

End of Life Care for Older Cancer Patients in China:

Lived Experiences from Patients, Family Caregivers and Health Professionals

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To my
GRANDMOTHER
1930-2010

Abstract

This thesis examines the lived experiences of end of life care for older cancer patients in China, as perceived by patients, family caregivers and health professionals. Data were generated from unstructured, in-depth, face to face interviews with 37 participants, including ten patients aged 60 and above with advanced cancer, twelve family caregivers who looked after older cancer patients, and eight doctors and seven nurses, from three healthcare settings, i.e. the oncology department of a hospital, a hospice centre and a community clinic. Three main themes were found from the data analysis, including diagnosis disclosure, living with cancer, and attitudes towards treatment. In each theme, several subthemes were identified for each group of participants as the main components of their experiences. Diagnosis disclosure in China followed a family-oriented paradigm so that patients had different ways of knowing and various levels of awareness of their illness. Chinese cultural and social background, as well as the ethical precedence of beneficence for the patients, contribute to the phenomenon of family-oriented disclosure practice. Cancer patients experienced psychological distress and existential challenges when living with cancer. They adopted different coping strategies with the confrontation strategy as the main approach. Family caregivers' stress was prominent, but their well-being was usually overlooked. Cancer patients and their families had a fighting spirit toward cancer and were actively involved in curative treatment due to unrealistic hope. Their attitudes would also lead to resistance to palliative care. The findings from this study contribute to the limited literature on relevant end of life care issues in China and have important implications for service users, health professionals and policymakers at local and national levels.

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List Abbreviation

ACP	Advance care planning
AD	Advanced directive
AMED	Allied and Complementary Medicine
BAME	Black, Asian and Minority Ethnic
BPI-C	The Chinese version of the Brief Pain Inventory
CAJ	China Academic Journals
CAM	Complementary and alternative medicine
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CNKI	China Knowledge Resource Integrated Database
EOLC	End of life care
EOL	End of life
GP	General practitioner
HC	Health Commission
NGO	Non-government organisation
NHC	National Health Commission
NRCMS	New Rural Cooperative Medical Scheme
NRPS	New Rural Pension Scheme
PC	Palliative care
PIS	Participant information sheet
RMB	Chinese yuan (*renminbi*)
TCM	Traditional Chinese medicine
UEBMI	Urban Employee Basic Medical Insurance
URBMI	Urban Resident Basic Medical Insurance
WHO	World Health Organization
WPCA	Worldwide Palliative Care Alliance
UK	United Kingdom
US	United States

Chapter One Introduction

1.1 Introduction

My interest in end of life care (EOLC) for older cancer patients came from my experience of caring for my grandmother towards the end of her life in China and my working experience with older people in the United Kingdom (UK). Before starting the PhD course, I had worked as a staff nurse in several public and private nursing homes and public hospitals in the UK. Many older people ended their lives in a nursing home. I have experienced many episodes of deaths in my career and witnessed the bereavement of family members. Some of them were cancer patients. As a health professional, I work with other colleagues, and we do our best to meet these people's needs so that they could die in the most dignified way they choose. Health professionals also provide comfort to their family members. By attending the end of life care training organised by my employer, I understand how EOLC services are provided in the Nottinghamshire region in the UK where I am working.

The Nottinghamshire Guideline for Care in the Last Year of Life (Healthcare, 2015) states that EOLC is the responsibility of all health and many social care providers that care for: people with less than one year to live, people with "chronic progressive eventually fatal illness", and people diagnosed with the condition from which they will eventually die, including long term conditions, organ failure, cancer, cerebral-vascular illness, and dementia. The provision of EOLC involves palliative care, where the goal is to achieve the best quality of life for patients and their families. This pathway provides a guideline for all staff from different departments and organisations to work as an effective team in order to provide a better quality of EOLC to individuals and their families and meet their needs. There is also a separate copy of the guideline for patients to understand their choices about their EOLC. This local document

supports the national EOLC strategy in the UK. Following the local and national policy and strategy, hospital clinicians, specialist palliative care teams, general practitioners (GPs), district nurses, Macmillan nurses, other health professionals, and voluntary organisations work together to provide person-centred EOLC to both patient and family.

My working experiences in the UK have made me retrospectively consider the process of caring for my grandmother at the end of her life in China. My grandmother was a very independent woman and used to live with my parents at home in China. She became ill in the winter when she was 79 years old, being struck by pneumonia and then deteriorated with acute heart failure during the treatment. My family did not give up life-prolonging treatment and took her to a big provincial hospital. After three weeks of aggressive treatment, the consultant said nothing more could be done to make her better in the hospital. Since there was no EOLC service in the hospital, we decided to look after her at home and tried our best to maintain the opportunity for her quality of life.

In order to keep her alive for longer and live as comfortable as she could, at great expense, an air conditioner was purchased to maintain the room temperature constantly at 22˚C, and an oxygen ventilator was hired from a local hospital. Since my grandmother had to stay in bed most of the time, with minimal mobility, two people were needed to provide complete personal care every day. Like many other cities in China, there was little support available in the community; for example, there were no district nurses, community carers, or respite care services. Private carers were available in the labour market, but most of them were not well trained. Family affection and her strong will to live meant we managed to support her at home for nearly a year.

During this one year, my parents were the main caregivers, and from time to time, shared duties with my uncle and his wife. My cousin and I also contributed to the care when we went back home. My father made most of the treatment and care decisions on behalf of my grandmother. He told my grandmother that she had common heart disease as other older people of her age. In the beginning, she was in a good spirit and expected to recover – she could easily walk a long distance or climb stairs before she got pneumonia. However, after a while of staying in bed, she seemed to have realised she would stay immobilised and highly dependent on others. She cried every time when I saw her. In that year, my parents were always under great pressure. To look after my grandmother, my mother took early retirement and my father temporarily suspended his business. They had to care for my grandmother day and night and worried about the often occurrence of heart attacks at any time. They both showed symptoms of heart disease during this period. My grandmother felt she became a burden to my parents and insisted on moving to my uncle's house to give my parents a break. After two weeks of moving to my uncle's house, she had another heart attack and was taken to hospital and died there. My parents' heart problems were aggravated by fatigue and fear when caring for my grandmother and the depression after her death. One year later, they both received heart surgery.

Comparing to my working experience in looking after older people in the UK, my family's experience in looking after my grandmother showed a lack of health professional and social care support during the end of life care in China. These personal experiences motivated me to explore more about what other older patients and their families have experienced at the end of their life in China. As a health professional, I also want to understand the perceptions of health professionals who provide treatment and care to older cancer patients in China. Comparing to the UK, China has a limited supply of EOLC services. The Economist Intelligence Unit (2010, 2015) reported that the UK is an acknowledged leader in palliative care and end of life care. It

has been ranked at the top of 80 countries in the overall Quality of Death Index and among the best of all indicators, such as the availability and affordability of end of life care, the environment, and the quality of the care. Other developed countries such as Australia, New Zealand, Ireland, Belgium, and Austria, are also high in such rankings. Contrarily, China, Mexico, Brazil, India, and Uganda are ranked at the bottom of the quality of death table. In particular, China had the lowest rank in 2010 regarding the availability of EOLC. The Economist Intelligence Unit (2015) report stated that the adoption of a palliative care approach in China is slow as most healthcare resources are used in curative treatment. There is limited availability of palliative care, and the quality of the care is inadequate. Only a few charity hospitals and health centres offer such kind of care services to the patient in China. If charitable donations are not available, the financial burden on patients will be high as public subsidies do not fully cover medical treatment costs.

In addition to the limited supply of EOLC, China faces difficulties in increasing demand for the EOLC due to the rapid ageing population combined with the increased incidence and mortality of some diseases, such as cancer, cardiovascular and cerebrovascular diseases. The proportion of the Chinese population older than 60 years has increased from 6% in 1964 to about 13% in 2010, and it is expected to rise to 24% by 2035 (Goss *et al.*, 2014; National Bureau of Statistics of China, 2010). The change in age distribution is a result of the one-child population policy (during 1979-2015) and the increase in average life expectancy (from 46 years in 1950 to 75 in 2010) (Goss *et al.*, 2014). Most of the deaths in China are now due to non-communicable diseases and injuries, with cancer, cardiovascular and cerebrovascular diseases being the top three common causes (about 70% of total deaths per year). Cancer has been the first cause of death in China, accounting for more than 25% of total deaths every year (National Bureau of Statistics of China, 2019). In 2015, there were about 3.9 million new

cancer cases and 2.3 million deaths. The all-cancer mortality-to-incidence ratio was about 0.6, comparing to 0.43 in the European Union and 0.3 in the United States (US) (Cao and Chen, 2019; Goss *et al.*, 2014).

Although the EOLC needs of older patients with cancer are significant, China has not established a well-structured national strategy or guidelines for the development of EOLC. The Chinese government has shown some signals of putting more support and investment in EOLC related services, but there are still cultural, financial and technical barriers to the development of EOLC in China (The Economist Intelligence Unit, 2015; Hu and Feng, 2016). Therefore, it is imperative to carry out research on EOLC issues for the population who are more likely to use it: that is, the older people who have cancer.

Although a considerable amount of literature has been devoted to different specific areas of EOLC in the UK and other developed countries, EOLC is still an emerging topic in China with limited original studies. Existing studies on EOLC issues of cancer patients in China examine the experiences of three different populations: health professionals (physicians and nurses), patients and their family members (detailed literature is in Chapter 3, section 3.4). The studies on the experiences of family caregivers are minimal. The main research themes in the literature include cancer diagnosis disclosure, attitudes toward EOLC, end of life decisions, psychological distress and quality of life.

The previous studies on China provide knowledge and evidence about the attitudes and issues related to the EOLC for cancer patients. However, knowledge is still limited and, to a large extent, based on quantitative surveys. In the majority of existing studies on China, attitudes toward EOLC issues, distress/stress levels, and quality of life are measured by scaled scores according to participants' responses to the pre-designed questions. The meaningfulness

embodied in these figures, respondents' thoughts, feelings and reasons for their behaviours could be further explored through qualitative research.

Based on my interest and experiences, my research aims to explore how people experience the EOLC of older patients with cancer in China. I would like to investigate the experiences and perspectives of both the people who have cancer (the patients) and the people who witness it (the family caregivers and health professionals) in their real-life context in China. In so doing, I use in-depth interviews with three types of participants in a municipal hospital, a charitable hospice and a community clinic in Liaocheng, Shandong Province in China from October 2015 to April 2016. The participants include 8 physicians and 7 nurses caring for cancer patients, 10 patients with advanced cancer, and 12 family caregivers. The data contain participants' own experiences, attitudes, and perspectives toward different aspects of end of life issues related to cancer. The data are analysed following the phenomenological methodology. In this thesis, I report three main themes identified from the data: diagnosis disclosure, living with cancer and death, and the attitudes to treatment at the end of life. Each theme involves different sub-themes from the experiences of the three groups of participants, as mentioned earlier.

To my best knowledge, this is the first study to use an interpretive phenomenological approach to gain a better understanding of EOLC for older cancer patients in China. This study focuses on the lived care experiences from three groups of participants: patients, families and health professionals. The careful design of the study allows me to provide a unique and comprehensive understanding of EOLC issues. It makes a substantial contribution to the limited literature capturing the lived experiences of patients and family caregivers in China and developing countries. The findings are useful to facilitate the development of knowledge that can be used by health professionals, caregivers, and Chinese authorities to improve the care for older people at the end of their life. The results are also helpful for other countries to understand

the EOLC issues in Chinese culture. Governments around the world are recognising the importance of including the voices of both users and providers in the development of services.

1.2 Structure of the Thesis

The thesis is structured as follows. Chapter two presents background information about the development of EOLC, the needs of EOLC for older people, and the Chinese health care system, including infrastructure and access to medical care, medical insurance coverage and limitations. It also introduces the development of EOLC and attitudes toward EOLC in China and the family's role as indispensable caregivers and decision-makers of older patients.

Chapter three provides an overview of EOLC research topics worldwide and a literature review of related research in China. This chapter highlights the importance of cultural factors in influencing the understanding of EOLC issues. The literature review on China helps identify the gaps and hence validate the aim and objectives of this research.

Chapter four describes the methodology and methods employed in this research, explaining why Heidegger's interpretive phenomenology is selected as the research approach. Detailed research methods are also reported, including the settings, participants recruitment, data collection, data analysis, and ethical considerations.

The next three chapters report the findings through three key themes: diagnosis disclosure, living with cancer, and attitudes to treatment, with a number of subthemes and sub-subthemes identified in each chapter. Chapter five discusses how the truth of cancer diagnosis was disclosed to the family members and the patients and how the participants thought of the ways of the disclosure. Cultural and non-cultural influences, as well as the preferences in medical ethics, are included in the discussion. Chapter six analyses the experiences of patients and

family members living with cancer and death. The analysis focuses on the meaning of having cancer, patients' and families' emotional difficulties and how they cope with these difficulties. Chapter seven examines the attitudes to anti-cancer treatments at the end of cancer patients' life. Since Chapters 5-7 cover different aspects of EOLC, each chapter is standalone and involves the findings and discussion around the corresponding topic.

Chapter eight concludes the thesis, comprising a review of the findings, a discussion of the contributions, practical and policy implications, the limitations in data collection and methodology, and an outline of future research.

Chapter Two Background

2.1 Introduction

In this chapter, I first introduce the development of palliative and end of life (EOL) care worldwide, including the definitions and the evolution of the ideas of palliative/EOL care. I then discuss the increasing need for palliative/EOL care for older people from the global level to the Chinese context. Next, I illustrate the Chinese healthcare system, including its infrastructure and insurance system. I then give further explanations of EOLC in China, including the evolution of EOLC and attitudes to death and EOLC. Finally, I explicate the role of family members in caring for older people in China.

2.2 The Development of EOLC

Palliative/EOL care is a relatively new concept in China but has been established many decades in developed countries. EOLC usually refers to health and social care for people towards the end of their life. EOLC and Palliative care (PC) are often used interchangeably. The theoretical framework of palliative care has been thought to be used in defining EOLC (Ross *et al.*, 2000). According to the website of the World Health Organization (WHO), palliative care is "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" (WHO, 2020). Palliative care includes hospice services and non-hospice palliative care services delivered in hospitals or the community. It involves a range of services provided by different professionals, including physicians, nursing, support workers, paramedics, pharmacists, physiotherapists and

volunteers. These professionals play equally important roles in supporting the patient and their family.

Unlike palliative care, EOLC does not have a shared definition across or within the health and social care services (Shipman et al., 2008). The term EOLC usually refers to the last stage of life, such as within the last year, the last few months or days of life (Goodman et al., 2012). Here EOLC is seen as a descriptive term related to any services provided to an individual with a serious chronic illness that cannot be stabilised or reversed until the point of death (Dy et al., 2012). EOLC is recognised to "include palliative care but also refer to broader social, legal and spiritual elements of care to the quality of death" (The Economist Intelligence Unit, 2010, p5). In this study, EOLC is also seen as including palliative care or as being interchangeable with it.

The development of modern palliative care originated in the modern hospice movement spearheaded by Dame Cicely Saunders in the UK in the 1960s (Clark, 2007; Seymour, 2012). Saunders introduced the idea of "total pain" by realizing the complex needs of cancer patients, encompassing physical, psychological, social, emotional, and spiritual elements experienced by patients and families. Therefore, "total care" should be provided to the patients, including effective pain management and addressing the practical, social, spiritual needs of patients and families. This new approach to caring for dying people formed the basis of palliative care and was a revolution to the traditional prevailing ethos that patients should be cured, with death as a sign of medical failure and the belief that hiding the true diagnosis from patients was acceptable (Clark and Seymour, 1999; Saunders and Clark, 2006). During the same period, theories in death and dying were developed in the USA. Glaser and Strauss published their study named "Awareness of Dying" (1965), which identified four distinctly different awareness contexts between hospital staff and patients: closed awareness, suspected awareness,

mutual pretence awareness, and open awareness. This seminal theory has influenced the prevalence of open communication between dying patients, health professionals, and their families and continues to provide relevant suggestions for improving the quality of EOLC (Armstrong-Coster, 2004; Andrews and Nathaniel, 2015). Elisabeth Kübler-Ross also published a book entitled "On Death and Dying" (1969), which first described five stages of grief in dying: denial, anger, bargaining, depression, and acceptance. This book impacted attitudes to death and dying at that period and caused much public reaction and awareness of death throughout the century, making it possible for palliative care to be considered (Milićević, 2002; Sheehan *et al.*, 2003). Since the 1970s, hospice and palliative care have developed in many settings closely related to oncology. Palliative care began to be synonymous with the physical, social, psychological, and spiritual support of cancer patients, delivered by a multidisciplinary team (Clark, 2007). For example, in the UK, there were a growing number of new hospices, some of which were funded by the National Health Service (NHS); more hospitals were equipped with multidisciplinary palliative care teams or specialist palliative care clinical nurses; and cancer charities, such as Macmillan Cancer Support and Marie Curie, played important roles in promoting palliative care to cancer patients.

Since the 1980s, the endorsement of the WHO has been important for the ongoing development of palliative care worldwide (Clark, 2007). In 1986, the WHO proposed a global Programme for Cancer Pain Relief, a three-step analgesic ladder, as a guide to using opioids in pain management for cancer patients (Meldrum, 2005). Following that, the WHO raised further debate about the relationship between oncological treatment and palliative care, which enhanced the acknowledgement that curative care and palliative care are not mutually exclusive. The WHO also recommended greater emphasis on palliative care in allocating care resources (Higginson, 1993; Clark, 2007) and promoting a multi-dimensional and multi-professional

approach in palliative care (Seymour, 2012). In recent years, the WHO called for palliative care to be further rolled out as part of health systems (Clark *et al.*, 2018). In 2018, the WHO published practical guidance on integrating palliative care into healthcare systems and highlighted that palliative care needs to be provided in the community or at home, as part of primary health care, considering people's values and preferences (WHO, 2018). The 2030 Agenda slogan 'Leave no-one behind' indicates that governments need to develop sustainable palliative care policies to meet the global palliative care needs (WHO, 2021).

In addition to the WHO, other international collaborations also supported the development of palliative care. International networks were firstly established in Europe and North America. For example, the First International Congress on the Care of the Terminally Ill was organised in 1976; the establishment of the European Association for Palliative Care was in 1988; and the publishment of the international newsletter of St Christopher's Hospice in London began in 1990 (Clark, 2007; Seymour, 2012). In the early 21st century, similar associations and network platforms extended to developing countries in Latin American, Asia and Africa.

From the early 1990s, a gradual transformation of the rhetoric of palliative care for cancer patients to end-of-life care for all occurred internationally (Seymour, 2012). The focus of palliative care expanded from cancer patients only to people with other terminal diseases (World Health Organization, 2004). The term "end of life care" also became popular due to the soaring cost of health care in the last year of life and increased awareness of the negative impact of aggressive treatments on dying patients (Seymour, 2012). This transformation to end-of-life care has led governments to make care policy in advance when facing a radically changed social demographic population structure. As a global leader in the EOLC, UK published a national "End of Life Care Strategy" in 2008 to promote high-quality care for all adults at the end of life by focusing on patients' needs and preferences (Department of Health, 2008). This

strategy draws attention to person-centred care and defines “a good death” as: being treated as an individual, with dignity and respect; being without pain and other symptoms; being in familiar surroundings; and being in the company of close family and/or friends. The Dying Matters coalition originated in 2009 and aimed to shift the culture and character of death, dying and bereavement in public (Seymour, 2012).

2.3 The Need for EOLC for Older People

According to the Global Atlas of Palliative Care (WHO and WHPCA, 2020), the global need for palliative care is increasing due to the world’s ageing population, increases in cancer and other non-communicable diseases and the recent emergence of COVID-19. The WHO (2020) estimates that there are 40 million people in need of palliative care each year.

Among all age groups, the need for EOLC for older people is huge. On the one hand, declining fertility and increasing longevity contribute to population ageing in most countries, and longevity comes with more advanced and chronic diseases that increase the complex needs of older people. Approximately 40% of patients in need of palliative care were aged 70 years or older in 2017, and almost 70% of adult palliative care needs are associated with a non-communicable disease, such as cancer, cardiovascular diseases, dementia, arthritis, and diabetes (WHO and WHPCA, 2020). On the other hand, economic development in the majority of countries has led to increasing demand for quality of life/death.

Meeting older people’s palliative care needs has become a public health challenge (WHO, 2011). It is estimated that only 14% of global patients received palliative care in 2020 and most of them are provided in developed countries in North America, Europe, and Australia (WHO, 2020). Even in these high-income countries, inequities still exist in palliative care. In the UK,

it is reported that older patients with non-cancer illness have less satisfaction with support and care received towards the end of life than patients with cancer (Burt et al., 2009; Burt, 2011). And in acute hospitals in the UK, health professionals still hold different opinions about whether to select a curative or palliative care approach for patients, and there is confusion over the roles and responsibilities of specialist and generalist palliative care providers (Gardiner et al., 2011). Furthermore, 78% of people in need of palliative care live in low- and middle-income countries and access to quality palliative care continues to be minimal in these countries (WHO, 2020). The need for palliative care in these countries is acute because diseases like cancer are normally diagnosed at a late stage when curative methods may be ineffective and inappropriate (Clark et al., 2018).

The unprecedented global pandemic of COVID-19 has caused a further challenge in providing quality EOLC for older people (Lapid *et al.*, 2020). COVID-19 brings a much higher fatality rate in older people (8.6% - 13.4% for people over 70 years old) than in those under 45 years old (0.0026% - 0.3%) (Ruan, 2020; Zhou *et al.*, 2020). With such large numbers dying worldwide, healthcare providers have been forced to consider end-of-life issues, particularly in resource-limited settings (Pattison, 2020). It is argued that the primary roles of beneficence and nonmaleficence in the allocation of limited ICU resources has led to older people being more easily diverted into palliative/ EOL care during the pandemic (Lapid et al., 2020). Furthermore, the COVID-19 pandemic has highlighted the global inequity in palliative care as people who live in impoverished and densely populated areas with weak health systems have been more likely to catch the virus and to have less access to medical care and to palliative and EOL care (Rodin *et al.*, 2020). The pandemic also underlined the absence of an integrated framework for coordination and decision-making across public health, clinical medicine and palliative/EOL care in most countries. Therefore, integrated planning across these domains is needed to allow

more coordinated resource allocation and better preparedness for future public health challenges.

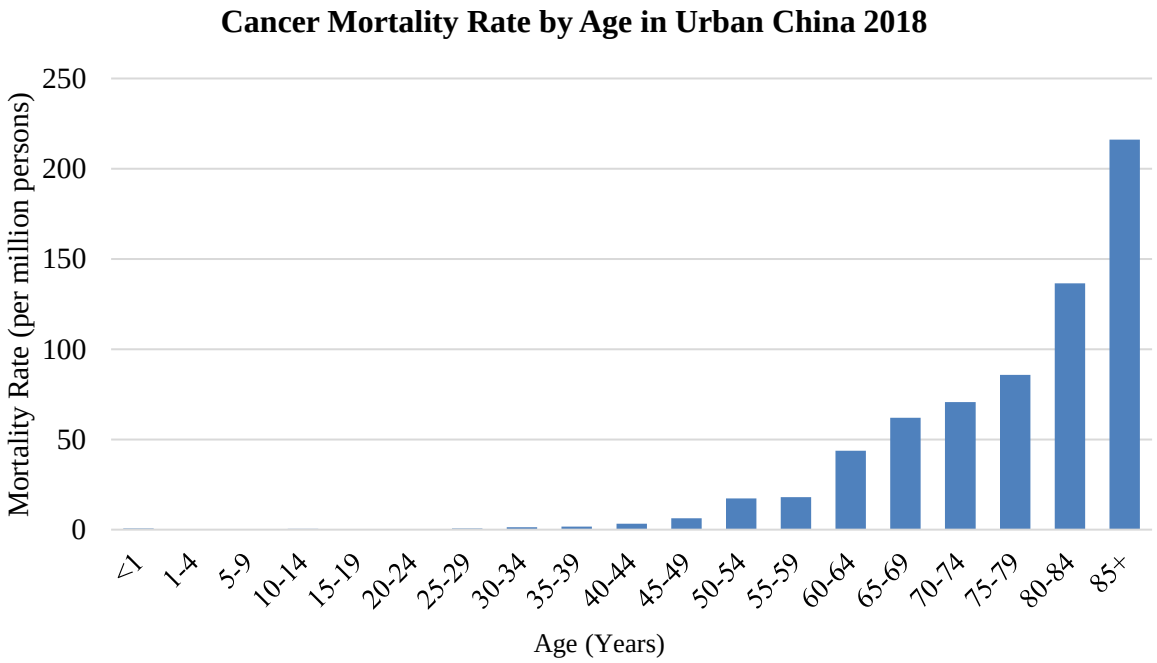
In order to meet the increasing demand for palliative and EOL care in developing countries, policymakers require research-based evidence on EOLC, such as assessing service users' increasing needs and evaluating the effectiveness and cost-effectiveness of interventions (Clark *et al.*, 2018). Although there is substantial literature on palliative care, limited research has been carried out in low- and middle- income countries (Singh and Harding, 2011; Clark *et al.*, 2018). Previous research shows that differences in culture and divergence in care settings affect how palliative care should be provided. For example, the community-based palliative care model is more suitable in Bangladesh, while the island hospice model is more successful in Zimbabwe (WHO and WHPCA, 2020). Research also demonstrates that the most challenging aspects of developing palliative/EOL care in China are not technical but cultural barriers, that is to say, how to develop an innovative approach to get the principle of palliative/EOL care situated into Chinese context (The Economist Intelligence Unit, 2015).

2.4 The Need for EOLC for Older People in China

China, a large middle-income country with a limited supply of palliative/EOL care, struggles to meet the rapidly growing demand from the public (The Economist Intelligence Unit, 2015). The Chinese population is ageing rapidly. At the end of 2019, China had more than 18% of its 1.4 billion population (around 250 million) aged 60years or above, with an average life expectancy of 76.3 years. As the leading cause of death in China, cancer accounts for nearly 27% of deaths and about one-fifth of the total global deaths (Zeng et al., 2018). During 2004-2005, cancer mortality in elderly Chinese people was over 65%, which is substantially higher than those less than 60 years old (Zou et al., 2012). It has been reported that cancer mortality

in mainland China will gradually increase in the next two decades, and the expected number of cancer deaths will be 3.5 million in 2030 (Chen et al., 2012; Dai et al., 2012). Furthermore, there is an increase in cancer mortality as people get older (Figure 1). Even though cancer is the leading cause of mortality in China, the majority of terminally ill patients do not receive appropriate care at the end of life (Lu et al., 2018), and very little is known about their experiences towards the end of their life.

Figure 1 Cancer Crude Mortality Rate in Urban China, 2018



Source: China Health and Family Planning Statistical Yearbook 2019.

2.5 Chinese Healthcare System

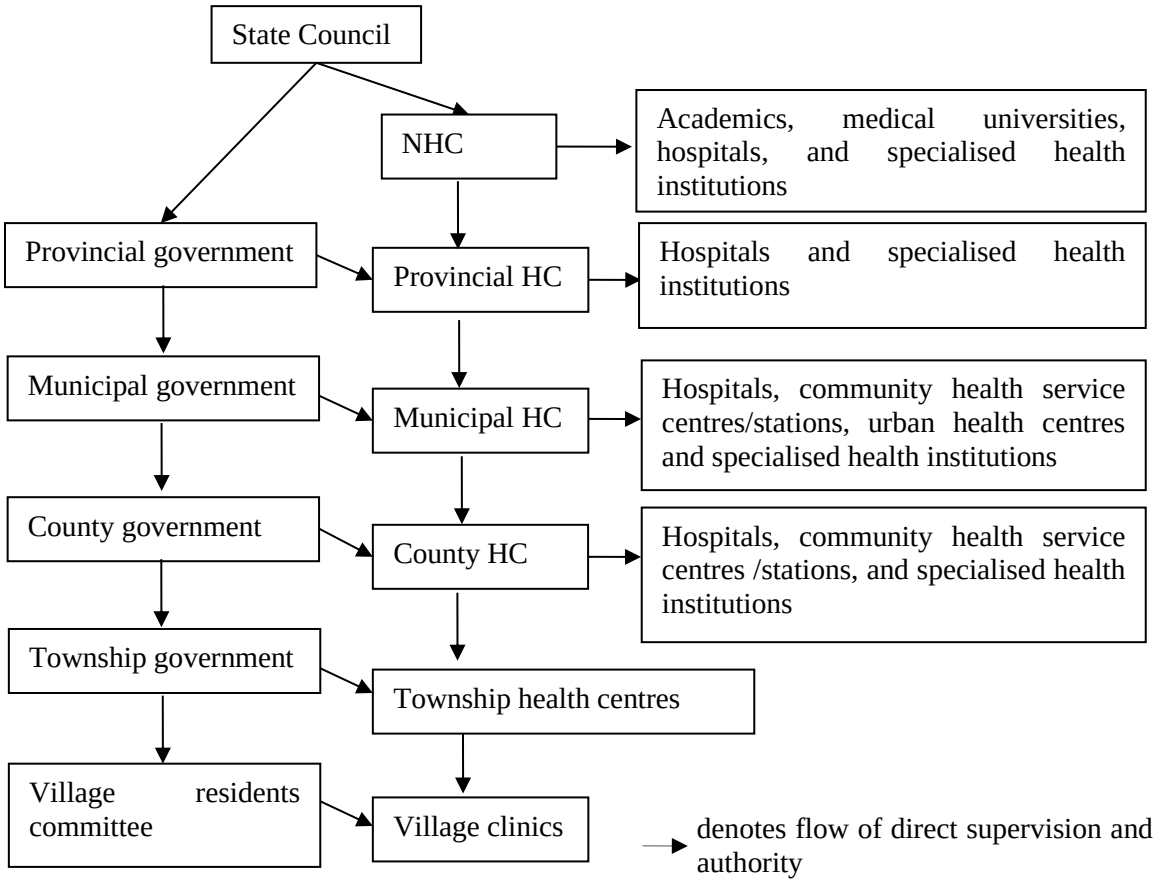
To examine the EOLC issues for older cancer patients, it is needed to understand some background related to China's healthcare system and EOLC. In the following sections, I introduce China's healthcare system, including the infrastructure and the insurance system.

2.5.1 Healthcare Infrastructure

In China, the healthcare system is led by the National Health Commission (NHC), a department of the State Council. Its predecessor was the National Health and Family Planning Commission, which was set up in 2013 following the central government's announcement of a national health reform plan in 2009. Its main responsibilities include drafting laws and regulations of health and sanitation; promoting public hospital reform; planning disease prevention and control; drawing up and implementing policy related to the ageing population and promoting elderly health services system; formulating national drug policy and essential medicine system; dealing with public health issues; raising health awareness and education; ensuring the allocation of health and family planning services; and monitoring the quality of healthcare services nationally. The governance of healthcare and the implementation of relevant laws and regulations are decentralised to Health Commissions (HCs) at different administrative levels in 31 provinces and autonomous regions. These HCs are also responsible for regional rules and technical regulations of health, family planning and the development of traditional Chinese medicine.

The administrative levels of the healthcare system are from the highest national level to the lowest village (see Figure 2). The government at the town level and above has a functional HC, which is subordinate to the corresponding government as well as the HC at a higher administrative level. The government at each level has hospitals and/or other healthcare institutions which are supervised by the corresponding HC.

Figure 2 Administrative Framework of Chinese Healthcare System



Source: Created by the author based on information of NHC (http://www.nhc.gov.cn/).

Generally, health services in China are delivered by three types of organisations: hospitals, healthcare institutions at the grass-root level, and specialised public health institutions. Healthcare institutions at the grass-root level include community health service centres/stations, urban health centres, township health centres, village clinics and outpatient departments and clinics. Specialised public health institutions include centres for disease control and prevention, specialised disease prevention and treatment institutions, women and children care agencies, health education institutions, first aid centres, blood gathering and supplying instructions, health supervision and inspection agencies, and family planning technical service centres.

In 2014 (the year when this research started), the total number of hospitals in China was 25,860, including 16,524 general hospitals (64%), 3,115 traditional Chinese medicine hospitals (12%) and 5,478 specialised hospitals (21%) (National Bureau Statistic of China 2019). Nearly 60% of hospitals are public hospitals and the number of private hospitals has been growing in recent years. There were 917,335 healthcare institutions at grass-root levels, consisting of 34,238 community health service centres (3.7%), 595 urban health centres (0.01%), 36,902 township health centres (4%), 645,470 village clinics (70%), and 200,130 outpatient departments (22%). In addition, the number of specialised public health institutions was 35,029 (38%). Over time, the number of different types of health institutions has kept growing, except for small reductions of township health centres and village clinics. The number of health professionals in 2014 was 10.23 million, including 2.89 million physicians and 2.37 million nurses. Hospital beds were about 5 million, or the hospital bed coverage was about 3.6 per 1000 population, similar to other upper-middle-income countries (National Bureau of Statistics of China, 2019; Goss *et al.*, 2014).

The quantity of medical services does not reflect the quality of services (Knight and Song, 1999). There are disparities in access to health institutions in China. Hospitals in China are classified into three tiers (primary, secondary and tertiary) based on their ability to provide medical care, medical education and medical research, and further into 6 different levels (A and B in each tier) based on their service provision, size, technology, equipment, and management. The best hospitals (at tertiary A or 3A) can be found in almost all major cities. These hospitals tend to have better medical equipment and attract competent and well-trained medical staff. Among the 3A hospitals, those in large cities (such as Beijing, Shanghai and provincial capitals) have the best resources. However, county hospitals, township health centres, and village clinics have low-quality of medical services. The inequity in resource

allocation makes it hard for the poor rural population to access high-quality medical services due to distance, personal *guanxi* (relationship or networks) and financial affordability. In addition to the urban-rural disparities, the regional disparities of the distribution of medical resources also exist. For example, there are 8.5 doctors or nurses per 100 people in the relatively rich eastern provinces but 2.8 per 100 people in the less developed, western provinces in China (Goss *et al.*, 2014).

In the 1950s, China started to build cancer hospitals in each province and some major cities. Nowadays, there are more than 200 cancer hospitals, with more than 30 tertiary-level hospitals that provide the highest level of care. In addition, many general hospitals have oncology departments. Overall, the number of beds for cancer care was about 134,395 in 2010 (Goss *et al.*, 2014). In China, patients are free to choose their health-care providers, regardless of institutional type and location. Given the fatal nature of cancer, cancer patients tend to go to large tertiary-level hospitals in urban areas. This can lead to overcrowding in these hospitals and increase the out-of-pocket expenses for cancer patients.

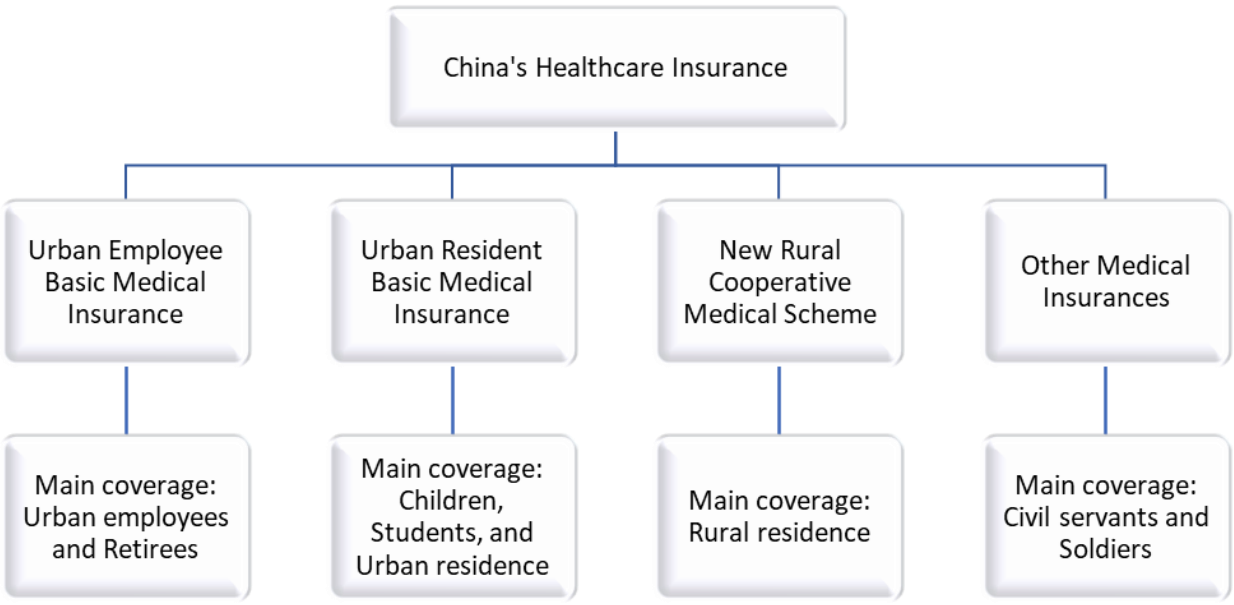
Apart from the hospitals and beds, there is a shortage of oncologists, which are unevenly distributed across the country. According to China Health and Family Planning Statistical Yearbook 2013, among the 2.14 million registered physicians, oncologists only accounted for 1.0%. Eastern provinces, which have a relatively high income, attracted 43.6% of the licenced physicians, while the poorer central and western provinces had 29.2% and 22.1% of the physicians, respectively. Some studies suggested that most oncologists have a sound knowledge of modern cancer treatments, but qualified health professionals for cancer care are concentrated in tertiary hospitals (Goss *et al.*, 2014). Besides, many physicians are subspecialised as tumour-specific oncologists, which further reduces the doctor-to-patient ratio for specific types of cancer.

2.5.2 Healthcare Insurance

In 2014, the total health expenditure was 3531.2 billion RMB (Chinese yuan), about 5.4% of its GDP compared to an average of over 10% of GDP in the European Union (National Bureau of Statistics of China, 2019; Goss *et al.*, 2014). The expenditure was generally evenly distributed among the government (30%), society (38%) and individuals (32%). In recent years, the share of the societal contribution increased to 42%, while the proportions of the government and individuals both declined to 29%. The cost of cancer care was about 0.11% of total national income per capita in China, much lower than those in the UK (0.51%), Japan (0.6%) and the US (1.02%) (Goss et al. 2014).

Over the past several decades, China's healthcare system has been privatised, with many rural residents uninsured. To address the inequality in healthcare access, the Chinese government aims to increase basic health insurance coverage by 2020. Nowadays, China has three basic medical insurance schemes: Urban Employee Basic Medical Insurance (UEBMI), Urban Resident Basic Medical Insurance (URBMI) and a New Rural Cooperative Medical Scheme (NRCMS) (as shown in Figure 3). Employees in the military, public management, social security and social organizations have other types of medical insurances coverage based on their employers. Although most Chinese people (95%) have been covered by the Basic Medical Care Insurance at present, when I was doing the fieldwork in 2015, the national coverage rate was less than 50%, according to the Chinese Statistical Yearbook.

Figure 3 China Healthcare Insurance System



Source: Created by the author.

The insurance schemes are implemented differently by region, type of insurance, type of disease, the medicine used and hospital levels. Some provinces, for example, require a minimum of 15 years of payment before retirement, while others may need payments for 30 years. UEBMI scheme charges a higher fee from individuals than URBMI and NRCMS and also has a higher reimbursement rate. Patients can claim a relatively high proportion of expenses if they go to nearby designated hospitals/clinics. If a patient has to be transferred to a hospital that is at a higher level or out of the designated area, transfer permission is required, but the reimbursement rate would be lower than that in a local hospital. Therefore, even though basic medical insurance schemes have covered most population in China, patients still have to pay for a large proportion of out-of-pocket expenditures. This is particularly true for those who go to higher-level hospitals in bigger cities far from their hometown without an inter-hospital referral. The same happens if they use new medicine or medicine that is not on the National

Drug Reimbursement List, which is very common for cancer patients. Costs of travel, accommodation and subsistence while receiving treatment in a large city are also added to the overall cost. In this case, individual financial condition determines what levels of hospitals the patient could access and what types of treatment they could sustain.

Given the above medical insurance system, cancer patients are at risk of having their access to medical resources restricted by their personal finances. The average cost of cancer care is estimated to be more than ¥100,000 ($15,076) (Hicks *et al.*, 2011). A study on non-small-cell lung cancer reported that the average cost of care in the final 3 months of life was $16,955 at 2007 prices. This cost was nearly 10 times the household disposable income per capita ($1,788 in 2007), even though some could be reimbursed by insurance providers (Zeng *et al.*, 2012; National Bureau of Statistics of China, 2019). Furthermore, the cost of cancer is compounded by the cost of anticancer drugs. China's approval for new drugs is slow. Many new drugs that have been approved in the US or Europe are usually delayed in approval or not approved, or have restricted approval. New drugs are often not on the National Essential Drugs List or local Reimbursement Drug List. As a result, drug costs take a large proportion of total cancer care in China (Zeng *et al.*, 2012; Goss *et al.*, 2014), and patients have limited access to the best anticancer drugs.

To address the high costs of cancer care for patients, China identified specific priority diseases in 2013 and aimed to cover 70% of the inpatient expenses. The cancers included in this scheme include childhood leukaemia, breast cancer, cervical cancer, chronic myeloid leukaemia, lung cancer, oesophageal cancer, gastric cancer, and colorectal cancer. Similar to basic medical insurance, most of the population has been covered by the insurance of priority disease. However, the reimbursement of the medical expenses of these diseases still has the same problems as the basic medical insurance: the reimbursement policy varies across regions; only

the drugs in the national or local drugs lists are covered; other related costs such as travel, accommodation, family care cost, and loss of wage, are not covered. Therefore, this insurance for priority diseases has a limited impact on reducing the medical expenses of cancer patients.

2.6 The Evolution of EOLC in China

Another reason that hampers cancer patients to access quality healthcare and drugs in China is the inadequate provision of EOLC. EOLC was introduced to China in the 1980s, but its development has been slower than in many other countries. EOLC services in China remains at a stage of preliminary integration into the mainstream healthcare system (WHO and WHPCA, 2020). At this stage, palliative services are usually locally provided and not accessible to a large population.

In 1990, the Chinese government and the WHO organised a conference and training course in Guangzhou to introduce the WHO's three-step analgesic ladder to cancer patients. In the following year, the Chinese Ministry of Health launched a national cancer pain relief policy to ensure the proper use of analgesia for cancer patients and prevent abusive usage of opioids. The subsequent collaboration programmes with WHO and some institutions in the USA had promoted the development of cancer pain relief in China (Zhang *et al.*, 1996). In 1996, a standard pain assessment scale – the Chinese version of the Brief Pain Inventory (BPI-C) – was validated and recommended as a national guideline for cancer pain control (Wang *et al.*, 2002). From 2006, the Ministry of Health allowed community health centres to register "a unit/department of hospice and Palliative/EOL Care" for advanced cancer patients. In 2007, it gave clinical physicians more permission to prescribe narcotic analgesias, such as opioids and transdermal fentanyl patches (Li *et al.*, 2011).

Consequently, opioids consumption increased from 10kg (morphine equivalents) in 1989 to 906 kg in 2008. However, according to the Opioid Consumption Maps (Pain & Policy Studies Group, 2012), the morphine use (morphine equivalents) remained low in China at 7.8 mg/capita comparing with over 100mg/capita in the US and the UK (The Economist Intelligence Unit, 2010). Goss et al. (2014) also mentioned that only 57% of hospitals were able to provide morphine for patients, and only one opioid analgesic was included in the National Essential Drugs List in 2012. Although there has been enhanced training and education to health professionals, research in Tianjin Medical University Cancer Institute and Hospital found out that the oncologists in China lacked comprehensive knowledge of pain management and narcotic analgesia and had misconceptions about the use of opioids. Similarly, Chinese patients' noncompliance to medication and concerns about opioid addiction were further obstacles for cancer pain relief (Wu *et al.*, 2016).

EOLC has been provided mainly in three forms in mainland China: a small number of specialised sites in some big cities, such as Beijing Songtang EOLC Hospital, Tianjin Medical University's EOLC Research Centre and Shanghai Nanhui Huiliyuan; EOLC wards in medical institutions, for example, Beijing Chaoyangmen Hospital's second ward, Shenzhen Longzhu Hospital's oncological ward and Shanghai Aiyide Hospital; and hospices, like charitable hospices (宁养院, Ningyang Yuan, which means a sanatorium that is filled with peace and serenity) funded by Li Ka-Shing Foundation. By 2012, there were about 200 different types of institutions providing Palliative/EOL care services. However, these institutions are mainly located in big cities such as Beijing, Shanghai, Guangzhou, Tianjin and Chengdu. There are rarely such services in some middle and small-sized cities, towns and villages (Yan and Shi, 2012). Furthermore, with the increased cancer mortality rate, these institutions only cover a tiny fraction of those in need. For example, it was reported that, in 2013, 242,500 people had

cancer in Shanghai, among which 83,600 people needed EOLC; however, there were only 234 EOLC beds available with 1,301 patients admitted, just meeting 1.56% of the total need (Wang *et al.*, 2015). WHO and WPCA (2014) identified that only 159 palliative care services existed in China, and the ratio of palliative care services to the population was 1:8.5 million, indicating low availability and accessibility of palliative care in this country. Moreover, it is reported that many EOLC institutions have challenges such as lack of recourses and facilities, lack of qualified professionals, and lack of public awareness (Ma, 2012). The National Health and Family Planning Commission issued the first 'End of Life Care Basic Standards' in 2017 to promote the development of palliative/EOL care in China.

Additionally, a few non-governmental organizations (NGOs), like the Chinese Association for Life Care, have been established in China to promote quality of life and maintain dignity in death and dying. Beijing Living Promotion Association (LWPA), established in 2013, aims to maintain the dignity and respect of people towards the end of life. LWPA also has connections with St. Christopher's Hospice in the UK, which helps Chinese health professionals to develop a skilled and compassionate EOLC.

After nearly four decades of introducing EOLC into China, there still have been many challenges in its development. It has low geographical coverage and a massive amount of unmet demands, mainly caused by a lack of resources and policy support, as well as a lack of EOLC professionals. Goss et al. (2014) report that courses about palliative care are only provided in a few universities and are optional for medical students. In addition, social-cultural barriers also exist as obstacles to the development of EOLC in China.

2.7 The Attitudes toward EOLC in China

China is the poorest country in public awareness of EOLC for both healthcare providers and receivers (The Economist Intelligence Unit, 2010; The Economist Intelligence Unit, 2015). Doctors are educated that their responsibilities should be more focused on curative treatment to save lives and protect patients, so they are less aware of EOLC (Zou *et al.*, 2013). Highly developed technology also makes the prolonging of life possible.

Recently, China intended to use mortality rate as an important criterion to evaluate the quality of service of hospitals. It is argued widely in China that this new policy may prevent the development of EOLC in hospitals. Profit-seeking practices, particularly for hospitals in less developed regions and resource-poor communities, maybe another factor for doctors to recommend more profitable life-prolonging treatment and examination rather than providing EOLC (Liu *et al.*, 2000).

Chinese culture, particularly the attitudes towards death and EOLC issues, plays an important role in the development of EOLC in China. For example, Chinese people have more consideration for good birth than for good death, and the one-child policy has pushed Chinese people further focusing on good birth. Many Chinese people believe that "a living dog is better than a dead lion", i.e. to live is better than to die. Thus, the whole society has given a relative lack of attention to the EOLC issues. EOLC is also new to many patients and family members. They are usually encouraged to fight death with cure-oriented medicine, whereas EOLC is considered or misunderstood as a failure or abandonment of scientific medicine and waiting for death without any hope (Li *et al.*, 2011; Zou *et al.*, 2013). Many Chinese people are influenced by the traditional view that having cancer and other terminal illnesses means short life expectancies, so patients and their families would be desperate and hardly accept the idea

of EOLC emotionally (Hu and Feng, 2016). Although some NGOs actively promote the knowledge of EOLC, their impact on increasing public awareness is still limited.

Given the low awareness of EOLC and the resistance to EOLC, the survival of the small number of EOLC services units has been further challenged. The Beijing Songtang Hospital, the first EOLC hospital in China, has been forced to relocate 7 times since 1992 due to local residents' resistance. In February 2014, residents in Shanghai Pudong New Area protested against building an EOLC hospital in their community. An EOLC hospital was considered "bad luck", contrary to traditional Chinese culture, having adverse effects on the house prices and leading to potential problems (Wang, 2014). The 30-bed EOLC ward in Shandong Province Qianfoshan Hospital, established in 2009, was forced to close after six months because patients refused to use it, and as such, it did not meet the required bed occupancy levels (Zhou, 2015). Such situations reflected special social-cultural issues in EOLC in contemporary China, which is different from some countries in the West. Facing these issues in the development of EOLC, it is imperative to research the phenomenon in order to reveal people's understanding of EOLC in contemporary China and find out what people want about EOLC.

2.8 The Role of Family in Caring for Older People in China

The inadequate provision of EOLC services and traditional Chinese culture of filial piety determined that the majority of older people in China rely on traditional family-based-care.[1] Looking after older people in the family is also written in the Chinese Constitution, the Marriage Law and the Law on the Protection of the Rights and Interests of Older People (Wong

[1] Filial peity is an important and central Confucian virtue in China. It refers to the obedience, devittion and care toward one's parents and elder family members. Filial piety requires children to offer respect, love, courtesy, support, reverence and loyalty to the parents. Children have to take care of the parents when they are old, and work hard to provide them with material comfort.

and Leung, 2012). Many responsibilities of healthcare for older people lie with the family rather than the government. It is reported that over 40% of older people aged 60 and over depended on their children or relatives for financial support in China in 2010 and the fraction raised to over 70% for those aged 85 and over.

Family members are not only the informal caregivers of the patients, but also play a more critical role in decision making than patients themselves. Family members usually make decisions with doctors regarding whether to disclose diagnosis and prognosis to patients and what kind of care/treatment to have. They consider traditional social-cultural value, enormous moral pressure and financial affordability most when making decisions (Wang, 2010). Additionally, considering family's requests and the negative effects on patients when disclosing information, doctors usually believe that family members are the best people to communicate regarding patients' preferences on care and treatments.

Furthermore, due to the disparity and imperfection in the endowment insurance system, for some patients with a terminal illness (like senior cadres[2]) the majority of medical care cost is paid for by the insurance while for many others (like workers, unemployed people and villagers), a large amount of the medical care cost is paid/shared by the patient and his/her family members (particularly the spouse and the children). Therefore, the financial burden to a family is a concern, not only for the family members but also for the patient, when determining the place of care and selecting treatment. Rural older people mainly live on financial support from their children because they have no or low income when getting old and losing their

[2] Healthcare insurance of senior cadres is out of the three insurance schemes discussed in 2.5.2. Senior cadres of the Chinese Communist Party and government organizations (including retired senior cadres) have superior in healthcare, in terms of priority in accessing the resources, using VIP inpatient ward, and high reimbustment rate of healthcare cost including medicines not on the National Drug Reimbursement List.

physical capacity to work (Lei *et al.*, 2012). Although the New Rural Pension Scheme (NRPS) has broad coverage, it does not change the family-based care model due to its low pension payment criteria. It is anticipated that in the future, elderly care in rural areas will still rely on children and family care (Cheng *et al.*, 2013).

In summary, cancer has been the leading cause of death in China, with an increased mortality rate for older people. The demand for EOLC, particularly for cancer patients, has been huge in China, but the provision of services and related policies are still inadequate. Chinese social-culture issues also affect the development of EOLC services in China at this stage. Family members have played the same, or even more, significant role in the process of medical treatment as patients and health professionals.

Chapter Three Literature Review

3.1 Introduction

With the spread of the western model of hospice movement across the world, the hospices appear diversified. The development is characterised by their local social, cultural, political and economic conditions, which also influence their understanding of the palliative care philosophy (Clark and Seymour, 1999; Saunders and Clark, 2006). Western health care is grounded in patient autonomy and promotes individual determination, informed consent, and illness disclosure. It reflects a belief in the importance, uniqueness, dignity and sovereignty of each person and the sanctity of each individual life. However, in many cultures, family duties and obligations take precedence over patient autonomy (Bowman and Singer, 2001; Bowman *et al.*, 2003). Even in geographically contiguous territories such as Western European countries or East Asian countries, there are distinct cultural differences in EOLC beliefs (Gysels *et al.*, 2012; Kwon *et al.*, 2012). It is impossible to form universal standards of EOLC, which can be accepted and applied in all different countries (Higginson, 2005).

In order to understand how EOLC is experienced in China, it requires understanding the central issues of EOLC identified in the western context and other cultures, as well as the key EOLC themes found in the limited research in China. In the following section of this chapter, I overview some key research topics that have been identified broadly in worldwide literature. Then, I focus on the cultural aspects of EOLC that affects the models in EOLC implementation and implies the necessity to carry out EOLC research in low- and middle-income countries, like China. Finally, I review the current research on EOLC in China.

3.2 Overview of EOLC Research Topics Worldwide

EOLC is a dynamic situation when people are facing death. It requires evolving decision making inclusive of others, with consideration of various and complicated factors in family, community or society (Daveson *et al.*, 2011). Most of the research on EOLC has been carried out in western countries or high-income countries. The research topics appear to be specific, such as advance care planning (ACP), care settings and type of care, pain and other symptoms management, cultural factors on understanding EOLC issues, communication, decision-making, and so on. For example, The National Institute of Nursing Research of the US (2013) reviewed 3,155 studies related to EOLC from 1997 to 2010. They found that 13% of these studies are on ACP; 12% on care settings and types of care; 11% on pain management; 5% on the impact of culture, religion and spirituality on the understanding of EOLC issues; 4% on communication; 1.5% on decision making related to EOLC but not under the criteria of ACP; and only 1.2% on personal experiences of living while dying from a terminal illness. Amongst these studies, more than half (52%) used quantitative, non-experimental research designs, and 13% were experimental studies. When reviewing the studies conducted in other countries, such as Canada, the UK and other European countries, as well as the developing countries, similar categories are also found. Recently, Kim *et al.* (2021) analysed 18,935 articles in EOLC published until 2019 and found several popular topics in the literature, such as ethical problems to end the treatment, symptom management to improve the quality of life, EOL education programmes, communication experience, consideration of patient preferences, ACP for older people, and home-based hospice. In the following section, I give a brief overview of the three key research topics: communication, experiences and perspectives of EOLC, and decision-making on life-prolonging treatment and symptoms control, which are correlated to my research findings.

Communication

Communication between cancer patients and health professionals has been seen as one of the essential aspects in order to provide high-quality EOLC (Hancock et al., 2007; Slort et al., 2011). On the one hand, patients wanted to know the whole truth of their situation and prognosis; on the other hand, they avoided or feared facing the truth, especially when it would relate to death and life expectancy (Deschepper et al., 2008). Whether to disclose or conceal the diagnosis to patients is deeply influenced by cultural factors (Davis et al., 2002). Many studies focused on whether to disclose or conceal diagnosis to patients and how to disclose the diagnosis to the patients. Health professionals may be reluctant to discuss some end of life issues with patients because this information might result in deeply emotional and spiritual pain to the patients (Hancock et al., 2007; Slort et al., 2011). Cancer disclosure is related to the cultural background of the parties involved. In general, medical ethics is based on four principles: respect for autonomy, non-malfeasance, beneficence and justice (Beauchamp and Childress, 2013; Shahidi, 2010). Respect for autonomy values patients' rights to make their own decisions and to take actions. Non-malfeasance requires avoiding harm to the patient, while beneficence requires doing good for the patient's interest. Justice refers to the fact that medical goods and services should be fairly distributed. Attitudes towards truth-telling are mainly shaped by trying to maintain a balance between autonomy and non-malfeasance/beneficence.

Open communication of a cancer diagnosis between health professionals and patients with a full reveal of cancer diagnosis is the dominant practice, particularly in the Anglo-American context (Surbone, 2006). Open communication aims to make patients aware of their condition so they can identify their personal needs and make their own decisions about their practical care needs and how to obtain quality of life. This disclosure approach reflects the fundamental

ethical principle of respect for a patient's autonomy (Gillon, 2003; Snyder and Leffler, 2005). Respect for autonomy in EOLC presents the primary value for patients to be fully aware of their illness. It is believed that full awareness empowers patients to make better decisions about their treatment and life plans (Surbone, 2006). Since disclosing a cancer diagnosis to patients has become a moral duty, research and debate focus more on how to disclose the diagnosis to patients than whether to disclose it to patients in western countries (Figg et al., 2010).

In some other cultural settings, complete and accurate disclosure to cancer patients is still considered undesirable (Mitchell, 1998), even though there have been changes in attitudes and practices related to cancer diagnosis disclosure. In these cultures, the ethical principle of non-malfeasance is superior to autonomy (Mitchell, 1998; Shahidi, 2010). Withholding information from cancer patients is seen as a practice to protect the patients and a way to respect their wish to exercise their autonomy, which is delegated to the health professionals and their families (Surbone, 2006). In Japan, cancer patients were more likely to prefer family involvement in decision-making than non-cancer patients and preferred that physicians use euphemisms (not the word "cancer") in communication after initial unambiguous disclosure of the bad news (Sekimoto et al., 2004; Fujimori et al., 2005). In Japanese society, evidence of whether patients want to know the full diagnosis is mixed. It is more often family members than patients who wanted the truth to be concealed from the patients, and family members had a power of attorney in the diagnosis disclosure process (Miyata et al., 2005). In Greek culture, families played an important role in cancer disclosure and care support, and they made decisions on patients' behalf (Mystakidou et al., 2005). A similar phenomenon of non-disclosure is also found in other countries, such as Turkey and Iran (Öksüzoğrlu et al., 2006; Shahidi et al., 2007). In all these countries, cultural differences in attitudes and communication preferences, as well as the

concern about potential psychological harm to the patients after knowing the diagnosis, are the main reasons to explain the phenomenon.

Experiences and Perspectives of EOLC

The proportion of studies focused on personal experiences of EOLC is relatively small. However, there is an increasing focus on service users' experiences because EOLC emphasises meeting individual needs. The care experiences of patients and families can be used to measure the quality of EOLC (Lendon *et al.*, 2015). Since EOLC involves both patients and their family members, it is worthwhile to explore their experiences related to the advanced illness, physical, functional and cognitive decline, and decision making towards the end of life. Studies conducted in different countries illustrate that patients have different and unique experiences of EOLC (Appelin and Berterö, 2004; Osse *et al.*, 2005; Harstäde and Andershed, 2004; Doumit *et al.*, 2007; Gysels *et al.*, 2012). Culture was seen as an important factor in understanding individual perspectives of EOLC.

With the progress of the advanced illness, older people become increasingly more dependent on their family members for their daily care and emotional needs (Gardner and Kramer, 2010). Many studies on patients' EOLC preferences are based on the description of family members (Teno *et al.*, 2004). For example, a study focusing on bereaved family members' experiences of EOLC has evaluated the quality of EOLC and found out the need for improvement in hospital EOLC care in Germany (Bussmann *et al.*, 2015). However, patients and family members might hold different opinions on the quality of life and have different concerns and preferences in EOLC (Gardner and Kramer, 2010). Autonomy was seen as a very important element in improving the quality of EOLC for patients (Sahm *et al.*, 2005; Tang, 2003; Koedoot *et al.*, 2003). Much of research in the US has illustrated that the family members emphasised

more on caring for older people's physical needs, and therefore, the patient's needs for autonomy and control in their EOLC were often underestimated by their family members (Singer *et al.*, 1999; Farber *et al.*, 2003; Gardner and Kramer, 2010). Some studies demonstrated that discrepancies of concerns and preferences of EOLC existed between patients' and family members' views regarding dependence, family burden and good death (McPherson *et al.*, 2008). To deliver and to improve EOLC in different care settings, it is found that fulfilment of people's needs and preferences was as important as improving patients' quality of life (Becker *et al.*, 2007; Bee *et al.*, 2009; Candy *et al.*, 2011; Bussmann *et al.*, 2015).

Regarding the perception of EOLC from health professionals, some studies mainly looked at health professionals' knowledge and attitudes towards EOLC and how their thoughts influenced their clinical practice for the quality of care (Borgsteede *et al.*, 2006; Hanratty *et al.*, 2006; O'Connor and Lee-Steere, 2006). Studies revealed that an open and trusting relationship with patients was important in EOLC, and the communication among health professionals, patients and family members played an essential role in the process of choosing the kind of care or treatment for the patients (Clayton *et al.*, 2005; Kirk *et al.*, 2004; Mok and Chiu, 2004).

Decision Making on Life-prolonging Treatment and Symptoms Control

End of life decision making is deeply influenced by social, moral and cultural values. Some studies illustrated that the process of decision-making was determined by weighing between patient's autonomy and individual preferences or collective, family-centred decisions (Davis *et al.*, 2002; Kwon *et al.*, 2012; Horn, 2014). EOL decisions cover a range of choices on the treatment method and symptoms management, place of treatment and death, advanced care planning, decisions to withdraw life-prolonging treatment, and so on. Here, I focus on decision-making on life-prolonging treatment and symptoms control.

Researches on treatment decision making at the end of life mainly focused on the selection between life-prolonging treatment and palliative care. Given that the current healthcare approaches are person-centred care, patients are more likely to get involved in decision-making regarding treatment and care. Therefore, recent research focused on the patients' preferences for participants in decision making, the role of physicians in decision making, social and cultural factors in decision-making and ethical consideration from surrogates (Wendler and Rid, 2011; Pardon *et al.*, 2011; Kwon *et al.*, 2012; Kelly *et al.*, 2012; Fritch *et al.*, 2013; Brom *et al.*, 2014). Studies reported that patients had different concerns when making treatment decisions: some patients intended to prolong life at any cost, some patients preferred to maintain comfort as much as possible, some patients valued their quality of life with their family members, and some patients considered the burden to their family (Boström *et al.*, 2004; Dawson *et al.*, 2005; Mystakidou *et al.*, 2004; Coyle, 2004).

Regarding symptom control, relevant guidelines of symptom management have been made by the WHO and national healthcare system in many countries. Relevant studies on improving pain management and symptoms control focused on the patients' and informal caregivers' awareness and communication of pain; health professionals' understanding of opioids and the impact on prescribing opioids; patients' and informal caregivers' education on pain management; and training to health professionals (Teunissen *et al.*, 2007; Bennett *et al.*, 2009; Oldenmenger *et al.*, 2009; Flemming, 2010; Luckett *et al.*, 2013).

3.3 Culture in EOLC

The impacts of cultural differences were reflected in all of the above-mentioned aspects, such as understanding of illness, communication, illness experiences, decision making and quality of care (Evans et al., 2012; Coolen, 2012). Evidence from previous research has found that

there were less awareness and less usage of EOLC by people of Black, Asian and Minority Ethnic (BAME) groups in the UK (Calanzani et al., 2013). Research on the importance and influence of cultural factors have been carried out in many developed countries such as the UK, USA and Canada. For example, Seymour et al. (2007) and Payne et al. (2008) considered the cultural impact on EOLC for Chinese people in the UK. These studies aim to provide better policy and practice of EOLC to migrants from other cultural backgrounds, particularly those from developing countries, such as India, Pakistan, and China (Bowman and Singer, 2001; and Calanzani et al., 2013).

Cultural issues have become important with the spread of care models from one nation to another (Clark, 2007). The resources and attitudes of palliative care appeared very positive in western cultures, whereas these showed to be different in other cultures. Western values of autonomy and self-determination in EOLC decision-making may become conflicted with those with collective and social values in some Asian countries. A study conducted in China, Japan and Korea illustrated that 'western values' on EOLC, which highlighted autonomy and freedom, should be carefully considered when transferring to different cultures (Kwon et al. 2012). In Japan, some hospice patients would like to have curative treatment towards the end of their life because they believed that curative treatment would be good care in the Japanese context (Davis et al., 2002). Similarly, many people in China also held a resistant attitude to EOLC facilities and refused to use EOLC services (Zhou, 2015).

Due to the differences in cultural, social, economic and political backgrounds across countries, it is impossible to directly adopt a healthcare system from one country to another (Higginson, 2005). Clark (2012, p.196) states that "putting culture at the centre of palliative care will be a key determinant of efficacy and sustainability". Even among European countries, evidence has shown distinguishable social-cultural issues in EOLC regarding the meanings, priorities and

expertise (Daveson et al., 2011; Gysels et al., 2012). The differences in culture and religion have influenced the attitudes to death and EOLC and the uptake of EOLC (The Economist Intelligence Unit, 2010; Calanzani *et al.*, 2013).

Furthermore, with the calling for the integration of palliative/EOL care into mainstream health system worldwide, there is an urgent need for more investment in palliative/EOL care research in low- and middle- income countries to provide research-based evidence to policymakers (Singh and Harding, 2011; Clark et al., 2018). Although there has been some evidence for the implementation of EOLC in these developing countries, greater investigations are still needed to understand the cultural context of death and dying for patients and their families and find the appropriate palliative/EOL care models that could be replicated in these resource-limited countries. Hence, my research will add new knowledge to the wider literature of understanding EOLC in China.

3.4 Current Research on EOLC in China

To collect the relevant literature on the experience of EOLC for older cancer patients in China, I searched on different databases, including Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science (including all of its databases), Ovid SP (including Allied and Complementary Medicine (AMED), Embase, and PsyclNFO), Pubmed and Cochrane library. The keywords for searching include the following groups:

- “end of life care” or “palliative care” or “hospice care” or “terminal care” and
- “understand*” or "attitude*” or “experience*” or “preference*” or “review” or “perception*” and
- “Older” or “elderly” and
- “cancer” or “tumour” and

- "China" or "Chinese"

After obtaining the results from different databases, I merged the results and removed duplicated records. Then, I examined the titles and abstracts of the identified studies to remove those not relevant. After that, a detailed assessment of the full papers was undertaken for the remaining potentially relevant studies. I excluded the papers that were not relevant to EOLC issues for cancer patients. Only empirical research articles were retained. Manual search was also carried out during my study from the references in relevant literature. Since the studies targeting older cancer patients in China are rare, I included a few relevant studies on adult cancer patients in China. There are some studies looking at EOLC issues in Hong Kong, Macao, Taiwan and Singapore, where Chinese traditional culture dominated, as well as the perceptions of EOLC issues among Chinese immigrants in other countries (e.g. Bowman and Singer, 2001; Ho and Sanders, 2014; Chan and Pang, 2011). These studies are useful to understand the attitudes towards EOLC in the Chinese context. However, these countries and regions have different political, economic, social, moral and healthcare backgrounds from mainland China. In addition to the traditional culture, mainland China is also affected by contemporary political culture and movements, such as Marxism. Therefore, studies out of mainland China were not included in the literature review but used for understanding the background and analysing the findings from this research.

Articles published in Chinese languages were also searched in China Knowledge Resource Integrated Database (CNKI) and China Academic Journals (CAJ), using corresponding keywords in Chinese. A substantial number of articles were identified at the first stage. However, after screening the titles, abstracts and full texts, most of the papers just provided descriptions of practical summaries and policy analysis. Chen and Bai (2011) also proved this condition that among 471 papers on EOLC published during 1997-2010, only 45 papers were

empirical studies employing the survey method. After reading the full texts of these articles, I found most of them were very short (less than 2 pages), with a simple research method and survey questions and some brief statistical results (Meng, Z. *et al.*, 2014; Li *et al.*, 2014). For some papers, the full text was not available. Therefore, considering the papers' quality, I excluded these studies published in Chinese in my literature review.

As a result, twenty-five papers were identified regarding EOLC research conducted in China. More details of these papers are summarised in Appendix 1. Based on the topics and the population of the research, these studies are classified into three groups: the experiences of the health professionals (5 studies), the experiences of the patients (17 studies), and the experiences of the family caregivers (3 studies). The 17 studies of experiences of the patients could be roughly grouped into three major themes: end of life decisions and diagnosis disclosure (6 studies including 2 of the views from the general public and nursing home residents and 1 on both patients and family); patients' distress and coping strategies (5 studies including 1 from the perceptions of patients, family, health professionals and the general public) and the quality of life of the patients (6 studies). The empirical studies cover the attitudes to different EOLC issues in China from the perceptions of patients, family and health professionals. They are relatively new and limited but within the main themes of the worldwide literature.

Among these studies, only seven examined the lived experiences of the patients and health professionals on EOLC issues using different qualitative methods (Hong et al. 2014, Zheng et al. 2015, and Dong et al. 2016 on health professionals; Chen et al. 2015, Yang et al. 2018, Liu et al. 2005 and Zeng et al. 2011 on cancer patients). All the other studies used cross-sectional questionnaire surveys, which provide a good understanding of each specific theme of a group of population. However, the meanings behind these figures and correlations need to be further explored to find out what situations influenced people's end of life experiences, preferences,

practices, decisions, and so on. Therefore, more qualitative research on the experiences of health professionals, patients and families are needed to provide more evidence on their lived experience for the development of EOLC for cancer patients in China.

Among these studies, some covered a broad range of themes related to EOLC, and some focused on particular EOLC issues or patient of a specific type of cancer. Therefore, I grouped these studies by the main targeted population for research: health professionals, patients and family caregivers, although some studies cover different groups of participants.

3.4.1 The Experiences of the Health Professionals

The five studies targeting health professionals looked at different issues in EOLC. The main research topic was the practice and attitude of diagnosis disclosure, followed by the perceptions of caring for dying patients and providing social support to the patients.

Wang *et al.* (2004b) is the earliest study assessing the clinicians' impressions on EOLC in urban areas of China, including questions on service availability in hospital, symptom management, communication between clinicians and patients, and delivery of EOLC. The findings revealed low availability of hospital-based hospice services in the late 1990s. Unrealistic expectations from the patients and family would be the main barriers to the development of EOLC in China, as perceived by the clinicians.

Family involvement in cancer diagnosis disclosure has been observed as a popular practice in several studies. Wang *et al.* (2004b) showed that clinicians believed that patients would like to know their diagnosis, but the family were more likely to withhold the truth. Wuensch et al. (2013) assessed the current practice in cancer disclosure of 24 oncologists and 7 nurses in Beijing Cancer Hospital. They found that in 78% of cases, health professionals would inform

family members first, although 75% thought patients would like to be informed first, independent of family. These findings are consistent with the evidence from some studies targeting patients and families. Jiang et al. (2007) and Yang et al. (2018) both revealed patients had a strong desire of knowing the diagnosis, but nearly 60% of oncology clinicians and over 60% of families preferred non-disclosure to patients. Zheng et al. (2015) and Dong et al. (2016) found the difficulties of ineffective communication between health professionals, patients and the family because traditional Chinese culture discourages communicating death and family members also requested avoiding such communications. Although most health professionals thought that patients should know the truth, they reported a lack of knowledge and communication skills with the patients on death and dying.

The above evidence indicates a tension of diagnosis disclosure between health professionals, patients and families in China. This phenomenon is similar to the evidence in Japan twenty years ago (Miyata et al., 2005) and in the US in the 1950s and 1960s (Surbone, 2006). However, the existing evidence only provides preferences for diagnosis disclosure among the three groups of participants. More in-depth investigations are needed to explore this phenomenon. For example, what are these three parties considering when deciding on telling and not-telling or knowing and not-knowing? What are other factors contributing to such a phenomenon in addition to traditional Chinese culture? And how does this phenomenon affect the wellbeing of the patients and families?

When caring for dying cancer patients, Chinese health professionals usually put more emphasis on patient's physical comfort and symptom control (Zheng *et al.*, 2015; Dong *et al.*, 2016). Health professionals recognised the patient's needs for other social support, including emotional/psychological support, information support, technical support, palliative care and mobilisation of social resources (Hong *et al.*, 2014). However, there was a big gap between the

perceptions and actual provisions, particularly in psychological care, palliative care and mobilisation of social resources (Zheng *et al.*, 2015; Dong *et al.*, 2016; Hong *et al*., 2014). The reasons for such unmet needs included the lack of awareness of how to find professional social support, the shortage of qualified staff and the lack of appropriate tools to assess their needs.

Besides the unmet social support in caring for cancer patients, Zheng et al. (2015) and Dong et al. (2016) also found that health professionals suffered from caring for dying patients (e.g. having emotional distress), although they also benefited from their work (e.g. personal growth, improved clinical skills). Therefore, more training and support are needed in China in order to provide quality EOLC to cancer patients.

3.4.2 The Experiences of Patients

There are more studies examining the end of life issues from the perspective of cancer patients. The key themes are within the popular topics in the other countries, including diagnosis disclosure, end of life decisions, psychological distress and quality of life at the end of life.

Diagnosis Disclosure

As discussed in section 3.4.1, existing evidence indicated the majority of the patients would like to know their illness directly and frankly from the doctor (Kwon *et al.*, 2012; Kwon *et al.*, 2015; Jiang *et al.*, 2007; Wuensch *et al.*, 2013; Yang *et al.*, 2018) and make joint decisions with the family and the doctor (Kwon *et al*., 2012). The patients' attitudes seemed to be contrary to the popularly used medical practice in China and East Asian countries – excluding patients from the diagnosis disclosure.

End of Life Decisions

A few studies explored the attitudes toward end of life decisions in China using questionnaire surveys. These decisions were related to the places of care and death, awareness of and attitude to advanced directives (AD), and perceptions of life-prolonging treatment at the end of life. Ni *et al.* (2014) found that more than half of the older residents in nursing homes preferred to live and die in their present nursing homes. About 20% of nursing home residents preferred to die at home, and only a few chose the hospital. They also found very low awareness of AD and reluctance of accepting this practice in the Chinese context. Kwon *et al.* (2012, 2015) and Ni *et al.* (2014) both found more than half of Chinese participants would like to use life-sustaining treatment, compared to a greater proportion of respondents in Japan and Korea who favoured withdrawing ventilator care. Kwon *et al.* (2012) found that most Chinese patients selected "uncertainty of the diagnosis of an irreversible condition" as the reason for continuing ventilator care. These perceptive findings are consistent with Gu *et al.* (2016) that, among the 446 cancer patients who died in a palliative unit of a cancer centre in China, about half of the patients received at least one life-sustaining treatments before death, with artificial nutrition, hydration and vasopressors as the most used treatments.

Regarding the decision-maker of end of life issues, Ni *et al.* (2014) found that most participants would choose their eldest child as the surrogate while less than half would like the doctor to decide (Ni *et al.*, 2014). Gu *et al.* (2016) also reported most EOL discussions were carried out between family caregivers and physicians. The primary decision-makers were the spouse and children. These findings confirm the role of family members, particularly spouse and adult child, in deciding EOLC issues on behalf of the patients in China.

Psychological Distress

Caring for cancer patients as a "whole person" and considering their "total pain" are essential in EOLC. Therefore, several studies examined the psychological distress levels of cancer patients using different assessment tools. It is not surprising that cancer patients had emotional and psychological distress, but their distress levels varied across patients. These studies then investigated the factors that affected the heterogeneity in distress levels, including non-disclosure, personality, age, coping pattern, hope, and social support.

While families usually preferred non-disclosure of diagnosis to protect the patients, Lee *et al.* (2017) found this practice was associated with the depressive symptoms of the patients with breast cancer. You *et al.* (2018) further explored that personality was related to distress levels of women patients with breast cancer. Patients who were neurotic tended to have negative emotions, while extravert patients had positive emotions. Conscientious patients were also found to be positive, particularly among older patients.

The patient's distress level is also associated with the coping strategy adopted. Li *et al.* (2017) found adaptive copers usually had better psychological adjustment than inconsistent copers and maladaptive cognitive copers. The adoption of adaptive coping strategies is determined by age, education, time in the illness, marriage status, residential status and whether the patient was receiving chemotherapy treatment. Similarly, Deng *et al.* (2013) and Hong *et al.* (2015) confirmed that confrontation coping pattern helped reduce patients' distress scores, while other coping styles, such as avoidance and resignation, positively correlated with the level of anxiety or distress.

Different coping strategies also mediated patients' distress levels caused by non-disclosure or personality. Self-blame would enhance the negative effect of non-disclosure on depressive

symptoms of the patients while practising benefit would moderate the adverse effects of non-disclosure (Lee *et al.*, 2017). Extravert and conscientious patients were more likely to adopt approach coping strategies that had mediation effects on the distress level, but neurotic patients usually adopted avoidance strategies and worsened their distress (You *et al.*, 2018).

In addition to the coping patterns, Chen et al. (2015) and Liu et al. (2005) also highlighted the importance of hope and social support to alleviate the distress of cancer patients. Chen et al. (2015) argued that advanced cancer patients hoped to cure and remission and prepared for death. Hope included attending an important future family event and fulfilling specific family responsibilities such as raising children. The construction of hope was an important source of coping among patients. Deng *et al.* (2013) and Hong *et al.* (2015) both argued that social support was significantly associated with patients' anxiety and distress scores. However, social support for cancer patients was mainly sustained by Chinese families (Chen *et al.* 2015). The findings in Liu *et al.* (2005) suggested that, although the patients had a substantial need to receive information and social support, they only actively sought information from doctors, nurses and fellow patients but did not expect emotional support from doctors. Patients only expressed emotional needs to close family members.

Quality of Life

Using data from a set of questionnaires, some papers found that differences in patients' distress scores, coping strategy and social support were also the predictors of their quality of life (Deng *et al.*, 2013; Zou *et al.*, 2014; Hong *et al.*, 2015; He *et al.*, 2019). Low distress score, positive/adaptive coping strategies and more social support would improve cancer patients' quality of life scores. In addition, quality of life varied across patients due to their employment

status, optimism level, the status of the illness and type of cancer (Li and Lambert, 2007; Zou *et al.*, 2014; Deng *et al.*, 2013).

Unlike the quality of life scores measured by questionnaires, Zeng et al. (2011) explored the meaning of quality of life by analysing the written responses from the cervical cancer survivors. They found that for cervical cancer survivors, quality of life meant being free from the disease, having a good living standard, having a harmonious family atmosphere, and having a harmonious sex life. Having cervical cancer had physical and psychological sequelae, particularly family distress, financial burden, disruption on social functionings and sexual life. However, the survivors also expressed that having cancer resulted in changes in life outlook, treasuring life and better family relationship.

In summary, most of the studies on cancer patients' experiences in China adopted quantitative research methods. They used questionnaire surveys to collect personal information and the perceptions of cancer patients on end of life issues or a set of questionnaire tools to assess patients' distress level, coping strategy and quality of life. There is a lack of qualitative research to explore each issue further, for example, the meaning of their specific attitude, their actual pain and feelings of having cancer, and details of how they adjust their life.

3.4.3 The Experiences of Family Caregivers

Family members are vital in caring for cancer patients, bearing the medical cost and making medical decisions in China. In the UK and some other developed countries, palliative/EOL care is patient- and family-centred, with family carers facing many challenges of their own. However, limited research in China examines the experience of family caregivers of cancer patients. The current studies mainly look at the stress and needs of the family.

Wu et al. (2013) found patients and family members had the same level (76.3%) of depression. The depression levels between patients and families were strongly associated. Zhang et al. (2014) found spouse caregivers usually spent more than 8 hours a day looking after cancer patients and experienced significant sleep disturbance and fatigue compared to the general public. Spouse caregiver's sleep disturbance was highly correlated with their physical and mental fatigue, the patients' treatment, and the financial burdens. However, positive coping strategies of the caregivers would improve sleep disturbance.

Cui et al. (2014) identified a number of dimensions of needs of family caregivers through a sample survey, including (in descending order of the mean score) knowledge about the disease and treatment, symptoms control for patients, support from healthcare professionals, maintaining health, psychological support for patients, information on hospice care, and support on the funeral. These findings suggest that the family caregivers prioritised the patient treatment-related needs over others, such as their health, patients' psychological needs, hospice and after death issues.

Although studies on family caregivers are limited and mainly based on questionnaires, the findings suggest caregivers' high stress and needs for support. A well-established EOLC does not only provide care and support to patients but also support to the families. Therefore, it is necessary to listen to family caregivers' experiences to understand their feelings and behaviours and identify how to meet their needs.

3.5 Conclusions

To summarise, the worldwide literature on EOLC shows that the number of studies on EOLC is enormous but can be grouped into some key research themes. Research findings from

different countries suggested that the philosophy of palliative care and EOLC might be workable in western culture but not always applicable in other countries. The experiences and perspectives of EOLC issues were different among patients, family members and health professionals, and such differences varied across countries due to cultural differences.

EOLC is an emerging topic in China. The research in this area is limited but increasing. The existing empirical studies covered different topics in EOLC but were all within the main themes of worldwide literature. These studies examined the experiences of health professionals, patients and family members. However, studies specific to older cancer patients have been rare even though older people have a higher prevalence rate of cancer and more complex needs for EOLC (Lipman, 2012).

Among all these studies, quantitative methods were popularly adopted, using cross-sectional questionnaire surveys to assess participants' attitudes on EOLC issues or evaluate the outcomes of having cancer, such as their distress level, coping strategy and quality of life. Given limited research in EOLC in China, the statistical evidence from a large sample size provided fast and effective information about the patterns of key EOLC issues in China. However, the meanings behind the numerical responses need to further explore what situations influenced people's EOL experiences, thoughts, preferences, practices, decisions, etc. Existing qualitative studies provided detailed understanding on a few EOLC topics, such as health professionals experiences and difficulties in caring for dying patients (Zheng *et al.*, 2015; Dong *et al.*, 2016) and their perception to meet the patient's need in social support (Hong *et al.*, 2014), cancer patients' perceptions and experiences of diagnosis disclosure and communication from patients (Liu *et al.*, 2005; Yang *et al.*, 2018) and the meaning of hope and quality of life (Chen *et al.*, 2015; Zeng *et al.*, 2011). However, the gap in the literature is still large because of the small number of studies. Many themes, such as health professionals' experiences and perceptions in

diagnosis communication and medical decisions at the end of life, patients' experiences of illness and care, family caregivers' feeling and needs, and the reasons for their thoughts and behaviours, are not examined in the existing qualitative research. In addition, qualitative research usually suffers from the limitations of small sample size and sample bias. More qualitative research will be useful for practice and policymaking.

In general, existing studies doe not provide sufficient evidence on lived experiences on EOLC issues in China for older people with cancer from the perspectives of patients, family caregivers and health professionals. There is a gap in research to offer more insight into thoughts, feelings and behaviours, as well as the "whys" while experiencing EOLC using qualitative research method from all the affected parties. This study aims to fill this literature gap by analysing the accounts on these EOL issues from all three groups of participants to explore how they have experienced regarding having cancer, living with cancer and dying, and caring for cancer patients. It is expected that the findings from this study will deliver a better understanding of EOLC in China and provide constructive suggestions to relevant clinical practice, education, and policy making in developing EOLC in China.

Chapter Four Methodology and Methods

4.1 Introduction

This chapter focuses on the methodology underpinning my study and describes how theoretical and philosophical principles have shaped my research design and conduct. The research approach chosen depends on the research question (Speziale *et al.*, 2011; Creswell, 2013). To select the most appropriate research methodology for the study, I need to establish what type of data could better understand EOLC for older cancer patients in China. Van Manen (1990) asserts that both objectivity and subjectivity are ways of knowing and understanding and they are not mutually independent categories in human science. "One research methodology is not necessarily stronger or more prestigious than the other" (Webb, 2002, p.28). The choice of methodology should maintain a certain harmony with the researcher and the research question, and the process of making that choice need to be rational.

There are two types of research methodologies: quantitative and qualitative. Quantitative research methods seek for the truth by applying the procedure of experimentation and quantitative analysis, whereas qualitative research methods look into different truths inductively by involving description, interpretation and self-reflection (Van Manen, 1990). Quantitative research uses numerical data to examine the cause and effect or probabilistic relationships of things deductively from existing knowledge (Carr, 1994). In contrast, qualitative research aims at explicating the meanings of human phenomena and understanding the structure of meanings (Van Manen, 1990). Qualitative research also emphasises the value of individual experiences and subjective views when encountered in real-life situations (Hewitt-Taylor, 2001). Therefore, a qualitative research approach is appropriate to explore the

understanding of EOLC for older cancer patients through the care experiences of patients who have cancer and the health professionals and family caregivers involved in the care.

There are different qualitative research methodologies (Polgar and Thomas, 2008; Burns and Grove, 2003; Silverman, 2011; Bowling, 2014). Generally speaking, there are five popular approaches in the social science and health science literature, namely narrative research, phenomenology, grounded theory, ethnography and case studies (Creswell, 2013). Each of them has its strengths in addressing certain types of questions. Narrative research usually explores the life stories of one or more individuals rather than focusing on the phenomenon. Grounded theory intends to develop a theory grounded in data rather than exploring and better understanding a particular phenomenon. Ethnography usually focuses on an in-depth description of a shared pattern of culture, and case studies look into a bounded case or multiple bounded cases identified at the beginning of the research. Here, I am not trying to define a pattern or develop a theory in my study, and I do not intend to keep something static or theorised. I am looking for a deep understanding of lived experiences involved in caring for older cancer patients in contemporary China, which drew me to phenomenology.

In the following sections in this chapter, section 4.2 explains why an interpretive phenomenological approach is selected for this research. Section 4.3 introduces the detailed methods to be employed in the study, including participants recruitment and selection, data collection and analysis, and ethical considerations.

4.2 Phenomenology

Phenomenology is the study of a phenomenon, i.e. something that people experience, and it involves the analyses of phenomena, which refer to what people say about their experiences of

a phenomenon (Greatrex-White, 2004). Phenomenology aims to achieve an experiential understanding of a phenomenon elucidate the meaning of the phenomenon by studying the objects of people's experiences (Crotty, 1996). There are two main phenomenological approaches in the nursing research literature: descriptive phenomenology elaborated by Edmund Husserl (1859-1938) and interpretive phenomenology founded by Martin Heidegger (1889-1976) (Cohen and Omery, 1994; Lopez and Willis, 2004; Greatrex-White, 2004). The differences between the two approaches are more to do with how to arrive at the findings based on different philosophical positions. By comparing these two philosophical traditions in phenomenology, I eventually chose to employ the Heideggerian approach in my study.

4.2.1 Husserlian Descriptive Phenomenology

Husserlian descriptive phenomenology intends to describe the essence of a phenomenon that exists independently of conscious experience by examining such experience (Mackey, 2005). Husserl's phenomenology recognises that experience is the ultimate basis and meaning of knowledge and intends to describe how the human world is constituted and experienced through consciousness. It focuses on the epistemological question of knowing with the beliefs that there are essential structures of consciousness of the human world. Husserl's phenomenology includes three dominant notions: intentionality, essences and bracketing (Koch, 1995).

Husserl refused to separate reality from consciousness, and this refusal became the hallmark of all phenomenologists (Crotty, 1996). Husserl held that object and subject are always united insights of *intentionality,* i.e. a directedness that mind is directed toward objects (Koch, 1995) because "consciousness is always consciousness of something" (Crotty, 1996, p.42). Therefore, our conscious awareness is the indispensable starting point and basis to know reality.

Intentionality is an epistemological concept or an ontological concept but not a psychological one (Crotty, 1996). It does not mean purpose and deliberation but indicates human experience is inseparably connected to something beyond itself. That is to say, the phenomenon (the object of experience) is intrinsically related to what is experienced by the subject. The concept of intentionality in Husserl's thought was purely an epistemological term to describe a phenomenon in pure consciousness, whereas, Heidegger took the concept of intentionality as an ontological term to describe how to understand a phenomenon from our being-in-the-world. This point will be discussed later in this section.

In Husserlian phenomenology, "to the things themselves" means "to the *essences*" that constitute the consciousness and perception of the human world and there is universal essence to present the true nature of the phenomenon being studied in any experience. Husserl emphasised the object as an object of consciousness (Greatrex-White, 2004). Husserlian phenomenologist believes that human consciousness has value and can be an object of scientific study (Lopez and Willis, 2004). This assumption results in generating the truth/reality through phenomenological research. Reality is seen to be objective and independent of history and context, and there is only one correct meaning of participants' experiences.

In Husserlian phenomenology, *bracketing*, a term taken from mathematics, refers to how the reduction of consciousness is achieved, and it is interchangeable with another term, *epoche*. Bracketing is a process of purifying our consciousness of all prior knowledge or bias from our natural attitude, i.e. "our straightforward involvement with things and the world" (Audi, 1999, p.405). The process of bracketing in Husserl's philosophy excludes the impact of culture, society and politics on people because he believed that people as free agents are responsible for influencing their living environment (Lopez and Willis, 2004). I argue that the experiences of older cancer patients and the witnesses cannot be separated from the impact of personal,

cultural and social factors, as noted in the literature. Crotty (1996) argued that in the case of researchers dealing with data derived from other people, the application of bracketing to other people was not mentioned and almost impossible because bracketing is a first-person, self-reflective process according to Husserl's view. Furthermore, it remains debatable as to how far a researcher can be totally intuitive him/herself (Greatrex-White, 2004). Bracketing means the researcher is not holding any presuppositions about the study. I do not believe that it is possible to bracket my Chinese culture and previous knowledge and understanding of cancer care of older patients. This is also against my research aim to gain a deeper understanding of what older cancer patients and their witnesses experience in the Chinese context.

4.2.2 Heidegger's Interpretive Phenomenology

Heidegger's Interpretive Phenomenology was founded by Martin Heidegger, Husserl's student. For Heidegger, phenomenology is to explore the meaning of "*Being*" (referred to as "*Dasein*" by Heidegger, which literally means "being-there") and increase new possibilities for a new or renewed understanding of a phenomenon. It is both a reflexive and critical endeavour because "the question of *Being* recognises that people understand themselves within the confines of ways of being that are not completely apparent and are not entirely the products of choice" (Greatrex-White, 2004, p.127). Being-in-the-world refers to the way human beings exist, act or are involved in the world, which is given in our cultural, linguistic, historical and social contexts. "*World*" is not simply the environment, it is the "meaningful set of relationships, practices, and language that we have by virtue of being born in to a culture" (Leonard, 1989: p.43). Human beings are characterised by uniqueness. Every person's opinion is limited in one way or another. Humans make decisions and choices when moving from one condition to another, and the choices are made in the world in which humans exist surrounded by other humans.

Heidegger also used the terms "*intentionality*" and "*essence*" in his work, but the meanings of these terms are distinct from Husserl's work. In Heidegger's view, *intentionality*, one of the important assumptions of phenomenology, "is present not only in the realm of consciousness, understood in terms of a person's cognitive and theoretical relation to their world, but already in terms of a person's *Being* in the world" (Greatrex-White, 2004, p.125). Different from Husserl's epistemological concern of knowing, Heidegger's philosophical focus was ontological existence and the understanding of "*Being*" itself (Mackey, 2005). In Heidegger's major work, *Being and Time* (1962), he illustrated that the primordial ontological question should be answered first, "what does it mean to be", before moving to what can be known (Mackey, 2005). Heidegger believed that *Being* is always the *Being* of an entity and so to study the being of something is to inquire into the nature or meaning of that phenomenon (Van Manen, 1990). The most important way for a human being *to be-in-the-world* is in being aware of one's own *Being*, which means being capable of inquiring into one's own *Being* and capable of wondering about one's own existence. Being-in-the-word, which is called *Dasein* by Heidegger (1962), can provide an account of everyday practices and activities, and the determinative structures of the *Being* can be revealed (Mackey, 2005). Therefore, Heideggerian phenomenology requires researchers to obtain rich descriptions of individuals' everyday life in order to find out how individuals' realities are influenced by the world they live in through their own accounts of their experiences. Greatrex-White (2007) argued that Heidegger fundamentally brought together subject and object, agency and structure, and even theory and practice. This is different from the descriptive phenomenology study on what people consciously know (Lopez and Willis, 2004).

Meanwhile, the term *essence* in Heidegger's work defines the meaningful relationships maintained within the world instead of describing the "whatness" of a phenomenon because

we are not merely talking about things but about meanings based on Heidegger's ontological position (Van Manen, 1990). For example, in my research, an interpretative phenomenologist would encourage the patients to describe their care experiences in details as an individual having cancer, including their interactions, relations to other people, the changes of the body, feelings of the time, the experience of living toward death, and how the EOLC being put in the context of daily activities and socialisation. Koch (1995) pointed out that in interpretive phenomenology, researchers accept and value the participants' descriptions as to their reality and their understanding of the phenomenon.

Heideggerian phenomenology emphasises not only the description of the experience of a phenomenon but also the disclosure of how the individuals experience the phenomenon. These descriptive activities are just a preparatory step in Heideggerian interpretive phenomenology which opens the way for interpretation and understanding (Mackey, 2005). "In every case this interpretation is grounded in something we have in advance, in a fore-having." It is also grounded by "something we see in advance, in a fore-sight," and finally by "something we grasp in advance, in a fore-conception", collectively the "forestructure of understanding" (Heidegger, 1962, p.191). Heideggerian phenomenology asks researchers to pursue the forestructures and thematic meanings in the data beyond the literal meaning of participants' words through a spiralling upward process of understanding of a phenomenon rather than a circle of understanding. Greatrex-White (2004, p.133) pointed out that "what we have been, and already experienced, and what possibilities or paths we see for the future, make possible an interpretation of what we are presently experiencing or attempting to understand." The forestructure of understanding combines past, present, and future to be experienced as a unity. I agree with the point of Greatrex-White (2004) that we cannot separate our past history from the notion of that which we are investigating. Things only have meaning when they are

discovered as being relevant to our lives, as playing a role in our world, or as making a difference to us (Greatrex-White, 2004). This concept is opposite to Husserl's point of view of stripping researchers' prior knowledge and excluding the impact of culture, society and politics.

The forestructure of understanding highlights temporality, or being-in-time, which means lived experiences are also the culmination of persons' past, present, and future being in the world. "Death" completes the existence of "being-in-the-world". Death is a loss, and "we have no way of access to the loss-of-Being as such which the dying man "suffers". The dying of Others is not something which we experience in a genuine sense; at most, we are always just "there alongside" (Heidegger, 1962: p282). Therefore, focusing on self-reflection of self-awareness and self-understanding, Heidegger's phenomenology is useful in analysing lived experience of cancer patients, who are struggling with physical pain and psychological distress while being-in-the-world, being-in-time, and being-toward-death (Heidegger, 1962).

The meanings of the phenomenon vary across participants' experiences, cultures, societies and political systems. It has been illustrated in some studies that the phenomenon of EOLC manifests differently in different countries and reflects the distinguishable cultural, social traditions and identities in each country (Doumit *et al.,* 2007; Kwon *et al.,* 2012; Gysels *et al.,* 2012). The knowledge of EOLC is culturally and socially relevant, so it is impossible to seek purely descriptive reality, as assumed by Husserl.

Based on the forestructure of understanding in the Heideggerian approach, interpretation is seen as disclosure, which allows what is already there or what is already understood to be revealed (Mackey, 2005). There is more than one reality as different people may have different understandings. Heidegger considered interpretation as a spiralling upward process, whereby the forestructure of understanding is made explicit, left behind, then considered in terms of the

whole understanding of the phenomenon, and then re-considered in new ways. The dynamic process of understanding a phenomenon is suitable to seek a better understanding of EOLC issues of older patients with cancer because EOLC issues are dynamic situation considering of differences in time, places, cultures, and involvement of other people.

Greatrex-White (2008) argued that the researchers' forestructure of understanding their Being-in-the-world should be declared before the beginning of interpretation. My working experiences in EOLC in the UK and personal experiences of relatives EOLC in China have equipped me with the forestructure of EOLC issues in advance of embarking on the process of interpretation.

After careful consideration of the philosophical foundations of the above two approaches, I decided that Heideggerian interpretative phenomenology might be more appropriate to guide my research. My study is not about "What is EOLC for older people with cancer in China?" but rather about developing a better understanding of the experience of EOLC issues for older people with cancer, stimulating further thinking, questioning and inquiring of the phenomenon. Furthermore, Heideggerian philosophy allows me to analyse the cultural, social, political factors that form and organise the experience. In addition, it is impossible for me to rid myself of the pre-understanding that has led me to my research topic in the first place. If I attempt to bracket my knowledge and experience of EOLC or cancer care, I will not persuade myself to accept it, which would influence the rigour of my study (Koch, 1996). Seymour and Clark (1998) illustrated that phenomenology undertaken with careful approaches and rigour would merit the research in palliative care by studying the perspectives of patients, informal carers and health professionals. I believe that interpretative phenomenology helps me effectively achieve the research objectives and lead to a new understanding of EOLC issues for older people with cancer in China. Phenomenology needs a specific mode of data collection and

analysis that lights up the phenomenon from the participants' individual perspectives. Unstructured in-depth phenomenological interviews are used in data collection, and the data collected are analysed following the tradition in phenomenology that requires the research to explicate the data along with his/her observation of everyday life and understanding of the literature (Van Manen, 1990). These details are further explained in the following section.

4.3 Methods

4.3.1 Study Settings and Recruitment Strategy

Purposive sampling technique was used to select participants as phenomenology emphasises that only those who have experienced the phenomenon are able to provide a detailed description of the phenomenon to the outside world. Considering the access restrictions, time limit of PhD study, and cost of data collection, three different care settings in Liaocheng city, were chosen to obtain participants who had the particular experience and were likely to give key perspectives on the research topic. These three settings are one oncological ward in the largest city hospital (Liaocheng People's Hospital), one community clinic (Wangtianfu Community Clinic), and a hospice (Li Ka-Shing Hospice Centre or Ningyang Yuan).

Liaocheng City in Shandong Province was selected as the priority location of the fieldwork for several reasons. Firstly, few studies have been carried out in north China. Secondly, Liaocheng, as a typical middle-sized city in China, represents how EOLC services are provided in China. It has a population of 5.9 million and a national average income level (GDP per capita of RMB 36,573 in 2013). It administers one city, 7 counties, 135 towns and thousands of villages, similar to many other cities in China at the prefecture-level. Thirdly, Liaocheng has various healthcare institutions at different levels, particularly the only hospice unit in Shandong

Province, founded by the Li Ka-Shing Foundation. Fourthly, I have reliable personal contacts for access to local institutions and patients, and it is near to my hometown, so I can better understand the meanings of the accounts from the participants (such as local dialect, idiom, customs etc.).

Among the three settings, Liaocheng People's Hospital is the leading medical and teaching hospital in Liaocheng City. It is also a provincial, regional general tertiary-level hospital in Shandong Province. It mainly serves people who can afford the cost of hospital care. Like many hospitals at the tertiary level, it has an oncology department called "comprehensive treatment department" to avoid using the sensitive word "oncology". Li Ka-Shing Hospice Centre is the only hospice centre located in Shandong Province founded by the Li Ka-Shing Foundation and working as a partnership with Liaocheng People's Hospital (see Figure 4). It aims to provide free home-based holistic care for cancer patients certified at a low-income level by relevant authorities. Wangtianfu Community Clinic aims to help outpatients living in the community. I chose these three settings in order to cover a wider population with different social-economic backgrounds in rural and urban areas.

The recruitment strategies for each type of participants are shown in Table 1, including eligibility criteria and rationales.

Figure 4 Locations of Hospice Services Founded by Li Ka-Shing Foundation in China



Note: ★ Liaocheng City, Shandong Province

Source: http://www.hospice.com.cn/en/#A1 *[Accessed on 1st September 2015]*

Table 1 Eligibility Criteria of Participants and the Rationales

	Eligibility criteria	Rationale
Patients	Inclusion criteria: 1. Age 60 or over*; 2. Diagnosed with advanced cancer; 3. The consultants would not be surprised if the patient died in the next 12 months or so; 4. Knowing their diagnosis; 5. Having the capacity to give informed consent. Exclusion criteria: 1. Having severe cognitive impairment by primary doctors' medical judgement; 2. Not knowing the diagnosis; 3. Not physically well enough to participate in the interview.	1. Cancer is the leading cause of death in China, and it accounts for nearly 26% of death among the total death in China (National Bureau of Statistics of China, 2019). 2. During 2004-2005, the mortality rate of cancer in elderly Chinese was over 65% which is substantially higher than those less than 60 years old (Zou *et al.*, 2012). 3. In terms of time, such as in the UK and Australia, EOLC usually refers to the last stage of life, such as within the last year, the last few months or days of life (Goodman *et al.*, 2012). 4. Due to the complexity and uncertainty of the disease, it is difficult to get the exact life expectancy. I asked the consultants whether they would be surprised if the patient would die in the next 12 months or so. 5. Only patients who knew their medical conditions were able to share their experiences of the phenomenon. 6. Only patients who had the mental capacity to give informed consent and could express themselves were included in the study.

Family Carer	Inclusion criteria: 1. Aged 18 or over; being a family carer of an older cancer patient aged 60 +. 2. Being aware of the patient's medical situation (advanced cancer, life prognosis less than 12 months); 3. Being the key household member in the patient's family who made the primary decision for the patient's treatment or care; Exclusion criteria: 1. Being a paid carer	1. According to Chinese Law, people become adult from 18 years old. 2. Family carer means the principal family member in the family who can make the primary decision for the patient's treatment or care.
Doctors and Nurses	Inclusion criteria: 1. Being a qualified doctor/nurse; 2. Being in a senior position or having been working in his/her department for at least two years;	1. The purpose is to recruit participants who have rich experiences of the phenomenon.

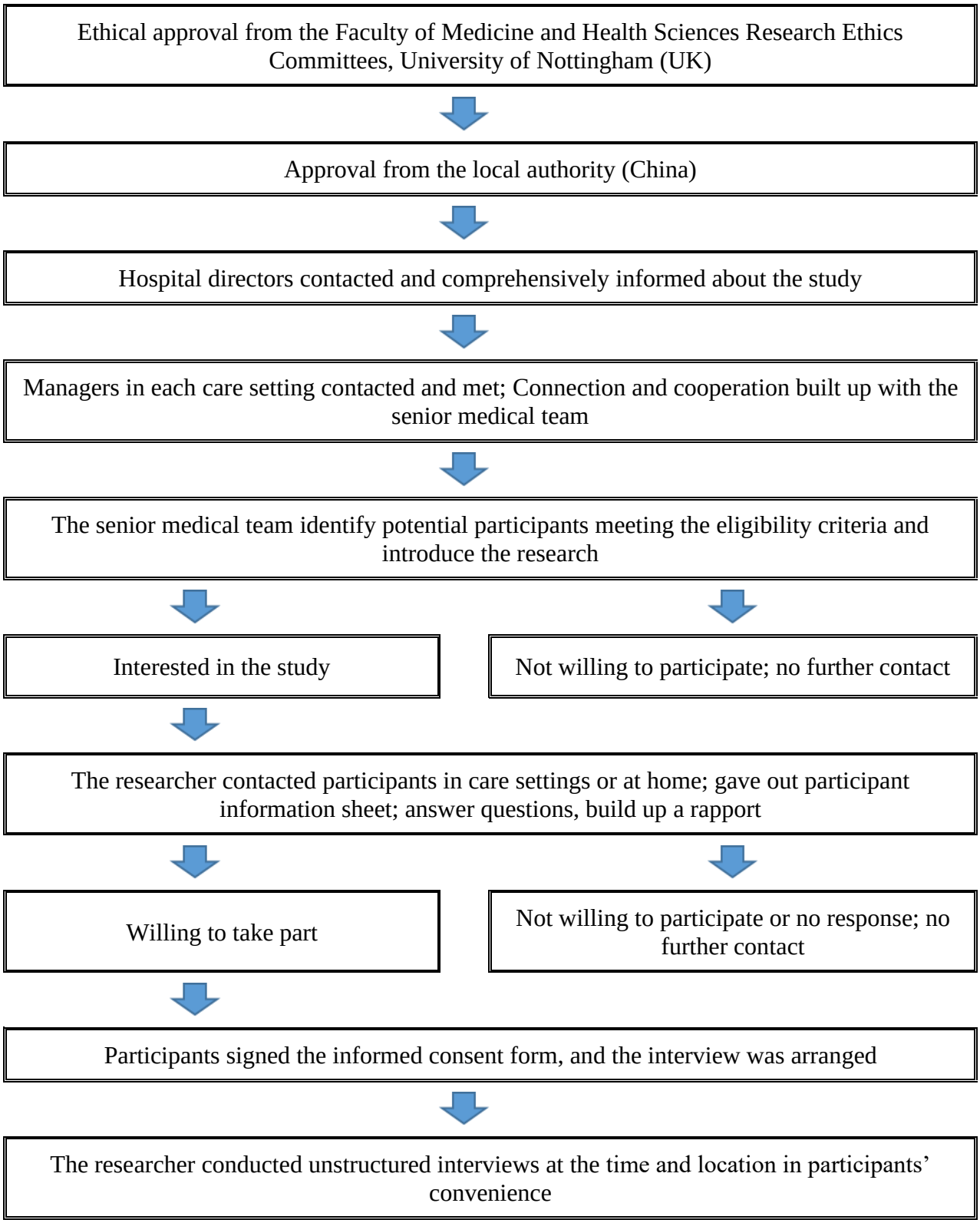
Note: *There is no standard numerical criterion for older people. In this research, the chronological 60 years is used as the beginning of old age, which is consistent with the cut-off agreed by the United Nations (World Health Organization, n.d.). China has accepted the age of 60 as a definition of an older person and set this age for retirement. This is different from many developed world countries that have accepted 65+ years to denote old age.

4.3.2 Recruitment of Participants

Seymour and Ingleton (1999) mentioned two separate but closely related phases to get into any fieldwork: negotiation with the participants about the nature of the study and how informed consent is gained from participants. The consent process would influence the way how participants see the researcher and how far to develop rapport between them. Gaining informed consent in EOLC research is an active, dynamic process and likely to be time-consuming; however, it is important to build rapport and trust between researcher and participants and hence access and obtain quality data (Schulman-Green *et al.*, 2010). All participants were given plenty of time to read the Participant Information Sheet (PIS) and discuss any questions with the researcher about the study before deciding to participate. The consent form was signed and dated by the participant before they entered the study. Inked thumbprint was used if participants had difficulty in writing, which is legally accepted in China. The patient's capacity to consent was assessed by the consultants when they were identifying participants by their clinical judgment.

Informed consent was collected before the interview and was verbally re-validated during the data collection. One copy of the form was kept by the participant, and the other was kept by the researcher. With full consent information provided at the outset, participants could understand the study better and could judge their contribution value. In addition, gaining informed consent was an on-going process. Participants were offered frequent and repeated opportunities to stop or avoid further participation in the interviews or the whole study. The general recruitment process is described in the following flowchart (Figure 5).

Figure 5 Flowchart of the Recruitment Process



Recruitment of Health Professionals

Having built up a connection with the manager in Liaocheng People's Hospital while applying for ethical permission, I contacted the hospital again to confirm their available date and time for the initial visit. I met up with the manager of the medical team in the oncological ward first and discussed the details of the study. With the manager's assistance, I was introduced to the team in their staff meeting on different days. In each setting, I usually organised an informal meeting to introduce my study to suitable health professionals. As mentioned earlier, I targeted experienced doctors and nurses who were able to provide a rich description of the EOLC issues they had experienced. The health professionals showed strong interest in the study. I approached suitable doctors and nurses at their convenience and discussed my study further. In the hospital ward, a few interviews were carried out on night shifts because doctors and nurses had more time during their night shifts. In Wangtianfu Community Clinic, the doctor declined to join the study because he thought he lacked experience in this area.

Recruitment of Patients and Family Carers in Liaocheng People's Hospital

The recruitment of patients started at the same time as recruiting health professionals. After understanding the study design, the senior medical team and ward sister agreed to identify potential patients and family participants who met the recruitment criteria. When they identified the potential participants and gained their verbal consent to know me, they introduced me to the patients and the family. I then spoke with patients and family carers later when they were free and gave out the participant information sheet (Appendix 2). My contact details were included in the information sheet. After at least 24 hours, I revisited patients/family carers at their convenient time to fully explain the study, answered their questions and completed the consent process. The consent form is available in Appendix 3. A maximum of 4

weeks was given to each potential participant from the beginning of contact to get informed consent. This time duration allowed the participants to clarify any questions with the researcher or discuss the research with their relatives or friends. It was also a great opportunity for me to be known by potential participants and build up a rapport with them.

Due to the study's sensitivity, Seymour et al. (2005) pointed out that it would be much easier and feasible to replace all references to EOLC in the study with alternative, more neutral words and phrases when introducing the study to the participants, especially patients. Therefore, considering China's cultural background, I avoided mentioning EOLC to the patients but focused on understanding the care experiences of the illness. More details are discussed in section 4.3.4 on ethical issues.

When identifying the potential patient participants, consultants, and senior doctors only considered patients who had been aware of their diagnosis and were able to give informed consent by their medical judgement. Patients who did not know their diagnosis and who were unable to give consent were excluded from the study, but this did not influence the recruitment of family carers.

There are several advantages of introducing the researcher and the study by the clinical staff whom the potential participants know and trust. It assists with access to the patients, makes participants more amenable to discuss further with the researcher, and helps gain support from family who are often protective of the patients (Wiegand *et al.*, 2008; Schulman-Green *et al.*, 2010). However, there are also concerns that the power of health professionals would affect recruitment. For example, health professionals might only recommend "good" patients and families who would respond in a way that professionals considered as appropriate, or they would induce patients and families to say yes to participate. To minimise these influences, I

clearly stated to the doctors and nurses about the recruitment criteria and voluntary participation. I also explained clearly to potential participants of patients and families that attending or not would not affect their treatment and relationship with health professionals in the setting. During the recruitment process, some participants directly declined to the study at the beginning, and some refused after I contacted them. The interview was unstructured without pre-set questions (see details in section 4.3.3). The interview accounts also showed diverse experiences, attitudes, feelings and behaviours among participants. Therefore, using health professionals to introduce the researcher did not force patients and families to participate in this study or respond in a way that the health professionals expected.

There were challenges in the recruitment process of patients and family carers in the hospital. Many family carers hid the diagnosis from the patients, so it was difficult for the doctors to identify whether these patients met the selection criterion of knowing the diagnosis. Besides, many family carers and patients who met the recruitment criteria tried to avoid talking about cancer and death (as reported in findings). In the first month, I gave out 5 information sheets to patients and family carers in the hospital, but none successfully signed the consent form. Then, the Chinese New Year was coming, and it would not be appropriate to continue the study for a few weeks (because it was believed to bring bad luck of talking about death during this festival). I used this period to reflect my recruiting strategy and made some adjustment. I remembered that I met a potential patient and gave him the information sheet to read. The next day, when I tried to contact this patient in the hospital, the patient had been already discharged home. Similar cases happened to some other patients or families. I decided to change my recruitment strategy and discussed this with the senior doctors after the Chinese New Year. With the manager's permission, I followed the medical team and nursing team in ward rounds to get familiar with the field environment and potential participants as early as possible. I also

changed the way of dispensing the information sheet. I spent more time talking with the potential participants, introduced myself and my study verbally. If some expressed their interests in sharing their experiences with me, I gave them the information sheets. By doing this, the patients and family members would know more about my study more and build up the trust between the participant and myself to join the study. In the end, I recruited 3 patients after distributing 8 information sheets and 3 family carers after distributing 7 information sheets in the oncological ward.

Recruitment of Patients and Family Carers in the Hospice

Recruitments of patients in the hospice and community clinic were different from those in the hospital. Li Ka-Shing Hospice Centre provides home-based hospice care to cancer patients with low-income level. I initially contacted the hospice director, who then informed other staff members and helped identify eligible patients and asked for their verbal permissions. Every Tuesday and Thursday morning was the clinic time in the hospice centre. During this period, hospice doctors saw patient or family members who came to get analgesia prescription. It allowed me to meet with patients or family carers in the clinic and start recruitment. However, after a few weeks, I noted several difficulties. It was usually the family members coming to get the medicine for the patients. The weather was terrible that winter, snowed a few times, and the traffic was often congested. Many potential participants tended to rush to go back after getting the prescription and would not like to spend much time in the hospice. Some people came from a faraway by public transport so that they had to rush to get the returned bus. This situation got better when the spring came and the weather got a bit warmer. I was able to recruit family carers in the hospice centre. However, recruiting patients was still a challenge because many patients were too vulnerable to visit the centre with their family carers. After a discussion with the director, I joined their home visiting team on Monday and Tuesday afternoons,

Wednesday or Friday, which allowed me to see more patients at their homes. During the home visit, I was introduced to the patients and family members. After a couple of home visits, some potential participants became familiar with me. I then gave them the information sheet and had their contact details with me. I then contacted them after 1 or 2 days, answered their questions, and made an appointment for the interview at their convenient place. I gave out 28 information sheets to potential participants. Finally, 7 patients and 7 family carers were recruited.

Recruitment of Patients and Family Carers in the Community Clinic

Wangtianfu Community Clinic provides medical service to outpatients and residents in the community. The person who assisted the recruitment process was a senior nurse. The recruiting process was similar to that in the hospital. While the patients were visiting the clinic, there was often about 30 minutes of waiting time. I was introduced to the patients during this period. If the potential participants expressed their interests in sharing their experiences with me, the information sheet was given to them either by the senior nurse or me. Two potential patients and six family carers took the information sheets, but eventually, only two family carers accepted the interviews.

The time was tight in the fieldwork. I spent all my time in the three healthcare settings with the potential participants and interviews. The recruitment of participants in different settings took place alternately, and the interviews were arranged following the consent whenever the participants were available. At each setting, I had two or more rounds of recruitment of patients and family carers to identify new eligible participants because cancer patients remained relatively stable within a certain period.

All participants were aware that the participation was totally voluntary. For patients and family members, this was clearly stated at the beginning that non-participation or withdrawal from the

study would not affect their current and future care or treatment at all, and it would not affect their relationship with clinical staff.

Regarding the number of participants, researchers recommend choosing between 5 and 25 participants who have all experienced the phenomenon (Creswell, 2013), or usually under 30 participants for an individual interview as interviews will generate a huge amount of data for analysis (Steinhauser and Barroso, 2009). Considering the time and cost restrictions of the PhD study, I planned to recruit 30 participants in total, ideally including 2 doctors and 2 nurses; 3 patients; and 3 family carers through each care setting. In the field, since the number of eligible participants was small in the community clinic, only 1 nurse and 2 family members were recruited in the clinic. On the contrary, there were more eligible participants in the hospice who expressed interests in participation. In the end, I had interviewed 37 participants, including 10 patients, 12 family members, 8 doctors, and 6 nurses (see distribution and the codes of their names in Table 2). The detailed demographic characteristics of participants in each group are reported in Tables 3-5. The real names of all participants are replaced with pseudonyms to maintain confidentiality and protect privacy.

Table 2 Number of Participants by Setting

	Hospice Centre	Hospital Oncology Ward	Community Clinic	Total
Patients	7 Patient TB Patient ZG Patient ZS Patient ZJ Patient JLQ Patient PC Patient QM	3 Patient LJX Patient GJG	0	**10**
Family carers	7 Family XG Family PCW (Patient PC's wife) Family YYS Family CXS Family XUW Family XJS Family MLK	3 Family PQ Family ST Family ZM	2 Family XX Family YZS	**12**
Doctors	3 Doctor GJ Doctor ZPF Doctor TY	5 Doctor ZX Doctor WB Doctor ZHP Doctor LM Doctor SG	0	**8**
Nurses	4 Nurse LY Nurse YR Nurse BF Nurse GC	2 Nurse CC Nurse LR	1 Nurse LX	**7**
Total	**21**	**13**	**3**	**37**

Table 3 Demographic Details of Patient Participants

Name	Code	Age	Gender	Occupation	Recruitment Setting	Type of Cancer	Remarks
Lee-Jix	LJX	61	M	Chef	Oncological ward	Cholangiocarcinoma with lymphatic metastasis	Knowing diagnosis from the doctor
Go-Jung	GJG	60	M	Government officer	Oncological ward	Lung cancer and pleural metastasis	Knowing diagnosis from the doctor
Yang-Zhe	YZ	63	M	Migrant worker	Oncological ward	Stomach cancer	Knowing diagnosis from family
Tun-Bao	TB	65	M	Farmer	Hospice	Lung adenocarcinoma with multiple metastases	Knowing diagnosis from daughter after a few weeks; Interviewed twice due to interruption
Zhu-Gua	ZG	72	M	Farmer	Hospice	Liver cancer	Knowing diagnosis from family
Zhu-Shen	ZS	61	M	Farmer	Hospice	Pancreatic cancer with lymphatic metastasis	Knowing diagnosis from the doctor
Zhan-Jin	ZJ	61	F	Bank manager	Hospice	Lung cancer and brain metastasis	Knowing diagnosis from the doctor
Jian-Liq	JLQ	60	M	Factory worker	Hospice	Cholangiocarcinoma	Knowing diagnosis from wife after a couple of days
Pa-Cha	PC	61	M	Unemployed	Hospice	Lung cancer	Knowing diagnosis from family after three years
Qi-Mo	QM	78	M	Teacher	Hospice	Oesophagal cancer with bone metastasis	Knowing diagnosis from family; Passed away 1 month after the interview

Table 4 Demographic Details of Family Participants

Name	Code	Age	Gender	Occupation	Recruitment Setting	Patient-Family Relationship	Remarks
Pa-Qin	PQ	55	F	Pharmacist	Oncological ward	Mother-Daughter	Not telling her mother (85 years old) with colon cancer and liver metastasis
Su-Tao	ST	52	F	Unemployed	Oncological ward	Mother-Daughter	Not telling her mother (71 years old) with lung cancer
Zho-Ma	ZM	46	M	Farmer	Oncological ward	Father-Son	Not telling his father who has bone metastases Died after a couple of days of the interview
Xu-Gu	XG	35	F	Health professional	Hospice	Father-Daughter	Diagnosis communication from the doctor to his father, then to his father's friend and finally to XG
Pa-ChW	PCW	57	F	Unemployed	Hospice	Husband-Wife	Telling her husband PC after 3 years of diagnosis; PC has lung cancer; interviewed together
Yu-Yu	YYS	50	M	Company employee	Hospice	Mother-Son	Telling his mum (71 years old) that it was a benign tumour in the stomach
Ch-XS	CXS	43	M	Migrant worker	Hospice	Father-Son	Telling his father (61 years old) the diagnosis (liver cancer)
Xu-XW	XUW	56	F	Company employee	Hospice	Husband-Wife	Not telling her husband (61 years old) with lung cancer and brain metastasis
Xia-JS	XJS	63	M	Farmer	Hospice	Father-Son	Not telling his father (85 years old) with stomach cancer
Ma-Luk	MLK	63	M	Farmer	Hospitce	Wife-Husband	Not telling his wife (61 years old) with pancreatic cancer
Xu-Xib	XX	40	M	Civil servant	Community clinic	Father-Son	Not telling his father (60 years old), who died with lung cancer a few days after the interview
Yu-Zis	YZS	50	M	Police officer	Community clinic	Mother-Son	Not telling his mother (75 years old) with colon cancer

Table 5 Demographic Details of Health Professional Participants

Name	Code	Age	Gender	Profession	Recruitment setting	Years in the Setting	Remarks
Ga-Ji	GJ	51	M	Doctor	Hospice	5	Director
Zu-Penfe	ZPF	31	M	Doctor	Hospice	3	
Tia-Yin	TY	36	M	Doctor	Hospice	4	Deputy Director
Zha-Xia	ZX	52	M	Doctor	Oncological ward	9	Director; Interviewed twice due to interruption
Wa-Bao	WB	45	M	Doctor	Oncological ward	6	Deputy Director
Zha-Pu	ZHP	32	M	Doctor	Oncological ward	3	
Le-Me	LM	33	F	Doctor	Oncological ward	3	
Su-Gui	SG	36	M	Doctor	Oncological ward	5	Deputy Director
Lee-Xi	LX	46	F	Nurse	Community clinic	8	Charge nurse Her father was a cancer patient
Lu-Yi	LY	35	F	Nurse	Hospice	4	Charge nurse Her father has stomach cancer
Ya-Ron	YR	29	F	Nurse	Hospice	3	
Be-Fern	BF	45	F	Nurse	Hospice	4	Charge nurse
Gen-Chu	GC	47	F	Nurse	Hospice	3	
Cha-Chun	CC	31	F	Nurse	Oncological ward	4	
Lee-Run	LR	29	F	Nurse	Oncological ward	6	Charge nurse

4.3.3 Data Collection

Time and Place of the Interview

The desired interview location should be a quiet, private and comfortable environment to avoid distractions as much as possible (Benjamin, 1981). The place and time of the interview were agreed upon by participants and me at the participants' convenience. All the participants from the oncological ward had their interviews in a private consulting room of the ward. For participants recruited from the hospice centre and community clinic, the interviews took place either in a private room in the hospice centre/clinic or the patient's/family's own home (particularly for the patients cared for at home).

There is no definitive answer to how many times each participant needs to be interviewed. End of life is a dynamic progress and people's views and preferences may change with time. However, Heideggerian phenomenology emphasised people's experiences at that particular time and situated place. "What is experienced in the present is coherent with what was experienced in the past and is expected to be experienced in the future" (Mackey, 2005, p.183). Illness, particularly cancer, is disruptive to the experience of time, such as diagnosis and treatment (Mackey, 2005). So one in-depth interview is sufficient for phenomenology, which fits the conception of time, space and being in the world and it would be inappropriate to conduct follow-up interviews (McConnell-Henry *et al.*, 2011). Additionally, a follow-up interview may become ethically challenging and unworkable due to patients' fluctuating health and social status (Smith, 1992; Taylor, 1995a). In reality, some patient might pass away soon after the interview so that follow-up interview was not practicable.

Therefore, in the field, most participants were interviewed once. However, some interviews were interrupted. For example, the interview with patient TB was interrupted by a visitor at home and that with Doctor ZX was stopped due to an emergency call of the hospital. This issue is commonly seen in qualitative research involving patients, such as in Broom and Cavenagh (2011), who were doing 20 in-depth interviews with patients receiving in-patient hospice care in Australia. If the interview was unable to continue but the participant was willing to have another interview at a different time, a further meeting time was arranged when it was convenient for the participant. Therefore, a second interview was arranged for patient TB and Doctor ZX because both would like to continue to share their experiences with me.

The duration of the interviews varied from 29 minutes to 109 minutes, depending on the type of participants and their conditions. All the interviews were digitally recorded.

Unstructured Interview

In phenomenology, data collection aimed to uncover participants' lived experiences of the phenomenon. The unstructured interview could reduce the researcher's influence and allow the participants to use their unique ways of defining the world (Silverman, 2011). Benjamin (1981) and Holloway and Wheeler (2010) pointed out that the unstructured interview usually begins with a broad, open question about the study topic and then followed by prompt questions depending on the responses of the participant. The use of prompts during the interview is an important tactic to encourage participants to reveal their experience or knowledge on a specific point (Denscombe, 2007). The interview was usually ended with a broad question which helped participants come up with data that had not been considered before. Schulman-Green et al. (2010) illustrated that the interviewer should likewise be prepared and consider the direction the research questions may take before the interview, even if not doing it purposely. My

unstructured interviews were carried out following the guidance of previous research in phenomenology.

Before the interview, some preliminary information about the participants was obtained from the referral source and the initial direct contact with the participants. The demographic information of patients and family carers includes age, sex, occupation, family carer's relationship with patients, and family structure. For health professionals, I also asked about their positions and years of working in the job. These details were useful for me to know more about the participants and prepare for the interview.

In order to access to patients' unique experience, I started with an open-ended question in the interview: Could you tell me about your care experience of your illness? (in the patient group); Could you tell me about your experience of looking after the patient in your family? (in the family group); Could you tell me about your experience of caring for patients at the end of their life? (in the health professionals group). The phenomenological interview is about getting participants to recall and talk about their experiences rather than the researcher's predesigned conceptions. Therefore, no predesigned questions were used during the interview. I drew on some prompts which might help patients talk more about the care they received (see Appendix 4), such as "you just mentioned … Could you tell more about …". When the participants did not respond to the prompt question and rather talked about some different issues, even though it was useful to let participants go where they wanted to go, some skills of redirection were applied. I maintained flexibility in the interview, which was important to respect the participant and discuss various aspects of individual experience. At the end of the interview, I asked participants a broad question: "Is there anything else you want to add?".

Self-reflection in the Field

Seymour and Ingleton (1999) suggested that the researcher should take up positions as self-reflective and interactive commentators and pay attention to insightful and credible accounts of how participants experienced their illness rather than seeking objective truth in the participants' experience.

To maintain a self-reflective stance in the field, I kept a research diary to record what I saw, what I thought, what the problem was, how I dealt with it, how the participant thought/responded. During the interviews, I listened carefully to the participants and paid attention to other hints, such as emotional change, sobbing, tone, body language, facial expression, etc. I put down these observations (or field notes) in my research diary as soon as possible after each interview. These clues from my observation were valuable for my data analysis and allowed me to understand the interview accounts further.

Self-reflection also helped to solve difficulties in the field. For example, the interview with the first patient was the most challenging experience. Since the patient did not talk much, I felt very uncomfortable when we were both quiet. I tried to use my prepared prompts but sometimes found the patient was not interested in continuing that topic. After the first interview, I immediately listened and re-listened to my recording and reviewed what I did in the interview and reflected on what to do in the future when facing similar problems. I also discussed with my supervisors through email and Skype conversation to get their advice. After interviewing a couple of patients, I felt the interview process became smoother.

4.3.4 Ethical Issues

There are some ethical issues that should be considered.

Sensitive Topic Area

Previous research has illustrated that some people like to take the opportunity to talk about the experience about EOLC to the researcher and want their voices to be heard, especially if they felt their experiences were valuable to help others (Barnett, 2001; Rigby *et al.*, 2010; Schulman-Green *et al.*, 2010). However, EOLC is a sensitive topic, particularly in China, where many people avoid using taboo words such as die, dying, death, and cancer, in conversations. It would be more comfortable and feasible to replace all references to EOLC, cancer and death in the study with alternative, more neutral words and phrase, particularly for patients and family caregivers (Seymour *et al.*, 2005). Thus, the study materials and information sheets were designed and presented to focus on care experiences of illness, avoiding any mention of EOLC directly. During the interview with the patients and family carers, I replaced cancer with "this illness". I also chose some vague and tactful language (euphemism) as an antonym of death, such as "pass away", "leave", "that day", and "when that day comes" that both the interviewee and I understood the meaning. In addition, patients who did not know their diagnosis were excluded from this study. When recruiting and interviewing the family carers, I respected their preference for concealing the truth from the patients. If they did not want me to speak with the patients directly, I followed their request.

Additionally, as EOLC is a highly sensitive issue, building rapport and establishing trust and safety are crucial to collect quality data (Wright and Flemons, 2002). Researchers should maintain participants' rights and wellbeing while attaining the benefits of the research (Seymour and Skilbeck, 2002). It has been suggested that one way to develop trust with

seriously ill patients is to acknowledge their situation by showing care about them and being sensitive to their experience (Benjamin, 1981; Schulman-Green *et al.*, 2010). In the study, the recruitment of patients and family appeared difficult when asking them to talk about their care experiences. It took time to get to know the patient and their family and gain their trust. In the study, I was introduced to participants by health professionals, which help me get access to participants, discuss further about the study, and build up trust between participants and myself, the researcher.

Emotional Harm to Participants and Researcher

Given the nature of the topic, it was inevitable that the interview reminded participants of some painful experiences and some participants became distressed. It was made clear that participation in the study would be voluntary, and the participant was free to withdraw at any time, without giving any reason. None of the participants changed their mind and chose to withdraw from the interview after they agreed to participate. However, many participants appeared to be sad and became upset and cried during the interview. When this happened, I usually gave them a hot drink and the tissues and waited patiently. Most participants felt able to continue after a few minutes. For example, Patient JLQ, who was in tears for a while, continued to share with me his unique experiences and perspectives of being a cancer patient. However, there was also a patient, GJG, who was not able to continue the interview when I wanted to explore more about the "bad things" of having cancer he mentioned. He suddenly became silent and his face lost vitality. He then went to the toilet, and when he came back, he said he was tired, lay on his bed calmly and closed his eyes, indicating that the interview should be finished.

Talking about EOLC and sharing experiences of such a sensitive topic may, in turn, cause emotional harm, such as distress and grief, to the researcher. Although I have much experience of caring for older people at the end of their life and I am able to cope with those difficult situations, the research may still affect me due to seeing and hearing about EOLC issues in such a short period. Considering the possible stresses and strains of research in palliative care, Clark et al. (2000) pointed out that supervision and support are important in palliative care research. I, therefore, had a counsellor who was available to me and I contacted my supervisors regularly.

Privacy and Rights of Participants and Neutral Stance of the Researcher

Participants' privacy and rights were always respected in this study. Medical care always took precedence over the study in the field. Considering patients' medical condition, if the patient would like a third person as company in the interview, it was accepted and documented in data. When interviewing the patients, I was always aware of, and flexible about, time in case they might become unwell.

During the study, I kept my neutral stance as a researcher in the field and did not intend to make any judgements on their experiences or perspectives. When some patients were confused about something or had concerns about their illness or treatment, they were referred to the relevant individual (usually the doctor or the family member).

Confidentiality

To protect the confidentiality of participants, I did not discuss the interview content from one participant with others in the field. Their real names are not used in the study and any future use of the data will also be anonymous. Cypher codes were used instead of their real names

and participants' personal data are only accessed by the researcher and the supervisors (as shown in Tables 2-5). Furthermore, all the data, including audio record, transcripts and field notes, have been kept safe in locked facilities. The audio records are stored in safe and password protected university computers.

Ethical Approval

Ethical approval from the University of Nottingham was obtained before conducting the study in China. In China, non-interventional qualitative studies were not subject to ethical approval from the hospital's ethics committee (Cao *et al.*, 2004). However, permission to do the study in each healthcare setting was obtained before starting the research (Appendix 5).

4.3.5 Data Analysis

According to Van Manen (1990), the interpretive phenomenological research method is "scholarship". The researcher is a scholar who is a sensitive observer of the subtleties of everyday life and an avid reader of relevant texts in human science tradition within his/her domain of interest. In theory, there is not really a method in interpretive phenomenology. But there is a tradition in Heidegger's interpretive phenomenology, which constitutes a source and a methodological ground for present research practices. The researcher needs to consider the broad field of phenomenological scholarship as a set of guides and recommendations for a principled form of inquiry that neither simply ignore the tradition nor slavishly follow it. So, in the process of phenomenological reflection, it is essential for the researcher to be discovered or invented as a response to the question at hand (Van Manen, 1990). My way of analysis is produced from my careful observing participants' experiences of having cancer and living with cancer, and my keen reading of relevant texts in the human science of tradition of EOLC, cancer research, philosophy, and Chinese social and cultural contexts. The analysis process includes:

Gaining immediate sense. I started to obtain an immediate sense of the phenomenon when I began the dialogue with participants by observing their real living environment and meeting participants in their daily life. Next, I listened to the audio recordings of each participant as soon as possible after the interview to recall my observations in the dialogue and foster my understanding of their experience of the phenomenon. I kept a diary in which I made notes of my observation and reflection on their experiences.

Transcribing verbatim. All interview data were collected in Mandarin and transcribed verbatim in order to provide a written text for analysis, including pauses, emotions and expressions. I listened to and transcribed the interview data myself to keep their personal information private and immerse myself in the dialogues and thought processes deeply. My understanding and reflection of participants' experiences of having cancer, living with cancer and seeking cancer care were derived from the process of constructing the transcripts through listening and relistening to the interviews.

Translating into English. The preliminary analysis was mainly based on the original transcription in Mandarin and then translated quotations into English. This would avoid changes in meanings due to the translation or losing the meanings of some words that cannot find an appropriate English translation. I translated the full texts of five interviews into English for discussion with my supervisors. One of my supervisors is proficient in both Mandarin and English. Another one is a native English speaker. They read through the five interview transcripts and offered valuable suggestions to maintain the quality of data interpretation.

Intensive reading and reviewing. I read and reread each transcript and my field diary to get a sense of the whole data. I was conscious that I was making sense of the phenomenon of EOLC of older cancer patients. During this period, I produced broad and unfocused notes that reflected

any of my initial thoughts that had arisen in response to the text. These notes comprised ideas, thoughts, questions, associations, statements, comments, and so on. For example, Patient JLQ asked me whether I had ever experienced pain like cancer pain. He called me one of the "normal people" who could not understand his feeling as a cancer patient. He also compared his experiences and feelings of being a friend of a cancer patient and being a cancer patient himself. By reading his story and linking with other patients' perspectives of reluctant talking their illness and feelings with "others", I noticed that cancer patients excluded healthy people as "others". Cancer patients believed that none of the "others" could really understand their situations without "being there", i.e. in the same situation of being cancer patients.

Seeking the meaning units. By reading, rereading the text line by line, I identified the meaning units in response to my research question. Since I felt comfortable when reading things on paper, I sought the meaning units from the printed transcripts. Meaning units were identified where there were significant shifts in meaning. A meaning unit could be a word, a phrase, a sentence, several sentences, a paragraph, or whole pages of text. A huge number of meaning units were discovered from the data.

Coding the meaning units. By doing line-by-line coding in this stage, the meaning units were condensed and abstracted into codes. I described these codes using the words from the participants or my own words to capture the texts' fundamental meanings.

Developing individual situated structures and merging them into situated structures of each participant group. In this stage, I returned to the individual transcript and all the transcripts in each participant group (i.e. health professionals, patients and family carers). The structure for each participant was formed as I read each individual transcript by organising the codes in the transcript onto A4 papers. Then, I merged all individual situated structures into the group's

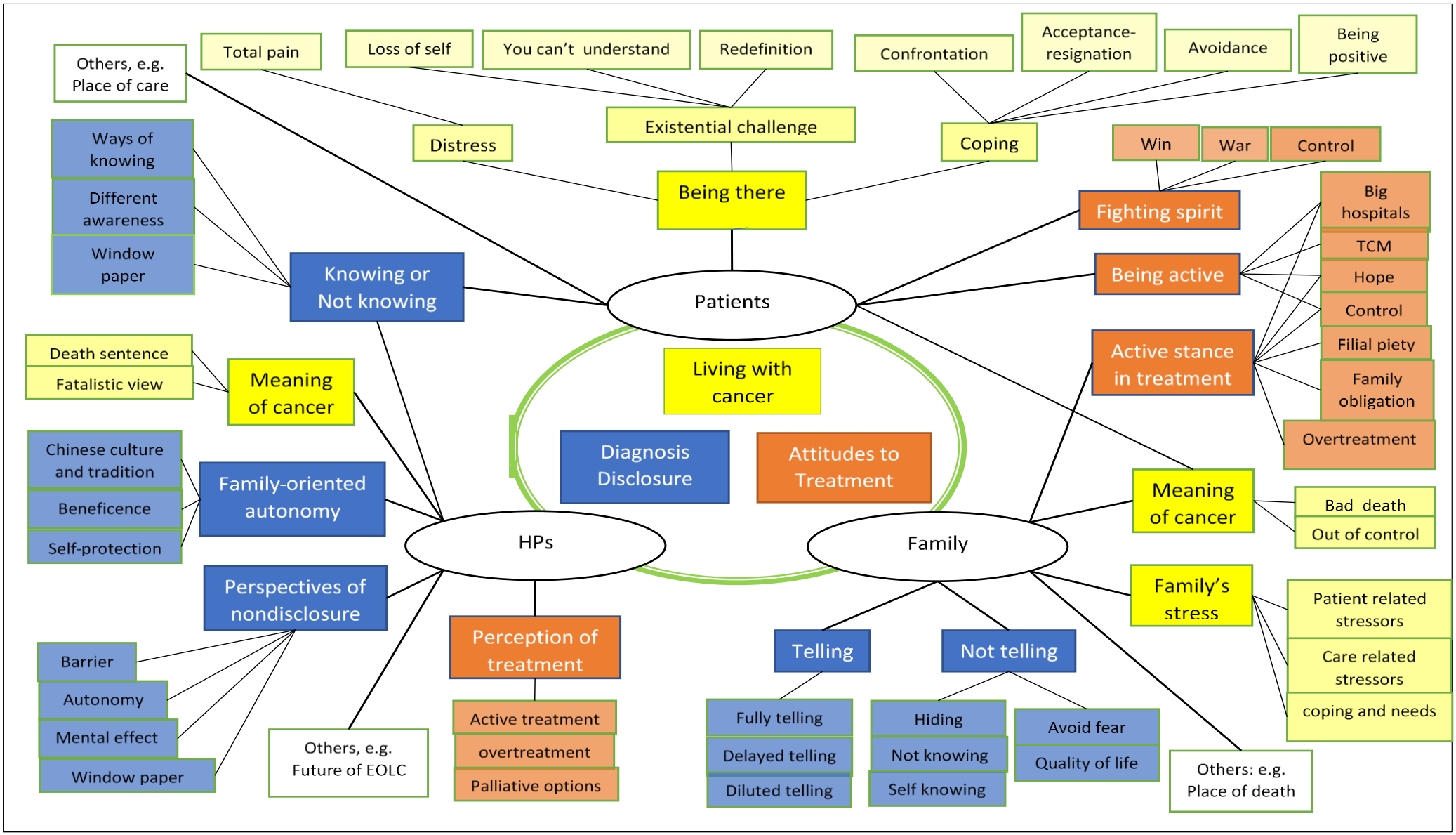
situated structures, putting in another word, my understanding of the structures of meanings situated in that group. When developing structures, some new categories, at different levels, were created to organise and reorganise these codes. Considering the complexity and enormity of the data, I called these different levels of categories as themes, sub-themes, sub-sub-themes and so on, which made the analysis clear. This process was not straightforward. It involved intensive reading and thinking between parts (individual transcripts) and whole (all transcripts in each participant group).

Forming general structures for the whole data. I put the situated structures of each participant group in front of me on A4 paper and reflected on them in my mind as a map. The analysis was a spiralling upward process and an amalgamation of different cycles of intensive and wide reading of literature and rereading of the texts. My past experience and knowledge formed my temporal interpretation of the meanings from the texts. The temporal interpretation inspired me to read more literature. By combining the literature with the meaning units, I then formulated a new understanding and interpretation of the phenomena. This repeated reflective process attributed to produce the new possibility of interpretation. Finally, I discovered three general structures for all participants (key themes), which allowed me to link three participant groups together and make my writing clear and explicit. These three themes are diagnosis disclosure, living with cancer, and attitudes toward cancer treatment (see Figure 6). In the three themes, I analysed the similarity and particularity among individuals and different groups while reflecting on how the phenomenon uncovers for the particular participants and, as interpreted by me, the researcher.

These three themes came from all three groups of participants. They were different from each other and involved different streams of literature and implications, although they also interlinked with each other in some situated structures for each group of participants.

Therefore, I decided to report each theme in one chapter with separate discussion and policy implications (Chapters 5, 6 and 7). In Chapter 5, I look at the experience of diagnosis disclosure from the perspectives of patients, family caregivers and health professionals, respectively. Patients expressed different experiences of knowing the diagnosis, their preferences for knowing and awareness of dying. Family caregivers showed their concerns when deciding to tell or not to tell the diagnosis truth to the patients, while health professionals adopted a family-oriented paradigm in practice and had their concerns and attitudes towards this paradigm. Chinese cultural and societal background, relevant theories and bioethics in diagnosis disclosure are discussed with the analysis. Patients and family caregivers' experiences of living with cancer are analysed in Chapter 6. The first subtheme contains an in-depth analysis of the meaning of cancer in China. Then, patients' experiences of "being-there" are analysed from their psychological distress, existential challenges, and coping strategy, followed by family caregiver's stress and coping strategy. A number of sub-themes are reported and discussed. Chapter 7 focuses on the attitude toward cancer treatment, given that many patients expressed a fighting attitude and active stance in anti-cancer treatment. This phenomenon is to be analysed with an emphasis on hope and family obligations.

Figure 6 Illustration of Situated Structures and General Structure



Chapter Five Disclosure of Cancer Diagnosis

5.1 Introduction

Cancer diagnosis disclosure is very important in oncology communication. This study found that, in China, diagnosis communication involves different parties: doctor and patient, as well as the patient's family. The disclosure of diagnosis of cancer is not static but a dynamic, iterative and interactive process along with the development of the illness over time.

The results suggest different ways of diagnosis disclosure and various levels of diagnosis awareness in Chinese culture, which evolve and change over time. Our findings contribute to the empirical literature exploring the phenomenon of cancer diagnosis disclosure in developing countries like China. The three major players in diagnosis disclosure – the patients, family members and health professionals, have their perspectives and experiences of communicating the diagnosis.

In this chapter, section 5.2 reports patients' experiences and perceptions of knowing the diagnosis and awareness of dying. Relevant experiences of some family members and health professionals are also used to support the analysis and discussion. Section 5.3 explores the experiences and perspectives of family members in diagnosis disclosure, focusing on their concerns of avoiding fears and keeping the quality of life of patients. Section 5.4 investigates health professionals' experiences, including the family-oriented disclosure paradigm, the contributing factors forming such a paradigm and concerns on non-disclosure. Section 5.5 concludes.

5.2 How Do Patients Know the Diagnosis?

In this study, doctors and nurses reported that the majority of the older cancer patients do not know their diagnosis, according to their care experiences. Following the ethical principle of the research, only the patients who knew their diagnosis were recruited in this study. Among the ten patients interviewed, four got the truth directly from the doctors when the diagnosis was confirmed, and six from their family members at different stages of the illness. Among the other twelve family caregivers interviewed, cancer diagnosis was usually communicated between health professionals and the family members in the first place. Only one family participant reported that her father got the diagnosis from the doctor directly. Two family caregivers informed the diagnosis to the patients after a period. All the others concealed the true diagnosis from the patients. Here I illustrate the different experiences and perspectives of diagnosis disclosure of older cancer patients.

5.2.1 Knowing from the Doctors

Among the older cancer patients that knew their diagnosis, their knowing patterns do not follow the same way. The following four patient participants were involved in the diagnosis disclosure with the health professionals.

Patient ZJ was diagnosed with lung cancer two years ago. I met her when she came to see the doctor in the local hospital for further examinations and treatments. When I introduced the study to her, she appeared interested and liked to have a chance to talk about herself. Patient ZJ was a bank manager before she retired. Every time I saw her, she was well dressed in decent clothes and footwear. She had a good bearing and style of communication. During the interview, she said that she had a CT scan about three years before the interview after coughing and having

a persistent fever for a long period. After the examination, the doctor said, in such a euphemistic way, that "*the result was not that optimistic, and it was suspected to be cancer*". She was very shocked and immediately went to a better hospital in Beijing to conduct further investigation. The examination confirmed the initial diagnosis, and then she decided to continue seeking treatments in Beijing and expected to cure the disease or prolong her life as much as possible.

Patient GJG was a government official who was diagnosed with cholangiocarcinoma. According to his recollections, he attended a physical examination in a local hospital organized by the employer. He was then notified to have some health problems that should be discussed with the doctor. At the beginning of the communication, the doctor said: "*your result is not that good. You need to have some emotional preparation*." Then Patient GJG said he would be fine and asked the doctor to let him know directly. Patient GJG expressed, "*I was very surprised when I heard it, thinking why it was me. I went to a larger hospital in Jinan* (capital of Shandong Province) *for another examination and then received some treatment there*".

Patient LJX, who was a chef, was diagnosed with liver cancer. He always went to the hospital himself to see doctors and receive examinations. He was the breadwinner in the family and usually made decisions for the whole family. He felt that patients should know their diagnosis. In his mind, those patients did not know their illness because they were afraid of knowing the diagnosis themselves. He said: "*I am a person is like this* (strong-willed and independent). *When a problem comes, hiding and concealing the problem won't solve the problem itself. We have to face the problem and find a solution.*"

Patient ZS was a farmer and migrant worker. His wife stayed in the village and looked after their farming land. ZS had some temporary jobs in the city, such as in a noodle factory, and returns home during the busy farming season. After long term abdominal pain, he went to the

local hospital for a CT scan. He recalled: "*after the scan, the doctor asked me if I came to the hospital with anybody else* (this is the typical opening when a doctor communicates with a patient for serious illness in China). *On hearing what the doctor said, I realized that it would not be good news. I answered, 'no, I come here alone. Please tell me straight away'. Then I was told that I had pancreatic cancer… I am the head of my family. I need to know the diagnosis and make future arrangements for my treatment and family issues.*"

From the responses of family members, only Family XG reported that his father knew the diagnosis from the doctor directly and then told it to one of his best friends. Then this friend phoned XG and informed her of the diagnosis. She said: "*I knew that he went to the hospital himself that day. I was not surprised that he knew the diagnosis first. But he didn't tell us, his children, straight away, instead, told his friend who we all know. He has arranged everything for himself. He used to be the village head. He helps residents to deal with different issues in the village… he makes decisions for his treatments and his daily activities.*"

The experiences in diagnosis disclosure of the above five patients are quite common in western countries where patients are more viewed as individuals (Beauchamp and Childress, 2013; Shahidi, 2010). For these five patients knowing diagnosis seems to be one of their own needs as individuals. These patients tended to communicate with doctors and nurses actively. From the interview and my observation, they also had open communications with the health professionals regarding other issues, such as treatment choices and prognosis, although sometimes their families were also involved in such discussions and decisions making. Their stories show that they shared some common characteristics or behaviours. They usually visited the doctors on their own, acted as the householder in the family, worked as the main breadwinner or had financial income, and was usually in charge of their own and or family

daily issues. Most of them expressed a strong willingness to know, which enabled them to act accordingly.

These findings are related to the debate on whether patients' characteristics would influence the pattern of communication. Some studies suggest that personal characteristics, such as age, gender, education, income levels, race and attitudes, as well as the seriousness of cancer, are associated with the preference of communication (as reviewed in Chaturvedi *et al.*, 2014; Miyata *et al.*, 2005). However, there is evidence that easily-identified characteristics do not have a significant impact on disclosure preferences (Miyata *et al.*, 2005; Kutner *et al.*, 1999). The shared characteristics and behaviours of patients are not always easily identified in practice, indicating that health professionals have to individually assess patient's attitudes and needs for open communication in cancer diagnosis (Kutner *et al.*, 1999). In this study, doctors usually considered the patient's competency case by case when deciding whether to tell, although in most cases, the diagnosis was first informed to the family. A doctor expressed the following.

A few patients insisted on knowing their diagnosis. We need to assess each patient's condition before we decide whether to tell them or not. For example, some patients come to the hospital independently to do examinations or they do not have any close family members, we have no other option. Some patients show an active attitude to know their diagnosis and have the competency to understand the information, we can tell them if the patients do not have other conditions like heart disease. Usually, we tell the patient when the family is here and the family also agrees to tell. However, such patients are not many (Doctor ZX).

Patients' active attitude and competency of accepting and understanding the information are important for them to be informed of the diagnosis. Such an active attitude was supported by health professionals. Through open communications, doctors and nurses knew the exact needs

of the patients. In the above statements, some patients also expressed that knowing the diagnosis would help them make decisions on treatment and plan the rest of their life. Such opinions are consistent with the views in western countries that open communication is beneficial for the patients. Open communication leads to a context of open awareness of dying, introduced by Glaser and Strauss (1965) and potentially empowers the patients to make better decisions (Surbone, 2006).

However, the open attitude and competency of patients were not always letting them acquire their medical information. For many older patients with terminal illnesses like cancer, open communications only occur between health professionals and family members. Family members are the gatekeepers of information to be transferred to the patients. They would instruct health professionals to disclose or withhold the diagnosis information. All the health professionals in the study expressed that the family's requirements were the determining factor in diagnosis disclosure in practice, and this will be discussed in the following sections.

5.2.2 Knowing from Families

During the fieldwork, I was told by many health professionals that, in China, it was normal to disclose the diagnosis to family members first, and then the family would make the decision whether to disclose the diagnosis to the patient or not. Six out of the ten patients reported that they knew the diagnosis from their families. Among the family participants, only two reported they told the patients the truth after a period of diagnosis confirmed. One family diluted the severity and said the tumour was benign. The rest of the family participants never disclosed the diagnosis, although two suspected that the patients had already known it themselves. These family carers expressed their preference for not telling whenever possible. They also asked the

health professionals to cooperate with their requirements of hiding the diagnosis from the patients.

Compared to knowing the diagnosis from doctors, the specific time and ways of knowing from families were diversified. Even so, one thing in common is that most families disclosed the diagnosis to patients when they could not hold it anymore, physically and emotionally. Here I use the experiences of three patients for analysis.

Patient JLQ mentioned that the hospital informed the diagnosis to his wife. His wife held the information for a couple of days and then told him the truth. Patient JLQ said, "*she did not know what to do. She knew that she couldn't hide the diagnosis from me for a long time because I would realise it when I go to the hospital for examination and treatment.*"

Like many other families of cancer patients, Patient TB's daughter hid the diagnosis from him at the beginning and told him he got pneumonia. After a few weeks of treatment, Patient TB started suspecting that he might get a severe disease because his condition was still getting worse. Patient TB described:

I started to ask her, 'Am I getting worse?' My daughter sighed, 'it was a bit difficult to treat.' I then asked, 'What is the matter then? Is it even harder than curing emphysema?' She said, 'Yes, it is worse than that'. Finally, I asked her whether it is lung cancer. She said yes and sobbed. I was shocked and very depressed. Why does it happen to me? (Patient TB).

Patient PC and his wife, PCW, were interviewed together when I visited them at home. Family PCW acted as the main participant. Patient PC had got lung cancer for five years. His family hid the diagnosis during the first three years. He was told that he had angina. Initially, he did not feel much differences because "*he did not know much of the medicine. So he believed it",*

as described by his wife PCW. However, cancer caused severe pain in the front and the back of his body, making him suspect that his illness might be different from angina. He compared and discussed his symptoms with those who did have angina. Gradually, he started to doubt whether his illness was angina. *"Two years ago, he became very ill and hospitalised for a long time. My son, daughter-in-law and I thought he would not live much longer. We could not conceal any more. So we decided to tell him the truth." (Family PCW).*

Patient PC was told when his family thought he was dying. His knowing experience reflects another fact that some cancer patients knew the truth shortly before death when there is no need to conceal it. Doctor ZPF also mentioned this phenomenon that when the patients kept asking about their illness, some families would tell the truth at the last moment, and doctors usually persuade the family to reveal some information in this case.*"However, at the last stage of the illness, some patients are in a coma and unconsciousness. They won't hear or understand anything." (Doctor ZPF).*

The experiences of other patients and family members show that the timing of knowing the truth varies from a couple of days to a few years. They also knew their true diagnosis in different contexts. The truth was usually told when it was no longer possible to conceal or there was no need to conceal. Similar to Patient TB and Patient PC, with the progress of the illness, some patients noticed the changes in themselves and began to challenge the false information they were told. Some might ask themselves, families or health professionals, such as "*Why am I not getting better after the treatment*?" or "*Do I get a more severe illness?*", "*Is it a fatal disease?",* and *"My symptoms like those of cancer as described on the website, do I have cancer?*" In this case, it is usually difficult to conceal the truth further, particularly for some patients who have certain levels of medical cognitions or can obtain information from other sources. Then, some patients were informed about the true diagnosis.

Some health professionals supported the way Patient TB knew his diagnosis as stated above, i.e. guessing, questioning, lowering expectations, insinuating, re-questioning and confirming between the patient and the family. This communication process enables the patient to be better psychologically prepared before the diagnosis is fully revealed.

With the development of the illness, the patients will get to know their physical changes and gradually knowing their diagnosis from their family. It is better that the information is released gradually. This could minimize the negative emotional shock to the patients (Doctor GJ).

Among the patients who got the information from their families, none complained about the concealment of the diagnosis. Some even expressed that they understood the difficulty and decision of their families.

After knowing the diagnosis, I felt very stressed. I understand why my wife did not tell me in the first few days. Cancer is a severe illness. She was just trying to protect me from knowing this bad news. She worried that I could not accept it. But she has no other options. Having cancer is my own thing. Who should take it and bear it except myself? Nobody can replace me. She (my wife) can't solely bear all the pressure herself (Patient JLQ).

5.2.3 Knowing by Self-Recognition: A Thin Layer of Window Paper

In addition to the above two types of knowing that the patients were explicitly informed about the diagnosis, the data show another kind of knowing between explicit knowing and not-knowing. Patients knew their diagnosis through self-recognition, even though the family or the health professionals never revealed the truth. Self-recognition might be achieved through patients' knowledge, experience, observations, etc. The patients kept their awareness to themselves, never confirm from the health professionals or the families, conceal the fact that

they had already known from others and skirted around the discussion about it. On the other hand, the family might have guessed or noticed that the patients had already known, but both sides pretended that they did not know in their daily interaction. Since the diagnosis was not explicitly communicated, patients with this type of knowing were not recruited in this study. This phenomenon was mainly reported by two family members and some health professionals, including the nurses who also had cancer patients in their families.

Nurse LY is a nurse in the palliative care centre and also the daughter of a patient with stomach cancer. She, as well as Doctors TP and ZX, described this type of knowing using a traditional Chinese slang - "*a thin layer of window paper*". This slang describes a condition that, in the interpersonal exchanges, both sides know one issue in their hearts but neither of them would like to say it outright. It is like a thin layer of window paper in the middle, which is weak and easy to be broken, however, neither side would like to break it. Several health professionals interviewed thought that this was a widely existing phenomenon in Chinese cancer families.

When Nurse LY got the results of her father's diagnosis, she managed to get a faked test result of gastric ulcer and showed it to her father. Her father did not mention anything when he saw the faked results. He then got actively involved in the treatment as advised by the doctor. But Nurse LY admitted that she could not conceal her sorrow expression from her face at that moment when showing the fake result to her father. With the progress of the illness, her father might have guessed what happened to him, but he chose to be silent.

I think that my father may have already known the truth gradually by now. He did not say anything, and we did not tell him frankly, either. It is just a thin layer of window paper, which can be easily pierced through, but nobody wants to step forward (Nurse LY).

Nurse LX, from the community clinic, also had a similar experience when caring for her father, who died five years before the interview. Her father was well-educated and the head of a government department before he was retired. Nurse LX had two siblings, a younger sister and a younger brother. Her mother was also a nurse. They hid the diagnosis from her father, who never questioned his illness or talked about the diagnosis with his family. He never showed a sign of knowing or fear of the disease and cooperated very well with the doctor's advice and treatment recommendations. Nurse LX used to believe that they had successfully hidden the diagnosis until her father died that her mother revealed that her father knew the truth. Nurse LX thought of this phenomenon as mutual protection, concern and love between patients and family:

My father understood that we did not tell him the truth because we were trying to protect him from further harm and pressure. In turn, he also avoided talking about it in front of us in order to protect us from more hurt. He did not want to change the atmosphere in the family, giving more pressure or adding more sadness emotions to his loved ones (Nurse LX).

Some participants in the family group also mentioned similar experiences they had.

I don't talk about illness and the future with my father. This is a kind of tacit understanding. We all know and understand the situation, but we don't say it thoroughly… They (the doctors) did not tell my father the diagnosis. They told him it was not cancer… My father knew it himself. Although we did not show him the test result, he knew it. We did not talk about it openly because when you said it, you felt that it produced an atmosphere of sorrow and giving up. We must look forward actively. We need faith and keep a good spirit (Family XX).

Another family participant said he was sure that his old father had known his illness (advanced stage bone cancer) even though they concealed it from him.

We didn't tell him. But he has always been in tears…(I think) he knows, 100% knows… He can read, his mind is clear… He never asked me, he never asked me the examination results. I used to wonder why he didn't ask…Now I realise he might have known (Family ZM).

Based on the experience of interaction with cancer patients and their families, Nurses LY and LX said the above-described phenomenon exists between many patients and the family. It is a coping strategy within their family about dealing with the bad news. When the patients and the family were not sure about how to communicate the illness and impending death in the family, pretending not knowing and avoiding open communication were used. Both sides of the "window paper" tried to protect each other from the sensitive topic in the family in order to maintain their normal life and hope.

Although such a phenomenon was only reported in the above three cases, several doctors believed that many patients had already known their diagnosis, along with the development of illness. For example, two of them said the following.

Only a small proportion of patients do not know. The majority of the patients would know (the truth), especially for those who have certain medical knowledge. They know their illness from the treatment process (Doctor LM).

For patients in the city, once they know they are receiving chemoradiotherapy, they know they got cancer. Patients in the villages, especially old patients, may not know what chemoradiotherapy is (Nurse BF).

This "window paper" phenomenon represents a relationship between cancer patients and family. This phenomenon is not simply knowing or not-knowing but in a grey area between the two. Even though health professionals thought this is a common phenomenon in China, it

has been rarely discussed in the previous literature. The closest theory to this finding is the context of "mutual pretence" in the awareness of dying in Glaser and Strauss (1965), which occurs when everyone involved (the patient, health professional, and relatives) knows the patient is dying but all pretend otherwise. The difference in the case of "window paper" is that mutual pretence does not exist between the doctor and the family but mainly between family members and patients.[3] Family members, instead of the doctors, take the role of diagnosis gatekeepers. Similar to the mutual pretence awareness, keeping a "window paper" comforts everyone in the family. It creates a fragile illusion and ensures the privacy and dignity of patients. As Doctor ZX described, "*keeping this window paper not pricked…will linger a glimmer of hope for the patient that it would probably not be cancer. So the patient is not willing to confirm his knowing from others, and such psychology is subtle*." In this case, conversations in the family only focus on safe topics, such as symptoms management. If something threatens or even pierces the thin "window paper", patients and the family members pretend they do not see it, or it does not happen. However, such mutual pretence becomes more challenging to maintain when patients' health conditions are getting worse along with the development of the illness.

It is difficult for me to identify and gather the perspectives of this group of patients who actually knew but pretended not knowing. However, Patient LJX, who knew his diagnosis from the doctor, expressed his opinion on this "window paper" of knowing. He thought fear was the main reason for not admitting of knowing, and such behaviour was not useful.

[3] It also exists between the doctor and the patient because in this case the family usually asks the doctor to hide the information from the patient, and family usually acts as a intermedia of doctor-patient communication.

I know that many other patients do not know (their real condition). Their family didn't tell them. Some patients actually know, they may guess it out, they may learn from others, but they do not want to admit that they have this disease because they are afraid. It is fooling themselves and useless. The results would be the same. For me, it is better to know rather than living in doubt because I can arrange my own things (Patient LJX).

5.2.4 Patients' Preference for Knowing and Awareness of Dying

All the patients I interviewed already knew their diagnosis and had the competency to give consent. Among these patients, their preferences for knowing are also different. Some patients firmly insisted that they should know the diagnosis. For example, Patient LJX did not want to live in doubt, and he would like to face the problem and get his affairs himself. Another Patient JLQ believed that cancer is his own business, so he, the patient, should be told.

It is my problem. If I was not told, who should be told? No one can replace me. It was difficult to accept at the beginning, but as time goes, that is it. If I am pain-free, I even do not think of it (Patient JLQ).

Although it is usually assumed that China has a dominant culture of non-disclosure, the active attitudes for information of Patients LJX and JLQ show that this group of patients value autonomy in diagnosis disclosure. The right to know is important for them to make decisions on the treatments and affairs before death.

For some other patients like Patient TB, they did not have an active attitude of knowing. They knew the diagnosis just because there was no way to avoid it, to some extent indicating a degree of reluctant of knowing.

Different preferences for knowing are found in many countries. The number of patients opting for not knowing or limited disclosure is relatively high in a culture of non-disclosure, like Japan, Iran and China (Ruhnke *et al.*, 2000; Shahidi *et al.*, 2007; Shahidi, 2010; Jiang *et al.*, 2007). Even in countries where telling the truth is a common practice, there are still a few cancer patients who do not want to be fully informed (Meredith *et al.*, 1996; Jenkins *et al.*, 2001). Therefore, understanding the difference in preferences is essential when the doctor or family ascertain whether to disclose the diagnosis.

Patients also expressed their fear and pressure after knowing the diagnosis, no matter they are active in knowing or not. Patient JLQ mentioned the difficulty to accept the truth. Patient PC showed high pressure after knowing, which led him to worry, lose appetite and weight. Therefore, there is a conflict between knowing the information and psychological pressure and fear for many patients. This phenomenon is consistent with the findings of other researchers (Kutner *et al.*, 1999; Jones *et al.*, 2004). On the one hand, patients want the doctors to be honest when informing the diagnosis; one the other hand, they fear receiving bad news and would like the doctors to give optimistic information. Such conflict also explains the existence of the above “window paper” phenomenon. The fears of patients and family will be discussed in the next section of families’ experiences.

Finally, the data also show patients’ knowing the diagnosis does not mean full awareness of the truth of illness and death because patients might process the information differently and react differently.

When the doctors informed Patients ZJ and GJG of the diagnosis, they both did not believe or suspected the initial diagnosis and found another better hospital to confirm. Then they both accepted the fact of illness and received treatments. However, Patient ZJ started a series of

aggressive treatments, hoping that she would recover or her life would be prolonged, while patient GJG chose to face it and actively planned his affairs before death. Patients like LJX and ZS seemed to fully understand what would happen. They chose to "*face the problem*", "*solve the problem*", and "*make future arrangements.*" Their treatment journeys and decisions will be explored in Chapter 7.

The experience of Patient PC was more complicated. He was informed when his wife, Family PCW, thought that he would die soon. However, he had lived five years since the diagnosis and two years after knowing the diagnosis. After he was told of the diagnosis, he had severe pain and his health condition was getting worse, so he thought, "*I am dying, everything is over*". However, when his condition improved and became stable, he turned to deny it.

Do you believe it is cancer? Is it cancer? Shouldn't you believe it, right? It is really not cancer. If it is cancer, I could have died… It has been several years, I don't feel anything different except the pain (Patient PC).

He felt dying when he has pain… He worried several months after knowing the diagnosis, losing 30 jin (15 kilos)… He ate well a few days before the Chinese New Year and gained some weight recently…He said it is not cancer. He does not believe in medical science. He really thought it is not cancer… He saw other cancer patients passed away within a few months, but he is still alive. So he does not believe it is cancer (Family PCW, wife of PC).

These findings show different stages of dying as identified by Kübler-Ross (1969): denial and isolation, anger, bargaining, depression and acceptance, which might overlap, occur together or even that some reactions are missed altogether. The experiences of patients show denial at the first stage, depression and acceptance at the final stage.

The findings also show different types of awareness after knowing the diagnosis, which can be interpreted using Timmermans' (1994) three contexts of open awareness. Suspended open awareness means the patients or families ignore or disbelieve the bad news communicated by the doctors. Uncertain open awareness refers to that patients or families dismiss the bad part of the information and hope for the best treatment outcome. Active open awareness suggests that patients or family fully understand and accept the medical conditions and make relevant decisions for the future. Patients and families usually change back and forth between the three contexts based on their understanding of the information. The different contexts of open awareness might be shaped by the information and ways of communication from the doctors as well as the cognition and emotion of the patient/family.

Although the diagnosis had been explicitly disclosed during the first consultation with the doctors, Patient ZJ and GJG had a short period of suspended open awareness, disregarding the initial diagnosis until a higher-level hospital confirmed it. Such disbelief is usually an initial reaction to cope with the shocking news. After confirmation, Patient GJG quickly moved to active open awareness. He accepted the impending death caused by the disease and took action accordingly. Similarly, Patients LJX and ZS showed to be in the context of open active awareness from the beginning. They understood they would not recover from their disease. However, Patient ZJ acted differently. On the one hand, she admitted the possibility of a fatal effect; on the other hand, she expected the uncertainty of recovery. She was in the context of uncertain open awareness. For her, “hope is more important than the certainty of death” (Timmermans, 1994; p330).

Patient PC shifted back and forth between the three contexts. When he was informed about the diagnosis, he was in an open active awareness. He was under great pressure and knew he was dying. However, when the illness did not deteriorate as expected (dying within a few months)

or even showed some improvement (being discharged from the hospital, having an appetite and gaining weight), he started to doubt the diagnosis and changed to uncertain open awareness. When the condition of no obvious deterioration or improvement had lasted over five years, the patient entered a state of disbelief or a context of suspended open awareness. Such kind of denial might be caused by the relatively low education of the patient PC who could not understand the nature of the disease; it might also be a defence mechanism against fears of death and a way to maintain hope (Peck, 1972).

5.2.5 Discussion on Patients' Knowing Experiences

In summary, cancer patients in China knew their diagnosis through different sources, including the health professionals, the family and self-recognition. Patients were not always involved in the communication of diagnosis disclosure. The timing, space, and the way of diagnosis communication between family and the patient varied from individual to individual. A group of patients and families mutually pretended not knowing the diagnosis, making the relationship and communication between everyone involved subtle and challenging. Patients showed different preferences of knowing, highlighting the importance of providing information for each patient based on his or her preference, personal characteristics and background. Open communication of cancer diagnosis was not equal to active open awareness. Patients who knew their diagnosis might be in different contexts of open awareness and might shift from one context to another. It is difficult for some patients to fully understand and accept the information provided.

Patients' differences in preferences for knowing and in the contexts of open awareness also suggest that "the right to know" does not mean "a duty to know" about the diagnosis for the patients (Furber *et al.*, 2015). In a country setting like China, where there is a culture of non-

disclosure, diagnosis communication between health professionals, family and patients is complex, diverse and dynamic. It gives a difficult task to the health professionals and family in ascertaining *whether* to tell, *how much* details to disclose, and *how* to communicate at any point through the course of illness.

Finally, patients' preference for knowing might change with the development of illness (Furber *et al.*, 2015). Cancer patients at the late/terminal stage of disease tend to know fewer details of information, including diagnosis or prognosis, than those at the early stage of disease (Kirk *et al.*, 2004; Meredith *et al.*, 1996; Jiang *et al.*, 2007). Such changes in preferences were not found in this study from the experiences of patients.

5.3 Family's Experiences and Perspectives on Non-disclosure

Most of the family caregivers interviewed had the experience of hiding the diagnosis information from patients. As to the date of the interviews, the majority of them never disclosed, but two of them were hesitant between telling and not telling. These families played the role of gatekeeper in diagnosis disclosure. Health professionals in this study also reported that they would like the family members to decide whether to disclose the diagnosis or not. In many cases, the family would choose non-disclosure at the beginning and would like to hide the information as long as possible. Later, when they thought the diagnosis could not be hidden or it would not be necessary to hide, some family members chose to tell patients (these cases have been mentioned in previous section 5.2.2). Nevertheless, some families still tried their best to hide the diagnosis until the death of the patients. White lies, cover-ups or deceit were used to disguise the truth. The family seems to be the surrogate decision-maker for the patient, including diagnosis disclosure.

5.3.1 Avoiding Fears and Keeping Quality of Life

In cultures of non-disclosure, it is assumed that withholding the diagnosis information would reduce the emotional harm to the patients (Surbone, 2006). This view is also held by the family members interviewed in this study.

"Fear" was frequently mentioned by the families while talking about their justification of not telling the diagnosis to the patients. Many families expressed their fears about the possible adverse outcomes to the patients after knowing cancer diagnosis. These fears comprise emotional influences such as pressure, despair, and losing the hope of living, as well as the potentially detrimental outcomes due to psychological harm, for example, accelerating deterioration of health conditions, shortening the life, reducing the quality of life, and giving up treatment and life. Here are two examples from the statements of the families.

We fear that once she (my mum) knew it (lung cancer), my mum cannot bear it emotionally. She would be under great pressure. The pressure will irritate her and make her anxious. The anxiety will produce a kind of pathogenic 'Qi' in her body and obstruct the circulation of blood and Qi in her body. [4] *This will shorten her life (Family ST).*

My mum doesn't know the diagnosis. I don't dare to tell. If I had told my mum, she would not live until now. She would have given up herself. She would not continue the treatment as there is no hope to get recovery. She would not survive until now if she knew the diagnosis… I told her it was just a small operation. She asked why she got many tubes in her body if it was a

[4] Qi (***qì,*** 气) is a concept in Chinese trational philosophy, Taoism and Traditional Chinese Medicine. It is an active principle forming part of any living thing. *Qi* literally translates as "breath", "air", or "gas", and figuratively as "material energy", "life force", or "energy flow". Qi moves around the body and can be acquired at birth from the parents and other sources like air, food, drinks, and emotions. Qi can be healthy and pathogenic. Anything that disrupts, blocks or unbalances the circulation of Qi will cause syptoms of illnesses.

small operation. Since she also has chronic heart disease, I told her the operation was for heart disease. She does not know much about medicine and it is easy to be deceived… She always believes that the tubes caused her infection so that she needed to stay in the hospital for another small operation. She has no doubt of this… We did not tell her the truth, so she is ok in spirit. She still believes she can get better. She is confident and cooperates well in the treatment (Family PQ).

Family PQ is a retired medical staff in the hospital. Her mother, 85 years old, was diagnosed with liver cancer with bowel mass. Her family tried their best to hide the diagnosis from patients. Family PQ, as well as her brother, seriously told me that their mother did not know the truth and repeatedly urged me not to talk with their mother directly. They hoped that their mother would maintain a good spirit and have a good quality of life before death rather than living with worries and desperation.

As discussed previously, Nurse LY also had the experience of caring for her father with cancer. She had similar fears and chose to show his father the faked results (gastric ulcer rather than cancer). She reported her feelings when she made such a decision and the reasons.

I don't dare to tell (my father) the true diagnosis. The more cancer patients we saw (at work), the more difficult for us to tell the patient in my own family. We have seen so many patients who gave up their living after knowing they had cancer. I don't want my father to become that hopeless (Nurse LY).

In addition to the "fears" of psychological harm related to dying, some families also mentioned they fear that the patients would consider themselves the family burden once knowing the diagnosis. Families worry that the patients might think of themselves as useless. Treatment would not cure their disease but cost a lot of money. To save money for the loved ones, the

patients might choose cheaper treatment options or even stop or not cooperate with the current treatment, which would not benefit the health conditions.

Considering the "*fears*", these family members "*don't dare to tell*". They tried their best to hide the diagnosis and protect patients from sadness and hopelessness that might happen after knowing the diagnosis. It is common among the family participants that different types of deception were adopted when disguising the truth, such as "*ulcer*" or "*inflammation*" instead of cancer, and "*angina*" rather than pain due to lung cancer, etc.

They feared that knowing the diagnosis would be a shock to the patient. Family PCW reported how the shock of knowing the diagnosis affected Patient PC emotionally and physically. As mentioned in section 5.2, Patient PC got lung cancer 5 years before the interview. He was told it was just angina in the first three years.

Two years ago, he became very ill and hospitalised for a long time… we decided to tell him the truth. After telling him, he started crying. He became not himself anymore. He appeared in very low mood and under great pressure. … He lost a lot of weight, from 120 jin to about 90 jin.[5] *His legs became very thin. We tried to comfort him. 'People have life and death. We are all going to die, the difference is just earlier or later. Relax and enjoy every day and be happy when you are still alive.' He improved a bit after a few months, about half of a year, of self-adjustment. He told himself, living for today and not thinking about it (cancer and dying) ... But he is still not himself as before. His mood swings. He often has a negative mood and is easy to be angry. Once the pain comes, he says 'It is over, it is to the end'. Sometimes, he even*

[5] *Jin* is a measurement of weight in China, with 1 *jin* equalling to 0.5 kilo.

said 'Give me some medicine to poison me. I want to die. I do not want to suffer the pain anymore. Let me die now'. His mentality is much worse than before (Family PCW).

When I asked Patient PC about his feeling after knowing the diagnosis, he also admitted that he got more pressure after knowing: "*Very stressful. A lot of pressure, who can't have pressure? Can I have no more pressure? Everybody (like me) is stressful… I will fall here, fall here (die of cancer). No way to get through it. Nobody can take my place… I can only persuade myself to be as happy as before and to have a better life. But saying is easy, doing is difficult… sometimes, I don't want to eat anything for days, just want to end my life quickly.*"

Such a suicide attempt is not an extreme, lonely example. Two doctors in this study also mentioned that some patients harmed themselves and jumped to their deaths after knowing the diagnosis (details to be discussed in section 5.4).

For the patients and family who were mutually pretending to not knowing, i.e. on two sides of the thin "window paper", Nurse LY reported her observation and perspectives about her father's struggles and feelings. She thought that her father had known the diagnosis from his physical change, such as rapid weight loss and oesophageal reflux.

He never talks it to me, and I think he still cannot accept it...Having this kind of disease, just like what I said earlier, is equivalent to a death sentence. The whole life is time-limited… Every early morning at dawn, it is the start of a new day. I can enjoy this day, but I also bear in mind that my lifespan is getting closer and shorter. I feel like this. I am not sure whether my father will have the same feeling as me, but like my father, a very thoughtful man, I am sure that he is thinking about this every day… Sometimes, when he was lying in bed, I could feel that he was not sleeping, not really sleeping, but keeps thinking there. Although his eyes were closed, I could feel that he was constantly thinking of his illness, struggling in his mind, and

considering how to face it frankly. I feel he is in such a situation. Sometimes, when I want to discuss his illness or the future with him, he turned to be silent. I don't know how to start the talk about the illness with him (Nurse LY).

In Nurse LY's case, both family and patient were not comfortable disclosing the diagnosis, or the family was not yet ready to tell the truth. Non-disclosure is maintained even though it is just a thin layer of window paper.

On the other hand, families who withheld the information reported that non-disclosure helped keep the quality of life. There would be less pressure in the family so that the family, at least the patient, could maintain life as usual.

In the study, Family YYS was looking after his mother, a very old lady who solely depended on the family for daily caring. The family did not tell her the diagnosis in order to protect her from the fear of dying. Family YYS believed that his mother could not bear it and would deteriorate faster if she knew it. During the fieldwork, I also met the old lady, who appeared to be in a happy mood. When the doctor chatted with her and the family about her concerns, such as reducing appetite and poor sleep, she was very relaxed. Most of the time, it was the family who was talking to health professionals. Her son told me that,

My mum is as happy as before. We are delighted that we hide the truth from her. She is very old now. She probably does not have much time left. We want her to be in a good mood all the time (Family YYS).

Family ST, who also cared for her old mother, expressed that non-disclosure would protect her mother and good for prolonging her mother's life.

My father died when we were very young, my mum raised my sister and me by herself. She had worked very hard and suffered a lot for us. Now it is our turn to look after her. We don't want her to know the truth and suffer more from the pressure of knowing. We will do our best to protect her and let her live as long as possible (Family ST).

In the above cases, the patients were very old, with little knowledge of cancer or the ability to care for themselves. Health professionals agreed with the family's wish to hide the diagnosis and were satisfied with patients' quality of life. As long as the perceived fears could be minimised and the quality of life maintained, telling or not telling the truth appears not bothering that much.

5.3.2 Discussion on Family's Preference for Non-disclosure

The above results suggest that although some patients preferred to know the diagnosis (as discussed in section 5.2), more families chose non-disclosure. Chinese families appear to believe that truth-telling to cancer patients would psychologically harm the patients, leading to other detrimental outcomes, which can be physical or mental. Non-disclosure would protect the patients and keep their quality of life. There is evidence that knowing the diagnosis had some adverse effects on the patient's psychological feelings and behaviours. These might include stress, depression, despair, the disorder in eating, a negative attitude to living, and even the intention to end life earlier. There is also evidence that non-disclosure protected the patients and was useful to keep the good spirit of some patients. It is more likely that families believe disclosure produces more harm than good (Shahidi, 2010). Although some patients seemed to emphasize the principle of autonomy, families would like to give priority to non-malfeasance (avoiding fears and harms) or beneficence (protecting and keeping the good spirit and quality of life).

The finding of family's preference for non-disclosure is consistent with previous studies on the attitudes towards truth-telling in China, Taiwan, and Korea (Jiang *et al.*, 2007; Shing-Yaw Wang *et al.*, 2004; Yun *et al.*, 2004). Such preference could be explained by Chinese culture that sick adults should be treated as children and deserves "protection" (Muller and Desmond, 1992). It is believed that cancer patients are already suffering from a grave illness so that it is unnecessary for them to suffer more from knowing the truth of the diagnosis. In this study, protection or deserving good care was directly mentioned by some family participants and fully manifested in the responses of others when talking about the fears of diagnosis.

Muller and Desmond (1992, p325) also mentioned that in Asian cultures, people fear that openly talking about death is like "casting a death curse upon the person; it will make the person despair and die even sooner". The family participants in this study did not say anything related to "casting a death curse", but many mentioned cancer or death is a taboo in Chinese culture (which would be discussed again in the following section and chapters). This is also echoed by Nurse L's description that having cancer is *"equivalent to a death sentence".* Fear of openly talking about death/cancer might partially explain the families' preference of non-disclosure, as well as the existence of the phenomenon of the patient-family mutual pretence of knowing.

Although non-disclosure is believed to be useful in avoiding psychological harm to the patient, previous studies found disguising the truth and unintentional deception also hurt, leading to fear, anxiety and confusion of patients (Fallowfield *et al.*, 2002). Psychological disturbance is common in Turkish patients who are not directly informed of their diagnosis and who have guessed their diagnosis through the treatment process or adverse drug effect (Atesci *et al.*, 2004). In my study, such a negative effect of non-disclosure was rarely mentioned by family participants. However, it was reported by Nurse LY in her description of her father, who might

have guessed his diagnosis through gastrectomy and interventional therapy. In addition, health professionals had more concerns about the risks of non-disclosure, which will be discussed in the next section. Even though truth and deceit both hurt, it is still difficult to deny the fact that non-disclosure produces more good for certain types of patients, especially for sick and ageing patients who have limited competency to understand the medical information.

In this study, family participants preferred non-disclosure and executed means to withhold the diagnosis information. However, not-telling by health professionals or family members does not mean the patients did not know the diagnosis. As mentioned in section 5.2.3, patients could still know their diagnosis later on through self-recognition. Health professionals also have their observations and opinions on this issue and will be explored in section 5.4.

In the context of China, family units are strong in society. The family is an entity that existed before one was born and will exist after one is dead (Muller and Desmond, 1992). Everything about an individual member belongs to the family. Decisions related to healthcare are family decisions. Within the family-centred system, it is difficult to exclude the family from cancer diagnosis communication and treatment decision makings. The family, rather than the health professionals or the patients, are assumed to be responsible for cancer patients and medical decisions. Families' preferences and requests would, therefore, shape the disclosure practices of health professionals. The importance of family in diagnosis communication is to be discussed in the following section.

5.4 Health Professionals' Perspectives on Diagnosis Disclosure

While section 5.2 shows mixed experiences, preferences, and awareness of patients about diagnosis disclosure, section 5.3 suggests a dominant preference for non-disclosure among

family participants. This section explores and analyses the experiences about diagnosis disclosure from health professionals' perspectives. Within the family-centred system in China, diagnosis disclosure is a challenge to the health professionals, particularly to the doctors, who have to balance the patients' autonomy and beneficence, as well as self-interest.[6] In this section, I will first introduce the widely used family-oriented autonomy practice adopted by Chinese oncology doctors. Then I analyse the contributing factors that might influence them to choose such disclosure paradigm, including China's cultural background, patient-centred beneficence, and doctors' self-protection. In addition, health professionals expressed their viewpoints on the non-disclosure culture, including the hurts of non-disclosure to patients, which the other two groups of participants did not consider.

5.4.1 Family-oriented Autonomy

Similar to previous studies on China and Asian countries, in this study, doctors frequently informed the diagnosis information to the families rather than the cancer patients. During the fieldwork in the oncology department in the local hospital, I observed that when a patient was diagnosed with cancer, it was quite common to hear the following conversation from the doctors: "*Is the family of patient ABC (name) here? Please come in to get the result*". If the patients came to the hospital on his or her own, the doctor would ask something like the following: "*Do you have any family or next of kin? Please leave his/her contact details, we will contact him/her later on"*; or *"Please ask your family to come to the hospital to collect the results.*" In some cases, as described by a doctor participant, the patient was driven out of the consultation room while the doctor was communicating the diagnosis information with the

[6] Diagnosis disclosure can only be informed by doctors, rather than the nurses. However, nurses also had their viewpoints on the paradigm of diagnosis disclosure in China.

family. Almost all the health professionals said the paradigm was to inform and discuss the diagnosis with the family rather than the patient.

Generally speaking, we first talk to the family after getting the diagnosis result. If the patients are old, above 50 or 60 years old, especially farmers, we tell their children. If the patients live in the city, having jobs, we usually tell the diagnosis to the spouse… it is more important to communicate with the family... Whether to tell the patient is up to them (Doctor LM).

Doctors GJ, WB and ZHP said that, in their department, they were "*not allowed to tell the patients without the accompany of the family*", and "*there is no exception*". The doctors left the decision of telling or not to the family, and they respect the family's decision.

If the family asks us not to tell the patient, we certainly respect the decision of the family...Doctors tell everything to the family (Doctor TY).

I asked some doctors what they would do if the patients keep asking about their illness. They had different strategies to avoid the topic or to kick the ball back to the family. Some said, "*I don't tell, but I don't cheat, either. I would tell them the result is not yet available; it is not confirmed.*" Some would ask back to the patient, "*What do you think it is?*" or "*Don't you know it*? *You should have already known*" to check to what extent the patient knew the truth from the family, and then changed the discussion from the illness diagnosis to information about symptoms. Communications on prognosis and informed consent were also mainly discussed between the doctor and the family, although some patients who knew the diagnosis were included in the communication and decision making.

Therefore, cancer diagnosis disclosure in China is dominated by family-oriented autonomy. This finding is similar to the evidence of previous studies such as Wuensch et al. (2013). Such

communication represents a doctor-family-patient relationship in diagnosis and medical decision making, which is different from a doctor-patient oriented relationship in Western countries.

In the doctors' opinion, although they had to adopt family-oriented disclosure, this practice was somehow against their wills. Patient's right was disregarded or "*deprived*" (as described by Doctor GJ) in this relationship. Doctor SG also said, "*Patients are isolated from all communications for tests, treatments, even from the beginning when they suspected to have cancer. The patients become an outsider.*" Several doctors, like LM and GJ agreed that excluding the patients from diagnosis communication was "*contrary to the principle of patient's autonomy*". Notably, patients of other severe illness seem to have more "right" to know their diagnosis. Doctor ZHP compared the autonomy between cancer patients and those with severe heart disease. In his opinion, the two diseases are both fatal, and severe heart disease is even more fearful. However, it is not a problem to let the patients know the truth. "*They (the patients with heart disease) don't fear knowing it*", said Doctor ZHP.

5.4.2 Contributing Factors to Family-oriented Paradigm

Regarding the contributing factors to non-disclosure of cancer diagnosis and prognosis in many cultures, Shahidi (2010) summarized seven general factors, namely fear of causing psychological morbidity to the patients, patient's reluctance to know, physician's self-interest, family's request, lack of training and guidelines, language barriers, and lack of time and appropriate place to tell. In the case of China, previous studies focused on exploring the attitude and preferences of the three parties involved (Wuensch *et al.*, 2013; Jiang *et al.*, 2007; Liu *et al.*, 2018; Wang *et al.*, 2004). The concerns of patients' depression and the influences of traditional culture and the role of the family were widely used when interpreting the statistical

findings and when comparing the cross-cultural differences in practices (Liu *et al.*, 2018; Wang *et al.*, 2004; Li, 2013). Other factors, such as doctor's self-interest, lack of training and guidelines, were also mentioned but not explored in depth.

In this study, doctors expressed different views regarding adopting the family-centred model. Their accounts provide more evidence to the understanding of each contributing factor in the context of China. In particular, the data enrich the meaning of the following areas, i.e. Chinese culture and tradition; beneficence to the patients; and self-protection.

Chinese Culture and Tradition

Chinese culture is highly complex as a melting pot. It is influenced by traditional cultures like Confucianism, Marxist philosophy and its development in China, and western culture after China's opening up from the late 1970s. The attitudes and behaviours of Chinese people are affected by complex cultural characteristics. Medical ethics and practices are also blended with western ones. In this study, when talking about family-centred autonomy, several doctors acknowledged that "*it is a Chinese tradition*" or "*custom*", which is "*different from the West*". Their interpretations of this *custom* cover different aspects of social norms, such as death as a taboo, the role of family, and avoiding conflicts. These social norms will be discussed with the values of Confucianism, Marxism, and pragmatism.

Firstly, doctors like WB, LM, TY and GJ believed that "*talking death is a taboo*" in China. Given that cancer is usually fatal, it is difficult for the doctors to communicate cancer and death related topic with the patient directly. Chinese patients seemed to have more fear of death or cancer caused death. Several doctors argued that this was because of the lack of religious beliefs or education about death in China.

I think the fear of death is a Chinese tradition. You may know more about foreigners in the West. They should be easier to accept death than Chinese. They might have a lower level of fear when talking about death or facing a fatal illness. They might believe death is a natural process. Some religions treat birth and death as a continuous cycle or Samsara. In China, people believed in Buddhism or Taoism a long time ago, but now religious beliefs are not encouraged. The majority of people believe in communism. We are educated as atheists. Death is death, your body becomes ash and dust, and everything about you is gone along with death. This leads to an innate fear of death (Doctor SG).

There is no education about death in China. I heard Taiwan has done well in this area, but we don't have an expert on this. We can't have a proper attitude when facing death. It is difficult to teach cancer patients how to face death after hospitalisation. Topics about death should be taught in the school; it is not the responsibility of the hospital. It is a law of nature that you are born, getting old, ill, and then die. Chinese people don't want to die … and don't want (believe) to go to heaven, the body is just buried after death (Doctor ZX).

Besides Doctor SG, some other doctors also mentioned that atheism made many Chinese people not believe in the afterlife and hence highly regarded the gains and interests of this life, and therefore feared cancer and dying. On the other hand, traditional Chinese philosophy makes death a "*must avoid topic*" in communication. Even Confucius did not face up to the discussion of death. When he was asked for the afterlife by his student, Confucius replied, "*life even not well known, how to know death*". For a large number of Chinese people, death has a strong negative image, even talking about death may cause "bad luck". Traditional philosophy and atheism together would influence their attitudes towards cancer diagnosis. It becomes, in particular, a barrier to open communication between doctors and patients.

Secondly, the family is the basic autonomous unit in China. In the previous literature, it is widely observed that when a patient was diagnosed with cancer, the family would deem it as their responsibility and even their natural right to make medical decisions (Wang *et al.*, 2018). Data in this study show more details about who usually took these responsibilities. Doctor LM mentioned that she usually informed cancer diagnosis to the spouse if the patients were city dwellers, educated and employed. For old patients and old patients from rural areas, she added, "*they (the patients) usually listen to their adult children. The adult children can make the decision (on behalf of the patients)*."

Doctor XZ mentioned that the situation was complicated for some old patients as more than one family member was responsible for the patients. The patients might have two or more adult children, and sometimes, the siblings of the patients were also informed of the diagnosis for the first time and involved in the decision making. He said, "*In some cases, the family members may have different opinions on one medical decision. They do not always agree with each other. Usually, they are asked to choose one member, we call an agent, to represent the patient to sign all the forms. During the hospitalisation period, the agent communicates with doctors and nurses. The decision of the agent is treated as the decision of the whole family. So medical decisions are not based on the patient's own idea at all… It becomes a tradition that non-disclosure is a protection to the patient. In the West, (I believe) knowing and making the decision is to protect the patient. It is a different mindset here.*" Another example that echoes Doctor ZX's statement is Family YZS. In the family of YZS, his aunt (YX) was the younger sister of the patient (YZS's father) and acted as *the agent* of the family because the family of YZS treated her (YX) as the "*backbone*" of the extended family.

The above experiences reflect China's paternalistic culture and preference for collective decision-making (Huang *et al.*, 2014; Li, 2013). The core family member, the spouse, or the

adult child, or a surrogate agent, make medical decision on behalf of the patient. The decision might be from a single authoritative person or the outcome of collective discussion. Either way, this is usually accepted by many patients, indicating a generally low awareness of the patient-autonomy in Chinese culture. The protection to patients also reflects the culture that sick adults should be treated like children, as discussed in section 5.3.2. It should be noted that such agent decision-maker in the context of China is different from the surrogate decision-maker used in the Western countries like the UK and US, although in both cases, the surrogate agent is more likely selected from the family and relatives of the patient and make healthcare decisions on behalf of the patient. The difference is that, in the UK and US, the patient must be incompetent for making the decision. By law, patients must meet certain criteria of having disabling conditions, such as mental illness or cognitive impairment. The surrogate agent is identified by either a medical power of attorney or a court or otherwise selected by medical personnel. However, in China, there are no such regulations; the surrogate agent is identified within the family.

Finally, some doctors admitted that informing diagnosis to the family would reduce the risks of severe physical harm (such as the suicide of patients) and conflicts with the family. Doctor ZHP said, "*there were many disputes (in my department) after some doctors told the diagnosis to the patients, then the family complained and claimed compensation for the psychological harm*". Doctor ZPF also expressed that "*it is common that there have been lots of contradictions and disagreements within the family of cancer patients. If the doctor does not follow the request of not-telling, it might cause unnecessary troubles… In the end, the doctors work together with the family to deceive the patient and disguise the diagnosis.*" More evidence about the doctor's experiences of doctor-patient/family conflicts will be explored later.

From the cultural aspects, on the one hand, the avoidance of conflicts is in line with Confucius value of creating and maintaining harmony in human relationships. On the other hand, the adoption of non-disclosure can be explained by Deng Xiaoping's pragmatism in contemporary political culture (Tian, 2016). To recover the barriers of opening up after the late 1970s, Deng promoted a pragmatist way of thinking, which emphasises on reform practices rather than theory (e.g. Marxism-Leninist that might not match the reality of China); and values the goals (or end results) rather than means (or methods). Deng's pragmatism has an immense impact in China. In the case of diagnosis disclosure, no matter how good the principle of respecting patient autonomy looks in *theory*, it might not match China's reality. Since it is difficult to predict the outcomes of telling to the patients, the *practice* of family-oriented disclosure using the *means* of withholding information from patients and even deceit is useful in preventing harm to patients and conflicts to the hospital. Therefore, it is not surprising that the oncological department in the field adopted a family-oriented disclosure paradigm.

Beneficence for the Patients

In sections 5.2 and 5.3, when analysing the preferences for knowing of patients and the preferences for not telling of the family members, we have discussed that family members prioritised non-malfeasance or beneficence over patient autonomy. Oncology doctors in this study also had similar concerns. They also worried about psychological hurts to the patients. Their accounts provide more evidence about how knowing hurt some patients and their difficulty to reduce the possible harm of telling.

It (having cancer) is a shock to everybody. Whether to tell depends. It might be better for some patients to know, they can quickly adjust themselves, accept the fact, and engage in the treatment. For some others, they may be narrow-minded. Telling them the truth will give them

more pressure, lead to depression or spirit collapse. In this case, we are blamed for telling (Doctor WB).

Doctor WB was not the only one concerned with the psychological hurts of the patients. Some doctors and nurses also observed extreme cases happening in their departments.

We worry that the patients cannot accept the truth. Several patients jumped out of the window of the building (after knowing). [How did they know the diagnosis? I asked] Sometimes (they knew) from the family, and sometimes from other channels, like reading the medical notes, through the medicine used and communication with other patients in the same ward. When I was in another department, a patient stabbed himself 8 times while the accompanying family member fell asleep at night ... That patient had already got depression and became hopeless after knowing (Doctor LM).

We fear that the patients take this too hard, have a pessimistic view and hurt themselves. Some patients have young children and are poor. They want to leave some money to the children, rather than spend it on the treatment. A disease like cancer has made lots of patients lose both life and wealth. Some patients think of different ways to kill themselves. When we are on duty, we pay attention to any abnormal behaviour of the patients. We always keep an eye on them... When we clean their rooms and make the bed, we check whether there is a knife around. We prohibit leaving a knife or sharp things near the patients because there were extreme patients who cut the wrist (Nurse CCW).

Although the probability was low, the occurrences of unexpected suicide forced the health professionals and the hospital to take precaution measures. Communicating diagnosis with the family might be the most convenient way not to harm the patients. Doctor WB said that some

patients would like to know the diagnosis. However, time and resource constraints challenged them to make an accurate judgment on who to tell during the consultation meeting.

We don't know whether the patient can accept it or not. It is difficult to assess. The time we meet the patient is very short. It is better to tell the family, and then the family to find a proper time to disclose some information according to the patient's acceptance level. … Every patient is different…Generally speaking, they don't honestly give full information, they usually dilute the severity (Doctor LM).

We have to see and diagnose so many patients a day. We don't have enough time to talk to each patient, understand their background or go through all the details about the causes, diagnosis, prognosis, etc. It is different from the UK. We have too many patients here (Doctor ZX).

Some doctor also reported that not all the patients would understand the meaning of the diagnosis. They might interpret the information communicated in different ways. The message they took away might be "*they have got an incurable illness, and they are dying, which would make them anxious and frightened*", said Doctor ZHP.

From doctors' perspectives, the family was the closest people to a patient. The family should know well about the patient's personality, communication habits, and ability to bear bad news. Therefore, it would be better for the family to decide whether to transmit the bad news to patients, the timing to tell and how to tell.

It should be done by the next of kin, or the one who has the closest relationship with the patient, to reduce the impact of the shock to the patient… The family member should be the one who they can communicate words in the heart (are trusted) (Doctor TY).

The families are their closest people and most trusted people. It is easier for them to talk about the diagnosis as a family, in the most suitable way (Doctor GJ).

Given the paradigm of informing diagnosis to the family, doctor participants also supported that bad news should be informed to the patients gradually. When the family decided to tell, they provided professional advice on how to tell, how much information to reveal and assisted the conversations. They distribute leaflets of communication skills with cancer patients to family members. Sometimes, they also analysed the gain and loss of telling the individual patient and persuaded the family to tell the truth. However, they left the decision to the family. Doctor GJ in the hospice said the following when he told me a story of the patient.

Before I saw the patient, the family asked me not to tell. Frankly, after the meeting, I knew the patient might have already known. I tried to convince the family, telling them the benefits of letting him know. It would be good for the treatment and for releasing the stress of the patient. I give similar advice to other families. Some family took my advice, and some didn't. I only gave advice. The family make the decision (Doctor GJ).

The above data show that China's medical ethics prioritised non-malfeasance and beneficence to the patients, even though they all knew patients' autonomy was neglected. The doctors seemed to have the same concerns as the family on the psychological shock to the patient. From their working experience, they were more concerned about the severe threat, such as conducting suicidal behaviour. The medical resources and conditions restrained them from accurately assessing the patient's capability. Therefore, for patients' benefit, as perceived by doctors and family caregivers, information of diagnosis was disclosed to the family but deliberately withheld from the patient, either temporarily or permanently. Later on, the family decided whether to inform the information to the patient, either with diluted severity or fully

revealed. The precedence of beneficence often led to paternalism in medical decision making in China.

It is arguable whether the paradigm of withholding diagnosis information from the patient in China is similar to the use of therapeutic privilege (or therapeutic exception) in the UK and other countries like the US, Australia and Canada. Therapeutic privilege refers to physicians withholding information from the patient when disclosing will cause harm or suffering to the patients (Hodkinson, 2013). In the UK, there have been years of debates about the ethical, legal and professional considerations in using it in practices. Recently, the UK Supreme Court in Montgomery v Lanarkshire Health Board (2015) gave more precedence to patient autonomy and stroke down medical paternalism (Choudry et al., 2016).[7] The therapeutic exception is only allowed when information would be seriously detrimental to the patient's health; it cannot be abused and is only applicable in very rare circumstances (The Supreme Court of UK, 2015). Similarly, in the US, this exception is only applied in an emergency situation when a patient is incapable of making an informed decision; otherwise, withholding information is ethically unacceptable (American Medical Association, n.d.). The therapeutic exception is used sparingly, and it requires the doctors to find a specific reason to justify withholding the information from the patient. Truthful and open communication between doctor and patient is essential and ordinary. The role of the family is not important in this exception as it is the patient's decision whether the family should be informed. However, in China, disclosing information to the family is common. Information is withheld from the patient but not from the family. The doctor-family-patient relationship for diagnosis disclosure in China is different

[7] *Montgomery v Lanarkshire Health Board (2015) or Montgomery* is a case that outlines the rule on disclosure of risks to patient for the informed consent. It replaces the previous tests founded in Bolam and refined in Sidaway. A brief background and guidance *can be found at* https://www.themdu.com/guidance-and-advice/guides/montgomery-and-informed-consent.

from doctor-patient relationship in the West. It seems that Chinese doctors need to find a specific reason to justify not withholding the information. Therefore, although both considering the beneficence of the patients, the paradigm adopted in China is different from the meaning of therapeutic privilege defined in the Western contexts.

Self-Protection

Some studies in the literature show that non-disclosure is also a way to protect the physician (Shahidi, 2010). Physicians might not feel comfortable or lose control in different ways when breaking bad news (Surbone, 2004; Friedrichsen and Milberg, 2006). Informing a bad prognosis can be interpreted as a confession to the physician's incompetence and hence damages the "good doctor" image in front of the patients (Shahidi, 2010). In this study, some doctors and nurses, particularly the young ones, expressed their stress at work. However, more doctors reported that family-oriented disclosure was a way to protect themselves from the doctor-patient disputes, or rather, doctor-family disputes, given the strong position of the family in medical decisions and in the doctor-patient-family relationship. The impact of medical disputes on diagnosis disclosure was not much evidenced in previous empirical studies.

"Medical disputes are defined as a patient proposal in return for the argument, which may or may not correlate with medical malpractice" (Zeng et al., 2018, p.2). Medical disputes manifest as complaints, filing of a lawsuit, and illegal behaviours such as threats, insults, violence, and setting a funeral hall with the corpse and wreaths displayed in the hospital lobby. These kinds of disputes have been increasing in China over the past two decades and have become more violent (Zeng *et al.*, 2018). The disputes might be caused by the supply and demand mismatch of health services, patient's increasing awareness of their rights, and the imperfection in the legal system. The prevalence of medical disputes resulted in distrust of health professionals

and distorted health professionals' behaviours. The doctor-patient relationship becomes unprecedentedly tense, complex and subtle. The patients do not fully trust the doctors but still need them for treatment, while the doctors keep alert when they treat the patients. It is a relationship combining competition and cooperation, as argued in Zeng et al. (2018).

In this study, many health professionals expressed their worries about the tension in communication with patients and their families. Doctors and nurses reported low trust between doctors and patients/families, as well as the inferior status of doctors in society. The well-being of health professionals was not well protected by the hospital or the law. Given the intense doctor-patient relationship, adopting family-oriented diagnosis disclosure was a way of self-protection. For example, it was common for health professionals to say the following.

The patient may give up because I tell him/her the illness. If the patient gives up and dies unexpectedly, the family will use this to blame me. I would get into big trouble. They may sue me and ask for compensation (Doctor, ZPF).

We used to have some cases that some colleagues told the patient the diagnosis without confirming from the family. Then the family made a scene (Doctor LM).

I have to say I can only avoid unnecessary troubles as much as possible in this condition. I need to protect myself well first. It doesn't mean we don't care for the patients or do harm to the patients. It is a way to protect myself as well as the patients (Nurse CC).

Another nurse expressed that the law or the institutions did not well protect healthcare staff members. The risk of telling is too high to bear for health professionals in China's current medical environment.

It is not we don't want to respect for the autonomy of patients. It is the reality in China. I need to protect myself. Otherwise, I can't carry on my work. I need to follow the situation of the society. The law doesn't protect us. Recently, the status of doctors is very low. When there is a medical dispute, doctors and nurses are not protected. If the family make a big fuss arguing that the patient has died because of fears of knowing (after being told by the staff), the hospital would like to smooth the thing over and make some monetary compensation. Sometimes staffs are beaten by the family. However, the government and hospital might overlook it unless someone is severely injured or even killed. Small body violence against the staff is ignored… The patient might die for different reasons, but how to justify it is because we tell the truth? We, the doctors and nurses, have to bear the outcome of telling. The cost of telling is too high even though a dispute might only happen in 1 of 10 cases of telling... so we don't tell the patient (Nurse YR).

Doctor GJ said some people deliberately overstress feared of knowing as the cause of death for cancer patients and used it as an excuse for non-disclosure. Under this public opinion, information of diagnosis to the family was a way to protect the doctors.

Now there is an opinion saying that one-third of the cancer patients die because of fear, one-third die because of treatment, I mean over-treatment, and one-third die because of the illness itself. Many people, including patients, families and some doctors, believe this. They also disseminate this idea and use it as an excuse for withholding the information from the patients. With this public opinion, doctors and family form tactic collusion… Even if the death is caused by fear, the family should be blamed, not the doctor, ...as it's the family to decide whether to tell…. It is a way for the doctors to avoid troubles and responsibilities… It is a way of the doctor's self-protection, kicking the ball to the family (Doctor GJ).

Informing diagnosis to the patient, which is regarded as the essential bioethics principle, has been used by some families to argue for malpractice of Chinese oncologist doctors. During the interview, I could feel how scared and worried they were about such medical disputes potentially happening to them. The above accounts from doctors and nurses provided evidence to what extent medical disputes had distorted health professionals' behaviours, such as resigning themselves to reality, using a self-protection-first approach, avoiding responsibilities, and even fostering some fake medical opinions. During the interview, Doctor GJ also mentioned a lack of clear guidance about information disclosure to the patient with a terminal illness so that health professionals adopt family-oriented disclosure practice for self-protection. In China, there are two relevant regulations regarding ethics in information disclosure to patients. Article 25 in the People's Republic of China Practitioners Act states that "Physicians should be truthful to patients or their families to introduce the disease but should be careful to avoid adverse consequences on patients." Article 11 in Medical Accident Treatment Ordinance requires that, "in medical activities, medical institutions and their medical staff should truthfully inform the patient about their condition, medical measures, medical risks and others, and answer their questions and requests in time; but medical institutions and their staff should also avoid the adverse consequences occurred to the patients."[8] These two regulations are ambiguous, with no definitions about adverse consequences or criteria for the physicians to make an assessment. Therefore, it provides scope for the hospital and medical staff to make their own judgement; as well as scope for the patient and family to argue the adverse consequences in medical disputes. Therefore, in the case of cancer diagnosis, informing

[8] http://www.china.com.cn/law/txt/2012-08/15/content_25242943.htm

diagnosis to the family does not violate the above regulations but also protects the interests of staff and hospital on the other hand.

Regarding the reasons for the intense doctor-patient relationship, the participants expressed their views. Since the reasons are not the focus of this chapter, I would not detail their accounts here. In their opinion, the reasons, no matter correct or not, can be summarised as: 1) institutional failures (e.g. "*hospital or the government do not care for the safety of health professionals*", Nurse YR); 2) imperfection in legislation (e.g. "*no clear policy to guide the practices or no law to protect them*", Nurse YR and Doctor GJ); 3) malpractice of a few doctors but exaggerated and hyped by the media (Doctor SG); 4) reduced quality of medical professionals (e.g. "*lowered entry requirement in medical schools; and medical disputes, in turn, discourage students from applying for medical schools and hence further lower entry requirements*", Dr ZHP); 5) people's blind belief that the modern medicine is almighty (Doctor SG); and 6) money. The sixth item of money was mostly mentioned and had a number of meanings. Firstly, there were a few families who wanted to blackmail the hospital (e.g. "*a local joke: if you want to be rich, do an operation and then sue the doctor*" Doctor GJ). Secondly, the medical cost was high. In China, although the hospital was called a "public hospital", more than half of the cost was covered by itself (Zeng *et al.*, 2018). It was common for some hospitals to make profits through some measures, such as over-prescribing drugs, prescribing expensive medicine and referring to profitable tests. Thus, "*some patients believed that all the money paid went into the pocket of the doctors*" (Doctor ZHP); or they thought that "*they paid so the illness should be treated and life should be saved; they were not paid for getting worse*" (Doctor SG).

The experiences and opinions of the doctors and nurses on medical disputes highlight two issues for the policy reform. The first is the inequality in medical resource distribution which leads to the mismatch in demand and supply of healthcare services as described in Zeng et al.

(2018). Medical resources and technologies are concentrated in large and good hospitals and force small and primary- and second-tier hospitals to use other methods for surviving and earning profits. The Chinese government has been undertaking further medical reform to optimise medical resource allocation, including reform in medical insurance, tiered diagnosis and treatment system, reforms in medical price, salaries, etc. The second is the requirement of legal system reform. The rights of both patients and medical staff should be protected. A safe working environment for medical staff is needed.

In summary, given China's cultural and traditional background, the precedence of patient beneficence in ethical concerns, legal imperfection and current medical environment, health professionals preferred to inform the diagnosis to the family rather than to the patients directly and then leave the family to decide whether to reveal the truth based on their assessment of the condition of the patients. This seems to be a common and realistic practice to protect health professionals, minimise the possible unexpected negative consequences on patients, and be consistent with Chinese traditions. However, we cannot simply conclude that patients' autonomy is absolutely neglected in this practice because the data also show some patients knew the diagnosis from the doctor or the family, although sometimes delayed, and health professionals usually convince the family to inform the truth to the patients, as reported in different sections in this chapter.

5.4.3 Health Professionals Perspectives on Non-disclosure

The above two subsections analysed the common paradigm (family-oriented disclosure) used by the doctors and nurses interviewed in this study and the contributing factors to the adoption of this paradigm in practice. During the interview, the participants also expressed their views on non-disclosure, including their perspectives of patients' knowing, as well as their concerns

of non-disclosure. The experiences of health professionals supplement the evidence discussed in sections 5.2 and 5.3.

The experience of a few doctors was in line with what was believed by the family, i.e. most patients did not know their illness. For example, Doctor ZPF thought that at least 60-70% of the hospice patients did not know their illness. He felt that, from the standpoint of patients, "*nobody wants to hear that he (or she) has got cancer. Some patients might be clear in their mind about their illness, but don't want the fact to be confirmed. Otherwise, they will be very sad. For patients who don't want to face the fact, the doctor has to deceive together with the family.*"

However, more doctors had different views and thought more patients had known their illness. For example, Doctors ZX, SG, and LM all thought the majority of patients would know the illness "*gradually*" and "*eventually*", through the treatment process, or "*once a patient knows the illness, then another patient in the same ward will know soon*" (Doctor ZX). Doctor ZHP also observed that "*some patients were told before the surgical operation, and more patients would know after the surgical operation during the chemotherapy process. But for those who have been already at the terminal stage in their first diagnosis, they usually don't know*".

This perception from doctors was also proved by a statement from Patient YZ: "*Only a few patients don't know. Very few, like very old men and women. Many know it clearly, we communicate with each other… It (diagnosis) can be concealed to others but not to the patients… Once you are in this environment (in the hospital), who can't know this in the heart? You know which department you are in, which medicine you use. You know you are receiving chemotherapy, you communicate with other patients. Then you know everything… it cannot be completely hidden*".

In addition, doctors also mentioned that many patients "*just guessed or figured out the fact by themselves and would not like to confirm it (from the family or doctors)*" (Doctor SG). Then, together with the doctor, the family kept "*using lies to cover up the truth*" and avoided the diagnosis topic in the conversation. It seems that the lack of open communication has led to different perspectives in patients' knowing between the family and the health professionals.

There are a couple of implications of the above findings. First, although it is common that cancer patients are excluded in the first diagnosis communication between the doctor and the family, more patients would be informed at a later stage. To many patients, it is a delayed and gradual disclosure rather than complete non-disclosure. Second, the number of patients who know the illness from self-recognition might be very large. However, this group of patients usually keep silent, so it is difficult to identify them in practice and in research, and their well-being might be largely overlooked.

When talking about their experiences with cancer patients, many doctors expressed their concerns about non-disclosure. Their concerns generally fall into three areas: non-disclosure disrespects the patients; it is a barrier of open communication between doctor and patient; and it is not good for the mental health of the patients.

As Doctor GJ said, non-disclosure deprives the right of knowing from the patient, "*not alone the respect for the patients*". Doctor LM added that it is also "*a disrespect for life*". More doctors and nurses described not knowing the diagnosis is a "*sad*", "*sorry*", "*regretful*", and "*miserable*" (in Chinese, they described using different words like *beiai, wanxi, yihan* and *beican*, respectively) thing for the patients at the end of their life. It prevents cancer patients from "*completing any unfinished wish*" or "*arranging any affairs after death like distribution of properties*". Not knowing causes the patients "*die with regrets*", which is "*the most regret*

of a life". It is "*miserable*" that the patient "*can't make any decisions*" or "*can't control life and death*".

According to what I observed and was told by the doctors and nurses during the data collection process, if the family did not want the patient to know the truth, they would tell the health professionals in advance, before the meeting between the doctor and the patient. The family usually accompanied the patient during the consultation, ward-round or home visit. They spoke to the health professionals on behalf of the patients most of the time. They tried to avoid any opportunity that the patients talked to the health professionals alone. They were very sensitive and alert about the questions raised by the patients or the answers from the patients. Sometimes, the patients started to talk about their physical problems and feelings to health professionals or asked why they were not getting better. In these cases, the family usually interrupted the conversation before the health professionals had direct responses to the patients. They usually said, for example, "*You are OK. Do not think too much*"; "*You just need to continue to take your medication. The illness won't be cured that quick, and it takes time*."; or "*You see the doctors are here, there is nothing to worry about*." Sometimes, they just changed the topic of conversation.

Health professionals faced such conversations every day. From their experiences and perspectives, not-telling would prevent doctors and nurses from discovering the patients' real conditions and knowing their inner feelings.

We cannot discuss the real situation with the patient during the home visit, including the initial visit. The family meet us in front of the door and tell us not to tell the patient his/her diagnosis. We can only get information on treatments and symptoms from the family. When we see the patient, we can only ask simple questions, such as, what is your feeling today? Have you had

any pain? How does the pain feel like? In the end, before we leave, we can only give the patient comfort, such as "it is OK, no worries, we will give you some analgesia. After you take it, the pain will disappear". It has become a routine or common practice for health professionals not to tell the patients if the family say the patient does not know the truth. As a result, communication between health professionals and the patient becomes so simple and short (Nurse LY).

Doctor ZPF from the hospice had similar responses as his colleague, Nurse LY. He added, "*Home visit to patients or scheduled meeting with the patients is just a pro forma. The patients rarely ask questions. Some just asked questions whether their illness could be cured. I have been working in the hospice for one year, and few patients asked me their illness*".

Since there was no open communication between doctors and patients, "*it would be very difficult for providing care and treatment*" as described by Doctor TP, "*if the patients have already known, all the problems are solved. We can ask about their conditions and feelings directly*".

Having cancer is a shock to every patient and telling the truth would lead to psychological hurt to them. However, health professionals in this study thought non-disclosure also hurt the patient emotionally. For example, Doctor GJ told me the following:

The family is evasive when discussing the illness in front of the patient. Everybody can feel that something is hidden, not say the patient. Sometimes, we (doctor and family) talk about the illness when the patient is sleeping. When the patient wakes up, the family suddenly stops the conversation. The patient can easily notice that we are talking something behind him. It is better to reveal without any cover-up. Hiding the diagnosis does not respect for the patients. It hurts the patients and creates a lot of pressure. For the patients, it is like walking in the dark

at night. They don't know anything in the front. This should be very painful and bitter for the patient. They need someone to accompany and to tell their real feelings. Family hide the illness in order to reduce the emotional pain for the patient, but they do this without considering the feeling of the patient. Hiding the information would lead to more emotional hurts for the patients, like depression and anxiety. If the patients know, we can comfort them and help them pour out their grievance out of their heart (Doctor GJ).

Doctors like ZX and TP both considered that although it is a painful process, most patients would gradually accept the truth. They found most patients merely complained if they knew the diagnosis and participated in the decisions of treatment plans. However, resentment and lack of cooperation in treatment were observed from patients who did not know their diagnosis. Doctor TP recalled his experiences with patients who did not know the diagnosis. At the terminal stage, patients' health conditions became worse and worse, and it would be difficult to carry out any effective treatment. But patients could not understand this because the family members kept telling them: "*it is OK. It is not a severe disease. You will be recovered in a few days, just take your time*". Then, in the patients' opinion, the family members were lying, or they did not want to spend money to cure the illness and hence lose the trust of the family. Some also blamed it was the fault of health professionals who were not able to provide the best treatment. Doctor TP said, "*they (the patients) are very resistant to care, and some even refuse to take medicine. They have lots of misunderstandings because of not-knowing… Gradually, they become lonely and disappointed and feel abandoned by the family. In the end, they do not trust the family and health professional anymore*." Doctor TP said many patients kept silent during the meetings with him. Some complained that the family covered up something so it should be a serious illness. "*Keeping silent is not a good thing for the patients., not good for their mental health*", said the doctor.

Nurse LY gave me an example when they visited an old lady with breast cancer. She had got tumours in her entire abdominal cavity and was suffering from nausea and vomiting day and night. Nurse LY said, "*Her husband does not want her to know the diagnosis… When she is not comfortable, she will torture her husband in different ways and complains why he won't take her for treatment. She has a grudge against her husband. But if he took her to the clinic for some kind of infusion, she would not torture him like that." (Nurse LY).*

The accounts of doctors also provide more evidence of the effects of knowing and not knowing in addition to that from the patients and families. Although non-disclosure is motivated to reduce the psychological harm to the cancer patients, non-disclosure also results in anxiety, depression, hesitation and resentment of patients. The deliberate white lies and ambiguous information may affect the patients' trust with family and health professionals, and change the behaviour of some patients. Since there is a lack of open communications with the doctors, the patients have reduced opportunity to release their psychological pains. These findings are consistent with previous studies that truth and deceit both hurt (Fallowfield *et al.*, 2002).

5.5 Conclusions

From the accounts of patients, family members and health professionals, we have an overall, all-sided understanding of the diagnosis disclosure in China. In addition to the knowing patterns and practices in diagnosis disclosure, we have more understanding about the concerns and contributing factors that form the precedence of family-oriented disclosure practice in China and its consequences in terms of the patients' autonomy, awareness of the illness and dying, and psychological changes. The findings provide more in-depth evidence to the existing truth-telling literature in non-disclosure dominated culture settings.

For a terminal illness like cancer, diagnosis disclosure, as well as other medical decisions, is a doctor-family-patient matter. Family plays as an intermediate and gatekeeper in doctor-patient communication and a surrogate agent in decision making. Excluding patients from diagnosis disclosure communication is not only common in China but also ethically accepted in Chinese cultural tradition and in medical practice. It is also in accordance with current legislation in China. Although patients have different attitudes towards knowing the truth, the family's autonomy overweighs patients' autonomy in information disclosure in oncology. Hospitals, health professionals, as well as families, believe that non-disclosure would reduce the psychological harm to the patients. Ethically speaking, principles of non-malfeasance and beneficence have more priority in China than autonomy. Given China's cultural background and the legislation, we cannot say family-oriented disclosure is totally, ethically wrong, even though it is different from the patient-autonomy precedence in the West.

Family-oriented disclosure or non-disclosure to patients at the time of diagnosis does not mean full unawareness of the illness for the patients. Patients can still know their illness from different channels, under different conditions and at different times. The truth-telling might be delayed or diluted about the severity of the illness. It is inconclusive from the accounts of participants about the proportion of patients who know the diagnosis because there are a number of silent patients who know the truth from self-recognition but pretend that they do not know. The finding of the mutual pretence of knowing between family and patients (or the phenomenon of "window paper") is believed to contribute to the literature. This is a grey area with little attention in practice and research. It is a challenge for both practitioners and researchers to identify them and to discover their real needs in end of life care.

Non-disclosure (or not knowing) has both positive and negative effects on the patients' physical and emotional conditions. It is difficult to draw a simple conclusion about which side dominates

the other or the net effect on the quality of life of cancer patients at the end of their life. In addition, given the different patterns of knowing/not-knowing, patients have different levels of awareness of the illness. Even open communication of diagnosis (knowing the truth) does not necessarily lead to active open awareness of the illness or full understanding of the impending death. The patterns of knowing and awareness, as well as the influences on the patients, are diversified.

Chapter Six Living with Cancer

6.1 Introduction

Having cancer is a chronic sorrow for the patients and the family. Cancer patients do not only bear the physical pain from the disease but also suffer from psychological distress. Family members of cancer patients in China usually act as the primary caregivers and surrogate decision-makers and hence carry huge stress from different sources. However, cancer care in Chinese hospitals is usually treatment-focused (e.g. curative treatment, adjuvant therapies, or treatment of other symptoms). Cancer patients' psychological distress is not always recognised or treated by health professionals. This is also true for family caregivers, whose stress and needs are largely overlooked in practice and literature in China. It is needed to raise the awareness of health professionals on the lived experiences of both cancer patients and family caregivers regarding their emotional reactions, stress and coping strategies of living with cancer. Understanding their feelings and needs would be useful to improve the quality of end of life care. Therefore, in this chapter, I explore the psychological distress of patients of having cancer and family caregivers' stress of caring for dying patients. I also analyse the challenges and coping strategies of living with cancer of both groups of participants.

I use Heidegger's phenomenological approach to analyse cancer patients' lived experiences of being-in-the-world, being-in-time, and being-toward-death. According to the accounts of patient participants in my research, having cancer affected their meanings of being-in-the-world. Their understanding of space and time in the world had been different after knowing the diagnosis. The illness had affected their ways of living in the current space, changed their perceptions of self in the past and their ways of living with others. Some patients felt they became different from their normal selves (in the past) after having cancer. These abnormalities

were represented by their changes physically, emotionally and spiritually. They also felt that "Others" could not understand them, or as Heidegger described that the "Others" could not access the experience of loss of being suffered by the patient. Given these, patients were trying to mediate a new strategy in their future remaining time. Similarly, family caregivers also had their experiences of being in the world when caring for dying patients. The findings from the lived experiences of patients and family add to the knowledge and understanding of the complex human phenomenon of living with cancer and offer professionals implications for providing more appropriate interventions to both patients and their families.

The rest of the chapter commences from the meaning of cancer to patients and the family. Section 6.3 analyses the experiences of living with cancer from the perspectives of the patients, including their distress, existential challenges and coping strategies. Section 6.4 explores the main sources of stress for the family as the primary carer of cancer patients, as well as their coping and needs for support. Section 6.5 concludes.

6.2 The Meaning of Cancer

Chapter 5 has discussed that death is a taboo in Chinese culture. Death carries a strong negative image and is usually avoided as much as possible in communication. Many Chinese people have a fearful and fatalistic attitude toward cancer. The word "cancer", like the word "death", is generally discouraged in communication for some Chinese (Goss *et al.*, 2014). A similar phenomenon is found for "cancer" from my data. The meaning of cancer is not only as a type of disease, but it also carries a social construct of personal and social perceptions shaped by personal experiences as a cancer patient or witnesses of cancer (family and health professionals). Furthermore, considering the physical and mental sufferings caused by cancer, cancer caused death is seen as a bad death in China.

6.2.1 Perception of Cancer

Recall that Nurse LY said cancer diagnosis is a "death sentence" (section 5.3.1), participants in this study explained how the patients feared death after knowing their diagnosis.

I feel fear. My brother had the same disease (lung cancer) and died after three months of diagnosis… I am frightened… and can't stop thinking about it (dying) (Patient GJG).

In my village, people are scared of having cancer (Patient YZ).

I was knocked when the doctor told me the diagnosis… I was really scared (Patient ZJ).

Although cancer diagnosis means a death sentence, many patients actively participated in the treatment, expecting cancer to be cured or their life to be prolonged. For example, after the doctor told Patient ZJ the diagnosis, her first question was: "*Is it (the tumour) found at the early stage?*", when the doctor said yes, she followed, "*Can it be cured?*". Patient GJG expressed that he had prepared to fight against cancer in the long term, using both modern medicine and traditional Chinese medicine. He described that he had a spirit as the "*eight-year war resistance against Japan*". He would comply with the treatment until nothing can be done.

In contrast, some participants viewed that cancer is not curable, the treatment is futile, and the consequence of cancer treatment is the loss of both life and wealth.

My illness can't be cured (Patient TB).

This illness is not a good disease. People die in the end with a lot of sufferings (Patient LJX).

When the cancer is a terminal stage, it can't be cured. The treatment is useless… We spent a lot of money on treatment, and now we will lose both the men and money (Family XUW).

The sense of the futility of anti-cancer treatment is also associated with the fear and hopeless attitude toward cancer.

6.2.2 The Fatalistic View of Cancer

While most Chinese people understand that cancer is caused by biological, lifestyle and environmental factors, traditional beliefs still influence fatalistic attitudes towards cancer, known as the stigmatisation of cancer (Sontag, 1979; Goss *et al.*, 2014). The staff in the hospice shared their experiences when communicating cancer with others.

People fear cancer, and many people "turn pale when talking about cancer" (which has been a new phrase in Chinese) (Doctor GJ).

Goss et al. (2014) and He et al. (2019) explained that the deep belief of Ming (or fate) in the Taoist belief system is responsible for the cancer fatalism in China. Ming is described as an invisible force that governs everything in human life, including birth, ageing, illness and death. Having cancer, survivorship or death from cancer are all the acts of Ming. In this study, some patients and family put having cancer in Ming. For example, when talking about his mother's disease, Family YZS said, "*My mother's Ming was not good. She had lots of frustrations in her life*". Patient TB attributed having cancer as "bad luck" in his Ming, while Patient YZ did not worry about his illness because he claimed, "*My Ming is hard and strong. I have survived many accidents since I was young…If you are not damned, you will not die anyway. If you are damned, you die anyway.*"

Worldwide, a fatalistic view of cancer is also found, in particular, in groups with low socioeconomic status, such as African-American and Latin-American, Australian Aboriginal populations (Prior, 2009; Goss *et al.*, 2014).

Cancer has also been viewed as bad luck and contagious in some cultural beliefs, which was also found in this study.

We sometimes promoted our hospice service on the street and distributed leaflets about cancer. Some pedestrians were curious and came closer to see what we were doing. For some people, when they noticed it was about cancer, they refused to take the leaflets, and some even didn't want to touch them. They didn't want to talk about cancer or hear anything about it. I still remember an old lady and her expression of disgust when I mentioned cancer. She immediately twisted her head and left before I finished my sentence. They might think talking about cancer or even touching the leaflet would give them bad luck or make them getting cancer (Nurse YR).

The fatalistic view of cancer is compounded in poor regions like rural communities. Some people thought that having cancer was a punishment for doing something bad, or it was contagious.

In some villages, cancer is seen as a kind of retribution for doing a bad thing. Having cancer is embarrassing if other villagers know. The family will be looked down on by others. Cancer has been stigmatised in some places in China (Doctor TY).

Some people think cancer is caused by something bad in your body. Some have misperception on cancer… A daughter-in-law of a dying patient asked me whether the patient's last breath is poisonous and harmful to her. I told her it is not poisonous. Cancer is not contagious, and it is different from hepatitis A and B (Nurse YR).

Family PCW (Patient PC's wife) also described the experience of rejection in the interaction with their relatives. Patient PC planned to go back to his hometown, alone, to see his four brothers before his condition got worse. Since his second brother was single and looking after

a new house which was to be the bridal chamber of their nephew, Patient PC thought that he could stay with this brother for a few days. However, when he phoned this brother about his planned visit, the brother said: "*don't come, I am no longer living in that house*". Family PCW interpreted it as a rejection of Patient PC's visit. "*His brother was not happy to have a cancer patient living in a new house. He (the patient) is sick. His brother might feel his visit is annoying*", said Family PCW. She then convinced her husband not to go alone. Instead, they visited PC's brothers together with their son. They did not live in any brother's house but stayed in a hotel for two nights. Family PCW expressed that she could not understand why the brothers treated their sick sibling like that. "*If he is dying soon, I can understand that they don't want to have him. But he is not that close to death. He is just ill. He is their brother. I feel puzzled."* This experience is similar to the finding of Seymour et al. (2007) that Chinese living in the UK viewed dying and dead body as a taboo of "*contamination*".

My recruiting process of patients and families and the interviews with them also proved their reluctance or even fear of talking about cancer and its associated death. Many patients and family turned away when they were aware of my research objectives. To some patients and family, it seems that talking about cancer in public would result in bad luck or even hasten the patient to death. Among those who agreed to participate, some still tried to avoid using words of "cancer" and "death" in the interview or did not want to go further about such topics. I usually used "*this disease*" and "*this condition*" instead of "*cancer*", and corresponding Chinese words meaning "*leave*", "*that day*", "*last days*", and "*end*" as the metaphors of "*die*", "*death*" and "*dying*" in the communication with the patients and family members. Sometimes, we just skipped these words as both the interviewee and myself understood the meaning of the unspoken words.

When talking about his illness, Patient GJG emphasised to me: "*It is not lung cancer, it is a malignant tumour on the lung, not lung cancer*" although later on, he also sighed, "*malignancy is cancer*". It seems that he felt more comfortable using "malignancy" than "cancer" even though he knew to him there was no difference in the meaning. Similarly, the hospitals also avoided using "cancer" or "oncology" as much as possible. "Oncology department" was named as "comprehensive treatment department", partially because some patients were not disclosed about the diagnosis and partially because "oncology" equals "cancer" which is a taboo to many Chinese people.

6.2.3 Death Caused by Cancer is A Bad Death

Given the above social construct of cancer, I find that some people viewed cancer as stigmatising, and hence cancer caused death would be a "bad death". In addition, the fact of physical sufferings of cancer also strengthened the perception that cancer death is a bad death.

In Chapter 5, Doctor ZHP mentioned that it would be easier to communicate the diagnosis of other fatal diseases with the patient than communicating cancer diagnosis. Similarly, dying from cancer is seen as different from dying due to other illness. Data from this study show Chinese people looked at cancer differently. They tended to have a more accepting attitude towards heart disease and cerebrovascular disease and were able to communicate openly about these diseases.

In addition to the account of Doctor ZHP, the experience of Family YZS explained how cancer held different meanings for the family than heart disease. Family YZS's father died from heart disease while his mother was at the terminal stage of colorectal cancer at the time of the interview. He expressed different feelings when caring for their dying parents. His father had a long term heart disease and put stents in the heart vessels 10 years ago. The family looked

after his father very well, paying attention to the lifestyle and following the doctor's instructions. Family YZS and his father both knew that the illness was severe and would lead to death, but they never felt the death was that imminent nor afraid of talking about it. Family YZS said, "*My father also discussed it with his friends and old colleagues, and shared experience of how to manage the disease".* One year before the interview, his father's heart problem got worse. He added: "*My father suffered a lot due to short of breath. He said he felt dying at every moment. We were scared. Luckily, his heart bypass surgery was successful. After the operation, my father immediately became as normal as before. All the family felt relieved. However, he still passed away after two months, very suddenly during his sleep…. But he had a good time in the last two months before he died… Yes, we had a happy time, and he died peacefully*."

Family YZS explained how the family grabbed any piece of hope to treat his father's heart disease. In his view, experienced doctors and advanced equipment in modern medicine gave them a chance to cure the heart problem and control the disease through treatment. Patients could prevent and control the progress of heart and cerebrovascular diseases by using medication and lifestyle changes. With proper self-care, the patients were able to achieve some years of good quality of life.

However, cancer is different and perceived as out of control. Caring for his cancer mother was absolutely different from caring for his father.

Not long after my father's death, my mother was diagnosed to have colorectal cancer and then renal failure. She had an operation, but her condition is not good at this moment… She has problems with urination and defecation. Since we knew her diagnosis, I always have a heavy heart. I always worry about the spread of cancer cells… The feeling is different from looking

after my father. Every time when my father had a heart attack, we were scared. We knew he would die from it at any time, but it might be the next day, in a month, in a year, or in five or even ten years. The doctor said a lot of people could live seven or eight years after the heart bypass surgery. Although his heart disease was severe, he felt fine after the operation and we had hope. But for my mother, I feel powerless. It is out of our hands… We can't do much about it. It can't be cured. I can only see her getting worse and weaker day by day until death. Every day is suffering for her and the family (Family YZS).

Family YZS's experiences show different perceptions and attitudes toward cancer and heart diseases. Although both are fatal and cause suffering, the expected quality of life of a heart disease patient could be better than that of a cancer patient so that the family experienced less stress. Therefore, the physical pain and psychosocial sufferings caused by cancer also explained why some Chinese people viewed cancer death as a bad death.

The meaning of cancer is not simply a type of disease. Cancer is viewed differently in China from other critical diseases. Cancer is considered to be a fearful, fatalistic, bad disease, and its associated death is a kind of bad death. This finding might not be a unique Chinese culture. A similar phenomenon, such as avoidance of talking about cancer and rejection in the environment, is also found from the lived experiences of cancer patients in other studies (Halldórsdóttir and Hamrin, 1996). The fatalistic view of cancer from some Chinese people is consistent with previous findings; for example, the perception of cancer of Australian Aboriginal women (Prior, 2009) and lower socioeconomic status groups in the UK (Wardle and Steptoe, 2003).

The fatalistic view of cancer and rejection of mentioning cancer would lead the cancer patients to keep distancing from others or feel self-loss. It also hampered the cancer treatment of patients

with this perception and resulted in passive coping strategies, which are to be discussed in the next section.

6.3 Being There – Cancer Patients' Experiences of Living with Dying

"Being there" (or being-in-the-world) for cancer patients means a person is being in a world of having cancer oneself and being with death (or loss-of-being). Cancer patients would explore their own consciousness about living with dying from inside themselves. Data in my study show that cancer patients experienced different psychological distress after learning the diagnosis and they experienced different types of existential challenges and concerns while living with cancer. It was a gradual process for cancer patients to adjust and accept the truth (subsection 6.3.1 refers). Emotions of anxiety, depression and sadness were more prominent than other types of emotional actions among the patient participants.

Regarding the existential challenges (subsection 6.3.2) in psychosocial feelings of having cancer, there is evidence such as vulnerability, isolation and being alone; however, the data emerge a phenomenon that cancer patients identified themselves as different from what they were in the past and different from "Others" now. This perception is reflected by the patients' loss of self-images of the past due to changes in themselves and their roles played in the family and the social networks. Besides, with this perception, cancer patients felt that "Others" could not understand the feeling of being as a cancer patient and tended to self-isolate and avoided sharing the feeling with others. Given the loss of previous self-image and places in the world, some patients redefined their goals and positions, changed lifestyle and values, increased appreciation for the time and loved ones.

To cope with the distress, cancer patients had a process of acceptance and self-adjustment. Patients coped their life in different ways. Some took a confrontation way of coping, seeking information and directions from an authority. Some accepted but in a passive resignation way. Some coped in an avoidance pattern, not talking or thinking of the illness and keeping distancing from others. And some thought the positive, taking each day and seeking support from hobbies or religion. Details will be discussed in the final subsection 6.3.3.

6.3.1 Psychological Distress from Knowing to Acceptance

Since all the patients interviewed had been aware of their illness, many mentioned their feelings after knowing the diagnosis. Having cancer involves physical pain and psychological distress, and social and spiritual struggles (or "total pain" as defined by Saunders, 1964). Almost all the patient participants showed or expressed their psychological pain during the interview. The interviews were usually interrupted by the emotional change of the participants, especially when they recalled the experiences that raised their inner pain. For example, Patient GJG told me that he could not sleep well during the night and could not stop thinking of good things and bad things after he had cancer. I asked him to give some examples of good things. He said good things were that he would be cured, suffered less, or enjoyed the rest of his life with his family. Then I asked him what the bad things were. He turned to be silent for a while and excused to the toilet with his family. When he came back, he said he was tired. He lay on his bed and closed his eyes, indicating that the interview should be finished.

Patient TB expressed his distress of having cancer:

After I got this disease, I started to think about a lot of things. When I am alone, I think I am going to die, maybe suddenly one day. One day, when I went to the hospital to treat my sore, I waited for my turn and looked at the other people in the hospital. Then I cried full of tears (he

choked with sobs) ... I thought that all the other people were healthier than me. Although someone had a fracture in the leg and couldn't stand up, he could get better one day. For me, I am just getting worse (Patient TB).

Patient TB's wife said physical pain from the illness never made Patient TB cry, but the pain in his heart did. The experience from the above patients shows the psychological distress of having cancer, which was usually not emphasised in the physical-focused treatment in the practices of health professionals in China.

Accepting the fact of having cancer is not an easy process. Some patients raised "*why me?*" questions about the incidence of cancer.

I felt shocked when first knowing my diagnosis. I kept asking myself why it is me. I have not done anything particularly bad, why it is me to have cancer (Patient JLQ).

I did not think it is fair that I got this (cancer). When I saw other people, especially my friends living as normal, I feel it is unfair. Why me? Why do not the others? Why do I have it in this life rather than the next life? (Patient PC).

Taylor (1995b) described this phenomenon as the *reason questions about the selective incidence of events* which are distressing because such questions are usually unanswerable – the science can only explain how they get cancer (e.g. a causal explanation) but not the why. Patient PC's feeling of unfairness is also related to the emotional reactions of anger and blame discussed in the literature (Peck, 1972; Taylor, 1995b).

Accepting the truth was a gradual process. Several patients reported that they had to accept the fact of having cancer, eventually.

As time goes, I started to accept it slowly. After all, it is my own disease, and nobody can replace me … If there is no pain, I would feel as normal as before. But the endless pain kept reminding me (the fact of having cancer) (Patient JLQ).

I am afraid of it (cancer). How can't I be afraid? I have been afraid of it since the beginning of the illness. Then, and then, gradually…(silent) accept it… worrying and scaring are useless (Patient ZG).

In the beginning, I had a lot of pressure. It (having cancer) was unexpected. I was expecting to look after the grandchild, see him grow up, and look for a good time in my old age (crying)… I felt the sky was falling. Then I adapted along with time…Yes, I gradually accepted it, inwardly. Every cancer patient must face it. I have done what I can do to treat it. If it cannot be cured, that is it and we can't do anything else (Patient QM).

Facing this shock in health, a patient also reported that he was not afraid of death and accepted that cancer is a way of death. To him, the process of dying is more suffering than death itself.

Everybody will go underground (die). It just comes earlier or later. The key is you have to accept it inwardly … I am not afraid of it. I don't think about it (Patient YZ).

During the interview, Patient YZ did not look stressed or worried about his cancer or death. This might be linked to his own experience. He was a builder and experienced several accidents at work. He used to fall off from the scaffolds, and his abdominal was pierced through by a steel bar. Luckily, he was saved from this accident. He was also injured his shoulder and arm in other accidents. He thought he had already picked up back to his life through previous accidents so that he was not afraid of death. He also claimed his Ming was strong to protect him. However, from the following interview with YZ, he mentioned that the pain and treatment

process was more suffering than facing death. To him, death itself was not fearful, but the process of dying was. The endless physical pain and other uncomfortable symptoms were the hardest part for him to live with cancer.

In addition, some family caregivers also reported anxiety and the bad temper of patients. For example, Family XG said his father usually threw a tantrum: "*He said he felt edgy. He swore at people, at my mother. He said he could not control his temper. Afterwards, he regretted what he said…His temper is getting worse and worse, very irritable…He always says I am so upset, so upset, better to die."* Some other family members like Family MLK also report the fiery temper of his wife, who had liver cancer.

The above evidence shows cancer patients' psychological distress from knowing to accepting the reality of having cancer and dying with cancer. Anxiety, pressure, depression and sadness are the most common responses to such a serious threat to life and are found in previous research (Peck, 1972; Aitken-Swan and Easson, 1959). A few patients in this study expressed other moods, such as anger or blame as described in Peck (1972) and Taylor (1995b), through *why me* questions and the feeling of unfairness.

Acceptance of having cancer could be understood as everybody has to die in the end, and cancer is one way of dying or patients try not to identify themselves as cancer patients with good symptoms control. However, in this study, the extent of acceptance or non-acceptance was not easy to judge. It is also difficult for them not to identify themselves as cancer patients.

6.3.2 Existential Challenges

Similar to previous studies on the lived experiences of cancer patients, data from this study show different challenges of cancer patients, such as feeling uncertainty, vulnerability,

isolation and being on their own (Weisman and Worden, 1976; Halldórsdóttir and Hamrin, 1996; Taylor, 2001). However, one evident phenomenon from the interviews is that cancer patients expressed views such as "*I am not the same as before*"; "*my life is different*" prior to the diagnosis of cancer; "*I can't find my place*"; and "*I am different from the others* (e.g. healthy people and other types of patients)". These perceptions were combined with the plights of psychological feelings and compounded by the changes in health condition and roles played in the "world". The following subsections explore how cancer patients lose their self and positions after diagnosis of having cancer, how they felt "others" cannot understand them and how they redefined themselves.

Loss of Self

Loss of self means that patients "experience a crumbling way of their former self-images without simultaneous development of equally valued new ones" (Charmaz, 1983: p. 168). The accumulated loss of former self-images results in a diminished self-concept. Having cancer will lead to spiralling consequences such as physical deterioration, loss of ability to work, stigma, and changes in the role played in the family and society. Over time, their physical self-images are changed due to the progress of illness and treatment. They also become more dependent and lose control over their lives and decision for the futures. These changes would affect the patients' self-esteem and self-identity, and as a result, a diminished self. Charmaz (1983) explains that the causes of self-loss include living a restricted life, existing in social isolation, experiencing discredited definitions of self and becoming a burden. In this study, cancer patients expressed they were not their "normal self" anymore, although many patients strived to maintain their normality. They explained how the physical sufferings and social psychological conditions contributed to the loss of self in their daily life of having cancer. In this study, the sources of self-loss are grouped into three themes similar to those in Charmaz

(1983), including restrictions in life, changes in the role in the family (or becoming a burden), and social isolation due to changes of positions in the society.

Facing uncertainty and suffering from many symptoms, cancer patients felt immediate physical or tangible changes (e.g. weight, appearance, mobility), subject to the type of cancer they had or the type of treatments or operations they received. These changes had affected their *freedom* in daily life. Many patients found they could not do the things they enjoyed in the past. Their lives became increasingly more restricted because of having cancer. For example, one patient said:

I lost appetite after the operation. I cannot eat my favourite food I used to have. I lost weight about 6kg in that year… I feel very weak and fragile. My hobbies are drawing and painting, but now I have lost my strength and concentration in them…They feed me using NG (nasogastric tube). I feel very strange that there is a tube hanging in front of me. I can't eat steamed bread or stir-fried vegetables using this tube (Patient QM).

Patient ZJ's lung cancer had metastasised to her brain. She reported that, at the early stage of the illness, she did not feel much difference. She played Tai Chi in the park, hung out with friends, enjoyed online shopping and watched her favourite TV series. However, over time, when I interviewed her, she said, "*Now the movement of my limbs are restricted. When my brain is clear, I still want to go outside to have a walk. But sometimes I am dazzled and dizzy all day, the feeling is like you just wake up… Then I don't want to talk. I don't want to eat anything. I can't taste the food I liked before*".

The uncertainty and unpredictable course of cancer narrowed the time frame of the patients. Their health conditions combined "good days and bad days" – like Patient ZJ, before and after cancer cells transferring to the brain, or on some days her brain was clear but on the other days

not. Therefore, such disruptions in their lives limited their activities and affected the maintenance of self-images.

Some other patients also reported living narrowed, restricted lives. They could not continue the normalities of their daily life. Their lives were restricted by the physical pains so that some previous activities became precluded. Another patient said that he was not able to continue their previous hobbies.

I liked Chinese calligraphy when I had free time before I had this illness. But since I had the illness, the pain made me not able to hold the pen for a long time. My hand and arm do not have much strength and my writings are not as good as before. I can't enjoy myself anymore. Now I seldom write Chinese calligraphy (Patient GJG).

As argued in Charmaz (1983), these tangible restrictions are reminders of having cancer and lessened freedom. Therefore, life restrictions usually result in losses of self of patients.

The fear of impending death also fosters the feeling and effects of tangible restrictions, and makes the patients more vulnerable and their lives more restricted than they need to be. A patient expressed her feeling of the foreseen dying, which made her stressful in the daily activities.

The illness (cancer) is like a bomb in my body. I don't know when it will be exploded. The illness is like a mountain suppressing in my heart, and I cannot take a breath… when I feel sad and discomfort, I don't want to do anything (Patient ZJ).

The increased restrictions in lives also affected the roles of the patients played in the family, the relationship with others and their social engagement, which would result in the loss of former positions in the family and society (e.g. in the workplace and interaction with old

friends). In this study, some cancer patients reported their experiences in changing the positions in the family. Tangible restrictions were combined with other problems elicited by cancer, such as loss of working ability, dependence on others, and financial burden. Some patients used to be the head of the family or the main breadwinner, but their leading role was affected by the illness. Over time, when they became more dependent on other family members for care or used up many of their family savings for medical treatments, these patients would think themselves useless and became family burdens. Such changes in their positions in the family were an emotional shock to the patients in this study. For example, some patients reported the following.

I think I am getting more and more useless now. Since I got this disease, I have been very weak. I have to take early retirement from work. My earnings become less, but my expenditure becomes more (Patient JLQ).

I have already been retired from work. I used to help my daughter to pick up my grandson after school. But now, my children and my wife had to spend time looking after me. Sometimes, I felt so useless (Patient QM).

I was able to help my son plant some seeds on the farm or look after the vegetables before I was diagnosed with cancer… But now I don't think I can do anything. And my family don't allow me to do any work on the farm, either. They look after me. But what else can I do except working on the farm? I feel I am a burden now (Patient TB).

Accounts from family caregivers show that some patients worried about the family's burden due to their illness, including the financial burden. Family XG said his father felt he owed a lot to his daughter (XG), who had cared for him and spent a lot of money for several years. Family MLK reported his wife used to be a sharp woman of action and usually acted as a leader in

village events, such as weddings and funerals. At the time of the interview, she had been dependent and immobilised. She always blamed herself that due to her illness, her son could not go far away from home to do business to pay off the bank loan.

As discussed in Charmaz (1983), becoming a burden or feeling useless demean identity. The above experiences suggest that the patients became fragile and more dependent. They lost identify as they could not control their situations or recapture previous positive self-images in the family. Self-concept was diminished when the patient could no longer claim the identities based upon prior activities and responsibilities or fulfil their prior obligations in the family relationship.

Self-identity is also situated in networks of social relations. For cancer patients in this study, life restrictions usually affected participation in work and social activities. During the interview, some patients who had jobs in the past took early retirement. The illness also limited their time, energy and ability to maintain past relationships. The fatalistic view toward cancer or cancer stigmatisation also excluded some cancer patients from keeping earlier social activities and connections. For example, Patient JLQ mentioned his loss of position in the interaction with old colleagues.

I don't want to meet my workmates now. We used to get together very frequently before. But when I see them now, I feel I am different from them because of the illness. I want to stay with myself alone now (Patient JLQ).

Patient TB who had lung cancer also shared his feelings, "*I was surrounded by many people outside before I have cancer, but now I cannot find my place and I do not feel that is me again in my heart*". It seems that inattentiveness of past acquaintances and existing in social isolation were emotional shocks to the patient and resulted in self-loss in society.

The above experiences show that previous social networks and relationships waned, so the cancer patients placed themselves in different social worlds to the past. These changes resulted in social isolation, which fostered loss of self (Charmaz, 1983; Taylor, 2001).

In summary, having cancer did not only reduce the time frame of living in the word for the patients, the associated life restrictions and existing social isolation also reduced their space living in the world. Living in narrowed and restricted lives made cancer patients lose their past positive self-images and previous positions in their family and society. As a consequence, they lost themselves and saw themselves differently from others.

"You Can't Understand"

Social isolation and exclusion from the "Others" would lead to patients feeling alone. This feeling would be enhanced by difficulties in communication (Kvåle, 2007; Peck, 1972). During the interviews, several cancer patients reported that "*I don't want to talk*". When they shared their experiences with me, some mentioned: "*I didn't say this to others*", indicating that they rarely shared their feelings and thoughts with other people. They were on their own. When I further asked why they did not share their feelings, some patients reported that talking to "*others*" were not helpful and their feelings were hardly understood by other people without cancer.

There is no use to talk to friends about it because it is helpless. They cannot help with anything (Patient TB).

There is no point to talk about it with others. It doesn't help at all. Nobody (others) can feel my sufferings or replace me (Patient ZJ).

During the interview, Family XX also expressed his father did not share the feeling with the family. Family XX understood that "*nobody else, except the patient himself, could experience the real feeling of having cancer and living with dying*."

These experiences reflected the difficulties in discussing and sharing their feelings with others. A similar phenomenon is also found in previous studies, such as Taylor (2001). The sources of such lack of sharing their experiences might include emotions of fear and embarrassment (like around cancers in bowels, breast and cervix), the taboo around cancer and death in some cultural context and the social viewpoint related to the stigmatisation of cancer (Taylor, 2001; Sontag, 1979). Liu et al. (2005) further explain that in Chinese culture, such communication difficulties of cancer patients might be affected by the unique features in their communication behaviours: a focus on insider(*zijiren* in Chinese) and implicit communication (*hanxu*). Insiders usually refer to family members and relatives, while acquaintances and strangers (including health professionals) are outsiders for cancer patients. Chinese people do not spell out everything but usually leave "unspoken" meaning to the listeners to interpret, particularly when they talk to outsiders. These two features also impeded cancer patients from communicating their feelings with others.

In my study, patients' difficulties in communicating their feelings with others can be explained using the insider-outsider concept. However, different from Liu et al. (2005), cancer patients in this study treated themselves as the "insider" while all the others were "outsiders" (not only the strangers but also their family members). In the patients' view, none of the "Others", except themselves, were *being there* in the same situation of being cancer patients. The following account from Patient JLQ is a good example that compares the experience of being a "witness" (outsider) of cancer and the experience of being a cancer patient oneself (insider).

Patient JLQ had a close friend who got cancer a few years ago before the interview. To improve his friend's negative emotions, JLQ invited his friend to go out to do what they enjoyed in the past, such as fishing and strolling around in the local markets. But these previous hobbies were no longer attractive or made his friend as happy as before. Then JLQ had cancer himself and started to understand the situations of his friend.

When I visited my friend with cancer and saw him in a low mood, I used to advise him to take it easy. Now I got the same illness, I realise that it is easier said than done… I cannot feel the same as myself as before. Sometimes I even don't want to think about or talk about my previous hobbies, because these hobbies will remind me of my previous happiness and make me feel more grieved as I cannot experience that happiness anymore (Patient JLQ).

Patient JLQ also described to me the pain he was suffering and asked: "*have you experienced this kind of pain?*" In his view, I, as a "normal person" (or outsider) was unable to understand the same pain and psychological feelings that a cancer patient experienced, no matter how he described that kind of pain to me. Patient JLQ also added:

You don't have cancer, you don't know that feeling, the pain and the sorrow. You, a normal person, can't understand, just as I couldn't understand my friend before (Patient JLQ).

I appreciated that Patient JLQ shared his experiences and perspectives before and after he had cancer. Whilst previous studies also suggest cancer patients felt people around them could not understand or share their experience, it is a rare opportunity to understand the patient's perceptions of being an outsider. Cancer patients (insiders) were being-toward-death and suffering the loss of being in the world. Such suffering cannot be easily felt by "Others" who were "*there alongside*" as described by Heidegger (1962). Many family members in my study reflected that they tried to inspire the patients as Patient JLQ did to his cancer friend, for

example, re-picking previous hobbies to regain happiness. However, patients' real feelings or needs might be different from the expectations of the outsiders. Old habits or hobbies might bring back some happiness and increase the quality of life of some patients, but might also remind the current restricted situations and bring more bitterness to the others.

The experience of Patient JLQ highlights that even the closest family or friend cannot thoroughly understand the feelings or needs of the patients. Other patients in this study also shared the view that healthy people could not understand their true feelings; and it was their own disease so nobody except themselves could help to alleviate their sufferings and symptoms. Another shared perception is that they had already been a burden to the family, so their inner negative feelings would cause family members to have more pressure and stress. From the family's perspectives, not mentioning cancer in daily communication would stop reminding the patients that they were ill. Consequently, both patients and families reached a tacit understanding: avoiding talking about illness and feelings. It further hindered patients from expressing themselves and the family from understanding the real needs; and hence fostered patients' exclusion, isolation, loss of self, and distress.

Redefinition

Reduced lifespan, tangible restrictions and loss of previous self-images and places in society changed patients' lifestyles, made the patients rethink what they had achieved, what they valued and what they should do in the future, and redefine their goals and places in the environment (Halldórsdóttir and Hamrin, 1996; Weisman and Worden, 1976; Taylor, 1995b).

Data from the interviews suggest many patients reviewed their past lifestyle and made some changes, for example, stopping smoking and drinking alcohol, having a healthy diet, and

exercising more. Many patients also claimed that they thought differently and saw things differently after having cancer.

Some patients expressed the meaning of time/life had been changed, and they valued more about time and the time left with their family.

My time becomes precious. I am counting down my days. Every day, when the sun rises, it means a new day to healthy people, and they probably plan to do some things. But for cancer patients, it means another day less in my life – a counting down of time every day. You know you will die sometime soon, so every day means another day less (*Patient ZJ*).

I used to think I would have a lot of time and a good old age with my family. Now, I know my time is limited. I want to live longer… stay longer with my family, my children and my grandchild. I have to cherish the time with them (Patient QM).

Along with cherishing the time, some redefined "good things". Patient YZ said although having cancer was "bad", but he thought his current life was "a good life": "*The surgery was successful. I sleep well and eat well. I am still alive, so I live a good life*".

Some patients also redefined their goals and reprioritised what they planned to do. Patient TB said his priority was the future of his wife, who had high blood pressure but did not have any income. He explained:

My child has grown up. My plan is all for her (my wife). Let her suffer less (from my illness and death). Leave more money to her. I spend where needed but save as much as possible… I had a piece of land… I built a house with 9 rooms on the land. Now I rent the rooms out to get about 20000 yuan (RMB, about £2000) a year. With this rent income, plus my savings, she would have a good life (after my death) (Patient TB).

Another patient also mentioned he would re-plan everything, but only important issues related to the family and work were prioritised.

I am running out of time. I have lots of things not yet completed. The key is to make a plan. It is not necessary to make a long-term plan, like the government's 13th Five-Year Plan. I can only make a short-term plan, only for the most important issues of my work and my family. I need to make some arrangement. All the other things won't bother me anymore (Patient GJG).

Sections 6.3.1 and 6.3.2 analysed the psychological distress and existential challenges of having cancer. The next subsection will discuss how the patients cope with these stresses and problems. Reviewing the past and redefining the goals discussed in this section are also related to some coping strategies.

6.3.3 Coping with Cancer

How people cope with cancer has been researched for many years. A number of coping strategies and patterns have been identified in the literature of psychology and cancer research. For example, Folkman and Moskowitz (2004) divided the coping strategies into four groups: problem-focused, emotional-focused, support-seeking and meaning-making coping. Feifel et al. (1987) identified three types of coping strategies of cancer patients: confrontation, avoidance, and acceptance-resignation. Confrontation is a set of problem-focused coping strategies that involve seeking information and advice from different sources, seeking support from family and friends, and being actively involved in the treatment. Avoidance is an emotional-focused coping that the patients try to forget the illness or not talk about the illness.

Acceptance-resignation is a passive form of acceptance that patients usually believe the disease is out of control, so they give up endeavours.[9]

The data show cancer patients adopted different coping strategies, and for each patient, multiple coping strategies were used and changed over time. Here I highlight some coping mechanisms that are more prominent from the data, including seeking more information or support from an authority (confrontation), acceptance-resignation, avoidance, and focusing on the positive.

Seek More Information or Support (Confrontation)

During the interviews, most patients actively sought more information about their disease. When we talked about their disease, it was very common they asked: "*I use this medicine, have you heard of it? Do you know whether it is useful?*". Some patients treated me as an oncological expert and asked: "*Do you know better medicine or treatment method?*" When they knew that I am a PhD student studying the UK, some would question whether there had been a more advanced treatment method in Europe.

Some patients also explained that they used different means to collect information about cancer and cancer treatment. Patient GJG explained how he and his family collected information related to cancer.

The local hospital asked me to use this medicine. My son also asked the doctors in Jinan Oncology Hospital (in the capital of the province), they also recommended this medicine. When

[9] Other categories of coping strategy exist in the literature. For example, Carver's (1997) Brief COPE groups coping strategies into 14 conceptually different coping reactions, including self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behaviour disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame. Dunkel-Schetter et al. (1992) identify five coping patterns with cancer: seeking social support, focusing on the positive, distancing, cognitive escape-avoidance, and behavioural escape-avoidance.

I was diagnosed, my son also took the test results and CT results to Beijing 304 Hospital (one of the best hospitals in China) to consult the experts there…I also search on my computer. Some (articles) said eating acidic food fosters the growth of cancer cells and eating alkaline food inhibits their development. What do you think of it?... CCTV-10 (a television channel) usually has health programmes. I watch it every day… Cancer is related to smoking, drinking and emotion... I drunk and smoked a lot (Patient GJG).

Other patients shared similar experiences that they sought information from authorities like doctors and experts in the field or people they believed to have that information.

Patient TB also expressed that patients with the same type of cancer usually communicated to share their conditions, treatment methods, and feelings. They obtained information from each other. "*We talk to each other. A lot of things you don't know without talking to each other*," he added.

Being actively involved in treatment is another important item in confrontation. The viewpoint of "actively cooperating with the treatment" was shared by many patient participants in this study. Patient TB said: "*If the doctor says there are ways to treat it, why shouldn't I receive treatment*?" He and other patients like GJG and ZS also used traditional Chinese medicine or folk remedy as additional auxiliary therapy. Their experience and attitudes toward treatment will be discussed in detail in Chapter 7.

The popularity of adopting confrontation strategy is also found in previous studies in China. Hong et al. (2015) and He et al. (2019) both found relatively higher average scores of confrontation strategies than avoidance and acceptance strategies among patients with gastric cancer and lung cancer. This is in contrast to previous evidence in the US, such as Dunkel-Schetter et al. (1992) that avoidance was the more common form of coping rather than seeking

information and others. He et al. (2019) explained that this might be correlated with Confucian beliefs that emphasise the importance of life and regard death as a taboo. In addition, the contemporary political culture, which highlights the spirit of "battle" against a negative event, like a disease, can also be used to interpret the confrontation strategy used by Chinese cancer patients – recall that Patient GJG described the battle against cancer as the war against Japan. Such a fighting spirit is also found in other countries. The fighting spirit is also reflected in their attitude toward anti-cancer treatment, which will be discussed in Chapter 7.

Acceptance-Resignation

Acceptance-resignation is a passive form of acceptance and different from active acceptance and commitment to treatment (Feifel *et al.*, 1987; He *et al.*, 2019). Goss et al. (2014) explain that this is mainly caused by the fatalistic perceptions that death is inevitable and predestined, irrespective of medical interventions, and hence hampered cancer treatment of Chinese patients more than western populations.

In this study, the adoption of the acceptance-resignation strategy was not prominent from the accounts of patient and family participants, probably because of the places of recruitment (hospital and hospice) where patients went there for treatment and medications. Most patients actively cooperated in therapy at the time of the interview. Even though some patients could not undertake surgical intervention, they still looked for ways to prolong their lives. For instance, Patient ZG consulted a number of doctors in different hospitals, but none suggested surgical removal of the tumour in his liver. He gave up and accepted to take conservative treatment. During the interview, he seemed to be not resigned and kept asking about the possibility of minimally invasive surgery. Nonetheless, a few participants admitted that they

knew their cancer was not curable. When their condition turned to be uncontrollable, they would give up. For example, one patient said:

It (health condition) will be out of control one day. By that time, if nothing can be done, I will eat what I like, drink and smoke as before, and wait for death (Patient GJG).

Although patient participants did not show a prominent pattern of using acceptance-resignation, they shared their observations of other patients who gave up treatment. Patient GJG recalled: "*Financial burden is a problem. I met a lady in the hospital in Beijing, the cost of treatment was more than 100,000 yuan (about £10,000). She thought her life could not be saved from the treatment even she spent money. So, she gave up.*"

Some doctors also shared similar experiences that poor patients were more likely to give up even at the early stage of cancer. For example, Doctor ZPF said:

Radiotherapy and chemotherapy are very expensive. Some pain killers and drugs are also very expensive. It is a huge burden for low-income families with cancer patients, particularly those in rural area. So many patients and family chose to give up treatment (Doctor ZPF).

The above "giving up" behaviours seemed to be due to a lack of resources to afford the cost of treatment. Unfortunately, I was not able to recruit patients who gave up treatment to explore their feelings further. It was not clear that giving up was due to their acceptance of the idea that death would be inevitable and anti-cancer treatment was futile or due to unaffordability (i.e. they would like to continue the treatment if they could afford it).

Regarding the perception that death is inevitable and predestined, Doctor SG explained that many patients withdraw from treatment because of the misery and hopelessness associated with medical treatment:

It depends on the willingness of the patients. Some patients have a strong will to survive even though they need to bear the pain from the therapy. But some patients, once they knew the diagnosis, they gave up directly. A patient who was just 40 years old gave up after the first chemotherapy and died soon. We tried to convince him to continue the treatment but he rejected. On one hand, chemotherapy is suffering. On the other hand, since his parents both died from cancer, he believes that there would be no hope for any endeavour (Doctor SG).

Avoidance

According to previous studies, Chinese cancer patients have relatively high mean scores in avoidance (or suppression) coping strategy (Hong *et al.*, 2015; You *et al.*, 2018). In this study, avoidance was firstly reflected by not talking about the illness in conversation. Chapter 5 discussed a lack of communication on diagnosis in Chinese families with cancer patients, particularly for those that the diagnosis was concealed from the patients or there was a mutual pretence of not knowing between family and the patient. For patients who knew their diagnosis, some also expressed their reluctance to talk about their illness, even to the family. Patient ZJ admitted that communication with others would help to release distress, but she still did not want to talk, particularly after her cancer had progressed.

When I was hospitalised in Beijing (after diagnosis at the early stage), I usually communicate about the illness with the patients in the same ward. After all, it is not bad to talk with somebody when you were outside in another city… Now (after cancer transferred to her brain), I don't talk this to others. I don' want to talk about it with my family or others outside (Patient ZJ).

Patient ZJ's experience suggests that the adoption of the coping strategy was dynamic and changed over time, and she used some avoidance strategies when cancer developed to the advanced stage.

Another patient's experience suggests that the adoption of an avoidance strategy was also up to the patient's characteristics. Patient ZG's wife described him as a quiet person who suppressed everything in his mind. He was never conversational in his life and reserved during the interview. His son explained that open communication was seldom in the family because his family did not want to talk about the illness.

Experiences from some family participants, including Family XX and Family XJS, were similar. They did not communicate much about illness and feelings. They only discussed the pain or other symptoms and how to control the symptoms.

The second aspect of avoidance strategy is not thinking of the illness and associated death in daily life. Some patients expressed once they accepted the truth, they tried to not think about it.

I don't think about these (illness and death). Many people I know have stomach cancer like me. They have survived more than seven years or even more than ten years. I don't need to worry... It is also not useful to consider it. Death is inevitable, anyway. When it comes, it uncontrollable. I can't manage when it comes. So, I don't even think of it (Patient YZ).

At the beginning (knowing the diagnosis), I had pressure. Now, I don't think much about it. Many patients are worse than me… When there are pains in my neck, legs and arms, I just think about how to control the pain. When the pain is controlled, I don't think about the illness anymore (Patient QM).

Another expression of avoidance is that the patients do something else to distract them from thinking of the illness. In this study, some patients reported making themselves busy or doing something they enjoyed was a way to distract them from thinking of the illness.

If I am not dizzy, I will walk outside or find something to do. Sometimes, I download some TV dramas, and sometimes I play games on my mobile phone. I also go to visit my sisters-in-law who are very kind to me. Last summer, I knitted 30 woollen hats and gave them to my friends. I still have some woollen yarn at home… A few days ago, I helped my work colleagues to make steamed stuffed buns… I like doing something that is easy but kills time (Patient ZJ).

I used to drink twice a day and smoke one bag of cigarettes. I stopped them so I need to find something new to enjoy. I don't have interests in fishing or playing cards or mah-jong, but I would like to walk along the lake and watch others fishing or playing these in the park. However, these only kill one hour or so… I still have a piece of land in my home village, so I plant some vegetables. Caring the vegetables involves a lot of time and mind, and distract me from thinking of the illness. It is also a good exercise (Patient GJG).

Patient GJG also added entertainments such as watching comedies, cross-talks and comedy sketches would let him forget about the illness. His experience highlights the importance of humour in lessening distress (McCaul *et al.*, 1999; Lee *et al.*, 2017; Li and Lambert, 2007).

Finally, another reflection of avoidance in this study is that some patients would like to keep a distance from their familiar environment (like home) or avoid contacts with previously close contacts (like old friends, colleagues and relatives). They reported staying at home and seeing old contacts would evoke the memories of the old days and remind them of having cancer. They tended to escape from them and go to a different space surrounded by unfamiliar people, which was another avoidance coping strategy to alleviate mental distress. Patient TB was the one who explained in detail about his feeling and escaping behaviours.

I don't like to stay at home. I feel much stressed when seeing this familiar environment. It reminds me of those normal days. I don't want to be alone myself, so I go outside when the

weather is good. I like to ride my tricycle on the road and hear the noise of the busy world… and watch the crowds on the street. These sounds are so close to me, but I feel that I am far away from the world (Patient TB).

Patient TB would like to place himself in a different, noisy environment, trying to distract him from the illness. This would give him a short period of comfort. However, Patient TB's experience also shows that this coping strategy was not always working well, as he could not really "live" within a different space. He still felt a distance "from the world". He was still on his own, which is linked to our discussion about the loss of self in section 6.3.2. Going to a different space did not mean that he was not "alone". During the interview, Patient TB also mentioned that he went outside to elude the visits of relatives.

When my relatives come to visit me, I go outside to elude them... They always tried to comfort me, asked me to take treatment, no matter how difficult. I know what they said is for my good. But my illness can't be cured, what can I do?... I told them: don't come to visit me. I tell them every time. They all have their own work. I don't want to see them… The closer the relationship, the sadder in my heart when I see them ... I go outside very frequently…There is a big square not far from my home. Some motor tricycle drivers are always waiting for business there. I chatted with them, having some fun with them… I can't stay with my old friends. If they don't try to comfort me, I am OK. If they try to comfort me, like saying: don't take the illness into your heart – such words will destroy me. So, I need something to distract my attention… I don't visit my close relatives. I go to the square, chattering and rambling with the tricycle drivers, which make me feel better (Patient TB).

Patient TB's experience shows the conflicts between the kindness of friends and relatives (or healthy others) and the true feelings of the patients. Similarly, the following two patients also would like to go out, avoiding interactions with previous close ones.

I don't like to stay alone as the quietness makes me think of the illness. I would like to go out, but I do not want to meet with friends. I would like to see people doing their own things, such as playing Chinese chess. I like to watch them. This will make me forget it (Patient PC).

Every morning I go outside for exercise and then I walk around the park and the river. I spend most of the morning outside. I do not like to stay at home. I do not want to meet my previous colleagues at work (Patient JLQ).

Putting themselves deliberately in a new environment, avoiding acquaintances, or staying with the unfamiliar reflected the psychological distress of having cancer and their coping strategy of avoidance. Such a strategy did comfort the patients and distracted them from thinking of the illness. However, it also hampered them from sharing their true feelings with others. Some family reported that the patients became more silent and less talkative than they had been. They might lose the chance to express themselves with an open heart, as well as the chances of receiving spiritual support from others.

Focusing on the Positive

Another coping pattern is focusing on the positive, which involves thinking things in a good way, living on today, discovering important things in life, and seeking religious support.

Many patients reported that they had been gradually thinking things positively (they use *想开, xiǎng kāi* in Chinese) after knowing the diagnosis.

I gradually think about things in good ways. I am not that distressed, but still a bit sad sometimes. I am experienced (in dealing with the sadness) now, I will go outside and look for some fun… I try to live in a way as before (Patient ZJ).

I don't have much pressure now. Positive thinking makes me more energetic (Patient QM).

As long as I don't fall (meaning serious ill or die), I hang around every day. Take each day to be happy (Patient ZG).

You have to live 24 hours a day, no matter you are sad or happy. Why shouldn't I live happily then? Why don't I enjoy what I like and fulfil my desire and demand if I can afford it? I'd like to be optimistic (Patient GJG).

Similar to Patients GJG and ZG, some others also reported they lived for today. For instance, Patient PC said: "*I lived day from day. Enjoy what I like and do what I want to do*." And Patient TB also expressed he was trying to take each day as it came, although it might be difficult. These experiences also show that coping strategies might change over time as the patients also adjusted themselves during the course of the illness.

Some patients discovered new things or rediscovered important things in life – recall that Patient GJG started to plant vegetables, Patient ZJ kept herself busy, and Patient TB built a house and rented it out for the future of his wife. Some patients also developed a new habit. For example, Patient ZS sang every day, which distracted him from the illness and made him happy and peaceful. He believed that being happy would improve his immune system, restrain the development of cancer, and enhance the effects of the drugs.

Religious support is another way to cope with distress. Some doctors and nurses in this study explained that patients with religious beliefs were more likely to have less psychological pain,

which is consistent with previous findings that religious faith becomes more important over the course of cancer and is associated with focusing on positive behaviours or a better quality of life of cancer patients (Gotay, 1984; Dunkel-Schetter *et al.*, 1992; Thuné-Boyle *et al.*, 2013; Ursaru *et al.*, 2014).

Since most Chinese people have no religious beliefs, only Patient ZS and the mother of Family ST had contact with religious support. Patient ZS's mother was a Christian; she prayed every day and went to church every Sunday. His mother read the Bible to him and took him to the church. Although he still had a reservation about Christianity, he felt the power of religion. He said: "*Praying in the church is different from praying at home. The atmosphere is different. It (being in the church) stimulates you from top to toe. It can activate you and fully motivate your passion to an extreme point.*" When I asked him to evaluate the impact of Christianity on him, he added, "*It has quite a lot impact. I think I should put more time into it… I will go to church more times when it is warmer*." His mother also thought Patient ZS had changed a lot, like another person. He became calmer and happier than he used to be.

Family ST said her mother had been a Catholic for over 20 years and prayed twice a day. Family ST agreed that religious belief helped her mother keep a good spirit. Her mother's church friends often came to visit her, which also alleviated the pressure of the patient.

In summary, the interviews with the cancer patients provided me with an in-depth understanding of what they felt and experienced in a situation of having cancer and living with dying. I value and appreciate that these patients would like to share their experiences and true feelings with me as a researcher. As discussed in this section, many patients reported that having cancer was such a shock and brought psychological distress. They experienced existential challenges of losing their previous positive self-images physically, emotionally and

socially. They believed that “other people”, as outsiders, could not fully understand them. Given these challenges, they had to redefine themselves and redefine their goals in life. To cope with distress, they adopt different coping strategies. A patient might take multiple strategies, which also changed over time. The diversity and variations in feelings and experiences indicate the importance of understanding their real thoughts and needs for health professionals and the family who look after them.

6.4 Families’ Experiences of Caring for Cancer Patients

Research on the experience of cancer family caregivers had tremendous growth in the past three decades (Weitzner *et al.*, 2000; Fletcher *et al.*, 2012). Family members of cancer patients also have psychological stress. The conceptual model from Weitzner et al. (2000) and Fletcher et al. (2012) suggests stressors of family caregivers include primary stressors and secondary stressors. Primary stressors are patient-related, for example, the stage of illness, prognosis, duration of illness, symptoms, dependency, poor coping, behavioural problems, etc. Secondary stressors come from the spillover effects of the patient’s illness, including changes in lifestyle, roles and relationships, financial and employment stress, sleep disturbance and fatigue, and so on. In terms of the coping strategies of the family (or cognitive and behavioural responses), the dimensions could be identified as problem-focused and emotion-focused, or approach behaviour and avoidance behaviour, similar to the identifications for the cancer patients. Examples of coping patterns include acceptance, humour, distraction, denial, rationalisation, social comparison, religious support, palliative coping, planning, seeking support, comforting thoughts, mobilization of family, avoidance, alcohol/drug use and disengagement (Fletcher *et al.*, 2012). Family caregivers’ wellbeing, such as health, mental health and quality of life, are correlated with stress, stressors, and coping strategies.

In China, family members, such as spouse and child(ren), act as the main caregivers of patients with severe illness. In Asian societies, it is also common as family caregiving is a part of family obligations or filial obligations (Ng *et al.*, 2016). When patients are hospitalised, daily care is usually provided by patients' family members and relatives. When the patients are discharged home, they also rely on their family members to look after their daily life and liaise between patients and health professionals. Some professional duties, such as dressing wounds post-surgery, managing medication regimes and injection of painkillers, are also sometimes undertaken by the family caregivers. If the family can afford it, a privately hired carer might be used. The reliance on family carer brings a heavy burden to the patient's family. Caring responsibilities are usually shared between family members. However, this would be difficult for certain families, including small households, elderly families without a child or living far away from their children, and families with other responsibilities like work, childcare, and caring for more than one patient.

Regarding the experience of family caregivers of cancer patients in China, the research is still limited, except for a few (Wu *et al.*, 2013; Zhang *et al.*, 2014; Cui *et al.*, 2014). Therefore, this study provides more evidence about the family's experiences in caregiving and living with cancer patients. The following sub-sections focus on their stressors from the patient-related issues and care-related issues, respectively, followed by their responses to the distress and their needs identified during the interview.

6.4.1 Patient-related Stressors

The main stressors of family caregivers were patient-related, with evidence from seeing the sufferings of the patients, the distress and other symptoms of the patients, uncertainties about the development of the illness, and the impending death.

Patients' Sufferings

Family caregivers were usually the spouse or the adult child of cancer patients. Seeing the physical misery and deteriorating conditions of their loved ones was the main source of their stress. This was prominent while the patient was receiving chemotherapy/radiotherapy or at the terminal stages (III or IV) with metastasis and other complications. Family CXS expressed not feeling well when his father had pain, and Family YYS felt intolerable pressure when his father suffered from the side effects of chemotherapy. Family caregivers of patients at the terminal stages expressed how miserable they were to see the sufferings at the end of life. For example, Family ZM's father was hospitalised and in extremis at the time of the interview. He was grieved when he saw the sufferings:

He is in awful condition...His lungs have turned to erosion, some bones have been black… There is full of gas in his tummy. He has a fever and pain every day. (He sobbed) … The condition of the patient at the terminal stage changes every day and every moment. His mind is clear now, but he might suffocate at any time. The doctor told us to be prepared… I heard from others that, when a lung cancer patient is dying, the whole body will turn blue… Now I just want to stop his pain and suffering. I feel intolerant pain to see his sufferings (Family ZM).

Family XX and Family PQ also expressed their distress of looking after the patients at the terminal stage as they could not help to alleviate the pain. "*It is torture to both the patient and the family. On the one hand, I don't want to see him suffer any more. On the other hand, I don't want him to go quickly*", said Family XX. What they expected was that the patients would not suffer much and die peacefully.

Patients' Distress and Other Symptoms

Many family participants reported the patients were not aware of the true diagnosis so that they had good spirits and maintained hope. Thus, these family caregivers do not have much pressure from the distress of patients from knowing. However, Family ZM and Family PQ both mentioned it was not easy for them to conceal their sorrow in front of the patients.

Some patients, such as Family XG's father, had already known the diagnosis (Section 5.2.1) and could not control his temper (Section 6.3.1). Family XG expressed she and her mother felt wronged when his father insulted them using abusive words. She also added the following.

He usually says, "I am dying. You might not see me next time when you come". His mood swings… We have to cook five or six times for him every day. Sometimes he said he wanted dumplings. My mother made dumplings, but he did not eat any. Then he said he wanted noodles then we cook noodles. He torments us. … He tends to dislike this and that. Every time I visited him, he did not like me talking in front of him. Sometimes he complained I eat too quickly when we dined together … He watches TV every day. I don't know whether he really likes it or not. The TV is always on, and he watches it until 1 or 2 o'clock at night…Sometimes he suddenly cried, with tears and snots, which made us very depressed (Family XG).

Some patients also developed mental symptoms due to illness or treatment. For example, Family XUW's husband had lung cancer which had spread to many organs. He also developed a severe mental problem. Family XUW said, "*He is insane now. He always says something crazy. Sometimes he has a hallucination. A few days ago, he shouted 'there is a fire', which scared me… I don't dare to sleep with him in the same room. I was scared when I was awakened by his convulsions during the night… I can't leave him alone at home for a long time. I worry that he would make some accident, like setting fire or something similar.*"

Health professionals also reported similar cases that they observed. Some patients had mood swings and changes in behaviours. The family had to understand and bear the changes and adjusted how to interact with the patient, which was not easy.

Uncertainty

Many family participants expressed their worries about the uncertainties, especially when the patients were still in stages I and II. Uncertainties were related to the progress of the illness, the prognosis of different treatment options, and the pressure of decision making.

Some family caregivers expressed the first thing they worried about was the spread of cancer. Family YYS said: "*They (the doctors) said this cancer might spread quickly after two years. I've always wanted to check whether it has been spread. If it has spread, what shall we do? I fear the spread*."

Similarly, many family participants concerned about the recurrence of the illness. They wished that the disease would progress slowly or maintain the current condition for an extended period.

Some family reported difficulties when considering the prognosis of different types of treatment and associated the decision making, giving that family members were usually the surrogate decisionmaker on behalf of the patients in China. For example, Family XUW said she struggled to take chemo- or radiotherapy for his husband.

He (husband) received chemotherapy five times and tried different drugs, but none of them worked. His health condition was getting worse and worse… We tried radiotherapy, his reaction was even worse… It is difficult to describe my feeling. I feel guilty that he suffered from the side effects of all the treatments that didn't take effect. To some extent, I am not regretted as if he didn't receive the treatments, how do I know they don't work? I would feel

guilty just in case the chemotherapy works ... I can't predict the outcome… The confliction emotions have always been with me until now when I know the outcome… If I knew this outcome, I would not choose any treatment so he could suffer less (Family XUW).

When the family caregiver was the key decision-maker, he or she had a lot of burdens.

In my family, I am the only person who knows some medical knowledge. They all rely on me to make decisions most of the time. So, I have to think of lots of things… I feel a big burden on my shoulder (Family XG).

I am the only son. My sisters usually relied on me to make big decisions of treatment. When the doctors gave us options and asked us to make decisions, I was under great pressure. I couldn't sleep for several days. I worried that my decision would be wrong (Family CXS).

The Impending Death

The impending death of the loved one was another source of emotional distress of the family throughout the whole course of the illness. Family ZM described that he felt the "*sky had fallen*" when he knew his father's diagnosis. Family PQ said she was so shocked by her mother's diagnosis that she could not remember how she returned home. "*Her time in the world could not be counted by years anymore. Instead, her time would be measured in days. I was so stressed but could not express in front of her*", Family PQ added.

Family MLK was very miserable when talking about the impending death of his wife. "*She doesn't have many days left…She has been cooking for me all her life… If she dies, who is going to cook for me? Where can I find another person to have meals together?*". As an old farmer, Family MLK could not use much rhetoric language to describe his love for his wife and his feeling of losing her, but I could feel his sorrow from his simple expressions.

Family XX told me he tried to be strong, "*I can't be knocked down, I still need to consider my mother*". But he knew he was under strain.

The death would not come suddenly, which enabled us to prepare and accept it gradually. It might be more difficult for me to accept a sudden death like a car accident. I can't tell which death (due to cancer or accident) would be better, neither is good anyway… The whole process was torturous. Emotional misery is natural when you are going to lose a loved one. It was a difficult process to accept this emotionally. The pressure was naturally created (Family XX).

At the time of the interview, Family XX's father entered the last few days of life. He described himself as a rational man, but he found that although he had been prepared for this moment for two years, the experience of caring for his dying father in the final days was more miserable than he expected. He felt anxious, flustered and scared. He could not stop these feelings. "*Every day is so hard. I feel one day like a year*," he added.

6.4.2 Care-related Stressors

In this study, none of the family participants used the word "burden" to describe the patient or the caregiving. They thought it was their responsibility to look after the patient and a way to express their love or filial piety. However, many did report their difficulties or pressure in looking after the patients. The main difficulties mentioned by the family caregivers were lifestyle change, fatigue, and stress from employment and finance.

Lifestyle Change

Some family caregivers reported that their life was not much affected at the early stage of the illness. However, when cancer progressed to the advanced stage, the patient lost their mobility, so they had to adjust their lifestyle. For example, Family XJS explained that his father preferred

to live in his own house, so he and his two brothers looked after their father in turn. Every month, each family stayed with their father for ten days, which was a great toing and froing for each sibling's family. Some patient was still living with the spouse in their own house, and then their children had to visit them regularly. It was a difficulty for those who were living far away from each other. For example, Family XX was the only child in his family and working in another city in the province. He had to regularly travel between two cities, which was a trouble for his life and work.

When the patient was hospitalised, family caregivers usually accompanied the patient day and night, which was reported as a struggle for many family participants. It is particularly true when it occurred in a hospital in another city. Family PQ said:

It was very inconvenient for us when my mother was hospitalised in Jinan (the capital of the province). She needed carers 24 hours a day, but the care roles could not be shared between family members. It was not convenient for meals. We had to buy food outside every day, and my mother preferred home-cooked food (Family PQ).

Family YZS also shared his experience when his mother was receiving treatment in Beijing. He and his sisters used to share one hotel room for 40 days – her sisters cared for their mother during the day and slept in the room at night while he took the night shift and rested in the room during the day. He had diabetes, and such day and night reversed life affected his health.

Fatigue

While the care responsibility was shared between siblings and relatives for some patients, it relied on one person in other families. In this case, the only caregiver usually felt tired or physical fatigue.

Some participants reported they could not have a good rest at night. As previously discussed that Family XUW's husband has a severe mental problem and relied on her for care. She said: "*It is only me looking after him… He is not safe to stay himself…He convulses at night so I can't sleep well… He had a relapse these days, so I feel dizzy today… I don't have much strength…I worry I would fall ill… I am thinking to hire a carer to look after him during the night. But it would be difficult to find a good one given his condition*."

Family MLK also explained he never had a good rest since the diagnosis of his wife. "*I look after her day and night…Since she was diagnosed, I have never taken off my clothes to sleep during the night… I need to lift her up to take medicine and drink water and give her an injection… In the winter, it's very cold. If I take off clothes, I need to put them on again when I look after her during the night. So, I just lean on the bed with a blanket and all my clothes on.*"

Family ZM also reported he did not have enough sleeping hours. He only slept 2 or 3 hours a day. In addition, he described how he looked after his father, who was dying in the hospital at the time of the interview. "*He has a high temperature every day. I need a wet towel to wipe his hands and head to make him feel comfortable. The medicine reduces the temperature but also makes him sweat heavily. So, I also need to dry him regularly using another dry towel. Every hour, I change his position; otherwise, he would be too hot lying on one side. But his pelvis is very weak now if you are not careful enough, it will be broken…So it is impossible to sleep well at night*."

Similarly, Family YZS explained the difficulty he cared for his mother with rectal cancer combined with renal failure.

I have to take my mother to do the haemodialysis twice a week. I have to carry her on my back up and down the stairs from the third floor. It is very hard… My sisters are now very selfish. They don't want to look after my mother anymore...I can't remember the last time I had a good, long sleep night. I think my health is getting worse… I have type II diabetes. I haven't tested my blood sugar for a long time, as I know it should be very high. I know it, I can feel it as I keep losing weight… I will care for my mother until she passes away; it is my responsibility as a son... It is not fair to my wife because she has to care for my mother when I am working. She also needs to look after our young grandson at the same time (Family YZS).

Similar to Family YZS's wife, Family PQ also expressed that she needed to look after her mother and her grandchild, which made her exhausted. When I communicated with these family caregivers, I could see and feel their exhaustion and powerlessness. Family YZS's view of caring for his mother as a son's responsibility also reflected the common social value in Asia – filial obligation, which would burden family caregivers (Ng *et al.*, 2016).

Employment and Financial Difficulties

Another spillover effect of caregiving is the influence on employment. When caring responsibilities were shared between spouse and adult children, those who were retired or did not have a formal job took more daytime duties than the siblings who were formally employed. Family ZM said, "*We put everything else away and looking after the patient became the priority. Fortunately, I have many siblings to share*".

However, the employment of some caregivers was significantly affected. Family YZS and his two sisters took their mother to the best hospital in Beijing, several times for operation and treatment. Every time the three siblings asked for leave from work, with the longest leave of 40 days. After episodes of treatments in Beijing, the two sisters refused to send their mother to

Beijing again for further treatment because they had childcare responsibility and the pressure of losing jobs. Gradually, the two sisters left all the caring responsibilities to YZS.

I was the deputy head of the county Police Office. But now I can't continue that position as I have to take time off work from time to time... For my sisters, their work and children are more important than my mother (Family YZS).

For the caregivers who were self-employed or took temporary jobs, their work was also affected. Family CXS could not continue his temporary job due to the caregiving and hence lost income. Family MLK also reported that his son was doing a small business. To back up MLK's care responsibility, his son had to suspend some business and only worked for clients nearby, which resulted in a huge loss of income.

At the time of the interview in 2015, less than 50% of the Chinese population has been covered by the Basic Medical Care Insurance, and the rate of reimbursement varied by region, type of insurance, type of disease, the medicine used and the level of hospital institutions chosen for treatment. Therefore, a large proportion of the medical expenditure was paid by the cancer patients in this study. Costs of travel, accommodation and subsistence while receiving treatment in another location out of hometown were also added to the overall cost. This was a huge challenge for patients from disadvantaged families.

Some family participants were reluctant to mention their financial condition. Some just said they could afford it, or the cost was shared between siblings. Only Family YZS said he had used all his savings – recall that his father had heart disease and bypass operation and his mother had rectal cancer, and his sisters then refused to share care responsibilities and the cost. In addition, Family CXS said his father had medical insurance which covered slightly less than

50% of the cost. His family could not afford the painkillers as it costs RMB 100 yuan per box, which would last for only one or two weeks. So CXS applied for support from the local hospice.

The patients registered at the local hospice were usually at the critical stage of illness and had financial difficulties so that they only received free painkillers to cope with the symptoms at the end of life. When interviewing patients and family members in the hospice, their financial difficulties could be clearly observed. A team from the hospice, including a doctor and a nurse, regularly visited these patients every fortnight. I visited some patients with the medical team in December 2015 and January 2016. After a few years, I still remember how poor they were. A patient and his wife were living in this 3-room mudbrick house. There was no decent furniture in the house except an old-fashioned square table and a pair of chairs. The patient was lying on a *kang*, a kind of traditional heatable adobe sleeping platform that is still seen in some traditional northern villages in China. There was no other heating system except the *kang*. There was a coal stove but not burning to save the coal. So the house was extremely freezing, like an ice cellar. The patient was wearing old cotton-padded clothes, covered by a thick quilt. Underneath him, there was another thin quit on the hard surface of the *kang*, used as a mattress. The patient was diagnosed with lung cancer earlier that year. He and his wife were both farmers, without any other income except selling crops and a few transfers from their children. They were not covered by the basic medical insurance at that time. The financial constraint stopped them from seeking earlier or better treatment. When his wife asked the doctor how to make her husband better, the doctor suggested increasing nutrition like eating some eggs, chicken or fish. After a long silence, the old lady sighed, "*we don't have much money*", which made everybody sympathise with them.

For many low-income families, having cancer was "*one disaster after another (or described as snow plus frost in Chinese)*" as it resulted in even lower income but more expenditure.

6.4.3 Coping and Needs of the Family Caregivers

To cope with the distress, some caregivers said they had no other ways but to adjust their emotions. Family YYS said, "*Along with time, I gradually accept and try to think positively*." Family XX said, "*It depends on yourself. ... I convince myself to face the problem rather than avoid it*."

Family XUW expressed difficulty in seeking emotional support from others:

It is hard to reduce my distress. My parents and sister are all in the Northeast (far away). If I tell them my difficulties and feeling, they will worry me more, as they have already been very worried... So when I phone them, I am afraid to tell them all the details… For my friends, I don't want to upset them either (she choked). So I just comfort myself, I tell myself any more sadness doesn't help… But, sometimes I am just sad… (she sobbed and could not continue) (Family XUW).

When talking about what they needed to support them, many family caregivers asked me whether I knew better treatment options, similar to the questions asked by the patients. This is also consistent with the findings in Cui et al. (2014) that family caregivers usually seek for more medical information. One participant, Family XUW, mentioned it would be better that the health professionals would explain more about the prognosis of chemotherapy to reduce the uncertainty in her decision-making.

Some caregivers recruited in the hospice acknowledged the free painkiller had released their financial burden. They also valued the work of the hospice staff, who usually answered their questions, provided medical and caregiving information and some psychological advice to the

patients. However, the hospice director mentioned they were always short of staff and could not meet the needs of every patient and family member.

Many caregivers could not identify other kinds of support they need. None mentioned the need for support to increase their wellbeing as caregivers, such as social support in counselling or other cancer services. Some family participants asked how patients were cared for in the UK. I shared some information about caregiving at the hospital and at home, as well as cancer services and social support to the patients and family. They expressed that at the current medical system in China, some of these practices used in the UK were impossible. I also talked about using palliative care or nursing home care with a few family participants, but they were very against this idea. To many Chinese people, sending elder parents to a nursing home would violate social expectations of filial and family obligations, and the child(ren) would be despised in society. Furthermore, the idea of palliative care was still not widely accepted. These will be discussed again in Chapter 7.

In summary, although the data show subthemes of stressors for family caregivers who were looking after the cancer patients, there was no clear pattern of their coping strategies. It seemed that many of their needs were unrecognised or unacknowledged, except the demands for information.

6.5 Conclusions

Culture and traditions are important for the understanding of the meaning of cancer and the experiences of living with cancer. Cancer is not only a disease but also carries social meanings. The fearful and fatalistic attitude toward cancer and the negative attitude toward cancer death

were found in this study. This is similar to the findings worldwide from particular culture groups (Prior, 2009; Goss *et al.*, 2014).

The attitudes toward cancer and associated death are linked with the emotional distress of knowing the diagnosis. Anxiety, pressure, depression and sadness were prominent from the participants of this study. These findings support the literature in other countries (Peck, 1972; Aitken-Swan and Easson, 1959) and the findings in distress appraisals studies in China (Hong *et al.*, 2015; Zou *et al.*, 2014; Lee *et al.*, 2017; Li *et al.*, 2017). There have been many existential challenges faced by persons who are having cancer and living with dying (Weisman and Worden, 1976; Halldórsdóttir and Hamrin, 1996; Taylor, 2001). Given that time and space of living in the society had been restricted after having cancer, patient participants in the data saw themselves different from what they were in the past and thought themselves distinct from the others who did not have cancer. These perceptions led to patients' self-loss regarding the previous image and place in life and society (Charmaz, 1983). They also resulted in self-isolation and redefinition of patients. These findings provide more evidence to the literature on existential challenges of cancer patients, and particularly to the literature on self-loss of patients with terminal diseases, through studying their lived experiences in the context of China.

Some commonly observed categories of coping strategies of cancer patients were identified in this study, such as seeking more information, acceptance-resignation, avoidance, and focusing on the positive. Seeking more information and being positive were widely adopted by the patient participants in this study. Avoidance coping was linked with the fearful and fatalistic attitude toward cancer, and the tradition of lack of communication on such a topic in China. These findings also supplement a more in-depth understanding of the results in previous studies that measure coping strategies using questionnaire tools (Hong *et al.*, 2015; You *et al.*, 2018). It also supports the findings in Liu et al. (2005) that patients actively sought information from

health professionals and fellow patients but did not expect emotional support from health professionals.

Regarding the experiences of family caregivers in China, which were not much focused on in the literature, their distress and stress mainly came from a number of patient-related and care-related sources, which would affect the wellbeing of family caregivers. These findings are generally consistent with the literature worldwide (Fletcher *et al.*, 2008; Weitzner *et al.*, 2000; Fletcher *et al.*, 2012). However, family participants from this study were not able to identify the support they needed to reduce their stress, in addition to more medical information related to cancer. This reflects low awareness of the caregivers about their needs and welfare. The finding of looking for more information is consistent with Cui et al. (2014).

These findings are of value for family caregivers to understand cancer patients' feelings and hence provide better day-to-day care to the patient. Sometimes, the feeling of the patients might be different as the caregivers expected. The findings also enable health professionals to understand better what cancer patients and their families are likely to be suffering. Health professionals should be aware of patients' emotional needs to provide the support that is meaningful to the patients to cope with cancer on the illness trajectory.

Chapter 7 Attitudes towards Treatment at the End of Life

7.1 Introduction

This chapter focuses on attitudes towards anti-cancer treatment at the end of life of cancer patients. During the interview, most patients and family caregivers expressed the view that they would "*treat if it can be treated*", indicating that they would take anti-cancer treatments as long as they were an available and affordable option. Among the patients recruited from the hospice, some were still seeking anti-cancer therapy or using traditional Chinese medicine. It seems that cancer patients and their families would like to try all the treatment possibilities to prolong their lives. This phenomenon is in line with the confrontation coping strategy that was usually adopted among Chinese cancer patients. Therefore, I would like to explore the attitudes toward medical treatment, as perceived by all three groups of participants in my study.

There are many types of cancer treatment, such as surgery, chemotherapy, radiotherapy, immunotherapy, targeted drug therapy and others. Some cancer patients only have one treatment, while most patients have a combination of treatments. In the case of China, traditional Chinese medicines are also used as complementary and alternative treatment. In this chapter, I would not examine participants' attitudes toward different types of treatment as the use of therapies might vary by the type of cancer, age of the patient, the stage of the disease and the financial situation. Instead, I take all these treatments as a whole and analyse participants' attitudes toward receiving (or prescribing for health professionals) medical treatment at the end of life.

Data from my study indicate that some patients and their families showed a fighting spirit and an active stance in looking for different types of treatments. Section 7.2 explores patients and

families' fighting spirit and their behaviours in seeking a cure, controlling against the illness and symptoms and prolonging life as long as possible. Section 7.3 shows that being active in receiving treatment had important socio-psychological meanings to patients and family, involving maintaining hope, showing filial piety or responsibility and avoiding regret. Different from being active in treatment, palliative care was seen as giving up and a hopeless and helpless option. Section 7.4 analyses the concerns of active treatment, such as overtreatment, hopelessness and palliative care options. Section 7.5 concludes.

7.2 Fighting Attitude and Active Behaviour in Treatments

During the interviews, many patients and their families reported their fighting attitudes and activity in seeking different types of treatment after the diagnosis of the illness.

7.2.1 Displaying Fighting Spirit

Many patients and family caregivers shared their treatment experience with me. "*Actively participating in the treatment*" was usually mentioned in their statements. They showed an active attitude and experience in fighting for life.

Patient ZJ, a former bank manager in a local branch, explained her determining effort to seek different types of treatment and choose various medical institutions. At the beginning, she had continuous cough and heartburn. She went to several hospitals in Liaocheng and Jinan (capital of the province), including general hospitals and traditional Chinese hospitals, but the symptoms were not relieved. She then went to a hospital in Beijing, where she was diagnosed with lung cancer. Over the past three years, she and her husband travelled many times to Beijing to see the doctors and receive treatments there. After the initial ten episodes of chemotherapy, she then took targeted therapy for two years until the cancer cells became resistant to the drugs.

She received another seven episodes of chemotherapy, but, unfortunately, she got brain metastasis. The physicians in Beijing suggested her not having any more chemotherapy, so she turned to radiotherapy. By the time of the interview, she had received 13 episodes of radiotherapy. The distance between Liaocheng and Beijing was about 500 kilometres. It took them about 5 hours on the train for a single trip. They rented a house in Beijing as Patient ZJ needed chemotherapy treatment every several weeks in the past and then re-examination every month after receiving the radiotherapy treatment. In addition to these treatments, she had taken some traditional Chinese medicine for three years. Her treatment journey required a strong determination, persistence and commitment from both the patients and the family. When talking about her attitude to the treatment, Patient ZJ added:

I would like to live for 5 years with taking treatments rather than for 10 years without treatments. I would like to fight for life but not waiting to die, even though the treatments might shorten my life (Patient ZJ).

Similar fighting attitude and active treatment experiences were also found in the accounts of other patients. For example, in Chapter 6, Patient GJG described that he treated the battle against cancer as the anti-Japanese War. He was very actively involved in the treatment. He also visited different hospitals and talked to different health professionals to get the best treatment option. At the time of the interview, he was receiving chemotherapy. He expressed that he would like to receive radiotherapy at the same time. If he were the doctor, he would increase the dose of the drugs to control the cancer cells. He also said, "*I need to run quicker than the cancer cells… I have to be actively involved in the treatment.*"

Another example is Patient ZG, who was in his 70s and receiving chemotherapy treatment. Since the cancer cells had spread to the surrounding tissues, he was not suitable for operation.

However, Patient ZG was still keen to ask the possibility of surgical treatment to cut his "lump". When he was in the hospital, he overheard that another patient received minimally invasive treatment to cut a tumour. Then he would like to try whether the same method would work for him. He said, "*I want to cut it…I want to try. I can be a volunteer to try the treatment.*" During the interview, his son agreed to take him to see the consultant again for the possibility of taking surgical treatment, although he admitted that the chance would be very low given the stage of cancer and age.

Some family caregivers also expressed their fighting spirit and determination in taking the patients for treatments. For example, Family ST explained that her mother had received almost all the possible treatments. She would not care about the medical cost as long as there was a method to treat the disease. She said, "*my opinion is that …receiving treatment until where we can achieve, I don't listen to the others (different views toward treatment)*".

Such a fighting spirit and an active stance in treatment are associated with cancer patients' optimism attitude and coping strategies that involve maintaining hope. Displaying a fighting attitude would benefit cancer patients in several ways. Fighting spirit is recognised to be important in adjusting to cancer (Watson *et al.*, 1994). Nordin and Glimelius (1998) found that the fighting spirit is associated with better emotional well-being, while hopelessness and helplessness are associated with poor emotional well-being, particularly among patients with incurable diseases. Having a fighting spirit is also advantageous throughout the cancer trajectory, including post-diagnosis, promoting engagement with others, and enhancing social support (Nordin and Glimelius, 1998; Hodges and Winstanley, 2012). Data from the interview show clear evidence that these patients who displayed fighting attitudes also had more confrontation coping strategies, as discussed in Chapter 6. They were more likely to engage with others to seek information and focus on the positive in their daily life. However, whether

having a fighting attitude would affect their survival was not clear. The evidence from previous studies is mixed about whether fighting spirit and helplessness/hopelessness would affect survival (Nordin and Glimelius, 1998; Petticrew *et al.*, 2002; Hodges and Winstanley, 2012; Taut, 2014), although many of the patients and families I interviewed would expect a positive outcome through the treatment.

Patients with high fighting spirit usually treat cancer as a challenge and believe it is possible to have control over the illness. They also attempt to regain mastery over the event and over life (Yeung and Lu, 2014). The interview with the patients also showed that patients with the fighting spirit would like to control the illness.

More than once, Patient ZJ expressed she would like to control the development of cancer cells. Doctor GJ, who worked in the hospice centre, was ZJ's old friend for many years. From his point of view, Patient ZJ had a strong character and was always successful. She had outstanding performances in her study, career, and life since she was young. Her character and experiences made her unwilling to accept the fact of having cancer (which was viewed as a failure of her life), the failure of medical treatment or giving away control of her life. Therefore, she had such a "fighting spirit" during the cancer trajectory.

Patient GJG also expressed his intention to have control over the illness and win the battle against the cancer cells. He would like to receive treatment as long as there is an option, even though cancer cannot be cured. He said, *"If there is a treatment option available, why shouldn't I receive it to control cancer development?*"

Recall that, in Chapter 6, I reported the experience of Patient JLQ, who compared his experiences between being a cancer witness (friend) and a patient himself. He also expressed his understanding of receiving aggressive treatments: "*My friend had a lot of therapy and*

suffered from the side effects. At that time, I thought if I were him, I would not do that, it would be just sufferings… Now I understand my friend's condition... I can't give up treatment, although there are side-effects… I just want to take any chance to control the illness and prolong my life (Patient JLQ).

The accounts from the patients and family caregivers showed a fighting attitude and active treatment to control the disease. This finding provides evidence to support previous arguments that Chinese people are encouraged to fight against the disease and prefer medical therapy to palliative care and hospice care (Zou *et al.*, 2013; Wu *et al.*, 2016; Lu *et al.*, 2018). Other attitudes and behaviours toward anti-cancer treatment, such as resignation, was mentioned by participants through their observations of other patients but not found among the patients and family caregivers in my fieldwork. Only a few family caregivers mentioned they would give up life-sustaining treatment at the end of the patient's life when anti-cancer treatment methods were not possible.

7.2.2 Active Stance in Treatments

Similar to the story of Patient ZJ, the experiences of active stance in treatments of patients and families were displayed in three patterns. The first was to receive a combination of different types of treatment. The second was that some patients received treatments at different levels of care settings, especially in a better hospital if they could afford the cost. The third was that many received traditional Chinese medical treatment at the same time when they were taking conventional medical treatment. Since taking a combination of treatments is common for cancer patients worldwide, I would like to focus on analysing the second and third patterns.

Preference of Better Hospitals

During the interview, I found that, after the initial diagnosis, many patients and family caregivers would like to choose top tier hospitals to recheck the diagnosis and receive treatments in big hospitals, as long as they could afford. People trust that there was hope to have better outcomes if they were treated at a higher-level medical institution. As mentioned in our first example, Patient ZJ's lung cancer could not be diagnosed at the local and provincial level hospitals until it was confirmed in Beijing. She complained that the misdiagnosis in local hospitals delayed the treatment of her cancer. She expressed:

I trust big hospitals in Beijing. They have advanced medical technology and experienced doctors. People (with severe illness) from all over the country go there… They have new medicines and equipment and better knowledge... The lower level hospitals can't compete…I think that there is always a better treatment plan in a big hospital than that in a small hospital (Patient ZJ).

Similarly, some other patients also tried their best to find the best hospital or the best treatment plan they could access or afford. For example, Patient JLQ searched online to find the best hospital in Shanghai for treating cholangiocarcinoma and received surgical treatment there. Patient GJG was receiving chemotherapy in the local hospital at the time of the interview. He explained that he had got the same treatment plan from different hospitals in Bejing and Jinan. He also compared his drugs and treatment plan with other patients who had the same cancer. Then he felt relieved of receiving the therapy in Liaocheng Hospital.

Some family caregivers also introduced their experiences. Family PQ went to Shandong Provincial Oncological Hospital to confirm his mother's diagnosis from Liaocheng Hospital. Doctors in Liaocheng Hospital said his mother was not suitable for surgery, but those in the

provincial hospital managed to operate a successful surgical treatment. Family PQ said, *"So, you see, the quality of hospitals and doctors is different at different levels… Although my mother's cancer recurred in the end, we believe the surgery has prolonged her life.*"

Some cancer patients preferred first-class medical technology in top-tertiary hospitals in Beijing and Shanghai. Medical resources and quality of the services are unequally distributed in China, and patients are free to choose their health-providers in most public hospitals regardless of location (Goss *et al.*, 2014). Good hospitals and physicians are concentrated in top tier hospitals and big cities. Therefore, Chinese patients with severe illness prefer hospitals with superior care and treatment options (Yu *et al.*, 2017), as long as they could afford it. Hope for cure or achieving better outcomes motivates people to seek better hospitals in big cities. They believe that receiving anti-cancer treatment in a better medical institution would be associated with a higher chance of good outcomes than receiving the treatment in a lower level hospital.

Using Traditional Chinese Medicine

Traditional Chinese medicine (TCM) has been widely used as a complementary and alternative medicine (CAM) in Chinese societies (Xu *et al.*, 2006; Pu *et al.*, 2008; Lam *et al.*, 2009; McQuade *et al.*, 2012). CAM is defined as a group of diverse medical and healthcare systems, practices, and products not included in conventional medicine (i.e. surgery, chemotherapy, radiotherapy, and targeted therapy). Globally, 7 to 64% of cancer patients received CAM with an average of 40% in western countries (McQuade *et al.*, 2012). In China and Chinese societies, CAM has been largely dominated by TCM.

Traditional Chinese medicine has a 5000-year history and is deeply embedded in Chinese history, culture, and politics and is promoted by the Chinese government. Nowadays, China

has more than 3200 TCM hospitals and about 267 225 TCM doctors, representing about 15% of all healthcare institutions and resources (Goss *et al.*, 2014). In TCM, diseases are believed to be caused by the disturbance in *yin-yang*, which are two opposite, but complementary, interdependent and exchangeable aspects of nature (Goss *et al.*, 2014). So, treatment in TCM aims to restore the balance of *yin-yang* and hence heal the disease. TCM consists of six common therapeutic methods: acupuncture, herbal medicine, massage, exercise (Tai Chi and Qi Gong), food therapy, and others (like cupping and moxibustion) (Goss *et al.*, 2014; McQuade *et al.*, 2012).

During interviews, I found that TCM methods were commonly used by cancer patients. Almost all the patients had the experience of using TCM, especially taking herbal medicines. Some used herbal medicines at the same time of receiving chemotherapy and radiotherapy and believed that TCM would improve their immune function and reduce the side effects of the therapies.

I feel better after having the herbal medicine. I insisted on taking the herbs that have "qu xie fu zheng" effects (detoxification and improving immunisation), to reduce the side-effects of chemotherapy (Patient ZJ).

TCM and herbal medicine are definitely useful for cancer. I think it is correct to use it as a complementary treatment. It is a combination of western and Chinese medicines… My immune system becomes weak after chemotherapy… I think TCM helped to improve my immune function… TCM can adjust and rebalance (yin-yang) (Patient ZS).

Some patients used TCM, particularly herbal medicine, to treat some symptoms associated with cancer. For example, Patient YZ used the herbs for his sleep problem, and some family

caregivers reported that they used the herbs to relieve other symptoms, like diarrhoea (Family PQ's mother) and constipation caused by the side effects of using opioid (Patient PC).

Some other patients believed that herbal medicine would suppress tumour growth. For example, Patient QM told me he bought some *"dong chong xia cao"* (cordyceps sinensis)[10] because some doctors said it has an anti-cancer effect and would *"suppress tumour development".* This medicine is very expensive so he only used it together with other medications.

In addition to herbal medicine, exercise methods of TCM, like *Qi Gong* and *Tai Chi*, were also used by some cancer patients. *Tai Chi* is an internal Chinese martial art, and *Qi Gong* is a traditional Chinese practice to cultivate and balance the "*Qi*" (or life energy). Patient ZJ played Tai Chi as a daily exercise before she lost some mobility. Patient JLQ went to learn Qi Gong to maintain himself to calm himself and to prolong the life. He formally acknowledged a famous Qi Gong master in another city as his teacher and had spent a lot of money on it.

I think Qi Gong is helpful… When I have pain, … Qi Gong helped me calm down and have more energy (Patient JLQ).

Regarding the effect of TCM, some participants fully trusted the effect of TCM. Patient TB chose the local TCM hospital for chemotherapy and TCM treatment. By the time of the interview, he had taken a type of herb, "ding du dou" (rhizome typhonii, the root of typhonium giganteum) for two years. He said, "*my uncle's neighbour gets the same type of cancer as me. He also takes this herb and has lived for 4 years... I take it between episodes of chemotherapy treatments…I spent 4000 yuan for two bottles of anti-cancer drugs but only took one bottle.*

[10] Cordyceps sinensis is a fungus that lives on certain caterpillars in Himalayan regions. It is used in TCM and in traditional Tibetan medicine. It is one of the most expensive Chinese herbs like Ginseng and Velvet antler.

The anti-cancer drugs didn't work for me. I felt sick after having that drug… So my anti-cancer drug is this herb. This is also a kind of treatment, I combat poison with poison (or like cures like)". The experience from peer patients seemed to be an important factor convincing the patient to seek TCM treatments. If one method worked for someone else, some patients would expect that it might work for them as well.

Unlike Patient TB, Patients YZ and GJG thought TCM and modern medicine (or western medicine called in China) followed two principles and contributed to cancer treatment in different ways. Patient YZ described that "*western medicine is like a pioneer soldier in the front and plays the leading role, and TCM is at the back playing the supporting role*." He thought TCM could not treat serious illness but would rebalance the body and improve some functions. However, he also worried that taking too many herbal medicines would have adverse effects, such as damaging liver function. Therefore, in his opinion, TCM would only "play the leading role" in the advanced stage when other western medicine treatments would be almost exhausted.

Using TCM was usually determined by individual beliefs rather than doctor recommendation. Many patients interviewed did not discuss their TCM treatment with their doctors, although some doctors were aware of it. Doctors participants held a different opinion about the use of TCM. Some thought TCM could be integrated into conventional treatment in western medicine, while others concerned about the lack of scientific evidence of the effect of TCM in cancer treatment and the safety of using TCM as some herbs might be poisonous. These different views have been debated in practice and literature (Pu *et al.*, 2008; Xu *et al.*, 2006; Lam *et al.*, 2009; McQuade *et al.*, 2012). Doctors participants expressed that, in practice, they did not support the use of TCM by cancer patients, but they could not stop the patients from using TCM.

Going to better hospitals and integrating TCM in anti-cancer treatment were driven by China's healthcare system situation, cultural grounding and self-beliefs. The patients expected and believed that they would benefit from the treatment in good hospitals or TCM methods would make them feel better. Hall (1990) illustrated that patients' hope involves finding a treatment in different care settings or systems that patients believe would contribute to their survival.

7.3 Reasons for the Active Stance in Treatments

The data collected from the interview show two main reasons behind the active stance in treatment. Being active in seeking and receiving treatment would maintain hope for both patients and family caregivers. This behaviour was also driven by the filial obligations of adult children or family responsibilities for the cancer patients within the cultural context of China.

7.3.1 Maintaining Hope from Active Treatments

Hope plays a critical role in human life and takes on special meaning as death nears. Hoping for a cure can coexist with the awareness of diagnosis and death (Yates *et al.*, 1993; Cotter and Foxwell, 2015). During the interview, Patient ZJ mentioned that at the beginning, she was expecting of being cured through surgical and chemotherapy treatment. After the treatment in the early stage of cancer, she felt her condition was as normal as before she got the disease. When the targeted therapy drugs failed and cancer metastasis occurred, she hoped to control the development of the disease and maintain her condition as long as possible. Her friend, Doctor GJ in the hospice, tried many times to convince her to stop the intensive, aggressive treatments but she rejected taking this suggestion. She expressed that she understood Doctor GJ's kindness and knew his advice was from his professional view. However, Patient ZJ could

not accept the advice in her heart. She said, "*Stopping treatment means giving up…and wait for death, it is hopeless … I can't accept it*".

Similarly, Patient QM's initial chemotherapy treatment was successful. Cancer cells were well controlled, symptoms disappeared, and he did not have any side effects. He and his family saw hope from the treatment. He continued re-examination and anti-cancer treatment. When I met him, he was just discharged from the hospital but unfortunately died a few weeks later. During the interview, he and his wife still expected his condition to be improved through some treatment. Many of the other patients actively involved in the treatments showed hopefulness and desire for positive outcomes of these treatments.

Some family caregivers also expressed that only the treatment would bring hope for being cured or hope for controlling the disease. For example, Family PCW said they would keep treatment as long as Patient PC would be alive and hoped his condition could be sustained. Family YYS said it would be "*absolutely no*" without taking surgical treatment for his mother and "*no surgery no hope*". The same account was from Family ST, who showed a desire for having treatments for her mother as every treatment option meant hope and a probability of success in prolonging her life.

As long as there is a glimpse of hope, we will go for it… We don't give up…If the treatment method has a probability of 40% or 50% (to take effect), I will try…When there is no treatment option available, it will be completely hopeless (Family ST).

Previous evidence shows that many cancer patients remain high levels of hope, even when they face a situation seemingly hopeless (Yates *et al.*, 1993; Cotter and Foxwell, 2015). Positive thinking and hope are also important strategies used by cancer patients when they cope with cancer diagnosis (Petticrew *et al.*, 2002; Feifel *et al.*, 1987; Kirk *et al.*, 2004). The above

findings, combined with the positive thinking mentioned in the previous chapter, also suggest that cancer patients and their families in my study remained largely hopeful, even though they also admitted cancer would be fatal in the end.

Hope is an important concept in different disciplines. In the classic theory of nursing research, Dufault and Martocchio (1985) defined hope as 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. Hope has two interrelated spheres - particularised hope and generalised hope. The accounts from patients and families in my research show that most of their hopes were particularised and centred on specific goals – the disease to be cured or controlled. Some patients had a more specific object. For example, Patient PC hoped to live long enough, at least to see his daughter, who was 14 years old, to be 18 or ideally 20 years old.

The full experience of hope involves uncertainty, fear, anger, suffering and despair, which are typical feelings for people with cancer. Some philosophers, like Gabriel Marcel, argued that the fullest sense of hope could only follow the experience of suffering (Cotter and Foxwell, 2015). People with cancer see their disease as "a wake-up call" that opened their eyes to a greater appreciation for life and an opportunity to confront their mortality and hence also inspired hope. This could be used to explain the fighting attitude and active treatment behaviour of cancer patients and their families after the cancer diagnosis, despite the realisation that no cure would be possible.

Dufault and Martocchio (1985) also identified six dimensions of hope: affective dimension that comprises the emotions of expectancy and confidence; spiritual dimension that is associated with spiritual well-being; relational dimension that is interdependence between hope and the

relationship with significant others; cognitive dimension that comprises positive perceptions and beliefs that the desired goal is realistically possible; behavioural dimension that results in activities to affect the desired outcome; and contextual dimension that refers to life circumstances and abilities that influence hope. Data from my research show that the active stance in receiving treatments reflected not only the behavioural dimension of hope but also other dimensions which fostered the activities in treatment, particularly from the affective, spiritual and cognitive dimensions.

The data show that many patients believed that receiving treatment in better medical institutions with excellent doctors and equipment would bring more chance of cancer being cured or controlled. Their past self-experiences of successful anti-cancer therapy (like Patients ZJ and QM), as well as the experiences of other cancer patients (like Patient TB in terms of using TCM) also boosted their positive feelings of expectancy and confidence in receiving different anti-cancer treatments. These are the affective dimension of hope for the outcome of anti-cancer treatment.

Receiving treatment, as a hope-fostering activity, met the spiritual need of the patients. Receiving treatment meant the patients would not identify themselves as dying. Putting in other words, not receiving treatment meant giving up, dying or waiting to die. For patients like ZJ and family caregivers like ST, any treatment was better than doing nothing even though the treatment had a high chance to fail. Even though there would be negative side effects of aggressive treatments that might even shorten life or reduce the quality of life, they still preferred receiving treatment to just "*waiting to die*". They could not accept the idea of "*stopping treatment*" in their hearts. Even at the terminal stage, Patient ZG was still keen on receiving minimally invasive surgery. In the absence of Patient ZG, his son told me they would take patient ZG to the hospital before the Chinese New Year, taking some "*symbolic treatments,*

like anti-inflammatory and painkilling medicine", to improve the patient's mood. Similarly, Family XJS also planned to admit his father to the hospital to treat his stomach bleeding and anaemic, which would comfort his father as "*staying in the hospital for a short period is spiritually good for him*". Therefore, receiving treatment, even symbolic treatment or treatment for the symptoms, would maintain patients' hopefulness and good for their spiritual well-being.

The cognitive dimension of hope related to treatment involves the positive perceptions and beliefs of the treatment, and the assessment and appraisal of the desired outcomes within a context of what is realistically possible (Cotter and Foxwell, 2015). The findings discussed in 7.2.2 have shown that the patients and families had positive perceptions on the outcomes of conventional anti-cancer treatment and complementary treatment like TCM methods.

Hope might not be appropriate if it is not realistic (Yates *et al.*, 1993). Cancer patients may have a will to live or high levels of hope so they might somehow not accept the reality that the treatment might fail and lead to negative health outcomes. For example, Doctor GJ believed that aggressive anti-cancer treatment would bring more negative effects on Patient ZJ's health, given her stage of illness, whereas this "reality" was denied by Patient ZJ who still had hope of radiotherapy. Similarly, although some oncologists in western medicine did not support the use of TCM considering its limited effects and safety issue, patients who were using TCM treatments had their positive perceptions and views on TCM methods.

Yates et al. (1993) also mentioned that individuals construct their own reality on the basis of their own beliefs and life experiences. In the context of dying, it is important to distinguish "reality" and "realistic hope" from "unrealistic hope", and whose reality we are referring to – the reality of the health professionals or the reality of the patients. Health professionals construct their reality based on their knowledge, experience and professional assessment, while

patients and family construct their reality based on their perceptions, experiences, hopefulness and so on. It is not surprising that what a patient viewed as realistic, the health professionals or others might view as unrealistic.

Doctor SG explained how they introduced different treatment options and the associated possible outcomes and side effects to the patients and family. The information provided by the doctors was mainly based on statistics; however, the consequences of treatment may vary across individuals. The reality, to the health professionals, was that chemotherapy or other treatments might fail for some patients. However, patients and family usually had higher levels of hope for the outcome of treatment. Doctor SG added: "*If we tell the family the chemotherapy takes effect for 50% of the patients, they would desire the patient would be part of the 50% with the positive effect but ignore the other 50% that the therapy would fail…Some also believed that chemotherapy could cure cancer but actually, it can't*". The uncertainty of cancer and treatment outcomes, plus fear of cancer and death, contributed to higher levels of the hopefulness of the treatment to cancer patients, which might not be that realistic to the others.

Finally, patients' hopefulness of treatment might be influenced by some cultural characteristics, such as truth-telling and the beliefs of control (Cotter and Foxwell, 2015). In China, it is believed that patients should be protected from the diagnosis information that could threaten hope. When the patients did not know the diagnosis, they might hold positive attitudes and were actively involved in the treatments. For example, Family YYS told his mother the tumour was benign so she had been very cooperative in the treatment and maintained a high level of hope to be cured.

Personal control is a core attribute to the hope process. Cotter and Foxwell (2015) argued that people with a fighting spirit and active stance would be more hopeful in espousing a desire to

control their illness or the dying process than those who take a more passive role. In my data, the patients discussed in section 7.2.1 all showed a strong willingness to control over their illness and the dying process. The desire to live was strong from the patients I interviewed. None of the patients expressed that they would like to let go of the treatment. This finding is different from Mok et al. (2003), who looked at the meaning of hope from the perspectives of cancer patients in Hong Kong. They found the participants remained hopeful if they actively chose to let go of control instead of passively losing control. They used China's traditional Taoist philosophy to explain this phenomenon that people should confront the nature of all things they dealt with and took non-action when facing nature, i.e. seeing the dying process as a natural process. However, the contemporary culture in mainland China seems to be different from Hong Kong, probably because of the criticisms on Taoism (and Confucianism) in the early 20th century and in the 1960s-1970s, as well as the popular view of the battle against the disease.

In summary, cancer patients and families maintain hope from the active stance in receiving treatment. The hopefulness was fostered by different dimensions of hope and would benefit the patient's spiritual well-being, although it might not be realistic from the perspectives of the health professionals.

7.3.2 Filial and Family Obligations

Filial obligation or family obligation is a key value endorsed in Asian cultures (Ng *et al.*, 2016; Mok *et al.*, 2003). Since some patients did not know their diagnosis and relied on the family to make medical decisions, from the family caregivers' perspectives, taking the patients for treatments was a part of filial piety and their responsibility to avoid regret in the future. For

example, Family ST recalled the difficulties that her mother faced while raising her and her sister alone. She believed that her mother deserved their endeavour to seek various treatments.

We would like to try any available treatments for my mum. We don't want to miss any opportunity to prolong my mother's life... We only have one mother. She endured hardship when raising us. No matter what, she deserves our fighting for it... As her daughter, I try my best and do whatever I can do. Then I would not regret in the future…Otherwise, in the future, when I think back and find I have not made all my effort, I would regret…I have to fulfil my filial duty…I don't know how others view this, but this is my opinion (Family ST).

Several other adult-children caregivers also mentioned filial piety when talking about caring for their sick parents. In addition to providing good daily care to the patients, being active in receiving treatment was a way to express their filial duty. Family YZS took his mother to the best hospitals in Beijing for a series of treatment. He regarded it as his responsibility as the only son in his family. Some patients, such as QM, PC and ZG also praised their children, saying that they were "*filial*", or "*more dutiful than others in the village*" who did not take their parents to accept proper treatment.

Considering family caregivers usually played the surrogate decision-maker, in some cases, the treatment decision might meet the needs of family obligations but differed from the patient's willingness. For example, Family YYS explained that his mother could not bear the side-effects of chemotherapy and would like to stop the therapy. However, the family members would like to continue the treatment so that they took turns to convince his mother.

In addition, some family caregivers also expressed that trying different treatment would avoid regret in the future.

I know it is not curable. But if I don't take him for chemotherapy, I am afraid I would regret not doing it (Family XUW).

We know the possibility of a cure is low, but we still want to have a try. It is a gamble, but if we don't try, I will regret of not making any effort… Now we have already done our best to look for the best treatment, we don't feel regret (Nurse LX also a family caregiver).

When the illness happened to the father of Nurse LY, who worked in the hospice centre, she eventually chose to have surgical treatment rather than palliative care, after discussing with her colleagues.

We were conflicted. He is very old. We could control his symptoms with palliative medicine and there is a risk of taking a surgery…However, if I don't try, I might regret in the future. It had seemed that I had done nothing for my father actively but waiting to die (Nurse LY).

Nurse LY had an awareness of palliative care and promoted palliative treatment in her daily work in the hospice centre. However, when her role changed from a health professional to a cancer patient's family, her attitudes, perception, assessment of the goals and behaviours were all similar to other family caregivers – i.e. taking therapeutic treatments.

The above evidence shows that active anti-cancer treatments were driven by family obligations or filial duty. These obligations were largely self-motivated by family caregivers within China's cultural setting. Besides, taking the patients to treatment could be motivated by societal expectations of filial obligations. Doctor ZX shared his observations of over 20 years of working experience in the hospital. Some families admitted the patients to the hospital to receive treatment because it was a behaviour expected by the society where the children and

family settled. With the treatment, cancer death would be a failure in medicine, rather than a result of making no effect.

Sometimes, it is done for the other people, representing that the children are filial … The family will be disgraced or lose face if the patient stays at home waiting to die (Doctor ZX).

In summary, it was salient in my data that filial duty and family obligations have encouraged offsprings to be active in seeking treatments for the old cancer patient. Such filial duty could be self-motivated by the adult children or motived by societal expectations. The Confucian value of filial piety made it difficult for adult children to forgo anti-cancer treatment or be passive in this process. They might be blamed by the third parties for violating the principle of filial piety and not asking for active cancer therapy for their dying parent (Li, 2013; Li *et al.*, 2011). It might be a virtue to let patients receive treatment until death (Cui *et al.*, 2014).

7.4 Influences of Active Treatment

The active stance in anti-cancer treatments may have some influences, such as negative emotions due to unrealistic hopefulness, overtreatment and low acceptance level of palliative care options.

7.4.1 Unrealistic Hopefulness

As discussed in section 7.3, many patients and family members showed a higher level of hope of taking anti-cancer treatment. Some desired outcome of treatment (e.g. the effectiveness of the drug) might be unrealistic because the patient's (or family caregiver's) reality was constructed on their own perceptions and experiences. They took actions in seeking treatment to meet the goal – controlling the disease and prolonging life. Active involvement in the

treatment increases the sense of personal control over the illness and would, in turn, increase hope (Cotter and Foxwell, 2015). However, if the desired goals from the treatment were not realistic, or they failed in attaining the desired goals, hopelessness and negative emotions would be raised, such as anxiety, depression and anger.

One example related to this was Family XUW, whose husband suffered the failure of chemotherapy and severe side effects. She complained that the doctor should stop her husband from accepting chemotherapy. She argued that the doctors were more experienced than her so they should know whether the chemotherapy would take effect or not.

I feel it was the doctors' fault. They are professionals and they should know what would happen to my husband as they treated many patients. They should have told us that there was no need for chemotherapy because the toxicity could make the patient worse… Now, we have spent a lot of money but no effectiveness (Family XUW).

The case of Family XUW demonstrates a common phenomenon that patients, family caregivers and health professionals had different perceptions in the "reality". Unrealistic hopes are associated with uncertainty in treatment (Cotter and Foxwell, 2015). In many cases, the available medical statistics on survival rates would not be that useful in predicting the outcome of treatment for an individual patient. It is common that patients and families expected they could "beat the odds" when responding to prognosis information with statistics. However, no one could predict the treatment outcome with absolute certainty. Also, Doctor SG explained that some patients and family caregivers believed that chemotherapy could cure cancer, which is also observed in the literature that cancer patients may not understand that chemotherapy is not likely to be curative and the survival benefits might vary from weeks to months (Weeks et

al., 2012). Therefore, patients and families might be too optimistic before taking the treatment and the failure of attaining the goal would lead to feelings of despair, anger and so on.

7.4.2 Overtreatment

The preferences of and insistence in receiving treatment might lead to overtreatment for patients with advanced cancer. There have been concerns of overtreatment in terminally ill cancer patients worldwide, and in particular regarding the overuse of end of life chemotherapy and its associated adverse effects, including reduced survival and lower quality of life (e.g. Harrington and Smith, 2008; Prigerson et al., 2015; Esserman et al., 2013). During my fieldwork, some health professionals mentioned their concerns about overtreatment to cancer patients.

Doctor WB believed that overtreatment existed in Chinese hospitals. To him, one reason for the overuse of chemotherapy was the existence of a wrong and extreme belief – "*chemotherapy on and on until the death of the cancer patient*". "*Diagnosis, surgery, chemotherapy and radiotherapy*" had become a stereotype in cancer treatment in China. The high level of hope to live made some patients (like GJG, ZJ, etc.) think that their lives would be sustained as long as the doctor prescribed chemotherapy or radiotherapy. However, chemotherapy or radiotherapy is a two-edged sword and not suitable for all patients with advanced cancer. These treatment methods are widely used in the last several months of life for cancer patients in China, but such treatments might have no beneficial effect on survival (Deng *et al.*, 2014).

During the fieldwork, the doctors in the hospice introduced several cases that the terminally ill patients were overtreated. Doctor TY said many patients had the idea of "*prefer to die in fighting rather than waiting*", similar to the view of Patient ZJ as discussed in section 7.2. Doctor GJ also gave me an example of a patient who was diagnosed with terminal bowel cancer.

He actively got involved in different types of treatment methods, including a trial of a new anti-cancer drug. After all the methods failed, he still received radiotherapy, which did not reduce the size of the tumour but resulted in a serious intestinal effusion of blood. He died quickly due to the bleeding in a haematologist department and he had spent RMB 1.2 million (about £135,000) in all treatments. Before death, he and the family regretted not taking palliative care options or spending more quality time together.

In addition to the demand for anti-cancer treatment from the patients and families, Doctor WB mentioned another reason for the overuse of chemotherapy was the lack of good criteria to guide the health professionals in practice. The guidance they used was a "Suggestion" based on similar guidance used in other countries plus the consensus of some Chinese experts. In Doctor WB's view, the expert consensus was not always reliable and this "Suggestion" was not good enough to guide the practice with different cases. The understanding and application of the "Suggestion" may vary across health professionals. Therefore, it would bring uncertainties and hence a risk of misusing chemotherapy.

Therefore, patients and families' fear of death, desire to live, fighting spirit, and high levels of hope for the outcome of anti-cancer treatment, plus the difficulties on the doctor side, all contribute to potential overuse of anti-cancer treatment method at the end of terminally ill cancer patients' lives.

7.4.3 Palliative Care Options

The perceptions and preferences to anti-cancer treatment may delay the acceptance and hamper the use of palliative care options and hinder the acceptance of and preparation for death. Palliative care is different from curative treatment and focuses on symptoms management, dealing with distress and aiming to improve the quality of life of the patient and the family at

the end of the patient's life (WHO, 2019). In China, palliative care is usually the last option when all the other treatment options are not suitable (Zou *et al.,* 2013).

During the interview, Health professionals in the hospitals were aware of these terms but did not think such services were provided in their hospital. This could be explained by the fact that education of health professionals in China focuses on curative treatment (Zou *et al.,* 2013) and palliative care education is historically a missing piece in the textbooks (Wu *et al.,* 2016).

Most of the patients and family participants were not aware of the concepts of palliative care or end of life care, even though some received the services from the hospice centre. For example, when we talked about the service of the hospice centre, Patient QM asked me, "*Any services? Are there any other services? Isn't it just providing painkillers? Anything else*?" When I explained that they also deal with emotional distress and caring skills at home, he and his family were surprised. Some patients in the hospice also expressed that they were satisfied with the analgesia, which they could not access elsewhere and saved their money. They also valued other services like advice on daily care and home visits. However, they did not think of palliative care as another caregiving approach that can be provided separately or together with other treatment methods.

Among the patients, only Patient ZJ was familiar with palliative care as she was a friend of Doctor GJ, the director of the hospice, and she lived close to the hospice centre. From her account, it is salient that Patient ZJ was very against the idea of hospice care. To her, the patients who were receiving hospice care were "*doing nothing but receiving pain killers and waiting to die*", even though Doctor GJ had explained the meaning of palliative care to her many times. She also expressed:

I live nearby…I saw the patients in and out, taking the painkiller and sleeping pills… I felt scared when I saw their drugs. I could not imagine one day I came to this hospice centre…That would be near the end (Patient ZJ).

Patient ZJ's view reflected a common understanding that palliative care means a failure of medicine, waiting to die, and hopelessness to live longer. Many important issues at the end of life, such as preparation of death, quality of death and quality of life, seemed to be less important than the hopefulness to live. The disparities in attitudes toward treatment and palliatives are a barrier of promoting EOLC or palliative care in China (Zou *et al.*, 2013; Wu *et al.*, 2016; Li *et al.*, 2011).

7.5 Conclusions

The data from this chapter show that many older cancer patients in China held a fighting attitude towards cancer and preferred to receive active treatment, such as surgery, chemotherapy, radiotherapy, and TCM treatment, whenever there was a treatment option available. Most of the patients and family caregivers interviewed would like to grab even a slight chance of treatment, expecting to cure the disease or prolong life as much as possible. Palliative options were the last option when all the other treatment avenues are inappropriate. These findings are related to the analysis in Chapter 5 regarding the fear of death. Fear of death is associated with the desire to live. Being active in treatment would maintain hope and spiritual comfort for the patients and the family. However, not many patients or families understood that aggressive treatment at the advanced stage is not curative or beneficial to the patients' survival (Weeks *et al.*, 2012). The desired goals and hopefulness of some patients and families might be "realistic" based on their own perceptions, beliefs and experiences, but not necessarily realistic from the perspectives of health professionals and others. On the other hand, many

treatment decisions were made by the family caregivers so that the filial obligations and family obligations also contributed to the preferences of receiving treatment. Personally, children and family would feel regret if they did not send the patient to receive the treatment. Socially, keeping treatment until death, as a virtue of filial and family obligations, was also an expectation in Chinese society (Ng *et al.*, 2016; Wu *et al.*, 2016). Li et al. (2011) argue that if the family do not ask for active cancer treatment for the dying patient, it would be regarded as a lack of humanity or disobey Chinese filial piety so that the family will lose face in the society.

The active stance in anti-treatment was reflected by the preference to go to better hospitals and use traditional Chinese medicine methods. The preferences for better hospitals were caused by disparities in medical resources between different levels of hospitals, compounded with patients' beliefs, confidence and hopefulness of receiving treatment in better equipped medical institutions. Similarly, the historical and cultural background of TCM also shaped the beliefs, hopefulness and popularity of using TCM methods. As a result, patients might suffer more from side effects and negative emotions caused by the failure of unrealistic hope of treatment. Family caregivers might be overburdened, such as physical fatigue, distress, and financial burden, as analysed in Chapter 6. With the fighting attitude towards cancer and preference of treatments, there was low awareness and acceptance of other treatment options like palliative or hospice care. Palliative care options meant hopelessness to live longer or waiting to die.

The fighting spirit against cancer has been widely encouraged in China by the government and the media (Xinhua Net, 2018). Using the battle metaphors in cancer treatment was also popular in other countries, such as in the US when President Nixon declared a "War on Cancer" when signing the National Cancer Act in 1971 (National Cancer Institute, 2016). However, more public debates emerged in recent years that thinking of cancer treatment as a war or battle might have negative effects on the behaviours of cancer patients (Lindberg, 2019; Hauser and

Schwarz, 2019), and whether it is ethical to advise patients to fight cancer (Taut, 2014). Health professionals in western countries start to shift thinking away from the war on cancer and treat cancer as a journey, promoting the idea of living with cancer, not dying from cancer. In terms of China, oncologists are highly valued than EOLC in hospitals due to the cultural emphasis on seeking cures through treatment (Zou *et al.*, 2013). Doctors and nurses have limited knowledge, skills and experiences in providing quality non-medical care (e.g. emotional and social support) to patients and families. This highlights the needs of related training and education at both hospital and national levels.

Chapter 8 Conclusions

8.1 Introduction

This chapter concludes the whole thesis. I first highlight the contributions of this study in the three key themes of EOLC for older cancer patients, i.e. diagnosis disclosure, living with cancer, and attitudes toward anti-cancer treatment. Based on the findings, I discuss the practical and policy implications for health professionals, managers in the hospitals, and policymakers at local and national government levels. The limitations in my research and reflection of the research process will be discussed before future research.

8.2 Contributions of This Study

This is the first study using an interpretive phenomenological approach to gain a better understanding of the phenomenon of the lived experiences of EOLC for older cancer patients in China. The research produces unique and comprehensive data from unstructured in-depth interviews of three groups of participants, i.e. older cancer patients, family caregivers and health professionals. Participants shared their unique perceptions of "being there", that is, while they were having cancer (for patients) or caring for the cancer patients (family carers and health professionals). The interview accounts uncover what they experienced, felt, thought and did during diagnosis communication, living with cancer, and taking anti-cancer treatment. Therefore, findings from the data contribute to different knowledge streams about EOLC for cancer patients in China and developing countries.

Regarding diagnosis communication, previous research on China focuses on disclosure preferences from the perceptions of patients, family and health professionals (e.g. Wang *et al.*,

2004; Wuensch *et al.*, 2013; Jiang *et al.*, 2007; Yang *et al.*, 2018). Data from unstructured interviews in this study allowed me to explore the preferences further. I find that three patterns of diagnosis communication, doctor-patient, doctor-family-patient and doctor-family, existed simultaneously in China, and all appeared to be common practice. In doctor-family-patient diagnosis disclosure, it was common that family caregivers delayed the time of truth-telling and/or diluted the severity of the illness. Health professionals preferred a family-oriented disclosure in practice and then let the family decide whether to tell the patients. Such a practice was caused by different factors and resulted in various types of awareness of dying among patients, which were rarely discussed in previous research on cancer diagnosis disclosure in China. Another prominent finding from this study is 'a thin layer of window paper'. Some patients, who were not told the diagnosis, already knew the truth through other channels or self-recognition but still pretended that they did not know; whereas family caregivers might realise this but also pretended that they did not know. Such mutual pretence of not knowing between family and patients, which I called the "window paper" phenomenon, has not been discussed in the diagnosis disclosure literature in China or other countries. Health professionals reckoned this phenomenon existed for a large number of patients and families in China. The distress and needs of this group of patients are difficult to identify and require more attention in practice and research.

Different from previous studies that assess the levels and correlations of distress levels and coping patterns (e.g. Li *et al.*, 2017; Deng *et al.*, 2013; Hong *et al.*, 2015; You *et al.*, 2018), this study investigates more details about feelings, thoughts, choices and behaviours of patients and family caregivers while they were living with cancer. Cancer itself brought pain and distress to patients, while the fearful and fatalistic attitudes toward cancer enhanced psychological distress and spiritual struggles to the patients and the family. This study focuses

on a number of existential challenges of older cancer patients while they were being in the world and toward death. Their time and space of being in the world had been restricted and changed so that they viewed themselves differently from what they were before and distinguishable from significant "others". As a result, patients had lost their previous self-image and place of being in the world, self-isolating in society, and redefining their goals of being in the world. These findings, particularly the loss of self of patients, add more evidence to the literature about the feelings and existential challenges of terminally ill cancer patients, not only in China but also in general. This study provides an opportunity for care providers to understand the older cancer patients' feelings and challenges.

The findings from this study also contribute to the literature on family caregivers' experience while caring for cancer patients, which was usually overlooked in practice and research in China. While caring for older cancer patients, family caregivers had significant stress, and the stressors were mainly from the patient- and care-related sources, such as patient's sufferings, patient's distress, the uncertainty of the illness and the impending death, lifestyle change, fatigue, employment and financial difficulties. The findings enable awareness of caregivers' emotional and social needs so that appropriate and effective support can be provided by practitioners and through the policy-making process.

While it is widely believed that Chinese people would like to fight against disease (Wu *et al.*, 2016; Zou *et al.*, 2013), this study provides the first evidence to examine the thoughts, behaviours and reasons of the active attitude toward anti-cancer treatment for older cancer patients in China. The findings suggest that being active in treatment meant maintaining hope for patients and their families, which reflected their beliefs and confidence in medicine and benefited the patients' spiritual well-being. However, some patients showed a higher level of hope for the treatment outcomes, which might not be that realistic from health professionals'

perspectives (or reality). High levels of the hopefulness of treatment would be associated with hopelessness and negative emotions when the treatment failed or the desired outcomes were not achieved. The active stance resulted in the overuse of some anti-cancer treatment at the end of life, which was not beneficial to survival but only brought more sufferings through the side effects. It also hindered the acceptance and usage of palliative care options in China. On the other hand, China's cultural characteristics of filial duty and family responsibility also motivated the families to choose and continue anti-cancer treatment until the death of the patients. These findings revealed the importance of maintaining hope in a seemingly hopeless situation for older cancer patients and their families in China when communicating diagnosis and prognosis. They contribute to the literature related to the hope of cancer patients and decision-making on treatment in EOLC.

8.3 Implications for Practice and Policy

The study provides a unique and comprehensive understanding of EOLC for older cancer patients in the Chinese cultural context. The findings demonstrate that the communication of diagnosis, attitudes to cancer and treatments, and the experiences of having cancer are not only medical issues but also ethical, cultural, and legal issues. These issues may be addressed by the healthcare professionals, healthcare settings, and policymakers so that they may be able to see the complicated circumstances in China and produce suitable and sustainable versions of PC/EOLC in China.

8.3.1 Practical Implications

The data highlight the complexity of the situation with regard to EOLC in China. Although the family still played an important role in diagnosis disclosure and medical decision, some

patients and doctors, particularly the young doctors, valued the principle of patient's autonomy. As shown in the data, there was no unique truth-telling approach used for all patients. For older cancer patients, whether to disclose the diagnosis to the patients and how to disclose should be decided case by case, taking into account the patient characteristics (such as the severity of the illness, attitude and preference, competence in accepting and understanding bad news, etc.), and family characteristics (such as family structure, attitudes and concerns). However, Chinese cultural characteristics may change along with the continuousness of carrying on reform and opening-up in China. Looking forward, younger generations, no matter which role they will play in the doctor-family-patient relationship, tend to respect and accept the principle of patient autonomy and are more likely to accept open communication in the future. Therefore, there will be a mixture of practices, including both patient- and family-oriented autonomy in cancer information disclosure, and more patients will be involved in diagnosis communication over time.

Given the popularity of family-oriented disclosure in China, older cancer patients had different levels of awareness of dying. Although family caregivers believed non-disclosure helped maintain patients' quality of life, health professionals report that it stopped health professionals identify the real needs of those 'protected' patients. Therefore, it is recommended that health professionals equip themselves and families with communication skills in diagnosis disclosure to achieve effective communication among health professionals, families, and patients. For example, a gradual disclosure procedure (like Patient TB) could be promoted in Chinese culture.

Next, the findings highlight the importance of health professionals in understanding and assessing patients' psychological status (and family caregivers), aiming to provide "total care" at the end of life for older cancer patients. The psychological appraisal might help health professionals identify their psychological pains beyond physical sufferings and refer them to

the appropriate support from the hospital or the community. Some tailored interventions would help patients and family caregivers cope appropriately to reduce their stress and improve their well-being while having cancer and living with dying.

As the authority of medical information, health professionals could help reduce the biased view of having cancer. They should provide more information to diminish the feeling of uncertainty as much as possible, which would reduce the stress of patients and their family in the medical decision-making process. Health professionals may also provide more information regarding the limited efficacy of active anti-cancer therapy for the advanced-stage cancer patient. Although there are cultural obstacles, it is also encouraged to introduce palliative care principles to some patients and families as another option to improve patients' quality of life. Such promotion may gradually change the biased attitudes that receiving EOLC is simply "waiting for death".

At the hospital level, the managers in local hospitals might consider the incurable nature of advanced-stage cancer, overcrowding in the best hospitals and potential needs of EOLC in local hospitals. Some in-house or out-house sourced training could be provided to health professionals in terms of the principles of EOLC and skills in breaking bad news and providing total care to the patients and family.

8.3.2 Policy Implications

The above implications for health professionals cannot be achieved without policy support at both national and regional levels. China has been in the process of reforming the medical insurance system, aiming to cover all the population, involve more insured items, and unify the payment standards between rural and urban residents and using different levels of hospitals. The reform would reduce the financial burden of families with cancer patients (Leng *et al.*,

2019). However, there are still some other policy implications from the results of this study to provide a good EOLC and include it in the mainstream of healthcare system in China.

Firstly, relevant laws and regulations related to diagnosis communication should be improved to protect the rights of all parties, including health professionals. The current regulations lack criteria for exceptional cases of non-disclosure or the role of the family as a surrogate medical decision-maker. A safe and healthy medical environment is needed to restore the trust between the three parties through improved regulations. In this case, health professionals would have fewer worries about their safety and hence would be willing to improve the effectiveness of diagnosis communication between doctor, family and patients.

Secondly, education programmes at the national and community levels are indispensable. Public education is a long term project and might include cancer, cancer treatment and care, attitudes toward death, and other EOLC issues. Educational programmes may promote the idea of death as a natural process, the concept of living with cancer, the efficacy of anti-cancer treatment, and the benefits of palliative care. Educational programmes also include encompassing PC/EOLC in higher education in medicine and on-the-job training for doctors and nurses.

Next, the mental health of cancer patients and their families need to be stressed in cancer care in China. More resources should be allocated to mental healthcare, including educating more specialists in higher education, training the existing health professionals, and providing counselling services in the hospitals, hospices and communities.

Finally, it is necessary to build an EOLC model that is suitable for the Chinese context. This model should consider the restrictions in healthcare resources, the importance of family in caring for older people, and other future challenges. A good model should provide support to

patients and family carers while the dying patients are cared for at home. In the meantime, it is essential to develop the EOLC department in hospitals and hospices to tackle future challenges to family-based care caused by rapid ageing and reduced birth rate in the past four decades. The EOLC system in the UK could be an example to learn. Patients and Family caregivers in the UK could gain support from the local government, charity organisations, community services and multidisciplinary teams as a result of integrating PC/EOLC into the mainstream healthcare system. In addition, the government may help with the cost for those who are caring for cancer patients, such as Carer's Allowance. Establishing such a comprehensive system needs reforms in healthcare, medical education, legal support and fiscal/financial policy.

8.4 Limitations of the Research

Heidegger's interpretive phenomenology was chosen as an approach for data collection and analysis. It has the advantage of an in-depth focus on human experiences as they are lived. However, it does not mean other research approaches would not be adequate in revealing the meanings or "phenomena" related to EOLC research topics for cancer patients in breadth and depth.

The limitations of using the phenomenological approach are that findings are context- and time-specific. This means that the generalisability of the findings is limited to the cultural and social groups represented in the study sample at the time of the interview. One qualitative study alone might not provide a whole picture of the phenomena, just as no single quantitative study does (Halldórsdóttir and Hamrin, 1996). However, as qualitative descriptions accumulate, it will be possible to recognise the phenomena gradually.

The data were as thorough as the participants chose to make it. However, it is difficult to assume that every participant's experience in the three topics discussed in the thesis was captured in its entirety. Participants' emotional experiences were bound to the limitations of the spoken word (Taylor, 2001). Although non-verbal data were recorded through the field notes, some of the information from communications might be lost. Taylor (2001) argued that one solution is videoing the interview but it would be intrusive and limit the recruitment of participants. Another possible solution is to have a follow-up questionnaire after the interview.

8.5 Reflection of Research Process

The research and writing of the thesis have been a journey for me. Several reflexivities in the fieldwork have been discussed earlier in the methodology chapter. Although my interview skills had been cumulated in the fieldwork, I still found areas for improvement during the data analysis. It was common to find "*here I should ask more details of this particular point*" and "*there I should follow a question to explore more about this feeling and reasons behind it before the participant moved to another issue*." I believe these reflections would benefit my future research.

If I do this research again, I would like to change places of interview for doctors and nurses. Most of the health professionals were interviewed in a separate consultant room in the health institutions. However, some interviews were interrupted by the others in this busy working environment. I may also carry out some follow up interviews with the family caregivers, although it might be difficult to re-interview most patients whose health conditions changed quickly. As recommended by Taylor (2011), I will also consider having a follow-up questionnaire to capture more information not captured in the communication.

8.6 Future Research

The data from the field research were rich. In addition to the findings of the three topics reported in this thesis, the data also include participants' views on other EOLC issues, such as places of care and death and using the life-sustaining treatment, as well as health professionals' concerns about the future development of EOLC in China. These materials could be used solely for producing other research papers or as a pilot study for future research.

The feelings of patients who pretend not knowing the diagnosis are an area that I have a particular interest to explore more. I would like to know their concerns about concealing the fact of knowing the truth and needs that could not be met due to mutual pretence, the concerns of family members, as well as the benefits and challenges of piercing that thin window paper of mutual pretending.

The findings of my PhD research indicate the importance of training and education on death and EOLC issues to the practitioners, patients and the general public. In the future, it would be useful to undertake some research, including design certain interventions and effect evaluations.

All in all, this thesis examines the experiences of older cancer patients, family caregivers and health professionals in China on three major issues – diagnosis disclosure, living with cancer, and attitudes toward cancer treatment and care. The findings contribute to the relevant literature in this field and provide important implementations to practitioners and policymakers.

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Appendix 1 Summary of Studies Identified

Experience of Health Professionals

Study	Aim	Setting	Sample	Methods	Relevant Findings
Wang, X.S., Di, L.J., Reyes-Gibby, C.C.,Guo, H., Liu, S.J. and Cleeland, C.S. (2004). End-of-Life Care in Urban Areas of China: A Survey of 60 Oncology Clinicians. Journal of Pain and Symptoms Management. 27(2): 125-132	To examine the clinicians' perspectives on EOLC in China, regarding service availability, pain and symptom management, communication and factors influencing the delivery of EOLC.	Clinicians attending the National Palliative Care Training Seminar in 1999 in Beijing, China. Clinicians came from Beijing and some provinces in northern China	60 clinicians, 38% from local general hospitals, 33% from cancer hospitals, and 29% from medical colleges.	Questionnaire survey, statistical analysis	Less than half of participants reported the availability of hospital-based hospice service in their current institutions. Pain management was reported available in most of the hospitals. Most clinicians believed that patients should know and wanted to know their situation of illness, while families usually strongly resisted informing patients the truth. The most significant barrier to delivering EOLC was thought to be the unrealistic expectation from patients and family. It is necessary to provide training and research to improve EOLC in China.
Wuensch, A., Tang, L., Goelz, T., et al. (2013) Breaking bad news in China - The dilemma of patients' autonomy and traditional norms. A first communication skills training for Chinese oncologists and caretakers Psycho-Oncology, 22 (5): 1192–1195.	To evaluate the first communication skills training on breaking bad news at Beijing Cancer Hospital, China	Beijing Cancer Hospital, China	31 oncologists	Assess the practice, evaluate the workshop, self-assessed performance rating, and questionnaires	Participants stated that in most cases (78%), they inform family members first. They think that about 75% of patients would like to be informed first, independent of family. Participants rated a high score for the workshop. After the workshop, they rated their performance significantly higher in talking about diagnosis, prognosis and death with the patient and the family.

Hong, J.F., Song, Y.X., Liu, J.J., Wang, W.L. and Wang, W.R. (2014). Perception and Fulfillment of Cancer Patients' Nursing Professional Social Support Needs: From the Health Care Personnel Point of View. Support Care Cancer. 22:1049-1058.	To explore cancer patients' needs of nursing professional social support through the perspectives of physicians and nurses; to identify the needs actually fulfilled and those to be improved and the reasons for the gap	Two teaching hospitals in Anhui province, China	A purposive sample of 32 healthcare professionals (10 physicians and 22 nurses)	Descriptive qualitative approach using focus group interview	The healthcare professionals perceived five main categorized needs among cancer patients, including information support, emotional/psychological support, technical support, mobilization of social resources and palliative care. A big gap existed between the perceptions and actual provisions by the nursing staff, such as palliative care and mobilisation of social resources. The reasons of the existence of these unmet needs include patients' lack of awareness of how to find professional support, staff's lack of training and ability to provide specific palliative care, heavy workload and shortage of staff, and lack of appropriate assessment tool.
Zheng, R.S., Guo, Q.H., Dong, F.Q. and Owens, R.G. (2015). Chinese Oncology Nurses' Experience on Caring for Dying Patients Who Are on Their Final Days: A Qualitative Study. International Journal of Nursing Studies. 52:288-296.	To investigated oncology nurses' experiences of caring for dying cancer patients	A specialized cancer hospital in Tianjin, China.	28 nurses	Semi-structured interview	Five themes were identified: EOLC for dying cancer patients; EOLC for family members; cultural sensitivity and communication; moral distress and self-limitations; and self-reflection and benefit finding. EOLC in China has been influenced by traditional Chinese culture. There are difficulties in effective communication between nurses, patients and families. Nurses suffered emotional distress because of self-limitation, lack of knowledge and confidence and inexperience in psychological care. Caring for dying patients has a positive influence on their daily lives.
Dong F., Zheng R., Chen X., Wang Y., Zhou H., and Sun R. (2016). Caring for Dying Cancer Patients in the Chinese Cultural Context: A Qualitative Study from the Perspectives of Physicians and Nurses: European Journal of Oncology Nursing. 21: 189-196.	To explore the experiences of Chinese physicians and nurses who care for dying cancer patients	A cancer hospital in northern mainland China	15 physicians and 22 nurses	Semi-structured face-to-face interviews	Traditional culture on disclosure of death information decreases the physicians' and nurses' effective communication with dying patients in EOLC. Both physicians and nurses had strong ambitions to provide high-quality care and they emphasized the importance of maintaining patient's hope. Nurses were more concerned with the patient's physical comfort and wish fulfilment, while the physicians placed more emphasis on patient's rights and symptom management. Both participants suffered and also benefited from caring for dying patients. The findings suggest the need of improving communication method on EOLC and support to provide quality EOLC.

Experiences of Patients: End of Life Decisions and Diagnosis Disclosure

Study	Aim	Setting	Sample	Methods	Relevant Findings
Kwon, I., Koh, Y., Yun, Y.H., Suh, S.Y., Heo, D.S., Bae H., Hattori, K., and Zhai, X. (2012). A Survey of The Perspectives of Patients Who Are Serious Ill Regarding End-of-Life Decisions in Some Medical Institutions of Korea, China and Japan. J Med Ethics. 38:310-316.	To understand the patients' perspectives of EOL decisions in some hospitals in China, Japan and Korea.	Six hospitals in two regions in Korea; five hospitals in four regions in China; and nine hospitals in one region in Japan	235 patients with cancer (Korea, 91; China, 62; Japan, 52)	Survey using self-reporting paper questionnaire forms, statistical analysis	Most respondents had thought of their own death. They wanted to know their own condition directly and frankly from the physician in all three countries. The most common reason for fear of death was separation from the loved ones. Many would like to make a joint-decision with family or the physician. Most respondents admitted the necessity to have legally authorised 'advance directives' for medical decision making and favoured to withdraw the ventilator care in irreversible conditions. Significant differences were observed in the responses to some questions according to variables such as patients' country of origin, age, gender and education level.
Kwon, I., Hattori, K., Lee, K., and Kim C. J. (2015). End-of-Life Decisions: A Survey of the Perspectives of People in Korea, China and Japan. Acta Bioethica. 21(2): 173-182	To investigate the perspectives of people regarding the end of life decisions in Korea, China and Japan	Ordinary citizens in downtown areas of Seoul (Korea), Shanghai and Beijing (China) and Tokyo (Japan)	899 citizens (300 in Korea; 295 in China; and 304 in Japan)	Questionnaire survey, statistical analysis	More than half of the respondents would like to know their health condition and prognosis from the doctors in a direct and frank way. Decisions on favourable treatment options are determined by the healthcare system in three countries so only Japanese respondents tended to refrain from aggressive medical treatment in an incurable state and preferred to hospice care. People in the three countries showed a willingness to follow the way of nature/heaven's will in end-of-life decisions, which is different from the approach that regarding a patient's autonomy or quality of life. People's willingness to determine their own decisions about end of life treatment conflicts with the current practice in Asia. There are also similarities and differences in terms of euthanasia and withdrawal of life-sustaining treatments.

Ni, P., Zhou, J., Wang, Z.X., et al. (2014) Advance Directive and End-of-Life Care Preferences Among Nursing Home Residents in Wuhan, China: A Cross-Sectional Study. *Journal of the American Medical Directors Association*, 15 (10): 751–756.	To explore the knowledge of advance directive and end-of-life care preferences of residents in Chinese nursing homes, and to explore the predictors of their preference for the advance directive	8 of 13 regions of Wuhan, China. All nursing homes are invited and 31 nursing homes participated	467 residents in nursing homes, aged 60 or above	Population-based cross-sectional survey Questionnaires	Most (95.3%) participants had never heard of AD, and about 30% of them preferred to make an AD. 52.5% of participants would receive life-sustaining treatment and 78.8% would ask their eldest child as the surrogate of the decision-maker for life-sustaining treatment, while43.3% chose the doctors. More than half wanted to live and die in nursing homes. The AD preference is determined by whether they heard of AD, preferences of receiving life-sustaining treatment, and illness condition. Necessary policy support, legislation, or practice guidelines about AD are needed with flexibility to respect nursing home residents' rights.
Gu, X., Chen, M., Liu, M., et al. (2016) End-of-life decision-making of terminally ill cancer patients in a tertiary cancer center in Shanghai, China. *Supportive Care in Cancer*, 24 (5): 2209–2215.	To explore the factors affecting the decision-making in terminally ill cancer patients in China	Palliative Care Unit, Fudan University Shanghai Cancer Center, a tertiary cancer centre	Records of 445 patients who died between March 2007 and December 2013	A single center, retrospective study, descriptive statistics and logistic regression	97.2% of end-of-life (EOL) discussions occurred between family caregivers and physicians. The main decision-makers were spouse and offsprings. 47.3 % of the patients received at least one of six life-sustaining treatments. 40.4 % patients continued artificial nutrition and hydration until death. 49.1 % patients received vasopressors before death. Only two patients received mechanical ventilation and only one patient received a tracheostomy. Patients who were older than 65 years old were less likely to undergo an intensive procedure. Patients living in urban settings were more likely to undergo an intensive procedure in the EOL period.

Jiang, Y., Liu, C., Li, J.-Y., et al. (2007) Different attitudes of Chinese patients and their families toward truth telling of different stages of cancer. Psycho-Oncology, 16 (10): 928–936.	To investigate the attitude toward diagnosis disclosure of patients and families in China and the differences at different stages of cancer	Six oncology departments of two university hospitals and four general hospitals in China	382 patients and 482 families; 1023 participants.	Questionnaire survey, statistical analysis	Cancer patients were more preferred to be informed of the diagnosis, and the families and that doctor-in-charge was the appropriate person to disclose the diagnosis. Most participants thought the patient should be disclosed immediately after the diagnosis; and in a quiet and undisturbed room. When the hypothetic diagnosis changed from early-stage cancer to terminal illness, fewer participants wanted the patient to know the diagnosis.
Yang, F., Zhang, Q., Kong, W., et al. (2018) A qualitative study on the attitudes of patients with gastrointestinal cancer toward being informed of the truth. Patient Preference and Adherence, 12: 2283–2290.	To investigate the attitudes and preferences of hospitalized patients with gastrointestinal cancer toward being informed of the truth and diagnosis.	A general surgery ward in a tertiary-level general hospital in Zhejiang Province from June 2016 to October 2016	Nine patients with gastrointestinal cancer	Semi-structured, in-depth interviews, and the descriptive phenomenological method	Five themes were identified: guessing the diagnosis of gastrointestinal cancer before being informed of the truth; eagerness to know the diagnosis results; expectations related to beginning treatment for cancer; stress and anxiety during treatment; and providing. Patients have a strong desire to survive and can confidently confront their diagnosis. Medical staff should carefully select the appropriate time to inform patients of their diagnosis, thereby actively meeting patients' needs for information and treatment.

Experiences of Patients: Psychological Distress and Coping Strategy

Study	Aim	Setting	Sample	Methods	Relevant Findings
Liu, J.-E., Mok, E. and Wong, T. (2005) Perceptions of supportive communication in Chinese patients with cancer: experiences and expectations. Journal of advanced nursing, 52 (3): 262–270.	To explore the experiences and expectations of patients with cancer of supportive communication in the context of Chinese culture.	Two of the largest oncology hospitals in Beijing, China, between June and August in 2002	20 Chinese patients with cancer during 2002.	Semi-structured interviews	Chinese cancer patients have a substantial need to receive informational and emotional support when they were hospitalised. Their support networks include doctors, nurses, family members, relatives and fellow patients. The expectations of support from different sources depend on the relationship between patients and support providers. Patients were active in seeking information from doctors, nurses and fellow patients but only express emotional needs to the family and did not expect emotional support from doctors. The caring behaviours of nurses and the emotional support of fellow patients as two important sources of support
Li, L., Li, S., Wang, Y., et al. (2017) Coping Profiles Differentiate Psychological Adjustment in Chinese Women Newly Diagnosed with Breast Cancer. Integrative Cancer Therapies, 16 (2): 196–204.	To explore latent profiles of coping strategies of women newly diagnosed with breast cancer, and differences in psychological distress, demographic, and medical characteristics across profiles	2 hospitals in Changsha, Hunan Province, China	618 Chinese women newly diagnosed with breast cancer	Latent profile analysis Questionnaires	Three classes of copers are identified. "Adaptive coper" are those using adaptive cognitive coping strategies, had the best psychological adjustment. "Negative coper," characterized by most use of maladaptive cognitive coping strategies and median levels of medical coping behaviors, had the worst psychological adjustment. "Inconsistent coper" had relatively high levels of psychological distress. Patients who are younger in age, less educated, with shorter time since diagnosis, widowed, living in rural areas, and having undergoing chemotherapy tend to adopt less adaptive coping patterns. Conclusions. Interventions should be developed according to the different coping profiles of patients, and the key group to target is "negative copers".

Lee, M., Song, Y., Zhu, L., et al. (2017) Coping strategies & benefit-finding in the relationship between non-disclosure & depressive symptoms among breast cancer survivors in China. American Journal of Health Behavior, 41 (4): 368–377.	To examine the relationship between non-disclosure and depressive symptoms, and the role of coping strategies and benefit-finding among breast cancer survivors.	Nanjing Cancer Survivors Association (NCSA) in China	Convenience sampling, 148 women in an early survivorship phase (up to 6 years post-Treatment)	A set of questionnaires	Non-disclosure was associated with more depressive symptoms. Non-disclosure related to depression through self-blame, but the impact is moderated by benefit-finding. Practising benefit-finding may reduce the negative impact of non-disclosure.
You, J., Wang, C., Rodriguez, L., et al. (2018) Personality, coping strategies and emotional adjustment among Chinese cancer patients of different ages. European Journal of Cancer Care, 27 (1): 1–9.	To examine the association between personality traits and emotional affects, the role of coping strategies and how these relations differed by age among Chinese cancer survivors	Cancer organisations in Beijing, China. The	234 Chinese cancer survivors	Questionnaires for personality, emotional affects, coping strategies, and demographic information	Neuroticism had a negative emotional affect, which was explained by avoidance coping strategies. Extraversion and neuroticism have a positive affect and adopted approach coping strategies. Conditional process (i.e. moderated mediation) analyses demonstrated that conscientiousness are more likely to have a positive affect directly and indirectly through approach coping strategies among older survivors than among younger survivors. The findings highlight the importance of personality traits for emotional adjustment to breast cancer and the role of approach coping strategies.
Chen, H., Komaromy, C., and Valentine, C. (2015). From Hope to Hope: The Lived Experience of Older Chinese People with Advanced Cancer. Health. 19(2): 1-18.	To explore the constructions of hope of Chinese older cancer patients	The committee, the hospice in Dehong and the ward of a general hospital in Kunming, Yunnan	20 patients; 5 family; 7 doctors; 7 nurses; 7 nursing workers, 1 committee director, 1 funeral service worker,.	Multiple embedded-case study; multiple methods and sources of evidence: qualitative interview and observation	Similar to Western studies of hope in terminal illness, There are significant divergences in the impact of different social culture values and their implications for clinical practice in an unfavourable healthcare environment for patients with advanced cancer and a social support system sustained mainly by Chinese families. Hope represents an important source for coping with terminal illness among patients.

Experiences of Patients: Quality of Life

Study	Aim	Setting	Sample	Methods	Relevant Findings
Li, J. and Lambert, V.A. (2007) Coping strategies and predictors of general well-being in women with breast cancer in the People's Republic of China. Nursing and Health Sciences, 9 (3): 199–204.	To identify the coping strategies of women with breast cancer in China and to identify which demographic characteristics and coping strategies were the best predictors of general well-being.	In one large city (8 million people) in China.	100 newly diagnosed women with breast cancer	Three paper-and-pencil questionnaires that measured demographics, coping strategies, and general well-being.	Planning, positive reframing, and self-distraction were the most commonly used coping strategies. The best predictors of general well-being were employment status and the coping method, self-blame.
Zeng, Y.C., Li, D. and Loke, A.Y. (2011) Life after cervical cancer: Quality of life among Chinese women. *Nursing and Health Sciences*, 13 (3): 296–302.	To explore the meaning of "quality of life" among Chinese survivors of cervical cancer and the impact of cervical cancer survivorship on their quality of life.	A tumour hospital in mainland China	35 Chinese survivors of cervical cancer A purposive sampling strategy	Written responses; analyzed by using a qualitative content analysis	The meaning of "quality of life", included being free of disease, having a good standard of living, having a harmonious family atmosphere, and having a harmonious sex life. The impact of cervical cancer on the quality of life included physical and psychological sequelae, family distress, financial burden, and disruptions to their social functioning and sexual life. Positive gains included changes in their outlook on life, treasuring their life, and better family relationships.
Deng, M., Lan, Y. and Luo, S. (2013) Quality of life estimate in stomach, colon, and rectal cancer patients in a hospital in China. *Tumor Biology*, 34 (5): 2809–2815.	To investigate the quality of life and coping patterns of patients with stomach, colon, and rectal cancer in a hospital in China	Chinese People's Liberation Army General Hospital, Beijing, China	118 stomach, colon, and rectal cancer patients	Questionnaires for quality of life, anxiety level, depression level, medical coping mode and social support requirements	The correlation between the quality of life and the anxiety and depression scores in stomach cancer patients were higher than those in the colon and rectal cancer patients. Cluster analysis revealed four coping patterns (resign, confront, avoid-confront, and avoid-resign). Subjective social support requirements were significantly higher than objective support needs but the extent of using the support was significantly lower than objective or subjective support. Anxiety and distress were negatively correlated with social support requirement scores. Coping patterns were reliable indicators of psychosocial side effects in patients with stomach, colon, and rectal cancers.

Zou, Z., Hu, J. and McCoy, T.P. (2014) Quality of life among women with breast cancer living in Wuhan, China. International Journal of Nursing Sciences, 1 (1): 79–88.	To examine the factors influencing quality of life of women with breast cancer: demographic factors, optimism, social support, illness, and coping strategies	Five teaching hospitals in Wuhan, China	A convenience sample of 156 Chinese women with breast cancer	A set of questionnaires for life orientation, social support, distress, illness appraisals, coping, etc. Path analysis	There is significant relationships between optimism, symptom distress, social support, appraisal of illness, a give-in coping mode and quality of life. Optimism, social support, symptom distress, lymph node status, appraisal of illness, and a give-in coping mode accounted for 66.6% of the variance in quality of life.
Hong, J., Wei, Z. and Wang, W. (2015) Preoperative psychological distress, coping and quality of life in Chinese patients with newly diagnosed gastric cancer. *Journal of Clinical Nursing*, 24 (17–18): 2439–2447.	To investigate the prevalence of preoperative psychological distress and its relationship with coping style and quality of life in Chinese patients with newly diagnosed gastric cancer.	Two teaching hospitals in Anhui province, China.	165 patients with gastric cancer	Questionnaires for quality of life and cancer coping A descriptive correlational survey study	The prevalence of preoperative psychological distress was 76·97% for gastric cancer patients. Significant correlations were found between the distress score and stomach pain, eating restrictions and anxiety subscale. Positive correlations exist between the distress scores and four subdimensions of coping (avoidance and suppression, resignation, fantasy and catharsis), and a negative association exist between the distress scores and confrontation coping. There were significant differences in the quality of life and coping style with different psychological distress statuses.
He, Y., Jian, H., Yan, M., et al. (2019) Coping, mood and health-related quality of life: A cross-sectional study in Chinese patients with advanced lung cancer. *BMJ Open*, 9 (5).	To examine the role of positive and negative mood in the relationship between coping and quality of life in patients with advanced lung cancer.	The inpatient unit in a hospital that specialises in chest-related disease in Shanghai, China.	261 patients diagnosed with stage III or IV lung cancer	Questionnaires for quality of life, mood and coping	The overall effects of confrontation on quality of life were not significant, but it has positive indirect effects through positive mood on mobility, usual activities, pain/discomfort and overall utility index; and negative indirect effects through negative mood on mobility, pain/discomfort, anxiety/depression and overall utility index. Resigned acceptance was negatively associated with quality of life, and negative indirect effects through positive mood on mobility, self-care, usual activities, pain/discomfort and overall utility index; and negative indirect effects through negative mood on overall utility index. Confrontation strategy can fuel ambivalent emotional experiences. Nevertheless, accepting the illness in a resigned way can be maladaptive for health outcomes.

Experiences of Family Caregivers

Study	Aim	Setting	Sample	Methods	Relevant Findings
Wu, X.N., Su, D., Li, H.P., et al. (2013) Relationship between the depression status of patients with resectable non-small cell lung cancer and their family members in China. European Journal of Oncology Nursing, 17 (5): 668–672.	To examine the depression status of patients and their family members, and the relationship between the two	Thoracic Department of The Second Xiangya Hospital of Central South University	194 patients diagnosed with non-small cell lung cancer as well as their family members	Questionnaires for personal information and depression assessment; Cross-sectional study; linear correlation analysis	148 out of 194 patients (76.3%) showed symptoms of depression. 148 (76.3%) family members had depression symptoms. The severity of depression in patients was positively correlated with that of family members ($r=0.577$, $p<0.01$). Patients with lung cancer and their family members suffered from depression, and the two were correlated.
Zhang, Q., Yao, D., Yang, J., et al. (2014) Factors influencing sleep disturbances among spouse caregivers of cancer patients in northeast China. PLoS ONE, 9 (10).	To explore sleep disturbances and fatigue severity between spouse caregivers of cancer patients, and the impact of age, gender and coping style.	Two departments in the Fifth Affiliated Hospital of Harbin Medical University and the Da Qing Oilfield General Hospital	300 spouse caregivers of cancer patients 600 general population in Daqing area	Questionnaires for symptom check, coping style and fatigue Summary statistics and regression	78.7% of the participants spent more than 8 hours each day taking care of their spouse. Compared to the general population, spouse caregivers had significant sleep disturbances and fatigue severity. Current poor health status, having a spouse under mixed treatment and financial burden are the significant predictors for sleep disturbances. Positive coping is the predictor for fewer sleep disturbances. Those who reported sleep disturbances also had higher physical and mental fatigue severity.
Cui, J., Song, L.J., Zhou, L.J., et al. (2014) Needs of family caregivers of advanced cancer patients: A survey in Shanghai of China. European Journal of Cancer Care, 23 (4): 562–569.	To explore the needs of family cargivers of advanced cancer patients and the possible factors associated with their needs	15 hospitals of Shanghai.	649 participants	Self-developed questionnaire Descriptive statistics, factor analysis, t-test, one-way ANOVA,etc.	Seven dimensions of needs are identified: maintaining health, support from healthcare professionals, knowledge about the disease and treatment, support on the funeral, information on hospice care, psychological support for patients and symptoms control for patients. The dimension with the highest score was 'knowledge about the disease and treatment' and that with the lowest score is 'support on funeral'. The factors associated with needs are the financial burden, former caregiving experience and length of caregiving time.

Appendix 2 Participant's Information Sheets

Participant Information Sheet (Health Professional)

Final version 1.0 15/09/2015

Title of study: Understanding care experiences: A phenomenological Study

Name of Researcher: Bing Cui

You have been invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Discuss it with friends and relatives if you wish to. If you decide to take part, you may keep this leaflet. Thank you for reading this.

Introduction

I am Bing Cui, originally from Dezhou, Shandong Province. I graduated from Shandong University of Traditional Chinese Medicine in 2002. I am currently a PhD student in the School of Health Sciences, at the University of Nottingham, UK. My study focuses on your understanding of the care that you know from your own experience.

What is the purpose of the study?

The study is part of a PhD in Nursing Studies in the School of Health Sciences at the University of Nottingham, UK. The overall aim of this study is to explore your experiences and perspectives of caring for elderly patients with advanced cancer at the end of their life.

Why have I been invited?

You are invited to participate in this study because you are a health professional who has experience of caring for older patients with advanced cancer at the end of their life. We are inviting 10 participants like you to take part.

Do I have to take part?

No. Participation in this study is voluntary. It is up to you to decide whether or not to take part. If you do decide to take part, you can keep this information sheet and you will be asked to sign the consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason. Participating or not will not affect your current health service and care.

What does the study involve?

In this study, you are invited to have a talk with me at a time and venue convenient to you. During our conversation, I would like you to share your understanding and experience of caring for older patients with advanced cancer at the end of their life. The duration of the interview will be approximately 30-45 minutes and the interview can be stopped at any time if you feel tired or uncomfortable. Follow-up interviews will be arranged with your agreement if you think you have more experience to share. The conversation will be recorded by a digital audio recorder with your permission.

What are the possible disadvantages and risks of taking part?

The interview may recall your past memories or experiences that might be upsetting. You will be encouraged to have a break or stop if you find it too stressful to continue. You can choose to have another interview in a different time. Bearing in mind, this study is voluntary and you have the right to withdraw from the study at any time without giving any reason.

What are the possible benefits of taking part?

Your participation will be extremely valuable and worthy as your experience is unique. The information we get from your participation in this study will provide a better understanding of the care in contemporary China. It is necessary to get your experience and voice heard by the public and policymaker in order to develop new policy and promote the development of the care service.

What if there is a problem?

If you have any concern about this study, you should inform the researcher and the researcher will do their best to answer your questions. The researcher's contact details are available at the end of this information sheet. If you remain unhappy and wish to complain formally, should you then contact the Research Ethics Committee Administrator, c/o The University of Nottingham, School of Medicine Education Centre, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: louise.sabir@nottingham.ac.uk.

What happens to the information?

We will follow ethical and legal practice and all information about you will be handled in confidence.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database. Any information about you which leaves the institution will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it. This means that you will not be identified in any report/publication.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty. If there is information having potential risks to another person or to myself or criminal behaviour, it will be reported to the relevant agent.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason. However, the information collected so far cannot be erased and may still be used in the project analysis. This is because once the data have been entered onto the secure computer system because it has been made anonymous and the data analyses draws together information provided by all participants, it becomes impractical to extract and remove individual data from the system. It will be up to you to decide whether the data collected from you can be used for further analysis or not.

What will happen to the results of the research study?

The result will be written up as a part of a higher degree at the University of Nottingham and submitted no later than September 2017. The outcome of the study will also be expected to publish as Journal publications and conference presentations. You will not be identified in any report/publication.

Who has reviewed the study?

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee, Liaocheng People's Hospital and local authority.

Contact for Further Information

Mr. Bing Cui

Email: ntxbc5@nottingham.ac.uk

Mobile:

Thank you for your support and taking part in the study.

[The information sheet in Chinese will be provided to potential participants.]

University of Nottingham, School of Health Sciences

Participant Information Sheet (Patient)

Final version 1.0 15/09/2015

Title of Study: Understanding care experiences: A phenomenological Study

Name of Researcher: Bing Cui

You have been invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Discuss it with friends and relatives if you wish to. If you decide to take part, you may keep this leaflet. Thank you for reading this.

Introduction

I am Bing Cui, originally from Dezhou, Shandong Province. I graduated from Shandong University of Traditional Chinese Medicine in 2002. I am currently a PhD student in the School of Health Sciences, at the University of Nottingham, UK. My study focuses on your understanding of the care that you know from your own experience.

What is the purpose of the study?

The study is part of a PhD in Nursing Studies in the School of Health Sciences at the University of Nottingham, UK. The overall aim of this study is to explore your care experiences of your illness.

Why have I been invited?

You are invited to participate in this study because you are a patient with an illness. We are inviting 10 participants like you to take part.

Do I have to take part?

No. Participation in this study is voluntary. It is up to you to decide whether or not to take part. If you do decide to take part, you can keep this information sheet and you will be asked to sign the consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason. Participating or not will not affect your current health service and care.

What does the study involve?

In this study, you are invited to have a talk with me at a time and venue convenient to you. During our conversation, I would like you to share the care experience of your illness. The duration of the interview will be approximately 30-45 minutes and the interview can be stopped at any time if you feel tired or uncomfortable. Follow-up interviews will be arranged with your agreement if you think you have more experience to share. The conversation will be recorded by a digital audio recorder with your permission.

What are the possible disadvantages and risks of taking part?

The interview may recall your past memories or experiences that might be upsetting. You will be encouraged to have a break or stop if you find it too stressful to continue. You can choose to have another interview at a different time. Bearing in mind, this study is voluntary and you have the right to withdraw from the study at any time without giving any reason.

What are the possible benefits of taking part?

Your participation will be extremely valuable and worthy as your experience is unique. The information we get from your participation in this study will provide a better understanding of the care in contemporary China. It is necessary to get your experience and voice heard by the public and policymaker in order to develop new policy and promote the development of the care service.

What if there is a problem?

If you have any concern about this study, you should inform the researcher and the researcher will do their best to answer your questions. The researcher's contact details are available at the end of this information sheet. If you remain unhappy and wish to complain formally, should you then contact the Research Ethics Committee Administrator, c/o The University of Nottingham, School of Medicine Education Centre, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: louise.sabir@nottingham.ac.uk.

What happens to the information?

We will follow ethical and legal practice and all information about you will be handled in confidence.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database. Any information about you which leaves the institution will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it. This means that you will not be identified in any report/publication.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty. If there is information having potential risks to another person or to myself or criminal behaviour, it will be reported to the relevant agent.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason. However, the information collected so far cannot be erased and may still be used in the project analysis. This is because once the data have been entered onto the secure computer system because it has been made anonymous and the data analyses draws together information provided by all participants, it becomes impractical to extract and remove individual data from the system. It will be up to you to decide whether the data collected from you can be used for further analysis or not.

What will happen to the results of the research study?

The result will be written up as a part of a higher degree at the University of Nottingham and submitted no later than September 2017. The outcome of the study will also be expected to publish as Journal publications and conference presentations. You will not be identified in any report/publication.

Who has reviewed the study?

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee, Liaocheng People's Hospital and local authority.

Contact for Further Information

Mr. Bing Cui

Email: ntxbc5@nottingham.ac.uk

Mobile:

Thank you for your support and taking part in the study.

[The information sheet in Chinese will be provided to potential participants.]

Participant Information Sheet (Family Carer)

Final version 1.0 15/09/2015

Title of Study: Understanding care experiences: A phenomenological Study

Name of Researcher: Bing Cui

You have been invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Discuss it with friends and relatives if you wish to. If you decide to take part, you may keep this leaflet. Thank you for reading this.

Introduction

I am Bing Cui, originally from Dezhou, Shandong Province. I graduated from Shandong University of Traditional Chinese Medicine in 2002. I am currently a PhD student in the School of Health Sciences, at the University of Nottingham, UK. My study focuses on your understanding of the care that you know from your own experience.

What is the purpose of the study?

The study is part of a PhD in Nursing Studies in the School of Health Sciences at the University of Nottingham, UK. The overall aim of this study is to explore your understanding and experiences of caring for the patient in your family.

Why have I been invited?

You are invited to participate in this study because you are the key family member who is caring for older patients. We are inviting 10 participants like you to take part.

Do I have to take part?

No. Participation in this study is voluntary. It is up to you to decide whether or not to take part. If you do decide to take part, you can keep this information sheet and you will be asked to sign the consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason. Participating or not will not affect your current health service and care.

What does the study involve?

In this study, you are invited to have a talk with me at a time and venue convenient to you. During our conversation, I would like you to share your experience of looking after the patient in your family. The duration of the interview will be approximately 30-45 minutes and the interview can be stopped at any time if you feel tired or uncomfortable. Follow-up interviews will be arranged with your agreement if you think you have more experience to share. The conversation will be recorded by a digital audio recorder with your permission.

What are the possible disadvantages and risks of taking part?

The interview may recall your past memories or experiences that might be upsetting. You will be encouraged to have a break or stop if you find it too stressful to continue. You can choose to have another interview at a different time. Bearing in mind, this study is voluntary and you have the right to withdraw from the study at any time without giving any reason.

What are the possible benefits of taking part?

Your participation will be extremely valuable and worthy as your experience is unique. The information we get from your participation in this study will provide a better understanding of the care in contemporary China. It is necessary to get your experience and voice heard by the public and policymaker in order to develop new policy and promote the development of the care service.

What if there is a problem?

If you have any concern about this study, you should inform the researcher and the researcher will do their best to answer your questions. The researcher's contact details are available at the end of this information sheet. If you remain unhappy and wish to complain formally, you should then contact the Research Ethics Committee Administrator, c/o The University of Nottingham, School of Medicine Education Centre, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: louise.sabir@nottingham.ac.uk.

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What will happen to the results of the research study?

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Who has reviewed the study?

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Contact for Further Information

Mr. Bing Cui

Email: ntxbc5@nottingham.ac.uk

Mobile:

Thank you for your support and taking part in the study.

参与者信息书（医护人员）

最终版本 1.0 15/09/2015

研究题目：关于疾病医疗护理经验的理解：现象学研究

研究员姓名: 崔冰

您已被邀请参加一项研究。在您决定是否要参加之前，重要的一点是您需要了解这个研究的内容。请花时间仔细阅读以下信息。如果您有什么问题或者您想了解更多信息， 请跟我们联系。您 可以与亲友讨论这项研究。您有足够的时间来决定是否要参加。如果您决定参加，您可以保持这个小册子。感谢您的阅读。

简介

我叫崔冰，山东省德州市人。我在 2002 年毕业于中国山东中医药大学。目前我在英国诺丁汉大学的健康科学学院攻读博士研究生学位。我研究的重点是通过您的工作经历来了解您本人对对病人接受医疗的护理的理解和看法。

您被邀请参加这项研究，因为您 从事对老年晚期癌症临终患者的医疗护理工作。

研究目的

这项研究是我在在英国诺丁汉大学健康科学学院博士学习研究的一部分。这项研究的总体目标是探索人们对此疾病的医疗和护理的理解和看法。

是否必须参加?

参加与否是本着完全自愿的原则。您 自己决定是否参加。如果您 决定参加，您可以保留该信息表并且在采访同意书上签字。即便您决定参加，您 依然可以在任何时侯退出而不用给出理由。参加与否不会影响您 现在的医疗护理服务。

您需要做什么？

在这项研究中， 我将邀请您参加一个访谈。访谈的时间和地点以适合您的需要为主。通过访谈，我希望您 能从医护人员的角度分享一下您 对老年癌症临终患者提供医疗护理的经验和看法。访谈的时间将约为 45～90 分钟，访谈可以在任何时候停止，例如，当您感到疲劳或任何

不适的时候。如果一次访谈没有如期完成或者您还有更多的经验分享，根据您的情况， 在您同意的前提下，我们可以再安排后续访谈。在您允许的前提下，我需要对访谈录音。

参与可能带来的风险？

访谈可能会涉及到您 过去的一些不愉快的记忆和经历。如果您觉得紧张或者变得焦虑，我们将停止访谈。 如果您愿意，我们可以再安排一个合适的时间再次访谈。请注意，这项研究是自愿参加的，您 可以在任何时候退出研究而无须给予任何理由。

参与可能带来哪些好处？

您的参与将是极其宝贵的，有价值的因为您 的经验是独一无二的。 您的参与和研究中得到的信息将有助于更好地理解当代中国医疗护理情况。让公众和政策制定者了解这些信息将有助于开发新的政策，促进养老服务发展。

如果您有疑问该怎么办？

如果您有关于这项研究的任何担忧，您可以告知研究人员。研究人员将尽全力为您解答。研究人员的联系方式都在这个信息表的结尾。如果您 对研究人员的解答不满意，并考虑投诉，您可以向英国诺丁汉大学的研究伦理委员会申报。如有需要，研究人员会立即给予联系方式。

研究收集的信息怎么处理？

研究过程中收集的有关您的所有信息将被保存在一个受密码保护的数据库，并严格保密。所有关于您 的姓名和地址将会被删除，从而使得您的身份无法通过数据辨认。您的身份和数据将被严格保密，并在任何发表的文章中使用匿名。这意味着您 不会在任何报告/出版物中被识别出真实身份。

谁来审查这个研究？

这项研究已通过诺丁汉大学医学院伦理委员会和聊城市人民医院的审查并且批准执行。

如需更多信息，请联系：

崔冰

电子邮件：ntxbc5@nottingham.ac.uk

手机：13678627167

感谢您的支持和参与。

参与者信息书（病人）

最终版本 1.0 15/09/2015

研究题目：关于疾病医疗护理经验的理解：现象学研究

研究员姓名: 崔冰

您已被邀请参加一项研究。在您决定是否要参加之前，重要的一点是您需要了解这个研究的内容。请花时间仔细阅读以下信息。如果您有什么问题或者您想了解更多信息， 请跟我们联系。您 可以与亲友讨论这项研究。您有足够的时间来决定是否要参加。如果您决定参加，您可以保持这个小册子。感谢您的阅读。

简介

我叫崔冰，山东省德州市人。我在 2002 年毕业于中国山东中医药大学。目前我在英国诺丁汉大学的健康科学学院攻读博士研究生学位。我研究的重点是通过您的经历来了解您本人对此疾病的医疗和护理的理解和看法。

您被邀请参加这项研究，因为您 被诊断有此健康问题。

研究目的

这项研究是我在在英国诺丁汉大学健康科学学院博士学习研究的一部分。这项研究的总体目标是探索人们对此疾病的医疗和护理的理解和看法。

是否必须参加？

参加与否是本着完全自愿的原则。您 自己决定是否参加。如果您 决定参加，您可以保留该信息表并且在采访同意书上签字。即便您决定参加，您 依然可以在任何时侯退出而不用给出理由。参加与否不会影响您 现在的医疗护理服务。

您需要做什么？

在这项研究中， 我将邀请您参加一个访谈。访谈的时间和地点以适合您的需要为主。通过访谈，我希望您 能从病人的角度分享一下您 自己的疾病医疗护理经验。访谈的时间将约为 45～90 分钟，访谈可以在任何时候停止，例如，当您感到疲劳或任何不适的时候。如果一次访谈没有如期完成或者您还有更多的经验分享，根据您的情况， 在您同意的前提下，我们可以再安排后续访谈。在您允许的前提下，我需要对访谈录音。

参与可能带来的风险？

访谈可能会涉及到您 过去的一些不愉快的记忆和经历。如果您觉得紧张或者变得焦虑，我们将停止访谈。 如果您愿意，我们可以再安排一个合适的时间再次访谈。请注意，这项研究是自愿参加的，您 可以在任何时候退出研究而无须给予任何理由。

参与可能带来哪些好处？

您的参与将是极其宝贵的，有价值的因为您 的经验是独一无二的。 您的参与和研究中得到的信息将有助于更好地理解当代中国医疗护理情况。让公众和政策制定者了解这些信息将有助于开发新的政策，促进养老服务发展。

如果您有疑问该怎么办？

如果您有关于这项研究的任何担忧，您可以告知研究人员。研究人员将尽全力为您解答。研究人员的联系方式都在这个信息表的结尾。如果您 对研究人员的解答不满意，并考虑投诉，您可以向英国诺丁汉大学的研究伦理委员会申报。如有需要，研究人员会立即给予联系方式。

研究收集的信息怎么处理？

研究过程中收集的有关您的所有信息将被保存在一个受密码保护的数据库，并严格保密。所有关于您 的姓名和地址将会被删除，从而使得您的身份无法通过数据辨认。您的身份和数据将被严格保密，并在任何发表的文章中使用匿名。这意味着您 不会在任何报告/出版物中被识别出真实身份。

谁来审查这个研究？

这项研究已通过诺丁汉大学医学院伦理委员会和聊城市人民医院的审查并且批准执行。

如需更多信息，请联系：

崔冰

电子邮件：ntxbc5@nottingham.ac.uk

手机：13678627167

感谢您的支持和参与。

参与者信息书（家庭照顾者）

最终版本 1.0 15/09/2015

研究题目：关于疾病医疗护理经验的理解：现象学研究

研究员姓名: 崔冰

您已被邀请参加一项研究。在您决定是否要参加之前，重要的一点是您需要了解这个研究的内容。请花时间仔细阅读以下信息。如果您有什么问题或者您想了解更多信息， 请跟我们联系。您 可以与亲友讨论这项研究。您有足够的时间来决定是否要参加。如果您决定参加，您可以保持这个小册子。感谢您的阅读。

简介

我叫崔冰，山东省德州市人。我在 2002 年毕业于中国山东中医药大学。目前我在英国诺丁汉大学的健康科学学院攻读博士研究生学位。我研究的重点是通过您的亲身经历来了解您本人对病人接受医疗和护理的理解和看法。

您被邀请参加这项研究，因为您 是患此疾病老年患者的的主要家属。

研究目的

这项研究是我在在英国诺丁汉大学健康科学学院博士学习研究的一部分。这项研究的总体目标是探索人们对此疾病的医疗和护理的理解和看法。

是否必须参加？

参加与否是本着完全自愿的原则。您 自己决定是否参加。如果您 决定参加，您可以保留该信息表并且在采访同意书上签字。即便您决定参加，您 依然可以在任何时侯退出而不用给出理由。参加与否不会影响您 现在的医疗护理服务。

您需要做什么？

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您的参与将是极其宝贵的，有价值的因为您 的经验是独一无二的。 您的参与和研究中得到的信息将有助于更好地理解当代中国医疗护理情况。让公众和政策制定者了解这些信息将有助于开发新的政策，促进养老服务发展。

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如果您有关于这项研究的任何担忧，您可以告知研究人员。研究人员将尽全力为您解答。研究人员的联系方式都在这个信息表的结尾。如果您 对研究人员的解答不满意，并考虑投诉，您可以向英国诺丁汉大学的研究伦理委员会申报。如有需要，研究人员会立即给予联系方式。

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如需更多信息，请联系：

崔冰

电子邮件：ntxbc5@nottingham.ac.uk

手机：13678627167

感谢您的支持和参与。

Appendix 3 Participant's Informed Consent Form

CONSENT FORM

Final version 1.0: date 15/09/2015

Title of Study: Understanding Care Experiences

REC ref:

Name of Researcher: Bing Cui

Name of Participant: **Please initial box**

1. I confirm that I have read and understood the information sheet version number 1.0 dated 15/09/2015 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that the interview will be audio recorded using a digital recorder and that anonymous direct quotes from the interview may be used in the study reports. ☐

5. I understand that all data will be anonymous and confidential with the exception of information being revealed during the interview which is of concern and may need reporting i.e. potential risks to another person or to myself or criminal behaviour. ☐

6. I agree to maintain the confidentiality of focus group discussions. ☐

7. I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred is will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed. ☐

8. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes.

访谈同意书

最终版本 1.0 15/09/2015

研究课题：关于疾病医疗护理经验的理解：现象学研究

伦理认证号：H13102015 SoHS OVS PhD

研究员姓名：崔冰

参与者姓名：

1. 我确认我已认真阅读并完全理解关于这项研究的参与者信息书，并有机会提问和讨论有关研究的任何方面。 ☐
2. 我完全理解我的参与是完全自愿的，我有权利可以在任何时候退出而不用给出任何理由。 ☐
3. 我同意接受采访时可以录音，我有权利可以在任何时候要求停止录音。 ☐
4. 我同意在成果报告和成果演示中使用我在访谈中提供的信息。 ☐
5. 我完全理解所有信息都将是匿名的，保密的。 但是 威胁他人人身安全或者犯罪的行为除外。 ☐
6. 我完全理解研究过程中收集的信息将被保存在一个安全的数据库。这些信息在传播过程中将会是匿名的。 ☐
7. 我愿意参加这项研究。 ☐

参与者姓名：　　签字或印章：　　日期：

研究员姓名：　　签字或印章：　　日期：

一式两份，一份由参与者保存，一份由研究员保存

Appendix 4 Prompts for Interview

Understanding Care Experiences

The open questions below were act as prompts for the interviewer as opposed to a list of questions that were asked in turn. These prompts were used to mirror the participant's words. It was anticipated the interviewees would be given the opportunity to talk at length about these issues.

Purpose: To build a rapport with the participants, gain an understanding of their current situation and care experiences.

General Prompts:

You just mentioned that …., Can you tell me more about that?

How do you feel about that?

What happened then? Or …And then?

Why do you think that happened?

What was it like?

What happened?

How do you feel about ….?

Prompts to Each Group:

Health Professionals:

Can you tell me about your experience of caring for patients at the end of their life?

How long have you been working in your department?

How about your daily work in your department?

How do you communicate with patients/family carers about their medical condition/ diagnosis?

How do you speak with patients/family carers?

How do they make decisions about future care?

Who involves in the decision making?

How does your daily work affect your own life?

Are there any challenges or concerns about your work experience?

How do you cope with those challenges?

How to do you cope with that situation?

How to improve the care in your work?

Patients:

Can you tell me about your care experience of your illness?

How long have you known your medical condition?

How does your illness affect your life?

Who told you the diagnosis?

How do you communicate with other people?

How do you make decisions about future care?

Who involves in the decision making?

Are there any challenges in your care experience?

Are there any concerns in your care experience?

How do you cope with those challenges?

How to do you cope with that situation?

How to improve care in your opinion?

Family carers:

Can you tell me about your experience of looking after the patient in your family?

How long have you been looking after the patient?

How do you communicate with patients / health professionals/ others about their medical condition/ diagnosis?

How do you talk about the prognosis with patients/ other family members?

How do you make decisions about future care?

Who involves in the decision making?

How does it affect your own life?

Are there challenges in your caring for the patient?

Are there concerns in your caring for the patient?

How do you cope with those challenges?

How to do you cope with that situation?

How to improve care in the future in your opinion?

Finishing Questions of the Interviews:

Is there anything that we have talked about that you wish to say more about?

Is there anything else you would like to say?

Knowing People:

Can you tell me a bit about yourself?

How about your family, children etc.?

In addition to the above, field notes and a reflective diary were kept.

Appendix 5 Permission Letters of Local Institutions

Permission Letter

This is to certify that Bing Cui, PhD student from the University of Nottingham, UK, is permitted to conduct the qualitative research in this hospital.

Title of study: Understanding End of Life Care for Older People in China: A Phenomenological Study.

Supervisors: Dr Sheila Greatrex-White, Dr Stuart Nairn, Professor Lina Song.

Aim of the study: Exploring care experiences for older people with advanced cancer at the end of their life.

Participants: Older Patients with advanced cancer, family carers, doctors and nurses in the oncological department.

Study method: in-depth interview.

Liaocheng People's

Hospital (seal)

24/08/2015

The original document has been translated by the researcher (Bing Cui) and checked by the supervisor Professor Lina Song.

I confirm that this is a true and accurate translation of the original Chinese documents.

Translator: Bing Cui

Supervisor: Professor Lina Song

Signature of the supervisor: 

Date: 21/09/2015

Permission Letter

This is to certify that Bing Cui, PhD student from the University of Nottingham, UK, is permitted to conduct the qualitative research in Li Ka-Shing Hospice Centre.

Title of study: Understanding End of Life Care for Older People in China: A Phenomenological Study.

Supervisors: Dr Sheila Greatrex-White, Dr Stuart Nairn, Professor Lina Song.

Aim of the study: Exploring care experiences for older people with advanced cancer at the end of their life.

Participants: Older Patients with advanced cancer, family carers, doctors and nurses in Li Ka-Shing Hospice Centre.

Study method: in-depth interview.

Liaocheng People's

Hospital (seal)

24/08/2015

The original document has been translated by the researcher (Bing Cui) and checked by the supervisor Professor Lina Song.

I confirm that this is a true and accurate translation of the original Chinese documents.

Translator: Bing Cui

Supervisor: Professor Lina Song

Signature of the supervisor: 

Date: 21/09/2015

Permission Letter

This is to certify that Bing Cui, PhD student from the University of Nottingham, UK, is permitted to conduct the qualitative research in this community clinic centre.

Title of study: Understanding End of Life Care for Older People in China: A Phenomenological Study.

Supervisors: Dr Sheila Greatrex-White, Dr Stuart Nairn, Professor Lina Song.

Aim of the study: Exploring care experiences for older people with advanced cancer at the end of their life.

Participants: Older Patients with advanced cancer, family carers, doctors and nurses in the community clinic.

Study method: in-depth interview.

Wangtianfu Community Clinic

(seal)

24/08/2015

The original document has been translated by the researcher (Bing Cui) and checked by the supervisor Professor Lina Song.

I confirm that this is a true and accurate translation of the original Chinese documents.

Translator: Bing Cui

Supervisor: Professor Lina Song

Signature of the supervisor: 

Date: 21/09/2015

山東省聊城市人民醫院信箋

采访调查同意书

兹同意英国诺丁汉大学博士生 崔冰 同学至本单位做采访调查研究。这个调查不属于临床医学研究范围。

研究课题：对癌症晚期老年患者临终关怀的理解：现象学质性研究。

导　　师：Dr Sheila Greatex-White；Dr Stuart Nairn；宋丽娜 教授

研究目的：理解老年癌症晚期病人的生活护理经历

采访对象：老年癌症晚期患者及家属，肿瘤科医生和护士

研究方法：通过访谈来探索医务工作者，患者和家属对临终关怀的理解

聊城市人民医院

日期：2015 年 8 月 24 日

年　　月　　日

山東省聊城市人民醫院信箋

采访调查同意书

兹同意英国诺丁汉大学博士生 崔冰 同学至本单位做采访调查研究。这个调查不属于临床医学研究范围。

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导　　师：Dr Sheila Greatex-White；Dr Stuart Nairn；宋丽娜 教授

研究目的：理解老年癌症晚期病人的生活护理经历

采访对象：老年癌症晚期患者及家属，李嘉诚宁养院医生和护士

研究方法：通过访谈来探索医务工作者，患者和家属对临终关怀的理解

聊城市人民医院

日期：2015 年 8 月 24 日

年　　月　　日

山东省聊城市东昌府区王天甫社区卫生服务站

采访调查同意书

兹同意英国诺丁汉大学博士生 崔冰 同学至本单位做采访调查研究。这个调查不属于临床医学研究范围。

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导　　师：Dr Sheila Greatex-White；Dr Stuart Nairn；宋丽娜 教授

研究目的：理解老年癌症晚期病人的生活护理经历

采访对象：老年癌症晚期患者及家属，社区卫生服务站医生和护士

研究方法：通过访谈来探索医务工作者，患者和家属对临终关怀的理解

王天甫社区卫生服务站

日期：2015 年 8 月 24 日