner on the night of May 24th; they asked me what I wanted to eat, I said duck; they

asked me not to drink, I did not respond, but when the table was set up, I went to get a bottle of "Lu Zhou Lao Jiao" and I had a sip; so the whole family- three children and their spouses and my son's two schoolmates, altogether 8 people, had a dinner together at Xue Cheng restaurent. The next morning, I went to hospital at 6am and stayed. I said to myself that I was 60 years by then, if I went to hospital and died there, I wouldn't be a short-lived ghost, so I would be happy. [I giggled] I just had this traditional thought. But I also had a thought that in my family, male or female, they all lived to over 79 years [I: Hmm], except for my 3rd brother who had special situation...[He said that this brother tried escaping to Burman but was seized; he described why he wanted to escape and how he was persecuted and got ill in custody then died; he said someone else who also escaped but survived and now had a prosperous life; he also described how his family was well treated by nice people although not as prosperous etc.] Then I became well; in 1998, I got Tai Su injection, a half year after the treatment, I went to get CT; at the beginning, it was a lump, then it looked like a crab, in the end, it looked like a spider, so my lump has become bronchial tubes; only the doctors could tell that where the lump used to be looks like a stain from tea; other doctors, like those in No. 43 hospital, could not see [the lump] from the photo, there is a bit shadow, but they could not tell from the photo. If I have any problem, I will go and see them. So it means that Tai Su worked well, more importantly, my herbal medicine worked; except the chemotherapies, I did not take any WM, but all TCM. I still have Jia Zhu now, I bought it by one kilo or two kilos, now it is hard to get it, as it is not allowed to kill pangolin... [He said he tried to get some for a friend who got cancer]. But some people don't understand that WM works faster, whereas TCM works slower, but it treats the disease by adjusting the body; it is about dialectical thinking, so it does not work if you only eat Jia Zhu or only eat scorpion, they are toxic, but when they are mixed, when more than 10 herbal medicine were concocted together and simmered, you then drink it, it works well. [I: Hmm] So I had much Jia Zhu, scorpion, centipede etc. ... [He said how he went about to find wild but not artificial scorpions]. Therefore, to some extent, it is attributable to TCM. Of course, WM suppresses the growth of my cancer cells.

I

What result did you hope to get by taking TCM?

Guo

You cannot find out the result of the TCM, first they wo

I

I mean when you decided to use TCM, what treatment result did you hope for?

Guo

At that time, when I decided to use TCM, it was because of this: first, it was before I went to the Cancer Rehabilitation Committee, my schoolmate told me not to use chemotherapy and asked me to take TCM; in the ancient times, there was cancer as well, it was not treatable so one died without knowing it was cancer; now the science is so advanced, medicine so progressed, so you know what cancer you get; but it is like you adjusts, and if you have got one year to live, you live for one year and if you have one month to live, you live for one month. My families also asked me to go back, my mother was in her 90s (...) Wang Hua Qing was asked to prescribe the medicine for

me; he read and referred to the books; so I took his medicine. My choice of TCM is because I have always preferred TCM; in 1970s, a surgery was necessary for my stomach, but I chose conservative treatment and I took TCM; my stomach healed.

I

So you believe TCM?

Guo

Yes I do. Because in my family, in the past, my brothers, my uncles etc. knew how to prescribe TCM; our family owned a TCM pharmacy; if some poor people came to get medicine, we gave them for free.

I

So when you wanted to take TCM, your main purpose, your hope was to prolong or maintain wo

Guo

Yes, it was to maintain and prolong life; that is, don't think about tomorrow today; today, I get up at dawn, I go somewhere to play for fun, and have some food, at night I go to bed, by the next morning, I say to myself: "don't think of tomorrow today"; I had this thought, but it is not temporary thought. I like working; now at home, I do laundry, mop the floor, clean the bathroom, cooking; I am willing to do these things wherever I go; in the hospital, as long as I could move, when it was a bit dirty, if I had a bit strength, I would get up and mop the floor of the room I stayed.

I

Was there anything you were scared of?

Guo

No, I didn't.

I

Was there anything that made you feel pessimistic or let you down?

Guo

Ah! Feeling pessimistic? I used to compare myself with some schoolmates who were senior engineers and the like and thought that I still had nothing like that. Then I said it did not have much meaning; in my factory, if I was asked to register as some kind of expert, they would give me 10 yuan for that, I'd rather just use 10 yuan less and I could also use my head less...[He talked about his work, how he made friends with some peasants and was treated nicely by them, how low his and his wife's income was, how hard it was for them to provide for three children etc.] My children wore patched clothes, I also had thoughts about it; but what could I do as I really did not have [money]; my income was just that little, it was impossible for me to dress them better. Some people laughed at them, but gradually, our life was getting better; once my oldest child graduated from the university, I managed to arrange for her to work in the Education Bureau of Pan Long District, then she got income and life was getting better gradually; besides, I was able to come to Kunming to work from the countryside...[He described how he fought for his benefit and managed to have his income increased to as much as those who had been always working in Kunming] So I felt content. I mean, don't expect too much.

I

I meant that after you got ill, was there any thing or any people that made you feel pessimistic?

Guo

Ah! Not much really. I just had a bit regret when I got ill and the thought was gone very soon; I said that my life was just getting better then I got ill, God was [unfair], I was a bit pessimistic; but then I thought that I could do nothing about it, so I ignored it. If I had some money, I first guaranteed that I had money for treating my disease; and I was nice to myself in terms of food; I only had that much money, so I made plans to last it till I was paid salary or after that...[He talked about how he managed to provide for the three children with the help of his friends- he always had to borrow money from them and paid back when he had money].

I

Was it when you were ill?

Guo

Not yet.

I

When you got ill, were your three children working?

Guo

When I got ill, they were working.

I

So you did not have to worry about them?

Guo

Basically, I did not have to worry about them.

I

So you only needed to look after yourself.

Guo

My wife and I looked after ourselves.

I

You had to pay for your medicine?

Guo

I could claim back the expense for the medicine from my factory. For cancer patients, medicine was 100% covered. The head of the factory was very nice to me, as I was never slack at work; even when the financial situation of the factory was no good, the head prioritized my reimbursement; the financial staff was nice to me as well and made sure I got money back in time... [He explained he worked well and had good relationship with them when he was in charge of purchasing; he described how he was also nice to people, how some people looked down upon him and how he reacted.]

I

What did you hope for when you went to the Cancer Rehabilitation Committee?

Guo

I had wanted to join in the committee after I got ill, but when I was discharged, I could not even walk; I was so weakened, I was so slim that I was afraid of coldness; the heavy coat I had at home

321

felt like heavy burden that pressured me, in the hospital when I felt cold, they bought for me very light space suit; when I went upstairs, my wife and children had to support me. What I considered was that there was no one at home to look after my wife, as all the children went to work and she was not as good as me in some respects; so when I was still ill, I helped to install the theftproof bars; I said that I was sorry that I had not installed it yet then went to hospital and asked them to do it on their own; but later my disease was cured and once I was discharged, I went to get someone to install the theftproof bar, so it was safer. This is the situation that I had; of course, as a human, is it as true as what a slogan says that one is not afraid of death? It is not possible, deep down, there are some thoughts because older people are gone but there are younger ones to care about, there are also colleagues and friends- some of them are better than brothers. I have always educated my children including my oldest child that they should get along well with people; of course, you cannot always be appropriate, but you cannot say if one is bad to you, you will be bad to him, you should always respect others; you read the bible just to do this, this is how the society gets harmonious, this is how it works; if you are lazy, you will have to steal, rob, kill, and set on fire; you are sinister, then you are corrupted as an officer; ah! about our country, I cannot say anything; over the past 30 years, among civilians, except the killers, there are no criminals; the majority are those who are in office, so this country's economy is empty; we said that it would be fine as long as we have this much salary, we use it up, but in fact, we leaves room for my treatment, if I have to go to hospital, I should have several 10000 yuan; we don't want anything from the children, we want them to live well; it is ok if she doesn't want to come back; I also think of going to America with them to play for a while...[He talked about the possibility and the procedures to go to America].

I

So you want to go to America to play for a while?

Guo

...[He talked about where exactly her daughter is in America and his daughter's family] Yes I will go, I said I did not want to go, but she said she missed me, so I have to go to fulfil her wish. I thought that it was costly to go; you could come back via Hong Kong before, which was cheaper; but now you have to go either via South Korea or Japan, which costs much more; of course, you have to spend money when necessary. I said that it was not necessary, you called me several times per month and heard my voice and knew that I was fine, which should be good enough. My voice is so loud, you may think that I am scolding you, [we giggled] but I can not turn my voice down, I have been always cheerful, if I argue a bit with someone, I forget about it afterwards, then if I see him again but he ignores me, I will call him; so I am just like this. Regarding filial piety, any older people among my relatives- my aunts, my parents, my brothers etc., I never dreamed of anyone, as I was nice enough to them when they were alive, I never dreamed of my father, my mother or anyone. I was nice enough to my parents, my relatives and my friends; some people I used to know, who I met when I was on business trips, remembered me after a long time- I was in charge of supply and marketing and travelled countrywide.

I

What do you mean by "dreamed of someone"?

Guo

Dream is what you dream at night wo

I

What if you dream of someone?

Guo

Like dreaming what I do or what happens to someone, I never had this. First, I sleep well; I have nothing in my heart, so I easily fall asleep; my sleep is good quality; besides, I have a habit- I don't nap much after lunch, it is short, because I read some books on medicine- particularly in European, or western countries, it is not recommended [a blind old lady was groping, so I stopped to help her find her way] They suggest not to nap for too long after lunch, over 10 minutes will be enough, particularly if the quality of your sleep is good. Now sometimes, I have to help my second child- I asked his child to come to my place after the school, she is in grade 4.

I

I asked you just now: when you went to the Caner Rehabilitation Committee, what did you hope to do? What did you hope for?

Guo

I had knew an old chairman who was from the Financial and Economic College, so I got to know that it was kind of public welfare work, it was about doing activities to show love; even now if you go there, they will tell you it is about showing love; I went there in June, 1998, and it was the case. When I went there to work, not only I dedicated myself to work, in charge of the office, but also I sometimes got people to give us some financial support, as we did not even have money for work lunch at that time; at that time, I was still ill, every year my child sent me 2000- 3000 dollars, so I used that money for work lunch; as long as I had money, I used it, after all, 100 dollars was worth 800 – 900 yuan, so it was ok to spend some on work; if I ordered a dish, I could have eaten it all by myself, but with one more person, I could also eat less. So first, I went there for collectively fighting against cancer- the patients who got the same disease gathered together; of course, for me, it is not a problem at all, but for some people, it is a problem to be with patients as they think that they are normal/healthy; so it can be helpful to get together with this community; but in my case, some healthy people also love to be with me; I told them the truth, but they don't evade me. When I went there, they asked me about my background, they really appreciated that I was good at this and that; there were also some patients who had known me and knew that I was a capable man; they also needed people in the office at that time, so I was asked to work there. At the beginning, I was just on duty, after some time, I became a member; then I was made in charge of the office with the other one; and then I became an executive member; I was there till 1995. Now it is quite different; I think that cancer patients are a group of vulnerable people, all with diseases, so when together, we should be peaceful and harmonious; but gradually, there are some people who have selfish ideas and personal considerations, there are bonded groups which are no good; it has been like this already, but I am like if I see something not right, I cannot tolerate it- it is like sands in my eyes, so I don't care who you are and I will say something; if it was someone I got along well with, he would know I had good will therefore we would not feel a gulf between us; but some

people were not happy about what I said, so we had some problems; I don't mean that all the honest people left and all those still there are not honest, but some people are really no good, so I stopped going there and gave up the elections over several terms; I found out these problems while working there, which had added to my mental burden, became a hindrance to my physical exercise, mental health and in other aspects, a hindrance rather than impetus... [He talked about how some members went about and suggested keenly that a Party branch be set up in the Committee and his objection] I had thought that we would not think of and pay attention to the politics as cancer patients, we would watch news about general stuff and chat about all but this thing; this is why I had thought that it would be better to go to the Committee. I went there aiming to make the work better wholeheartedly, but they are different, they are thinking of this, so I stopped going there... [He descried how he worked differently as chairman- in a economical way, how the original purpose of showing love is not the case anymore, how some honest chairmen also left and the donation has been reducing, how the Committee is misleading and doing wrong to the poor patients through involvement in marketing some medicine and pressing patients to buy the medicine etc.] I told people that I can live out at least 5 years, I never worry about how many years I should live, I don't consider this at all; I don't suggest that one should take lots of medicine, lots of snacks- eat whatever delicious; now I am old and cannot eat much, but I make sure I eat two bowls per meal; I have a little snack to taste it, why? if I have too much snack, I will not eat the main meal, then I feel hungry before the next main meal and my stomach problem will come back, so I only taste a little; when I eat main meals, I am not picky at all, I will buy and cook whatever available; I only choose and prepare particular food like chicken or duck when we have guests; but with my own families, it is simpler, but not exactly, since every time my grandson comes, he asks for meat; so we always have one meat dish, that is enough. So as human, it is hard to say, but in conclusion, the mental attitude boils down to the life and death issues; you have to take it lightly.

I

Do you have any plans now?

Guo

I just plan to be like this- exercise every day, of course, to help my children if they have problems; like my second child, she is busy and her husband drives tourist coach- so does my son, so my daughter has to help him collect money, so I would help look after their kid when they need me and try to play less [his phone rang again, he told his wife he was going back soon]

I

I am sorry to have taken up so much of your time.

Guo

Don't worry, if you have anything to ask, just tell me. But is what I just told you ok?

I

Yes of course, what you told me is really interesting wo

Guo

Don't worry... [He explained his wife urged him because they had an appointment with some old friends, but he had told them he would go meet them after our talk]

I

Then is there anything else you want to tell me?

Guo

Not really! [I giggled] What else do you feel I should tell you?

I

I feel that you have told me a lot of things in detail, very interesting indeed!

Guo

About the illness, whoever you are, you must truly set your heart at ease, it is the same as doing other things; the way you treat your life should be that based on your own abilities, you don't treat yourself unfairly, whatever it is; but you cannot be too selfish that you don't owe yourself but owe others, like I have one yuan, but they don't have any, I share; even my son is like this, he has work, but other young boys did not, he had some money but it was not enough to buy everyone a bowl of rice noodle, so he used up his money and bought them the rice noodle but two shared one bowl. We are just like this, when there is a disaster and donation is needed, we donate 10% of our salary when we go to the church, it comes to 100 yuan or so, we don't have more than that, but it is enough that we have this good will.

I

Do you have any long-term plan?

Guo

Long-term plan? How could it be long-term? Even when I was ill, I was hired by someone to work; I am still in my right senses, but it is impossible to work any more. [We both giggled], what else could I make long-term plans on? It is just to play and eat; I asked my little grandson to study hard, and if I can still be around and see him when he is in the middle school, I will be happy to see him around. I have already made my tomb ready, it is in my hometown- Chuxiong, so I will go back there, my brothers ask me to go back. I don't really care about this actually, once one die, there is nothing left. As long as I am alive, I am just like this.

I

Where do you wish to go after death, heaven or wo

Guo

Oh! After you die, according to the bible, if you are like this, for sure you will go to heaven;[we both giggled] according to the principle of classical physics that matter cannot be created or destroyed, soul does exist, so it is like this; that one cannot resurrect from the dead means the body cannot resurrect, but soul still exists. My oldest child is genuine; I said to her that I did read the bible, so she did not need to read for me- she read the bible on the phone for one hour or two, so I said that I could read it myself, no need for her to read for me; I just have bad memory, but it is ok that I just listen (...) I am a bit pure; I can see through those things in the society easily. That is it. So you should work hard!

~ The End ~

Appendix 8: Thematic frameworks

Tree Node Structure in NVivo- The committee

context beyond end-of-life care	
end-of-life care culture	care-related information handling
	co-morbidity
	diagnostic process
	disclosing diagnosis and prognosis
	financial situation
	present health status
	relating to families
	relating to other patients
	relating to the wider community
	self care
	TCM
	treatment decision making
	WM
hopes	
patient's inner focus	belief or religion
	biography
	perceptions about life and death
	perceptions of cancer
	positive qualities

Tree Node Structure in NVivo- The hospice

context beyond end-of-life care	
end-of-life care culture	diagnostic process
	disclosing diagnosis and prognosis
	financial situation
	present health status
	relating to families
	relating to the wider community
	self care
	specialised hospice care
	TCM
	treatment decision making
	WM
hopes	
patient's inner focus	

Tree Node Structure in NVivo- The ward

context beyond end-of-life care			
end-of-life care culture	diagnostic process		
	disclosing diagnosis and prognosis		
	financial situation		
	present health status		
	relating to families		
	relating to the wider community		
	self care		
	specialised palliative care	Individual patients	Care arrangement & negotiation
			perceptions
			reasons for admission
		organisational culture	management of death
			ways of doing and talking
			ways of thinking
		me in the field and reflection	
	TCM		
	treatment decision making		
	WM		
hopes			
patient's inner focus			

Appendix 9: Thematic charts
(Two empty sample charts for each organisation)

The committee
End-of-life Care Culture: Community aspects

	Self care	Relating to families	Relating to the Cancer Rehabilitation Committee	Relating to the wider community	Context beyond end-of-life care
R1	Data	Data	Data	Data	Data

The committee
End-of-life Care Culture: Clinical aspects

	Disclosing diagnosis and prognosis	Treatment decision making	WM	TCM	Financial situation	Co-morbidity
R1						

The hospice
Mental adjustment (inner focus)

H1	

The hospice
Hopes

H1	

The ward
End-of-life Care Culture: Specialised Palliative Care (individual patients)

	Reasons for admission	Perceptions	Care arrangement & negotiation
A53			

The ward
End-of-life Care Culture: Specialised Palliative Care (organisational culture)

	Ways of doing	Ways of thinking
Doctors		
Nurses		
Nursing workers		
Management of death		
Relationships		
Physical environment		
Context beyond organisation		

Appendix 10: An example of a data analysis chart

The Committee: Chart One- End-of-life Care Culture (Clinical aspects)

	Disclosing diagnosis and prognosis	Treatment decision making	WM	TCM	Financial situation	Co-morbidity
R10	Doctors told families; families tried to conceal the truth; the fact that she was hospitalized in Tumour Hospital and patients in her room all got cancer dropped a hint and her suspicion was confirmed by other patients in the same room;	Son and husband made decisions without consulting with her, and coaxed her to receive the surgery despite her rejection due to awareness of other patients' bad experience;	Became frail after 1st surgery; 2nd surgery went wrong- shock, loss of blood, unconsciousness, felt extremely cold, saw yellow waterfall etc.; ashamed of and anxious about artificial excretory opening, then learnt to deal with it on her own; surgery caused life-long sequela- hernia but doctors didn't inform her and make up for it; suffered from hernia and her son found an European doctor to repair it temporarily;	"Took TCM for one month";	"I had to pay 10000 yuan myself, except 40000 or 50000 yuan covered by the insurance;" had no financial problem;	Fitter than before; living with life-long postoperative sequela- hernia
R1	He went to see a doctor alone, but the doctor asked him to get his families to come to get	Decisions were made between his son and doctors as diagnosis was concealed from	Had a surgery and 6 sessions of chemotherapy; suffered from	Healed and prevented ulcers caused by chemotherapy and helped to endure it;	Medical insurance doesn't cover the bags for collecting faces from the	No any reoccurrence or metastasis;

330

	his result, and then doctor talked to his son in privacy, which dropped a hint; in the end, his son told him the truth before the surgery; prefers to be told the truth even if it is advanced cancer because he could then "make good use of this period of time, and leave behind no regrets."	him and then as he was conscious during surgery	chemotherapy- hair fell out, felt cold and ulcers in oral cavity, nasal cavity etc., but was psychologically prepared as doctor already told him what to expect before therapies; reoccurring multiple polyps in intestines removed during check-ups over 5 years, doctors suggested eating yogurt, which helped cure the problem; didn't get any guidance from health professionals regarding postoperative care of the opening and relied on himself to find out how;	prescribed by his TCM doctor friends;	opening, which is 6 yuan per day, not cheap at all; for poorer patients, they could have given up on the bags and compromised on their dignity and quality of life;	
R2	Doctor told his colleague who accompanied him to hospital; then this colleague told him the truth;	He drew on his doctor friends' info and suggestions regarding surgery; he chose chemotherapy medicine on his own having considered cost, credibility, effect and safety issues; he	Surgery was not an option due to the location of tumour; suffered from 7-week chemotherapies- weight loss, felt cold, frail and dying; chemotherapy injection was very	Long-term use due to family tradition and previous positive experience; attributed recovery partly to TCM- it worked slower than WM but it did work; "dialectical thinking"- mixture of certain toxic	For cancer patients, medical expenses were 100% covered, but he had to spend his money on it first then claim it back from his factory after discharge; since chemotherapies	"Feel balanced"; lump totally disappeared;

			preferred TCM because of doctor friend's suggestion, previous positive experience, and family tradition	expensive and those produced abroad were more reliable than domestic ones; "chemotherapy guaranteed the lump was removed" but killed both good and bad cells; WM worked faster than TCM	herbs worked well, it helped body adjust so as to maintain and prolong life; also used TCM injection; it was expensive; prescribed by TCM doctors in polyclinics;	were so expensive, he had to borrow money from families and relatives etc. to get treatment; some medicine he used was self-borne by patients, which was expensive as well; he and his wife are financially independent from their children, so they have to save money for medical treatment;	
R3		Doctors told him directly; he kept his own diagnostic reports and therapeutic reports;	He drew on medical experts' suggestions; he rejected chemotherapy due to his previous negative experience	had systematic radiotherapy but no chemotherapy; had a surgery to remove spleen; receiving biological immunization therapy; got treatment for fractures; taking medicine for epilepsy; felt inconvenient to get treatment in over subdivided policlinics;	Much cheaper, and easier and quicker payment with insurance card than WM; prescribed by policlinic; taken when "there is no severe problem or special situation that entails surgery"; basic principal- treat problem of Yin nature with medicine of Shi nature and vice versa to gain a balance between Yin and Shi	Cancer is one of the "Special and chronic diseases", patients should pay only 20% of the medical expenses; but he found hospitals not really implementing the policy and he had difficulty paying for medicine with his medical insurance card;	Living with neurological problems and shoulder fracture;
R4		Doctor told her husband; her husband concealed	She drew on other patients' suggestions	Unwell after surgery; oversensitivity to	Two strands for cancer treatment: "using	Her factory paid 100% for her treatment	"Haven't got a relapse yet"; sometimes suffer from

	the truth; when hospitalized in one hospital, her roommate suggested her to go to another hospital, so she borrowed her medical record from a nurse, while waiting for the doctor to see her in another hospital, she read her record and found out the truth; prefers to know the truth because then patients can actively seek treatment in time and be cooperative in treatment;	regarding TCM; struggled in deciding whether to take chemotherapies with no one to consult with; one of the doctors delivered info regarding chemotherapy in a confidant and reassuring way, so she accepted chemotherapy; quit immunization therapy as the factory stopped paying for her medical cost and she felt she was fine;	minimal chemotherapy-extreme frailty; allergic to blood transfusion; except one doctor no one decided to give her treatment, some even asked her to go home and live the remaining days well; this doctor's "intensive chemotherapy" caused her kidney pain so she quit it after a half course of treatment; then she got 5-6 courses of immunization therapy till workplace stopped paying for it; both chemotherapy and immunization therapy were expensive;	poison as an antidote to poison" and "strengthening body's self defence/restoration"; chose the latter one and relied on own immunization to inhibit the growth of cancer cells; chose Xuang's medicine because it is "more dialectic" than Huang's- Huang had 7 fixed prescriptions for different cancer locations while Xuang adjusted ingredients based on individual's changing health status; had Xuang's for 5 years non-stop and it worked well; prescribed by TCM doctors in policlinic;	over 5 years; when her factory went bankrupted and stopped paying, she quit immunization therapy, and she had to pay 10% of TCM she took, which caused her financial plight; in addition to burden from medical cost, she also had to provide for her daughter, and her own and her husbands' parents, so she always had financial plight and had to rely on friends and relatives to get by financially; she also worked in private companies to provide for her daughter when she was in the university;	backache due to single kidney;
R5	Doctors told her directly;	Avoidance of surgery, non-adherence to chemotherapies were corrected with her sister's help and with relevant info/knowledge provided for her; chose to take TCM	Tried hard to avoid surgery to create an artificial excretory opening; suffered from both surgery and chemotherapy-weight loss, frailty, loss of appetite,	First, used it to avoid necessary surgery, it was expensive and did not work and prescribed by a private TCM doctor; after chemotherapies, long-term TCM prescribed in a district	She was rich and could afford expensive TCM prescribed by a private doctor; her factory paid for her medical expenses despite that it was in	Recovered from cancer and accompanying long-term depression;

		because of inaccessibility to WM hospital and previous bad experience there;	diarrheal, abdominal pain, felt extreme cold, felt like dying etc.; embarrassed and ashamed of defecating through the opening; also had some immunization therapies; upset about tumour hospital because of physical environment- mosquitoes, noise, witnessed people dying, and because doctors stopped her treatment and wouldn't resume it till workplace gave them advance;	hospital helped her to recover;	debt; the hospital refused to continue treatment when her factory didn't pay advance in time;	
R6	Doctors concealed the truth but in operation theatre, he saw his surgical report on the bulletin board which included his diagnosis; thought doctors did the right thing not to tell him, had he known earlier, he could have fallen apart that his health could have gone so bad that he could not endure a surgery-	Doctors made surgical plans without consulting with him, having concealed the diagnosis from him; he decided to take no treatment as the factory stopped paying for his medical expenses and he felt he was fine;	Surgical plan of flap transposition worked out, otherwise backup plan was amputation; had some physiotherapies after surgery; then it took another year for his foot to function;	Had a course of Huang's medicine, stopped it because it caused him diarrheal and he couldn't afford it;	Despite the policy of full reimbursement for cancer treatment, his factor paid 100% at the beginning, then as it had financial problems, it paid 90%, then 80%, then totally stopped paying, which forced him to stop getting check-ups and	Feeling fine;

	"sometimes it is better to be ignorant".				treatment including TCM; he was laid-off for 4 or 5 years after he got ill, not only he couldn't afford his own medical treatment with his meagre payment but also failed to provide for her daughter when she was in greatest need, and her wife became the main bread-winner;	
R7	Doctors told her directly; her diagnostic process was eventful and time-consuming, so "I didn't care even if it was cancer, but I needed to know what it was to be able to do something about it, otherwise what should I do?"	She stopped treatment as hospitals started to restrict the amount of medicine one can get at one time;	Had a surgery and two sessions of chemotherapies-instilling medicine into bladder; took "biological missiles" for three years, and stopped it due to hospitals' restriction on the amount of medicine given at one time;	Tried 6-day Tibetan TCM prescribed by a private doctor; not expensive, no side-effect, no much effect either;	"Cancer patients could get a "special disease" card; every year, at the outpatient department, we had to pay 980-yuan threshold fee first, then the "comprehensive arrangement for serious disease programme" of the medical insurance [大病统筹] would pay 80%, and we would pay 20%, but I was a civil servant for which the	Suffering from reoccurring multiple polyps in intestines and postoperative sequela-hernia;

335

				government set up a medical subsidy program, so half of the 20% would be paid by the program, so I would pay 10%"; found that not all effective cancer treatment were covered by the insurance;	
R8	Went to see a doctor on her won, and the doctor told her directly;	Decisions made between herself and doctors	Had a surgery and 6 sessions of chemotherapy; found chemotherapy most unbearable in her whole life- hair fell out, looked like a dead, repulsion for smell and food;		As a civil servant, her employer paid for her treatment;	Had another health problem fixed with a surgery; new symptom- bleeding to do with uterus;
R9	Doctors always required to talk secretly with her husband; her husband then tried his best to conceal the truth; she found out she was getting chemotherapies from other patients so she realized it and her husband had to admit it;	Husband made decision with doctors having concealed the truth from her; after she knew the truth, husband assisted her through consulting reliable sources, accompanying her to hospitals and counselling her; doctors' attitudes	1st surgery followed by 8 sessions of chemotherapies from which she didn't suffer; then got radiotherapies with Iodine-125; had reoccurrence at original location, other hospitals refused to give her surgery because of		Paid for Iodine-125 radiotherapy with her pocket money, otherwise her treatment was paid by her employer; well-paid and has better benefit than others as a civil servant, thus has no financial problem;	Had reoccurrence once and other kinds of minor health problems once a while;

336

		either encouraged her to take their suggestions or put her off; she also considered expertise, credibility, and accessibility of the hospitals; rejected by desired hospitals as a difficult case, she could only go to the one which accepted her;	Iodine-125; got 2nd surgery where she got 1st one and Iodine-125; had treatment for other health problems she suspected to be tumour;			

Appendix 11: A patient's gestures

A patient who could not speak because of throat cancer was gesturing: "well done, doctor!"

The patient was gesturing: "Thank you, doctor!"