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University of Southampton

Faculty of Environmental and Life Sciences

School of Health Sciences

"Falling leaves return to their roots": families' experiences of decision-making when transferring patients home to die from an intensive care unit in China

by

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Abstract

Background: Transferring patients home to die from critical care remains an unusual event in Western healthcare systems, but is more usual in China. Despite this very little is known about the transfer decision-making and families' experiences of transfer in China.

Aims: This study sought to understand families' experiences of decision-making when transferring home patients to die from intensive care units in China, focusing on the decision-making processes, the decision-makers, their information and support needs, barriers to, and facilitators of transfer, and meaning making of their experiences.

Methods: A constructivist qualitative study methodology was adopted. Interviews were undertaken with thirteen family members sharing their experiences of transferring ten patients' home to die from one intensive care unit in mainland China. Data analysis followed the thematic process outlined by Braun and Clarke and generated four themes (*"Stay here or go home?": two steps to decide transfer; "His sons discussed and others were not involved": the decision-makers in the process of deciding to transfer; "Falling leaves return to their roots": the meaning making of transfer; and "It's a gap in the care": the unmet information and support needs*) and one overarching theme (*"Nowhere else to go": a single path towards a home death through a web of power*).

Findings: Transfer decision-making by family members progressed through two steps: accepting the inevitable death and transferring home to die. The decision-making process was driven by Chinese cultural values and norms about a home death which obligates family members to achieve this outcome despite the lack of transit and home care services. Transferring home to die in China was a family-led decision-making process with limited choices and little support pre, during, and post transfer, and was informed by a web of interrelated and conflicted power.

Conclusion: Family members have limited choices regarding place of death for relatives due to the unique societal culture and healthcare system in China. Powerful cultural drivers and expectations of a home death were identified as factors that obstruct service development which would provide meaningful end of life care choices for family members in China. A lack of choice of transfer decisions reflects inadequate end of life service provision in China. Findings of this study suggest the need to develop end of life care provision in China, including transfer services. This would improve both support for family members and the death and dying experience for people in China.

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Research Thesis: Declaration of Authorship

I, Yanxia Lin, declare that this thesis and the work presented in it are my own and have been generated by me as the result of my own original research.

“Falling leaves return to their roots”: families’ experiences of decision-making when transferring patients home to die from an intensive care unit in China

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

   Parts of this work have been published as:

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Signed:

Date: 13th September 2020

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Definitions and Abbreviations

Barriers: factors that would limit or restrict implementation of decision-making (Légaré and Zhang 2013), regarding transferring home to die.

Critical Care Units (CCUs) and Intensive Care Units (ICUs): Critical care units in China refer to general ICUs, specialty ICUs, and subspecialty CCUs within some primary specialties, for example, pulmonology, surgery, emergency medicine, and anaesthesia (Du and Weng 2014). Because the study was placed in an international context and evidence from the UK dominated in the literature the classification of CCUs by the UK is used for discussing these literature: ICUs, intensive therapy units (ITUs), and high dependency units (HDUs) which is one level down from intensive care (NICE 2009; NHS Choices 2015). In some healthcare systems these terms refer to differing specialities (Cardiac Care Unit for example) but the study in this thesis was carried out in an ICU in Mainland China.

Culture: the character of a group of people who share a common history and perception of appropriate normative behaviours, values, and beliefs (Glazer and Karpati 2014).

Decision-making: the cognitive process of identifying and choosing alternatives based on the values, preferences and beliefs of the decision-maker. Three interrelated constituents in decision-making are decision situation, decision-maker and decision-making procedure (Zachary et al. 1982).

End of life (EoL): end of life, terminally ill, and terminal care period are synonymous and apply to patients with progressive disease with months or less of expected survival (Hui et al. 2014).

End of Life Care (EoLC): the care provided during the end of life stage and involves palliative care and hospice care for patients with months or less of expected survival without limitations to illness and settings.

Facilitators: factors that would promote or help implement decision-making (Légaré and Zhang 2013), regarding transferring home to die.

Family: Family is a cultural concept and its function and structure changes with social context. For Chinese, family is a collective unit with physical and emotional connects between nuclear and extended family (Zang and Zhao 2017).

Gatekeeper: individuals or institutions who have the power to either grant or withhold access to a research population (De Laine 2000).

Health Care Professionals (HCPs): people who “study, advise on or provide preventive, curative, rehabilitative and promotional health services based on an extensive body of theoretical and factual knowledge in diagnosis and treatment of disease and other health problems” (World Health Organization 2010 P1).

Healthcare system: healthcare system, health system, or health care system all refer to the interconnections of all the people, organisations and actions whose primary purpose is to promote, restore or maintain health (Pittet et al. 2009).

Home death: a death occurs at home and home is the place where the patient lived usually and is claimed as home by themselves or their family members.

Institutional death: all deaths occurring in places other than home are institutional deaths including hospitals, long-term care facilities, hospices, and other institutions.

Patient: individuals with a critical illness who need specialised monitoring, treatment and attention being treated in ICUs and other CCUs (NICE 2009).

Place of care: the location where formal or informal care is provided.

Place of death: the location where the death of an individual occurs.

Story: the account about experience of family members elicited through interviews.

Transfer: the process of relocating individuals in the course of receiving health care. In this study, transfer means the relocation of patients from ICU to their home.

Abbreviations

ACP: Advanced Care Planning

ACSQHC: Australian Commission on Safety and Quality in Health Care

ADs: Advance Directives

CPR: Cardiopulmonary Resuscitation

CVD: Cardiovascular Disease

EAPC: European Association of Palliative Care

GP: General Practitioner

JBI: Joanna Briggs Institute

LST: Life Sustaining Treatment

MV: Mechanical Ventilation

NHFPC: National Health and Family Planning Commission of the People’s Republic of China

NICE: National Institute for Health and Care Excellence

PCC: Participants, Concept, and Context

PPI: Patient and Public Involvement

PTSD: Post-Traumatic Stress Disorder

QoL: Quality of Life

RNCMS: Rural New Cooperative Medical Scheme

SDM: Shared Decision-Making

SES: Socioeconomic Status

THtD: Transferring Home to Die

UEBMI: Urban Employee Basic Medical Insurance

UK: United Kingdom

URBMI: Urban Resident Basic Medical Insurance

USA: United States of America

WHO: World Health Organization

WLST: Withdrawing/Withholding Life Sustaining Treatment

Chapter 1 Introduction

Chapter One presents the introduction and background to the study presented in this thesis. The aim of this chapter is to present the topic of interest and to situate this topic in the informing contexts: the sociodemographic and unique cultural context; healthcare system of China; end of life care service provision and what is known about preferred place of death in China. This chapter concludes with an overview of the structure and content of the thesis.

1.1 Rationale for research

Dying in a favourite place, which is often home, is viewed as a good death by many ethnicities and races (Hattori 2007; Bülow et al. 2008; Ko et al. 2013; Huang et al. 2015a; Cottrell and Duggleby 2016). Going home to die is discussed as being preferred by patients in critical care (Antonelli et al. 2010). However, the prevalence of home deaths varies significantly between countries (Pivodic et al. 2016). Home deaths are less common in many Western countries, such as the United Kingdom (UK), Europe, the United States of America (USA), and Canada (Broad et al. 2013; Cohen et al. 2015), and more common in Eastern countries, particularly China (Gu et al. 2007; Cai et al. 2017; Dong et al. 2019).

One group of patients who are frequently not offered the option of transferring home to die (THtD) in the West are patients who are dying in critical care units (CCUs), some of whom might prefer a home death rather than a CCU death or a hospital death (Coombs et al. 2015). Healthcare professionals (HCPs) in the UK are reported as viewing THtD from critical care as complex and challenging (Coombs et al. 2014) and recommend that a great deal of consideration is required before, during and after transfer (Coombs et al. 2015). In mainland China 35% (74/211) - 60% (96/159) of dying patients are transferred home to die from intensive carer units (ICUs) (Xu et al. 2001; Sheng et al. 2012; Zhao et al. 2014). What was of interest to me as an intensive care nurse working in an ICU in mainland China was that despite THtD being more common in China, the transfer decision-making process itself remains unclear, and the perspective of family, who are crucial to successful transfer, is largely neglected in the research literature. My experience was that this was a challenging and often distressing experience for family members that I had worked with and so in order to gain an in-depth understanding of family members' decision-making regarding transferring patients home to die from ICU the study presented in this thesis was undertaken by applying a constructivist qualitative design, interviewing family members who undertook THtD of a dying family member from an ICU clinical context in mainland China.

1.2 Sociodemographic of China

Covering approximately 9.6 million square kilometres, China is the third-largest country in the world by land area (World Health Organization 2015). In 2017, China had 34 provincial-level administrative regions, 23 provinces (including Taiwan), five autonomous regions and two Special Administrative Regions (SARs), Hong Kong and Macau; 334 prefecture-level regional administrative units, 2851 county-level regional administrative units, and 39,888 township-level regional administrative units (National Bureau of Statistics of China 2018). According to China's economic development and administrative divisions, China is divided into three regions, namely Eastern China, Central China and Western China (Cai et al. 2017).

China is the most populous country in the world. The population of China reached 1.39 billion in 2017 (National Bureau of Statistics of China 2018). The population in a prefecture or province can be equal to or larger than the population in a medium or small country (Sun et al. 2017). China is rapidly ageing. According to World Health Organization (WHO) criteria, China became an ageing society in 1999, with 11.4% of its population over 65 years old in 2017 (National Bureau of Statistics of China 2018). The population of China is distributed unevenly across the country, with higher densities in eastern and central areas and a lower density on the western plateau (World Health Organization 2015), and a higher proportion in urban areas than rural areas (58.5% vs 41.5%) in 2017 (National Bureau of Statistics of China 2018).

China has a diverse composition of ethnicities. Not including the unknown ethnic groups as well as foreigners with Chinese citizenship, a total of 56 ethnic groups inhabit China, the largest of which is the Han, accounting for 91.6% of the total population (Guo 2017). This diversity contributes to China being a multilingual country, with over 80 languages spoken and some 30 written languages (National Bureau of Statistics of China 2017). Mandarin (Pu Tong Hua,普通话) is the predominant language, spoken by over 70% of mainland Chinese (O'Connor et al. 2015).

1.3 Chinese philosophies and religions

Taoism, Confucianism, and Buddhism are the main three philosophies or religions in Chinese culture (Hsu et al. 2009). Taoism is considered both a religion and philosophy emphasizing the independence of the individual and connection to natural forces of life. Buddhism contains the rituals of the spiritual life (Hsu et al. 2009). Confucianism provides the moral code of ethics of behaviour and emphasizes the virtues of filial piety, family values, and social responsibilities (Hsu et al. 2009). However, Confucianism is not generally considered a religion by most Chinese people (Bülow et al. 2008). Chinese people have integrated these philosophies and religions to form the basis of their culture, norms and traditions in relation to health, death and dying (Hsu et al. 2009).

People' attitudes toward end-of-life decision making can be understood through the lens of values from Confucianism, Buddhist and Taoist traditions.

1.3.1 Confucianism

The term Confucianism refers to the venerable, all-encompassing tradition rooted in Chinese culture and philosophical-religious thought. Confucianism suggests the comportment with Li (礼), Xiao (孝), Ren (仁) and Yi (义) for an individual, which shape how he or she should live and interact with others, in the realm of family, community, and society. Following these teachings, a person achieves his or her self-cultivation to become a superior person (Junzi, 君子) (Hsu et al. 2009).

Propriety (Li, 礼) refers to the ritualized norms of proper conduct regulating all aspects of human interactions according to one's position and rank in family and society. For example, children are taught to honour the Li, honouring parents, loving siblings, respecting elders, trusting friends, and retaining loyalty to the family. The procedure of funeral and death anniversaries needs to be based on the ritualized norms of proper conduct to secure the quality of the deceased's life in the other world (Hsu et al. 2009). The rituals and ceremonies associated with death are important to the living. First, the extent of the rituals (i.e. the number of people at the funeral, who attended, the extent of the venues such as dance, music team, etc.) reflects the stature and reputation of the dead and his/her associated family. The event of death serves as another opportunity for bonding, socialization, and networking among family members, friends, and other associates (Xu 2007). There are numerous culture-based procedures and rituals to conduct with death, from embalming of the corps to burial services. Many of these rituals, procedures, and taboos are unwritten based on custom and tradition and can only be learned from the elders through the oral tradition (Xu 2007). The core of Chinese tradition customs is for burial of the body in the ground even though cremation has become mandatory practice in cities, burial is still most common in rural areas (Zhao et al. 2014).

Filial piety (Xiao, 孝) is the primary duty of all Chinese requiring obedience of children to parents during their lifetime and taking the best possible care of them as they grow older (Hsu et al. 2009), and is considered as one of the key values necessary to maintaining social stability (Bowman and Singer 2001). It is the duty of family and friends to ensure that the final days of a person's life are the best they can be. Thus, a child who agrees to a parent's refusal of treatment would be violating the principle of filial piety.

Humanity (Ren, 仁) refers to the attribute of being fully human, indicating a relationship between persons in the community, with the root of filial piety (Hsu et al. 2009). It is a theory of virtue ethics and deontology which sheds light on modern Chinese medical practice (Li 2013). Doctors have a responsible to do good for patients. To a large extent, Chinese bioethics is profoundly influenced by Confucianism.

Appropriateness (Yi, 义) emphasizes that individual behaviour and manners must be proper, right, and fitting in relation to other people (Hsu et al. 2009). Taking care of older parents, especially when they are ill, is an important obligation of Chinese people. Confucian concepts of Yi, and filial duty are reflected in the process of caregiving and the patient-caregiver relationship. Consequences of the process include finding meaning in life and peace of heart and mind (Mok et al. 2003).

The philosophy of death in Confucianism has impacted Chinese people's thoughts and behaviours, including whether they accept talking about death or do not (Deng et al. 2019). Death is a taboo and most Chinese families will not discuss issues of death and dying for fear of invoking bad luck or further precipitating the patient's death while also acknowledging that death is part of the lifespan (Hsu et al. 2009). Words that sound like 'death' are avoided as far as possible (Chan and Chow 2006). Chinese tend to use euphemistic expressions such as “go to the heaven,” “pass away,” or “become old” instead of the word 'death' (Huang et al. 2015a). The cultural taboo on talking about death openly can result in most family members avoid talking about death with patients, which makes it difficult for HCPs to carry out advanced care planning (ACP) or advanced directives (ADs) with patients, their families, and physicians (Cheng 2018; Liao et al. 2019). This can hinder Chinese HCPs' effective communication with dying patients at end of life (EoL) (Li 2013; Zheng et al. 2015; Dong et al. 2016; Lai et al. 2018; Deng et al. 2019).

1.3.2 Taoism

The Tao is a central concept of ancient Chinese thought and simultaneously embodies both 'being' and 'non-being' in constant, cyclical, and evolutionary flux of production and destruction (Hsu et al. 2009). From this notion, the system of Yin–Yang (阴阳) and Wu-Xing (五行) is produced and these become the fundamental philosophies of Feng-Shui (风水), reversion, and meditation. Good Feng-Shui will bless residents and descendants with wealth, health, and success and harmonize the natural environment of their dwellings and tombs. Poor Feng-Shui of the ancestors' tombs or memorial tablet located at home may lead to ancestors' displeasure, and illness and misfortune sent as a reminder for communicating displeasure. Reversion is a concept emphasizes that all things ultimately revert to their primordial, original tranquil state of equilibrium, the Tao itself. For the Taoists, this means to escape from the mundane world to enjoy the unbounded freedom that Tao affords, recognized as immortality. Taoist meditation seeks to break free of all myriad things of the individual body and mind to achieve immortality and unbounded freedom. This meditation aims to deconstruct the body and mind from material actuality back to the fluidity of potentiality in order to create an ideal and embryonic construction to embody a perfected body and mind (Hsu et al. 2009).

In terms of its values on illness and death, Taoism is divided into philosophical and religious Taoism (Bowman and Hui 2000; Bülow et al. 2008). In philosophical Taoism acceptance is the only appropriate response when facing death, and artificial measures to preserve life contradict the natural events. The Taoist regards death as a natural part of the lifespan. Death in older age is more likely to be accepted as 'nature taking its course' (Tang et al. 2010). In religious Taoism death may lead to either an afterlife of endless torture in hell (Chan and Chow 2006) and therefore a Taoist may cling to any means of extending life to postpone that possibility. Taoism speaks of death as an inauspicious event, to be avoided (Hsu et al. 2009). Taoists suggests that death is not an achievement for life and that people should perform self-cultivation techniques, such as Feng-Shui (风水) and Tai-Chi Chuan (太极拳), in order to prolong physical life. When a family member experiences life-threatening illness, it is common for Chinese people to attribute it to one of these ascriptions: retribution (报应), poor Feng-Shui, misfortune, and bad luck, and Taoist rituals might be performed by Tao-Shih (道士) to seek its cause, in order to relieve the symptoms and prolong the patient's life (Hsu et al. 2009).

1.3.3 Buddhism

Buddhism is one of the world's major religion, with a significant influence on Chinese culture for thousands of years. Samsara, nirvana, and karma are the main beliefs of Buddhism for understanding suffering and the nature of existence (Hsu et al. 2009). Buddhist thought places emphasis on the transitive and impermanent aspects of life. A central focus of Buddhism is the attainment and maintenance of a clear, calm, state of mind, a state in which one is undisturbed by worldly events (Bowman and Singer 2001). Buddhism draws on monasticism, celibacy, and withdrawing from societal practices. Buddhists, also, accepted the traditional Chinese value of filial piety and ancestor worship, and the Buddhist concepts of samsara and karma not only relate to the individual but adapted to include ancestors and families, even descendants (Hsu et al. 2009). A person who decides to forego life-prolonging treatments because of the emotional or financial burdens that his illness incurs would be performing a compassionate act which may derive from the Buddhist value of justice (Bowman and Singer 2001).

Understandings of death and dying in Chinese Buddhism have combined with the original Buddhist teaching and Chinese indigenous philosophies (Hsu et al. 2009). The concept of life cycle is based on the Buddhist belief that once a person has entered the cycle of life, aging, illness, and death are inevitable (Bowman and Singer 2001). In Chinese Buddhist belief, the last thought during a person's last moments, whether good or evil, will influence the individual's next rebirth. Therefore, from the Chinese Buddhist view, caring for the dying person focuses on the patient's state of mind at the moment of her/his death. When death is imminent, reciting Sutra around the dying person will instruct him to go freely in peace (Hsu et al. 2009).

In summary, Taoism, Confucianism, and Buddhism are the three combined philosophies in China that contribute to the unique cultural context for end of life decision-making. In this cultural context, family members have the obligation to provide end of life care and make decisions on behalf of their relatives. Attitudes towards death based on different beliefs may lead to different treatment decisions. Death and dying have to follow culturally meaningful rituals and procedures and take place in a particular location. Furthermore, death and dying are also influenced by the healthcare system in China.

1.4 The healthcare system in China

The healthcare system in China is more complex than that of many other countries because of the country's large population and regional diversity (Meng et al. 2019a). China has a three-tiered system for healthcare delivery: health organisations and providers operate at county, township, and village levels in rural areas, and at municipal, district, and community levels in urban areas (Meng et al. 2019a). This is generally organized according to government administration comprising the central government, and local governments in provinces, cities, counties and townships (Sun et al. 2017).

Public hospitals dominate health care delivery in China (National Health Commission 2018). Hospitals in China are accredited at three levels: primary, secondary and tertiary. Primary hospitals are at township level for primary public and clinical health care. Secondary hospitals correspond to hospitals at the county and prefectural levels providing a comprehensive health service with coverage for certain regions. Tertiary hospitals are more likely at the provincial level, providing a comprehensive or advanced health service with coverage for the province or even the whole nation. Hospitals at each level are ranked A and B on the basis of the functions, size, technical skills, equipment, and quality of service. A hospital ranked as A at level three is considered to be the best (Sun et al. 2017).

China has three basic health insurance schemes: urban employee basic medical insurance (UEBMI), urban resident basic medical insurance (URBMI), and rural new cooperative medical scheme (RNCMS) (Fang et al. 2019). Rural and urban resident based health insurance is funded mainly by government subsidies (about 70% of the total funds), and employee based health insurance is funded by employer and employee contributions (Meng et al. 2019a). In addition to the three basic health insurances, insurances for critical illness, medical assistance (MA), and emergency disease assistance as well as private insurance exist (Sun et al. 2017). Although more than 95% of the Chinese population was covered by health insurance in 2011 (Liang and Langenbrunner 2013), the out-of-pocket expenditure remained 29% of total health expenditure in 2017 (Fang et al. 2019).

China has implemented a health system reform over the past decade (Liu et al. 2017; Meng et al. 2019a). Although good progress and achievements have been made, issues exist. China's health system remains hospital centric. The capacity and use of primary care providers are inadequate. The healthcare delivering system is vertically segmented (Sun et al. 2017) and collaboration between different health sectors is poor (Meng et al. 2019b). China is still facing many health challenges such as non-communicable diseases, an ageing population, and people's rising expectations about health (World Health Organization 2015; Meng et al. 2019b).

1.5 End of life care service provision in China

1.5.1 The availability of palliative care services

China is the most populous country in the world, but access to palliative care is extremely limited (Yin et al. 2017; Lu et al. 2018). In 2017, 15.8 million people in China (11.4%) were aged over 65. The national mortality rate in 2017 was reported as 7.11‰, that is, more than 7 million people (National Bureau of Statistics of China 2018). However, most of the hospice and palliative care services are still provided in secondary and tertiary hospitals, while beds for hospice and palliative care are in great shortage. There are almost no palliative institutions in small cities and rural areas in China (World Health Organization 2015). In addition, general end of life care (EoLC) services in non-palliative care settings, for instance ICU, are underdeveloped in China (Lai et al. 2018). Most patients spend their last weeks in tertiary/ secondary hospitals before going home to die, being transferred from one location to another, receiving illness- and symptom-focused treatment, with no other places as options for end of life (Lai et al. 2018).

Community and home palliative care in China are in their infancy. Palliative care programmes are limited across the country and the number of them providing community-based and home-based palliative care is relatively small. For instance, among three representative palliative care programmes in Beijing, Chengdu and Kunming, only the one in Chengdu provides a home palliative care service, delivers pain medications for patients in the last days of life and offers bereavement counselling at home, with a daily census of 10 patients (Yin et al. 2017). Shanghai is the pilot and leading city providing community hospice care in mainland China. Before 2012, there was only one Community Health Service Centre in Zhabei district offering hospice care in Shanghai.

In 2012, the Hospice Care Service Programme (安宁舒缓疗护服务实事项目) was launched in Shanghai to provide hospice care to terminally ill patients (Shanghai Health Bureau 2012). The local government website (Shanghai Health and Family Planning Commission 2019) shows that currently there are 76 institutions providing hospice and palliative care across the city including 20 community hospice care centres, about 300 palliative care wards, 890 institutional beds and 801 palliative care beds for home-based terminally ill patients. However, this is extremely limited compared with the large population of the city. In 2017, the total population in Shanghai was 24.18 million and of them, 14.3% (3.46 million) were aged 65 and over, and 18,154 died within the year (National Bureau of Statistics of China 2018).

Home care services for dying patients at home have been well developed in Western countries with the European Association for Palliative Care (EAPC) recommending the ratio of one home palliative care service per 100 thousand inhabitants (Radbruch and Payne 2010). In the UK, there are 258 home palliative care services available across England, Wales, and Northern Ireland (one team per 224 thousand inhabitants) (The National Council for Palliative Care 2012). In 2014, about 67,000 paid, regulated long-term care service providers served about 9 million people in the USA, with services provided by 4,800 adult day services centres, 12,400 home health agencies, 4,000 hospices, 15,600 nursing homes, and 30,200 assisted living and similar residential care communities (Harris-Kojetin et al. 2016). Canada also has a good home care support system. A survey in the central west region of Ontario reported that patients received five different home care services during the last four weeks of their life and 81% of them died at home (Brazil et al. 2012).

China remains at a preliminary stage of integrating palliative care into mainstream service provision with a relatively low ratio of palliative care services to population (1: 8.5 million) (Lynch et al. 2013). In the Quality of Death Index, China ranked 71st of 80 countries, a worrying result reflecting a slow adoption, limited availability and poor quality of palliative care (The Economist Intelligence Unit 2015). To date, there is still no national certification program for hospice and palliative care physicians and nurses in China. The public have misunderstandings about, or a low awareness of, palliative care (Hu and Feng 2016; Yin et al. 2017; Yan et al. 2019). Both hospital- and home or community-based formal EoLC services are not widely available (Gu et al. 2007). An EoLC system has yet to be fully realized or created in China (Deng et al. 2019).

In 2017, the Chinese government released the first national policy and standards for EoLC practice in China, namely the Basic Standards and Regulations (Trial) of the Palliative Care Centre (安宁疗护中心基本标准和管理规范（试行）) (NHFPC 2017a) and the Guideline for Palliative Care Practice (Trial) (安宁疗护实践指南（试行）) (NHFPC 2017b). The policy defines that EoLC is to provide pain and symptom management, comfortable care, psychological, spiritual and social support to terminally ill patients and their families through a multi-disciplinary collaborative mode (NHFPC 2017a, b). However, the national policy did not provide the criteria by which service providers assess that patients are at their end of life stage, and the policy and standards do not appear to be being implemented by service providers in clinical practice in China (Gong et al. 2018; Lai et al. 2018). Limited palliative and hospice provision may be part of the reason why home deaths are usual in China (along with other factors).

1.5.2 Usual place of death in China

In mainland China, evidence shows that most deaths occur at home and an extremely small proportion occur in hospitals or other institutions. A large scale national survey in China identified that 88% of the 23,098 deaths between 1998 and 2012 occurred at home (Cai et al. 2017). Another national survey found that 82% of the 352 Chinese decedents between 2014 and 2016 died at home with 72% of the deaths occurring at home in urban areas, and 91% of the deaths occurring at home in rural areas (Dong et al. 2019). A similar figure was reported by a study about ten years ago that 92% of 6,444 Chinese oldest decedents (aged 80 years and over) died at home, with only 7% dying in hospitals and 1% in other institutions (Gu et al. 2007).

Compared to other countries, more Chinese people die at home than in hospitals. A cross-national comparison of 45 countries of information from published reports and available data showed that more than half (54% and more) of all deaths across populations occur in hospitals and residential elderly centres with the exception of Albania, China (20%, 868,484 decedents), Chile, Lithuania, and Serbia (Broad et al. 2013). In England hospital deaths accounted for 45% of 228,811 deaths, and home deaths accounted for 24%, with 23% in care homes and 6% in hospices in 2018 (Public Health England 2019). The rates of home deaths varied between 22% of 294 decedents (Sweden) and 52% of 163 decedents (Greece) within13 European countries between 2005 and 2012 (Penders et al. 2017). In the USA 30% of 2.7 million decedents died at home while 37% died in the hospital (Aldridge and Bradley 2017) and 25% of 1,361,870 deaths occurred in nursing homes in 2015 (Teno et al. 2018).

Given that so many people die at home in China, the quality of death at home is essential. However, there is very limited evidence about the quality of death at home in mainland China. In the global Quality of Death Index, China ranked 71st of 80 countries, a worrying result concerning the overall quality of death (The Economist Intelligence Unit 2015). Evidence from other countries or regions indicates that the quality of patients' end of life and families' bereavement may be better for patients dying at home, where home care services are available. In Taiwan, Yao et al. (2007) found that home deaths with palliative home care are better than hospital deaths except for physical comfort. In Canada, Hales et al. (2014) reported that home deaths with palliative care services have better overall quality of dying and death, better symptom control and death preparation than deaths in other places. In the USA, Wright et al. (2010) revealed that compared with patients who died at home or in a hospice, patients who died in an ICU or hospital experienced more physical and emotional distress and worse quality of life (QoL). In addition, families were more likely to experience post-traumatic stress disorder (PTSD) in the group of ICU deaths and prolonged grief disorder among hospital deaths. A recent survey in the UK suggested that a home death could be more peaceful and better for grieving processes than a hospital death if the following provisos were in place: patient's preferences are discussed, their GP can visit them at home, and they have the support of their family (Gomes et al. 2015). Thus, the quality of home death can be better if necessary support is available.

Compared to the West, home deaths are more common in China but the quality of home deaths in mainland China seems poorer based on the limited evidence published. This is of concern in view of the needs of a critically ill patient who may be transferred home to die from an ICU.

1.6 Factors influencing preferred place of death

Evidence shows that patients who have a preference for a home death as opposed to a hospital death are more likely to die at home (Gomes and Higginson 2006; Gomes et al. 2015). A systematic review reported that most people worldwide, including patients, caregivers and members of the general public prefer to die at home rather than in hospitals or other institutions (Gomes et al. 2013). Furthermore, a recognition of the patients' preferences by the HCPs and family members involved in care can increase the likelihood of a home death (Gomes and Higginson 2006; Hunt et al. 2014; Lee et al. 2014a; Gomes et al. 2015).

However, the evidence shows an incongruence between the preferred place of death and the actual place of death. Table 1.1 presents the reported figures of the percentage of people expressing the wish to die at home, and the percentages of actual home death among people in general and patients (i.e. residents in a nursing home or across the country) in China and Western countries.

Table 1.1 Reported figures of preferred place of death and actual place of death in China and other countries

Comparing items	Western countries (UK, Europe and USA)	Mainland China
Preferred home deaths	Most patients, families and members of the public (Gomes et al. 2013)	23% - 26% (Ni et al. 2014; Kang et al. 2017)
Actual home deaths	22% - 57% (Aldridge and Bradley 2017; Penders et al. 2017; Public Health England 2019)	82% - 92% (Gu et al. 2007; Cai et al. 2017; Dong et al. 2019)

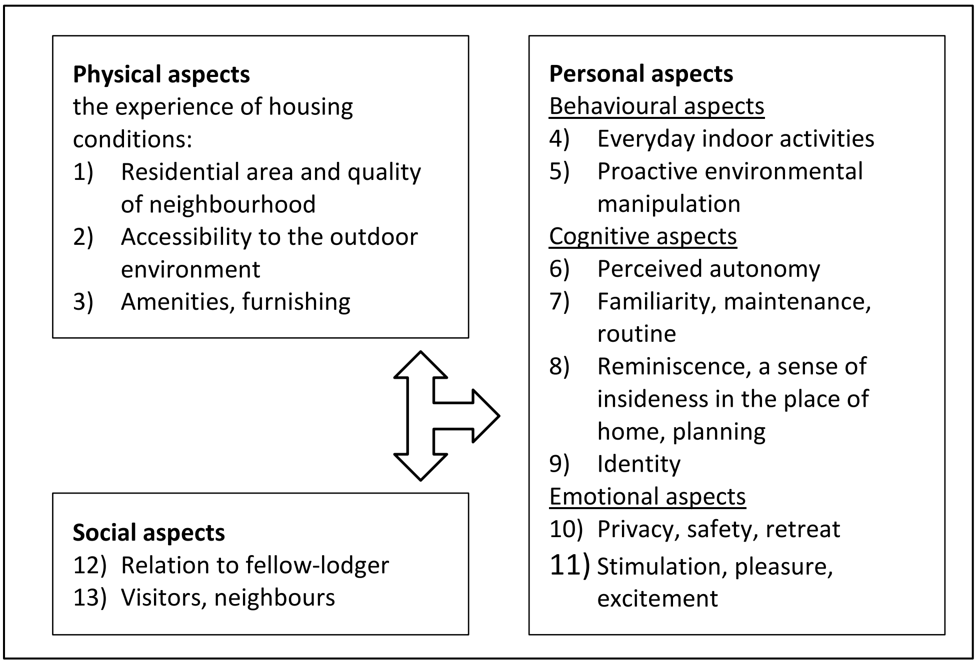
In mainland China, the majority of Chinese die at home but only a small group of people express this preference. Surveys in China reported that fewer than a quarter (23% of 467 respondents) of nursing home residents wanted to die at home, but more than half (58%) would prefer to live and die at their present nursing home (Ni et al. 2014), and a little more than a quarter (26% of 1,084 respondents) of general patients preferred to spend their last days of life at home whereas most of them (44%) chose general hospital (Kang et al. 2017). The low expressed preference for a home death among these participants in mainland China might be a result of multiple factors, such as the decreasing access to family caregivers due to the increasing number of single households with fewer generations, the concerns about quality of life at home and burden upon family members when home care service is not available, and the cultural taboo about talking about dying and death. The significant incongruence between the preferred place of death and the actual place of death among Chinese population indicates that personal preference has an impact on the decision but other factors are more influential which are discussed in following sections.

1.6.1 Factors influencing choice of place of death

Personal reasons for preferring a home death may change over time (Murtagh et al. 2012; Gomes et al. 2013), with a shift away from home to institutions (Higginson and Sen-Gupta 2000; Higginson et al. 2010; Gerrard et al. 2011; Sue Ryder 2013). Reported reasons for change of preference include: the perceived level of family support, and health care input (Murtagh et al. 2012; Gomes et al. 2013). The increasing burden of care or consideration of the carer/family burden (as well as personal considerations) are a major influence on the preferences of patients (Higginson and Sen-Gupta 2000; Murtagh et al. 2012), and the preference of a home death is conditional on the support available from both family carers and professional services (Gomes and Higginson 2013). Empirical research identifies the benefits of distinguishing preferred place of death and preferred place of care before death (Gerrard et al. 2011). However, ‘going home’ is an important metaphor which carries multiple meanings in different social contexts (Long 2004). At least two layers of meanings are ascribed to home as a place of death by Chinese people.

First, home is connected with physical comfort, emotional safety, connection with family members (Gott et al. 2004; Long 2004; Horsfall et al. 2015), a peaceful place with no mechanical medical treatments (Ko et al. 2013), a sense of belonging, freedom and control of being in a familiar environment, and a sense of normality (Tang 2000; Lin and Lin 2007; Tang et al. 2008). These meanings about home can be mapped to the model by Oswald and Wahl (2005) that home is a setting comprising physical, behavioural, cognitive, emotional and social dimensions, which is illustrated in Figure 1.1. These meanings of a home can be altered by the care of dying relatives (Morris et al. 2015; Milligan et al. 2016) and appear to be universal across cultures, including Chinese culture (Huang et al. 2015a).

Figure 1.1 The meanings of home at the end of life stage



Physical aspects
the experience of housing conditions:
1) Residential area and quality of neighbourhood
2) Accessibility to the outdoor environment
3) Amenities, furnishing

Social aspects
12) Relation to fellow-lodger
13) Visitors, neighbours

Personal aspects
Behavioural aspects
4) Everyday indoor activities
5) Proactive environmental manipulation
Cognitive aspects
6) Perceived autonomy
7) Familiarity, maintenance, routine
8) Reminiscence, a sense of insideness in the place of home, planning
9) Identity
Emotional aspects
10) Privacy, safety, retreat
11) Stimulation, pleasure, excitement

Source: (Oswald and Wahl 2005)

Figure 1.1 illustrates the model by Oswald and Wahl (2005) about a variety of meanings of home in old age which comprises three domains (physical, personal and social), five categories/dimensions and thirteen items (Fellow-lodger in item 12 refers to the person who lives in a rented house with the house owner).

Second, home is connected with cultural, religious, and spiritual meaning as a place of death, which is very important for Chinese people. Two qualitative studies mentioned that Chinese culture and norms about going home to die are the reasons for some ICU patients forgoing life-sustaining treatment (LST) to be taken home to die by their family members in mainland China (Xie et al. 2015; Liu et al. 2016), but the primary focus of the two publications was on ICU families' decision to withdraw/withhold life-sustaining treatment (WLST) with little insights into the underlying patterns about THtD.

Chinese traditional beliefs about a good death are that dying at home is as natural as the leaves falling down to the roots of a tree (Tang 2000). For the Chinese, dying at home is a way of continuing bonds with ancestors (Hsu et al. 2009). The cultural, religious and spiritual meanings of home imply that a home, to many individuals, might not be replaceable by other places (i.e. hospice) as a place of death. The study presented in this thesis further explored the cultural and religious meaning of home in families' decision to THtD from ICUs in China by identifying the more in-depth mechanism and role of cultural values and norms in this decision-making process.

1.6.2 Social demographic factors

Many social demographic factors are reported as influencing actual place of death, including age, gender, minority and socioeconomic status (education, social class, income). These factors informed the collection of demographic information of participants in the study presented in this thesis.

There are inconsistent findings about the influence of age in home deaths (Gomes and Higginson 2006). Older age was found associated with increased likelihood of dying at home in Taiwan (Lin and Lin 2007; Yeh et al. 2019), New York (Decker and Higginson 2007), and Italy (Cohen et al. 2010), but decreased likelihood of dying at home in the UK (Decker and Higginson 2007; Gao et al. 2013) and other European countries (Cohen et al. 2010). A systematic review indicated that older patients, especially those with dementia, were most likely to die in care homes (Murtagh et al. 2012).

In mainland China, some studies found no age difference in place of death (Gu et al. 2007; Li et al. 2019), and WLST in ICU (Zhao et al. 2014), but others found that a home death was more likely as age increased (Cai et al. 2017) and patients aged younger than 40 were more likely to die in the ICU than go home to die (Xu et al. 2001). For Chinese people, a young death is not easy to accept and it is less likely for family to give up a younger family member according to Chinese culture about death and filial piety. Therefore, the pattern of age influence on place of death might reflect the underlying societal culture in China, however, the current understanding about the age influence is based on a limited number of publications generating inconsistent findings, without a direct evidence about the underlying reasons for the difference.

Inconsistent findings are also reported on the gender difference in home deaths. Being a woman decreased the likelihood of dying at home in the UK (Decker and Higginson 2007) and other European countries (Cohen et al. 2010) because historically women play the role of caregiving in the family and men go to work, so that there is a lack of spouse caregiver when the dying family member is female. But the likelihood was increased in New York (Decker and Higginson 2007), Italy (Cohen et al. 2010) and Taiwan (Lin and Lin 2007), suggesting that other factors played a role among the participants in these contexts, for instance in Taiwan, the fact that females are more attached to home than males and are more likely to stay at home when dying. In mainland China, a gender difference was not found between home deaths and hospital deaths (Gu et al. 2007; Cai et al. 2017; Li et al. 2019) and WLST in ICU (Zhao et al. 2014). This might be because the primary decision-makers for most of the dying patients or ICU patients are their children, whose decision-making is influenced by filial piety according to Confucian philosophy (Bowman and Singer 2001; Ni et al. 2014), and their decisions about place of death for father could not be different from those for mother. However, further investigation is needed to confirm the influence of gender on going home to die from ICUs and reveal the underlying interpretations which findings of the study presented in this thesis can inform.

Evidence from the West showed that ethnic minorities are more likely to die in hospital (Gomes and Higginson 2006; Murtagh et al. 2012) because many people from ethnic minorities feel they are not provided with enough choices, and the different access to home care by socially disadvantaged people could contribute to more likelihood of a hospital death (Gomes and Higginson 2006). China might tell a different story. Two large scale quantitative studies in Mainland China reported that minority ethnicities were less likely to die at the hospital than the Han majority (Gu et al. 2007; Cai et al. 2017). The cultural beliefs about a home death and the limited access to hospital beds and social care services or inability to afford the costs of a hospital death are possible causes for this difference (Gu et al. 2007), which the findings of the study in this thesis could inform.

In the West, higher socioeconomic status (SES) as indicated by further education, higher social class, and higher household income are associated with a home death (Gomes and Higginson 2006; Murtagh et al. 2012), whereas lower SES reduces the likelihood of death at home (Decker and Higginson 2007). In contrast, in China, a better SES reduces the chances of a home death (Gu et al. 2007; Cai et al. 2017; Li et al. 2019) and this is reported to be related to the availability of or access to health care services that can be paid for, because the family with a higher SES can afford the cost of a hospital death in China (Cai et al. 2017). The influence of SES on family decision-making regarding THtD was explored in the study presented in this thesis.

1.6.2.1 Financial burden and health insurance support

Evidence from mainland China shows that financial hardship in relation to the coverage of healthcare insurance is a barrier to patients being cared for and dying in ICUs or hospitals or other institutions. These patients are more likely to be taken home to die because home deaths are cheaper than hospital deaths. Studies in China reported that if patients whose family finance was good and/or whose medical costs were covered by public medical care or medical insurance, they were less likely to die at home (Gu et al. 2007; Cai et al. 2017), and their families intended not to forgo LST in ICU (thus not to THtD) (Liu and Zhu 2016). In contrast, if the costs were not covered by insurance and/or the further stay and treatment were a burden to the family, it was decided that patients would forgo LST (Liu et al. 2015; Liu et al. 2016) and were more likely than those covered by insurance to go home to die (Xu et al. 2001). A retrospective observational study reported that out-of-pocket was the source of medical expense for 88% of 82 patients with the choice of WLST, and the huge financial cost of critical care was a leading obstacle for many patients to proceed (Zhao et al. 2014). Based on their findings of a large scale study Gu et al. (2007) suggest that the primary reason that most people died at home in mainland China is not because they can access to home care, but because they cannot afford the hospital costs.

Some evidence shows that the care costs increase at the end of life stage which indicates that dying and death become expensive due to the use of care services and resources. A population-based retrospective study in urban China found that costs increased rapidly as death approached (Li et al. 2019b). This was consistent with findings of a scoping review which identified that caregiver costs were highest when the care recipient was in the palliative phase of the disease (Coumoundouros et al. 2019). The high medical costs during end of life stage might be related to the use of ICU. In the USA, the prevalence of high-intensity care at the end of life is on the rise, including ICU stay (Aldridge and Bradley 2017).

Deaths in ICUs or spending time in ICUs before death are very expensive in mainland China. A population-based study from urban China reported that the average expenditures per capita during the last 6 months of life were $18,235, and 6% of the 894 deceased patients were admitted once into the ICU and the use of ICU services increased the EoLC costs (Li et al. 2019b). In contrast, another retrospective review of an ICU in China showed that WLST, following which many went home to die, reduced the length of stay and financial costs in ICU (Zhao et al. 2014). The cost of the ICU department is among the highest within the healthcare industry (van der Sluijs et al. 2017). The ICU cost in China is higher than other countries such as the USA (Ye et al. 2017).

Home deaths are cheaper than hospital deaths, including deaths in ICUs. Population-based retrospective studies in mainland China reported that patients who died in the hospitals spent 1.5-fold, 2.3-fold, 3.5-fold and 3.2-fold higher than those who died at home during the last one week, one month, three months, and six months of life (Li et al. 2019b); hospital deaths utilized more inpatient hospitalization services and emergency department visits than home deaths (Li et al. 2019a).

Most countries with high performing health systems and good palliative care development do provide some financial support for caregivers (Courtin et al. 2014; Gardiner et al. 2019). A systematic review identified that studies from countries with comprehensive public funding reported less medication, physician and home care costs (Gardiner et al. 2014). In China, health insurance does not cover all individuals (Liu et al. 2015). The limited palliative care services are generally not supported through the national health insurance (Hu and Feng 2016; Yin et al. 2017) and the full funds approved by the government have not yet been allocated (Huang 2015).

1.6.3 Family support and decision-making

Family can be defined as people related by marriage, birth, consanguinity or legal adoption, who share a common kitchen and financial resources on a regular basis (Sharma 2013), or in a very broad sense as people connected by emotional and functional connection (Mirabelli 2014). A function-based definition of family is that family is a basic unit of human society to support and regulate human sexual interaction, reproduction, childrearing and socialization, elderly care, and other important functions (Zang and Zhao 2017). From a structural perspective, family comprises nuclear family and extended family. The nuclear family, for example, is composed of two generations, the parents and the children, while the different extended family types are composed of at least three generations, for example, the grandparents, the parents, the children, as well as kin on both sides (Georgas 2003).

Family is not an objective, fixed existence but has a fluid dynamic nature within the social context in which a family is embedded. The structure, function and meaning of family will change with the change of social context. For example, the family structure in China is highly influenced by policy changes, and the One-Child Policy enacted in 1979 (Xia et al. 2014) was replaced by a Two-Child policy in October, 2015 (Zeng and Hesketh 2016). Family is a product of social construction (Holstein and Gubrium 1999), as the characteristics of the family change due to real time and place, through interpretive practice. The meaning of family is produced in the interaction between family members and the social context.

The concept of family is culturally sensitive (Georgas 2003; Bornstein 2012). In China, Confucian teachings suggest that formal behaviour and manners are followed in personal family life: children are taught to honour parents, love siblings, respect elders, trust friends, and retain loyalty to the family; these reflect the virtues of propriety, filial piety, appropriateness, and humanity (Hsu et al. 2009).

Family centeredness is a remarkable characteristic of traditional Chinese societies, which attach less importance to the principle of autonomy (Kang et al. 2017). The individual is considered an integral part of the family, and the family, in turn, is seen as an entity that exists before one is born, and shall continue to exist after one has died. Thus, the accomplishments and choices of individuals are not theirs alone, but belong to the family (Bowman and Singer 2001). Familial relationships are stressed more than an individual's rights (Li 2013). Important personal decisions, such as marriage, job seeking, or ACP in death, are often made in consultation, if not in conjunction, with family members (Cheng 2018). China values collectivism more than individualism and relies on families rather than a social security system to care for the elderly (Xu and Xia 2014). The Chinese culture represents one of the most collectivistic cultures in Asia (Lee et al. 2014b).

1.6.3.1 Family support and home death

Family play a key role in achieving a home death. Reliable evidence from a systematic review showed that living with relatives, extended family support, being married and caregivers' preferences were associated with the likelihood of a home death for cancer patients (Gomes and Higginson 2006). Similarly with non-malignant conditions, another systematic review suggested that patients who lived alone (single or widowed) were less likely to die at home, and more likely to die in care homes, while those who were married were more likely to die at home (Murtagh et al. 2012). Consistent findings about the presence and absence of family members related to home deaths were also reported in other studies from Europe (Cohen et al. 2010), UK (Gao et al. 2013), and Taiwan (Yeh et al. 2019).

Wishing to die at home and having that wish come true requires not only advance planning, but also is heavily dependent on family caregivers being available, willing, healthy, and capable to support patients in the home (Tang et al. 2005). The contemporary family, in its many forms, is fundamental to the character of modern dying (Broom and Kirby 2013). The availability of family members is also found to be an influential factor of home deaths in mainland China. Representative quantitative studies revealed that the elderly who were cared for by spousal caregivers and children were more likely to die at home compared with those cared for by other caregivers in China (Cai et al. 2017) and when a spouse, and especially children and/or grandchildren, are available as primary caregivers, it is almost impossible for the Chinese elderly person to be institutionalized and to die there (Gu et al. 2007).

Family caregiving at the end of life stage has the cultural meaning in China. It is a stigma for adult children to place their elderly parents in nursing homes (Xia et al. 2014), because if the elderly with children or offspring enter institutions for care, it normally indicates that children or offspring are not filial (Gu et al. 2007). Caring for the parents at the end of life stage is not only the last opportunity to practice filial piety derived from Confucian philosophy, but also provides children with a sense of fulfilment and preparedness for loss (Zuo et al. 2014). In fulfilling patients' wish of dying at home underpinned by a patient-caregiver relationship, Confucian concepts of Yi (appropriateness or rightness), and filial duty can give the family caregiver meaning of life and peace of heart and mind (Mok et al. 2003). These cultural expectations impose a specific decision-making context for family members that is not replicated in Western cultures, and which is a gap in the knowledge base informing Chinese palliative and EoLC.

1.6.3.1 The role of family in decision-making

The importance of involving family members in the decision-making process for EoLC has been found across all racial or ethnic groups, although preferences for how family members are involved in the process differs (Kwak and Haley 2005). Huge variations have been reported in family involvement in ICU EoL decision-making with more family involvement in Asian countries (100% in India, 98% in Hong Kong) than in Western countries (51 79% in Spain, 44% in France) (Curtis and Vincent 2010). In China, families are more commonly involved in patients' care decision-making even when patients have capacity to make decisions (Rui 2015; Lu et al. 2018). Gu et al. (2016) reported that 97% of 436 patients' end of life discussions in China excluded patients, occurring between family caregivers and physicians; the main decision-maker involved in decision making was usually spouse (46%) and offspring (44%) with only a minority of decisions made by parents (3%), son-/daughter in-law (2%), and relatives (1%) (Gu et al. 2016). In Chinese culture, seriously or terminally ill people, especially elderly patients, would not be told about their real situation because relations think they would break down if they knew the truth (Kang et al. 2017).

Therefore, differing from the individual-based and autonomy-oriented bioethics in the West, Chinese bioethics is a family-based and harmony oriented ethical system embedded in the Chinese culture (Li 2013) (Table 1.2). In China, the legal consent for medical decisions can be provided by patients themselves, but more commonly, by their adult children or spouse.

Table 1.2 The differences in the informed consent between China and the West

China	West
Family autonomy	Individual autonomy
Doctor-family-patient relationship	Doctor-patient relationship
Chinese doctors would need a special reason to justify telling the truth to the patient	Western doctors would need a special reason to justify not telling the truth to the patient

Source (Li 2013)

Dying in a family-oriented society is more complicated (Lai et al. 2018). The practice of excluding patients from EoL decision-making results in many patients not being able to die in the way they prefer. Overtreatment is common. To extend an ailing parent's life is to extend the opportunity to show filial piety (Bowman and Hui 2000). Family members would abandon the choice to WLST due to concerns about social judgement (Xu et al. 2001). In addition, family disagreement influences the decision to WLST in the ICU in China (Liu et al. 2016) leading to not forgo LST in ICU (Liu and Zhu 2016) or even conflicts with ethical values (Lee et al. 2014b). Finally, family members can experience profound feelings in EoL decision-making for patients such as shock, pain, helplessness, and guilt in deciding WLST (Xie et al. 2015).

The evidence suggests that in China family members are not only the primary caregivers for those dying at home, but also are intensively involved in the decision-making about THtD from ICUs. However, previous studies provided limited understanding about how the decisions regarding THtD were made in China, and particularly how family members were involved in the decision-making process and interacted with other individuals. It is also necessary to understand the role of family in the decision-making process regarding THtD in other societies, which is a key finding of the literature review in Chapter 2.

1.6.4 Transferring patients home to die from CCUs

Global evidence shows that approximately one fifth of patients die in ICUs after admission. Audits or surveys reported that the ICU mortality rates worldwide were 16% (of 10,069 patients) (Vincent et al. 2014), and the figure in European ICUs was 17% (of 4,852 patients) (Vincent et al. 2018), 17% (of 38,168 patients) in the UK (West et al. 2014), 15% (of 12,265 patients) in Canada (Bagshaw et al. 2018), and 18% (reported by ICU directors without specific number of patients) in Latin American countries (Estenssoro et al. 2017). In the USA the overall hospital mortality decreased to 20% (of 1,361,870 decedents) but the use of ICU during the last 30 days of life increased and the rate of use of ICU was 29% (of 1,361,870 decedents) in 2015 (Teno et al. 2018). China has an ICU mortality rate close to that of other countries. A large scale and representative study reported the ICU mortality rate in mainland China was 17% (of 1,297 patients) (Du et al. 2013).

The percentage of THtD is reported to range from 40% (74/184) to 60% (96/159) in ICU dying patients in mainland China (Xu et al. 2001; Sheng et al. 2012; Zhao et al. 2014). THtD usually followed the decision to WLST being documented. WLST has become a common practice in much of the world (Curtis and Vincent 2010). WLST is the decision to actively stop a life-sustaining intervention presently being given for example cardiopulmonary resuscitation (CPR), endotracheal intubation, mechanical ventilation (MV), vasopressor therapy, total parenteral nutrition, dialysis, blood products, antibiotics, and intravenous fluids (Sprung et al. 2014b). The practical triggers for initiating discussions on WLST include multi-organ failure, predicted short-term survival, and predicted poor neurologic outcome (Joynt et al. 2015).

Evidence from quantitative studies, which is limited, shows that family members play a central role in the decisions to WLST and go home to die from ICUs in mainland China. Retrospective case reviews of ICU in China reported that 79% of the 136 requests to WLST (Sheng et al. 2012) and 98% of 96 cases of self-discharge for a home death (Xu et al. 2001) were raised by family members without patients' participation, and all the decisions were finally signed by family members including adult children and spouse (Xu et al. 2001; Gu et al. 2012). In China, family members can make a decision against doctors' advice and patients' own wishes. For instance, the retrospective review of an ICU by Zhao et al. (2014) reported that most (93% of 82 patients) of the decisions to WLST were made by patients' families without the intervention of physicians.

Although the prevalence of WLST is reported to be lower in Asia (Phua et al. 2015) than in the West (Mark et al. 2015; Lobo et al. 2017), a variation caused by the differences in the case mix of patients, their severity of illness, and differences between attitudes, religions, and cultures of patients and their surrogates (Sprung et al. 2015), WLST is not uncommon in critically ill patients in China (Zhao et al. 2014). For example, retrospective case note reviews in China revealed that 68% (137/202) of patients in one ICU (Gu et al. 2012) and 65% (136/211) of dying patients in another ICU (Sheng et al. 2012) had a decision to forgo LST. Following the decision to WLST, what happens next is a key question for family members of patients in CCUs. In the West death is most likely to take place in the CCU or hospital setting (Coombs et al. 2017) whereas the expectation in China and indicated in preceding sections is that death will occur in the patients' home. The family related decision-making process regarding how these decisions are made, discussed, shared, and implemented are not known. Therefore, based on my personal experience and observation in the previous clinical practice as an intensive care nurse, the study presented in this thesis was designed to explore this gap in the knowledge base with the aim of informing end of life care practice and policy in Chinese ICUs.

The study aimed to address the following research question: What were the experiences of families who made the decision to transfer their relative from the ICU in China to die at home?

1.6.5 Conclusion

Macrosocial factors play a key part in where patients die, including health policies, stages of development of palliative care, cultural beliefs and attitudes towards place of death and dying at home; these might explain the variations in place of death between countries and regions (Gomes and Higginson 2006). Overall, China has the largest proportion of home deaths, followed by a relatively small proportion of hospital deaths, and a low proportion of deaths in other institutions (i.e. nursing homes). Such a pattern is mainly determined by the Chinese healthcare system, its traditions regarding family, and cultural values on place of death (Gu et al. 2007; Cai et al. 2017; Li et al. 2019). The healthcare system in China has very limited input in supporting home deaths due to the early stage of development of EoLC systems. In addition, the limited coverage of health insurance and high out-of-pocket expenses is a reason for many patients to go home to die in China, because hospital deaths are expensive. In Chinese tradition, family is both the primary caregiver and the primary decision-makers for many EoLC decisions. For Chinese people, home has the cultural and religious meaning, thus going home to die is a common event which presents specific challenges to family caregivers. These challenges are the basis for the exploration presented in this thesis.

The study in this thesis addressed a major gap in the knowledge about decision-making and families' experiences, and provided important evidence to inform the development of care services, evidence-based guidance and policies for THtD and EoL decision-making in critical care contexts in mainland China.

1.7 Structure of the thesis

This thesis presents a qualitative study exploring the decision-making regarding transferring patients home to die from an ICU in China, through understanding family members' stories elicited in interviews about their experiences of taking a dying relative home.

Chapter Two presents a systematic scoping review of the global literature related to transfer practice and underpinning the decision-making required for a transfer in the international context.

Chapter Three illustrates the philosophical position and methodology guiding the research process, justifying choices of methods.

Chapter Four presents the methods and research processes with rationale for specific approaches for sampling and data collection, as well as the reflexivity on research processes.

Chapter Five outlines the data analysis, which was a six-stage process of thematic analysis.

Chapter Six presents the findings of the study including four themes and an overarching theme that addressed the research question and objectives.

Chapter Seven discusses the findings of this thesis, positioning it in the wider literature and international context, directly linking to the research question and objectives.

Chapter Eight concludes the study, makes recommendations for future research, policy and practice, and reflects on the whole study in terms of limitations and challenges, as well as the researcher’s self-reflections.

Chapter 2 International practices of transfer home: a scoping review

2.1 Introduction

Chapter Two presents a systematic scoping review aiming to illustrate the current state of knowledge related to the practice of transferring patients from CCUs, home to die. Literature reviews offer a starting point for researchers as they identify existing knowledge and the historical, theoretical, social, and clinical context within which the topic of interest is embedded (Thompson 2009). Furthermore, reviews can inform decision making around data collection and analytic method choices following a critique of retrieved studies (Maggio et al. 2016). A literature review is a first step in uncovering what is currently known about the phenomenon to be investigated.

The primary purpose of the literature review presented in this chapter is to map the current practice of transferring a critical care patient home to die from an international perspective, identify what is known about this practice clarifying: what research designs have been chosen to explore this practice, what challenges have been identified and what recommendations are in place. By setting the scene the contextual knowledge of conducting the following study in this thesis is provided, the rationale for further research is established and the methods for further research are determined.

Chapter Two concludes with the description of the research question and objectives, and the justification for the conduct of the research.

2.2 Scoping review methodology

A scoping review is "a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting and synthesizing existing knowledge" (Colquhoun et al. 2014). Scoping review methodology is particularly suitable for a field with emerging evidence, where the literature has not been comprehensively reviewed, or is complex or heterogeneous nature (Mays et al. 2001; Peters et al. 2015b; Peters et al. 2017).

2.2.1 Strengths and limitations of scoping reviews

Scoping reviews include several incomparable strengths as a type of literature review. Scoping reviews aim to include a broad evidence base and range of research methodologies and in addition to quantitative, qualitative and mixed method studies would also include non-empirical work such as discussion and opinion text. Evidence and insights about the phenomenon of interest are presented in an accessible and summarised format (tabulated or charted). With the established guiding frameworks, scoping reviews provide a rigours and transparent approach for mapping literature of a particular area (Peters et al. 2017; Tricco et al. 2018). It is a type of literature review that is widely used to identify the gaps in literature, inform the future research priorities on a specific topic and are being used increasingly in healthcare to inform clinical practice and identify research questions (Anderson et al. 2008; Davis et al. 2009; Pham et al. 2014).

Some limitations of scoping reviews have also been discussed in the literature. The balance between breadth and depth of a scoping review is a challenge for researchers (Arksey and O'Malley 2005; Pham et al. 2014). The relatively broad questions addressed in scoping reviews can generate a substantial amount of data from papers included. A coverage of all available literature can result in challenge in providing a detailed analysis that is easier on a smaller number of studies. A decision on the breadth of the literature has to be made with a consideration of the resources for synthesis of data. Another limitation of scoping reviews is that some relevant papers may be missed for inclusion (Pham et al. 2014). Scoping reviews seek to cover a broader scope so that a complete map of the literature can be drawn. However it is impossible to include all papers met inclusion criteria in a scoping review. Scoping reviews often select a limited number of databases, exclude some sources of grey literature, and include papers written in English. Finally, a scoping review is not a “rapid” and “cheap” option compared to other types of review (Anderson et al. 2008). The choice of the scoping review methodology is decided by the objectives of study rather than by time and finance reasons.

A debate about the scoping review methodology is the need for quality assessment. The lack of critical appraisal of literature was reported as a major limitation in some scoping reviews (Brien et al. 2010; Feehan et al. 2011; Boström et al. 2012). However, other researchers stated that the primary aim of a scoping review is to pursue a broad coverage of relevant literature rather than to generate a standard evidence for addressing a focused question (McColl et al. 2009; Njelesani et al. 2011). The quality assessment is set as an optional step in most frameworks and is not used to exclude papers on grounds of quality (Arksey and O'Malley 2005; Peters et al. 2017).

The drawbacks of scoping reviews can be limited by articulation of a clearly defined focus and ensuring there is an audit trail for transparency. A scoping review approach is suitable for the current review, to broadly map the available international literature reporting or discussing the practice of THtD from CCUs.

2.2.2 Scoping review frameworks

Several frameworks are available for conducting scoping reviews and four of them are influential.

The first methodological framework for scoping reviews is considered the framework published in 2005 by Arksey and O’Malley. Arksey and O’Malley outlined this framework based on their experiences of reviewing the literature on services for carers for people with mental health problems (Arksey et al. 2002; Arksey and O'Malley 2005). The scoping studies in this framework referred to ‘map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as standalone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before’ (Mays et al. 2001: 194). The Arksey and O’ Malley framework comprises six stages: identifying the research question, searching for relevant studies, selecting studies, charting the data, collating, summarizing, and reporting the results, and consulting with stakeholders to inform or validate study findings. The Arksey and O’ Malley framework is the most widely applied methodological framework for scoping reviews (Pham et al. 2014).

However, some researchers encountered challenges in applying the Arksey and O’ Malley framework in their scoping reviews and made recommendations to enhance the framework (Brien et al. 2010; Levac et al. 2010; Daudt et al. 2013; Peters et al. 2015b).

Levac et al. (2010) clarified some detail and made recommendations to the Arksey and O’Malley framework: a) linking the purpose and research question (stage one); b) balancing feasibility with breadth and comprehensiveness of the scoping process (stage two); c) using an iterative team approach to study selection (stage three) and d) data extraction (stage four); e) incorporating a numerical summary and qualitative thematic analysis, reporting results, and considering the implications of study findings to policy, practice, or research (stage five); f) incorporating consultation with stakeholders as a required knowledge translation component of scoping study methodology (stage six). The advancements by Levac et al. (2010) provide more explicit detail regarding what occurs at each stage of the review process and this enhancement increases both the clarity and rigor of the review process. Levac et al. (2010) also called for additional considerations on the consistency of the terminology and further discussions on the quality assessment for scoping study methodology.

Daudt et al. (2013) further enhance the framework of scoping reviews surrounding the types of questions for which Arksey and O’Malley’s framework is most appropriate and suggestions to the six-stage framework based on their experience of working with Arksey and O’Malley’s framework. Daudt et al. (2013) argued that questions portraying comparisons such as between interventions, programs, or approaches seem to be the most suitable to scoping reviews. Recommendations by the authors included piloting the Arksey and O'Malley's framework, keeping flexible, using a large, inter-professional team, and assessing the quality of studies.

2.2.3 The Joanna Briggs Institute framework for this scoping review

Based on earlier work by Arksey and O'Malley (2005) and Levac et al. (2010), the Joanna Briggs Institute (JBI) developed a guidance for the conduct of scoping reviews (Peters et al. 2015a; Peters et al. 2015b) and this guidance was updated in 2017 (Peters et al. 2017). JBI guidance outlines a review process that includes the elements presented in Table 2.1. In line with the JBI framework, the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) reporting checklist was published recently to assist in standardizing the conduct and reporting of scoping reviews. The PRISMA-ScR checklist comprises 20 items plus 2 optional items (Tricco et al. 2018). In addition, The JBI guidance provides a distinctive framework for defining the components involved in a scoping review: Participants, Concept, and Context (PCC). Outcomes, interventions or phenomena of interest do not need to be stated explicitly for a scoping review; however elements of each of these may be implicit in the Concept (Peters et al. 2017).

The current review chose the JBI framework to systematically search literature and map the available evidence on the practice of THtD. The choice of the JBI framework rather than other frameworks was underpinned by the consideration that it should be, to date, the most rigorous and clearly defined framework for conducting scoping reviews. The JBI framework is an advanced guidance to the collective work by Arksey and O'Malley (2005) and Levac et al. (2010) and therefore has the least deficiencies as a methodological framework for scoping reviews. Since it was first published in 2005, a number of scoping review studies about various topics related to health care published or on-going has used the JBI framework (Peters 2016).

As a part of a PhD thesis, the process of JBI scoping reviews was amended for use in this thesis with the process followed outlined in Table 2.1.

Table 2.1 The JBI scoping review framework and PRISMA-ScR with amendments and associated rationale

The JBI framework for scoping reviews	How implemented in this literature review.
Review authors: at least two reviewers	Author with 41 papers being reviewed by supervisors.
PCC structures: Participants, Concept, and Context	The PCC structure in JBI framework directly guided the process of this scoping review, including the development of the review objectives and review question, inclusion and exclusion criteria, search strategy, data extraction, and presentation of results.
Review question(s): underpinned by review objectives Review objective(s)	Stated in section 2.3. Review objectives outlined in Table 2.2.
Inclusion criteria: the basis on which sources will be considered for inclusion in the scoping review; be clearly defined; Types of participants: characteristics (i.e. age) Concept: the core concept or the principle focus, including the components of 'interventions' and/or 'phenomena of interest' and "outcomes"; Context: specific clinical settings, cultural context/ countries; Types of sources: the design/methods, empirical and non-empirical work.	See section 2.4. Inclusion criteria with justification is set out in Table 2.3.
A three-step search strategy if recommended: 1) an initial limited search of at least two appropriate online databases relevant to the topic, and an analysis of the text words contained in the title and abstract of retrieved papers, and of the index terms used to describe the articles, 2) a second search using all identified keywords and index terms across all included databases,	The search strategy is outlined in section 2.5.

3) the reference list of identified or selected from full-text and/or included in the review is searched for additional studies; be comprehensive including both published and unpublished papers; author contact; hand search for key journals; the input of a research librarian; limitations such as language and timeframe.	
Study selection: the screening of title and abstract and subsequent reviewing of full text by two reviewers independently. Quality assessment: optional, usually absent.	The paper selection was incorporated in the search process which is described in section 2.5. Quality assessment was not conducted in this review.
Data extraction: referring to 'charting the data', extract all data relevant to inform the scoping review objective/s and question/s, develop a tool (charting forms or tables) for charting, determine and define the items of data to be extracted: author, year, objectives, participants, concept, context, and two reviewers carry out the data extraction.	See section 2.7. The following data were extracted and tabulated: author(s), year, study title, country of origin, study population & sample size, methodology/ methods, the number /percentage of transfer, characteristics of patients transferred, participants in the decision making process, barriers to, and facilitators of THtD. The charting form and data items were established by thesis author with review by supervisors.
Synthesis of data: describe the methods of handling and summarizing the data that were charted.	See section 2.8.
Presentation of results: describe the results in brief and how they have been organized in relation to the objective and question/s of the scoping review. Classify the results under the concept categories. The results can be presented: in a narrative format, table, or visual representation, including a map or diagram.	A narrative summary and the themes of results are presented in section 2.9. A PRISMA flow chart presenting the search decision is shown in section 2.6. All data extracted are presented in Table 2.5.

2.3 The review question and objectives

A broad review question was developed to guide the scoping review: "What is known in the international literature about the practice of transferring patients home to die from hospital critical care units?"

Specific objectives for the review are justified in Table 2.2.

Table 2.2 Review objectives and the rationale

Review objectives		Rationale
1	To identify the countries where the practice of transfer is reported	A geographical distribution of the practice provides the information on the national, social and cultural context of the transfer practice.
2	To identify the types (characteristics) of patients transferred in these countries	A better understanding about the population that the practice of transfer targeted, including the criteria for transfer on the patients' characteristics (who were transferred, who were not considered for a transfer)
3	To identify the barriers to and facilitators of transfer	A summary of the factors influencing the process of transfer reported in the literature gives an overview of the main findings of included papers and in-depth knowledge of the complexity of practice

2.4 Inclusion criteria

The inclusion criteria for the review is presented in Table 2.3.

This review considered papers concerning the transfer of dying patients who were aged 18 and older, of any gender, diagnosis and ethnicity. Papers about other individuals' perspectives or views on the practice of transfer were also considered, including HCPs, patients' families and policymakers.

Dying patients in this review were defined as terminally ill or critically ill patients who were treated in critical care settings. Such patients are often in complicated conditions: severe respiratory, cardiovascular or neurological derangement, often in combination, unconscious, maintained by MV and inotropes (Bangash et al. 2012; Bauchmuller and Faulds 2015; Sprigings and Chambers 2017).

Table 2.3 Inclusion criteria for the scoping review

Inclusion criteria	
Types of participants	Dying patients who were critically ill or terminally ill in CCUs; Age: 18 years and older
Concept	Papers provided information about the practice of transferring home to die
Context	Setting: CCUs (ICUs, ITUs, HTUs); Transfer destinations: patients' home; Any geographical locations: any countries or regions
Types of sources	any types of sources: quantitative, qualitative, mixed methods, text papers such as reviews, service description, discussion and opinion papers, book or book chapter, newspaper, government policy documents, websites
Date range	1970-2019

Sources about transferring non-adult patients including new-borns, infants and children, were excluded. The age limitation was determined by the objectives of the review. This review targeted the adult group to inform the research priorities in the field of transfer practice for adult patients. The transfer for non-adult groups differs from this process for adult patients in many aspects (Hawdon et al. 1994; Zwerdling et al. 2006; Stark et al. 2008; Simpson and Penrose 2011; Laddie et al. 2014). For example, the decision-maker for the transfer often has to be the parents instead of the patients themselves.

Papers reporting or discussing the practice of transferring or discharging adult patients home to die from CCUs were sought for inclusion. Specifically papers that described any following information were included: number of patients transferred over a specified period of time, individuals involved in the transfer decision-making process, and barriers to, and facilitators of THtD.

Studies that reported the number of transfers over a specified period of time or the rate of transfer in a particular CCU were sought to provide context to how this process is operationalised.

The identification of individuals involved in the decision-making process for a transfer was essential for understanding the practice of transfer so that initial barriers to, and facilitators of transfer could be reviewed. An analysis of this evidence would inform an in-depth understanding about the complexity of the transfer practice.

The setting or context was CCUs including ICUs, intensive therapy units (ITUs), and high dependency units (HDUs) which is one level down from intensive care (NICE 2009; NHS Choices

2015) in any countries or regions. Transfer from non-CCUs was excluded. Studies carried out in any geographic locations were included (Objective One) so that transfer practice from an international perspective could be mapped.

Papers that reported the destination of transfer that was not the patients' home were excluded. These included locations such as general hospital wards, other hospitals and institutions, such as hospices, or nursing homes. In this review, home has been defined as the place where the patient lived usually and is claimed as home by themselves or their families.

No limitation was imposed on the types of sources for this scoping review or design or methodology. Both published and unpublished sources, were reviewed including grey literature including government information and reports, books or book chapters, newspapers, and websites.

The papers published from 1970 to present (2019) were included. The timeframe was determined by the emergence in the literature of discussions on place of care for the dying, place of death, home death, discharge home to die and intensive care practice. The debates about place of death entered are recorded in literature from 1970 (Lerner 1970; McNulty 1970; McNulty 1973), therefore 1970 to 2019 was the date range set for the coverage of this review.

2.5 Search strategy

As recommended by the JBI framework for scoping reviews, a three-step search strategy was utilized.

Step One: the search terms listed in Table 2.4 were entered into an initial search in MEDLINE and CINAHL. The two databases were selected as they are the main sources of literature in the field of medicine and nursing and therefore appropriate for the search of evidence on the topic of transfer practice which involves doctors and nurses.

Step One generated four papers, three of which were relevant to the topic. The title, abstract and keywords of the papers produced 18 new search terms (end of life care, discharge, transfer, transfer patient, transfer home to die, transfer home, discharge home, discharge planning, transitional care, transition of care, continuity of care, continuity of patient care, location of death, site of death, home care service, home hospice, home palliative care, critical care) that were added to the search terms and the second step.

Table 2.4 The initial search strategy on MEDLINE

Database	MEDLINE (EBSCO)
Timeframe	1970 - 2019
Search terms	"dying patient*" OR "terminally ill patient*" OR (MH "Terminally Ill") OR "terminally ill" OR (MH Terminal care") OR " withdrawal of treatment" OR "withdrawal of life sustaining treatment" OR "treatment withdrawal" OR "end of life" AND (MH "Patient Transfer") OR "patient transfer" OR (MH "Patient Discharge") OR "patient discharge" OR (MH "Patient Handoff") OR "patient handoff" AND "home death" OR "dying at home" OR "death at home" OR "place of death" OR "dying location" AND (MH "Intensive Care Units") OR "critical care unit*" OR (MH "Critical Care") OR "intensive care unit*" OR "critical care setting*" OR CCU* OR ICU* Limiters - Language: English and Chinese; Date of Publication: 1970-2019.

Step Two: using identified keywords and index terms a full search was undertaken across all included databases and websites (see appendix A.1). The search strategy for Step Two was reviewed by a medical librarian at the University of Southampton. Revision advice was offered in line with the review objectives and question, including the search terms and adding the literature sources of Scopus and NICE.

The full search strategy in database MEDLINE is provided in appendix A.2. Adaptions of the actual search on each database or website was made where necessary.

Step Two produced 239 records from the search of all platforms, comprising 172 papers from bibliographic databases and 67 papers from grey literature sources (Identification stage in Figure 2.1). All identified papers (n=239) were imported into the software Endnote X7.2 (Clarivate Analytics, PA, USA)). After removing duplicates 163 records were obtained. The title and abstract of each paper were screened against the inclusion and exclusion criteria and selected articles were discussed with supervisors. At the screening stage 122 papers were excluded and 41 were selected and retrieved for full-text review and the scan of reference lists in step three (Screening stage in Figure 2.1).

Step Three included review of the reference lists of the 41 papers retrieved in step two. An additional seven papers were obtained resulting in 48 papers eligible for full-text review (Eligibility stage in Figure 2.1).

Two authors (Maureen A Coombs and Anne-Sophie E Darlington) of the key/highly relevant papers were contacted and no published, unpublished and ongoing studies related to the question were added by them.

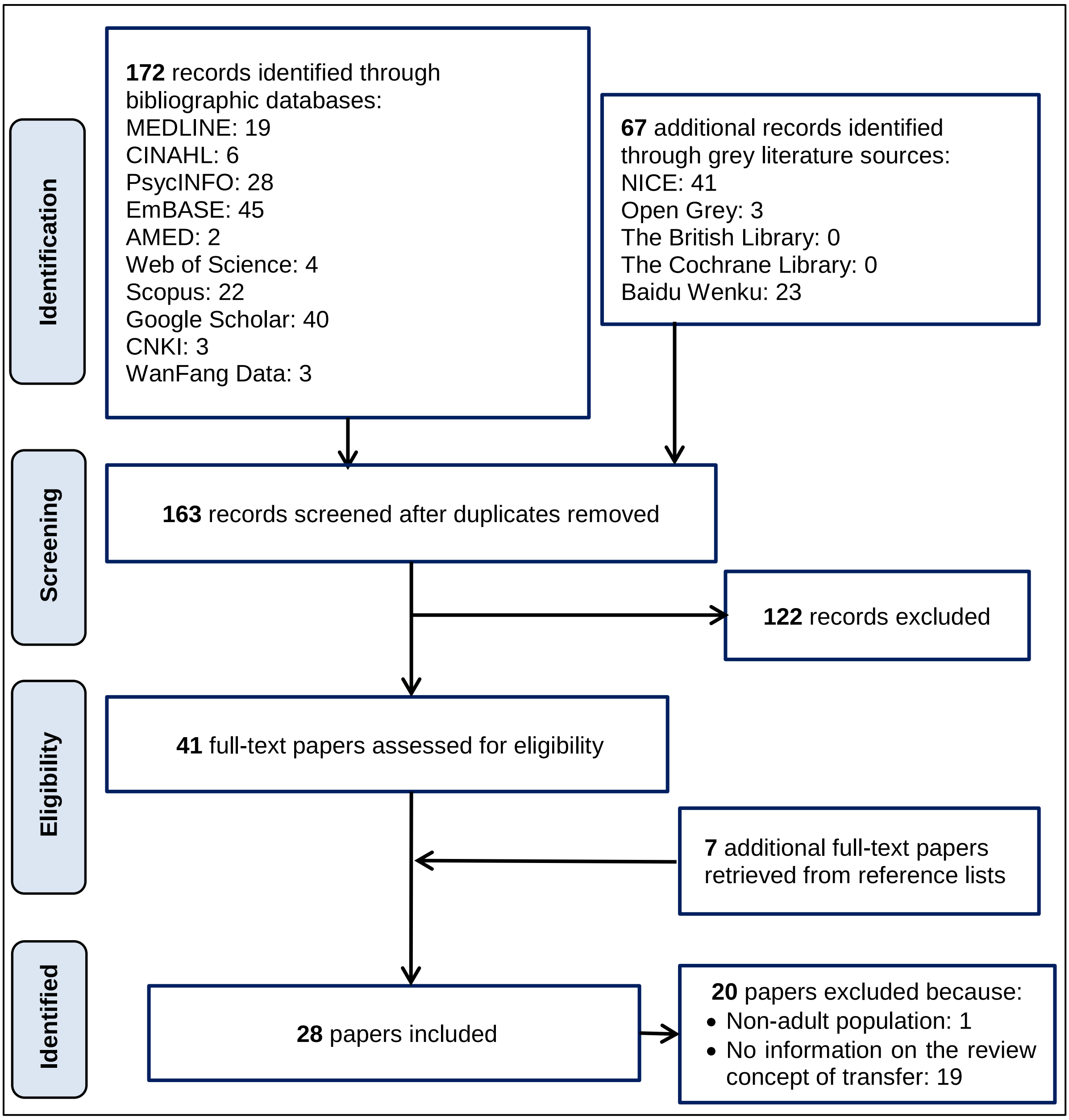
2.6 Outcome of searches

The outcome of searches including the paper selection process are presented in the PRISMA-ScR flow chart in Figure 2.1.

Papers written in English and Chinese were included as the author is bilingual. Of the 48 papers reviewed in full, 28 papers, five of which were written in Chinese, met the inclusion criteria. The papers excluded (n=20) and rationale for exclusion are shown in appendix A.3.

In this review, quality of papers included was not rated as this is not the aim of a scoping review (Peters et al. 2017; Tricco et al. 2018). Although the quality assessment was not formally conducted this review took a critical stance to the retrieved literature.

Figure 2.1 The flow chart of search and paper selection



2.7 Extraction of data

The data extraction in scoping reviews refers to “charting the results” (Peters et al. 2017 P15) . A data extraction template was developed to collect key information: 1) author(s); 2) year of publication; 3) country of origin: the location where the transfer was conducted or considered; 4) number /percentage of patients transferred home: the size of transfer over a period of time or the rate of transfer in total death in a particular unit; 5) characteristics of patients transferred: the demographics (age, gender and ethnicity), cause of death, clinical status (blood pressure, mental capacity) and life support interventions (i.e. MV and inotropes), and time to death following transfer; 6) participants in the decision-making process of transfer: the individuals involved in the process of deciding the transfer of a dying patient; 7) barriers to, and facilitators of transfer: factors that prohibit or facilitate the practice of transfer.

2.8 Synthesis of data

The synthesis of data refers to summarizing and presenting the charting results aligning with the review's objectives (Peters et al. 2017; Tricco et al. 2018). Findings were presented as a map of the data in the tabular form. These findings were grouped and synthesized into nine themes: study design, country of origin, transfer size, the perspectives of investigation, patient characteristics, participants included in transfer decision-making process, barriers to and facilitators of transfer, the transfer practice in China, and gaps in literature.

2.9 Findings

Linking to the review question and objectives a map of all the data extracted from the 28 papers about the international practices of THtD from CCUs was generated, including an overview of all the retrieved papers, the transfer size and characteristics of patients transferred home to die, participants included in transfer decision-making and the barriers to, and facilitators of transfer (Table 2.5).

Table 2.5 The retrieved papers about the practice of THtD (n=28)

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
Coombs et al. (2017) Transferring patients home to die: what is the potential population in UK critical care units, UK	To determine the size and characteristics of the critical care population who could potentially be transferred home to die	All patients admitted to the ICU/HDUs during 1 January 2011 to 31 December 2011 and who subsequently died in the ICU/HDU or within 5 days of discharge from these units (n=7844)	Retrospective cohort study	-	-	-	-	-
Hutchinson and Van Wissen (2017) Home to die from the intensive care unit: a qualitative descriptive study of the family's experience, New Zealand	To gain insight into family members' experiences when an adult ICU patient is taken home to die	Four family members of patients transferred	Qualitative descriptive study	4 (in 14 months)	Conscious (2); tracheostomy (1)	Patient, family, ICU doctors and nurses, community care services	Barrier: family inability to cope with the patient at home; Barrier: everything happened quickly; Barrier: the knowledge and skills of the ICU teams; Barrier: the distance to be travelled	Facilitator: the patient's wish, supported by family; Facilitator: respect it as an option; Facilitator: in collaboration with the family; Facilitator: information for families around: support availability, staff responsible after leaving ICU, and options if they do not cope at home; Facilitator: a single facilitator with in depth knowledge of the process and services
Liu and Zhu (2016) Influencing factors of	To understand the reasons that families	Family members of ICU patients (n=10)	Phenomenological study	-	-	Family members, ICU physician	Barrier: health insurance coverage; Barrier: a lack of place of care before death;	-

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
clinical decision of family members of end of life patients in intensive care unit, Mainland China	refused to forgo treatment for ICU terminally ill patients						Barrier: attitudes towards death in Chinese culture; Barrier: family disagreement (all were factors influencing WLST)	
Liu et al. (2016) Qualitative research on refusing to give up treatment of family members for ICU end-of-life patients, Mainland China	To understand the factors associated with family members' decisions for terminally patients in ICU	Family members of ICU patients (n=10)	Phenomenological study	-	-	Family members	Barrier: a lack of place of care before death Barrier: family disagreement Barrier: filial piety Barrier: the taboo about death	Facilitator: doctors' poor prognosis; Facilitator: family financial difficulties Facilitator: patients' wishes of going home to die; Facilitator: the cultural norm about going home to die
Coombs et al. (2015) Transferring critically ill patients home to die: developing a clinical guidance document, UK	To develop clinical guidance on the practice of transferring patients home to die for doctors and nurses in critical care	Doctors and nurses from secondary (n=57) and primary care trusts or palliative care teams (n=18), allied health professionals (n= 4), service users (n= 6)	Mixed methods involving consensus methodology and nominal group technique	-	-	Patient, family, ICU staff, community-based teams, GP, Macmillan/hospice visits, bereavement services, in-hospital teams (including home team, rapid discharge)	Barrier: the traditional technological and curative focus of critical care Barrier: unrealistic expectations of family members about death at home; Barrier: a complex, time-dependent process; Barrier: access to care in the community	Facilitator: patient's wish, patient's capacity to undertake decision-making; Facilitator: preparing families for what will most likely ensue; Facilitator: a complex, multifactorial process involving health care agencies across the primary and secondary care interface; a single person/point of contact to lead on transfer arrangements; Facilitator: the guidance developed from the study will enable staff to actively consider the practice of THtD in appropriate patients

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
Darlington et al. (2015) A national survey exploring views and experience of health professionals about transferring patients from critical care home to die, UK	To examine (1) HCPs' experience of transferring patients home to die from critical care, (2) HCPs' views about transfer and (3) characteristics of patients, HCPs would hypothetically consider transfer	180 lead doctors and senior nurses working in 409 CCUs across the UK	National online survey	-	-	-	Barrier: poorly explored in the literature, an uncommon event in critical care; Barrier: a minority of respondents viewed as a waste of health service resources or the critical care staff have more pressing clinical priorities than transferring patients home to die; Barrier: clinically unstable; Barrier: very little time to make important decisions and organise THtD	Facilitator: most participants held largely positive views; Facilitator: more clinical guidance would assist in decision-making to identify appropriate patients for this practice; building consensus around characteristics of patients and supporting guidelines might improve choice and care at end of life in critical care
Xie et al. (2015) Feelings of withdrawal of life sustaining therapy in families of ICU dying patients, Mainland China	To understand family members' experience of forgoing treatment for patients at end of life stage in ICU in multi-ethnic regions of Xinjiang	Family members of patients with decision to WLST in ICU (n=15)	Phenomenological study	-	-	Family members, ICU physician	-	Facilitator: poor prognosis and no hope of recovery; Facilitator: cultural and religious reasons about going home to die Facilitator: family financial burden Facilitator: poor quality of prolonged life (all were factors with WLST)

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
Battle et al. (2014) Enabling ICU patients to die at home, UK	Unspecified	See Column Patient perspective	CCR	2	F, 68, COPD, conscious, tracheostomy and ventilation, a few minutes; F, 71, ovarian adenocarcinoma, conscious, ventilation, 3.5 hours	Patient, family, a friend, ICU doctors and nurses, consultant; ICU nurses, healthcare assistant, district nurse liaison team, local bereavement team, hospice staff, end of life care programme manager, the ward manager	Barrier: a unique request in our unit's experience, a relatively innovative concept in the UK; Barrier: specialised and technical nature of ICU, the existing paradigm of intensive care; Barrier: local bereavement team be confused about the contact by ICU staff, a death certificate by the GP; Barrier: the estimated arrival time	Facilitator: a patient's final wish to go home; Facilitator: an option for a small but significant proportion of patients, the right thing to do, family agreed with the patient's wishes; Facilitator: the family or friend was prepared for what was likely to happen; Facilitator: a multidisciplinary approach; good organisation and communication between primary and secondary care; Facilitator: a 'standard of work' formulated to support similar discharges in future; an 'end of life at home' group was established, including the ward manager, ICU consultant, four staff nurses and a healthcare assistant; an information leaflet for relatives and carers, based on family feedback and staff consultation
Coombs et al. (2014) Doctors' and nurses' views and experience of transferring patients from critical care home to die: a qualitative	To examine current experiences of, practices in and views towards transferring patients in critical care	49 HCPs: doctors and nurses from four ICUs, GPs and community nurses; members of a Patient and Public Forum; 15 nurses and 6	Exploratory two-stage qualitative study: focus groups, follow up interviews	-	-	Patient, family members, CCU staff, community colleagues: GP, district nurses, palliative care teams, specific hospital-based personnel, rapid discharge teams, ambulance services and finance managers	Barrier: a rare event in the UK, not a usual end-of-life care but a response to a request from the patient or family; Barrier: moving a patient from curative interventions to end-of-life care; Barrier: 'certain types of patients' with high care needs who were ventilated, had an	Facilitator: participants were generally positive and supportive of THtD; the family's willingness to transfer; Facilitator: staff spoke with family about what care would be required to care for a patient at home; how family members could be prepared for the THtD;

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
exploratory study, UK	settings home to die	consultants from CCUs					ischaemic bowel (with continuous diarrhoea), needed regular surgery, had open wounds, a tracheostomy, experienced uncontrollable pain, were receiving high levels of sedation, were unconscious or were assessed as having inadequate mental capacity; Barrier: the perceived capabilities of the family to cope with a death at home; Barrier: uncertain time to death; Barrier: uncertain about community service provision; Barrier: making a difference to the staffing on the unit, legal cover to undertake care in people's homes; requiring a skill set that most critical care doctors and nurses have not yet developed	Facilitator: a complex process requiring multi-agency collaboration and engagement; a coordinator to lead the THtD
Zhao et al. (2014) Current situation and associated factors of withdrawing or withholding life support to patients in an intensive care unit of cancer	To investigate the current situation and analyse the associated factors of withdrawing or withholding life support	ICU patients (n=322, in two years)	Retrospective observational study	52% (64/124) of all dying patients (calculated based on available data)	-	Family members (adult children and spouse), physicians	-	Facilitator: in emergency or critically clinical condition Facilitator: cultural requirements Facilitator: financial difficulties (all were factors influencing WLST)

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
center in China, Mainland China	in ICU of the authors' cancer centre							
Campbell (2013) Opinion piece: Honouring the wishes of a dying patient: from intensive care to home with palliative care, Australia	Unspecified	See Column Patient perspective	CCR	1	M, 64, Urosepsis and multi-organ failure, conscious, no ventilation and inotropes, a few days	Patient, family, ICU medical team, a clinical nurse consultant from palliative care	Barrier: transition from curative care to palliative care, the culture of ICU focuses on saving lives rather than palliation; Barrier: it is impossible to arrange home mechanical ventilation; Barrier: little training to ICU physicians in providing palliative care	Facilitator: wish to go home Facilitator: a multidisciplinary team effort
Nielsen (2013) Getting critical care patients home for end-of-life care, Denmark	Unspecified	See Column Patient perspective	CCR (conference abstract)	7 (in two years)	Age: 68-84; Cause of death: end-stage lung disease, cancer, surgical complications, conscious; Time to death: a few hours-four days	Patient, family, ICU HCPs, primary care physician and nurse	Barrier: stable enough to go home	Facilitator: a wish for the patient to go home; Facilitator: HCPs' positive experiences
Sheng et al. (2012) Investigation on decision-making of ICU dying patients and their families, Mainland China	To understand the participation of patients and their families in decision-making in ICU and analyse the types and	Patients who were not cured or died in the ICU of two hospitals (n=211, in one year)	Retrospective chart review	40% (74/184) of all dying patients (calculated based on available data)	-(no characteristics of patients discharged)	Family members (adult children and spouse), physicians	Barrier: high household income	Facilitator: family members' request for WLST Facilitator: family financial difficulties (all were factors influencing WLST)

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
	reasons of forgoing ICU treatment							
Tellett et al. (2012) End of life in intensive care: is transfer home an alternative?, UK	This paper seeks to challenge assumptions and practices about the options for transferring the critically ill patient home at end of life	A patient's wife	Collaborative writing between authors and participant	1	M; 58; Ebstein anomaly; conscious; haemofiltration and dopamine support which were stopped before transfer; three days.	The patient, family (wife, two children), intensive care team, palliative care team, different clinical teams involved in the treatment (congenital cardiac, heart failure, respiratory, electrophysiology, hepatology; and renal)	Barrier: an option not for all but only for some patients; Barrier: physiological reserve to survive the transfer; Barrier: the family may not be in position to cope; Barrier: decision-making took time and negotiation; Barrier: lack of support from the hospital palliative care consultant, GP and hospital and community based specialist nurses; Barrier: the feasibility of access at home	Facilitator: there are choices for some patients and families; a large and supportive family; getting agreement from patients, families and all staff on decisions to transition to end of life care; Facilitator: ensure family aware of all contact details for support and the risk of dying in transfer and course of events at home; Facilitator: co-operation between critical care and community care colleagues, and support from the palliative care and hospital teams
Clinch and Le (2011) Withdrawal of mechanical ventilation in the home: a case report and review of the literature, Australia	Unspecified	See Column Patient perspective	CCR	1	M, 71, meningoencephalitis and pneumonia, conscious, ventilation, 4.5 hours	Patient, family, ICU clinicians, GP, local domiciliary palliative care, hospital palliative care physician, respiratory clinical nurse, hospital management, registrar	Barrier: not previously reported in the literature; Barrier: significant family conflict on arrival home; Barrier: the withdrawal of life-sustaining therapy at the venue of home from a conscious patient; Barrier: prognostic uncertainty about time to death; Barrier: local domiciliary palliative care service were not prepared to be involved directly with the withdrawal	Facilitator: patient's main request, supported by his family, was to be allowed to die at home; Facilitator: consensus and respect for a patient's needs and wishes; the complete consensus amongst his family, treating clinicians and the institution up to executive level; Facilitator: clear and explicit explanations of the procedure for withdrawal of ventilation, prognostic uncertainty, and the

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
							of ventilation itself; Barrier: be covered from a medico-legal perspective for care of this patient outside the hospital setting; Barrier: delivery of a hospital bed to the home	use of medication for symptom control
Lusardi et al. (2011) The Going Home Initiative: getting critical care patients home with hospice, USA	Unspecified	See Column Patient perspective	CCR/ Service description	7 (2009-2011)	M: 5, F: 2, Age: 66 (55-74), Cause of death: cerebrovascular accident, respiratory failure (1); respiratory failure (4); hypotension (1); pancreatitis, chronic; renal failure (1); no life-sustaining treatment, Time to death: 8 - 48 hours	Patients, families, ICU nurses, the clinical nurse specialist, and the intensivist, primary care physician, local hospice staff, the case manager, an interfaith chaplain, a social worker	Barrier: little guidance from the literature; Barrier: an ICU culture of aggressive interventions, transitions from cure- to comfort-oriented care; Barrier: disagreements among family members about handling the death at home; Barrier: unstable hemodynamic and respiratory conditions; Barrier: physically and/or emotionally unable to provide the necessary care; Barrier: hastening the implementation is difficult; Barrier: lack of family resources, lack of primary physician; Barrier: a substantial distance from the hospital	Facilitator: the desires of each patient and the patient's family; Facilitator: transferring patients home to die has been limited, but overwhelmingly positive; Facilitator: the need to fully prepare families to understand what will happen post-transfer; Facilitator: assessment by a multidisciplinary staff; the multidisciplinary palliative care committee; Facilitator: developing the Going Home Initiative for THtD
Huang et al. (2009) Going home to die from surgical intensive care	To better understand events related to going home to die from	See Column Patient perspective	Retrospective observational study	346 (around 25%, in four years)	M: 227, F: 119; Age: 62.6±16.2; Ethnicity: 98% Han; ventilation; vasopressive medication; Time to	Family, the attendant physician, nurse	Barrier: relevant literature is rare; Barrier: the primary goal is to treat and cure;	Facilitator: a special cultural meaning for Chinese patients and their families; Facilitator: the family chose to take patient home

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
units, Taiwan China	the ICU, with the hope that this information might improve the palliative care of ICU patients				death: within minutes to hours		Barrier: invasive life supportive treatments and monitors	
Kompanje (2009) Should we discharge comatose patients from intensive care to die in their own bed at home after withdrawal of mechanical ventilation? The Netherlands	Unspecified	-	Discussion paper	-	-	-	Barrier: not see the best interests of an unconscious or sedated patient to be transported home to die; Barrier: requiring a physician-staffed mobile intensive care unit, which is a more expensive form of transportation than a normal ambulance	Facilitator: substantial meaning for some cultural or religious groups of patients
Kumar et al. (2009) Withdrawal of intensive care treatment at home - 'a good death', UK	Unspecified	See Column Patient perspective	CCR	1	F, 71, multi-organ failure, conscious, inotropes, 90 minutes	Patient, relatives, ICU doctors and nurses, GP and district nurse, the palliative care team, clinical government bodies	Barrier: having not provided this service before, an uncommon, exceptional event; Barrier: requiring much time, effort, work and compassion by all involved; Barrier: cardiovascular and respiratory instability; Barrier: not be able to cope with the process of home death; Barrier: district	Facilitator: the patient's "last wish is to die at home"

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
							nurse/hospice/palliative led care in place; cooperation by GP for death certification; Barrier: nurse safety;	
Tellett and Davis (2009) Case 43 Fulfilling a patient's wish to go home from intensive care, UK	Unspecified	See Column Patient perspective	CCR	1	M, 58, Ebstein anomaly and multi-organ failure, conscious, inotrope and hemofiltration, three days	Patient, family (wife), cardiac intensive care unit nurse consultant, community, clinical nurse specialist in adult congenital heart disease	Barrier: the stretcher would not go through the front door	Facilitator: the patient's wish to go home
Crighton et al. (2008) Transitioning to End-of-Life Care in the Intensive Care Unit: a case of unifying divergent desires, USA	(1) To gain insight into the multi-dimensional aspects of patient's, family's, and medical providers' approaches to EoLC and (2) To consider how conflicting goals of treatment influence the transition to EoLC in the ICU	See Column Patient perspective	Ethnographic case study	1	F, 62, glioblastoma multiform, unresponsive, no life-sustaining treatment, Time to death: five months	Family, ICU physician, palliative care consultant	Barrier: different goals of care between clinicians and family members; Barrier: family be not prepared to address the reality of the eminent death; Barrier: the amount of time left to live was uncertain	Facilitator: communication: a process of probing the family about the patient's wishes; understanding the family's needs for time for decision-making

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
Beuks et al. (2006) A good death, The Netherlands	Unspecified	See Column Patient perspective	CCR	2	F,56, non-Hodgkin lymphoma, conscious, extubated in ICU, several days F, 58, probably tumour, conscious, extubated in ICU, one day	Patients, families, ICU nursing staff and doctors	Barrier: the primary focus on cure, the first goal is to treat and cure	Facilitator: the strong wish to die at home; Facilitator: when the patient and the family make such a choice we should do our utmost to accommodate their wishes
Boussarsar and Bouchoucha (2006) Dying at home: cultural and religious preferences, Tunisia	Unspecified	See Column Patient perspective	Discussion paper	Nearly 10% of deaths per year (10/102 in 2005)	Ethnicity: Muslims society; Cause of death: late septic shock state and multi-organ failure; respiratory and hemodynamic life support	Family, ICU medical staff	Barrier: clinical stability; Barrier: geographical conditions	Facilitator: a situation culturally strongly desired and approved; Facilitator: requested by family members
Jackson (2006) Withdrawal of care at home: transfer from the ICU to provide end of life care at home, New Zealand	Unspecified	See Column Patient perspective	CCR (conference abstract)	15 (since 1999)	Maori (66%), Pakenham (20%), Samoan (7%) and Pacific Island (7%)	Family, ICU HCPs	Barrier: out of date policies and procedures; Barrier: concerns surrounding nursing safety, inadequate nursing knowledge and experience of the procedure, unfamiliarity in providing care in the home environment	Facilitator: positive experiences
Kallel et al. (2006) A good death: another break in the wall, Tunisia	Unspecified	See Column Patient perspective	CCR	1	M, 76, Muslim, COPD, arterial hypertension, congestive heart failure and diffuse cerebral haemorrhage, deep coma, intubated, ventilation and	Family (wife and two sons), ICU doctor and nurses	Barrier: the major goal is to treat and cure	Facilitator: patients' and family's religion, culture, and wishes; Facilitator: we strongly believe that helping them and their families to choose the circumstances of death and their "deathbed" is also a very important role of the medical

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
					inotropes, a few minutes			team; the family (wife and two sons) told us that the patient wished to die at home in his own bed, and hence they asked us to discharge him home
Ryder-Lewis (2005) Going home from ICU to die: a celebration of life, New Zealand	Unspecified	See Column Patient perspective	Service description	14 patients(over four years)	Maori and Pacific Island families	Family, nursing staff and intensivist, community HCPs, palliative health care teams, ambulance officers, the flight retrieval service, and the coroner	Barrier: safety of the patient and family and any eventualities during transfer; Barrier: difficult to predict the timing of a death; Barrier: challenges of supportive resources in the community; Barrier: a strain to provide a transport team or take staff out of the unit for a period of up to 4 hours for THtD	Facilitator: a celebration of life, the family see it as a desirable option, Facilitator: an open relationship with the family; Facilitator: families are prepared in the ICU for what will be happen at home, and for the community supports that will be in place to help care at home; Facilitator: a multidisciplinary approach; close cooperation with community HCPs; bringing divergent (primary and tertiary) health services together; open communication; careful planning for all eventualities
Mann et al. (2004) Caring for patients and families at the end of life: withdrawal of intensive care in the patient's home, New Zealand	To describe our experience of transporting 17 intensive care patients home to die.	See Column Patient perspective	CCR	17 (1996-2002)	M: 8, F: 9, Age: 51 (19-83), Ethnicity: Maori (who are the indigenous people of New Zealand) or Polynesian; Cause of death: brain injury (4); community cardiac arrest (1); intra-	Family, ICU medical staff, district nurses, GPs, palliative care practitioner or hospice service	Barrier: a death certificate issued without referral to the coroner; Barrier: the patient's home is within a reasonable distance of the hospital (15 kilometres) and transporting the patient is logistically possible;	Facilitator: Maori and Pacific Island families have a powerful sense of family and familial duty and be willing and able to share the burden of caring for a dying relative; Facilitator: the new initiative is a positive practical option; Facilitator: the decision is made on the relationship

Author, Year, Title, Country of origin	Aims	Participants	Design/ Methods	Transfer size	Patient perspective*	Participants in transfer decision-making	Barriers to transfer	Facilitators of transfer
					cerebral haemorrhage (3); brain death (1); multi-organ failure(2); respiratory failure(1),complications following surgery(2); on both ventilation and inotropes (9), only on ventilation (6), only on inotropes (1), neither (1); Time to death: 0.1-72 hours			between the treating nursing/medical staff and the patient's family; Facilitator: families understand what is likely to occur, and have been given the necessary support; Facilitator: a multidisciplinary approach; a palliation plan; a dedicated bereavement team
Xu et al. (2001) The prevalence and factors of self-discharge in ICU, Mainland China	Unspecified	Patients who were classified as "self-discharge" or who died in the ICU (n=159)	Retrospective chart review	60% (96/159, in two years) of dying patients	M: 57, F: 39; Cause of death: traumatic brain injury (n=14), stroke (n=33), tumour (n=7), COPD (n=7), MODS (15), others (n=20)	-	Barrier: younger than 40 of age; Barrier: cremation policy; Barrier: public blame because of filial piety	Facilitator: family financial limitations; Facilitator: cultural norms

*Patient perspective: gender, age, ethnicity, cause of death, capacity of decision-making, life-sustaining treatment, time to death following transfer (not all items were available in every paper); M=male, F=female; COPD= Chronic Obstructive Pulmonary Disease, MODS=Multiple Organ Dysfunction Syndrome;

CCR=Clinical case report; '-' indicates no available data or not applicable item

2.9.1 Study design

Of the 28 included studies (Table 2.5), the majority used the design of clinical case reports (n=11), followed by qualitative study (n=6) and retrospective chart review or observational study (n=5). Diverse designs and methods by the remaining papers included: one service description, two discussion papers, one national online survey, one referred to as collaborative writing, and one mixed methods involving consensus methodology and nominal group technique.

2.9.2 Country of origin

The country of origin informed objective one of the review. Of the retrieved papers, most papers (n=19) were published in the West with a predominance in the UK (Table 2.6). Seven papers offered information about THtD in China with one paper from Taiwan and six from mainland China. Findings indicated that transfer was an international phenomenon which was limited to a small number of countries.

Table 2.6 The country of origin of papers

Country of origin	Number of papers included
UK	8
China	7
New Zealand	4
USA	2
Australia	2
The Netherlands	2
Tunisia	2
Denmark	1

2.9.3 The size of transfer

The number of patients transferred home that were reported to have taken place in each paper of clinical case reports (Table 2.5) ranged from one to17, with most reporting the transfer of one or two patients (Mann et al. 2004; Ryder-Lewis 2005; Beuks et al. 2006; Jackson 2006; Kallel et al. 2006; Crighton et al. 2008; Kumar et al. 2009; Tellett and Davis 2009; Clinch and Le 2011; Lusardi et al. 2011; Tellett et al. 2012; Campbell 2013; Nielsen 2013; Battle et al. 2014; Hutchinson and Van Wissen 2017).

Compared to other countries, it was more common to transfer home to die in Tunisia (Boussarsar and Bouchoucha 2006) and China (Xu et al. 2001; Huang et al. 2009; Sheng et al. 2012; Zhao et al.

2014), particularly in mainland China where 40% (74/184) - 60% (96/159) of dying patients were transferred home to die from ICUs (Xu et al. 2001; Sheng et al. 2012; Zhao et al. 2014).

2.9.4 The perspectives of investigation

The included papers showed that the practice of transfer was investigated mainly from the perspective of HCPs (n=20) in the West, and only two of them primarily explored the experiences of family members in THtD process in the countries outside China (Tellett et al. 2012; Hutchinson and Van Wissen 2017) and three of them described families' experiences of decision-making focusing on WLST for ICU patients in China (Xie et al. 2015; Liu et al. 2016; Liu and Zhu 2016).

Within the retrieved papers, the perspectives of HCPs, largely from the critical care teams, were conveyed in the 11 clinical case reports and sought in papers derived from a three-phase mixed methods research study based in the context of the UK (Coombs et al. 2014; Coombs et al. 2015; Darlington et al. 2015; Coombs et al. 2017). These papers mainly shared and reflected CCU clinicians' limited experiences of the decision-making process and implementation of THtD. In the view of most of HCPs, THtD was a positive option to some patients but a rare and complex practice in critical care.

Two papers explored bereaved family members' experiences of transferring a dying relative home from an ICU, in the UK (Tellett et al. 2012) and New Zealand (Hutchinson and Van Wissen 2017) respectively. The two studies generated stories (Tellett et al. 2012) and themes (Hutchinson and Van Wissen 2017) through qualitative interviews, revealing both the meaning/value and challenges/complex process in families' overall experiences of the event regarding THtD. However, neither paper explicated the process of family decision-making which was not a focus of the two papers.

Three phenomenological studies explored the decision-making for WLST in ICUs in mainland China from family members' perspective with some findings about the practice of THtD in the context of China (Xie et al. 2015; Liu et al. 2016; Liu and Zhu 2016). All three studies gathered data through face-to-face semi-structured interviews and generated categories/themes from analysis regarding the factors influencing family members' decision regarding WLST, following which some patients were taken home to die. Although the three studies mentioned some factors relevant to the choice of THtD (Table 2.5), the relevant findings were superficial, explicit and only suggested some facilitators of transfer, because THtD was not the primary focus of the three studies.

2.9.5 Patient characteristics

Findings about patient characteristics linked to objective two of the review. Information about the characteristics of patients who were transferred home were mainly available from the retrieved papers published in the countries or regions in the West. Only one retrospective chart review briefly reported the patients' gender and cause of death in an ICU in mainland China (Xu et al. 2001). Therefore, little was known about the characteristics of patients transferred home from ICUs in mainland China.

The available demographic information showed that more male patients than female patients (302 male, 175 female), aged between 19 and 83 were transferred home to die, with a time to death following transfer between a few minutes to five months.

Patients reported in the retrieved studies who were transferred home to die could be categorised into three types: conscious or unconscious, intubated and ventilated or not, and stable or instable.

It was usually conscious patients who were transferred home to die in the West (Beuks et al. 2006; Kumar et al. 2009; Tellett and Davis 2009; Clinch and Le 2011; Campbell 2013; Battle et al. 2014) as unconscious patients were not considered suitable for a transfer by HCPs (Kompanje 2009; Coombs et al. 2014; Coombs et al. 2015). However, two CCUs specified they transferred unconscious patients home to die (Kallel et al. 2006; Crighton et al. 2008). Another explanation might be that only conscious patients had the capacity to express their wishes of going home to die.

Patients who did not require intubation and ventilation during the transfer were more often reported (Beuks et al. 2006; Crighton et al. 2008; Tellett and Davis 2009; Lusardi et al. 2011; Tellett et al. 2012; Campbell 2013) than patients who were intubated and/or ventilated. In addition, patients who could not be extubated before transfer were not considered for transfer by some HCPs (Lusardi et al. 2011; Coombs et al. 2014; Coombs et al. 2015; Darlington et al. 2015). In contrast, other practices were able to transfer such kind of patents (Mann et al. 2004; Ryder-Lewis 2005; Kallel et al. 2006; Huang et al. 2009; Clinch and Le 2011; Battle et al. 2014; Hutchinson and Van Wissen 2017).

Unstable patients, such as those with low blood pressure, on inotropes, and who might die soon after reaching home, were not considered suitable to be transferred home to die (Lusardi et al. 2011; Darlington et al. 2015), while some extremely unstable patients were transferred home to die in other settings (Mann et al. 2004; Kallel et al. 2006; Kumar et al. 2009). Huang et al. (2009) reported that terminal status (the blood pressure below 80/40mmHg) was a requirement for implementing the transfer in surgical ICUs in Taiwan China. However, in the UK HCPs considered such patients were not suitable for this option (Darlington et al. 2015; Coombs et al. 2017).

2.9.6 Participants included in decision-making process of THtD

Participants in the transfer decision-making process identified from the retrieved papers included the patient, family, HCPs from critical care, community care, palliative care, hospice care, and staff from other bodies (Table 2.5), with variations of the individuals involved across societies.

In the West, it was common that THtD was requested by patients themselves or they had expressed their wish of going home to die (Beuks et al. 2006; Kumar et al. 2009; Tellett and Davis 2009; Clinch and Le 2011; Tellett et al. 2012; Campbell 2013; Nielsen 2013; Battle et al. 2014; Hutchinson and Van Wissen 2017). These patients were conscious and had capacity for decision-making. The wish of going home to die was often expressed when no curative options available (Beuks et al. 2006; Kumar et al. 2009; Clinch and Le 2011; Campbell 2013; Battle et al. 2014), discussing the WLST (Nielsen 2013), or the patient was aware of and accepted the end of life (Tellett and Davis 2009).

A similar number of studies also stressed the important role of families in the decision-making around THtD (Mann et al. 2004; Ryder-Lewis 2005; Boussarsar and Bouchoucha 2006; Kallel et al. 2006; Crighton et al. 2008; Huang et al. 2009; Coombs et al. 2014; Coombs et al. 2015; Hutchinson and Van Wissen 2017). In those successful transfer practice, the patients' wishes of dying at home and the choice of going home to die were supported by their family members. Alternatively, the family directly made the request for transfer on behalf of the patient as a home death was the best interest of the patient.

The retrieved studies from China suggested that WLST and then going home to die was often requested by family members (Huang et al. 2009; Sheng et al. 2012; Liu et al. 2016; Liu and Zhu 2016), and the decision of not to WLST could be made by family members even when going against the patient's own wish or the doctors' advice (Zhao et al. 2014). These findings suggested a key role of family members in decision-making for THtD in Chinese culture but further studies are needed to understand the implicit and underlying patterns about the family decision-making.

Some retrieved studies in the West reported the involvement of palliative care or hospice team (Kumar et al. 2009; Tellett and Davis 2009; Lusardi et al. 2011; Campbell 2013; Battle et al. 2014), and community care team (Battle et al. 2014; Coombs et al. 2014; Coombs et al. 2015), and clinical specialists (Tellett and Davis 2009; Clinch and Le 2011; Tellett et al. 2012) in the discussion and implementation process of THtD. In cooperation with other colleagues, such as hospital management and ambulance officers, critical care teams mainly collaborated with HCPs from palliative/hospice care, and GPs and district nurses from community care services. The available data suggested that besides critical care teams other staff appeared being involved in the decision-making process about implementing transfer rather than directly engaging in the decision-making of transfer. However the detail about their participation in the process of transfer and interaction with other teams remain less clear.

2.9.7 Barriers and facilitators

The barriers and facilitators summarised from the retrieved papers are related to the third objective of the review. Barriers to transfer included the scarcity of transfer with little evidence, the curative nature of care in CCUs, negative views and disagreement on transfer, patients' high care needs and dependence on LST, families' unrealistic expectation and inability for home care, uncertainty and time pressure of transfer, the unknown or limited support/resources, staffing issues, and practical and logistical barriers. Facilitators of transfer included personal wishes or cultural needs of dying at home, positive views and agreement on transfer, a good relationship between HCPs and families, families' preparation, a multidisciplinary approach, and establishing guidance for transfer.

The factors in relation to the implementation process of THtD were mainly derived from the practices outside China because this was not investigated by the included papers from China which only reported several factors influencing the decision of WLST (and subsequent going home to die) (Table 2.5) (Xu et al. 2001; Huang et al. 2009; Sheng et al. 2012; Zhao et al. 2014; Xie et al. 2015; Liu et al. 2016; Liu and Zhu 2016).

The identified barriers to, and facilitators of THtD can be classified as factors related to context of practice, decision-making of transfer, patients, family members, the implementation process and the broader environment of THtD.

2.9.7.1 Barriers to transfer

Barrier: The scarcity of transfer with little evidence

A key barrier to transfer in the West is the fact that transfer is a rare event and little evidence is available for guiding the clinical practice (Kumar et al. 2009; Coombs et al. 2014; Darlington et al. 2015). Data about the numbers of patients transferred home from CCUs to die support the point that transfer is a rare event in those countries that carry it out. It is often a response to a request to go home to die by patients or their families rather than a routine option offered by the units (Coombs et al. 2014). Many units had no experience of transfer previously (Ryder-Lewis 2005; Beuks et al. 2006; Kumar et al. 2009; Battle et al. 2014).

Barrier: The cure-oriented nature of care in CCUs

The cure-oriented nature of care in CCUs prevented moving to EoLC, including THtD. THtD was not a usual consideration in critical care and authors linked this to a clinical focus on curative care as opposed to EoLC (Beuks et al. 2006; Huang et al. 2009; Campbell 2013; Battle et al. 2014). The initiation of decision-making about end of life in CCUs was difficult for HCPs (Campbell 2013).

Barrier: Negative views and disagreement on transfer

Individuals' negative view or disagreement on transfer was a barrier to transfer. A national survey in the UK found that although most of HCPs agreed with THtD a minority of HCPs viewed the transfer as "a waste of resources" or "not a priority compared to other care" (Darlington et al. 2015). A negative view on transfer was also reflected in the debate about the transfer for unconscious patients who were not able to experience the process of dying at home (Kompanje 2009). These negative views among HCPs on transfer would hinder they offer this option routinely in the settings of critical care.

Disagreements among family members was an obstacle to transfer encountered in an ICU in the USA (Lusardi et al. 2011) and another case study from the USA also showed that the patient would not be transferred home to die until the family and HCPs achieved consensus on the transition from curative care to EoLC (Crighton et al. 2008). Family disagreement was also identified as a barrier to the decision regarding WLST by qualitative studies from China, which was usually a decision prior to THtD (Liu et al. 2016; Liu and Zhu 2016).

Barrier: Patients' high care needs and dependence on life-sustaining treatments

In the UK, barrier to transfer was an assessment that the physical care needs of the patients were high, for example, continuous diarrhoea, open wounds, experiencing uncontrollable pain, or receiving high levels of sedation (Coombs et al. 2014). A further barrier to some transfer practices was the patients' characteristics and clinical conditions. If the patient was considered instable for a transfer and might die during transfer he or she would not be transferred home to die (Boussarsar and Bouchoucha 2006; Kumar et al. 2009; Lusardi et al. 2011; Tellett et al. 2012). Furthermore patients sustained on MV were considered as the most complex patients to transfer home in the West (Clinch and Le 2011; Lusardi et al. 2011).

Barrier: Families' unrealistic expectation and inability for home care

Barriers to transfer related to families included their unrealistic expectations about transfer and inability to cope with the transfer, home care and death at home. HCPs in the UK recognised a barrier to transfer was families' unrealistic expectations about death at home after transfer

(Coombs et al. 2015). An American transfer practice found that some families did not understand the emotional demand to maintain the dying patient at home and key family members might refuse the transfer after the decision was made (Lusardi et al. 2011). These families were not very clear about what would happen if the patient was taken home to die and what care was required at home. Several practices of transfer highlighted that the achievement of transfer required families to understand what would happen during and after transfer (Mann et al. 2004; Ryder-Lewis 2005; Lusardi et al. 2011) and be able to cope with the care at home post transfer (Coombs et al. 2014). In their limited transfer practice, some units excluded patients from transfer if the family could not cope with the process of home death physically or emotionally (Ryder-Lewis 2005; Kumar et al. 2009; Lusardi et al. 2011; Coombs et al. 2014).

Barrier: Uncertainty and time pressure

Transfer was a complex process filled with uncertainty, which partly contributed to the fact that transfer was a rare event in the West. One major uncertainty was the timing of a death or the life expectancy post transfer (Ryder-Lewis 2005; Crighton et al. 2008; Clinch and Le 2011; Hutchinson and Van Wissen 2017). It was difficult for HCPs to predict the time of a death which varied significantly in the reported transfer practices, from minutes to months after the withdrawal of treatment. The uncertainty involved in transfer resulted in difficult decisions around the care or support needed.

In relation to the uncertainty of time to death, time limitation became a hinder to transfer. Due to the critical status of patients, the time for decision-making and implementing transfer was often short (Clinch and Le 2011; Coombs et al. 2014; Coombs et al. 2015) and a consequence of this was that families perceived “everything happened quickly” (Hutchinson and Van Wissen 2017). However, some HCPs stated that the process of decision-making and transfer was time-consuming because many individuals involved in negotiation and many types of work required for a transfer (Lusardi et al. 2011; Tellett et al. 2012).

Barrier: Limited support and resources from community

The unknown or limited support and resources available for transfer and home care, especially from community care, acted as one central barrier to many transfer practices in the West (Ryder-Lewis 2005; Beuks et al. 2006; Clinch and Le 2011; Lusardi et al. 2011; Coombs et al. 2014; Coombs et al. 2015). For the HCPs in critical care transfer was unlikely if they did not know what support was available for a dying patient who was transferred home for death, in particular from the community where the patients live.

The support or resources needed in place included symptom management, support to families by district nurses and GPs, and provision of equipment (i.e. a bed) (Ryder-Lewis 2005; Kumar et al. 2009; Tellett et al. 2012). If community HCPs were not available or unable to offer home care support transfer could not be achieved (Lusardi et al. 2011; Coombs et al. 2014).

A particularly required care support was the death certification process for the patients transferred and died at home (Mann et al. 2004; Kumar et al. 2009; Battle et al. 2014). This was widely completed by GPs but an unit in the UK was training nurses to complete this work in future transfer (Battle et al. 2014).

The limited support available from community determined only particular types of patients could be transferred home. For example, ventilated patients could be transferred home by some practices but not by others as the community could not accept such patients or deal with the extubation at patients’ home (Beuks et al. 2006; Clinch and Le 2011).

Barrier: Staffing issues

There were barriers to transfer related to staffing in Western countries’ CCUs. First, providing a transport team for THtD from the busy units was a barrier to transfer (Ryder-Lewis 2005) because it was expensive (Kompanje 2009). Second, the legal cover of transfer for HCPs was another barrier to transfer which needed the support from hospital executive (Clinch and Le 2011; Coombs et al. 2014). Third, transfer was concerned with the HCPs’ safety, as well as skills and knowledge for transfer and these were issues with the largely nurse-led process of transfer (Jackson 2006; Campbell 2013; Coombs et al. 2014).

Barrier: Practical and logistical barriers

Practical and logistical barriers were reported in some practices. For example, the distance between the hospital and patient’s home was considered by HCPs in the transfer decision-making process (Mann et al. 2004; Boussarsar and Bouchoucha 2006; Lusardi et al. 2011). A long journey home increased the likelihood of death during transit which prohibited the consideration of transfer. Another logistical barrier reported in the retrieved papers was the accessibility to patients’ home that the bed or stretcher could not get through the door of the patient’s home (Tellett and Davis 2009; Tellett et al. 2012).

2.9.7.2 Facilitators of transfer

Facilitator: personal wishes or cultural needs of dying at home

Facilitators underpinning transfer include: a recorded/reported patients’ wish or cultural expectation of death at home. HCPs in the West would consider agreeing to the transfer of the patient home if that was their wish (Jackson 2006; Kumar et al. 2009; Nielsen 2013; Coombs et al. 2015). It was essential to meet the patients' wish of dying at home and honour the personal choice of transfer for both patient and the family (Tellett et al. 2012; Campbell 2013; Coombs et al. 2015; Hutchinson and Van Wissen 2017). Within the papers retrieved many transfer practices in Western countries reported that the transfer was to respect patients' personal wishes about place of death (Beuks et al. 2006; Kumar et al. 2009; Tellett and Davis 2009; Lusardi et al. 2011; Tellett et al. 2012; Campbell 2013; Battle et al. 2014) and the death at home after transfer was viewed as a good one by families and HCPs (Beuks et al. 2006; Kumar et al. 2009; Tellett et al. 2012).

Cultural and religious traditions that required a death at home also acted as a facilitator, particularly for the populations of Maori and Pacific Island families (Mann et al. 2004; Ryder-Lewis 2005), Muslims (Boussarsar and Bouchoucha 2006; Kallel et al. 2006), and Chinese living in China (Huang et al. 2009; Zhao et al. 2014; Xie et al. 2015; Liu et al. 2016).

The 'wished for' transfer and the 'culturally required' transfer were key drivers for transfer actually taking place.

Facilitator: Positive views and agreement on transfer

In contrast to negative views and disagreement prohibiting transfer, positives views and agreement on transfer by family members and HCPs could facilitate transfer decisions. The retrieved literature suggested that the majority of doctors and nurses in critical care held a positive view on the option of transfer with a careful selection of patients and planning for transfer (Mann et al. 2004; Ryder-Lewis 2005; Beuks et al. 2006; Boussarsar and Bouchoucha 2006; Jackson 2006; Kallel et al. 2006; Huang et al. 2009; Lusardi et al. 2011; Campbell 2013; Nielsen 2013; Battle et al. 2014; Coombs et al. 2014; Hutchinson and Van Wissen 2017). Findings from the literature suggested that if doctors and nurses involved in transfer events had a positive experience this would encourage this practice being embedded in the unit culture (Darlington et al 2015). Furthermore, a full consensus among all individuals was central to transfer (Clinch and Le 2011; Tellett et al. 2012; Coombs et al. 2014). This included that all family members agreed with the decision of taking the dying relative home (Beuks et al. 2006; Kallel et al. 2006; Battle et al. 2014) and the whole treatment team had to support the patients' choice of going home to die (Beuks et al. 2006; Clinch and Le 2011; Tellett et al. 2012).

Facilitator: A good relationship between families and HCPs

Some transfer practices in the included papers showed that a good relationship between HCPs and families was a facilitator of transfer. For example, an ICU in New Zealand selected patients for transfer based on a criteria of a close and trust relationship between clinicians and family (Mann et al. 2004). Another ICU in New Zealand also stressed the success of transfer was a result of the established open relationship with families (Ryder-Lewis 2005). The insight into families' experience of transfer in this country found the importance of collaboration with family for THtD from ICU (Hutchinson and Van Wissen 2017).

Facilitator: Families' preparation

Preparing families before transfer was considered a key facilitator of transfer in many reports retrieved from the West. Several transfer practices prepared families about what was likely to happen, what care would be required at home, what support was available, and introduced community HCPs to families (Mann et al. 2004; Ryder-Lewis 2005; Lusardi et al. 2011; Tellett et al. 2012; Battle et al. 2014; Coombs et al. 2014). An information sheet for families was also useful to facilitate transfer including detail about comfort care, judgement of death, and contact details of HCPs in community (Ryder-Lewis 2005; Battle et al. 2014).

Facilitator: A multidisciplinary approach

A multidisciplinary approach was recommended for ensuring a successful transfer in the West (Mann et al. 2004; Ryder-Lewis 2005; Battle et al. 2014; Coombs et al. 2014; Coombs et al. 2015). It facilitated transfer by connecting divergent HCPs from primary, secondary and tertiary care (Ryder-Lewis 2005; Coombs et al. 2015).

A transfer multidisciplinary team could include doctors and nurses from hospital CCUs, GPs and district nurses from community, and hospital- or community-based, palliative, hospice, and bereavement team staff (Mann et al. 2004; Ryder-Lewis 2005; Lusardi et al. 2011; Tellett et al. 2012; Campbell 2013; Battle et al. 2014). Co-operation for transfer between different care teams and planning for transfer had to be established through communication or meeting and clarification of individuals' roles and responsibilities (Ryder-Lewis 2005; Lusardi et al. 2011; Battle et al. 2014). However, again, little evidence about the roles and responsibilities of all individuals in transfer process can be extracted from the retrieved papers.

In addition to a multidisciplinary approach, a single person was advised to facilitate and lead the process of transfer as a single point of contact (Coombs et al. 2014; Coombs et al. 2015; Hutchinson and Van Wissen 2017).

Facilitator: Establishing guidance for transfer

In line with the first barrier to transfer related to little evidence available, to establish guidance for transfer or evidence-based practice appeared to be a practical facilitator of transfer. In the included reports, some practices in the UK and the USA had established some evidence-based guidance for transfer. HCPs in an ICU of the UK formed a standard of work from their experience of transferring two patients home to die from the ICU and a multidisciplinary team was built for future transfer (Battle et al. 2014). A further step was taken by a research team in the UK that a guideline for transfer was developed based on empirical studies of a three-phase mixed methods study (Coombs et al. 2014; Coombs et al. 2015; Darlington et al. 2015; Coombs et al. 2017). This guidance comprised five key phases: assessing potential for THtD, preparing for transfer, during transfer, on arrival home and after death. The usefulness of this guidance required further application and test in clinical practice.

An ICU in the USA also made efforts in developing a “going home initiative” to transfer limited types of patients (Lusardi et al. 2011). The Going Home Initiative included three phases: the workup, the day of transfer, and contact with the patient after transfer. The characteristics of patients transferred by this initiative were stable, independent from ventilation, owning a primary physician for home care, and supported by family members.

2.9.8 Transfer practice in China

The phenomenon of THtD was the focus of the study presented in this thesis. This section provides a summary of the seven papers retrieved in this review offering information about THtD in China. Of the seven papers, six papers explored the practice of WLST in mainland China which involved the decision of THtD (Xu et al. 2001; Sheng et al. 2012; Zhao et al. 2014; Xie et al. 2015; Liu et al. 2016; Liu and Zhu 2016), and one was a retrospective observational study reporting the prevalence of THtD and characteristics of patients in surgical ICUs in Taiwan (Huang et al. 2009). Of the six papers from mainland China, three were a qualitative study design exploring families’ experiences of decision-making for WLST (Xie et al. 2015; Liu et al. 2016; Liu and Zhu 2016), and the other three were a retrospective chart review reporting the prevalence and factors of the decisions in ICUs (Xu et al. 2001; Sheng et al. 2012; Zhao et al. 2014).

Findings of the included studies suggested that THtD was often a phenomenon following the decision to WLST. The patients who were transferred home to die was documented as ‘self-discharge’ in patients’ medical records (Xu et al. 2001; Sheng et al. 2012), suggesting the family members’ legal consent for the decision.

A high prevalence of THtD from ICU in mainland China was reported in the retrieved studies, which ranged from 40% (74/184) to 60% (96/159) of dying patients in ICU (the figure was not direct findings of two papers and was calculated based on available data by me) (Xu et al. 2001;

Sheng et al. 2012; Zhao et al. 2014), suggesting that about a half of dying patients in ICU were taken home to die.

Some factors associated with WLST and relevant to THtD were identified by these studies and most of them were unique to China. First, the severity of clinical condition including emergency or critical condition (Zhao et al. 2014), and the use of intensive LST (Huang et al. 2009), was a feature of patients in WLST/THtD group in China while this was a barrier to transfer in some Western countries (see p56 section 2.9.7.1). Second, financial difficulties of family were reported as a reason for WLST and then THtD because of the expensive ICU treatment was unaffordable without healthcare insurance (Xu et al. 2001; Zhao et al. 2014). Third, a lack of options for place of care prior to death was a reason for some family members to refuse WLST (Liu et al. 2016; Liu and Zhu 2016) which could hinder THtD. Lastly, China had the cultural tradition that required a home death (Zhao et al. 2014; Xie et al. 2015; Liu et al. 2016).

The seven papers provided a preliminary understanding about the overview of the THtD practice in China but limited to the prevalence of transfer and some factors influencing WLST. In addition, the methodological limitations of retrospective chart reviews with existing data that have been recorded for reasons other than research should be taken into account, such as issues with the accuracy of recorded data and bias in case selections and data extraction (Hess 2004). Furthermore, an in-depth understanding about the patterns and underlying assumptions regarding decision-making remains a gap of knowledge which is outlined in next section.

2.9.9 Gaps in literature

An important outcome of scoping reviews is the gap of knowledge about the topic of interest surrounding the map of what is known in literature (Anderson et al. 2008; Pham et al. 2014). The key findings about what can be known in the literature about THtD from CCUs have been outlined and mapped in the previous sections. This section discusses about the gaps in literature that are essential areas for understanding the complex but meaningful event of THtD.

Based on the current knowledge in the literature, the gaps in understanding the practice of THtD included: a) what actually happened at home after transfer, particularly when critical care HCPs left and around the time of death; b) what understanding could be generated about transfer from the perspectives of patients, family members, HCPs of community, hospice and palliative care; c) how the decisions around THtD were made in the countries where going home was more about the cultural expectations rather than personal choices, such as China; d) given the various practices existing in different contexts whether an international guideline is needed for transfer and if yes, what contents should be included; and e) what training programmes could be developed that are useful for training HCPs involved in transfer from different care services.

First, the findings suggest that it remained less clear what happened at home post transfer, including the process of dying and death at home, the care and resources needed, the interaction between patients, family members, and HCPs, and the challenges and difficulties encountered. The available evidence was largely from case reports or service description by HCPs based in the critical care who often handed over patients to community care at home or data was extracted retrospectively from case note reviews with little about the post transfer.

Second, the current understanding about transfer was dominantly from the perspectives of HCPs in the critical care from the West. The views and experiences of patients, community HCPs, and hospice or palliative care professionals who were involved in transfer are missing in the literature. In addition, although there were two papers exploring families' experiences of transfer process, a full and in-depth understanding about their views and reflections of transfer is still lacking, particularly surrounding the decision-making for THtD.

Third, the distribution of papers specifically exploring THtD dominated in the West including the UK, New Zealand, and the USA, and very limited information has been reported about the process of THtD in eastern countries. Seven papers included (Section 2.9.8) had provided some preliminary understandings about the THtD in China but this was limited to the high extent or large size of transfer which could be partly explained by the identified factors associated with WLST. Despite it was so common in China, attention had not been paid in the area of THtD in critical care by Chinese researchers and little was known about the process of decision-making and implementation for THtD.

Fourth, there was a lack of guidance for implementing transfer. Only one formal guidance was developed based on empirical studies in the UK but it still needed to be applied, appraised and refined (Coombs et al. 2015). The majority of units carried out a relatively small number of transfer and learned from lessons and experiences from their limited transfer practice. There is an urge to carry out rigorous research studies and establish guidance for the complex care service of transfer. However, various types of patients were being transferred by different units and it may not be feasible or necessary to develop one single international guideline for all practices. The development of guidelines for transfer should be situated in the context and be oriented with the types of patients transferred home to die.

Lastly, little has been reported about the training of HCPs for transfer which may be a result of the limited practices and lack of evidence and guidance related to transfer. The skills and knowledge required for a transfer has not been developed (Coombs et al. 2014). A smooth process of transferring patients home to die by skilled and experienced care teams was satisfied to families (Hutchinson and Van Wissen 2017).

2.10 Research question and objectives

To address the gap of knowledge identified from this scoping review, this study sought to answer the following research question: What were the experiences of families who made the decision to transfer their relative from the ICU in China to die at home?

The study objectives were to:

I. map the process of decision-making, including the processes and steps in decision-making and the decision-makers,
II. identify families' information and support needs,
III. identify barriers to and facilitators of transfer,
IV. understand the meaning of the experiences to families.

2.11 Justification of study: filling the gap

The literature review showed that some insights about transfer practice have been gained from research in the West, where fewer patients are routinely transferred home to die from critical care. Little is known about the decision-making processes of THtD from critical care internationally or where the practice is more common. A handful publications suggest that it is common to THtD from ICUs in China (Xu et al. 2001; Huang et al. 2009; Sheng et al. 2012; Zhao et al. 2014) and identified some factors influencing family members' decision making regarding WLST before some were transferred home to die from ICUs in mainland China (Xie et al. 2015; Liu et al. 2016; Liu and Zhu 2016). However, little has been published about the process of decision-making and family members' information and support needs and factors influencing the decision-making that were derived from the implementation process. Therefore China has been chosen as the focus of the study.

Families' perspective on transfer practice was another focus of this study. The reason for this was that the available literature was mainly investigating this practice from Western HCPs' perspective. Families play a vital role in the decision-making of taking their relative home to die, but their voice on this particular event has not been heard yet. The understanding of this complex process from families' perspective could add important insights into the existing knowledge and inform the strategies to support the family members in the decision-making process.

A better understanding of transfer can potentially improve the practice of transfer so that more patients' wish can be met or the difficulties and challenges in decision-making can be lightened. Understanding families' experiences of decision-making might enable the identification of their difficulties, needs, barriers to, and facilitators of transfer, as well as the benefits and meanings to them. Therefore, evidence-based strategies and guidance could be generated from the study to support family members and facilitate the process of transfer. Finally the study had practical and financial implications because the increase of transfer could reduce the length of ICU stay and further reduce medical cost.

2.12 Summary

This scoping review summarised the international literature about the practice of THtD from CCUs and addressed the review question and objectives.

THtD from CCUs is an international phenomenon and various practice are undertaken. In the West, THtD from CCUs is a rare, complex practice and is motivated by personal preferences while in some eastern regions, particularly China, it is more usual and is an expectation of local culture and tradition.

Transfer is not an option for all patients and families who would like to go home to die in the West. Criteria for the selection of patients varies between units and countries. The decision-making process is complex involving multiple processes, agencies and objects. Many barriers to, and facilitators of transfer have been identified but the understanding of which is mainly generated from the limited experiences of HCPs, based in the critical care in Western countries.

Transfer is an area under-researched. The current knowledge is obtained based on a small number of relevant papers and most of them are non-empirical studies and retrospective observations (i.e., clinical case reports), with the methodological limitations such as a lack of ability to generalize, no possibility to establish cause-effect relationship and danger of over-interpretation (Carlson and Morrison 2009; Nissen and Wynn 2014). A major gap of knowledge has been found in countries like China where going home to die is common but little published information is available about the detail of THtD that can explain the features of this usual event in the country.

Gaps in literature for understanding transfer suggest the directions and areas for future research. First, more insights should be obtained about the decision-making process of transfer, the process of dying and death at home and the views and experiences of families and HCPs from non-CCUs. Second, more studies are needed to understand the practice of transfer in countries where transfer is a routine in critical care and China should be such a country to be considered. Third, guidance and training programmes should be developed based on evidence generated from research studies and expert opinions. Further studies should employ quantitative, qualitative and mixed methods design in line with the defined research questions and objectives to produce different types of evidence. To meet these objectives, a joint effort is needed from clinical practitioners, researchers, and government or policymakers.

This thesis reports a study addressed the research question about families' experiences of decision-making when transferring a dying relative home from critical care in mainland China. The paradigm and methodology are explained in next chapter.

Chapter 3 Methodology

3.1 Introduction

Chapter Three outlines the methodology and underpinning philosophy of the study. As the study aim was to explore people’s perspectives and experiences of decision-making to transfer a relative home to die, the decision to select constructivism as the underpinning philosophy, and a qualitative research methodology to address the research question and objectives is outlined.

3.1.1 Philosophy of science and paradigm

Philosophy of science is concerned with the assumptions, foundations, methods, and implications of science (Ponterotto 2005). Different stances in philosophy of science formulate different paradigms for research. Paradigm is a set of generalizations, beliefs, and values of a community of researchers (Kuhn 1970). It is the “basic belief system or world view that guides the investigator” (Guba and Lincoln 1994 P105).

Hence, as a researcher, it is essential to clarify the paradigm that underpins a particular study and ensure the coherence of the conduct of study including the methods used and the findings generated. The selection of the paradigm for a study relies on the researcher’s understanding of the basic principles involved in the paradigm and these are determined by the following parameters: ontology, epistemology, axiology, rhetorical structure, and methodology (Creswell and Creswell 1994; Guba and Lincoln 1994, 2005; Ponterotto 2005).

3.1.2 Ontology and epistemology

Ontology and epistemology are linked (Crotty 1998). Ontology refers to the nature of reality, for example ontology is concerned with “what is” (Crotty 1998): what is the form and nature of reality and what can be known about that reality?

As ontology is concerned with the philosophy of reality, epistemology is concerned with how we come to know that reality. The question asked by epistemology is ‘how do we know something and what is the nature of the relationship between researcher and participants?’ (Guba and Lincoln 1994). There is a range of epistemologies. Objectivism views reality as being independent from the operation of any consciousness (Crotty 1998). Subjectivists view reality as a construction produced in the interaction between researcher and participants (Guba and Lincoln 1994). Therefore, a paradigm of inquiry comes with ontological and epistemological assumptions about reality and how knowledge is produced. However, knowledge production is also informed by the values of the researcher articulated here as axiology.

3.1.3 Axiology

Axiology is the branch of philosophy dealing with values and ethics (Guba and Lincoln 2005). Creswell (2011) discusses that this is about how researchers 'position themselves' in the study and states that 'All researchers bring values to a study, but qualitative researchers make their values known in a study' (P20). My positioning is outlined in section 3.9 by the end of this chapter and I reflected on the influence of my values and beliefs on the research process in chapter4 and chapter 5.

Axiology involves the beliefs that can influence the researcher's decisions on methodological issues. For example in this study, based on my cultural insights into the clinical research context in China, with regard to the recruitment process, it was considered that using gatekeepers to recruit participants was more likely to increase the number of potential participants than a poster invitation.

3.1.4 Rhetoric

Rhetoric refers to the strategic use of language in research. It deals with how language is used to present the procedures and results of study to the intended audience (Ponterotto 2005). An objective of rhetoric practice is to convince members of scientific communities about the importance of the study and the contribution to the existing knowledge (RhetInfo 2012). The content and form of writing varies in line with the ontological and epistemological assumptions that underpinned the research. The language used in the objective and value-free research is scientific, precise, factual and objective. Conversely, the writing of research prevailing with subjectivity and interaction is literary, personalised, contextual, and the researcher self is often present in the report (Richardson and St. Pierre 2005). Therefore the paradigm of choice also defines how language is used in the process of knowledge production, including the content and form of reporting findings, in the current study (see chapter 6). Rhetoric is also related to methodology which is discussed in next section.

3.1.5 Methodology

Methodology is the strategy or plan of action driving the choice and use of particular methods, whereas methods are the specific techniques and procedures used to collect and analyse data (Crotty 1998). Thus, methodology defines why, what, from where, when and how data is collected and analysed (Scotland 2012). Methodology and the methods therefore need to be congruent with the paradigm of inquiry.

3.1.6 Selecting a paradigm

Paradigms of inquiry include: positivism, postpostivism, critical theory, constructivism, transformative, and pragmatism (Creswell and Creswell 1994; Denzin and Lincoln 1994; Patton 2002; Mertens 2014) (Table 3.1).

Table 3.1 Common paradigms of inquiry

Paradigm	Definition
Positivism	Stresses objectivity, experimentation and generalizability
Postpositivism	Has a similar emphasis as positivism but with a critical lens and acceptance of the role of participants.
Critical theory	Views reality historically, and focuses on interaction between researcher and participants, and dialogic/dialectical methods.
Constructivism	Emphasizes constructed realities, interaction with participants, and changes with social context.
Transformative	Focuses on issues of social justice, human rights, and cultural complexity.
Pragmatism	In favour of methodological appropriateness as the primary criterion for judging methodological quality, recognising that different methods are appropriate for different situations.

Sources: (Creswell and Creswell 1994; Denzin and Lincoln 1994; Patton 2002; Mertens 2014)

In designing a research study, as part of a transparent research audit trail, the researcher should articulate not only the chosen methodology and methods but also the underlying assumptions involved in a specific paradigm (Crotty 1998). The philosophical parameters of the paradigm need to be clearly defined and explicitly outlined (Ponterotto 2005). This study selected constructivism as the paradigm of inquiry and a qualitative methodology with associated methods and a detailed rationale for the choices and decisions made is presented.

3.2 Constructivism

3.2.1 Constructivism as a paradigm

Constructivism as defined by Crotty (1998) is "the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context" (Crotty 1998 P42). Constructivism proposes that multiple and diverse realities exist in the social world created by humans and therefore that reality is socially constructed (Guba and Lincoln 1994). Constructivists claim that each individual constructs a reality, or at least interprets it, based upon his or her perceptions and experiences (Jonassen 1991). From a constructivist standpoint, external reality independent of an individual is non-existent. Instead, reality is relative, multiple, socially constructed, and ungoverned by natural laws (Costantino 2008).

Epistemologically, constructivism articulates the intimate relationship between the researcher, the phenomenon under study, the context and the mutual creation of knowledge by the researcher and participants. Knowledge is co-constructed through the interaction between individuals and between individuals and objects (Guba and Lincoln 1994).

However, from an axiological standpoint, the generation of knowledge is also shaped by the researcher's values and lived experience which cannot be divorced from the research process. Therefore, the researcher's own experience, expectations, biases, and values are acknowledged and the impact of the research process on the life of the researcher is reflected (Ponterotto 2005). For example, hearing some participants' stories (or reading their transcripts) had an emotional impact on me and influenced how I understood their stories and how I viewed the research topic about the decision and practice of taking a dying relative home to die: pain and difficulty in the data noticed in my analysis. Detail of my reflection is outlined in section 4.4.4 chapter 4 and section 5.4 chapter 5.

In research conducted under the constructivism paradigm, the aim in writing and reporting is not to represent a true reality that exists apart from the influence of subjects, but to provide a story illustrating the meaning constructed between researcher and participants with quotations often used to illustrate the developing story and findings (Ritchie and Lewis 2003).

Constructivism needs to be distinguished from the paradigm social constructionism despite the two paradigms both refer to the reality is socially constructed. Social constructionism is the assumption that the meaning of the state of things, practices, conditions, behaviour, and others is always interpreted or constructed in specific linguistic (discursive), social, historical, and material contexts (Holstein and Gubrium 2013). Constructivism differs from constructionism in terms of the primacy, the role of language, and the ontological believes that are outlined in Table 3.2.

Table 3.2 Constructivism and constructionism

Constructivism	Constructionism
Personal experience (Holstein and Gubrium 2013)	Relatedness/ social action (Holstein and Gubrium 2013)
Language is a means of accessing the person's interior realm (Holstein and Gubrium 2013)	Language determines the nature of experience and reflects the origins of power relations (Raskin 2002)
Personal constructivism and radical constructivism: knowledge is produced through personal construction (Raskin 2002)	Relativism: knowledge production is relativistic with associated context, linguistics, and relations (Smith and Hodkinson 2005)

3.2.2 Methodology and constructivism

As mentioned previously, constructivism inquiry advocates the use of naturalistic/ interpretive rather than positivist/ scientific methodology to achieve a co-constructed understanding of experience and meaning. Constructivism underpins many qualitative approaches involving dialectic and iterative process of inquiry, including ethnography, grounded theory, discourse and narrative (Holstein and Gubrium 2013). Qualitative methods such as interviews, observations, and document reviews are predominant in the constructivism paradigm (Mertens 2014).

Constructivism inquiry begins with issues/concerns and unfolds through a 'dialectic' of iteration, analysis, critique, reiteration, reanalysis, and so on that leads to a joint construction of an issue/ concern/ phenomena aimed at generating understanding of that issue/ concern/ phenomena to inform the knowledge, insights, evidence, strategies for resolution to the issues/ concerns/ phenomena, in terms of research, practice and policy.

Constructivism focuses on understanding rather than measuring and therefore is appropriate for investigating phenomenon in human science. Specifically, constructivism is suited to studying the social world created by humans including the built environment, social institutions, language, culture, and belief systems. This means that it was the most relevant paradigm for situating this study where the aim was to explore and understand the decision-making of family members when taking a patient home to die from an ICU.

3.2.3 Influence of research culture and context of loss on methodological decision making

The context within which the research topic was embedded was one of death and loss and the key concept of decision-making. Such an inquiry could have been informed by a range of paradigms, however constructivism was considered to be the most appropriate as human experience of loss is shaped by the need to look for meaning in that experience. For example, research has demonstrated that a central response to loss is an individual quest for meaning (Neimeyer 2005; Neimeyer et al. 2010; Neimeyer and Burke 2015), whereby human beings actively shape and structure their experiences to give it personal and social significance. The work of Walter (1996, 1997, 2000), challenges dominant models in the existing literature (Kübler-Ross 1973; Parkes 1986; Raphael 1994) that posits grief as working through emotions with the end goal being that the 'living' can 'move on' and live a life without the person who has died. Instead Walter presents a sociological model of bereavement and grief which suggests that making sense of loss can be achieved by constructing a story or a biography, where the role of grief is the conversation or story construction rather than the feelings, and the purpose is keeping hold and finding a place for the dead rather than letting go. Walter's model of grief offers a story construction lens for understanding bereavement (Walter 1996; Walter 1997; Walter 2000).

Walter claims that this model of understanding grief through a story lens may be grounded in Giddens' theory of identity in late-modern capitalism (Giddens 1991). "Bereavement is part of the never-ending and reflexive conversation with self and others through which the late-modern person makes sense of their existence". Furthermore, such a construction of biography is mediated by other family members, by family norms and dynamics (Walter 2000). The continuing bonds between the deceased and the family is attached to home (Jonsson and Walter 2017).

A story construction lens to bereavement is applicable to understanding this process amongst Chinese populations. In Chinese culture traditional rituals of funeral, stories around the deceased person were told between family members, relatives, friends and neighbours, and people felt the reestablishment of connections. In psycho-social-spiritual terms, such a ritual is a debriefing experience as well as an occasion for the living trying to pave the way for the deceased to move into the next world (Chan and Chow 2006).

The meaning of loss is unique to an individual and also shaped by those shared by the local society. What has a common meaning to a group of people may have a unique meaning to an individual member of the group (Krauss 2005), which is why both the individual and shared experience of end of life decision making is context dependent informed by the community to which the people belong and through which social meanings are constructed (Kim 2001). Understanding personal meanings within the experience of a specific event cannot be separated from the broad context or the shared culture that the individuals in connection to, therefore the need to gather data at the individual level (as in this thesis) but to analyse at both the individual and group (of participants who have shared a culturally informed event) level.

3.3 Qualitative research methodology

Qualitative research is “a theoretically driven enterprise” (Silverman 2016 P3) and seeks to understand social phenomena in natural rather than experimental settings, giving emphasis to the meanings, experiences, and views of participants (Pope and Mays 1995). By investigating a purposive number of cases, qualitative research facilitates detailed and in-depth understanding of the situation (Patton 2002).

3.3.1 Characteristics of qualitative research

Qualitative research is a broad term including a family of inquiry approaches, such as ethnography, phenomenology, grounded theory, case study, and narrative inquiry (Denzin and Lincoln 1994). However, they share some similar characteristics as a qualitative inquiry.

The aim of qualitative research is to provide in-depth and interpreted understanding of the participants’ social world by knowing the sense they make of their circumstances, experiences, perspectives and histories. Participants are usually purposely rather than randomly selected. The sample size aims to focus on gaining an in-depth understanding as opposed to broad representation (Ritchie et al. 2014). The methods for data generation are chosen to be flexible and sensitive to the social context. Date collection methods often include (either solo or mixed) interviews (face-to-face, telephone, group), observations and document analysis. Qualitative data analysis respects the uniqueness of each participant as well as recurrent, across-case patterns aiming to generate themes, concepts, understanding, or theoretical and explanatory frameworks based on thick description of the phenomenon under study, grounded in the perspectives of participants. Co-construction of findings are underpinned by the use of direct quotations from participants’ stories. Qualitative research requires iterative, reflexive practice in which the researcher’s role and perspectives are acknowledged (Patton 2002; Denzin and Lincoln 2011; Silverman 2011; Ritchie et al. 2014).

3.3.2 Rationale for selecting qualitative research methodology

A qualitative approach underpinned by constructivism was chosen as it offered the most appropriate methodology for the current study which aimed to explore and explain families’ attitudes, views, perceptions, actions, and interactions with objects and others, and the decision-making process behind transferring a relative home to die from an intensive care environment.

This study sought to answer the following research question: What were the experiences of families who made the decision to transfer their relative from the ICU in China to die at home?

The study objectives were to:

- I. map the process of decision-making, including the processes and steps in decision-making and the decision-makers,
- II. identify families' information and support needs,
- III. identify barriers to and facilitators of transfer,
- IV. understand the meaning of the experiences to families.

3.4 Selecting data sources

A primary aim in qualitative research is to acquire data from information-rich cases that is useful and meaningful for understanding the depth, complexity, variation, or context surrounding a phenomenon, rather than to represent larger populations permitted by random and statistically representative samples as in quantitative research (Sandelowski 1995; Gentles et al. 2015). Data sources can include: people, organisations, texts, settings, objects, or events and non-probability sampling strategies, including purposeful sampling, theoretical sampling, and convenience sampling are used to gain, in this study, the participants who could provide the rich data being sought (Ritchie et al. 2014).

3.4.1 Participant selection

The key data source in this study was the people who had the experience of making the decision of THtD and had a story to tell. However, it should be noted that what was actually investigated was not the individuals but the experiences of individuals in relation to the event, including decisions, actions, processes, perceptions, attitudes, views, and beliefs.

Alongside the story of experience, demographic data are gathered (age and gender) so that participants may be allocated to demographic categories as a means of clarifying differing sources of meaningful information that can advance the researcher toward an analytic goal rather than to generalize to other people of similar age, gender, or race (Sandelowski 1995).

3.4.2 Research context

The principle for selecting a research setting is guided by the potential for the generation of data (Mason 2002). For this study, the context or setting was interpreted at two levels: the specific space where the transfer practice was discussed or carried out, and where participants were located and recruited, and the broader societal context, that is, the country where the study was conducted.

3.4.3 How many participants

Deciding on how many participants to include in a study is always in debate. Ritchie et al. (2014) provide issues to consider when making decisions in regard with sample size: the purpose of qualitative inquiry is not to provide estimates or determine statistically significance through sufficient scale; the data generated in qualitative inquiry is rich in detail and a large sample size does not allow the analysis of the rich data; qualitative research is intensive and time-consuming and a great amount of data is unmanageable; there is a point that the further data collection does not generate new evidence. This study included thirteen participants which was informed by the methodology and the richness of data for addressing the research question.

At the outset of the study, a maximum of twenty participants was decided based on the literature about the sample size in most qualitative studies and studies. A widely applied range of sample size in a qualitative study irrespective of the methodology appear to be 15 - 30 (Baker and Edwards 2012; Marshall et al. 2013), which is also adopted by most (80%) of the PhD studies (Mason 2010). For studies with a detailed focus and analysis on the process of decision-making in stories like current study much less participants are needed (Creswell 2011). The two qualitative studies of participants' stories, with a similar focus with current study related to families' experiences of transfer decision-making, only included one and four participants respectively (Tellett et al. 2012; Hutchinson and Van Wissen 2017).

The decision to sample size for this study also considered the requirement by data analysis approach (see section 3.6) which involved comparison across cases. Braun and Clarke's pragmatic "rule of The thumb" for sample size to a thematic analysis is at least five or six interviews for a small project when the data are rich, the sample relatively homogenous, the research question focused, and the output an unpublished dissertation (Braun et al. 2019).

No limitation was posed on the minimum of participants for current study which meant the sample size could be one which depended on the richness of data (Patton 2002), rather than the number of subjects, or a saturation point where no new information was generated (Guest et al. 2006). An appropriate sample size for a qualitative study is one that adequately answers the research question (Marshall 1996). Sampling adequacy rather than the number of participants is key as 'adequacy' relates to gaining enough data to address the research questions. Unlike the concept of saturation (Glaser and Strauss 1967), the concept of richness of information (Patton 2002) or information power model (Malterud et al. 2016) focuses on the richness or quality of data. If the data from one case is rich, in depth, and provides sufficient and meaningful information for fully understanding the phenomenon under study, then the sample size could be as small as one (Baker and Edwards 2012).

Decisions around sample size in qualitative approaches are influenced by practical limitations and difficulties (Mason 2002) which is common to doctoral studies. For instance, sample size is often constrained by time and budget rather than data adequacy for addressing the research questions (Green and Thorogood 2018). Other practical factors include the accessibility to ‘hidden’ populations, the institutional demands of ethics committees, the researcher’s experience or expertise with qualitative research (Baker and Edwards 2012).

3.4.4 Sampling strategy

All sampling is purposeful in qualitative research (Coyne 1997). Patton’s typology of purposeful sampling strategies is highly influential in qualitative research (Patton 1990; Patton 2002, 2015) in which sixteen different types of purposeful sampling strategies are outlined. The most common ones are maximum variation sampling, typical case sampling, critical case sampling, and theoretical sampling (Patton 2002). The purpose of all the strategies is to select the information rich cases. For example, maximum variation sampling is selecting a broad range of subjects with a great deal of variation. The underlying logic of all types of purposeful sampling is selecting the information rich cases from which one can learn a great deal about matters of importance and therefore worthy of in-depth study.

3.5 Methods for data collection

Gaining an understanding of the experiences, attitudes, views and drivers underpinning family decision-making around transferring a dying relative home from ICU was the aim of data collection in this study, gaining insight into participants’ experience of decision-making in the context of death and loss (Gilbert 2002) and specifically the health care environment and clinical context in which decisions were made (Zachary et al. 1982). For example, interactions between service users and service providers as a means of identifying the barriers and facilitators to transfer.

A fundamental proposition of constructivism is that humans are motivated to construct and maintain a meaningful self-narrative, defined as ‘‘an overarching cognitive-affective behavioural structure” that constructs the small stories of daily life into a big narrative which defines and establishes understanding, emotions, goals, and performance on the stage of the social world (Neimeyer 2004 P53-54). Serving as the backbone of the self-narrative are core beliefs and assumptions about the world (Neimeyer et al. 2010) and gaining access to these beliefs and assumptions was the focus for the interviews carried out with participants.

3.5.1 Selecting interview methods

Interviews, observations, and document reviews are predominant approaches in constructivist qualitative research (Mertens 2014). Qualitative interviews use open-ended questions and probes to yield in-depth responses about people's experiences, perceptions, opinions, feelings and knowledge (Patton 2015).

Qualitative interview has a wide variety of forms (Denzin and Lincoln 2011; Ritchie et al. 2014; Silverman 2016). This study conducted three forms of interview to obtain families' experiences of transfer decision-making: seven individual face-to-face interviews, two family joint face-to-face interviews, and one telephone interview.

In this study, individual face-to-face interview was the interview between me and one participant whereas a joint face-to-face interview took place between me and more than one participant from a same family. A telephone interview was the one conducted on a telephone without physical presence of me and the participant.

Face-to-face interview has traditionally been the preferred mode of conduct in qualitative research (Ritchie et al. 2014). First, it provides basis for the establishment of a good rapport between the researcher and participants which is very important for ethics and the quality of data. Second, unstructured face-to-face interview helps to create an environment where the participant can tell the story by responding in a free and full way. Third, the researcher is able to take non-verbal communication into consideration.

However there are certain circumstances suitable for telephone interviews and it is not necessary one mode is superior over another (Irvine et al. 2013). Riessman (2008) clarified that the face-to-face interaction for eliciting stories may not be suitable when the topic is related to traumatic experience such as loss. Thus, telling the story of transfer through non-physical interaction became a more practical and ethical option for the participant. The choice of a family joint interview by participants also reflected its meaning to participants such as a share of participation of study and construction of story because it was a family event to participants.

3.5.2 Rationale for data collection via interviews

The choice of data collection methods should consider which type of data will best address the research topic and the practical limitations (Ritchie et al. 2014). In this study, interviews were chosen as the data collection method because of the aim of the study, the underlying paradigm and methodology, and practical considerations.

This study aimed to understand experiences of families who made the decision to transfer their relative from the ICU in China to die at home. Interviews are used when the purpose of study is to find out something about inner perspectives that cannot be found by observing such as feelings, thoughts, intentions, behaviours that took place in the past, any situations without the presence of the observer, and how people have organised the world and the meaning people make in the world (Patton 2002). The fundamental principle of qualitative interviews is to provide a framework within which participants can express their own understanding in their own language.

Compared to observations and document reviews, the interaction and co-construction activities in interview are the most intensive in which the researcher play the most active role. Interview data includes participants' explicit interpretations and understandings of events which cannot always be captured by observational data (Ritchie et al. 2014). Interviews offer an effective way of exploring the ways in which participants experience and construct their lives (Ritchie et al. 2014).

Interview is also the most common means for eliciting participants' stories. Most narrative projects in the human sciences are based on interviews of some kind (Riessman 2008). Researchers from different disciplines are interested in how to gather stories from qualitative interviews and have identified the characteristics of the interviews that can facilitate the production of story: unstructured interviews (Mishler 1986), narrative interviews (Jovchelovitch and Bauer 2000), and active interviews (Holstein and Gubrium 1995). The underlying philosophical assumptions for these interview methods are derived from constructivism.

3.5.3 Constructivism interview for eliciting stories

Jovchelovitch and Bauer (2000) described a narrative interview method which allows an unstructured process and encourages storytelling, active interaction and social construction during interviewing and therefore was used by this study to gather stories from participants.

According to the extent to which the interview questions are pre-determined and standardised, the mode of interview can be structured, semi-structured, and unstructured (Fontana and Frey 1994). Structured interview asks each participant a series of pre-determined questions with a limited set of response items which is more usually undertaken in positivist paradigms of inquiry (Silverman 2011) whereas, unstructured interview requires the researcher to avoid structure allowing the conversation "go with the flow" (Patton 2002 P343), or "follow participants down their trails" (Riessman 2008 P24).

The key aim of unstructured interview is to *understand* the complexity of the individuals' world (Fontana and Frey 1994) and are appropriate to address the questions about how individuals perceive, organise, give meaning to, and express their understandings of themselves, their experiences and their worlds. Indeed, ‘unstructured’ is also the major characteristics of the interview when the purpose of it is to gain participant’s stories, which is termed ‘narrative interview’.

However, a completely unstructured interview is impossible in practice because the researcher will have some sense of the themes to explore and interviews will generally base on some guide or interview schedule (Ritchie et al. 2014). In addition, completely unstructured interviews may yield stories that are too different across cases, making systematic comparison impossible (Groleau et al. 2006) which is the aim of this study. Questions were prepared for the unstructured interviews which were not to ensure all participants will be asked the same questions without flexibility but to be sensitive to individual differences and situational changes (Patton 2002).

In addition to unstructured, interviews have been described as an ‘actively constructed’ conversation through which story data are produced (Holstein and Gubrium 1995, 2016) and in which the researcher take a more ‘active’ perspective, begin to acknowledge, and capitalize upon, interviewers’ and respondents ‘constitutive contributions to the production of interview data’ (Holstein and Gubrium 1997 P14). To constructivists, interview is a site of narrative practice (Holstein and Gubrium 2016).

Context for the interview and the construction of story and meaning is paramount. The form and content of what is said in interview conversation are inherently shaped by interview situations or environments, including age, gender, race, social class of the interviewer and the interviewee, and local culture (Holstein and Gubrium 2016). The influence of my background on the interview was carefully considered (section 3.9 this chapter) and reflected during the study (section 4.4.4 chapter 4). The cultural context for the current study included critical care, and societal culture of China. For instance, ICU might suggest a cure-centred context to the public (Chan and Chow 2006; Myburgh et al. 2016). In terms of the societal culture, this study was embedded in a family centred culture that family had superior power in decision-making than individuals (Li 2013). This explained why some participants in this study selected to take part in a family joint interview rather than an individual interview process. Combining the option of family joint interviews with individual interviews in this study allowed a joint construction of a shared experience in relation to transfer which was essential and meaningful to individuals who preferred a family approach according to the Chinese family culture.

To sum up, the selection of narrative interviews, which were unstructured and actively constructed, both individual and joint, generated stories that addressed the research question and study objectives.

3.6 Methods for data analysis

3.6.1 Qualitative data analysis

Qualitative data analysis comprises inductive analysis and deductive analysis. Inductive refers to identifying patterns, themes and/ or categories from the data while deductive analyses data according to an existing framework. Qualitative data analysis is typically inductive in the early stage and then moves to deductive process to test and affirm those identified in inductive analysis (Patton 2002).

Generally, some analytic practices are used across different qualitative research types (Miles et al. 2014), including: a) assigning codes or themes to data, b) sorting and sifting these coded data to identify patterns, themes, categories, commonalities and differences, c) taking the identified patterns to the next wave of data collection, d) noting ideas in analytic memos, e) generating assertions, propositions and generalizations, and f) comparing those generalisations with existing constructs or theories.

These are the fundamental analytic activities and procedures in qualitative studies. However, this study aimed to identify potential patterns about a specific phenomenon and dealt with stories which required a specific data analysis approach.

There are a number of data analysis methods used in qualitative research including qualitative content analysis (Mayring 2000; Elo and Kyngäs 2008), thematic discourse analysis (Taylor and Ussher 2001), narrative analysis (Riessman 2008; Sparkes and Smith 2008), and thematic analysis (Braun and Clarke 2006). For this study thematic analysis was selected as the most appropriate method because it enabled the generation of themes in the stories told by families about their experiences of decision-making.

Qualitative content analysis quantifies the codes and themes and reports frequencies of them (Vaismoradi et al. 2013), which is similar to coding reliability and codebook thematic analysis that is underpinned by positivist (Braun and Clarke 2019). Qualitative content analysis generates more descriptive understanding of data (domain summary) while (reflexive) thematic analysis reveal underlying meanings through themes.

Thematic discourse analysis also generates patterning themes but the focus is on the use of language (Taylor and Ussher 2001). Discourse analysis examines how language is used to accomplish personal, social, and political projects (Starks and Trinidad 2007). The close examination of language requires researcher’s skills in language practice (Braun and Clarke 2019). The current study involves the attention to the constructive nature of language or story but how language is used is not the focus of the study. In constructivist studies, language is treated as constructing and creating meanings (Clarke and Braun 2014). There is a lack of clear defined procedure for doing thematic discourse analysis.

Narrative analysis is a particular analytic approach focusing on storied data looking at both the content (whats) and the structure (hows) of stories told by participants (Sparkes 2005; Riessman 2008; Sparkes and Smith 2008). The current study only addressed the questions about the meaning and content in data and how stories were told was beyond the scope of current study. When the focus of study is about the underlying meaning or the circumstances that shape the narrative, the analysis should put aside the hows of narrative practice and pay attention to the stake in the narrative construction process (Holstein and Gubrium 2016).

Thematic analysis which was used in this study is a qualitative analytic method that identifies and determines themes or patterns of meaning across data (Clarke and Braun 2014). It is an analytic process from raw data, through coding for potential patterns, to identify final themes capturing the essence of data to answer research questions (Braun and Clarke 2006). A central competency for researcher is pattern recognition (Patton 2002). It is an analytic approach that can be widely used across a range of epistemologies and research questions (Nowell et al. 2017).

3.6.2 Three schools of thematic analysis

Thematic analysis is not one method but an umbrella term for a cluster of different approaches that share a focus on capturing themes or patterns in data (Braun et al. 2019). In order to clarify the distinctions between different thematic analytic approaches, Braun et al. (2019) categorise thematic analysis into three schools based on the underlying philosophical assumptions and procedures of data analysis: coding reliability, codebook and reflexive. A tabulated illustration of the three schools of thematic analysis is presented in Table 3.3. The reflexive thematic analysis approach as developed by Braun and Clarke (2006, 2013) was selected for the analysis of current study.

Table 3.3 Three schools of thematic analysis by Braun et al. (2019)

School	Coding reliability thematic analysis	Codebook thematic analysis	Reflexive thematic analysis
Authors	Boyatzis (1998), Guest et al. (2012), and Joffe (2011)	Framework (Ritchie and Lewis 2003), template (Brooks et al. 2015) and matrix analysis (Miles and Huberman 1994)	Braun and Clarke (2006, 2013), Langdridge (2004)
Epistemology	Positivist	Realist-constructionist	Realist-constructionist
A typology by Kidder and Fine (1987)	Small Q	Medium Q	Big Q
Analytic process	Reliable and accurate coding, use of a codebook	Using a codebook	Reflexive
Conceptualisation of theme	Domain summary	Domain summary	Pattern of shared meaning

Coding reliability thematic analysis uses qualitative techniques but its underlying paradigm is positivist as the focus is to ensure the reliability and validity of the codebook/ coding frame (Boyatzis 1998). It is classified as a “small Q” (Q: qualitative) by Kidder and Fine (1987) because of the underlying philosophy of this qualitative thematic analysis approach. Inter-coder agreement is often measured. Coding reliability thematic analysis conceptualise themes as domain summaries.

Similar to coding reliability, codebook thematic analysis employs a codebook which can be a framework, template or matrix, to index, sort and display data for structured coding and typically generates domain summaries. However, it concerns less in positivist reliability and validity with a more qualitative underlying philosophy and is considered as a “medium Q” approach.

Reflexive thematic analysis is purely qualitative because its underlying epistemology is from critical realist/essentialist to constructivist/constructionist. Reflexive thematic analysis has the characteristics of qualitative approaches such as depth of engagement, subjective, open-ended and flexible. Analysis usually follows the process: code - concept – theme. Coding is an iterative process. The researcher is a ‘storyteller’ actively engaged in coding and theme development through the lens of their assumptions and background. Themes are conceptualised as patterns of shared meaning with a central organising concept.

In responding to criticisms of thematic analysis, or potential misuse of the approach, Braun and Clarke provided guidance on how not to use themes (see their website for detail: https://www.psych.auckland.ac.nz/en/about/thematic-analysis.html). For example, researchers may state a theme but (according to Braun and Clarke (2019)) are providing an overview-type statement that simply summarizes what participants said in relation to an aspect or domain of topic. In contrast, themes are patterns of meaning that are more abstract and reflect implicit concepts in data, maintain the richness of data by telling a story organised around the central concept and therefore make sense of what participants said. Braun et al. (2019) refer to domain summaries as a “bucket theme” which do not consider shared meaning or difference like their “storybook theme”.

Themes are also conceptualised as semantic and latent (Braun and Clarke 2006, 2013, 2016; Braun et al. 2019). Semantic themes report the explicit content of the data and present a more realist and descriptive understanding of the data. In contrast, latent themes report the implicit concepts and assumptions underpinning the data and present a more constructionist and interpretive understanding of data. Latent themes move away from the explicit and obvious content of the data to the implicit and underlying patterns of the data. Thematic analysis at the latent level involves interpretive and theorising work. Both semantic and latent themes can be identified in a thematic analysis but one of the two dominates the analysis and which is determined by the paradigm underpinned the study: latent themes are more appropriate for a constructivist analysis (Braun and Clarke 2006) and therefore latent themes were the focus of analysis in this study.

A further debate in thematic analysis is use of the term “emerged themes”. The message here is that meaning is already existing in data and waiting to be discovered. Themes do not emerge but are identified or developed through active, creative, reflexive, interpretive analysis involving researcher engagement (Braun and Clarke 2016). Thus, the conceptualisation of theme for current study was that themes were latent, shared meaning based patterns, and were identified through reflexive interpretation.

3.6.3 Rationale for selecting thematic analysis

With the purpose of identifying pattern or themes, thematic analysis is an ideal choice for a PhD student who is a novice researcher. It is one of the most accessible and flexible qualitative analytic methods and involves procedures that are common and fundamental to most forms of qualitative analysis (Braun et al. 2014). Braun and Clarke’s thematic analysis approach has a set of clearly defined procedures that are not difficult for a novice researcher (Braun et al. 2014; Braun et al. 2019).

Braun and Clarke’s reflexive thematic analysis aligned with the constructivism paradigm of this study because it is theoretically flexible and can be situated from critical realist to a more constructive paradigm (Clarke and Braun 2014). A constructivist/constructionist thematic analysis focuses on multiple realities created or constructed in data rather than to discover or verify a single true reality. Language is not a transparent reflection of participants’ experiences and behaviours but a construction of the meanings and realities in the data.

Braun and Clarke’s thematic analysis approach was selected as the most appropriate for this study. Thematic analysis can be applied to various types of data, including data generated from face-to-face or virtual interviews or focus groups, data generated from qualitative surveys, story completion tasks, vignettes, and diaries, and secondary sources of data such as printed materials, online and electronic materials, and broadcast media and film (Clarke and Braun 2014).

3.6.4 Context for analysis

The analysis must take the environments in which the story was constructed into consideration including circumstantial and cultural contexts (Holstein and Gubrium 2016). The context for the current study included the setting of critical care, and the broader culture in China and these were integrated into the interpretation of data. This was achieved by clustering themes around a central organising concept, which can be explicit and concrete meaning (Braun et al. 2019), but is more often related to assumptions, believes, norms, and culture at a broader societal level (Braun and Clarke 2019). This study mapped the meaning of data to the Chinese culture about death, family relationship and moral values, cultural values on place of death, and the healthcare system which are outlined in chapter 6 and discussed in chapter 7.

3.6.5 Language and translation

With participants and I speaking the same language (Mandarin), no language differences were present in data gathering, transcription and early analysis (coding) in this study (van Nes et al. 2010). However, translation of interview transcripts was needed in order for these to be shared with my doctoral supervisors who are native English speakers and because the thesis is written in English for degree examination and dissemination (Santos Jr et al. 2015).

Translation is a process in which an interpreter conceptualizes the meaning and, using vocabulary and grammatical structure appropriate for the target language, reconstructs the meaning of the statement in a new cultural context (Larson 1998). For this study, the translator was me. The aim of translation was not to produce a full and accurate representation of the concepts in original language (Hermans 2003) but was to reconstruct the meaning of data in the English culture which involves my interpretation of meaning (Larson 1998), and self-reflexive practice (Hermans 2003).

Language and culture differences between Chinese and English were considered in this study's translation to reduce the loss of meaning and enhance trustworthiness of data (Chen and Boore 2010; van Nes et al. 2010; Al-Amer et al. 2015). Xian (2008) found that it was difficult to translate Chinese idioms and proverbs which originated from Chinese historic stories and mythologies, and complex social phenomena. The author applied a "dynamic equivalent" and "contextual consistency" approach in translation (Xian 2008) which is meaning-based. A more interpretive and constructivist methodology for translation is the "thick translation" (Hermans 2003) which highlights a detailed, descriptive and narrative style of translation. For example, a sentence in Chinese can be translated into a paragraph in English in terms of length with rich description. These principles for translation were adopted in this study.

However, this study also required textual and content equivalence (Twinn 1997; Esposito 2001), where a meaning-based translation could not reflect the terminology attached specific cultural meaning in original language. For instance, death metaphors vary between Chinese and English due to the vast differences between the religious formulations of death and afterlife in Chinese and Western religions (Cheung and Ho 2004; Tian 2014). A literal translation was used to preserve the words said by Chinese participants, with additional contextual interpretation.

In practice, this study used the most common and highly recommended procedure for translation: forward and backward-translation with an expert panel committee for trustworthiness (Chen and Boore 2010). Back-translation is translating from the target language (English) back to the source language (Chinese) and the consistency of meaning can be evaluated (Brislin 1970). Situated in the different cultural contexts, back-translation approach can be used to minimise mistranslations of stories (Santos Jr et al. 2015).

3.7 Quality of qualitative inquiry

Methodological rigour in constructivist inquiry is established through an assessment of trustworthiness and authenticity (Guba 1981; Lincoln and Guba 1985; Guba and Lincoln 1989). Trustworthiness in qualitative research is assessed via the concepts of credibility, transferability, dependability, and confirmability, which was first proposed by Guba (1981), and evolved in the later work by Guba and Lincoln (Lincoln and Guba 1982, 1985). Authenticity is the fifth criteria in this model (Lincoln and Guba 1985, 1986; Guba and Lincoln 1989).

How the model was applied in assessing the quality of inquiry presented in this study is laid out in Figure 3.1 and discussed in the following sections.

Figure 3.1 The quality model and application in this study

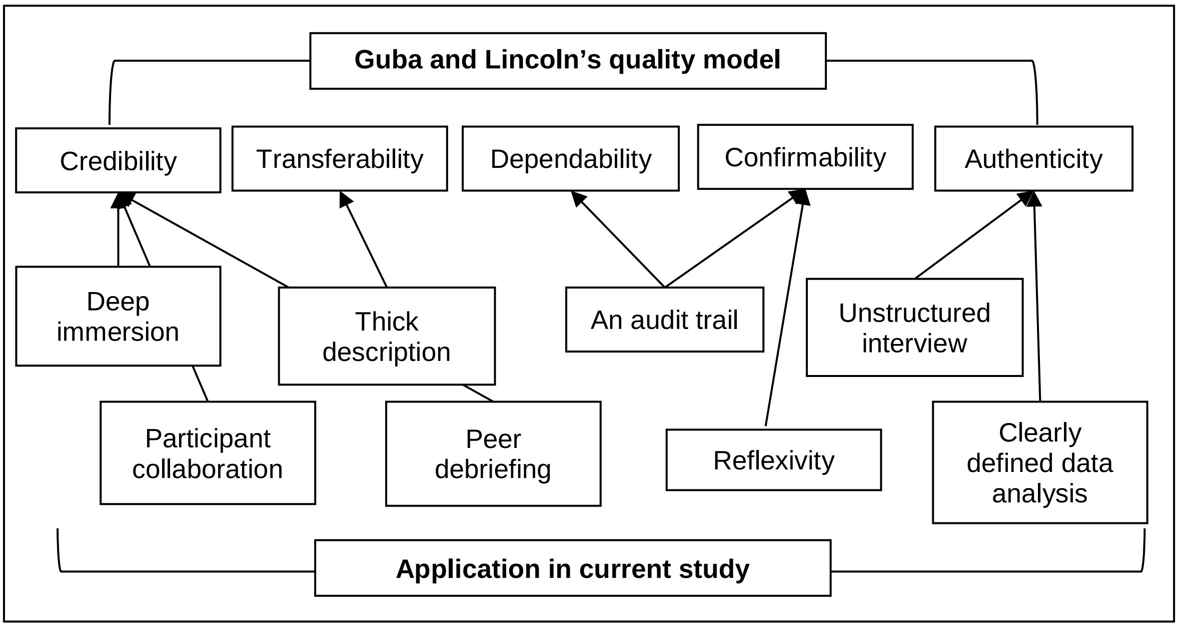


Figure 3.1 shows the five criteria in the model by Guba and Lincoln with the associated strategies or procedures to establish the quality of injury in the current study, including prolonged engagement, participant collaboration (rather than member checking), unstructured interview, well-defined thematic analysis, thick description, peer debriefing, an audit trail, and reflexivity.

3.7.1 Credibility

Credibility is concerned with the truth value in research (Guba 1981; Lincoln and Guba 1982, 1985) and addresses the question: “How can one establish confidence in the “truth” of the findings of a particular inquiry for the subjects or informants and the context in which the inquiry was undertaken?” (Guba 1981 P79). In constructivist inquiry, credibility concerns “multiple constructed realities” (Lincoln and Guba 1985 P295).

This study used deep immersion in the field, participant collaboration and peer debriefing to support credibility. Member checking and triangulation were not adopted because consistency or verification was not pursued (Braun and Clarke 2019). Peer review was used with a purpose of ensuring the most appropriate approaches, processes and decisions regarding the inquiry on the particular topic were used.

I spent two months in the field for recruitment and collecting data through interviews in addition to the pre-connection between me and the setting, and the informal conversations between me and the clinicians about the situation of transfer practice. This deep immersion of myself within the environment was sufficient for establishing rapport, identifying the assumptions and perceptions of the participants of the study and me, with reflexivity on fieldwork. Guba (1981) suggests “six months into the site engagement” for intensive contact with the phenomena or participants in the field and identifying saliencies in the situation (P84). However, there are no rules regulating the length of time one should be involved in the fieldwork and it depends on the design and the particular purpose of the study (Krefting 1991).

Participant collaboration was used in this study to replace “member checking” (Lincoln and Guba 1985; Guba and Lincoln 2001; Schwandt et al. 2007). During the research design stage, input from patient and public contributors was obtained who provided a lay, but informed perspective. By actively involving participants in research, the collection of credible data was more likely. Such collaboration enabled the study design to be open to scrutiny by those who were members similar to the study population (Riessman 2008).

Peer debriefing was used to ensure the quality of study at all stages of inquiry. Regular meetings with the supervisory team were carried out during the research process to discuss my decision-making, and provide support. The supervisory team possessed expertise in the conduct of qualitative research and carrying out research on sensitive end of life topics. In addition, the study was reviewed by external researchers based in the University of Southampton over time in terms of the development of research questions, literature review and research proposal (the milestone approach and the application of ethical approval).

3.7.2 Transferability

Transferability is concerned about generalizability and applicability and addresses the question “How can one determine the degree to which the findings of a particular inquiry may have applicability in other contexts or with other subjects (respondents)?” (Guba 1981 P79). Qualitative findings can be transferred from one context to another depending upon the degree of similarity or fittingness between two the contexts.

This study used purposeful sampling and “thick description” (Guba 1981) to establish transferability. The theories about purposeful sampling have been articulated in section 3.4.4 this chapter. Here briefly discusses the strategy thick description.

A “thick description” means providing sufficient detail about the context in which the study was conducted so that others can determine the degree of fittingness to another context (Guba 1981). “Thick descriptions are deep, dense, detailed accounts…. A thick description should include the informants’ background information, the research context and setting, data collection, data analysis, and the context for the production of the final report (Krefting 1991; Anney 2014). In this study, a thick and rich description was applied in reporting and presenting the research process and study findings. The setting, participants and the themes generated were described in rich detail. Quotes were carefully selected and every effort was taken to ensure the context of the interview was preserved.

3.7.3 Dependability

Dependability is concerned with consistency and auditability of research process (Lincoln and Guba 1985) and addresses the question "How can one determine whether the findings of an inquiry would be consistently repeated if the inquiry were replicated with the same or similar subjects in the same or similar context?" (Guba 1981 P80). Dependability include the elements of stability of findings over time, and trackable variance that can be ascribed to identified sources.

Dependability in this study was mainly established through the use of an audit trail (Guba 1981) which was the documentation of the inquiry process through maintaining a journal and writing memos (Lincoln and Guba 1982; Creswell and Miller 2000). This study maintained a research diary and different memos to document all activities throughout the inquiry process, including research decisions, actions, as well as reflexive activities in design, sampling, data collection, data analysis and report writing.

3.7.4 Confirmability

Confirmability, roughly parallel to objectivity within the traditional paradigm, is concerned about neutrality or separation of values from inquiry (Lincoln and Guba 1985) and addresses the question "How can one establish the degree to which the findings of an inquiry are a function solely of subjects or respondents and conditions of the inquiry and not of the biases, motivations, interests, perspectives, and so on of the inquirer?" (Guba 1981 P80).

Confirmability in this study was established through arranging for a confirmability audit after study and practicing reflexivity (Guba 1981). The audit focusing on the process of inquiry is related to dependability discussed above while the audit focusing on the product of the inquiry is related to confirmability (Lincoln and Guba 1982; Schwandt et al. 2007). To ensure every interpretation that is made by the research is supported by the available data, extensive documentation was made by this study in the research diary and memos.

Reflexivity practice refers to how the researcher acknowledge or disclose the underlying epistemological assumptions that shape the inquiry (Guba 1981). Reflexivity is "an awareness of the identity, or self, of the researcher within the research process", and it means "the tendency critically to examine and analytically to reflect upon the nature of research and the role of the researcher in carrying out and writing up empirical work" (Elliott 2005 P153). In the research diary, I recorded introspections on a regular basis, including my own perceptions, changing insights, affective responses, experiences, ideas, fears, mistakes, confusions, breakthroughs, and problems that arose during the fieldwork (Spradley 1979; Lincoln and Guba 1982). My reflexivity activities for the current study are outlined in chapter 4 and chapter 5.

3.7.5 Authenticity

Authenticity concerns a set of actions by the constructivist researcher including balance of perspectives, learning by the researcher and respondents, shared knowledge, and social action (Schwandt et al. 2007). All strategies discussed earlier used by this study could enhance authenticity. Furthermore, this study increased the authenticity in terms of data collection and data analysis.

Guided or dialogical conversation was an important strategy for enhancing authenticity (Manning 1997). The current study applied unstructured, active interview methods in the production of data to maximise the quality of stories collected from the participants. The interviews were dialogical conversations rather than a one-way, information gathering process (see chapter 4).

The quality of data interpretation was achieved by using a clearly defined, widely applied approach of thematic analysis (see chapter 5). The thematic analysis enabled the understanding of the phenomenon of interest to be a co-product between me and the participants. It preserved the perspective of the participants by reporting the patterns of meaning in the content of their stories and this was achieved through the analysis work done by me.

Authenticity can also be strengthened by ethics including informed consent and confidentiality which are outlined in next section.

3.8 Ethics

When carrying out research that is sensitive in nature, an ethical framework is needed to ensure the study is conducted in an ethical manner (Patton 2002). Guided by the ethical principles for qualitative inquiry (Ritchie et al. 2014), and bereaved research (Parkes 1995), ethical applications in this study comprised ethical considerations, informed consent, anonymity and confidentiality.

3.8.1 Ethical considerations in recruitment

As the research was informed and approved based on the principles of Western research ethics (UK), but recruitment and data collection were carried out in China, differences in ethical practice between Chinese and Western cultures were considered in decisions such as the recruitment strategy.

A main comment from the University of Southampton's Research Ethics Committee, who provided ethical review for the study, before granting approval was whether it was feasible to recruit participants only relying on a poster instead of through the gatekeeper of clinicians. A final approval was granted by ethics for gatekeeper recruitment for this study because of the following considerations. First, poster recruitment is a model more suitable for research in Western contexts and this type of self-selection sampling is not common in research in China. As a result it was likely that the response rate would have been extremely low. Instead, to recruit through a gatekeeper giving out the information sheets was more culturally appropriate for such a study in China. Second, a concern of the Ethics Committee was related to ensuring participants took part of their own volition. They stated that potential participants should not feel pressured into taking part in the study due to the power relationship that existed between clinicians and families of patients. However, because the relationship between clinicians and families ended once the patients were discharged home to die, this was not a consideration in this study. In addition, families were allowed to take the information sheet away and make the decision after leaving the hospital. To ensure voluntary participation, recruiting participants via a third party (Parkes 1995), was seen as suitable for interviews with a sample population of bereaved families in China.

3.8.2 Informed consent

A core principle of qualitative research is that informed consent should be obtained from participants (Ritchie et al. 2014). Potential participants should be told about the purpose of the study, the funder of the study, the individual and associated organisation conducing the study, the duration and content of interview, confidentiality and anonymity, as well as the voluntary nature of participation, including the freedom to withdraw at any time prior to data analysis.

An ongoing informed consent is favoured to provide the detail at different occasions throughout the process and allow participants to reflect on the benefits and potential costs of participating. In addition, potential participants should be given sufficient time to weigh up the pros and cons of participation before giving their consent, a staged approach to informed consent (Ritchie et al. 2014). These strategies could reduce the effects on informed consent introduced by the gatekeepers who first contacted potential participants in this study, such as unfairly excluding some families from the participation and pressure to participate.

3.8.3 Confidentiality and anonymity

The close interaction between researcher and participants in constructivist inquiry raises potential ethical issues about confidentiality and anonymity (Guba and Lincoln 1994). This is particularly the case for a study dealing with stories which entailed rich detail about the participants (Josselson 2007). Assurance of confidentiality and privacy was central to the conduct of this study.

Confidentiality means not disclosing who has taken part, and not reporting what they say in ways that could identify them or be attributed to them (Ritchie et al. 2014). Confidentiality may be inadvertently breached in the way in which qualitative data is reported where the researcher refers to characteristics or circumstances that might identify an individual or organisation. In this study, both participants and the setting were protected from disclosure and the detail of data and confidentiality were balanced. In addition, the collection, storage and transfer of research data complied with the Data Protection Act (2018) (General Data Protection Regulation) and the standards by the University of Southampton.

3.9 Positioning me in the study

From an axiological standpoint, the generation of knowledge is shaped by the researcher's values and lived experience which cannot be divorced from the research process. Therefore, my own experience, expectations, biases, and values that had a potential impact on the research process were acknowledged (Ponterotto 2005).

3.9.1 My biography

I am a young Chinese woman. I was born and grew up in northeast of China and moved to a city in southeast of China after graduation from the university. I worked as a registered nurse in one of the largest hospitals in the local area for ten years with two years working in the general ICU, before I came to the UK for the PhD.

My PhD study was about family members' experiences of decision-making when transferring a relative home to die from the ICU where I worked before. The data collection through interviews was conducted in China and the language of data was Mandarin. I shared a same cultural background with the participants and all spoke a same language which did not introduce significant cultural and language difference in the knowledge production but subcultural differences exited because we came from different parts of a large country. The ten years living experiences in the city where the participants were recruited enabled me to have a good awareness of the local subculture.

I moved back to China three years after I commenced my PhD in the UK because my funding was only for three years. This could influence on the quality of knowledge production because of a lack of physical meeting between me and my supervisory team. I got married during the time when analysing the data in my home country and gave birth to my son about a year later. This means I have my own family and new family relationships. My family beliefs could influence my interpretation of data. For example, I valued filial piety more and this cultural concept was noticed by me in the data.

3.9.2 My experiences in relation to THtD

I have never been involved in the decision-making of transferring home a relative in my family from critical care. My experiences or pre-knowledge about the phenomena of THtD were mainly from the working experiences in the ICU and these influenced my decisions in selection of research problem, recruitment, data collection and analysis. During the two years, I witnessed a number of families take their relatives home to die from the ICU. In most cases, the discussion took place between doctors and family members without the involvement of patients and nurses. These patients were recorded as “self-discharge” in the classification system to show that it was a choice by the family against the physician’s advice (which was contradict to the finding that some doctors offered families the option in my study). Medical disputes were not rare in the ICU and public had a mistrust of the healthcare system in China. As a nurse, I knew little about the process of decision-making and what happened after the patients were taken away from the unit. My personal thoughts prior to the study were that transfer should not be an easy process because the choice was made when the patients were dying. In addition, families should be the key ones to the decision-making according to our societal culture.

3.9.3 My values into the study

My values about death, family, and going home to die were brought into the study.

Going home to die involves the attitudes towards death. To me, death is a fear but I can accept it when it comes. I think the acceptance of a relative’ death is more difficult for the family than for the individual in China.

From my point of view, family are essential but they should not be the only decision-makers to my end of life decisions including when to give up and where to die. I hope I can determine the way of death for myself.

Personally, I prefer to die in my own bed with my family members around. I respect the choice of going home to die if this is what patients and families prefer. I think it is important to fulfil their wishes about where to die and therefore efforts should be made to support them in the process of THtD.

To me, THtD is an essential area in clinical practice for China but little was known in literature. It is necessary to understand the difficulties in the decision-making so that evidence-based recommendations could be made to advance the relevant areas including clinical practice, policymaking, theory developing, and further research.

3.10 Chapter summary

This chapter has outlined the methodology and paradigm that have informed this study. The paradigm assumptions were explicated in relation to ontology, epistemology and methodology, furthermore the choice of paradigm for the study was justified by the knowledge about the theory of decision-making and human’s reaction to loss. It is, a central task for the bereaved to construct meaning from the experience of loss. Aligning with constructivism, the selection of a qualitative research methodology to address the research question and the choice of methods for data collection, data analysis, quality of inquiry and ethical practice have been justified. The following chapter will present the overall research process including sampling and recruitment, and data collection.

Chapter 4 Methods

4.1 Introduction

Chapter Four presents the methods applied and procedures undertaken in completion of the research presented in this thesis. This chapter includes an overview of the research strategy, participant selection and recruitment, the methods used for data collection, my reflexivity on data collection, and ethics. The methods for data analysis are outlined in Chapter Five.

4.2 Research strategy

4.2.1 Preparation for research

At the research design stage, input was sought from patient and public representatives who were invited to provide feedback and constructive criticism on the design of the proposed study. Employing the strategy of patient and public involvement (PPI) in the research design is good research practice and can ensure the research is practical and valid from the public perspective (INVOLVE 2012).

This PPI representative was a family member who had experienced the death of a relative in the ICU where subsequent recruitment was carried out. They were selected and introduced by a doctor who was one of the team who had treated the patient. Following explanation of why they were being contacted, they were willing to offer comments on the proposed study and selected methods and gave their permission to be phoned by me. The conversation lasted about one hour and focused on the research question and objectives, methods for data collection, including the interview schedule to be used in the study, and recruitment.

The outcome from discussion with the PPI representative suggested that the research topic was meaningful from the participant’s perspective and interviews were an appropriate method for data collection. The PPI representative also thought it was acceptable for clinicians to help with the identification of participants in China but that support resources for participating family members should be in place because the research topic was sensitive (see appendix A.4).

4.2.2 Research setting

The context in which the research took place was a 22-bed general ICU in a tertiary hospital located in the southeast of mainland China. The selected hospital was in a port, prefecture-level city but it was a metropolitan area which was well developed in economy and international communication. A number of migrants from other parts of the country worked and lived in this city. This was consistent with the participants of the study whose relatives were discharged to their hometown in different parts of the country.

The implications of the population composition were that the language and culture in this area were diverse although the ethnicity was primarily Han. Mandarin was the official language and many dialects were used in the mixed populations. The indigenous population had their own dialect which was often spoken between themselves, or by those who had a lower levels of educational attainment and had not learned speaking Mandarin (Mandarin is taught in primary school in China).

The selected hospital had 2,500 beds and was one of the biggest hospitals in the region. It served not only residents in the local city but also those from the cities, towns and villages in the surrounding region.

The ICU in which relatives of participants in this study were patients was the only general one in the hospital. The age range of patients admitted to this ICU was from new-born to elderly. In 2015, the year before recruitment of this study, there were 891 admissions to this ICU, and the mortality rate was 9% (81/891) (data from the ICU Year Report, unpublished). HCPs comprised 15 doctors and 46 nurses, including a head nurse and a director, and six unqualified support workers.

This location was chosen for two reasons: I) the ICU was based in a large and representative hospital in an urban area of China. This ensured a high likelihood to gather sufficient data in a short period of time and obtain rich, useful and meaning data to address the research question, II) the hospital was based in a city that shared similar norms and traditions reflecting the broader culture of the whole country. This opened up the potential for findings of this study to be transferred to similar settings and contexts.

4.3 Access and recruitment

Access to potential participants is one of the practical considerations in sampling (Mason 2002). Issues relating to access in this study involved negotiation with gatekeepers and providing ethics committees evidence for how potential participants would be accessed and recruited (see 4.3.1 and 4.5.1). There were pre-existing connections between me and the hospital, which made accessing to potential participants more practical.

As a nurse, I had worked in the selected hospital from 2004 to 2014, of which two years were spent working in this ICU. There are a number of benefits to sampling from an organization where the researcher has worked, such as existing knowledge of the organizational context, easier access to the setting and assistance from the clinicians for the recruitment of families. In addition, as it had been some time since I had worked in the hospital I did not know the patients and families who were invited to participate in the study.

Potential participants were identified and recruited between 13th July 2016 and 13th September 2016, with the assistance of clinicians working in the ICU. The recruitment process comprised contacting the gatekeeper, entering the field, recruiting participants, and exiting the field.

4.3.1 Contacting gatekeepers

Informal contact with clinicians in the ICU was made to discuss their current practice of THtD. Following approval from the University of Southampton's Research Ethics Committee, I contacted the head nurse of the unit, to introduce the project and request help with participant recruitment. Documents written in Chinese were sent to her via email, including the inclusion and exclusion criteria of participants, and information and consent forms for potential participants. The head nurse introduced this project to all the doctors and nurses at the change-of-shift report meetings and asked them to identify eligible patients and their families on my behalf.

The head nurse and the clinicians involved acted as gatekeepers to the research setting. Gatekeepers are typically identified as individuals or institutions who have the power to either grant or withhold access to a research population (De Laine 2000). It is common practice to request that gatekeepers assist with recruitment in bereavement studies (Gamino et al. 2002; Koffman et al. 2012; Sque et al. 2014; Whitfield et al. 2015). An existing relationship built on trust between the HCPs and patients' families is likely to facilitate recruitment. Furthermore, the focus of the study was the decision-making of a clinical practice which involved the interaction between participants and the HCPs in the hospital. The interactional nature of the phenomenon allowed the staff in the organisation to identify potential participants. Lastly, recruitment from a third party replacing the direct contact by myself as the researcher eliminated the need for passing on the contact information of the potential samples to me and avoid the related ethical concerns such as privacy invasion and consent (Ritchie et al. 2014).

Sampling through gatekeepers had limitations as decisions may be biased toward/against certain participants. For example, it may be that clinicians are less likely to approach the families who had a poor relationship with the staff and the organisation. The extent to this situation was reduced by working closely with the gatekeepers through regular debriefing and clarification about the sampling strategy (see section 3.4.4 chapter 3).

4.3.2 Entering the field

One week after contacting the head nurse, I entered the unit to learn how the process for identifying potential participants had gone and provide clarifications to the clinicians based on the purpose of the study and the participant's inclusion and exclusion criteria (see Table 4.1). Having previously worked in the ICU, and been a colleague to some of the current clinical staff, I did not encounter any challenges in entering the environment. A small office was provided for me to use for discussions with clinicians and receiving telephone calls from interested families.

4.3.3 Recruiting participants

4.3.3.1 Justification for participant selection

Participants that were included in this research were all Chinese family members who transferred a patient home to die from the ICU in mainland China, or those where a discussion about transfer took place between them and the clinical team but in the end did not happen. This study took a constructivist perspective and accordingly defined family as a product of social construction (Gubrium and Holstein 1990; Holstein and Gubrium 1999) and sensitive to context, with the concept and meaning of family varying from culture to culture. In China, family is often conceptualised as “collective” and “extended” (Zang and Zhao 2017) in terms of structure and function of family. The nuclear family interacts with and relies on extended family physically, emotionally and financially. As a collective unit, most elderly Chinese people die in an extended family (Xu and Xia 2014). Therefore, family members for this study were defined as individuals from the nuclear or extended family including parents, children, siblings, grandparents, grandchildren, and other relatives, or individuals without genetic relation.

4.3.3.2 Inclusion/Exclusion criteria

Participants who were adult family members (aged 18 and over) and had an adult relative in the ICU transferred home to die were included (Table 4.1). As evidence reported that the transfer work for non-adult patients and the families' decision-making was relatively different from those for adult patients (Hawdon et al. 1994; Zwerdling et al. 2006; Stark et al. 2008; Simpson and Penrose 2011; Laddie et al. 2014) those family members transferring home a baby or child were excluded.

The ethnicity of participants was limited to Chinese as the objectives of the study was to understand the practice of transfer in the context of mainland China and the perspectives of Chinese family members. Perspectives of family members from other ethnicities were beyond the scope of this study.

Participants were those family members who had transferred a family member home to die in the previous 12 months. This timeframe was intended to increase the potential response rate which was reported as low (around 20%) in the sensitive area of bereaved research (Williams et al. 2008; Aoun et al. 2015; Bentley and O'Connor 2015). Family members who had experienced the death of their relative at home, or were still caring for a relative, were included in recruitment strategies.

Families of patients who survived more than six months after transfer were excluded from selection (Table 4.1) as the aim of this study was focusing on families' experiences of decision-making of THtD not of caring for a patient when at home. If patient were predicted by the doctors to survive longer than six months after discharge were excluded.

Participants included family members who had capacity to read, write, and communicate in Chinese Mandarin or English. Family members who could only speak local dialects specific to a region and could not speak Mandarin were excluded.

Table 4.1 Participant inclusion and exclusion criteria

Inclusion and exclusion criteria	
Inclusion criteria	Adult family members (aged 18 and over) who had a relative (aged 18 and over) in the ICU transferred home to die or the transfer home had been discussed but was not achieved
	The decision-making of transfer took place within twelve months
	Family members who had capacity to read, write, and communicate in Chinese or English
	Family members who felt able and were willing to take part in the research and tell their story
Exclusion criteria	Family members whose relative had been discharged home and survived or had a clinical prognosis of survival beyond six months
	Family members who spoke local dialects but could not speak Mandarin or English and could not write in these languages

4.3.3.3 Sample size

The aim of recruitment was to gain a maximum of twenty family members of patients who were transferred home to die from the ICU.

4.3.3.4 Recruitment process

Clinicians approached eligible families (section 4.3.3.2) at the time of discussing the options for the patient about where to die. A brief introduction of the study and invitation for participation were offered to potential participants. A pack comprising the invitation letter (appendix A.5), participant information sheet (appendix A.6) and informed consent form (appendix A.7) was provided to a family member who expressed an interest. All documents offered to participants were translated into Chinese by me and the translation was reviewed by a Chinese research colleague in the UK for accuracy and comprehensibility.

Potential participants interested in the study contacted me by telephone after discharge and their relatives' death. Further explanation of the research and background on me was given to the families. Their willingness to take part in the research was confirmed.

Potential participants who expressed an interest but had not made contact with me within two-four weeks following discharge were reminded about the study and asked if they had thought about taking part by an ICU clinician as a follow-up telephone call.

The decision of the timing to approach the families was made based on a range of considerations. Firstly, inviting the families at the time of discussing the transfer avoided issues such as invasion of privacy that may happen by sending a letter or telephoning after discharge (Steeves et al. 2001; Williams et al. 2008; Pollock 2012). Secondly, the potential participants were able to take away the participant information sheet and given sufficient time to consider if they wished to take part. This reduced the impact of the power relationship between them and the clinicians and participants were less likely to feel pressured to take part in the study. More importantly, using this method of recruitment meant families of patients only contacted me when they felt ready and happy to share their stories. Thirdly, although many studies suggest that it may be more ethical and practical to research the bereaved families after six months of the patient's death (Dyregrov 2004; Moss and Moss 2012; Aoun et al. 2015), there is no consensus on the appropriate time to involve the bereaved people in research (Dyregrov et al. 2011) and depends on the individual (Beck and Konnert 2007).

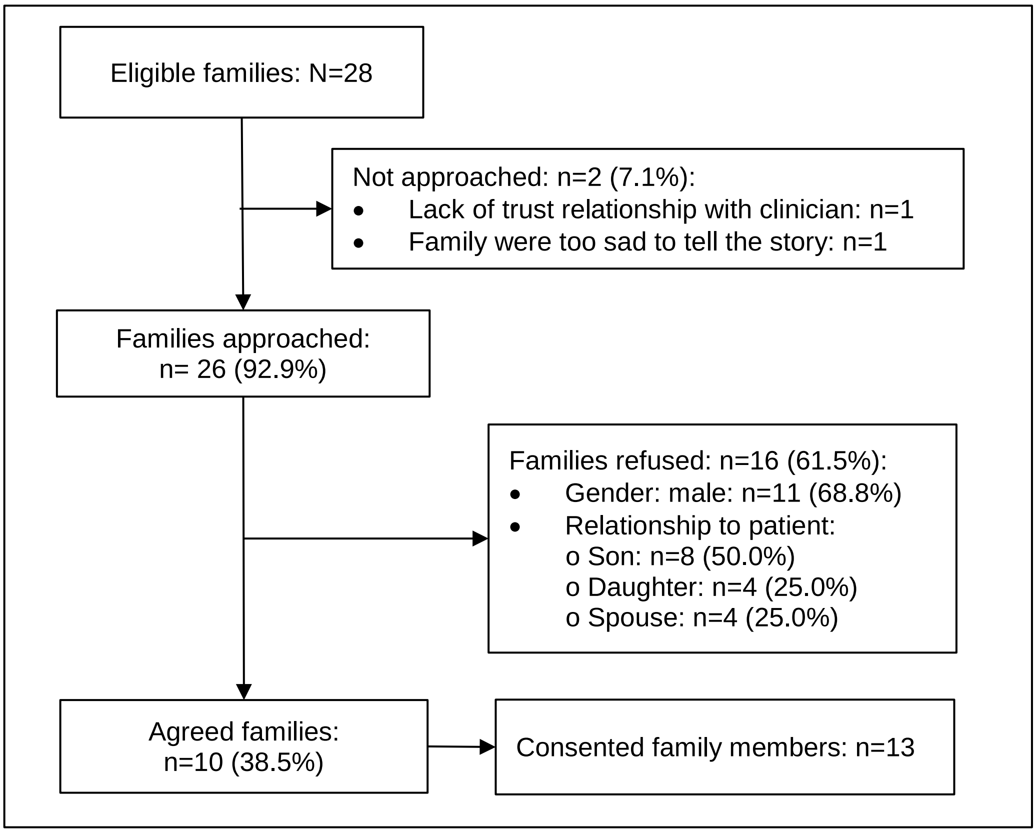
4.3.3.5 Outcome of recruitment

After two months of recruitment ten families involving thirteen family members agreed to participate in the study (Figure 4.1) and recruitment ceased. Recruitment initiatives could not be extended due to practical and legal constraints regarding UK visa requirements that only permit a non-UK citizen living in the UK temporarily to be outside of the country for eight weeks.

The hospital and the unit were informed that I was leaving and would no longer be recruiting participants. The head nurse and clinicians at the unit were thanked for their assistance on the study. No interested families contacted me or the hospital about taking part in the study after I left.

The outcome of recruitment are presented in Figure 4.1 and Table 4.2. Within the timeframe of recruitment, 26 families were approached by five doctors and six nurses. Ten families agreed to take part in the study. The number of participants was 13 because two families had more than one individual who participated in the study.

Figure 4.1 The flow chart of participant recruitment process



As shown in Table 4.2, a pseudonym has been assigned to each participant. The thirteen participants aged from 28 to 63 years of age. Most were male (n=9), and nearly all participants were married (n=12). In terms of level of educational attainment had eight interviewees had graduated from middle school (aged between 13-15) and four were private business owners while three were in temporary work. In terms of their relationship to the patient, the majority (n=9) were their adult child and among which most were son (n=6). A little more than a half of them (n=7) were Buddhist.

4.3.4 Challenges of recruitment and meaning of participation

A challenge encountered in recruiting participants who were bereaved family members. In debriefing discussions, clinicians stated that many families expressed no interest in the study and refused to take part directly when being approached at the time of discussing the decision of transfer. I stressed the sensitive nature of study and the importance of voluntary in the recruitment.

Families in this study were approached at the meeting between clinicians and families about the end of life options including taking the patient home to die. The response rate might be better if the participants were recruited in a separate discussion to end of life decisions. Families would be in a more relaxed emotional state and the invitation to participation of the study be more acceptable. In future studies, it is worth to consider multiple and carefully designed strategies for recruitment of family members on such a sensitive topic in China. For example, combining gatekeeper approach and poster invitation. Full explanation should be made to participants about the pros and cons of their participation and reassurance of confidentiality and anonymity.

Some participants in this study reported benefits from their participation. For example, one participant explained it was an opportunity to share her story to a non-judgemental researcher who took her seriously. There was also altruistic reasons for taking part with several participants indicating that part of their motivation for telling their stories to inspire the researcher and help other patients and families in the future. A positive meaning was made by these participants in their decision to take part in the study to share a private and sensitive story.

Table 4.2 Characteristics of participants in interviews

Interview order	Family member who participated in the interview							Relationship between the participant and patient
	Pseudonym	Gender	Age	Highest education level	Marital status	Occupation	Religion	
01	Wei	Male	44	College*	Married	Telecom manager	Buddhism	Son
02	Qing	Male	48	High school*	Married	Business manager	Buddhism	Son
03	Jun	Male	63	Middle school*	Married	Retired	Buddhism	Son
04 a	Hui	Female	50	Middle school	Married	Temporary worker	Buddhism	Daughter
04 b	Ling	Female	48	Middle school	Married	Housewife	Buddhism	Daughter-in-law
04 c	Dong	Male	48	Middle school	Married	Private business owner	None	Son
05	Ying	Female	37	College	Unmarried	Hotel manager	Buddhism	Daughter
06 a	Lili	Female	52	Middle school	Married	Housekeeper	None	Wife
06 b	Jianguo	Male	53	Middle school	Married	Temporary worker	None	Cousin
07	Zhi	Male	45	Middle school	Married	Private business owner	None	Son
08	Kai	Male	28	High school	Married	Temporary worker	None	Grandson
09	Siming	Male	47	Primary school*	Married	Private business owner	None	Son
10	Quanxin	Male	35	Middle school	Married	Private business owner	Buddhism	Grandson

*Primary school: Year 7 - 12, Middle school: Year 13 - 15, High school: Year 16 - 18, College: Three - year college Education.

4.4 Data collection

The data collection method chosen for this study was interviews. Participants were offered three options: face-to-face interview (individual or joint) or telephone (Table 4.3). Written stories option was offered but no participants requested this method.

Table 4.3 Three forms of interview for data collection

Form of interview	Number of interviews	Number of participants
Face-to-face individual interview	7	7
Face-to-face family joint interview	2	5
Telephone interview	1	1

4.4.1 Family joint interview

In two cases a joint interview took place at the participant request. A joint interview offered an opportunity to look into the shared experiences of a family event (Sakellariou et al. 2013). Family joint interviews enabled a capture of the collaboration among family. When the story was a family event, the interview became collaboration among family members (Hydén 2011). The meanings and disruption consequent should be understood through interviewing the family rather than interviewing the individual (Radcliffe et al. 2013). Family joint interviews offered a method to address ethical considerations including, giving a voice to those who might otherwise be silent, eliciting shared and/or dissimilar understandings, and generation of rich data.

What makes joint interviewing different from individual interviewing is the interaction between participants, who have a pre-existing relationship or not, and access to this interaction is a central feature of joint interviewing (Morris 2001; Polak and Green 2016). Joint interviews are different from focus groups with a context including not only the researcher but also other participants, making focus groups a more public venue. In particular, joint interviewing places emphasis on the relational possibilities of participants (i.e. a familial situation) and mutually created meaning, asking them to represent themselves not just as individuals but also as concurrent participants in a relationship (Morris 2001). Joint interviews provide two kinds of opportunity afforded by interaction between participants: first, the opportunity to study the interaction itself, and second, the opportunity to obtain data that are generated by that interaction (Polak and Green 2016). The nature of joint interview data is the latter is an individual reconstruction of events, qualitatively different from that obtained during one-to-one conversations (Arksey 1996).

The interaction styles in joint interviews can be diverse. For example, Morris (2001) identified that cancer patients and their carers used a combination of styles in their joint interview, sometimes taking turns to produce semi monologues for the researcher, sometimes dialoguing mainly between themselves, and sometimes presenting a united “we” stance. It was common for participants to echo the other’s words to the researcher, providing emphasis and pointers to issues of shared importance. Some pairs seemed to favour one of these styles over the others. The authors categorized these styles as “I and I,” “working it out together,” and “we,” respectively (Morris 2001).

Most of the advantages and disadvantages of joint interviewing stem from the interaction between the two or more participants (Polak and Green 2016), and these are summarised by Arksey (1996); Hilary Arksey and Knight (1999), as listed in Table 4.4.

Table 4.4 The advantages and disadvantages of joint interviews

Joint interviews method (Arksey 1996; Hilary Arksey and Knight 1999)	
Advantages	a. May establish rapport and an atmosphere of confidence more easily. b. Can contain two versions of events rather than one, which may, or may not, produce a coherent joint account. c. The story that emerges may be more complete as interviewees fill in each other’s gaps and memory lapses. d. The information obtained may be more trustworthy as bias in one account may counterbalance that in the other. e. Researchers may gain insights into the interactions and nature of (power) relationships between interviewees through observation of verbal and non-verbal modes of communication.
Disadvantages	a. One informant may dominate, to the extent of silencing the partner; the literature suggest that men are likely to be the more vocal and overbearing. b. The risk of stirring up antagonisms and conflicts of interest. c. If the research topic is especially sensitive, or there is any likelihood of provoking friction, individuals may not be willing to disclose detailed, honest information in front of their partner and instead provide a more acceptable, ‘public’ response. d. Partners may collude to withhold information from the interviewer. e. Interviewees may not concentrate as well when two people are present.

Joint interviews offer many examples of shared storytelling, providing strong evidence that constructing a coherent and presentable story can be a team effort rather than a solo project (Polak and Green 2016). Drawing from a narrative-based study on the experiences of living with motor neuron disease, Sakellariou et al. (2013) identified joint interviews as a method sensitive both to the shared experience of illness and to the multiple perspectives around illness and enabled researchers to explore the intersubjective and heterogeneous nature of illness experiences.

4.4.2 Telephone interview

One family member requested a telephone interview and this was facilitated. Data was collected without physical interaction between me and the participant which the preference of the participant. The key challenges in undertaking telephone interviews were that physical cues, body language or facial expression were not available to me. The telephone interview was shorter than face-to-face interviews in this study but meaningful data was rich in the story told on telephone by the participant.

4.4.3 Conducting the interview

4.4.3.1 Preparation for interviews

An important part of interview preparation is ensuring the researcher has the skills to conduct interviews (Ritchie et al. 2014). I participated in interview training courses organised by the University of Southampton which addressed theory and interview simulation practices. Furthermore, the potential difficulties and issues in interviews, such as the complex interaction in family joint interviews, and emotional situations were discussed at supervisory meetings.

Another preparation was deciding on how to present myself, including my identity, my gender, and my dress, as this might influence data collection (Fontana and Frey 1994). For example, participants might tell a different story if I were an older researcher, or I were a male interviewer, or I were from a different social class (Manderson et al. 2006). I positioned myself as a young Chinese research student who was studying for a PhD in the UK. I explained that I was independent from the ICU, the hospital, and any other organisations with which the participants were linked.

I prepared the option of family interview and discussed about how to conduct the family interview with supervisors. Family members from one family could be interviewed individually or jointly which was decided by participants. Two families chose a joint interview with me and this was facilitated. The differences between individual interview and joint interview were disclosed to participants, including the presence of other family members in telling the story to me and the potential interaction and distraction from other family members during interview. Participants were given time to discuss about the participation and make a joint decision before giving me their informed consent.

As it was anticipated that some participants might become distressed as a result of telling personal and often difficult experiences of taking a dying relative home, support strategies (see appendix A.4) were in place to deal with any distress that arose. Distress suffered as a result of talking about experiences of grief can have therapeutic effects for bereaved families. For this reason research has suggested that it might not be necessary in all instances for a researcher to interrupt or stop an interview immediately if a participant show signs of emotion or distress (Cook and Bosley 1995; Parkes 1995; Elliott 2005). Two participants became emotional during the interview. However, none of them asked to terminate the interview. They were given time to relax and allowed to continue at their own pace.

4.4.3.2 The interview schedule

During the preparation phase, a short list of open-ended questions were generated and this was further developed into an interview schedule to guide the interview process (see appendix A.8), through five steps: 1) retrieving existing knowledge about THtD in literature; 2) formulating the initial questions; 3) discussing the questions and language with supervisors; 4) pilot testing the guide with a research colleague; and 5) establishing the complete interview schedule (Kallio et al. 2016).

The questions included in the schedule were informed by the aim of the study and the findings from the literature review (Chapter 2). Questions on the schedule were designed to address the research question and objectives, and arranged according to the flow of narrative interview: broad questions to initiate participants' storytelling, what and how questions to obtain more detail and clarify confusions, why questions to conclude the talk (Jovchelovitch and Bauer 2000).

Demographic data were collected at the end of each interview (if not covered in the interview) including age, religion, occupation, level of education, marital status, and relationship to the patient. The patient's age, gender, diagnosis and time of death were also checked with the participant. This data were collected as the social context for interpreting the patterns in data and to make comparisons between the participants in this study and participant demographics cited in the literature.

4.4.3.3 The venue and interview environment

The time and place for interviews were negotiated between the participant and me. All the interviews were carried out in public places such as a Café or a meeting room at the participant's place of work (details in section 6.2 chapter 6). The Café selected by the participants to meet me and tell me their story was comfortable, relaxing and safe to them. The space of the café was large and the interview was carried out in a corner with no people around in the scope that the interview could be heard or interrupted. No participants suggested carrying out the interview in their own home.

4.4.3.4 Interview procedure

After participants agreed to take part in the study, the procedure for the interview was introduced to participants, including: the use of audio recording and note taking during the interview. Participants' informed content was obtained prior to interview.

All interviews began with efforts to gain trust and establish rapport with participants. Before the interview began a broad context of the research project and its purpose was explained to the participants again. I answered the questions raised by participants, including the nature of the study, the use of the data, the identity of me and the relationship between me and the hospital. Participants were informed that I was independent from the hospital so they were more likely to share their experiences openly in the interviews. Participants were reminded that no identifiable information would be used in publications and thesis. Time was given to participants to make the decision again whether to take part in the study or not. It was found that this step was very useful for participants to feel safe and respected and thus trust me and be willing to share their story.

In building rapport, as argued by Colbourne and Sque (2004), instead of splitting my role of nurse and a nurse researcher, the role of nurse was included in the process of research, and I was confident about taking a personal investigative approach because drawing on the interactive skills of the nurse can benefit and not detract from the research process.

To elicit participant's story, a broad question was asked: 'Would you please talk about what happened to your relative and how did you make the decision to take him/her home?' While most of the participants were able to begin recounting their story, some participants were unsure of the question and needed me to clarify, for example, "Start from when your relative felt unwell".

At this stage, attempts were made to avoid interrupting participants' narration. I listened to participants' story attentively with occasional responses such as "Um", "Err", "Uh", "Oh", and nodding head, maintaining the eye contact naturally. This conveyed my interest in the story told by participants and encouraged them to continue their story.

Participants often liked to engage me in conversation and sometimes this was in the form of asking questions or confirming some information. At these times, I responded briefly and avoided altering the flow of their story. For example, a participant asked ‘Do you know the (a place)?’ when his story was related to the location where the relative lived. I said “Yes” and the participant carried on his storytelling.

I used terms that the participant used instead of those prepared in the interview schedule to avoid imposing researcher’s form of language. For example, the words “no hope”, and “gone” were used by many participants instead of “died” and such euphemisms were replicated by me when speaking to participants. By doing so, I perceived that the rapport between us was further built and the participants felt comfortable and open to talk with me about the sensitive topic of THtD.

Questioning generated a rich story that was highly relevant to the research questions. Some participants even told ‘another’ story in this phase. As the interview unfolded, not only me but participants learned more from the story they told which become more focused and more in-depth. It appeared that the participants became more comfortable and relaxed as they recounted their experience.

Taking into account Patton (2002) advisory to take care when asking questions that start with ‘Why’, as they pre-suppose that things happen for a reason and presume cause-effect, ‘these type of questions were asked to understand the reasons behind their decision-making and the meaning of their experiences.

Some participants expressed their views and made arguments about the events related to THtD, without my questioning. Others reflected on their experiences only when I asked questions.

During data collection, participants expressed concerns about providing their personal information and as such I was required to provide reassurance with regard to anonymity and stated: “It is a fundamental principle for research that your participation is anonymous and no identifiable information will be included in any publications or reports. I will strictly comply with this.” The concerns about privacy and confidentiality in participation were prominent among the Chinese participants of the current study.

At the end of all interviews, participants were thanked for their participation and sharing their story. I reaffirmed that they were happy with the interview and emotionally they felt able to leave. Some participants made comments about their experience of the interview and how it had a cathartic effect for them. For example, one participant told me: “I prefer to talk about my feelings with a stranger like you rather than with my family or friends”, and another commented: “It feels good to tell you about these things.”

4.4.3.5 Field notes

In addition to audio recording the interviews, field notes were written during and immediately after each interview. Even though interviews were audio recorded, strategic and focused notes taking is still necessary (Patton 2002). During interviews, notes were taken to record participants’ body language and emotional reactions, key terms or phrases, and major points made by the participants. Unclear or important information in participant’s story were written down so that new questions could be formulated to check what participants had said.

After each interview, I checked the audio recording to make sure the entire interview had recorded successfully. Then notes were written to record information regarding setting and context and any issues arising in the field. More importantly notes were made on my thoughts and reflections on the way interview questions asked and the process interview carried out. Notes taking and reflection after interviews were undertaken immediately with an attempt to ensure the quality of data.

4.4.4 Reflexivity on data collection

The conduct of narrative interviews was not easy for a novice researcher. As stated by Riessman (2008), unstructured interviews shifts the control from the researcher to participants and this may generate anxiety for me especially if participants tell a story that is less relevant to the focus of the research.

The most difficult situations in the interviews for this study were participants’ emotional reactions. Two participants became upset and distressed during the interview. However, I understood that this did not mean they wanted to withdraw (Ritchie et al. 2014). In this instance I asked what the participants want to do: carry on, take a break, move on to another topic or end the interview. Both the participants responded that they were comfortable proceeding with the interview.

My reflections on data collection focused on the relationship between the participants and me. I considered how my age, gender, origin, social class, accent, physical presence, and even experience of interview had influenced the stories told by participants in the interviews. For instance, a female participant who transferred her husband home to die called me “little sister” which suggested a close and trust relationship between her and me. Also, I perceived the power relationship had an impact on the data collection. All participants were initially approached by the ICU clinicians during recruitment. Some of them asked me at the beginning of interview about my relationship with the hospital and my motivation for doing the research. I told them the truth that 'I was a nurse of the ICU but now I am a researcher independent from the hospital'. Participants might have told a different story when they were concerned with the researcher's close connection with the hospital where their relatives were discharged. For example, they might choose not to tell me some negative aspects of their experiences with the hospital.

Furthermore, the identity of me as a nurse and a researcher doing a PhD study may also have shaped the way participants shared their story. Families viewed me as an expert in critical care who understood much more than them about medical practice and this might be the reason they did not expand on some events or processes in further detail as they took it for granted that I must already know these things. In addition, families even sought help from me to explain them the confusions in their experience. Such consultations from participants were not rare in the course of interviews. It could be also a reflection about that they would like to make sense of their experiences, which was shaped in the interaction between them and me.

4.5 Ethics

4.5.1 Ethical approval

This research was approved by the University of Southampton's Research Ethics Committee (Reference No. 18845, see appendix A.9). In China, permission was granted from the hospital and ICU prior to data collection being conducted. The hospital informally reviewed the research proposal and approved the access to its ICU for participant recruitment.

No formal approval was granted by the hospital as the committee had no expert reviewers who were familiar with qualitative research and could conduct a formal review on the research protocol. As the research project had been approved by a University Research Ethics Committee in the UK they were satisfied that the study would adhere to good ethical practice. Verbal approval was given by the hospital committee for the study and for recruitment to proceed.

4.5.2 Informed consent

Voluntary and informed consent was obtained from all interview participants. Potential participants were approached by the gatekeeper ICU clinicians. Participants were informed that they could withdraw at any time after giving consent prior to data analysis (see appendix A.7).

Each participant was fully informed of the purpose and process of the study. Ongoing informed consent was obtained prior and during the process of interview.

Written consent was obtained from seven families and for the remaining three oral consent was given and audio-recorded as this was the preference of the participants. The selection of oral consent against written consent by the participants was discussed with supervisors and written in field notes. Of the three oral consent, one was given by the participant selecting the telephone interview, who agreed with each point on the consent form that was read out by me. The other two oral consents were provided by the participants of two face-to-face interviews because they were concerned with signing their name on the informed consent form. The preference of oral consent reflected the participants' concerns about their privacy and requirement for confidentiality. Therefore, in addition to written consent, oral consent should be considered for research conducted into sensitive topics.

4.6 Chapter summary

Chapter Four has outlined the methods of the study that were informed by the paradigm and methodology discussed in Chapter Three, and determined by the nature, scope and purpose of the study.

Chapter Four has demonstrated a clearly defined study project that addressed the question about families' experiences of decision-making when transferring home patients to die from one ICU in mainland China. The understanding of families' experiences of transfer decision-making was achieved through the current study by using purposeful sampling, gatekeeper recruitment, unstructured narrative interview (and thematic analysis that is outlined in Chapter Five). An ethical practice was conducted including informed consent and protection of confidentiality and anonymity.

Chapter 5 Data analysis

5.1 Introduction

Chapter Five outlines the data analysis process undertaken. The data analysis process followed was that developed by Braun and Clarke (Braun and Clarke 2006, 2012, 2013; Clarke and Braun 2014; Braun et al. 2019). The methodological justification for choice of analytic process is presented in Chapter Three therefore Chapter Five illustrates the analytic process following the six-stage thematic analysis developed by Braun and Clarke. This approach (Figure 5.3) has been widely applied in studies adopting qualitative paradigms of inquiry that do not have a specified data analytic process, for example, Interpretative Phenomenological Analysis or Grounded Theory and where the aim is to gain understanding of the data through the identification of meaningful patterns in the data that address the research question.

Before the outline of the six phases of thematic analysis, preparation for analyses is illustrated including transcription, translation, implication of the data sources and data management.

5.2 Preparation for analyses

5.2.1 Transcription of interview data

Interviews were digitally recorded and transcribed verbatim to retain the context of data. I carried out transcription of each interview and all transcripts were anonymised by replacing all names of participants, HCPs and locations, interview settings, with pseudonyms. Transcription was time-consuming. However, transcription offered the opportunity for me to become familiar with data and gain a preliminary understanding of the meaning in data (Braun and Clarke 2006). It also provided me with the skills for close reading and interpretation needed in data analysis (Lapadat and Lindsay 1999).

During transcription field notes were reviewed which were written in English and shared with supervisors at data analysis meetings. An extract of field notes is presented in Textbox 1.

Textbox 1 An extract of field notes during interview

The interview was dominated by the older sister and the wife of the son made comments or provided detail occasionally. The son said very little. It reflected that the older sister was the person who dominated the decision-making of the transfer. This is different from the previous three interviews. Here the rank of siblings played a more important role. The family decision-making could be in various styles.

Audio recordings were re-listened to and checked against the transcripts to ensure accuracy (Braun and Clarke 2006) and as the stories were co-constructed between a participant and me (Riessman 2008), my presence was not removed from the transcripts. For example, whenever I as the interviewer spoke, mainly asking a question, this was denoted by “YL” in the produced transcripts.

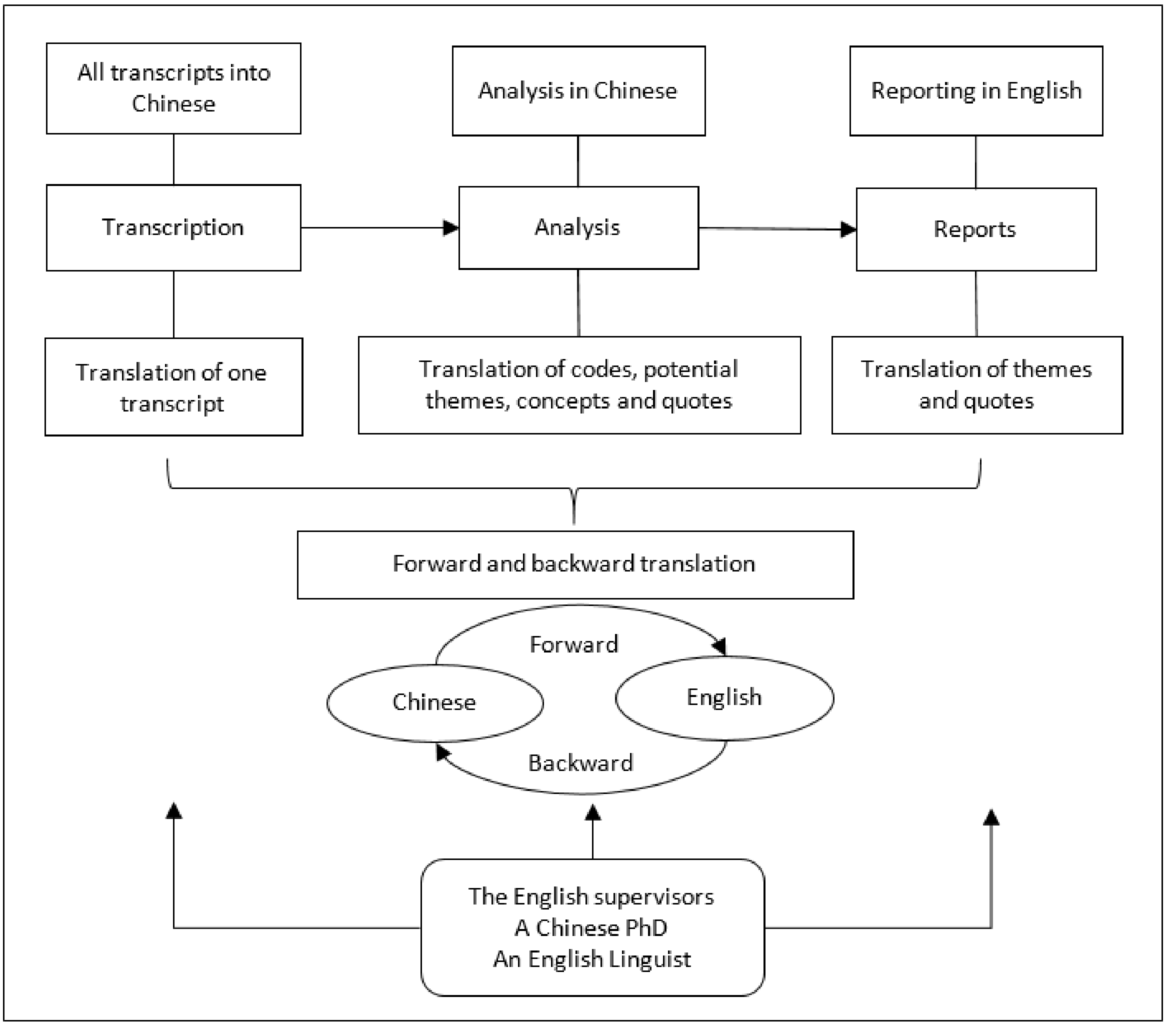
5.2.2 Language and translation

All transcripts were prepared in their original language, Mandarin for analysis. It was decided that transcription would be firstly into Mandarin and then from Mandarin into English for the needs of discussion about the analysis with supervisory team and reporting findings so that colloquialisms in Chinese would be retained in analysis. Although language was not the focus of analysis, analysis based on transcripts in Chinese enabled nuances of stories to be captured that would be lost if translation into English was undertaken too early in the process (van Nes et al. 2010).

Translation used in this study process is presented in Figure 5.1.

One complete interview (the first interview) was translated into English to enable discussion with the supervisory team and ensure trustworthiness of data. The full transcript and translation is available on appendix A.10. After analysis of data in Mandarin, initial and developing themes and examples of data were translated into English for discussion with supervisors. All quotes were translated to English for illustrating the data analysis in this and findings chapter.

Figure 5.1 The process of translation



A forward and backward translation approach was used (Chen and Boore 2010) to ensure the translated materials conveyed the meaning of the original texts and were understandable for English readers. The specific procedure of translation was: 1) I translated the materials in Chinese into English, 2) I translated the English translation back to Chinese after a time interval (hours or days), 3) I checked the consistency of meaning and revisions were made, 4) the quality of translation was further established: the translation was reviewed by a Chinese PhD colleague at the University of Southampton (see Table 5.1); the English quotes and themes in findings (chapter 6) were reviewed by a paid English linguist; all English version materials were reviewed within the English supervisory team with discussion on confusions or disagreements.

The translation reviewed by the Chinese PhD colleague at the University of Southampton included about 10% of the first transcript, all themes and illustrative quotes. The anonymised documents in original Mandarin with associated English translation were sent to her. To ensure the reviewer understood the content and meaning of the translated materials a brief introduction of the study was provided. The reviewer highlighted the translation where they believed it was not correct, not appropriate and raised questions where they could not understand the translation. Table 5.1 illustrates examples of the translation with questions and agreed outcomes.

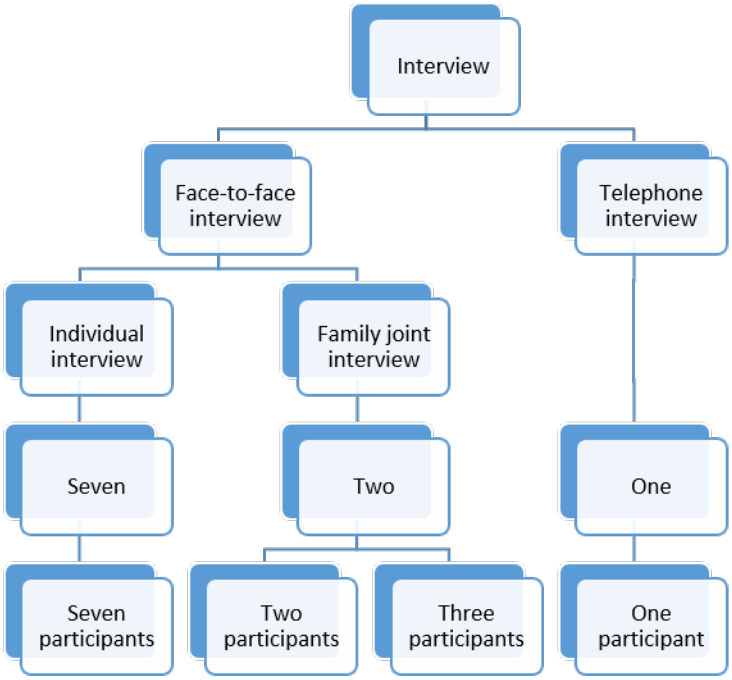
Table 5.1 Examples of translation and quality checking for the first transcript

Mandarin	English	Reviewer's comments	Resolution
(…)那反正我也有给他20 块钱包一个红包嘛，我也给他一个意思嘛, 因为毕竟那么晚了，他也辛苦，他也是在路上，他一开始有在发牢骚，他说这么晚了，他一般也不爱出来.（…）	And I also gave him 20 Yuan, wrapping in a red envelope. I gave him a little Yisi (sense?) because it was so late and he also worked hard. He was also…on the way, at first he was complaining usually he did not work so late.	Tips	Agreed. Because the red envelope was about tips which could reflected the meaning of the data
(…)那要回去呢就是说还要签一个就是说我自愿放弃治疗那个手术，他就省得去起纠纷嘛，说不好听点，（…）	If you take him home you need to sign on a sheet that you give up the operation yourself.' This is to avoid a dispute, in words sound not good.	Which means that To be frank	Agreed. The meaning was accurate and clear. Discussion was made with the reviewer. They believed that my translation was too direct and was not the right expression in English. "To be frank" was authentic and accurately showed the meaning in the participant's words. I finally agreed with the revision.

5.2.3 Data sources and implication for analysis

The data collection approach for ten interviews including thirteen family members from ten families is outlined in Figure 5.2.

Figure 5.2 The number of participants and interviews



A key consideration in analysis was that data collected from joint interviews introduced the issues of recognising words and sentences said by different participants. There were occasions that participants talked to each other in their dialect and I could not understand. These were not transcribed but following discussions with my supervisory team it was decided that this should be indicated by brackets in the transcript. The talk in dialect was not the content of the story the participants wanted to share with me because they did not influence the intactness of the story but appeared to be those only shared between the participants and seemed to remind each other about the talk. The formal analysis of the story constructed by two or three participants together was situated in the context of the relationship between them and the different relationship between the participants and the patient. The focus of analysis was on the phenomenon of THtD rather than the specific language.

The duration of the telephone interview was a little shorter than other face-to-face interviews but the data was rich to allow the identification of meaningful patterns.

Although three forms of interview were used most of the data were collected from the individual interview (7/ 10) and the content of all transcripts of interviews focused on the phenomenon of THtD. Therefore, the thematic analysis approach was applied to all transcripts in this study.

5.2.4 Data management

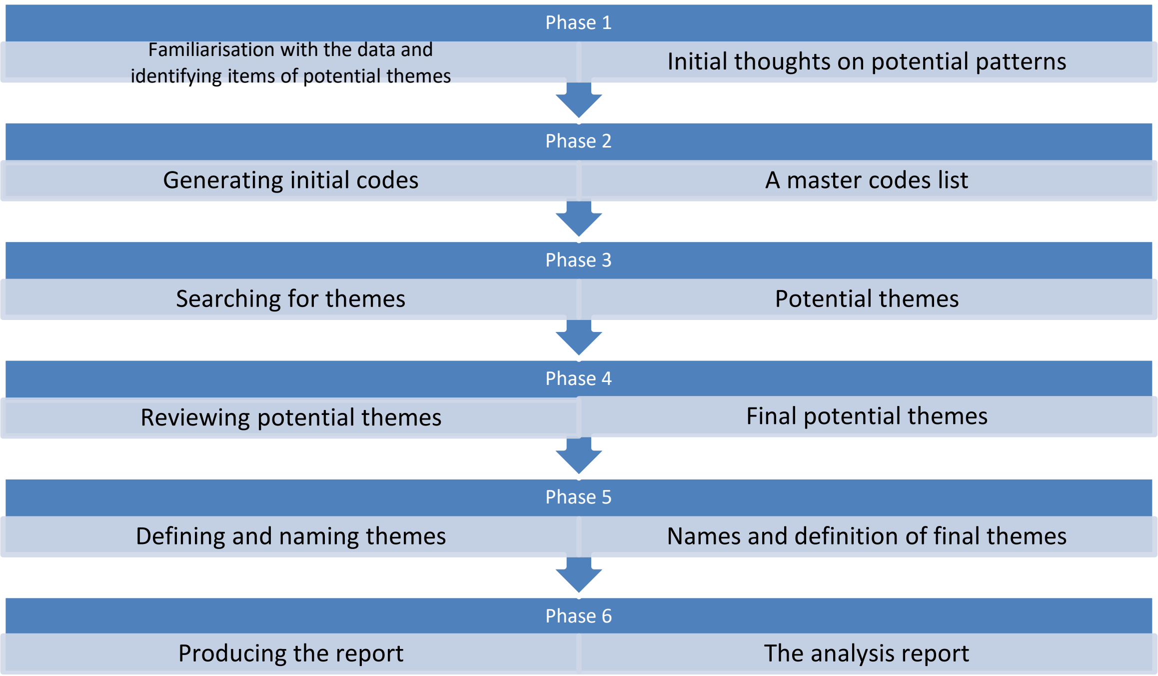
To protect confidentiality and privacy of participants, names of participants, locations and institutions and any information that could reveal the identity of participants were anonymised and pseudonyms were used throughout the data and reports, including interview transcripts, field notes, research diary and memos, and the final thesis. Only I had access to the raw data. All documents were stored in a locked filing cabinet at the University and electronic data was stored on a password-protected university computer. After the study is completed, in line with University of Southampton policy the data will be kept for 10 years.

5.3 Data analysis

5.3.1 Illustration of analysis process

This section illustrates how data was analysed by using the six-phase thematic analysis approach (Braun and Clarke 2006, 2013; Braun et al. 2014; Braun et al. 2019). Figure 5.3 illustrates the process of the thematic analysis and the end product of each phase.

Figure 5.3 The six-phase thematic analysis (Braun and Clarke 2006)



The terms used in the analysis and their definitions are:

A code is a short label that captures something interesting about the data and potentially relevant to the research questions (Braun and Clarke 2012; Clarke and Braun 2014). Coding is to assign a label to interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code (Braun and Clarke 2006).

A theme identifies a meaning patterned across the data, which is important for illuminating the research question (Braun and Clarke 2006). A theme is a pattern of shared meaning underpinned by a central organising concept (Braun and Clarke 2019), which is a clear core idea that underpins a theme, the essence of what the theme is about (Braun and Clarke 2013). The central organising concept can ensure themes are internally coherent, and also distinct from each other (Clarke and Braun 2014).

In following sections, examples of analytic activities are incorporated in each phase to illustrate the development of one theme from initial ideas to final theme. Phase One and Two illustrate the reading and coding linked to the decision making process of one family as they transferred their relative home to die. The initial coding list from the transcript was applied across all data, ending up with a master code list.

In Phase Three, codes were clustered into potential themes. The development process of one potential theme from codes is illustrated and shown in a graphic map (Figure 5.4). At the end of phase three a set of potential themes with associated codes were generated and are presented in figures (section 5.3.5).

Phase Four was checking if the themes worked with raw data. The potential themes were reviewed and revised involving creating new themes and discarding existing themes. A final set of potential themes was established at the end of Phase Four. The development of one final theme from potential themes is illustrated in detail.

Phase Five focused on naming and defining individual themes. The same theme is used to illustrate how Phase Five was undertaken. The analysis report was generated in Phase Six.

My thinking and reflection during analysis were recorded in the research diary about analytic memos (i.e. Textbox 3) including the procedures or steps of analytic work, the decisions made from initial reading, to coding and theme development, and reflections on my role in shaping the data analysis and interpretation.

5.3.2 The analysis context

To illustrate my analytic work, the first interview with the participant anonymised as Wei is used to illustrate coding and the generation of initial ideas. To provide the context of the family, a vignette (Textbox 2) was written summarising the family structure, the background information about the patient, and the main content of the story. The start point for my illustration was the conversation between the ICU doctor and Wei where the decision to transfer regarding his father was outlined. The vignettes of other interviews are placed in appendix A.11.

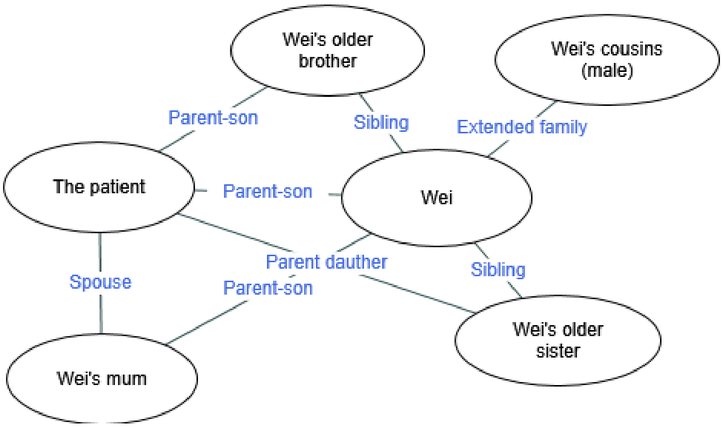
Textbox 2 A vignette developed for Wei's story

Interview 01 Pseudonym: Wei

Wei was a 44 years old man who were married and worked as a telecom manager. The interview took place 30 days following the death of Wei’s father and was conducted in a room where he worked and lasted one hour and 21 minutes. Wei’s deceased father was 81 year of age and had lived about an hour’s drive from the hospital in which he was treated and discharged home to die.

Wei’s father had been admitted for insertion of a cardiac stent in 2012 and was re-admitted in 2016 due to swollen feet. After treatment, he was transferred to the respiratory ward in Hospital A due to a fever. Wei’s father continued to decline and was transferred to ICU at about 10am of 3rd July. Around 7pm, the doctor told Wei his father was getting worse and he dared not to do any further treatment. The doctor said: ‘Look, you either stay here or take him home’. Wei discussed with his older brother and (male) cousins but not his mother. The decision was that Wei’s father should be transferred home as this was the ‘custom’. Following extensive arrangements Wei's father was successfully transferred home at about 9pm of 3rd July (the same day). In caring for his father at home, Wei complied with the custom requirement to place his father in the Hall of the house. A decision was made by Wei not to remove the endotracheal tube in his father's mouth due to the risk of death but this brought him regret that his father did not say anything before death. Wei’s father died around 2am the next morning but he was unsure of the exact time. Wei cleaned up his father's body including removing all tubes which was more complicated than he expected. At the end of his story, Wei made negative comments about the doctors, the healthcare system and the broader societal context. He considered his father's death was partially caused by clinical malpractice (the heart doctors rather than the ICU doctors). His view was that the aim of the healthcare system was to pursue money rather than save lives.

The figure below shows the family structure of Wei according to the individuals and their relationships mentioned in his story. The relationship between them is marked. The centre is Wei because he was the person told the story and all the relationships were unfolded around him.



5.3.3 Phase 1: Familiarisation with data

I familiarised myself with the story told by Wei by listening and re-listening to the audiotape of the interview, and reading and re-reading the transcript alongside the field notes for further immersion into the data. The repeated listening and reading was done in an active, analytic and critical way so that meanings and potential patterns were searched for and jotted down (Braun and Clarke 2006).

Initial thoughts about the meaning or potential patterns about transfer decision-making by the Wei family were noted down in memos illustrated in Table 5.2. These initial thoughts were observational and casual rather than systematic and inclusive and served as memory aids and triggers for coding and analysis in later phases (Braun and Clarke 2012).

Table 5.2 Examples of initial ideas in reading the first interview transcript

Transcript 1	Initial thoughts (memo)
Wei: Then around 7pm, he told me my father’s condition was getting worse, worse than ever. So he did not dare to do it. ‘… then you see if to stay here, or take him home now.’ YL: Did the doctor say it like this? Wei: Right. He just said this. He… because he would not say it explicitly, ‘well you must…’ He said ‘you think about your own customs, and your family's decision.’ Then I, I heard this… because if he said so, he was certainly inclined to mean basically there was no hope. So he told us ‘you stay here, or go home according to your custom.’ Then, later I discussed with my brother, and also with my family. That is, my family also would like that... Because I don’t dare to tell my mum all these things, I just told my cousins (male) such and such. He, they anyway also.... My brother heard that, and my cousin heard that, they also said, ‘if this is the case, maybe we still have to go back, go home. Because according to the habits here, because of that… still go home, come back.’ Then at 8pm-9pm, around 8pm, we were looking for an ambulance, 120 (The number for ambulance, like 999 in the UK) that sending patient back. It may extend such a kind of… a department, a small department, which specially transfer those outside here. I rang this one to ask. He said 2000 yuan, sending back to D. (01: 200 -218)	The **doctor's recommendation of transfer** was constructed into the decision by Wei which was a **positive meaning** or **facilitator**. **The doctor implicitly rather than explicitly told** the family about the end of life options. The family could understand what the doctor conveyed in his account. The implicit way of telling the death was meaningful in the culture shared by the two parties.
	For transfer, it was a decision made by the extended family but female members were excluded or were not the primary decision-maker, it was often sons. Transfer was **a family decision** rather than an individual decision. However, this share was not allocated to every family member evenly. **Gender difference** was reflected in the authority of decision of transfer. Only males were authorised to be the decision-maker, by family culture in China.
	The situation/context of transfer decision-making: poor condition, futile or inapplicable treatment, dying, no hope. **Futile** treatment was constructed into the decision of transfer. **No hope** was said to describe the certain destination of the patient, that is, death. Only when it was sure that there was no hope of recovery transfer was considered. Transfer was equal to death. This was why transfer decision was painful. The **agreement or acceptance** of the dying condition or no hope by the family was constructed into the decision of transfer. It was the **logic or premise** of the decision of transfer.
	Custom was the root reason behind the family’s decision of transfer. But only custom was not sufficient for a transfer to occur. As the doctor stated: consider the custom, and your family decision. **Custom and family decision** together made the transfer come true. This might be able to explain why some families did not transfer patients home to die even though they shared a similar culture. Family played an important role in the decision of transfer. The family respected the custom and so made the decision to take the patient home. The family complied with the custom as others did. **The logic behind the decision** of transfer was custom and family choice.
	The selection of the transportation was a problem to the participant. The availability of transportation was **a practical issue or barrier** to transfer. **The lack of knowledge and experience** in selecting the ambulance for transfer was a negative meaning/barrier to the family.

Questions guiding phase one analysis included: 1) how the decision was made (including the processes and steps of decision-making, the decision-makers, the situation or context of decision-making); 2) what barriers and facilitators, and information and support needs were outlined in Wei's story; 3) how the participant made sense of their experiences (the meaning and the reasons for the decision); 4) what assumptions (i.e. worldviews, traditions/ customs) the participant made in interpreting the family's experiences. The answers to these questions could be initially identified from the repeated reading of the transcript of Wei and the generation of commentary memos recording my initial thinking (Textbox 3).

Textbox 3 Memo outlining meaning making around transfer decision-making

The logic and the mode of transfer decision-making by Wei comprised no hope of recovery, futility of treatment, recommendation of transfer by doctors, custom and family decision, a joint decision of transfer by male family members. These components were not isolated but meaningfully organised by the participant to reflect his meaning making of the experience of transfer.

The initial thoughts identified in Wei's story about transfer decision-making were taken forward in analysis of the further nine transcripts.

5.3.4 Phase 2: Generating initial codes

Coding was the systematic analysis of data, including transcripts, noting ideas, concepts, and points of interest relevant to answering the research questions (Braun et al. 2014).

Inductive coding was undertaken to generate codes from raw data without imposing a prior theory. The data-driven analysis could ensure the themes were identified from the raw data, and any potential crucial aspects related to the research questions were not missed (Braun and Clarke 2006).

Initial coding on participant Wei's transcript comprised indexing, coding, and giving a definition for codes. Examples of the process are presented in Table 5.3. At first, indexing was carried out to give a short name for the data chunk (varying from sentences to paragraphs). After initial indexing, formal coding started. Once an extract of data was identified to code, a label was written down and the text associated with it was marked. Each code was given a working definition to ensure the clear boundary of each code and the consistency of coding across data. This process was repeated throughout the first and subsequent transcripts once each was fully coded (Braun and Clarke 2012).

Table 5.3 Examples of initial indexing, coding and code definitions on the first interview transcript

Transcript 1 Wei (Line 200-218)	Initial ideas	Indexing	Coding	Code definition
Wei: Then around 7pm, he told me my father's condition was getting worse, worse than ever. So he did not dare to do it. '… then you see if to stay here, or take him home now.' YL: Did the doctor say it like this? Wei: Right. He just said this. He… because he would not say it explicitly, 'well you must…' He said 'you think about your own customs, and your family's decision.' Then I, I heard this… because if he said so, he was certainly inclined to mean basically there was no hope. So he told us 'you stay here, or go home according to your custom.' (01: 200-208)	The **doctor's recommendation of transfer** was constructed into the decision which was a **positive meaning** or **facilitator**. **The doctor implicitly rather than explicitly told** the family about the end of life options. The implicit way of telling the death was meaningful in the culture shared by the two parties.	Options for staying or going home	Hinted the death: no hope	The doctor implicitly rather than explicit or openly told the family that the patient was dying and there was nothing to do.
	The situation/context of transfer decision-making: poor condition, futile or inapplicable treatment, dying, hopelessness. Only when it was sure that there was no hope of recovery transfer was considered. Transfer was equal to death. The **agreement or acceptance** of the dying condition or no hope by the family was constructed into the decision of transfer. It was the **logic or premise** of the decision of transfer.	Poor condition	Constructing the logic of decision: dying condition	A reason for the decision was the condition of dying that was hinted or confirmed by the doctor or other staff.
Then, later I discussed with my brother, and also with my family. That is, my family also would like that... Because I don't dare to tell my mum all these things, I just told my cousins (male) such and such. He, they anyway also.... My brother heard that, and my cousin heard that, they also said, 'if this is the case, maybe	Transfer was **a family decision** rather than an individual decision. However this share was not allocated to every family member evenly. **Gender difference** was reflected in the authority of decision of transfer. Only males were authorised to be the decision-maker, by the family culture in China.	Family discussion	Shared decision between male family members	Decisions needed to be made jointly with other male family members.
		Male not female	Gender authority based family decision	Male family members rather than female family members had the right to make the

Transcript 1 Wei (Line 200-218)	Initial ideas	Indexing	Coding	Code definition
we still have to go back, go home. Because according to the habits here, because of that… still go home, come back.’ (01: 208-212)				decisions that need to be shared responsibility.
	Custom was the root reason behind the family’s decision of transfer. But only custom was not sufficient for a transfer to occur. **Custom and family decision** together made the transfer come true. This might be able to explain why some families did not transfer patients home to die even though they shared a similar culture. **The logic behind the decision** of transfer was custom and family choice.	Custom of going home to die	Custom oriented decisions	The reason for a decision was the custom, including THtD, giving a red envelope with money for the death, and the way of dying at home.
Then at 8pm or 9pm, around 8pm, we were looking for an ambulance, 120 (a number for emergency, like 999 in the UK) which can send patients back home. So as for the ambulance, there was a problem. (…) It may be an extended department, a small department, which specially transfer patients to other areas. So I rang this one, which said a price, 2000 yuan, for sending us back to D (a county in another city). (01: 212-218)	The selection of the transportation was a problem to the participant. The availability of transportation was **a practical issue or barrier** to transfer. **The lack of knowledge and experience** in selecting the ambulance for transfer was a negative meaning/barrier to the family.	The available ambulance for transfer	"There was a problem"	A negative description on the options available for making a decision and the behaviours of the individuals involved (The transfer service)

Coding was undertaken building on the initial thoughts and indexing. The descriptive and brief indexing was developed to codes capturing the meaning of data and potential patterns relevant to the research question. Two types of coding were undertaken: semantic and latent. Semantic codes were descriptive and often named using the original words said by participants if they met the requirement for a code name, namely code in vivo. Latent codes were interpretive and used the label derived from the researcher's conceptual frameworks (Braun and Clarke 2006; Clarke and Braun 2014). For example, "*I am a lay person*" was a code in vivo. It was a quote of what actually said by Wei in terms of his lack of the ability for making the decisions. The term "lay" was useful to capture the meaning of the data extract: the participant did not possess the necessary information, knowledge and experiences for medical decision-making because he was not professional like doctors suggesting the needs on information and support. The code '*gender authority based family decision*' was different. It identified the essence of data that there was gender difference in the family decision-making. I generated the code based on my background cultural knowledge as a Chinese woman and I shared the same Chinese culture with Wei. It was more abstract and interpretive in capturing the meaning of data. It explained who could be the decision-maker within a family.

The research question and objectives of the study were kept in mind when coding but coding was inclusive (Braun et al. 2014). Data that seemed 'not relevant' to the research question were coded at this early stage of analysis. For instance, Wei's story contained data about his father's illness history, symptoms and signs, hospitalisation and treatment, deterioration and the views about the cause of death (see the vignette in Textbox 2). These were 'background' information for the family's decision of transfer and were considered not direct relevant to the research question. However, they were coded, such as *abnormal appearing*, *ascribing the death to malpractice*, and *divergent views on treatment*. The initial codes list generated at the end of coding Wei's transcript is presented in appendix A.12. Indeed, the codes generated in phase two were "potentially" relevant to the focus of the study as termed by Braun and Clarke (2006) because the broader analysis searching for patterns was in next phase.

The initial codes generated from Wei's transcript (appendix A.12) were applied to further transcripts with confirming and refining of codes as coding progressed. The order of coding different transcripts was the same order the interview was undertaken. Phase two ended with a list of master codes across data which can be seen in appendix A.13.

Some recoding and new coding of earlier coded data were necessary because the codes developed during the coding process (Braun and Clarke 2012). Table 5.4 shows the revisions made on the initial codes of Wei's transcript to master codes and the rationale for revisions.

Table 5.4 Revisiting codes as coding progressing from transcript 01 to transcript 10

Coding	Initial code definition	Revised to mast code	Master code definition	Explanation (in memo)
Hinted the death: no hope	The doctor implicitly rather than explicit or openly told the family that the patient was dying and there was nothing to do.	Style of communicating death	The way of talking about the dying condition or the death was ambiguous, implicit, and indirect.	The focus of the code was 'hinted' or 'implicitly' or 'not openly' which was the way informing the family the patient's dying condition, by giving the end of life options. Finally it was a code about the death communication culture which was the context of transfer decision-making.
		Decision facilitator: the staff acknowledged the decision	HCPs clearly recommended or agreed with the choice of going home to die according to their custom.	In coding Transcript 3, the ICU doctor "clearly" recommended or agreed with the family's choice of going home. Therefore, the initial code was revised to reflect that the doctors also respected or were ruled by the custom. The culture about death was powerful to all individuals: families, doctors, nurses, and even unqualified support workers. The term 'acknowledge' was used to indicate the staff's 'awareness of' rather than 'support on' the custom needs from the participants' perspectives. This code is a facilitator to transfer.
Shared decision between male family members	Decisions needed to be made jointly with other male family members.	Family shared rather than individual decision-making	The responsibility of some critical decisions, including transfer were made by the joint family rather than a single member, including share of the cost and any outcomes of the decision.	'Shared decision between male family members' was revised to 'family shared rather than individual decision-making' because it overlapped with code 'gender based authority in family decision making' and did not clearly reflect the 'joint and shared' nature of transfer decision-making (coding Transcript 3). The revised code also inclusive to the data in Transcript 5 in which all family members including male and female were involved in the decision of transfer and data in Transcript 6 where transfer was decided by the wife of the patient and their extended family.
Gender authority based family decision	Male family members rather than female family members had the right to make the decisions that need	Gender based authority in family decision	Decisions were shared by family members but there was a selection based on gender that male family members, especially the sons of patient had more authority in decision-making.	This was a very salient code or potential pattern across data. Although transfer was a family joint decision, who could be the main or more powerful decision maker within a family was selected and predetermined by Chinese family culture.

Coding	Initial code definition	Revised to mast code	Master code definition	Explanation (in memo)
	to be shared responsibility.			
Constructing the logic of decision: dying condition	A reason for the decision was the condition of dying that was hinted or confirmed by the doctor or other staff.	Hope and hopelessness	From a desire accompanied by expectation or a belief in fulfilment of recovery to losing such a desire, expectation and belief.	The ‘poor condition’ or ‘dying condition’ was linked to ‘no hope’ and ‘with hope’ in family decision-making (Transcript 2). Family members might agree (no hope) or disagree (with hope) with the dying condition and made decisions subsequently (Transcript 6). With hope, families continued the LST and ICU stay. Without hope, families took the patient home to die. The concept of hope was constructed into the decision of transfer or stay.
Custom oriented decisions	The reason for the decision was the custom, including THtD, giving a red envelope for the death, and the way of dying at home.	“Falling leaves return to their roots”	An in vivo code, which was a Chinese proverb said by participants. The reason for the transfer was to respect the Chinese custom that a person should die at home rather than the hospital or other places, including all related activities, procedures such as funeral, burial.	The custom of dying at home was a reason for transfer across all transcripts. The code was revised to focus on the cultural reason for transfer. Recoding was undertaken: data about the custom related to giving a red envelope were uncoded from this code. Data about the reason for transfer was the farewell with family members or relatives were coded here. The label was revised to “falling leaves return to their roots”, which was in vivo coding in Transcript 8.
"There was a problem"	An in vivo code, a negative description on the options available for making a decision and the behaviours of the individuals involved (The transfer service)	Gap of care	Discussion about the lack of standardised transfer service, the problematic ambulance available for transfer, and lack of information, resources for the family to transfer the patient home to die.	‘Gap of care’ was commented by the participant in relation to the ambulance service (Transcript 2). It was a broader concept and could cover the data about the lack of care service or support for THtD from the ICU: the ambulance, information and resources for home care (Transcript 5, 6, 7, 8, and 10). The code was about the barrier to family’s transfer.

5.3.5 Phase 3: Development of potential themes

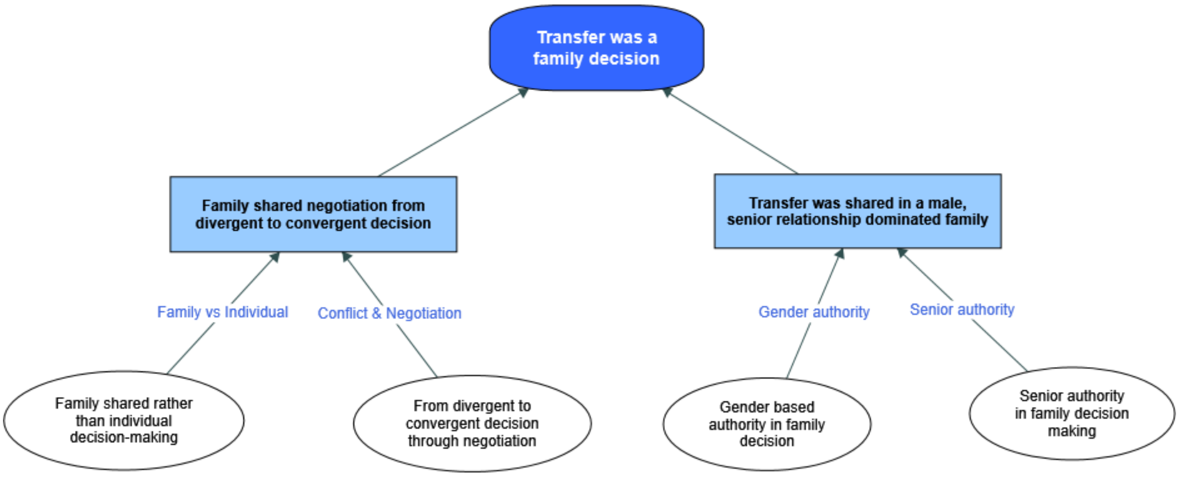
Once all data were initially coded and collated, and the master code list developed, the analysis moved to a broader level: searching for potential themes across data (Braun and Clarke 2006). A potential theme is a potential pattern of shared meaning underpinned by a central organising concept.

A potential theme could be created by 'promoting' a particularly large and complex code to a theme or clustering similar codes together (Clarke and Braun 2014). Codes were collapsed or clustered when they were identified to share some unifying feature together that reflected a coherent and meaningful pattern about transfer decision-making in the data (Braun and Clarke 2012). Thematic mapping was used because it was useful for visually representing codes, identifying relationships between codes and clustering different codes to develop potential themes (Braun and Clarke 2006).

An example of mapping and clustering codes to illustrate a potential theme development *decision-makers regarding transfer* is illustrated in Figure 5.4. According to Braun and Clarke's approach, a central organising concept links codes. In this illustration two codes (ovals) *family shared rather than individual decision-making* and *from divergent to convergent decision through negotiation* were clustered to an initial pattern (blue boxes): *Family shared negotiation from divergent to convergent decision* because they indicated that the decision-makers regarding transfer were family and the family's decision-making was a joint, shared and negotiated process. Code *gender based authority in family decision* and code *senior authority in family decision making* were clustered together to form an initial pattern *transfer was shared in a male, senior relationship dominated family*. These two codes were similar and reflected a senior role in the family's joint decision-making: gender and other senior relationship, for example, adult children and sons rather than spouses deciding the transfer. Clustering these codes formed the potential theme *transfer was a family decision* (dark blue box).

Recoding was carried out when data was not coherent with others or did not support the potential theme. For example, in clustering codes, data about convergent and divergent decisions on treatment between doctors were not relevant to the decision to transfer and did not support the potential theme *transfer was a family decision*. Thus, they were uncoded from the potential theme.

Figure 5.4 The map of developing a potential theme: Transfer was a family decision



The process of clustering codes to potential themes illustrated above was applied to all codes on the master code list (appendix A.13). Six potential themes were generated at the end of phase three, illustrated in Figure 5.5 – Figure 5.9. In all figures, codes are illustrated in ovals at the bottom, initial code clusters are illustrated in middle light blue rectangles and the potential theme is illustrated in dark blue rectangles on the top. Codes that did not fit with any potential themes were grouped into a separate theme 'miscellaneous' and were preserved for a later stage when all coded data were reviewed and final themes were established.

Figure 5.5 The map of developing a potential theme: Transfer was a death decision

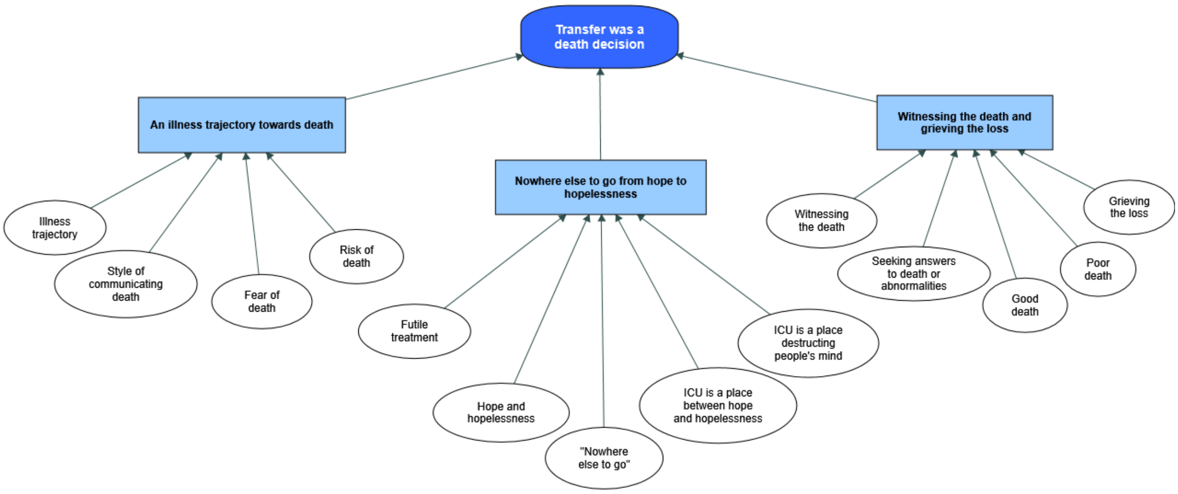


Figure 5.6 The map of developing a potential theme: Transfer was a custom decision

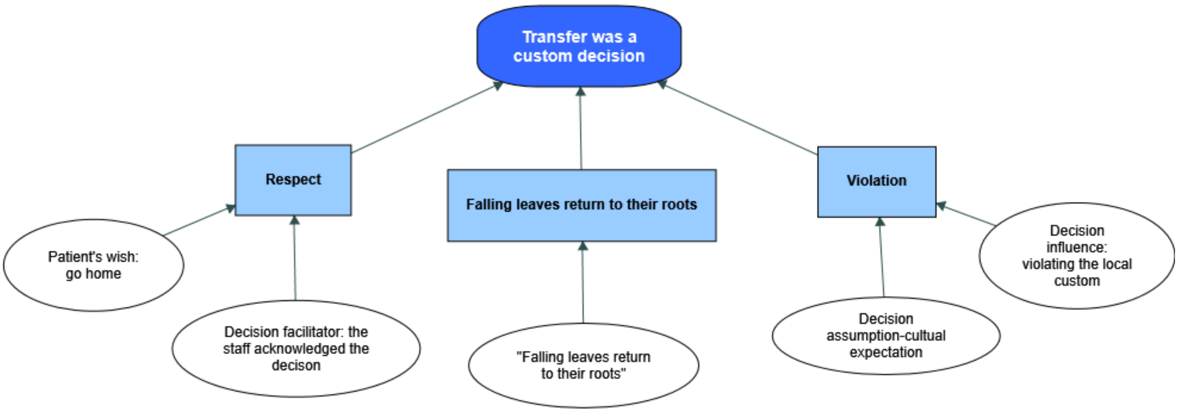


Figure 5.7 The map of developing a potential theme: Transfer was a moral decision

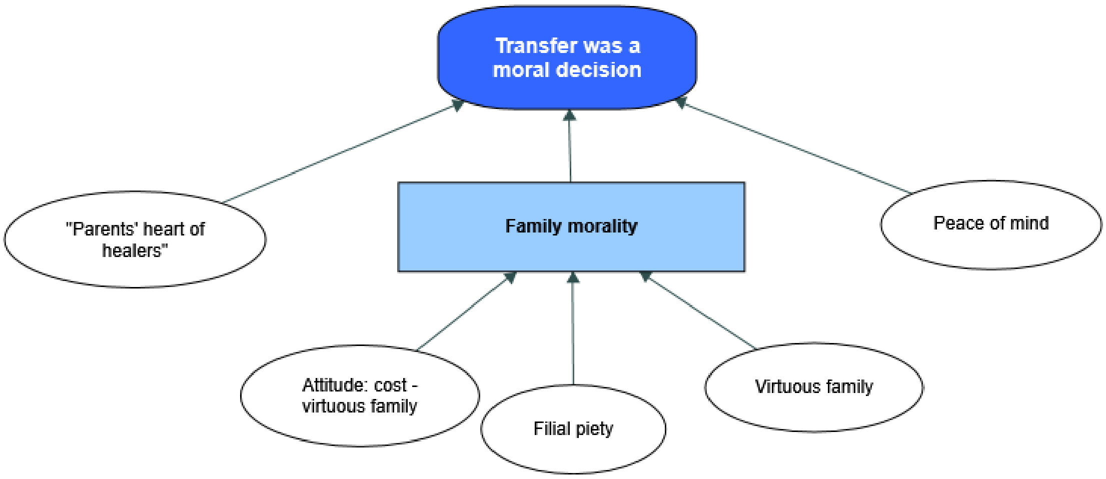


Figure 5.8 The map of developing a potential theme: Transfer was a demanding decision

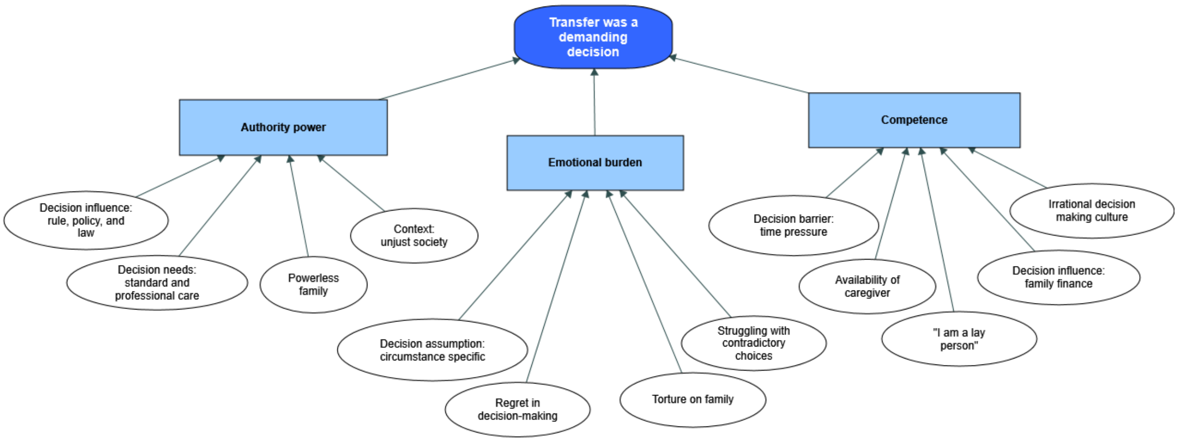
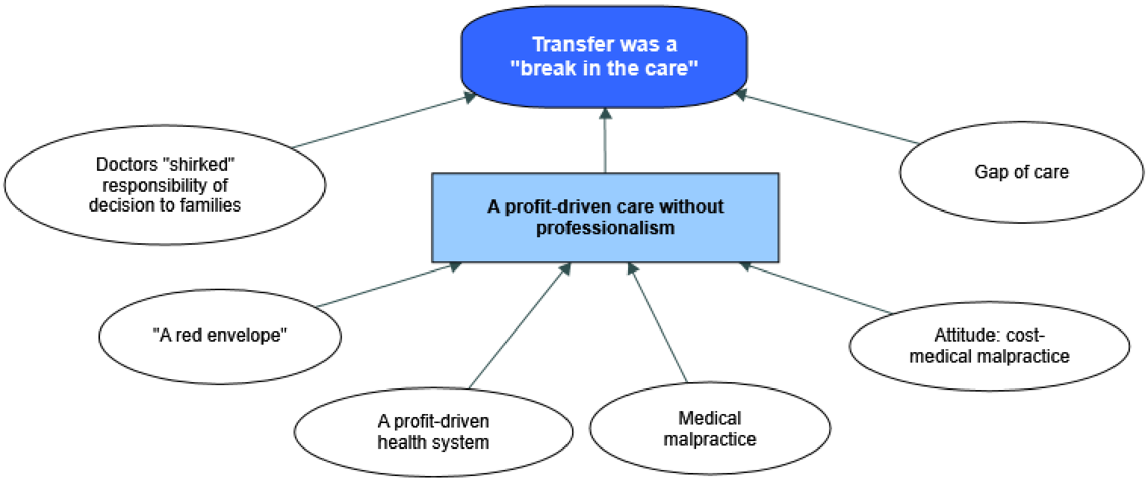


Figure 5.9 The map of developing a potential theme: Transfer was a “break in the care”



When clustering codes to develop potential themes, the relationship between potential themes and how potential themes could work together in telling an overall story about the data were considered (Braun and Clarke 2012). Figure 5.10 illustrates the six potential themes developed in phase three analysis. The potential themes were connected logically and meaningfully, for example, building on previous themes to tell a coherent story about the data.

Figure 5.10 The initial relationship identified between the potential themes

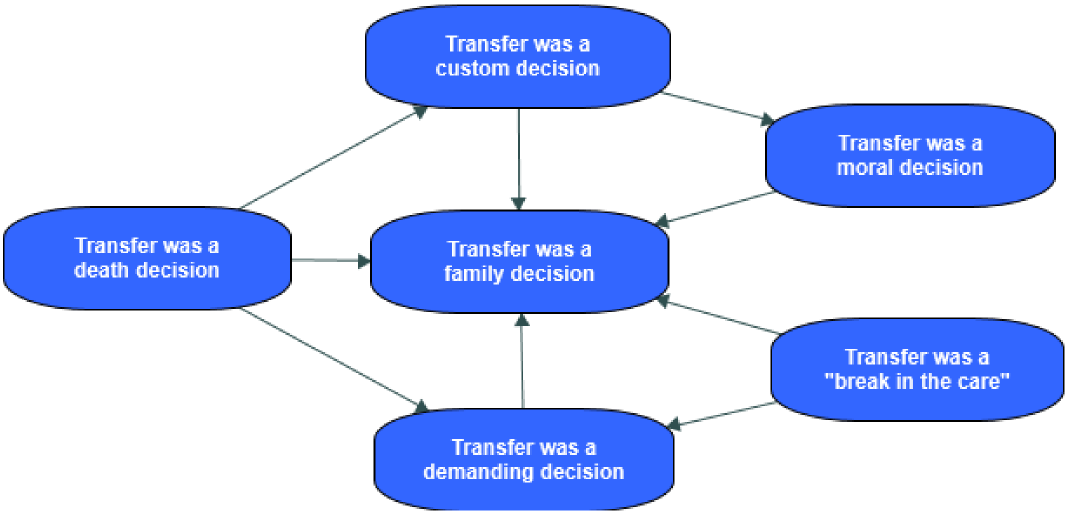


Figure 5.10 maps the relationship between the potential theme *transfer was a family decision* and other potential themes. The map shows *transfer was a family decision* as a central concept, however this was dependent on death being diagnosed (imminently, or shortly) (*Transfer was a death decision*) and the culture about death (*Transfer was a custom decision*) in which the transfer decision was made. *Transfer was a demanding decision* as the custom of death required families to take the patient home to die and overcome practical barriers to transfer (*Transfer was*

a break in the care). Transfer was a demanding decision as it impacted on decision makers physically and emotionally and morally (*Transfer was a moral decision*) as they complied with the custom requirement.

The six potential themes developed in Phase Three were reviewed and revised to final themes in next phase.

5.3.6 Phase 4: Reviewing potential themes

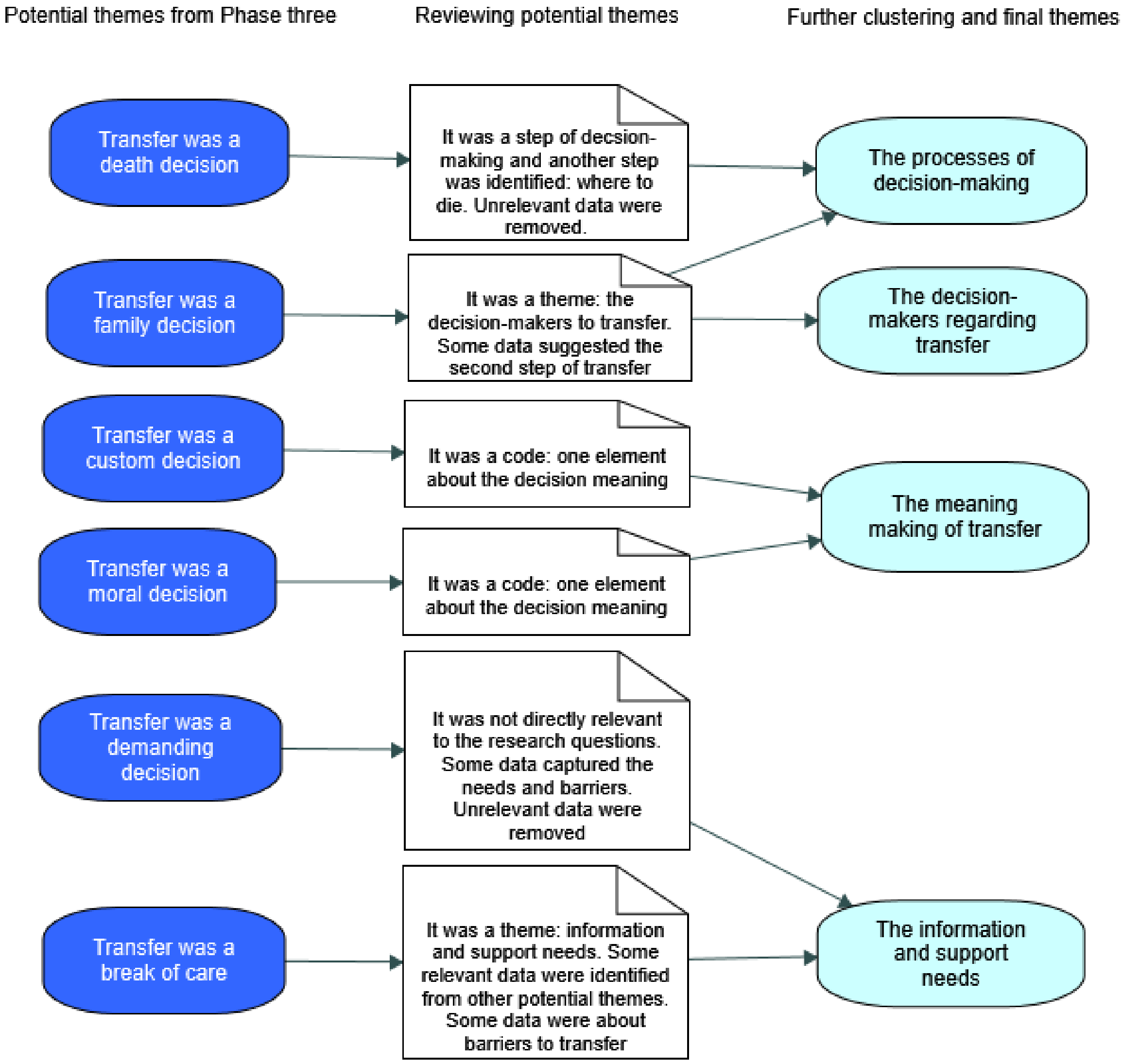
Phase Four was primarily reviewing and revising potential themes to identify final themes, and the structure of final themes (Braun and Clarke 2006, 2012). The six potential themes identified in Phase Three were reviewed by going back to read all the collated extracts for each theme and the entire data (ten transcripts). The definition of themes in Braun and Clarke's approach guided the review and revision of potential to final themes. A good theme has a singular focus, organised, coherent and distinct. Themes are related but do not overlap or are not repetitive. Themes work together to create an overall pattern and address the research question (Braun and Clarke 2012, 2013).

In reviewing potential themes the following questions (Braun and Clarke 2012) were asked to facilitate the understanding of the theme:

1. Was this a theme or just a code?
2. If it was a theme, was it directly relevant to answering the research question?
3. Did the theme include too diverse and wide-ranging data (lacking coherence)?
4. What did the theme include and exclude (boundaries)?
5. Was the theme too small or too big?

Revision on potential themes involved creating additional themes, discarding existing themes, collapsing a number of potential themes together or splitting a big broad theme a number of more specific or coherent themes. As part of the refinement, subthemes of themes (Braun and Clarke 2006) were considered but this analysis did not generate subthemes. A subtheme shares the same central organising concept as the theme, but focuses on one notable specific element or facet of a pattern (Braun and Clarke 2019a). When the themes are focused, without substantial sub-patterns like the current analysis, there could be no subthemes. The development process from potential themes to final themes is demonstrated in Figure 5.11.

Figure 5.11 The development process from potential themes to final themes

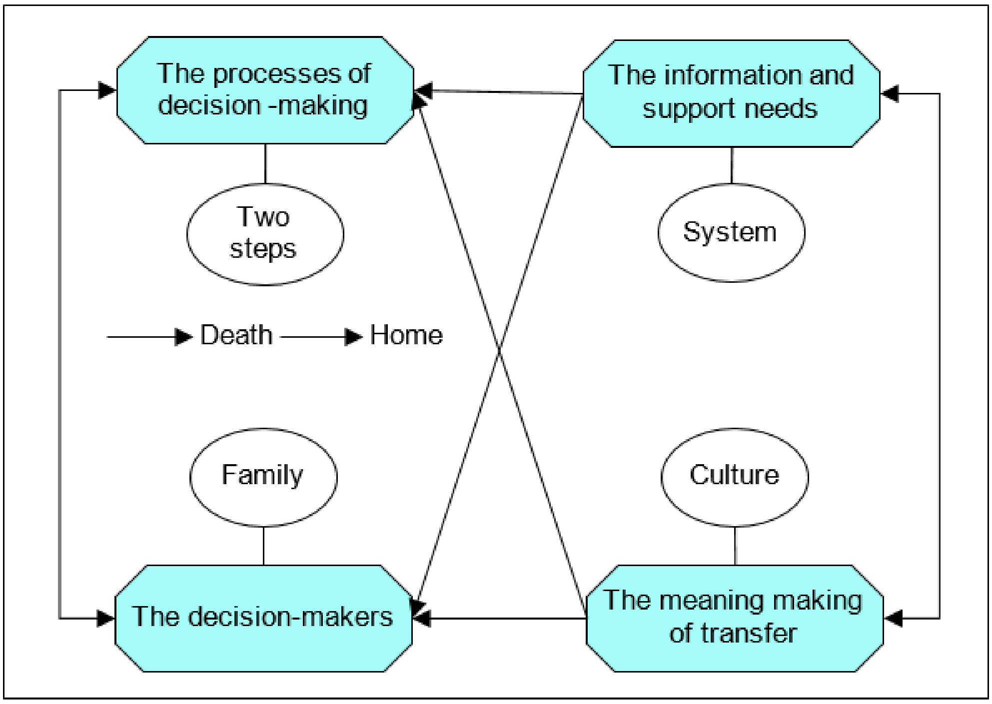


The three lists from left to right in Figure 5.11 are the six potential themes (dark blue), the notes of reviewing and revising work guided by questions (white note text box), and the further clustering to final themes (sky blue). The number of themes reduced to four from six.

The final theme *the decision-makers regarding transfer* was developed from the potential theme *transfer was a family decision*. In Phase Four, the potential theme had been initially understood as a step of the process of decision-making but it was re-interpreted as the decision-makers theme because the central idea was about “family” who were the ones decided to transfer. The theme captured who were involved, who were excluded, the role of individuals involved and the uneven allocation of decision power. Some data in this theme suggested the step of decision-making were collated to the final theme *the processes of decision-making* which explained two steps to decide the transfer.

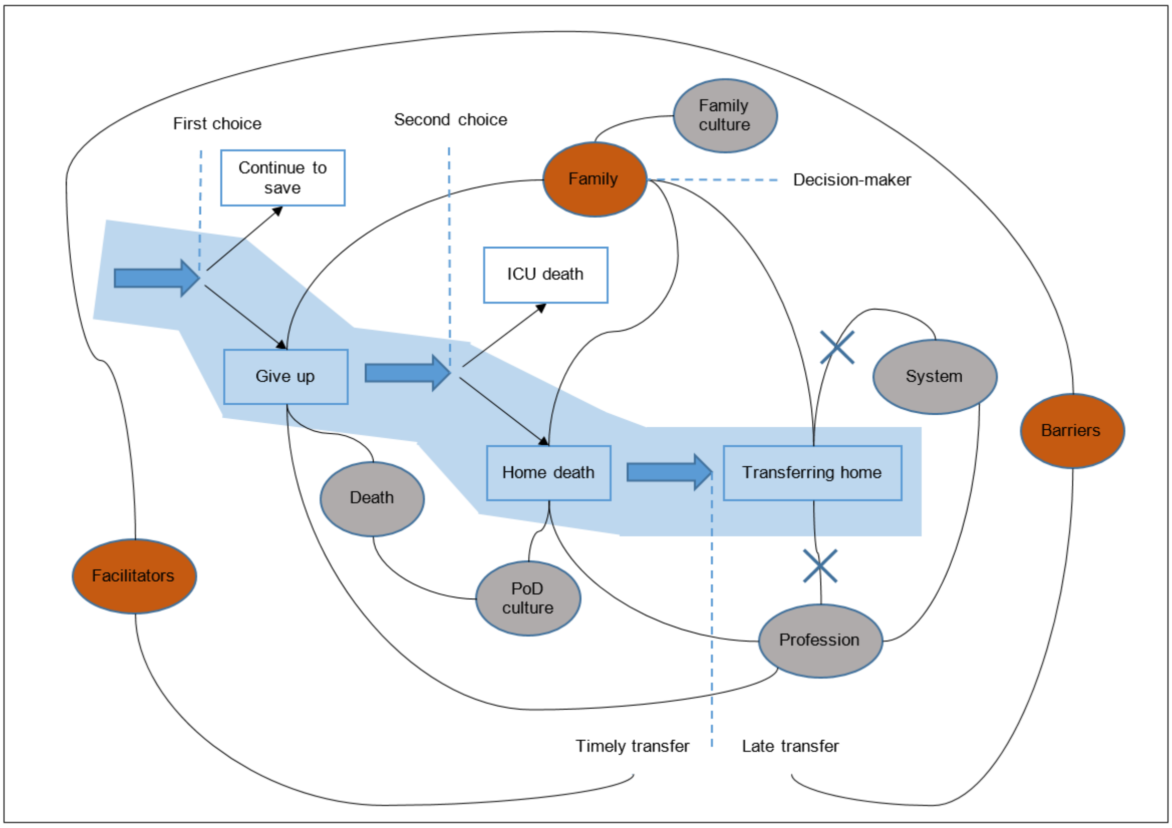
All themes (Figure 5.12) together captured the focus of the study: families' experiences of decision-making when transferring a patient home to die, including the processes of decision-making, the decision makers regarding transfer, the meaning making of transfer, and the information and support needs for decision-making. The theme *the decision-makers regarding transfer* explained one fundamental aspect of transfer and was related to other three themes in different ways. "Family" (oval) captured in *the decision makers* theme (sky blue) were the individuals who undertook the two steps from accepting death to selecting a home death, that were explained in the theme *the processes of decision-making*. The "cultural meaning" captured in the theme *the meaning making of transfer* shaped *the processes of decision-making* and gave *the decision makers* the meaning in their choice. "Family" were the decision-makers and they had *unmet information and support needs* from the healthcare "system" in *the processes of decision-making*.

Figure 5.12 The relationship between themes



At the end of Phase Four, one overarching umbrella theme that organised the analysis was developed: *a single path towards death through a web of power* (see Figure 5.13).

Figure 5.13 The map of developing an overarching theme



PoD is short for place of death

The overarching theme developed as the themes developed from potential themes to final themes. Initially, an overall pattern supported by the six potential themes was identified as *a familial death decision twisted by a web of power* which explained the ‘nature’ of decision was one towards death made by families and the decision was influenced by multiple sources of ‘power or forces’ including death, family, custom, morality, profession and the system. As the potential themes were reviewed and the final themes were established, a final overarching theme was generated, particularly through the use of graphic mapping (Figure 5.12 and Figure 5.13). A very interesting pattern about ‘processes’ and ‘factors’ or ‘contexts’ of the decision-making was identified from the relationship between final themes. The ‘processes’ involved *a single path towards death* which explained the path that families followed in decision-making and the destination of the path- the final choice by all participants. Such a path was an outcome that *a web of power* shaped and informed the decision which were made of the inevitability of death, cultural values and customs about place of death and family moral values, and the lack of support from the healthcare system; these constituted the cultural drivers in, barriers to, and facilitators of transfer. The overarching theme addressed an overall pattern about the experiences of decision-making, and together with all themes answered the research question and achieved the research objectives.

5.3.7 Phase 5: Defining and naming themes

In Phase Five, themes were named and defined (Braun and Clarke 2006), which was the most substantive, interpretive analytic work. The final themes are presented at the end of this section.

5.3.7.1 Naming themes

An important task in Phase Five was to name themes. Naming themes was a process from giving a working title to potential themes, through revising the working titles in reviewing themes and producing a formal name after themes were confirmed. The process of generating the name for all themes is illustrated in Table 5.5.

For potential themes, a working title was used to briefly capture the central idea of theme in relation to the research question so that it could quickly remind me what the potential theme was about. For instance, *transfer was a family decision* was a working title used for the potential theme that I understood initially was about the 'decision-makers'. The working title was concise and clearly reflected the focus of the theme and was distinctive to other themes such as *the meaning making of transfer* which was concerned with another aspect of transfer decision. When the potential theme was developed to the final theme capturing the decision-makers regarding transfer, an informative, concise and punchy name was assigned to the theme to capture its 'essence' (Braun and Clarke 2006 P23), and was derived from participants' original words. The quote "*his sons discussed and others were not involved*" from a participant was selected because it properly captured the central meaning of theme about who could be the decision-makers and who could not be. Following the quote, a subheading was used to explicitly indicate the underlying pattern captured by the theme. Naming themes in such a way also reflected the constructivist stance of the study.

Table 5.5 The process of naming themes

Working title for potential themes	Working title for final themes	Formal name for final themes
Transfer was a death decision	The processes of decision-making	Theme 1: “Stay here or go home?”: two steps to decide transfer
Transfer was a family decision	The decision-makers regarding transfer	Theme 2: “His sons discussed and others were not involved”: the decision-makers in the process of deciding to transfer
Transfer was a custom decision	The meaning making of transfer	Theme 3: “Falling leaves return to their roots”: the meaning making of transfer
Transfer was a moral decision		
Transfer was a break in the care	The information and support needs	Theme 4: “It’s a gap in the care”: the unmet information and support needs
A single path towards death through a web of power		The overarching theme: “Nowhere else to go”: a single path towards a home death through a web of power

5.3.7.2 Defining themes

A detailed definition for each theme was produced and are illustrated in Table 5.6.

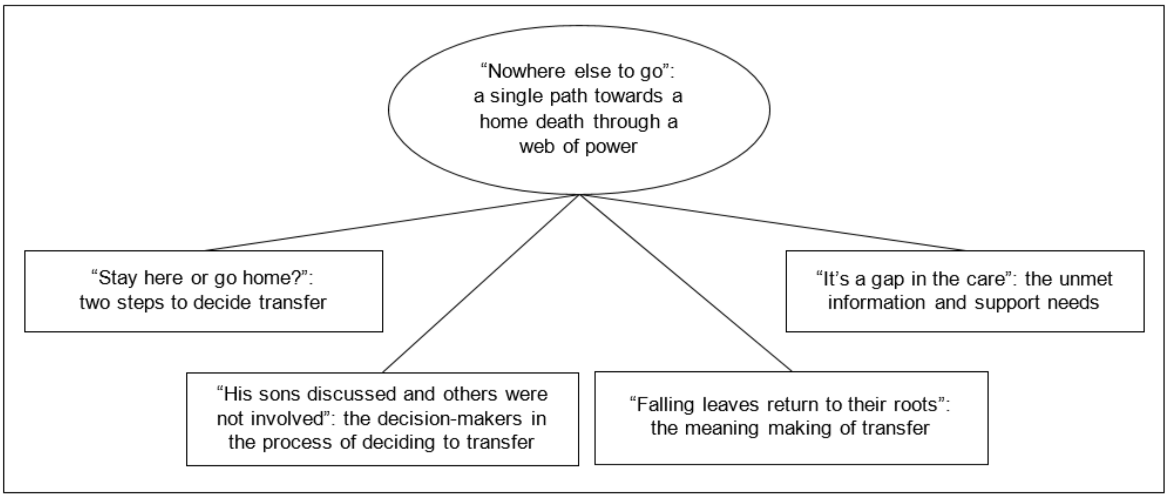
Table 5.6 Final themes with definition

Final themes	Definition
"Stay here or go home?": two steps to decide transfer	This theme explains the processes of decision-making in THtD from the ICU which comprised two steps: accepting the impending death; selecting the place of death between ICU and home, and determining when to transfer. Factors that influenced the processes of decision-making are explained.
"His sons discussed and others were not involved": the decision-makers in the process of deciding to transfer	Theme 2 explains the decision-makers regarding transfer were family members. Transfer was a family-centred decision, who jointly negotiated it and shared the decision responsibility. A hierarchy of decision power with gender imbalance is another feature of the decision-makers regarding transfer which was informed by the family culture.
"Falling leaves return to their roots": the meaning making of transfer	This theme captures the cultural drivers to the decision which was the meaning of the experiences. Families' decision to transfer was driven by the cultural values and norms about place of death and family morality.
"It's a gap in the care": the unmet information and support needs	Theme 4 explains families' information and support needs for making the decision. General information included what would happen and what would be needed while specific information included the cause of death and time to death following transfer. Support needs comprised the responsibility of decision and practical care as well as the micro-context of ICU and macro-context of the healthcare system.
"Nowhere else to go": a single path towards a home death through a web of power	This is the overarching theme which explains the overall pattern of the decision-making experiences. A single path towards a home death captures that families had only one path to follow and the only destination was a home death. Families' decision-making was shaped by a web of power which was made of drivers, forces, barriers to, and facilitators of transfer derived from the culture and healthcare system.

5.3.7.3 The final themes

The final themes are presented in Figure 5.14. The oval on the top is the overarching theme and the four themes in boxes underneath underpinned the overarching theme which form an umbrella structure.

Figure 5.14 The final themes



5.3.8 Phase 6: Producing the report

Chapter Five has generated the report of the analytic process undertaken. Writing of the report was not separated from analysis (Braun and Clarke 2012; Braun et al. 2014) as all phases of analysis involved writing, from informal writing of notes and memos to the more formal processes of analysis illustrating how themes were developed in a logical and meaningful order resulting in four final themes linking to one overarching concept.

5.4 Reflexivity on data analysis

I have learned how to conduct coding and identify themes from interview data. Despite the six phases of thematic analysis are clearly defined, it is complex in practice and highly relies on my skills and experience learned from the process. The initial codes appeared to be descriptive and less relevant to the research question. My ability of coding, which is identifying a meaningful label to a piece of data extract, was weak at the early stage but was enhanced through a longer familiarisation with data and memos of my thoughts on data. Similarly, the potential themes were semantic rather than latent and reviewing stage was essential, during which, revisiting the research question and objectives was useful and the graphic mapping of concepts and relationships was helpful.

I tried to be explicit of my own response to the stories collected from interviewing families, for instance, by jotting down the interesting points or themes. Then I stepped back to think about why these drew my attention. I considered my own personal biography, my experience of death and loss, my beliefs about what constitutes a good death, my cultural values on the decisions to go home to die, and my attitudes towards the quality of transfer service. Some of what I noticed resonated with my own experience and beliefs while some were unexpected and interesting to me.

For this constructivist study, I was part of the understanding generated from the analysis of families' experiences shared through interviews. I interpreted the raw data from participants through situated perspective or paradigm (Riessman 2008). The story and interpretation were a collective product by the participants and me. The interpretation by me was a socially constructed reality and there were multiple 'realities' about the decision-making regarding THtD.

I have gained the experience about how to construct a coherent story about the findings informed by the analysis including the selection of powerful quotes to support the themes and a commentary account surrounding the quotes to make sense of findings. I have learned to balance the description of content of quotes and the interpretation of underlying meaning and to avoid the over interpretation beyond the data (quotes).

As stated by Richardson (1990), "as researchers we… make choices regarding what is significant, what is trivial, what to include, what to exclude." (P10). I made decisions on what to report, what not to report, how to structure the writing and what language and terms to be used. The key was that the decision-making about writing was acknowledged in a reflexive way.

Richardson (1990) suggests to think the authorship or power relationship in writing research findings. The relationship between researcher and participants shapes the 'narrative' accounted by the researcher in reports. I am an experienced nurse with the wish to improve the transfer practice from families' perspective by understanding their experiences. I tried to retell families' stories in their way so that their voice was given. However, what I wrote was a 'narrative' instead of a simply transparent representation of reality. Therefore, the report is not ''about'' the participants but ''about'' the researcher's meaning making (Josselson 2007 P549).

5.5 Chapter summary

Chapter Five has outlined the data analysis process undertaken to answer the research question and address the research objectives. Thematic analysis was selected as the most appropriate data analysis method and Braun and Clarke's method was selected as the best approach because it offers an approach that can be easily applied by a novice researcher. The analysis from this chapter inform the findings reported in Chapter Six.

Chapter 6 Findings

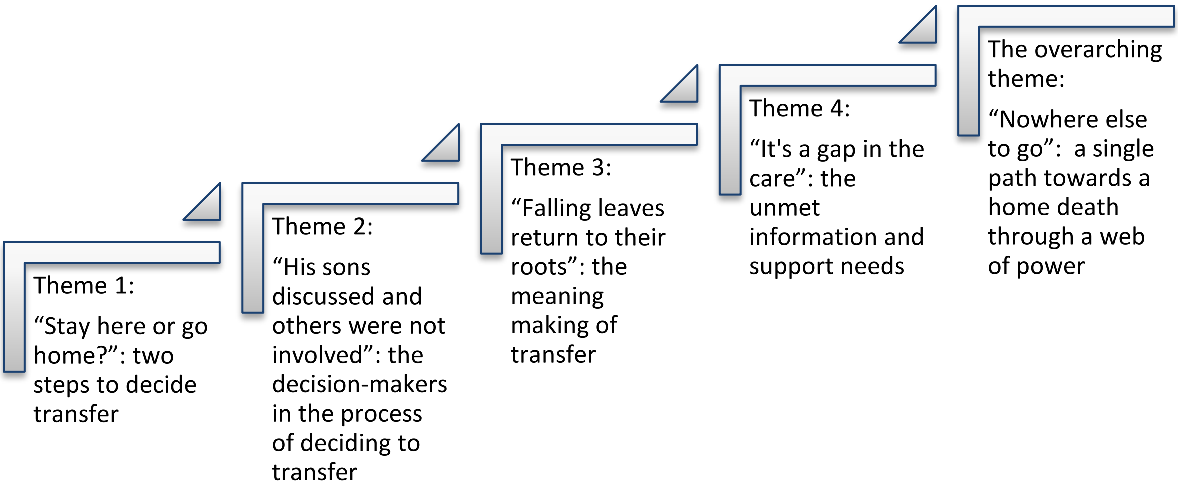
6.1 Introduction

This chapter presents the findings of the study which have been generated from a thematic analysis of interview data collected from family members of patients that were transferred home to die from a hospital ICU setting in China. The analytic process is described in the previous chapter and aimed to identify patterns of shared meaning in family members' experiences of decisions about transferring home their dying relatives. Analysis generated four themes and one overarching theme from participants' stories. These are explained in this chapter to demonstrate how the findings address research question and objectives which are:

Research question: what were the experiences of family members who made the decision to transfer their relative from the ICU in China to die at home?

Research objectives to: I) map the process of decision-making, including the processes and steps in decision-making and the decision-makers; II) identify families' information and support needs; III) identify barriers to and facilitators of transfer; and IV) understand the meaning of the experiences to families.

Figure 6.1 The themes identified in the study



As shown in Figure 6.1, the four themes are presented in the following order: the processes of decision-making, the decision-makers, the meaning making of transfer, and the information and support needs. This is followed by the overarching theme which concludes the chapter. Each theme starts with an introduction encompassing the definition of the theme and a diagrammatic representation of the theme’s meaning. A detailed illustration of each theme is then presented, using selected quotes from the original story by participants.

Quotes are presented in English and the translation of all quotes is presented in appendix A.14. Some necessary explanation or complements in English text are made which are bracketed. “(…)” was used to indicate the omitted lines/paragraphs in the quote from one participant that were not relevant to the claim or argument.

However, before discussing the themes, and to provide context for the study, the interviews and characteristics of patients are presented.

6.2 Interviews and patients’ characteristics

The context of interview (form and venue) and the characteristics of the ten patients who were the subject of participant’s stories are shown in Table 6.1 (Characteristics of participants are presented in section 4.3.3.5 chapter 4). Ten interviews were conducted with thirteen participants. Of these, two were family joint interviews in which more than one family member took part. All interviews were undertaken in a public place but in an environment that offered privacy and a quiet space for the interview.

As shown in Table 6.1, patients were aged from 51 to 91 years. Seven of them were male and there were female. All were married. The cause of death was constructed as brain haemorrhage (n=2), lung infection (n=1), duodenal perforation (n=1), intestinal fistula (n=1), meningioma (n=1), and lung cancer (n=1) and for three patients’ cause of death was uncertain.

All patients were taken home from the ICU, and the majority died at home (n=7), with two deaths in the ambulance on the trip home and one in the ICU before transportation. The majority were unconscious at the time of transit (n=9). Time to death at home ranged from several minutes to a week, with more than half (n= 4/7) surviving for a matter of hours.

Table 6.1 The characteristics of interview and patients transferred home

Interview order	Interview form	Interview venue	Time of interview after death (days)	Gender	Age	Cause of death	Decision capacity	Time to death at home following transfer	Place of death
01	Individual face-to-face interview	A staff room where he worked	30	Male	81	Lung infection	Unresponsive	2-5 hours	Home
02	Individual face-to-face interview	A room at a restaurant (as customer)	36	Male	89	Brain haemorrhage	Coma	Overnight (approx. 20 hours)	Home
03	Individual face-to-face interview	Café	38	Male	91	Duodenal perforation	Unresponsive	3-4 hours	Home
04	Family joint face-to-face interview	A staff room where they worked	28	Female	75	Uncertain (Mite infection?)	Dead prior to transit	--	ICU
05	Individual face-to-face interview	Café	56	Male	66	Unknown	Unresponsive	4 hours	Home
06	Family joint face-to-face interview	A meeting room in the hospital	49	Male	51	Brain haemorrhage	Coma	--	Ambulance
07	Telephone interview	An office room in the hospital	52	Female	67	Intestinal fistula	Probably coma	Half an hour	Home
08	Individual face-to-face interview	Café	45	Female	77	Meningioma	Unresponsive	Several minutes	Home
09	Individual face-to-face interview	Café	58	Male	75	Uncertain (Septicaemia?)	Coma	--	Ambulance
10	Individual face-to-face interview	Café	43	Male	88	Lung cancer	Alert	1 week	Home

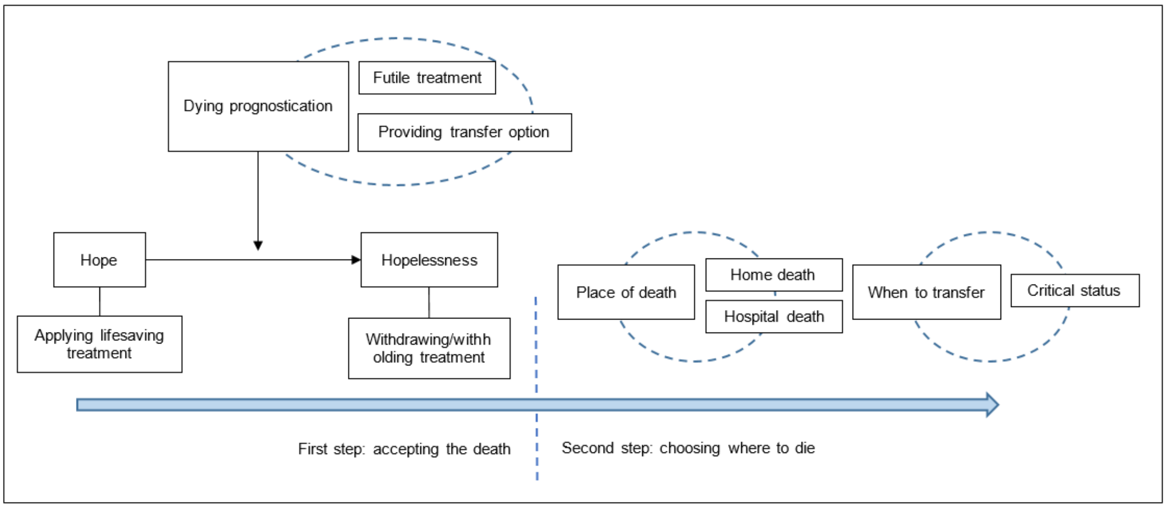
‘—’ indicates the death occur before reaching home

6.3 Theme 1: "Stay here or go home?": two steps to decide transfer

Theme 1 explains the processes of decision-making to transfer patients home to die from the ICU in China (Figure 6.2). A family's decision to transfer comprised two steps. The first step was to accept the death, which comprised the dying prognosis by ICU doctors and families' transition from hope to hopelessness, linking to the decision to WLST. The second step was to determine the place of death including selection between dying in the hospital and at home and considerations about when to transfer. The facilitators of, and especially barriers to, the two steps of decision-making were influential in the timing of THtD.

Figure 6.2 shows the two steps to making a decision to transfer home to die. An arrow indicates the direction of decision-making from step 1 to step 2. Each step comprised two major elements and these elements are laid out on the top of the arrow. Step 1: dying prognosis; transition from hope to hopelessness. Step 2: place of death; when to transfer.

Figure 6.2 Theme 1: "Stay here or go home?"



The decision-making process to transfer was initiated by ICU doctors who informed family members that the patient was dying. In one case (Zhi) transfer was requested directly by the patient's family. Clinicians explained to family members that the declining condition of the patient was irreversible, and that LST was futile or inapplicable due to the unstable clinical status of the patient. The conversation between clinicians and family members signalled that there was no hope of recovery and that the death was inevitable and near. With this information it was then the family members' decision whether to accept the prognosis of impending death or not, and the following decisions to WLST and considerations about whether to transfer home to die. Therefore, the first step in families' decision-making to transfer was to accept the impending death.

> Wei: Then around 7pm, he [doctor] told me my father's condition was getting worse, worse than ever. So he didn't dare to do it [dialysis]. (…) 'So you see if to stay here, or go home now'. (…) He (…) because he wouldn't say it explicitly, 'well you must' (…) He said 'you think about your own customs, and your family's decision'. Then I, I heard this… because if he said so, he's certainly inclined to mean definitely there was no hope. So he told us 'you stay here, or go home according to your custom.' (01: 200-208)

> Zhi: At the time, we told the ICU doctor 'if my mum is really not right (dying), in our AA (the local area), my mother's siblings all required us to bring her home with her last breath'. (07: 39-41)

An interesting aspect in the end of life decision-making about THtD was the style of communication between doctors and family members. The death was communicated between them without saying the word 'death' or 'dying' because it was "embarrassed" for doctors to tell the truth (Lili). However, the indirect end of life discussion did not hinder the decision to transfer. Family members well understood unequivocally the doctors' meaning about the inevitability of death of the patient and the choices they had to consider about transfer. Such a way of communicating about death between doctors and family members was a reflection of their shared culture and traditional societal customs. In China death is a sensitive topic and speaking the word 'death' considered to bring the bad luck and make bad things happen. Thus, many metaphors were used to convey the meaning of death/dying such as "no hope", "gone", and "not alright" when communicating about death. Participant Siming even used the word "old" to mean 'die' which indicated the various expressions of death in Chinese language. The shared culture and customs of death shaped how people talked about death in order to comfort each other, but the meaning was not altered.

> Lili: However, the doctor shook his head. He said that 'you should know that there is only 0.5 percent of the hope (of recovery)'. Then I thought there must be no hope and he was embarrassed to tell me the truth, so he said 'only 0.5 percent'. Because his heart beat declined rather than increased when they resuscitated him. (06: 58-62)

> Siming: Because (my father's) elderly, and my hometown has a custom, that the elderly are not allowed to old [die] outside [not at home] which means he couldn't be left outside, we considered if we could take him home before death. (09: 65-67)

Families' understanding and acceptance of death involved a transition from hope to hopelessness. How much hope of recovery was predicted by ICU doctors was the key in families' decision to WLST, which was often an important decision connected to THtD. To families, hope of recovery was the reason for continuing the LST while hopelessness was a reason for WLST.

> Qing: At about 10 o'clock. Was it 10 o'clock that day or the next day? The doctor said when communicating with us, that '(my father's) condition isn't optimistic, the rate of cure is very low, and there is basically no hope'. Well for our family members, we considered my father's physical condition was still good at the time. We still held a glimmer of hope, held a glimmer of hope, and then (my father) entered the ICU. (…) But when my old father didn't wake up after a week, we felt a dilemma, because we already believed that the hope of waking up was no longer there. Was it beneficial or not that my old father lay still in the ICU and was maintained on those machines? It's painful to us. (…) Forty days later, the doctor said there was no hope, because the organs were beginning to fail. So in the custom of our AA, it's better for the elderly to pass away at home. (02: 4-7, 9-12, 14-16)

The ICU setting was a factor influencing family members' acceptance of death or expectation of the impending death, through their construction of hope within the setting of ICU. In the view of some participants, for instance Qing, ICU was considered to be a place of hope, characterised by skilled clinicians and high-tech equipment, so that they did not expect an impending death. Transfer was not considered by families until the ICU doctors made the dying prognosis. Through their experience participants reconstructed their understanding, perception and expectations of ICU. In contrast, if families constructed ICU as a place of hopelessness, associated with death, ICU could be a facilitator to an early decision to transfer. Ying conceptualised ICU as created for death rather than for life. Therefore, Ying had started to consider transfer very soon after her father was transferred to ICU from the ward after deteriorating.

> Qing: I used to think that ICU was a place to save the critically ill. When a patient came, he was cared for in a particular environment, which was in hope [of recovery]. (...).So you asked me how about the ICU, I don't think there is any specialty. It's just an advanced ward. For me, it's an advanced ward. For my old father, this state is only an advanced ward. Nothing else (02: 395-398, 462-464)

> Ying: It's the first time or the second time (day in the ICU) I already planned to take him back. By the third day, I had decided to contact the ambulance and take him back. (…) I think dying people all go there [ICU]. (...) I always believe that people going to the ICU have no way to come out again, and all come out to die. (...) I think the door is exactly the same as what I watched on the TV. When the door is closed, I feel that there is no hope at that moment. There is no hope in the ICU. (05: 86-87, 491-497)

When the inevitability of death was understood and accepted, decisions about transfer were the next step in the process. The second step started with a consideration about where to die. Some doctors' involvement in the second step of the transfer decision was to offer family members two choices: stay here or go home, which meant to choose between an ICU death and a home death.

> Wei: He [doctor] said 'you think about your own customs and habits, and your family's decisions'. (…) 'It's up to you.' Some have the customs of going home rather than passing away in the hospital. This is the custom in AA (the local area). It varies in different places. Some don't take it seriously while others do. So he [doctor] did talk about it. (01: 205, 376-378)

Family members had to choose the location of death between the ICU or home; participants were faced with a dichotomy of death in the two sites suggesting a limited choice regarding place of death. Some participants decided to transfer patients home to die without any consideration of a hospital death. Other participants reported that they had considered an ICU or hospital death for practical reasons (with no need of transportation, a simple process, and cheaper) or legal disputes which caused a conflict about the transfer (i.e. suspicion of malpractice that caused the death), but after initial deliberation their final decision was to take the patient home. The reasons for all families' choice to transfer were the custom and family morality (filial piety) about going home to die in Chinese culture (Theme 3).

> Lili: It's [transfer] up to you. It's your family's business. It depends on how you treat it. There are still such fellows who don't take [the relative] back and choose cremation. We're different. (…) If he died in the hospital, if we still had the chance to take him away we would try our best. If they [the hospital] didn't allow us to take him away, and no way, then went for cremation. (06: 353-355, 366-367)

> Jun: I have three younger sisters and one of them supported me to go back. The younger brother, and another two younger sisters suggested to let him [my father] pass away in the hospital, in the morgue. I said '(he's) so old, and I feel it's very unworthy (if he) passed away silently there'. (…) Well, my younger brother (laughing) didn't want my father back as well. Because it (hospital death) saves time, costs less, isn't it? If we take him back we have to do the funeral. Ah, there is a lot of etiquette, too much. And we have to guard him for three days and three nights. We cannot sleep, and just close eyes for a little while. (03: 60-65, 129-132)

> Zhi: If she [my grandmother] really died in the ICU, we wouldn't take her back. We would do what we should. We would hire a lawyer to have a look at how the doctors did the surgery. We would just give the relevant documents to the person who knew medicine. (…) If we were not native, she was absolutely placed in the hospital, to see how to deal with it [the suit], isn't it? (07: 103-106, 278, 286-288)

A direct recommendation of THtD by ICU doctors might prompt some families to consider the choice of transfer in a timely fashion. Some patients' transfer, as illustrated by Lili and Kai, was decided by families after doctors acknowledged families' local customs and provided families with the option of transfer or agreed with a family's decision to take the patient home to die. However, it appeared that the doctors' option of transfer in most cases was given late because the decision-making to transfer did not take place until patients were very clinically unstable. This resulted in families being given a very short time to decide or even that families were unable to take the patient home to die and breached the cultural expectations. In the case of Hui's mother the ICU doctor asked the family to pay more for the LST even though it was futile, and the family then selected to continue the treatment. Hui's mother died in the ICU after a few hours, and before she could be taken home.

> Lili: A person working inside, among the doctors, said that he had seen a lot of such cases and most died. 'You are only waiting here' he said, 'and it's useless.' He said 'if you have the custom to take him home, you'd better do it quickly. It's better to go earlier.' So I decided to go. (06: 434-436)

> Kai: So why we took her away? Based on the advice of the doctor, what the doctor said, and all sorts of our own reasons we made the decision. It wasn't that we sensed that she had no hope (of recovery). It wasn't our own decision. Instead we were forced to accept (the death), forced to decide (to transfer), against our intentions, to be honest. (08: 306-308)

> Hui: (The doctor) talked about the treatment and cost at about midnight. He said the money wasn't enough. Then we asked "how is my mother?" He shook his head like this. He said 'if you pay, if you pay 1,000 or 2,000 yuan today, the money will be run out tomorrow but your mother wouldn't (survive), wouldn't be saved.' (04: 130-133)

The timing of transfer was an essential aspect in the decision-making process. The transfer could not be too late, as patients might die before reaching home which went against cultural expectations. Most transfers were decided and undertaken immediately by families after the dying prognosis because the patient was in a terminal state and death could happen at any time. Therefore, the boundary between the two steps in decision-making were not always clearly distinguishable.

> Siming: At about one o'clock in the morning, (the ICU doctor) called me. The attending Dr H, said 'your father isn't alright (dying). What's your plan?' Then I said if he's dying, we cannot do anything, right?' So we hurried to take him home. (...) He wasn't clear at the time. He's already on the ventilator. The (endotracheal) tube, everything was

> already there and we were about to go. (…) The doctor told us, 'drive fast, see if he can get home and will not (die) on the road.' (...) I mean let’s see if he could reach home because the elderly are not allowed to old [die] outside (home). (...) We went home on a high speed road. All of us four brothers were in the ambulance. (...) and then suddenly we saw his breath stopped. He passed away at the time. He passed away when we just arrived at City G. (...) Well we were only crying in the ambulance at the time. (09: 112-115, 119-120, 271-271, 277-278, 126-133, 280-281)

Time related factors such as the distance of transfer had an impact on families’ decision-making. A short journey was a facilitator while a greater distance of transfer, which was common for the participants in the current study, was a barrier to the decision. It required families to transfer the patient home as soon as possible with more concerns in relation to the limited time available. As argued by Zhi, if his family lived far from the city he would not have complied with the custom and would have chosen not to take his mother home to die from the ICU.

> Zhi: If we were not native, she was absolutely placed in the hospital, to see how to deal with it [the suit for medical malpractice], isn’t it? (…) For a non-native who live far away how could she be taken home? Impossible. Just because we are the local residents in City A, where we were born and raised, right? We must take her home for the funeral. (07: 278, 286-288)

Factors that were associated with a difficult or easy acceptance of death could serve as barriers to or facilitators of transfer and influence considerations of the timing of the transfer. As an illness factor a non-curative cancer was a facilitator to transfer to the family of Quanxin. Family members would consider the option of transfer early as it was easier to accept the inevitability of death. In contrast to accepting the death, a denial or refusal of death/loss by family members was a barrier to transfer. An extreme case in the study was Hui whose mother was not transferred home until she died in the ICU. A denial of death by family members reflected the unbearable pain of loss as well as the filial piety between children and parents, or spousal duty for the case of Lili. An early abandonment of efforts to save parents or spouse was not acceptable by the societal culture of China.

> Quanxin: It isn’t that we give up the treatment. It’s really a tumour, which was impossible to cure. Under the circumstances, we took (my grandfather) back. After we went back the outpatient clinic nearby came over to give the general IV treatment. Because it’s impossible to cure in the hospital and the critical notice has been issued, and we only took him back when the phlegm (symptom) couldn’t be resolved. (10: 45-48)

> Hui: She didn't breathe at all. She was dead. She was dead when we took her out of the ICU.
> Ling: She was already dead.
> Hui: She didn't (breathe at all). It's not that she was so ill and couldn't be cured so we took her home. No. She was dead. She was dead in the ICU. (04: 232-236)

> Lili: If he hadn't been resuscitated here in the morning and had been taken away he might have got home (alive). With the oxygen, and he might have got home counting the time assumed (for the journey). However, how could we bear not to save him here and directly take him home? We must save him and if there was any hope (of recovery) he would survive. (06: 514-516)

Finance was a factor influencing participants' decision-making and their attitudes towards money for THtD showed moral values regarding family. Family members should be willing to pay for the ICU treatment, transportation for going home to die and a funeral at home which were often very expensive. The attitudes towards money were intended to show families' commitment to save the patients and transfer them home to die only when nothing could be done. Before transfer, all efforts had to be made to save the patients' life. Transfer should be only because of the custom of dying at home (Theme 3) rather than families' unwillingness to pay for the treatment and to remove a patient from ICU for who there may have been hope of recovery. Transfer was ethical when it was decided because LST was futile and nothing could be done to save the patients by families and doctors. Therefore families would not give up and transfer patients home too early in accordance with the family moral values informed by the culture. Family moral values and traditions informed families' decision to transfer and the timing of transfer which should only be the last resort.

> Quanxin: We took him back, as I just said, because it's impossible to cure. If it's possible to cure him, we would save him regardless of how much we had to spend. The reason we took him back isn't the medical expenses that we cannot afford. It's purely the custom that he must go home. (10: 96-99)

> Jun: Two or three days after using the albumin (an expensive medication paid by out-of-pocket), it seemed not useful for (my father who) was old. My siblings said that since (our father) was in the hospital, we should be filial and apply the second operation, dialysis, use dialysis again. (…) Doctor Fu said 'if you want to do dialysis again, then let's do it. It might work or there is nothing to do'. The dialysis is to exchange the blood of the whole body, isn't it? However it didn't work, didn't work. (03: 44-46, 147-148)

> Lili: It’s the way when we really had nowhere else to go. It’s the way when he couldn’t be cured. We really didn’t have any choice. (06: 516-517)

However, for families who had a poor financial status, this could be a barrier to the decision that was related to a too early or premature transfer, because they could not afford further expensive ICU treatment. An early, active decision to transfer the patient due to financial limitations brought the family financial dilemma and emotional suffering.

> Kai: Because we had no choice. If we hadn’t taken her [my grandmother] home and left her here [in the ICU]. Then a lot of expenses were also (…) because we are limited in money. (…) Due to economic reasons, due to such and such reasons, we agreed to take her out. If, for example, the actual situation wasn’t so bad as the doctor said, but he told us like that, or what miracle there would be later, but now we, we gave her up first and took her out. It meant that there was no hope at all. Then as her family we are very sad. (08: 63, 102-105)

Given that different family members were involved in the decision to transfer, it was not uncommon for family disagreements to arise which acted as a barrier to transfer. For example, there were differences of opinion between withdrawing LST and continuing LST, and between a hospital death and a home death. When the early joint decision by the family was to continue LST the transfer was delayed, whereas if the final decision was a hospital death transfer was rejected.

> Jun: I was informed for the first time, that (my father) was critically ill. I (said to) my siblings ‘since the doctor said so, let’s (take father to) go home soon. It would be useless, or meaningless, to stay’. (I have) four little siblings and the little brother said to try another course of treatment. (03: 143-145)

An unexpected finding of the study was several participants’ suspicion of doctors’ malpractice contributing to the patient’s death, which served as a barrier to participants’ acceptance of the death. They considered that it was the doctors’ improper treatment (medication, surgery, and dialysis) that (partly) caused the patient’s death, which made it difficult for families to accept the death and take the patient home to die. This was because transfer was a choice that conflicted with potentially taking out a litigation case and suing the hospital for malpractice. Where families suspected malpractice they might refuse transfer and decide to leave the patient to die in the hospital so that a post-mortem could be carried out, or chose transfer despite intense conflict and psychological pain. Such a frequent instance of suspicion of malpractice suggested an overall mistrust with medical practice.

> Zhi: What I’m most tangled about is the (doctors’) medical skills. I think it must be a problem of medical skills, then how could it always be like this (four surgical operations)? (…) We definitely struggled. Why wouldn’t we struggle, right? If we left (my mother) there (in the ICU), we could sue the hospital that it’s a medical accident. I’m sure the hospital absolutely had a little responsibility for it [the death], didn’t it? (…) But what we struggled with was that if she was left in the hospital, if we didn’t take my mother home, our town folks would scold us, right? And my uncles and aunts (the patient’s siblings) would also blame us. (07: 162-163, 276-277, 289-291)

> Kai: She already passed away. If I raised this (malpractice complaint) she would be dissected. We don’t want her to experience this suffering after she died. I mean this. If I requested for this it (the hospital) would go through a procedure and dissect her, and such and such. Then I couldn’t take her home. (08: 160-163)

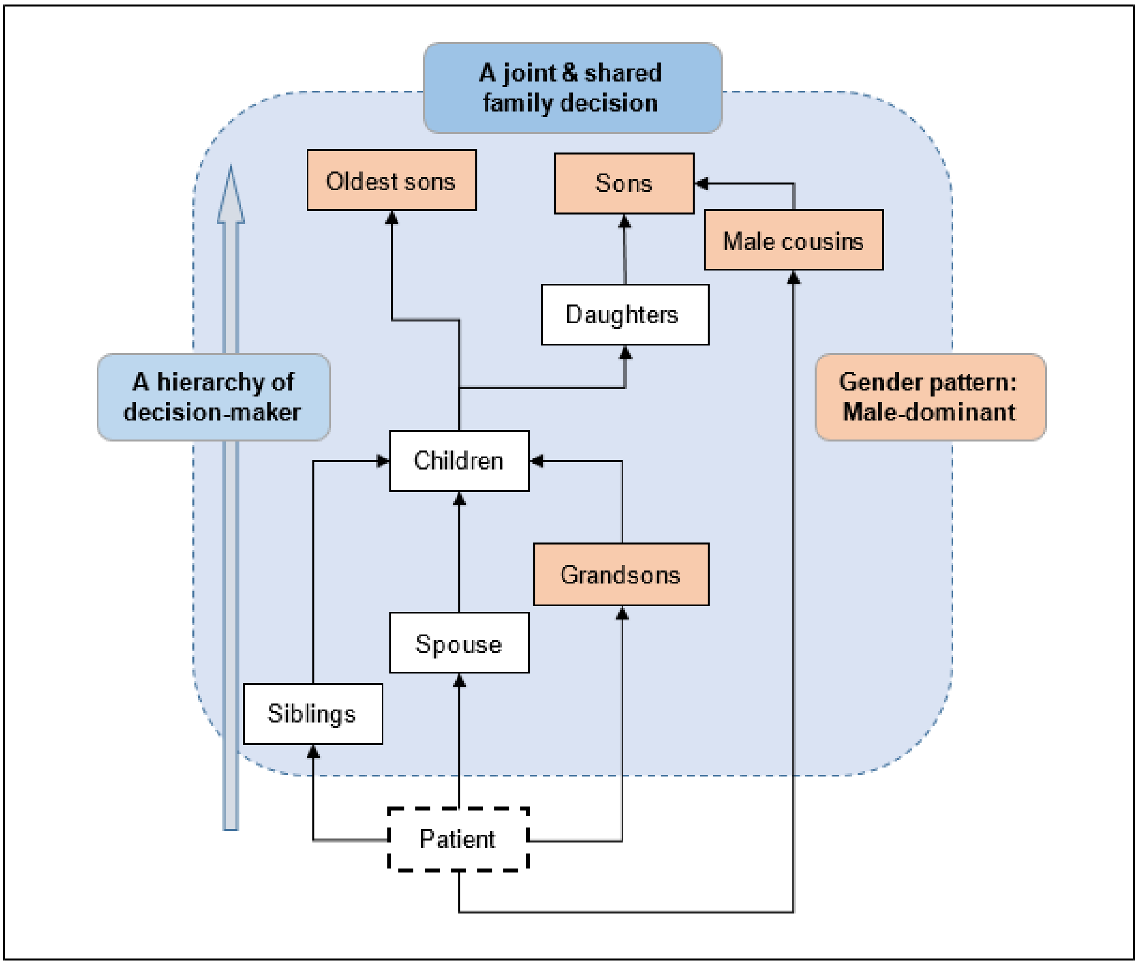
Summary Theme 1: The family decision to transfer was to accept the impending death, following the dying prognosis by ICU doctors, through transition from hope to hopelessness, and then select where to die and when to transfer. The first step regarding the acceptance of death was not an easy process for family members while the second step was a choice between only two options and transfer was only undertaken when patients were in the last hours of life. In participants’ constructions, conceptualising the ICU as a place of hopelessness, a direct recommendation to transfer from ICU doctors and a non-curative cancer could facilitate their acceptance of death and a timely transfer, while conceptualising the ICU as a place of hope, a denial of death/ loss, not giving up underpinned by filial piety, family disagreement and a suspicion of malpractice contributing to the death were barriers to their acceptance of death, and resulted in a late transfer. Poor financial status might lead to a transfer that was too early from the point of view of family members, and which caused them emotional distress.

6.4 Theme 2: “His sons discussed and others were not involved”: the decision-makers in the process of deciding to transfer

Theme 2 focuses on who the decision makers were in the THtD process. As indicated in the theme’s name (quote from Quanxin, grandson of the patient), transfer was jointly decided by the patients’ family members and there was a hierarchy for the extent of involvement by different family members. Theme 2 is illustrated in Figure 6.3. In making the decision to transfer, the patient’s adult children were at the top of the hierarchy and patients were excluded from the decision-making process. A gender pattern was identified with male family members dominating the decision-making and women having little opportunity to input.

Figure 6.3 illustrates the joint and shared decision-making involving multiple individuals. Within the joint family decision, the hierarchy reflects the least powerful family members who are situated the bottom to the most powerful decision-maker who occupies the top position. The male individuals in the hierarchy who had more power than females are highlighted in pink colour to show the gender pattern.

Figure 6.3 Theme 2: "His sons discussed and others were not involved"



Family members were tasked with making the decision about THtD. Doctors told families the dying prognosis and required families rather than patients to make the choice. Patients themselves were not (or not directly) included in the conversation between family members and doctors. Excluding patients was based on the fact that most patients were unconscious or had lost the capacity to make decisions for themselves at the time of transfer decision-making. However, an important finding was that participants' stories suggested that there was no advance discussion between the patient and their family members regarding preferences for place of death.

> Ying: He’s [my father] completely unclear. Only on the first…one day I went in (the ICU), and told him I would take him home. I could say he grabbed my hand. Actually he couldn’t speak at all because a tube was inserted in his mouth. (…)
> YL: How did you know he wanted to go home?
> Ying: I don't know, I just knew he wanted to go home.
> YL: Had you talked about this before?
> Ying: No, we hadn’t. (05: 80-82, 284-287)

Furthermore, Quanxin’s explanation showed that even though the patient was alert, which meant he may have had capacity to be involved in the decision-making, he was excluded from this process by his family members. The family’s decision not to discuss EoLC was in keeping with societal customs and preferences which do not condone discussing terminal illness and death.

> Quanxin: No, it’s impossible to communicate with him (my grandfather) about the fact he was dying. (...) We may not be like the European and American countries. Because you are still studying in the UK, your thinking is avant-garde since you had contact with the European and American countries, where perhaps the patients know all the diseases and pathologies. In China, not just City A, across the country, I don’t dare to say a hundred percent but 98 percent (of families) will not tell the patients about such a critical illness [lung cancer]. (10: 267, 339-350)

Some participants conveyed that going home was a wish of the patient while others did not mention the patients’ preferences about where to die. Families made the choice to transfer on behalf of patients and some of them considered that transfer was also the wish of the patients, so that it was a decision in the best interests of the patients. As a shared cultural norm, most family members could make a guess that the place where their dying relative wanted to die was home.

> Jun: When (my father) was critically ill, I don’t know how to say, his body showed that ‘go home, go home’. (...) On the way home, he opened his eyes wide and looked at me. I was in the ambulance and held the oxygen for him. He looked at me with his eyes opened. Ha-ha. (…) He was very happy being sent back. (03: 257-263, 352)

The decision to transfer was a joint negotiation between different family members, including patients’ children, spouse, grandchildren, siblings, cousins, other relatives, and even friends. Transfer could be a joint decision by the nuclear family (children and parents, spouse) or across nuclear and extended family (cousins, friends). Lili’s story showed that it was difficult for a single family member to make the decision. When there was no other competent or available family member to share the decision she chose to seek help from friends. Furthermore, Ying’s account suggested despite transfer was a family decision there was an order of the negotiation that the patient's spouse was consulted after the children, which suggested a pattern of hierarchy in regard with the involvement extent.

> Lili: I rushed (to the hospital), cried while walking, and called them [relatives]. Later my relatives and friends, my family all came over. I had no idea what to do on my own. My child (son) wasn't here and there was only we couple. (06: 56-58)

> Ying: We negotiated, because every one of us had to. Everyone was his child. Everyone had to decide, and (we) also asked my mother. (05: 231-232)

Families' decision to transfer was joint in the form of the decision-making and shared in the meaning and responsibilities of the decision. THtD was not a decision made by one single family member but a negotiation between multiple members. Going home to die was not an individual and personal wish but a family event relying on collective efforts. This reflected a collective family culture among Chinese people that the important decisions of an individual are made by the family. Furthermore, a joint family decision was meaningful for family members practically as more individuals were able to share the difficult process and the painful outcome. In practice, transfer was costly because families had to pay for the transportation and for a big funeral at home. A joint family process would enable sharing these costs and thus reduced individuals' difficulties in decision-making which was usual among participants.

> Jun: Anyway, 10,000 or 20,000 yuan isn't a burden to five siblings. (...) Everyone took a share which was more than 10,000 yuan. The funeral cost more. The home funeral cost about 100,000 yuan. (...) Our (funeral) is the cheapest. This is the case in the countryside. Now this is universal in our countryside. If the (family's) economy is better, they spend two to three hundred thousand to (celebrate with) the relatives and friends. (03: 93, 96-97, 109-112)

The negotiation process about the decision was joint and shared but the allocation of decision power was uneven within a family because the negotiation was often dominated by family members who appeared to have seniority when it came to decision-making. In this study with a majority of participants having children-parents relationship, the phenomenon of decision hierarchy was common. First of all, children were the primary decision-makers for their parents, while the spouse of the patient became a secondary decision-maker or in some cases was not involved in the process at all. According to Wei's account, a possible reason was that mothers were protected by their children from the pain of the potential loss by being excluded from the transfer decision in relation to their husbands which suggested a vulnerable position of female especially mother in a family decision. When the patient was a mother, the patient's husband might or might not be involved in the decision-making process, and children remained the primary decision-makers so that children possessed more decision power than spouse with little influence of gender of the spouse.

> Wei: Later I discussed with my brother, and also with my family. My family also would like... Because I don't dare to tell my mum what happened, I just told my cousins (male) such and such. My brother and my cousin heard that, and they also said, 'in this case, perhaps we should go back, go home. Because according to the customs here, because of that, we should go home, come back.' (01: 208-212)

Second, while the child-parent relationship might be given precedence over other family members in the decision-making, this tended to be the case when the child was a son, but by comparison daughters had less authority. In the hierarchy of involvement or decision power, a gender imbalance among children in the role for decision-making was identified.

> Qing: There are a lot of different opinions in treatments among the patient's family, especially for our generation with many siblings. (…) When we siblings were discussing, I could say this to my brother, but I couldn't say this to my sister, because this is different, because my sister had a very good relationship with my father. What I mean is this was also a torture, because there was really no hope. I couldn't see any hope. To cut him and he might go (die) earlier. We couldn't do the job after death. So we (reached agreement) through communication, and we are relatively rational. (02: 24-25, 96-100)

> Jun: I said 'I will take (father) home even though you don't agree'. Later my little brother also agreed with me. Because we brothers matter the most, if we both agreed, my sisters didn't have any choice. So we took (father) home. (03: 193-194)

In relation to sons' central roles, male family members (sons, husband, and male cousins of the patient) possessed more power in family transfer decision-making. Female individuals (wives and daughters of the patient) were excluded or invisible in participants' story about transfer decision-making. Gender differences and family relationship intertwined in the power of decision-making about THtD. The gender pattern in transfer decision-making was underpinned by the traditional Chinese family culture. For instance, traditionally, men often make the most important family decisions, such as buying a new house or moving to a new place. In most family events, it is not uncommon for women to follow what is decided by men (Xia et al. 2014).

Third, the senior authority of the children-parents relationship in transfer decision-making was also applied between generations. The adult grandchildren of patients felt they had no right to decide the transfer even though they might be involved in the decision-making process. Although adult grandchildren took more responsibilities of taking care of the patient in terms of seeking formal care during treatment, when the decision came to THtD they stepped back and the patients' children played the leading role in decision-making. Grandchildren had a 'distant' or 'extended' family relationship with the patient compared to their children. The decision about transfer showed the underlying Chinese family culture in the aspect of closeness of relationship. An important family decision like transfer could only be made by the 'closest' family members, who were children rather than other generations.

> Quanxin: My uncles and my parents made the decision. My father and his siblings, six siblings made the decision. (…) I couldn't make the decision and only took him [my grandfather] to see doctors. I have no right to decide because I'm his grandson. My senior generation have. (…) His sons discussed it and others were not involved. Others, we just gave some advice. (10: 94, 101-102, 279-280)

Fourth, the order of birth among children also contributed to the hierarchy of decision-making. The eldest or older children's choice was respected and they were expected to take more responsibility for the decision than younger ones, which suggested a hierarchy based on age among siblings. This was consistent with the broader Chinese family culture that younger members should respect the older ones, while the older ones have the duty to take care of the younger ones. The hierarchy of family relationship is an important component in the bond of the family as a whole unit in the society.

> Kai: I was against it (the decision to transfer) at the beginning. I said 'let's have a look before 8am.' My father and his brothers are not rich. One of them is better off but he couldn't make the decision. I don't know whether he wasn't willing to spend money, or something else. He was able to afford for (my grandmother) to stay (in the ICU) for a few days longer. However, my grandmother was in such a condition (dying) and they have so many siblings that he didn't want to spend so much money alone (because other siblings couldn't afford the share). I think so. So I have complaints with him and furthermore he is the oldest. (08: 371-376)

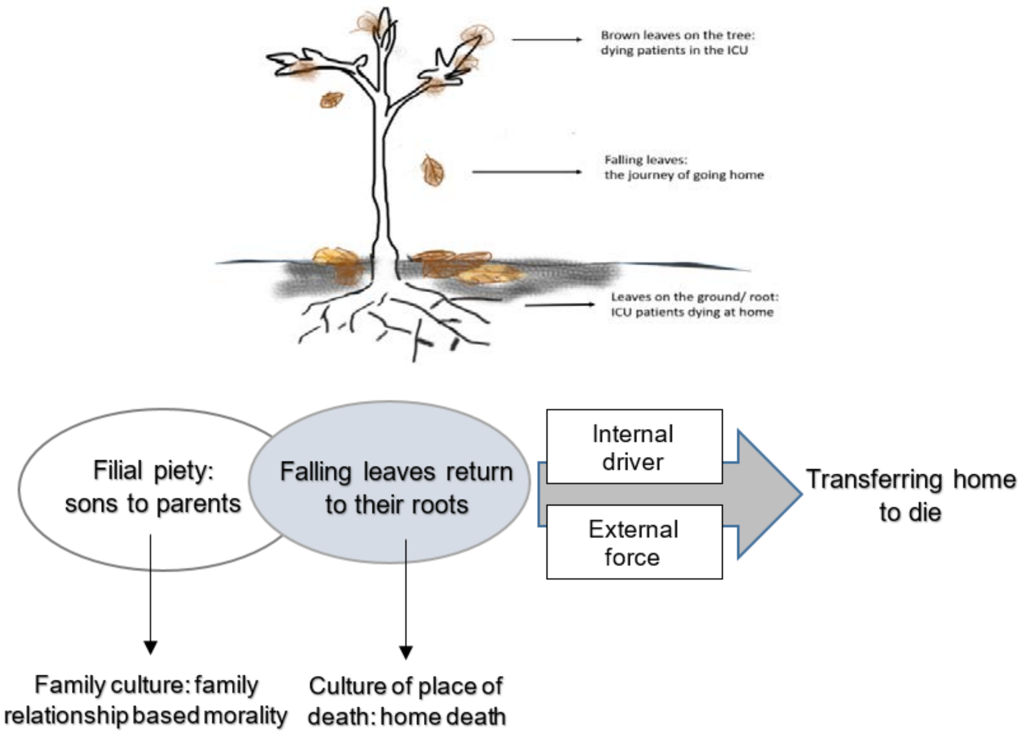
Summary Theme 2: The decision-makers in the process of deciding to transfer were the family. Patients could not make the decision for themselves because they lost the capacity for decision-making, and more essentially the custom in China prevented family members to discuss death related decisions with alert patients. The role of doctors in ICU was to inform family members the dying prognosis and sometimes make recommendations regarding where to die for families. Transfer was a joint family negotiation to share the responsibility, the difficult process and the painful outcome of loss. Within the collective family decision, there was a hierarchy entitling the dominant decision-maker based on family relationship and gender difference. Patients' adult children, particularly their sons possessed more power in decision-making. The individuals at a lower level in the hierarchy had to follow what the ones at a higher level decided to achieve a consensus even though they might had a conflict choice. Who the decision-makers were was driven by the strong cultural norms about family relationship and obligation. These underlying patterns regarding the decision-makers in the process of THtD were underpinned by Chinese family culture which was collective rather than individualised, and by gender differentiated roles. How the cultural values and norms drove the family members' choice of transfer is explained in Theme 3.

6.5 Theme 3: "Falling leaves return to their roots": the meaning making of transfer

Theme 3 explains how families made sense of their choice of THtD (Figure 6.4). Two key drivers to the decision were identified in participants' stories. The fundamental driver to THtD from ICU was a cultural phenomenon termed in in vivo code "*falling leaves return to their roots*", which was a Chinese proverb in Chinese culture meant that people should go home to die. The other driver was the family moral values and duty between family members; the filial piety between children and parents in most cases in the study, which were powerful influences on transfer decision making, even when THtD was not what family members felt prepared for. In participants' construction of meaning about transfer, the culture of going home to die and family filial piety acted as both an internal driver and an external force upon families' decision-making.

Figure 6.4 illustrates Theme 4. The phenomenon of "falling leaves return to their roots" constructed by participants was reconstructed in the figure, with the representations of the leaves on the tree to the ICU patients, the falling leaves referring to the patients being transferred home and the leaves on the ground to the patients at home. Underneath the tree, the underlying patterns about how participants made sense of the decision are illustrated. The two cultural drivers are connected to each other to show the filial piety was acted upon with regard to the culture of home death in the decision-making. The decision followed the drivers, with an arrow to show that it was the outcome of the two drivers. On the arrow is the mechanism of how culture drove the decision to THtD.

Figure 6.4 Theme 3: “Falling leaves return to their roots”



“Falling leaves return to their roots” was the culture-rooted driver behind participants’ decision to THtD from the ICU. Although there was a choice of a death in the ICU, all participants in the current study chose to take the patient home. When participants explained and justified their decision with the Chinese custom after the impending death was accepted, the custom was proposed as an internal driver for families’ decision to transfer patients home to die. “Falling leaves return to their roots” was the Chinese idiom or proverb illustrating the historical custom of dying at home and home death: going back home, lying in one’s own bed or in the hall of the house, surrounded by family members, saying farewell with relatives and friends at the funeral, and being buried in a tomb for worship. It was the Chinese culture that defined the meaningful place of death. An essential part of the custom was that the dying person must go home before death occurred as it is traditional in China for home to be the place of death.

> Quanxin: Why did we go home later on? Because first, in our AA area (locality), I don't know where you are from. In our AA area, when the elderly person is in critical condition, we have to take him home. (...) It may be a culture of thousands of years, in our City A. We belong to the rural area of City A. Falling leaves return to their roots, so he must go home. (10: 31-32, 42-43)

> Wei: In the AA the custom and habits are that, so later we also placed a bed in the hall in our old house. If he’s alive, for an alive person, normally his head is placed toward this

> side. If he passed away, his head is placed toward the other side. We also complied with the custom. (01: 279-282)

In addition to the driver of the culture of going home to die, another key driver to transfer was the family moral values. To participants, respecting the Chinese custom and making efforts to take patients home to die from the ICU was a major sign of family morality impacting on their decision to transfer. The custom of dying at home which determined the choice of transfer played a role through family as the decision-makers. Sons showed filial piety when they transferred home their parents. A wife showed her duty for her husband when she transferred her husband home to die particularly when the family had no adult children available for this role. Filial piety or spousal duty were reflected in the moral values of family relationships, and informed by Chinese family culture. A transfer was meaningful to family members when the family showed their respect for the custom based on demonstrating moral values within a family. This enabled the family to obtain peace of mind regarding their role and performance in the decision-making process.

> Jun: Because we are in a village, and this (going home to die) is the custom. The relatives and friends would scold us: ‘(Your father) has sons and daughters, so many (children) and you let him (die in the hospital)’. It’s [death] quiet in the hospital and nobody knows when we send him there. He will be burned there quickly [cremated]. Because he’s so old we should send him away with a big celebration [funeral]. If it’s quiet, and far away (from the village), nobody would go (to the hospital). So usually (the funeral) is celebrated at home. (03: 187-190)

> Lili: We brought the corpse (of my husband) back so that relatives and friends could have a look and we felt a little rest. (…) If I brought his ashes back, what did they look at? Nothing. We have a good relationship with relatives and friends and the doctor agreed with us to bring him home so that everyone took a look. Then we also felt peace of mind and everyone felt peace of mind. (…) As a couple, he passed away before me so I did his things well based on my own conscience. I’m also relieved. In short, when he’s alive, he was kind to me. When he died, I was kind to him. (06: 385-363)

Not all patients included in the current study were transferred home to die successfully with deaths occur before and during transfer. Therefore, it might not be possible or easy for some families to take patients home to die under some circumstances (too critical to transfer, death in the ICU, too far to transfer). If family members were unable to transfer patients home to die they violated the custom of dying at home and broke the norms about family moral values. One implication was that the family members blamed themselves for the death of the patient, like Ying who would feel restless, which was not a home death and lost a valuable cultural meaning (internal value). Another implication of failing to transfer home to die was that the family members would be blamed by others or by the public (relatives, friends, or neighbours) who shared the same culture regarding place of death, for instance, the case of Jun. Then the culture or custom became a source of external pressure upon families who were involved in the decision-making process. The culture of dying at home and family morality became an external force, transformed from an internal drive through its power in the process of families' decision-making. This was how families made cultural meaning of their decision to THtD.

> Ying: We must take him [my father] home and let him sleep in his own bed. (…) Then I felt peace of mind. Otherwise I would feel very restless. (05: 305, 307)

> YL: Did you worry about that, if your father would pass away on the way?
> Jun: Yes, I did. I did ask (the doctor) whether my father could survive the trip. He [doctor] said "Yes". I stressed whether he could reach home, because if he stopped breathing before reaching home, he wasn't allowed to enter the village. (...) If others knew that he returned to the village (after death) they would scold and spit on us. (03: 237-241)

Qing's account provided insights into the cultural expectation bearing upon children's decision in relation to their parents in China. China is a relationship-oriented society and the family relationship is at the centre. Within such a cultural environment, family members' decision for patients to transfer was a relational one which was shaped by family relationships. Children took the burden of decision-making in their parents' death and the burden was mainly from the cultural expectation: the custom of going home to die, and filial piety for children to parents in end of life decisions.

> Qing: Because in China, a society emphasizing relationships between people, it's very difficult to do this (transfer). Because the Chinese people prefer to die naturally than to take some more active and effective measures to alleviate or slow down anything. Because there are always some people who will point at you. If you aren't prepared psychologically that you are going to do these things… Or you think 'oh why am I doing this?' (…) To my children, telling them what I want is only to reduce their psychological burden. As for whether they will do it or not, because I will be lying there, how can I supervise them to do it? There is no way. (02: 227-230, 236-237)

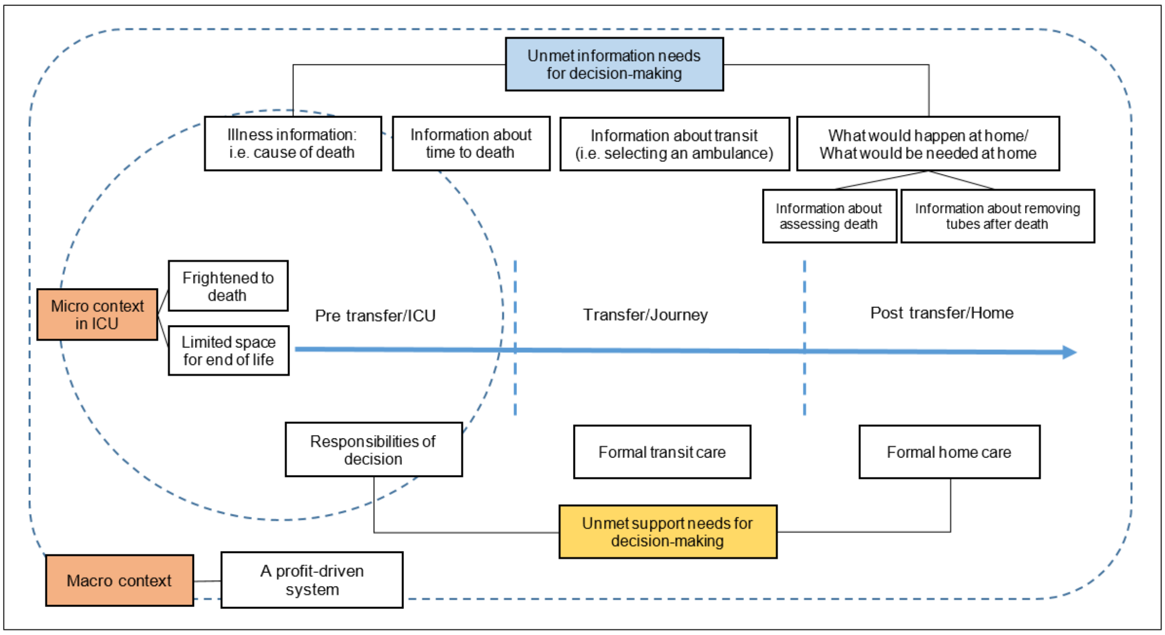
Summary Theme 3: The decision of THtD from ICU in China was culturally meaningful to family members as well as those who shared the same culture. Families made sense of their decision to transfer by mapping to the culture of place of death and the culture of family. A process or mechanism was identified about how the culture informed families' decision-making in the process of deciding to transfer: the culture was both an internal driver and an external force on the decision to transfer which suggested the power of shared meaning of the culture. Clearly for most families, THtD from the ICU in China was not in order for patients to experience quality of life prior to death at home, because the majority at the time of transfer were unconscious and in the last hours of life, but to achieve a culturally meaningful home death that met the cultural expectations. However, THtD from the ICU in China could not be as natural as “falling leaves return to their roots” stated by participants in this study because their needs for information and support were not met by doctors and the healthcare system, as explained in Theme 4.

6.6 Theme 4: “It’s a gap in the care”: the unmet information and support needs

Theme 4 explains families’ information and support needs in their decision-making process of THtD from the ICU. As indicated in the name of the theme, a quote by a participant (Qing), THtD was a “gap in the care” because no formal transfer service to access, and families had little professional support from doctors, the ICU and the broad healthcare system, with unmet needs to family members. Theme 4 is illustrated in Figure 6.5. The ICU doctors did not support family members, by avoiding all responsibilities of the decision, and leaving transfer to be a familial decision without medical input and support, including a lack of necessary information for the decision, and no support for practical care and psycho-social needs. The lack of information and support served as a major barrier to THtD. Furthermore, both the micro-context in the ICU and the macro-context in the healthcare system were perceived to be unsupportive to families’ decision. As shown in Figure 6.5, the environment of the ICU with a focus on intensive LST was “frightened the patient to death” and the strict regulation of visiting time showed a lack of capacity and practice of end of life decision-making. This micro-context of the ICU was expanded and situated in the profit-driven healthcare system.

Figure 6.5 shows the needs for information and support in the process of decision-making and implementation of THtD as laid out from left to right alongside the central arrow showing the process of pre, during and post transfer, corresponding to the locations of ICU, the journey and home. The unmet information needs on the top of the arrow are related to the blue box while the unmet support needs beneath the arrow are related to the yellow box. The contexts that were not supportive to participants are presented with a circle showing the scope which comprised the ICU as the micro-context and the healthcare system as the macro-context.

Figure 6.5 Theme 4: "It's a gap in the care"



The primary support need constructed by participants was the responsibility of the decision to transfer the patient home to die. Family members were the decision-makers in the process of deciding to transfer and doctors divested these responsibilities to families. Study participants viewed themselves as "lay persons" compared to doctors, who were without clinical knowledge to inform their decision and often made the decision at a time when families were vulnerable (experiencing grief). The hospital required families' written consent, which represented that discharge for the patient was a decision by families rather than by the ICU doctors, and therefore that families took the medical and legal responsibilities of the decision to accept any potential adverse outcomes, such as death, without questions or disputes afterwards. The common use of signatures indicating the legal consent of family members for a complex decision (surgery, self-discharge) by the healthcare system was understood by participants as a means for doctors to avoid disputes and absolve themselves of responsibility, which reflected a poor relationship between doctors and families and a professional risk mitigation context.

> Zhi: At the time, we hurried to get my mother home with her last breath. So we signed all that the hospital and the ICU required us to sign. We didn't have the mood to check them and just signed everything, because it's important to come back soon. We signed all that were given to us, because if we didn't sign them they [doctors] wouldn't let us go. (07: 106-110)

> Kai: Now it's common in China, if there is any emergency in clinical treatment, he [doctor] will not resolve it until you sign it first. (…) The signature, actually I cannot say all of them. In fact, a large part of it is suspected to shirk responsibility. I think so,

> because most of us don’t understand (risk), and only listen to what he [doctor] says. Well, we can only say roughly. For example, he said how much risk the operation is, we can only believe how much risk he said. We don’t have, we don’t have the ability to judge it. (08: 25-26, 234-238)

Because family members took all the responsibilities of the decision they had many medical information needs, but these were often not met. In the decision to transfer, families needed specific information, especially about the cause of death, to facilitate their acceptance of the impending death prior to making the decision to transfer. However, some participants reported not receiving sufficient information and took the patient home with unknown causes of death. A transfer with unknown causes was difficult for these participants because in Chinese culture, it cannot be a good death if someone died without a clear reason. The acceptance of death by participants was complex and could be influenced by many factors (Theme 1).

> Ying: To be honest, there is no data or report showing what cancer it was. Nothing. I forgot to take a look at the cause of my father’s death (in his medical record) because he left the hospital and I took him back to C [hometown] using an ambulance. He died at home. So there isn’t any proof about what his disease was. I’m also very, I’m also confused. (05: 71-74)

To make the decision of THtD, information about the length of time to death was essential. Family members needed this information to estimate whether the patient could survive the trip. There were two patients in the current study who did not make the journey and died in the ambulance. This suggested it was not easy for the ICU doctors to provide the family with a certain answer to the time to death. Family members had to bear the uncertainty in their decision to transfer home to die. However, it was a very difficult situation for the decision to transfer in China, where a home death was a cultural requirement and an obligation upon family members. A transit death was not acceptable in the culture, as death must occur at home.

> Siming: Because (my father’s) an elderly, and my hometown has a custom, that the elderly aren’t allowed to old [pass away] outside [not at home] which means he couldn’t be left outside. So we considered if we could take him home before death. (...) We prepared for it (risk of death on the way home) at the time. We already prepared for it. (...) The doctor told us, 'Drive faster, see if he can get home and will not (die) on the road.' (...) I mean let’s see if he could reach home because the elderly aren’t allowed to old [pass away] outside. (09: 65-67, 271-271, 277-278)

Participants in this study stressed the needs for information and support for practical decisions they made involved in THtD which suggested that the implementation of THtD in this study was a family-led process. Transfer was a demanding decision for family members because it required the decision-makers to own medical knowledge in relation to specific decisions, including choosing an ambulance, home care, assessing the signs of death occurrence, and removing inserted tubes in the body after death. However, participants like Qing complained that the ICU did not provide them with the necessary information or support about what would happen and what would be needed for transfer as the general information needs. For instance, Wei accounted that he did not possess the knowledge and experience for selecting the ambulance, and only an unqualified support worker from the ICU was involved in the selection, who offered Wei a more expensive option with no better resources for a safe transfer.

> Wei: Perhaps fifty percent (of the death) was because of my father himself, while the other fifty percent should be due to the hospital, or the treatment wasn't the right one, such kind of thing. However, to be honest, I'm a layperson. I cannot judge what the main cause was. (…) Then a support worker took my phone away and said 'you have to ask him (ambulance service staff) clearly if he has any oxygen'. To be honest, I hadn't been involved in this and had no experience for it. (…) It's [death] confirmed in the morning of 4th (in July) because I don't know exactly, it's 1am or 2am. To be honest, since it's impossible, I didn't dare to touch him, his heart [chest], etc. (…) (YL: Did the ICU doctor or nurse tell you how to handle the tubes?) No, I remember no. Because, to be honest, I didn't expect the tubes to be so complicated at the time. (01: 308-311, 224-226, 505-508, 493-495)

> Qing: It wasn't that we didn't want to give up, but we didn't know what to do. There was no such information to tell us what to do. (…) If my father, like what they [doctors] said, had exited the ICU 10 or 20 days earlier, and returned home, the doctors at least should have told us what we should try to prepare at home. If they didn't even tell about these, or perhaps because we did not agree (to transfer), he didn't say anything. We don't know. (…) We couldn't even get a simple medication in time or he [doctor] couldn't prescribe more to us. (02: 128-129, 290-292, 294)

The ambulance was essential in the decision to transfer because it influenced whether the patient could be taken home safely to achieve a home death. However, the ambulance services that families could refer to were private businesses rather than the hospital's routine care services. The ambulance services used by families provided limited resources and unqualified service providers who facilitated families' decisions such as assessing death taking place in the ambulance and extubating the patient after death in the ambulance or after reaching home, which resulted in a quick death.

> Kai: So in order to take her [patient] back. At the time there were many ‘black ambulances’, which were fake ambulances. They hung the patient on a ventilator, to show that she was still alive so that we could take her back to our hometown. So we hired a black ambulance. (…) they (ambulance service staff) shouted out the price randomly. How to say? It’s like an unspoken rule that its existence is known to everyone, the insiders (in the ICU) all know that they are fake ambulances. I mean the ambulance is from an external, private-owned company rather than the hospital, but it’s marked as an ambulance. (…) They charged thousands (Chinese yuan) for only about 100km. The trip they charged thousands for is only hundreds or about a thousand yuan by a routine ambulance. (…)
> YL: Who pulled the ventilator tube out when you got home, your family or the people in the ambulance?
> Kai: The guys in the ambulance. Only they knew how to pull them out.
> YL: Was he a doctor?
> Kai: He wasn’t a doctor but just did the business. Frankly speaking, they just earned the money. (08: 43-46, 52-54, 58-59,113-116)

As expressed by participant Zhi, the official ambulance, which was the routine ambulance for taking “in” to hospital in an emergency, was not available for transferring “out” to die at home. The official routine ambulance was viewed as a guarantee to ensure the patients could survive the trip. As commented by Qing, it was a “gap” in the care system because the family had no access to formal transfer service. THtD meant the patient was discharged and the relationship between the patient/family and the hospital was finished. The healthcare system contributed little to support for the discharged patients/families.

> Zhi: We couldn’t get the internal ambulances of the hospital and only called for an external ambulance. We had no choice at the time because the hospital’s ambulances are regulated to transport in rather than transfer out. (07: 123-126)

> Qing: We think it (ambulance) wasn’t specialised. We also think it’s a gap in the care between the hospital and the social security agencies because they never take into account that this is a custom in A (the city where the hospital located) or AA (The local region), that people wish to go home (to die). So there is a lack of a controller. (02: 60-63)

Participants in the current study also had little formal care input in their decision-making after transfer. The treatments of unconscious patients were either withdrawn soon after reaching home by the unqualified ambulance service providers, or removed by family members after death at home. Home care was not an issue for most patients in the current study because they died shortly after transfer or even before reaching home but some patients still required home care for hours or days. For instance, Quanxin's grandfather survived for a week post transfer. The caregivers were family members, who provided intensive home care such as ventilation and symptom management, with help from paid informal carers (or without this help for other poorer families). There was no access to formal care resources for home care and the ICU refused to provide the family members with medication after discharge. Home care for dying patients transferred home from the ICU was not covered by the public health care which suggested a gap of funding for home care in the healthcare system. The implication of this missing formal support was that the patient suffered poor palliative care provision and his family members experienced the burden of care (i.e. taking shift as caregiver, with no access to resources).

> Quanxin: His breath had been, due to the tumour, half of his lungs weren't working. (…) With the mask, he couldn't even breathe at all because he's so uncomfortable. (…) We took shifts for 24 hours. Both the older generation and we were around during the day time and two or three of us took the night shift. We also paid for two carers. One was hired before and the other was a full-time carer we used after discharge. We had two paid carers. (…)
> YL: Who gave him the medicine at home? Did he have IV infusion?
> Quanxin: The medication was prescribed by a community outpatient clinic (...) He [the clinic doctor] came to our house and reviewed (my grandfather's) medical records.
> YL: Was he a doctor? A community doctor?
> Quanxin: No, no, it's a private, privately licensed clinic. (...) It's impossible for us to get those doctors (community public doctors) to our home. (…) In terms of medicine, only IV medicine was provided. Perhaps because we didn't request, no other medicine was prescribed. So I suggest for the similar patients in the future, (the ICU doctors should) ask the family whether they should prescribe all the medicine needed. I couldn't get medicine the next day. (…) He [doctor] said the patient had been discharged, so any medicine couldn't be prescribed. (10: 82-83, 88, 154-156, 159-168, 394-397, 399-400)

Besides the lack of support for practical aspects, there was also a lack of support for family members' psycho-social needs in the process of decision-making. Transfer was a painful decision for family members because it was a decision followed by a certain death. The decision-makers' guilt could be reflected in the words of Kai: "she was sentenced to death." The implementation of intensive care involved in transfer was also challenging emotionally to participants like Wei who had regrets in his decision-making, such as assessing the occurrence of death and withdrawal of treatment. However, there was no formal support for the bereavement for family members.

> Kai: What he [doctor] said was to sentence to death. Nobody was willing to withdraw (her) out (the ICU) if there was hope (of recovery). (...) It's on the day when withdrawing her out, (...) I was worried about the sun burning her eyes and so blocked it for her. It's the moment when my heart was broken. At the moment it meant that we were pushing her on the way (to die), completely ruining hope. (08: 64,365, 367-369)

> Wei: This is what I wonder but haven't told my mum, that I regret that, for example, what if I had pulled out those tubes at the time. Sometimes we might be able to say a few words to him. But I didn't dare to pull it out. (...) For the (endotracheal) tube, I became struggled and didn't ask (the doctor) about it. I reflected afterwards, perhaps he could be able to open his mouth if I pulled it out. I was thinking about it afterwards. He could be able to speak even though his voice was low, and we might hear what he would say at the end. It turned out we had no talk. (01: 285-287, 441-444)

A lack of information and resources for home care post transfer was a major barrier to some families' transfer where transfer was delayed that could have been implemented earlier if resources had been in place. In other words, the decision to accept the death and THtD could be made early, but the implementation of transfer had to take place later to reduce the length of time dying at home prior to death, especially for the patients who relied on LST and required intensive care at home. Family members were the caregivers at home, with little or no professional input, and they were incapable of dealing with a long intensive home care. Also the patients were suffering poor quality of life in the eyes of the family members. As a result, patients were maintained in the ICU, "waiting to die". ICU became a place of care for the dying patients and home was the place for death only. For family members, there was limited choice regarding the place of care prior to THtD and ICU was the only option which was a better choice than home but was not the best one.

> Qing: Was it beneficial or not that my old father lay still in the ICU and was maintained on those machines? It's painful to us. (...) Because he [father] was a vegetative person, 88 years old and couldn't undergo the surgery, and there was no further treatment. To be frank, Chinese people say that he's waiting to die. (...) I mean, the ICU resources are so scarce but it seems a ward waiting for death. Why? My father occupied a place there. (…) The doctor, I don't know if it's after about 20 days in the ICU or when, said that 'your father is declining.' But we said 'what could we do if going home?' To be frank, if he went home, we didn't have the good equipment as they [doctors] did, did we? We aren't as professional as they are, right? Then he's maintained at home for five or six days long, who were available to take care of him? (...) He [doctor] also advised us to return home as soon as possible, but we, from our consideration, we still think that it's

> better to place him [father] in the ICU than in our home. (…) We wouldn't take him home until he was in a critical status. (02: 11-12, 33-34, 116-117, 131-134, 238-240, 256-257)

To participants, their decision of transfer was embedded in a non-supportive context in the ICU. For example, the intensive care in families' view could "frighten the patient to death". The fixed and short amount of time allowed for visiting offered families little chance to talk to the terminally ill patients, or even to say farewell, because patients died within a short period. Participants' account could be interpreted as that the ICU provided an illness and treatment centred rather than a patient and family centred care, and there was little space and time for family members and their dying relatives in the ICU. This also reflected the intensive care and cure-oriented practice and a lack of EoLC practice in the setting of ICU.

> Wei: The ICU there only allowed one visit a day at 3pm. Only once a day and no other time (was allowed). (…) My first feeling with the ICU was that even normal people in there, wouldn't be able to bear it. Why? Once he entered there, all his clothes were removed, tubes were inserted everywhere, in his nose, in his mouth, then, in his urethra too. And he was bound on the bed. (…) And he couldn't speak and communicate. (…) I said to myself in my mind, 'Damn it, such kind of treatment, even healthy normal people could be scared to death.' (…) around 7pm I told him [the doctor] 'if you go in please tell my father, giving him a chat about the family.' I said 'I forgot to tell him these', which I always regretted later. (01: 175-177, 458–465, 476-478)

Participants expanded on the non-supportive context for their decision to the broader healthcare system. A central issue of the current care practice to the participants was the profit-driven rather than professionalism-driven care. The primary aim of the profession was perceived to have transformed to pursuing money from saving lives and reducing pain. A particular issue in clinical practice in China was the tips for doctors in a red envelope provided by families. Offering a red envelope containing money to someone in happy or difficult events such as marriage or death is a Chinese custom for happiness or good luck. However, the purpose that family members gave doctors the money in a red envelope was different, which was for a better care and to avoid unnecessary treatment; it became the name for commercial bribery in clinical practice, which is illegal in China. These perceptions by participants were related to the finance mechanism used by public hospitals in China and the medical service reform launched by the government in 2009 (Meng et al. 2019a), mentioned by participant Qing, who focussed on how public hospitals financing appeared to him to be ineffective as well as to other participants in the study. In the broader context, there was a tension in the relationship between doctors and family members and mistrust between them resulted in a non-conducive context for families to accept the death and take the patient home to die.

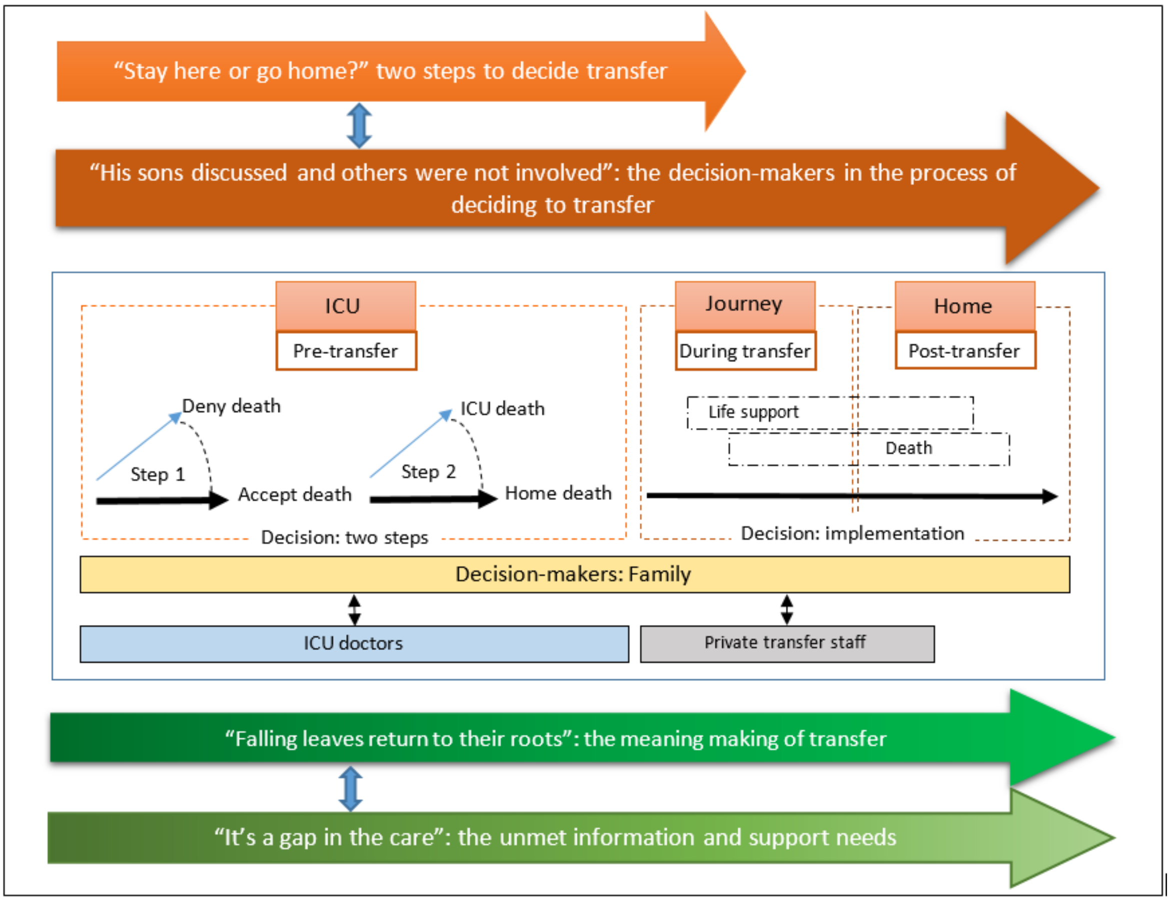
> Qing: In fact, a doctor should take the responsibility in his professional role and can't say, 'oh, it might be like this or like that.' They should be responsible for it. Why? Doctor, in the past, people called a doctor Mr, and teacher, only the two (professions) can be called Mr. Doctors have been looked down. (...) Seriously, I look down at the doctors. I really look down at them. From my point of view I really look down them. First, they aren't responsible. Second, they aren't dedicated. (...) If they [doctors] are wrong, the patients sue them. They receive the red envelope [tips] given (by patients/family members) (laugh) (...) Chaos, it's really chaotic. The medical reform is a failure. So we don't know how to face the doctors. (02: 435-441, 462-465)

Summary Theme 4: The primary unmet support needs of participants were the responsibility of the decision to THtD, which were totally avoided by the ICU doctors and passed instead to family members. This resulted in many information and support needs not being met because of the lack of professional input. Participants needed information about a clear cause of death to facilitate the acceptance of death, a prediction of time to death to avoid a death during the transit, the relevant information for selecting an ambulance to ensure a safe journey, access to medication post transfer, assessing the occurrence of death and removing treatment after death. Participants needed formal care support during the transit, for instance, the provision of formal and standardised ambulance services to ensure a safe journey, and home care to reduce family members' burden of caregiving and improve patients' quality of life. As for the context participants were not satisfied with the the support they received at both the micro and macro levels. The micro-level context in the ICU was perceived as lacking in humanity, care for families, and EoLC for their relative, and the macro-level context of the healthcare system with its focus on pursuing money rather than professionalism. The unmet information and support needs was a substantial barrier to THtD.

6.7 The overarching theme: "Nowhere else to go": a single path towards a home death through a web of power

One overarching theme underpinned by the four themes was identified, which explains the overall pattern of experiences in decision to THtD from an ICU in China, and is illustrated in a graphical model in Figure 6.6. The name of the overarching theme was derived from a participant (Lili), who constructed her decision to transfer home as the only and last choice as there was "nowhere else to go". The underlying overall pattern of family members' decisions was a single path towards a death at home through a web of power. All participants in this study followed a single path which led to the final destination of a home death. Along this path to a home death, the decision-makers had limited capacity for making a choice with transfer being the only option driven by the sociocultural expectations in China and shaped by a web of power resulting in difficulties and challenges. The participants' central justification for the decision to transfer was "Nowhere else to go".

Figure 6.6 The overarching theme: "Nowhere else to go"



In Figure 6.6, the single path has two steps commencing with an acceptance or denial of death which would influence the location of death (denial = ICU, acceptance = home). The path takes family through three phases (pre, during, post transfer) and three locations (ICU, journey and home). This path constitutes a complex process of decision making involving multiple formal (ICU doctors, transfer service personal) and informal (extended family members) negotiations and conversations. Family members led the process of transfer as the decision-maker, particularly male head of the family.

Drivers, facilitators and barriers to implementing transfer derived from patients, family members, community and society, and healthcare system, woven into the decision-making process embedded in a web of power informing and shaping the decision-making process. Key drivers to transfer were the society and culture. Key facilitators of transfer included recognition of an inevitable death and the ICU clinicians' recommendation. Key barriers to transfer were the lack of a supportive and coordinated EoLC service and transfer service. The 'web of power' is constituted by the power of the medical decision making, the lack of support services, and lack of alternative socially acceptable places to die. Once a decision was made (by the medical team) that death was inevitable family members had to make decisions about transfer home quickly with no information on how to organise this process and with no support facilities available in the home situation. A key conflict at this stage was if family members agreed to transfer the patient out of the ICU quickly, potentially shortening the person's life, they were not showing the necessary filial piety to the patient, but a late transfer risked reaching the cultural expectation of the person dying in their own home.

This conflict between fulfilling filial piety and meeting cultural expectations was compounded by the lack of care support. The sociocultural expectations as "falling leaves return to their roots" drove the family members to take the patient home to die despite lacking sufficient support from HCPs leaving them to navigate the complex process of arranging the move of the patient from the ICU to the home situation, where their only option was to organise this working with unlegislated, nonprofessional, less coordinated and financially focused transfer services. The conflict between the cultural expectations and achieving a safe transfer home when the patients was still alive was the most difficult task in the participants' decision-making to transfer home to die.

The overall story constructed by participants in this study captured in the overarching theme is that transfer home was their only choice ("nowhere else to go" but home). This outcome was a product of a set of multiple interrelated factors shaping the decision-making embedded in Chinese culture and healthcare system. The overarching theme displays a central feature of transfer decision-making from family members' perspective: complexity, in the form of 'processes' and 'a web of power'.

6.8 Chapter summary

This chapter has presented four themes and one overarching theme generated from the analysis of the study with the characteristics of patients as the context.

The findings addressed the research question and objectives of the study. Theme 1 explained the processes of decision-making. Theme 2 addressed the decision-makers. Theme 3 identified the cultural meaning and drivers to transfer. Theme 4 illustrated the gap in information and support needs. The barriers and facilitators associated with the steps and processes of decision-making were identified in different themes. Underpinned by the individual themes, the overarching theme explained the overall pattern of participants' experiences of decision-making and how participants made meaning from the experiences.

Discussion of the findings is presented in Chapter Seven.

Chapter 7 Discussion

7.1 Introduction

Chapter Seven discusses the findings generated by the research presented in this thesis articulating the gap in the knowledge base and how this work contributes to that knowledge base. This chapter clarifies how the research question: *what were the experiences of family members who made the decision to transfer their relative from the ICU in China to die at home?* has been answered and how the study objectives have been achieved: *I) to map the process of decision-making, including the processes and steps in decision-making, and the decision-makers, II) to identify families' information and support needs, III) to identify barriers to and facilitators of transfer, IV) to understand the meaning of the experiences to families.*

The chapter commences by addressing the study objectives and then discusses the barriers to and facilitators of, and cultural meaning or driver of, transfer which made up of the web of power shaping family decision-making process. The decision-makers and the information and support needs are discussed followed by proposed good practice. Chapter Seven concludes by answering the research question.

7.2 The processes of decision-making

As reported in Chapter Six family decision-making to transfer home to die comprised two steps. The first step was to accept the impending death, which involved the decision to WLST and transition from hope to hopelessness. The second step was to select the place of death and decide when to transfer. The two steps followed by a three-phase implementation (pre, during and post transfer) within three locations (ICU, ambulance, and home) were not a straightforward and smooth process because they were shaped and informed by a web of interrelated and conflicted power.

7.2.1 Decision-making: acceptance of death

This study identified that discussions about WLST when treatment was considered futile by ICU doctors was the start point for the transfer decision making process for family members. This is consistent with findings from previous Chinese publications, that the decision referred to as "self-discharge" (Xu et al. 2001; Sheng et al. 2012) or "going home" (Zhao et al. 2014; Xie et al. 2015; Liu et al. 2016) was made after the decision to WLST in ICUs.

The decision to WLST would, in participants' views, lead to death, and therefore even though the term 'death' was not used by medical doctors in discussions with family members, the fact that WLST , was voiced signposted death to family members.

In this study an implicit, rather than open and explicit style of communicating death was used by the participants and HCPs with various words replacing 'death' and 'dying', and this appeared to be an essential aspect in the decision-making for participants. The use of language in discussions to transfer was not investigated in previous studies, which mainly focused on the practice rather than on decision-making. However, there is a common awareness that death is a sensitive topic in many societies including China, where death is often talked about using euphemisms which are mutually understood (Mok et al. 2003; Lee et al. 2014a; Huang et al. 2015a). Chinese people believe that using the word 'death' might bring people bad luck and thus should be avoided (Hsu et al. 2009). Findings of the study implies that in the decision-making process, communicating about death and dying is inevitable and the way this is done should be implicit using euphemistic expressions such as 'old', 'gone' and 'the last breath' according to the death culture in China.

In line with the cultural taboo in talking about death a barrier to transfer in this study was some participants' attitude of denial towards death and loss as embedded in the societal culture. A study of doctors in China stated that families' not accepting the patient's condition and death was the greatest challenge to their end of life decision-making (Lai et al. 2018). Although the Chinese philosophy in Confucian (willing to die to preserve virtue), Taoist (life and death unified) and Buddhist (Life and death are natural processes) is not to fear death but to accept it and respect it (Cheng 2018), it is not easy for family members to accept death and give up treatment for a family member in China, which is also partly underpinned by filial piety in Confucian teachings. Findings of this study suggest that an attitude of denial towards death influences the decision to THtD and that this is shaped by the Chinese culture about death. In the current study, the setting of ICU influenced the transition from hope to hopelessness which underpinned the acceptance of death.

7.2.2 Decision-making: ICU vs home

Once the unavoidable fact that WLST would be the medical teams next step this required family members to make decisions about where death should take place, in the ICU or at home. All participants in this study selected to take the patient home.

This study identified that the factors associated with the decision to transfer home to die constituted a web of power shaping participants' decision-making process. The web of power comprised of the unsupportive context of ICU and healthcare system, the lack of support for transfer practice and service, and the specific cultural values and norms regarding place of death for Chinese.

7.2.2.1 The non-supportive care context

Participants in this study perceived that the ICU did not provide a supportive context for the decision-making to transfer, and was a frightening environment offering limited visiting time for family members and the dying patients. This image of ICU constructed by participants in this study was similar to the early ICUs described in the literature which were somewhat isolated, slightly mysterious, and rather frightening places; visiting hours were highly restricted to avoid any increase in physiological stress for the patient, any interference with the provision of care, and to limit the spread of infection in these vulnerable patients (Vincent 2013).

Participants' reported that the care offered in ICU placed the illness rather than the patient at the centre, and did not respect humanity. More importantly it did not encourage decision-making regarding transfer, as limited space was provided for the communication between dying patients and their family members. Findings of this study suggest that there is a lack of EoLC practice in the ICU and cure-oriented practice prevails in this ICU, despite the fact that a proportion of patients spend their last days of life or some of them even die in the ICU. Lai et al. (2018) reported that EoLC in non-palliative care settings, including ICUs, is underdeveloped in China. The context of ICU is not supportive to the decision to THtD from family participants' perspective.

Participants in this study were also not satisfied with the macro-context of the broader health system which was constructed as profit-driven rather than professionalism-driven. This finding suggests that in participants' views, the HCPs are not as dedicated and skilled as the profession should be. The healthcare system should have placed the patients and family members' needs at the top but has failed to do so. The worrisome healthcare context as perceived by the public in China has been discussed in many publications, including the criticism of hospitals' profit-seeking behaviour and a lack of devotion and skills by doctors (Lancet 2010; World Health Organization 2015), negative feedback on healthcare services on social media platforms (Hu et al. 2019) and an increase in seeking justice for medical disputes (Yu et al. 2015). The Chinese healthcare system hinders family decision-making regarding THtD from ICUs in China.

7.2.2.2 The lack of transfer services

Furthermore, participants in this study had information and support needs that were not met by the HCPs and the healthcare system. Family members do not have clinical skills and relevant experiences of the dying process, what would be needed, how to gain help, support, equipment and other resources. Importantly, the lack of such resources would be a barrier to transfer home to die from ICU in many Western cultures with other clinical settings being considered, for example a hospice (Topf 2012). Findings indicate that THtD from ICU is informed by a lack of choice of other options speaks to the inadequate end of life service provision in China (Deng et al. 2019). Palliative and EolC services are in short supply for the majority of the population in China (Yin et al. 2017; Lu et al. 2018) with what is available limited to secondary and tertiary hospitals in large cities and urban areas (World Health Organization 2015). In addition, EoLC practice in ICU is underdeveloped in China (Lai et al. 2018) and home or community-based formal EoLC services are not widely available (Gu et al. 2007).

Key findings from this study are that whilst participants reported that Chinese culture underpinned the view that ICU was not a good place to die, they also did not view ICU as a good place for end of life care and therefore family members were facing a conflict, feeling compelled to take the patent home to die but having no idea of what was needed, how to care for their relative, or where to get any support.

A further consideration in decision making regarding death at home or ICU identified by this study was financial hardship. For instance, to show their filial piety, children must be willing to spend money for ICU treatment with the aim of saving the patient and pay for the expensive transit service if death was to take place at home. Most participants in this study were in a low social-economic status (low education level, temporary worker) and therefore if they did not have full coverage by health insurance they could not afford for the death to take place in ICU (even if they would have wanted this), however, THtD was also expensive and once at home costs would be incurred. In the literature about THtD practice in other countries, costs were not reported as a factor influencing families’ decision which might because of the full coverage of funding by the healthcare system. Evidence from a systematic review suggests that the financial costs for EoLC had a significant impact on caregivers but less costs for families regarding medication, physician and home care are reported in countries with comprehensive public funding (Gardiner et al. 2014) such as Australia, Canada, Ireland, New Zealand, UK and USA (Courtin et al. 2014; Gardiner et al. 2019). Despite a nearly full coverage (more than 95% of the total population) of health insurance is reported in China (Liang and Langenbrunner 2013), findings of this study shows that the healthcare insurance does not cover the dying patients transferred home to die from the ICU and the service of THtD, and the high costs of ICU treatment and THtD become an influential factor on families’ decision-making.

7.2.2.3 The role of culture in decision-making

The web of power comprised of pressures and conflicts imposed on family members, for example cultural values, beliefs and norms regarding death, place of death, and responsibilities of the family during death in China.

Glazer and Karpati (2014) define culture as the character of a group of people who share a common history and perception of appropriate normative behaviours, values, and beliefs. Cultural values and beliefs are likely to shape what people attend to when gathering information about a situation that requires a decision, how they interpret the information, and the kinds of explanations people give to justify their decisions (Glazer and Karpati 2014). A constructivist stance emphasizes the role of culture in decision-making is situated and adapted to the external cultural environment (Weber and Morris 2010).

7.2.3 Culture of death and family in China

7.2.3.1 The power of death culture

Findings from this study have identified that the choice of transferring home for a home death was driven by the Chinese custom of going home to die, as captured in the proverb and in vivo code “falling leaves return to their roots”. This proverb is a metaphor rooted in Chinese culture and has been reported as a key driver to WLST in other studies carried out in mainland China (Zhao et al. 2014; Xie et al. 2015; Liu et al. 2016) and Taiwan (Tang et al. 2005). This study has found that the Chinese cultural norms about home deaths are the most powerful factor that drive family members to take the patient home from the ICU and these cultural values and beliefs are both the motivation and the source of pressure on the choice of THtD. For Chinese people, if death occurs at home, the spirit of the dead can reunite with the ancestors (Tang 2000). The spirit of a dead person cannot return home if that person dies far from his or her hometown, and would become a wandering soul and wild ghost (Mitty 2001; Shih et al. 2015). In China, for dying patients and their families, dying at home is a way of continuing bonds with ancestors (Hsu et al. 2009) and is achieved when the dying person is moved into the main hall of the house where the ancestral tablets are located for worship (Tang 2000). These cultural believes that were also identified by this study explained why families made efforts to take patients home and how they made sense of their experiences regarding THtD.

However, more importantly, what added by this study is that the strong cultural driver is also a pressure for family members because this norm has reduced choice on place of death and has an impact on the perceived ‘good death’ from families’ point of view. For instance, watching a loved family member die and pulling the tubes at home were distressing to participants. Tang (2000) suggested that the Chinese saying, “falling leaves return to their roots” reflects the traditional beliefs about a good death and dying at home is as natural as the leaves falling down to the roots of a tree. However, for participants in this study the process of THtD from the ICU was not natural and smooth with the dying patients maintained on ventilation and intravenous treatment and even death occurring in the ambulance despite the achievement of returning home was meaningful in the culture. In addition, home was not a good place of care prior to death according to participants in this study with a lack of home care services. Therefore most patients were not transferred home earlier and only needed to exhale their last breath at home to meet the cultural expectations. Patients who survived days and longer experienced a poor QoL and placed a care burden upon their families. Findings of this study show that the social norms regarding place of death posed challenges to family members. As a cultural requirement, study participants were aware that a failed transfer was not acceptable and families had to conform to such expectations even though doing so might be difficult and costly. Culture is a source of meaning/ inner driver but it is also a source of burden/ external force on family decision-makers.

7.2.3.2 The power of family culture

A driver to THtD in this study was the concept of filial piety. As an important doctrine of Confucian philosophy, filial piety is the primary duty of all Chinese people, which requires complete obedience of children to parents during their lifetime and taking the best possible care of them as they grow older (Hsu et al. 2009), remaining by their side when their parents are nearing the end of life and handling funeral arrangements after their death (Zuo et al. 2014), venerating them with the proper rituals and continuing the worship by producing descendants when parents are dead (Hsu et al. 2009). Filial piety is a very essential family and cultural concept to maintain social stability in China. This study identified that filial piety as a moral norm between parents and children extended to shape the decisions about THtD. Filial piety was indicated in findings as a conflicting force to transfer because it underpinned children’s decision to continue LST rather than give up, and a burden for families when transfer was very difficult. In Chinese culture, if parents die in institutions, it is viewed as their children not being filial (Gu et al. 2007). Participants in this study indicated that the cultural expectations informed by filial piety are rooted in the family relationship oriented Chinese culture, wherein each individual has an ascribed role which then determines relationships to one another (Mak 2007). Findings further suggest that these roles are influential in determining ‘who’ is able to make decisions regarding THtD and shaping how the decisions should be made.

7.3 The decision-makers

THtD was a family-centred decision, which was a joint and shared decision involving multiple individuals from a family. However, a hierarchy of involvement based on family relationship and gender imbalance were identified which suggested an uneven allocation of decision-making power within a family. The individuals at a lower level in the hierarchy had to follow what the ones at a higher level decided to achieve a consensus on THtD even though they might had a conflict choice.

7.3.1 A family centred, joint and shared decision

From the findings it was evident that family members were responsible for transfer decision-making, with little involvement from patients. Most patients as reported in participants' interviews, were unconscious and could not participate in the decision-making. This is consistent with existing evidence which has shown that it is common in China for family members to make end of life decisions for patients, and that often patients are not included in discussions related to their care (Lu et al. 2018). Findings from the study reported in this thesis support these findings as participants reported a lack of advance discussion about patients' preferences or wishes about how and where to die. Some participants guessed that transfer was the patient's wish or made the choice without knowing the patients' wishes, respecting the shared cultural meaning of a home death.

In China, telling patients the truth about a terminal diagnosis is considered not only dehumanizing but also immoral from a cultural perspective (Gong et al. 2018; Deng et al. 2019), as it destroys patients' hope of life (Bülow et al. 2008; Zheng et al. 2015). Thus, patients are often excluded from the decision-making of EoLC including the decision to THtD.

Furthermore, this study identified that the family centred decision-making for THtD was a collective family decision rather than a decision by an individual family member. For example, the patient's son could not make the decision to transfer his parent home to die alone and usually discussed with other siblings or relatives despite that sons were the most influential decision-makers. Transfer was decided after a joint negotiation among all family members excluding the patient or some selected family members according the family relationship culture in China such as children of patient or male members. In Chinese culture, individuals are part of the family (Xu 2007) who collectively make healthcare decisions (Zhang et al. 2015). This study found that the underlying reason for joint family decision-making was to share the meaning and responsibilities related to the transfer decisions. Multiple members took part in the negotiation process to share the difficult process and painful outcome of the transfer as well as the cultural meaning and pressure about achieving a home death. In China, financial, physical, and spiritual burdens related to death tend to be shared and thereby spread among all family members (Huang et al. 2015a). By doing so, the burden of decision on individual family can be reduced and the meaning of family is reconstructed. A family collectivism rather than individualism is meaningful in the decision to THtD.

Therefore, the decision-making for THtD was a collective family decision, however some individuals in the family had more influence on decision making than others which presented as a hierarchy of different levels involvement. This suggested a complex family dynamic in the decision to transfer embedded in the Chinese family culture.

7.3.2 A hierarchy in the joint decision-making

Findings from this study identified a hierarchy of decision-makers in the process of deciding about THtD which also reflected a gender imbalance. Adult children were the primary decision-makers for their parents' transfer, with a superior role compared to the patient's spouse, which remained the case even when the spouse was male.

The hierarchy of decision-makers reflected the birth order of children in respect of their parents' transfer in this study. The eldest child possessed more decision-making power than other children. A traditional Chinese saying is that: "eldest brother is like father, eldest daughter is like mother" (Zuo and Li 2013; Zuo et al. 2014), which means the eldest son or daughter often take on the most important care responsibilities for dying parents.

Findings indicted gender difference in families' transfer decision-making processes, whereby male relatives, particularly sons, tended to assume the dominant role. This reflects a son-centred family culture and gender biased filial expectation deriving from a patrilineal family system and Confucian values (Liu 2014; Zuo et al. 2014; Cong and Silverstein 2015). In China, sons are the family members who have the responsibility of caring for their parents in their final days of life and made decisions regarding care, death and funeral (Zuo et al. 2014; Cong and Silverstein 2015). Findings of this study have added that, as one of the end of life decisions, the decision regarding THtD is also an obligation of sons rather than daughters or other female individuals. Sons are more powerful in difficult family decisions.

The gender pattern identified in the decision-makers regarding transfer is consistent with gender theories. Gender theories posit that societies develop different expectations for social roles and behaviours between men and women, and a gender-based division of labour extended to and developed in the family (Zuo et al. 2014). The gender differences in the decision to transfer taken within a family are similar to the 'masculinity vs. femininity' dimension in Hofstede's framework of cultural values in work situations (Hofstede 2001) which shape decision-making (Glazer and Karpati 2014). Masculine cultures emphasize decision-making involving the power of force, and distinct roles for men and women, while feminine cultures emphasize egalitarianism, nurturing, and are in favour of group decision making. Mapping to this theory, the decision makers regarding THtD reflect a masculine culture which believes that the role of men and women within a family is distinct. Men have more power than women in decision-making regarding THtD, and women have to follow what men have decided.

The complex family dynamic in the decision to transfer is shaped by the Chinese family culture, including family centred collectivism, gender bias and hierarchy of family relationships and are impacted by the fact that family members are poorly informed about the process of transfer, the form of death and the dying process. Participants indicated their overwhelming feelings of a lack of support when faced with transferring patients home to die.

7.4 The information and support needs

This study sought to identify the informational and support needs of families undertaking THtD from Chinese ICUs. Information and support needs were related to: making the choice of transfer home, practical care pre, during and after transfer, and both physical and psychological support needs among family members. The unmet needs for information and support resulted in a poor quality of death and a burden upon family members.

7.4.1 Informational needs

A number of different types of information were essential in family members' decision-making about THtD, including a clear cause of death, a prediction of time to death in relation to risk of death during transfer, and practical information to implement the transfer such as ambulance/ transit, withdrawal of treatment, death assessment, and home care. However, information was not provided by ICU clinicians, especially about what would happen and what would be needed pre, during and post transfer.

Information about time to death was important in participants' decision-making because dying in the ambulance before reaching home went against Chinese cultural norms. The time to death varied among the patients, as shared in interviews, including one death in ICU before transfer, two deaths during transit and seven deaths following transfer ranging from several minutes to a week after reaching patients' home. The difficulty of predicting survival time has been discussed in relation to other countries' transfer practices (Crighton et al. 2008; Clinch and Le 2011; Coombs et al. 2014) suggesting this is an international problem in critical care. In these reports, transfer is recognised to be highly time-dependent and a transfer might not be considered if time is not sufficient to make decisions and organise a transfer. For participants of this study, THtD was the only path to go and thus their decision to transfer comprised uncertainty, and they had to expect the possibility of death in transit, which happened to two patients in this study.

It was also important for families in this study to understand the cause of death, and some patients were transferred home to die without a clear diagnosis. In Chinese culture, if a person dies without a clear cause of death being known it is thought their soul will not rest after death due to some injustice or wrongful treatment (i.e. malpractice by doctors). Evidence shows that family caregivers for dying at home have need for general disease-related information to comprehend and/or accept the terminal diagnosis in addition to information about the practical aspects of EoLC (Funk et al. 2010). However, ICU physicians in China tend to provide very limited information to patients and family members. Comparative surveys of attitudes or practice of ethical problems in critical care between Chinese doctors (Weng et al. 2011) and European physicians (Vincent 1990) showed that compared to European ICU physicians, Chinese ICU physicians provided less information about clinical condition and therapeutic errors to patients and family members. The survey in China reported that only 19% of the 315 Chinese ICU physicians would provide complete information about patient’s clinical condition to patients and family and only 28% of the 315 doctors would disclose all details of an iatrogenic incident (avoidable mistake) and possible complications. The patient’s clinical condition, prognosis and level of education, and doctor- family relationship were factors influencing the Chinese doctors’ information disclosure (Weng et al. 2011). Thus, information provision for end of life decision-making in Chinese ICUs, including THtD is a common issue in mainland China.

The sensitivity of discussion about death and dying in China discussed earlier was also a factor influencing the disclosure of the clear diagnosis to patients and family members. Without knowing the cause of death, the decision to transfer for participants in the current study was difficult. In addition, family members might have questions or doubt about the medical skills of the ICU doctors in diagnosis, and even develop a suspicion of malpractice in relation to the patients’ death. Therefore, providing general and comprehensible information on the disease, including diagnosis and prognosis, to family members is essential to their decision-making about THtD according to the findings of the study.

In terms of practical information, participants in the current study reported that the HCPs did not provide them with the specific information about what would happen and what would be needed pre, during and post transfer, therefore participants were not prepared for what took place in the process of THtD. What participants needed was what ambulance and resources were necessary and available for a safe transfer, what medications and equipment were required for the home care, and how to deal with the death post transfer, including how to assess the occurrence of death and remove the endotracheal tube, and these information were needed because all the practical decisions were made by family members with little input from HCPs in the process. The current study identified the lack of information provision and sufficient communication contributed to the practical and emotional support needs among family members.

7.4.2 Practical and psychological support needs

Participants in this study reported that they were not supported by the healthcare system in the responsibility of decision-making, and in practical care during transfer, including the availability of ambulance, transit care and home care. Participants perceived that they were not supported in the medical decision to transfer and they considered that the ICU doctors transferred the responsibility of the decision to them by requiring them to authorise the transfer. In this study, a very important but difficult decision for families was how to facilitate the actual moving of the dying patient from ICU to home. Ideally families stated they would have preferred a hospital ambulance, but the actual transport service used for transfer was a private-owned business. This study found that there was no special transport for THtD offered by the healthcare system. Without an appropriate ambulance service, the decision to transfer was stressful as participants were very concerned about the risk of death during transfer. In countries where THtD from ICUs is undertaken an ambulance arranged by staff to transport patients home to die is usual (Beuks et al. 2006; Kallel et al. 2006; Kumar et al. 2009; Lusardi et al. 2011; Tellett et al. 2012; Battle et al. 2014).

Arranging transport was expensive and problematic as family members in this study did not know what services were available. The lack of formal transit services resulted in the provision of expensive transfer service by private businesses whose primary aim was profit and the quality of their service was poor with the unqualified service providers and limited resources that were not satisfied by the participants in this study. This is not a rare problem in THtD across China because it is sometimes reported by Chinese newspapers or other media with intensive critique to these private transportation services and the illegality of the fake ambulances, which were called “black ambulance” by participants in this study. The costs of ambulance have not been reported as a problem for family members in other countries’ transfer practice. The transport costs are borne by the CCU in New Zealand which can be a burden to the unit (Ryder-Lewis 2005). Transfer is hindered when the costs of transit service are paid by the family members as revealed in this study.

Participants’ support needs were not met in relation to the practical care and decision-making during transit and post transfer at home. The process involved the withdrawal of treatment and assessing the occurrence of death both in the ambulance and at patients’ homes, and these matters were decided by family members with assistance from the unqualified services providers, or without any sources of support. Furthermore, participants encountered issues in gaining access to formal home care and the necessary resources, such as medications for symptom management. The ICU in this study refused to provide family members any care resources after discharge and the formal home care service from community care was not accessible for the dying patients post transfer from the ICU. Lack of sufficient support and resources also acts as a barrier to transfer services in Western countries (Ryder-Lewis 2005; Beuks et al. 2006; Clinch and Le 2011; Lusardi et al. 2011; Coombs et al. 2014; Coombs et al. 2015), and the strategies used or developed by these countries to increase their healthcare support on THtD might be useful for developing transfer services in China.

Given the reported absence of support from the healthcare system, participants perceived that patients’ quality of life at home was less likely to be good compared to dying in the hospital, because patients who spent hours or days at home often experienced pain or breathing difficulty, even though the quality of dying in an ICU was also poor. In addition to patients’ poor quality of death, and the practical care burden, family members in this study expressed intense psychological suffering such as guilt and regret as a result of making the choice of THtD for the patients. A qualitative study of eighteen bereaved family caregivers in Canada revealed a similar emotional suffering among family members who failed to maintain the dying relative at home and achieve a home death that was a wish of the patient due to a lack of preparedness for caregiving, difficulty with accessing professional support and information, and frustration with the inadequate help they received (Topf 2012). The consequences of this were the negative impact on grief that family members carried profound sorrow, grief and regret for a long term. For participants in the current study, the achievement of a home death is part of the good death or reflection of their filial obligations, according to Chinese death culture but the consequences for family are lasted grief with profound difficult reflections.

In their work undertaken with four participants from two families in New Zealand Hutchinson and Van Wissen (2017) reported that family members they had interviewed described their experience of THtD from an ICU in New Zealand as a kaleidoscope of events which comprised the ‘value’ of fulfilling patients’ wish of going home to die and a difficult ‘process’, even with support from HCPs. In the ‘process’ family members perceived that ‘everything happened quickly’ (Hutchinson and Van Wissen 2017). The family culture in New Zealand is also recognised to shape the decision of THtD, especially among Maori or Polynesian people (Mann et al. 2004; Ryder-Lewis 2005). This body of evidence underlines cultural power in shaping dying trajectories. Dying trajectories with conflicts in decision-making that whilst ‘expected’ by society, in China, are not supported by healthcare provision.

Findings from this study clearly indicate that home support for death at home, despite being the preferred option in China, is lacking. There is an evidenced lack of formal home care services in China for these patients transferred home from ICU. Existing evidence indicates that formal and informal support can facilitate families’ coping with dying at home (Funk et al. 2010). In China home palliative care is at an early stage (Gu et al. 2007) and access to EoLC services is extremely limited with only a small number of programmes (Yin et al. 2017). Community-based and home-based palliative care is only accessible in a small number of large cities such as Shanghai (Shanghai Health and Family Planning Commission 2019). In this study the decision to transfer home to die received no support from the healthcare system in China and families led the process, bearing an intense burden and resulting in a poor quality of death after discharge from ICU.

A key issue for healthcare development in China is increased provision of a palliative care service that facilitates the option of a death at home for all patients, but most importantly, a good death at home for both patients and family members where this is their preferred option. This can only be achieved by establishing evidence-based good practice for THtD.

7.5 Good practice

With an aim to propose good practice for transfer in China, the findings from the current study were compared with the relevant literature about transfer practices in other settings and social contexts identified in Chapter Two. Key similarities were that: a) the process of transfer commenced when doctors’ initiated a discussion recommending to transfer home to die (Mann et al. 2004; Ryder-Lewis 2005), b) family members were primary decision-makers (Boussarsar and Bouchoucha 2006; Kallel et al. 2006), and c) transfer had a cultural or religious meaning for family members, specifically Maori or Polynesian people (Mann et al. 2004; Ryder-Lewis 2005), Indian (Mani et al. 2009) and Muslims (Boussarsar and Bouchoucha 2006; Kallel et al. 2006).

Key differences identified in the comparison include: patients transferred home to die from ICU in China are more complex than those in Western countries because most of Chinese patients were unconscious, medically unstable, using life sustaining interventions, with death imminent at the time of transfer. This situation would require a sophisticated transfer service which according to authors is not available in Western countries (UK) (Lusardi et al. 2011; Coombs et al. 2014; Coombs et al. 2015; Darlington et al. 2015) or the option is not provided due to the family could not cope with the process of home death physically or emotionally in the West (UK and USA) (Ryder-Lewis 2005; Kumar et al. 2009; Lusardi et al. 2011; Coombs et al. 2014).

In this study THtD was not instigated until the dying patient was very close to death. Differing from transfer in the West, it is not necessary for Chinese ICUs to distinguish patients with different care needs in the support for family's transfer decision-making. Western policies officially require an assessment of palliative care needs (ACSQHC 2015; Aslakson et al. 2017; NICE 2019).

Furthermore, this study identified that THtD in China was a family-led process, with little formal care input resulting in unmet information and support needs. In contrast, transfer was led by ICU clinicians and most families were supported by formal care services in the West. Some aspects of transfer practice in the West might be useful for China which are discussed in following sections. This study suggests that the focus for China for THtD from ICUs is to establish evidence-based practice and standardised care service.

7.5.1 Evidence-based transfer decision-making practice

There is little international guidance available related to THtD which may help shape transfer practice in China. The decisions about THtD have not been included in most of the international critical care guidelines (Truog et al. 2008; Mani et al. 2012; Australian and New Zealand Intensive Care Society 2014; Sprung et al. 2014b; Bosslet et al. 2015; Joynt et al. 2015; Kon et al. 2016; Bandrauk et al. 2018; Long et al. 2019), and two of these international guidelines only briefly mention the phenomenon of going home to die following WLST for Chinese based on religious and cultural values (Sprung et al. 2014a; Morgan 2015). The only national guidance for ICU practice in China also does not cover anything about place of death and THtD (Critical Care Medicine group of Chinese Medical Association 2006). Chapter Two has identified that in the West lack of evidence and guidance is a barrier to their transfer practice while establishing guidance is a facilitator.

Four strategies are proposed which could facilitate the development of a supportive service that is family centric and socially acceptable: a) ensuring that the option of transferring a patient home to die is part of formal ICU planning discussions, b) adopting a shared decision making model to underpin transfer decision-making, c) promoting family agreement on transfer, and d) developing culturally sensitive and values based decision-making system.

Transfer home to die options should be part of ICU end of life care planning. This study clearly identified that one facilitator to transfer was the recommendation of going home to die by ICU doctors. Transfer options were routinely provided by the surgical ICUs in Taiwan where about 25% of the ICU patients were transferred home to die (Huang et al. 2009). This is a different feature of transfer practice between China and some Western countries where transfer is only considered by ICU clinicians when the patient or their family made the request (Creechan 2000; Beuks et al. 2006; Boussarsar and Bouchoucha 2006; Kallel et al. 2006; Crighton et al. 2008; Kumar et al. 2009; Poucher 2010; Clinch and Le 2011; Ouanes et al. 2012; Tellett et al. 2012; Campbell 2013; Battle et al. 2014; Hutchinson and Van Wissen 2017). Three settings in Western context started to actively provide the option of transfer to families they considered eligible after the request by patient or family members became more (Mann et al. 2004; Ryder-Lewis 2005; Lusardi et al. 2011). Clinicians' positive views on THtD is a facilitator of transfer in the West but their negative views on the meaning of transfer also exist as a barrier to transfer (Kompanje 2009; Darlington et al. 2015). Therefore, a routine recommendation of transfer by ICU clinicians is closely linked with the normalisation of transfer in ICUs. The guideline for transfer decision-making in China should include a role of HCPs to routinely provide this option for ICU patients.

Second, the current model for transfer decision-making identified by this study, which is family-centred decision-making and family-led process of transfer, need to be revised. This model is different from the patient-centred model or a shared decision-making model used in Western countries. In the west, a patient-centred decision-making is to protect patients' right to know and give a time to prepare for end of life (Broom and Kirby 2013); families' role is to respect and support the will of the dying patients (Hattori 2007). In this model the patient autonomy is the primary focus of decision-making at the end of life stage which emphasizes the rights of patients to be informed about their condition, their possible treatments, and their ability to WLST (Gu et al. 2016). However, including patients in EoL decision-making in China is difficult and ACP and ADs are not well accepted in traditional Chinese cultural beliefs (Ni et al. 2014; Zheng et al. 2016; Kang et al. 2017; Cheng 2018; Deng et al. 2019; Liao et al. 2019). Another clinical decision-making model adopted in western contexts is shared decision-making (SDM) (Charles et al. 1999). SDM requires information to be shared between doctors and patients/ families and a consensus on decisions is achieved. The responsibility for decisions is shared jointly by physicians and families (Charles et al. 1997). SDM has been recommended as the guideline for decision-makings in CCUs by international associations (Carlet et al. 2004; Davidson et al. 2007; Sprung et al. 2014b). SDM is also recommended for THtD by some authors in the West (Crighton et al. 2008; Lusardi et al. 2011; Campbell 2013) and a good relationship between families and HCPs is an influential facilitator for THtD (Mann et al. 2004; Ryder-Lewis 2005; Hutchinson and Van Wissen 2017). This study identified that family members preferred ICU clinicians to take the medical responsibility of transfer decision, provide them the necessary information for decision-making and support them practically in achieving a home death after discharge; these fell into the scope of SDM model. Thus SDM model might be an alternative for THtD in China.

Third, promoting family agreement is an area to improve transfer decision-making in China because this study identified that family disagreement is a barrier to transfer while family agreement is a facilitator; this is consistent with transfer practice in other countries (Beuks et al. 2006; Kallel et al. 2006; Crighton et al. 2008; Clinch and Le 2011; Lusardi et al. 2011; Tellett et al. 2012; Battle et al. 2014; Coombs et al. 2014). Evidence shows many strategies can be utilised to facilitate family agreement upon home transfer. For example, physicians and medical professionals play an important part in supporting the decision maker in his or her role or in supporting the family as a collective through respecting multiple voices in the family decision and encouraging family meetings about the decision (Trees et al. 2017). Family conference is a valuable clinical intervention, a useful therapeutic tool for information sharing and care planning, and mainly present in the context of ICUs, in the event of a life-threatening illness or end of life care, positively impacting the care practices of these patients through effective communication and the consensual establishment of an action plan (Silva et al. 2018). Early, frequent, and scheduled family meetings combined with a repeated multidisciplinary time-out meeting may support decisions for end of life care in ICUs (Kerckhoffs et al. 2020).

Fourth, a culturally sensitive value based decision-making system need to be developed and established for THtD from Chinese ICUs because transfer was culturally expected. Clinical care and policy should recognize the variety of values and preferences found among diverse racial or ethnic groups (Kwak and Haley 2005). The consideration and respect for cultural and religious needs are highlighted in THtD practice for Maori or Polynesian people who emphases a family culture (Mann et al. 2004; Ryder-Lewis 2005), for with a preference for the deceased person lying on the ‘ground’ as part of the death ritual in Hinduism (Firth 2005), and dying in hospital is not viewed as a good death (Bülow et al. 2008), in Muslim societies with religious rituals of death and funeral at home (Boussarsar and Bouchoucha 2006; Kallel et al. 2006; Ouanes et al. 2012). The core values in decision-making for THtD in this study comprised the meaning of a home death (falling leaves return to their roots), family obligation/ filial piety, family collective action, hierarchy of decision-makers, gender imbalance, cultural taboo in language use regarding dying and death. One of the most important areas was that ICU clinicians have to understand and assess the culture and values into the decision to THtD to facilitate an evidence-based decision-making process in China.

7.5.2 Standardised transfer care service

Apart from an evidence-based decision-making guidance, a standardised transfer care service is necessary for THtD from ICUs to support family members achieving a home death for their relative. Evidence shows that a transit service from ICU to general wards can improve the outcome of patients such as reducing the risk of ICU readmission (Niven et al. 2014).

First, a care package should be developed to cover three phases in three locations: pre-transfer in ICU, during transfer in an ambulance and post-transfer at home. A similar package has been reported by researchers from the West. Coombs et al. (2015) have developed a clinical guideline regarding THtD based on the insights of HCPs in the UK which explains that discussion with family and HCPs is needed pre transit, individuals and resources should be in place during transit, and meeting the care needs at home, debrief and follow-up are essential post transfer. An ICU in the USA also developed a three-phase Going Home Initiative: the workup, the day of transfer, and contact with the patient after transfer (Lusardi et al. 2011). In addition, the key elements of safe inter-hospital and intra-hospital might be useful for THtD which involve decision to transfer and communication, pre-transfer stabilisation and preparation, choosing the appropriate mode of transfer, i.e., land transport or air transport, personnel accompanying the patient, equipment and monitoring required during the transfer, and finally, the documentation and handover of the patient at the receiving facility (Kulshrestha and Singh 2016).

Prior to transfer, preparing family members is essential to facilitate their decision-making. This was considered a key facilitator of transfer in the West but a missing step in transfer decision support for participants in the current study. Transfer practice in other countries has stressed that family members should be prepared about what was likely to happen, what care would be required at home, what support was available, and introduced community HCPs to families (Mann et al. 2004; Ryder-Lewis 2005; Lusardi et al. 2011; Tellett et al. 2012; Battle et al. 2014; Coombs et al. 2014). Tools that can facilitate patient discharge from ICU (discharge survivors to a ward) focus on patient evaluation for discharge, discharge planning and teaching, and optimized discharge summaries (Stelfox et al. 2015).

Developing an information booklet would be a useful strategy for information provision to support family members' transfer decision-making in China. The literature shows that information provided to families for transfer in other social contexts included: risk of transit death (Ryder-Lewis 2005; Clinch and Le 2011; Tellett et al. 2012), contact information for support (Creechan 2000; Ryder-Lewis 2005; Tellett et al. 2012), ambulance and transportation (Mann et al. 2004), care during transit (Poucher 2010), course of events or dying process at home (Ryder-Lewis 2005; Tellett et al. 2012), care needed at home (Creechan 2000; Ryder-Lewis 2005; Coombs et al. 2014), available support for home care (Mann et al. 2004; Ryder-Lewis 2005; Poucher 2010; Lusardi et al. 2011), withdrawal of treatment at home (Mann et al. 2004; Ryder-Lewis 2005), uncertainty of time to death (Clinch and Le 2011), assessment of death (Ryder-Lewis 2005), death certification (Mann et al. 2004), and an information pamphlet was offered (Ryder-Lewis 2005; Battle et al. 2014). Most of the information described above were not provided to family members in current study except a short discussion about time to death and risk of death during transit. Therefore, to meet family members' information needs, this study suggests to develop a booklet that include cause of death/ diagnosis, predicted time to death following transfer, ambulance, resources needed for transit and home care and the access to them (medication, equipment, management of intubation and ventilation), HCPs available for consolation and support, symptoms and signs of dying and death, death certification, and bereavement support.

Although a multidisciplinary approach for EoLC is required by the Chinese national policy (NHFPC 2017a), the current study found that this standard has not been implemented in the end of life decision regarding THtD from ICU and THtD is a family-led process with little healthcare input. A multidisciplinary approach has been stressed for ensuring a successful transfer in the West (Mann et al. 2004; Ryder-Lewis 2005; Battle et al. 2014; Coombs et al. 2014; Coombs et al. 2015). It facilitates transfer by connecting divergent HCPs from primary, secondary and tertiary care (Ryder-Lewis 2005; Coombs et al. 2015). In Western settings, the quality of transit care and home care are ensured by staffing HCPs from a multidisciplinary team including a transit service led by experienced CCU nurses (Lin et al. 2017), the caregiving at home supported by community care services (Mann et al. 2004; Ryder-Lewis 2005; Kumar et al. 2009; Clinch and Le 2011; Lusardi et al. 2011; Tellett et al. 2012; Battle et al. 2014), and community- or hospital-based palliative care services (Clinch and Le 2011; Tellett et al. 2012; Campbell 2013), or hospice care (Creechan 2000; Mann et al. 2004; Crighton et al. 2008; Lusardi et al. 2011), the withdrawal of treatment by CCU nurses (Mann et al. 2004; Ryder-Lewis 2005; Boussarsar and Bouchoucha 2006; Kallel et al. 2006; Huang et al. 2009; Kumar et al. 2009; Clinch and Le 2011; Ouanes et al. 2012; Battle et al. 2014). a follow up and feedback sought by CCU staff (Creechan 2000; Mann et al. 2004; Ryder-Lewis 2005; Lusardi et al. 2011; Tellett et al. 2012), and the death at home certificated by GPs (Ryder-Lewis 2005; Kumar et al. 2009; Battle et al. 2014). In addition to a multidisciplinary approach, a single person was advised to facilitate and lead the process of transfer as a single point of contact (Coombs et al. 2014; Coombs et al. 2015; Hutchinson and Van Wissen 2017). The introduction of a critical care outreach team can significantly improve survival to discharge, reduce readmission to critical care (Ball et al. 2003), and reduce mortality in general hospital wards (Priestley et al. 2004). Therefore a transfer multidisciplinary team involving doctors and nurses from hospital ICUs, GPs and district nurses from community, and hospital- or community-based, palliative, hospice, and bereavement team staff could be a resolution for supporting family members' transfer process in China.

The whole model of transfer used by Western countries might not be applicable to China and revision is needed. Transfer in the West is largely a process led by CCU nurses. However, in this study, nurses appeared not involved in the decision-making process for transfer because they were not included in the stories told by the participants. It is less clear whether they can play a similar role with those in the West for transfer and therefore further study is needed. Furthermore, an aspect should be considered in the transfer service for China is staffing issues that are barriers to transfer from a busy CCU in Western contexts in relation to costs (Ryder-Lewis 2005; Kompanje 2009), legal cover (Clinch and Le 2011; Coombs et al. 2014), HCPs' safety, as well as skills and knowledge for transfer (Jackson 2006; Campbell 2013; Coombs et al. 2014).

Finally, a major issue with transfer decision-making identified in this study was the limited choice for place of care prior to transfer. When early transfer was not an option due to the lack of support, patients were maintained in the ICU. Apart from ICU and home, there were no other choices for place of care prior to THtD. However, patients' quality of life in the ICU was poor and only waited to die in a place where lifesaving was the central task in the participants' view. This lack of place for end of life care was also identified by previous Chinese papers as a factor influencing family members' decisions to WLST (Liu et al. 2016; Liu and Zhu 2016). In other countries or healthcare systems, there are more options for dying patients to be cared for in their final days of life besides acute hospitals and their own home: for example hospice, nursing home, or other elderly residential facilities (Murray et al. 2009; Broad et al. 2013; Zimmerman et al. 2013; Aldridge and Bradley 2017; Penders et al. 2017; Public Health England 2018). If more options for place of care were created (hospices, palliative care settings, long-term care facilities), the decision to transfer might be less challenging for family members in China which could reduce the burden upon family members and improve the ICU patients' quality of end of life. The increase of options for place of end of life care relies on the development of end of life care services in China.

7.6 Family meaning making: a single path towards a home death via a web of power

The overall or overarching pattern underlying the decision to transfer home to die from ICU in China identified by the research presented in this thesis is that for family members there was "nowhere else to go": there was a single path toward a home death, navigated through a web of power. The four themes provided the detail of the answer to the research question and addressed the objectives, including the processes of decision-making, the decision-makers, the cultural drivers, the unmet information and support needs, and a web of power comprising barriers, facilitators and meaning of transfer embedded in the Chinese culture and health system.

The single path started with the dying prognosis through acceptance of death, driven by the powerful cultural values and norms related to death, place of death and family moral meaning that participants in this study had little room to make choices. Participants encountered conflicting forces to the decision to transfer, and went through the process with feelings of helplessness, complexities and difficulties.

7.7 Chapter summary

Chapter Seven has discussed the findings presented in Chapter Six in answering the research question and achieving the research objectives. Family member experiences of transferring a family member home to die from a Chinese ICU was articulated as a single path navigated through a web of power shaped by Chinese culture and healthcare system. Chapter Eight will conclude the study, make recommendations on decision-making guidelines, service or practice development, training, policymaking and future research, and reflect on the research process.

Chapter 8 Conclusion

8.1 Summary of study

THtD from critical care was informed by a very slim international evidence base. A key gap in the knowledge base available to guide practice provision in China was that little was known about the families' perspectives, experiences and participation in the transfer processes and decision-making in the societal context like China where THtD and home deaths are cultural expectations. This study has contributed to the knowledge base by: undertaking a scoping review which systematically identified the current evidence base exploring transfer practices across countries and healthcare systems. Main findings from the review suggested THtD from CCUs was relatively rare in Western countries where transfer was complex and motivated by personal preferences but more common in Eastern societies where transfer was an expectation of local culture. However, the international literature did not provide an in-depth understanding of the family decision making, lacked methodological rigour and focused on the complex implementation of transfer from HCPs' perspectives.

In view of these findings, the current study was designed and a qualitative inquiry was chosen to achieve an in-depth understanding via interviews with family members purposefully selected. With analysis generating rich data, four themes and one overarching theme were identified which answered the research question about the experiences of families' decision-making regarding transfer in the context of China and achieved the research objectives in terms of decision-making processes, decision-makers, information and support needs, barriers and facilitators, and meaning-making of the experiences. Findings of the study addressed the gap in the literature and made essential contribution to the knowledge by providing the patterns of family decision-making regarding THtD and uncovering the reduced choice, pressures, difficulties and gap of care support in decision-making as a product of the the culture and healthcare system in mainland China.

8.2 Recommendations and future research

Findings from this study have several implications for service development, clinical practice, guideline generation, training and education provision, and policymaking in China.

8.2.1 Recommendation: developing guidelines for decision-making in ICUs

As the focus of this study is the decision-making practice for THtD in ICUs, a recommendation is to establish guidelines for end of life decision-making in critical care by hospitals and relevant academic associations. The guidelines should cover WLST, place of death, and THtD, and define the role and responsibility of decision-makers and other stakeholders participated, the processes and steps of decision-making and the factors or power shaping the decision-making process. This study recommends to support transfer decision-making throughout the process involving two steps commencing with an acceptance or denial of death which would influence the location of death. Family members can play a central role in decision-making but patients' participation and a shared process between family members and clinicians should be encouraged. Family conferences might be useful to achieve family agreement on transfer. Finally, a culturally sensitive values based decision-making support system should be established because THtD is a strong cultural and social expectation in China.

The transfer decision-making guidance needs to define the role of doctors and findings of this study suggest the ICU doctors to take their responsibility of the medical aspect of decision. Good practice should be developed to reduce families' perception of the risk mitigation context and physicians' absolving responsibility such as a full informed consent, avoiding exaggerating the risk of decision and presenting dedication and professionalism. Alternatively, SDM between doctors and family members (Charles et al. 1997) can be considered because it is recommended by international guidelines in critical care such as Statement of the 5th International Consensus Conference in Critical Care (Carlet et al. 2004) and Consensus for Worldwide End-of-Life Practice for Patients in Intensive Care Units (WELPICUS) Study (Sprung et al. 2014b), with further studies on its implementation in Chinese context (Charles et al. 2006; Huang et al. 2015b; Yao et al. 2017). Regardless what models are used, a trusted and supportive relationship between physicians and families should be established in the process of decision-making for THtD in China. This can be achieved by approaches informed by trust building models such as The Reina Trust and Betrayal Model (Reina and Reina 2007): practicing humility, engaging in inquiry, honouring the patient's choices, keeping agreements, managing expectations, rooted in respect and based on truth-telling (Rushton et al. 2007; Rushton et al. 2010), with evidence from instrumental assessment (Eveleigh et al. 2012).

8.2.2 Recommendation: developing transfer service and practice

This study recommends the hospitals with ICUs in China to develop the service and practice for THtD, because going home to die from critical care is usual in China but there is a lack of formal transfer services in ICUs. According to findings of this study, the development of the transfer services should focus on information provision and formal care support pre, during, and post transfer, with an aim to reduce families' burden of decision-making and caregiving, improve the quality of dying and death, and increase the chances for going home to die.

Prior to transit, clinicians in ICUs should provide families the necessary information that is needed for the decision-making including specific information such as cause of death, time to death and risk of transit, and general information about what would happen and what would be needed (resources, medication, equipment). Families need to be prepared before transfer by the unit about the process of implementing THtD, what events would happen, what decision-making work would be required, what resources are needed and available, what to do when death occurs and who they can contact when help is needed. In addition, families' information needs should also be met post transfer and provision of an information sheet could provide them the contact details of those who could provide support when they seek help. The language used in communication should be comprehensible to the lay families and acceptable in the culture.

In terms of transportation, the currently used private expensive transit services need to be replaced by formal care services. A resolution is to investigate if existing prehospital emergency transport and staff could be utilised, although this would need to take into account the economic costs that this would incur. A second solution is to explore if there are available resources, or if resources could be mobilised to provide a discharge team for this particular transit.

HCPs from ICUs need to engage in the care provision during and post transfer by accompanying the transit, carrying out the withdrawal of treatment, prescribing death certificate, or handing over the patient to the home care team when this is available in the future. As patients are critically ill when being transferred, it is necessary to have a HCP from ICUs facilitating the transition from critical care to EoLC. It should be considered whether a specialist nurse could be placed in this role and further research is needed to explore the utility of such a role in China.

Post transfer, to enable a home death which does not place a heavy workload on families, the availability of support from HCPs is essential to reduce their burden and improve the quality of dying and death at home. The community HCPs could provide this role and take on the responsibility of providing support in the home. GP system is under development in China. Since China's introduction of GP in 1989 when Capital Medical University established the first GP Training Centre, great efforts have been put into the training of qualified GPs and family physicians. For instance, at the meeting on the Work of National Health and Family Planning Commission in 2015, it was specified that the pilots of special position plan for GPs will expand to cover 680 counties in 19 provinces in China (Li 2016). In addition, ICU HCPs should continue to engage in the home care especially for guidance on intensive care treatment such as MV. While it is not being suggested that practices in the West are held up as an example that China should look to emulate, a move towards home-based palliative or hospice care in this area of China is something to consider. For example, home visits to the dying patient could be incorporated into routine work for community HCPs to provide medication prescription, symptom management, ventilation related care, and certificate death and withdraw intensive treatment in patients' home as well as bereavement support to family members.

For patients who survive for hours or days at home, there should be a mechanism for ICU HCPs to enable follow-up by contacting family members to ask if they have any physical and emotional support or informational needs. If a transfer service is established comprising HCPs from community, palliative care or hospice care in China, cooperation between critical care and other teams will be essential.

8.2.3 Recommendation: increasing EoLC services in China

This study recommends healthcare policy in China to address an increase in EoLC services and enhance EoLC practice in China to provide more options for place of care/death, improve the quality of death in institutions and at home, and facilitate the establishment of THtD practice. The EoLC service provision in China should include hospital-, ICU-, community- and home-based palliative care or hospice care.

The current study found a lack of EoLC services in China because family members only had ICU and home as options regarding place of care/death. More options should be available for the place of care prior to transfer. Home might be the place for death for most Chinese, because it is a cultural expectation but the place of care is not necessarily limited to patients' home. For families who cannot take the patient home early but are also not satisfied with ICU as the place of care/ death, more options for place of care prior to transfer should be provided to family members such as palliative care wards or hospices when these resources are available.

Another recommendation related to EoLC services is that the healthcare policy develops EoLC practice in ICUs because there are dying patients who spend their last days in the unit before transfer or die there. ICU doctors and nurses should provide the dying patients palliative care rather than only intensive illness-centred treatment, and support on family members in their decision-making. EoLC practice needs to be integrated into the intensive care and a special palliative care team based in the hospital is also available to the ICUs. The EoLC practice should take into account the characteristics of patients in critical care and the high expectation of patients and families as transition from curative care to supportive EoLC is challenging in critical care context.

8.2.4 Recommendation: establishing training and qualification system

To establish transfer and EoLC services in China, a key is to develop training programmes and qualification system for service providers by hospitals or other institutions involving these practices (community and home care services). The areas identified by this study for the training programmes are: a) knowledge about the Chinese cultural norms and traditions in relation to death and family, b) culturally sensitive ways of interaction with family members, according to the complex family relationship and moral values, c) culturally sensitive ways of communicating diagnosis, prognosis and place of care/death options, d) knowledge and skills about providing information regarding the process of THtD, and facilitating transit and home care. The training should also improve HCPs' awareness and capacity to provide EoLC to patients and support for family members.

A validated qualification, following training for THtD, is needed to ensure standards and quality of care practice. Training for HCPs and other service providers involved in the process of THtD, such as support workers, ambulance personnel need to lead to a recognised and validated qualification and the qualification system should set up the assessment and tests model to evaluate the knowledge, skills and behaviours required for THtD.

8.2.5 Recommendation: public education

Education is needed to increase the public awareness and understanding of EoLC, develop a positive societal attitude towards death and loss, and change the social aversion to discussing and planning for death. Findings from this study showed that denial of death and high expectation of critical care were barriers to transfer while the awareness of the incurability of cancer was a facilitator of transfer. Public education needs to address the meaning of terminal illness, death, loss, palliative care, hospice, ACP, ADs, and the purpose of critical care, death as an outcome of intensive care, and the incurability of some disease. Public education can be achieved through information giving by doctors and nurses in clinical practice at inpatient and outpatient of hospital and communities, by media such as internet, newspapers and books, and by government policies (Ni et al. 2019; Xie et al. 2020; Yan et al. 2020).

8.2.6 Recommendation: increasing health insurance coverage and reforming healthcare system

A key finding of this study is the negative influence of financial hardship on families' decision-making and therefore a recommendation from this study is to increase funding for THtD and reduce financial burden in transfer decision-making by healthcare policy. A resolution could be that the service costs for transfer are covered by healthcare insurance in China to reduce the families' out of pocket payment. Financial support to families can reduce their practical burden for an expensive transportation and psychological burden for a premature transfer due to the unaffordable ICU treatment. As implied by participants in this study, financial limitation should not be a factor that influences their decision-making about THtD.

Furthermore, the reform on the current healthcare system need to be deepened by governments in China, with a focus on the financial strategy used by public hospitals in addition to the development of community care, long-term care and EoLC care. Changing the fee for services strategy in public hospitals has been a central area in the 2009 reform by China (Fang et al. 2019; Meng et al. 2019a) but there is still a gap between policy and implementation. Greater efforts are needed for China to fill the gap. Only when the poor image of doctors and public hospitals and mistrust to the overall healthcare system are improved a good practice of THtD can be embedded in the context of China.

8.2.7 Recommendation: policymaking

The development of transfer practice and EoLC services in China relies on policymaking by national and local governments of China, because policy is a fundamental factor in EoLC as without it other changes are difficult to introduce (World Health Organization 2014). Policies are needed to specify the establishment of transfer services in ICUs, national standards for transfer service, and a culturally sensitive model of practice and guidelines (i.e. criteria of patients and families, a multidisciplinary approach, the role of different service providers, decision-making model managements and regulations).

Currently, there is a lack of national and regional policy regarding THtD in mainland China. The first and only policy providing the standards for EoLC was released in 2017 (NHFPC 2017a, b), and China needs time to establish the EoLC service provision across the large country. Governments in China can learn the experiences of some countries where palliative care and EoLC services have been well developed. For instance, the UK government has established many policies for EoLC services and most of them are implemented effectively in practice such as the first national policy document on EoLC in 2008: *End of Life Care Strategy: Promoting high quality care for all adults at the end of life* (Department of Health 2008) (this policy was updated with the latest annual report published in 2012 (Department of Health 2012)) and this policy aimed to facilitate the decision about where people wish to be cared for and die, to encourage people talk about death and dying openly. Since it was launched, there has been an increasing number of home deaths and a reduction in hospital deaths in the UK (Gomes et al. 2012).

However, THtD service provision in critical care has not yet been specified in the UK government policies because it is rare and has no relation to cultural expectations in the UK. China is different, having a high proportion of THtD but a great shortage of EoLC services to provide support.

Therefore, filling the gap between the cultural expectations upon a home death and the limited care support is the primary area of policymaking to improve THtD practice in China.

8.2.8 Future research

The study has generated new findings about the practice of THtD in China through understanding family members' experiences. However, decision-making around THtD is a largely unexplored area in China that further research is needed so that local and national service provision can be developed. To gain a more in-depth understanding, this study has identified the most important areas for further investigation.

First, a proportion of patients still die in the ICU in China even though going home to die is the cultural expectation. Some barriers have been identified from the families of the patients who were taken home from the ICU by the current study. Further qualitative research is needed to understand how families make sense of their experiences of a relative's death in ICU.

Second, there is a paucity of evidence of the experiences of HCPs and other individuals involved in the decision-making and implementation of THtD in China. Qualitative research should be undertaken to understand what promotes and prohibits the practice of THtD from Chinese HCPs' perspective. In particular, ICU nurses' role and their potential in THtD should be explored in China to understand if they could play a similar role to ICU nurses in Western countries.

Third, this study was an explorative qualitative study investigating the decision-making of THtD practice in a single ICU of one hospital in China. Although in-depth understanding has been gained about families' experiences, it is less certain whether the practice of THtD in other regions presents similar patterns with what was found in this study. A high rate of THtD implies that transfer is a special need for the society and also more practical experiences can be revealed through research. To understand the prevalence and characteristics of THtD across the whole country, large scale cross-sectional surveys or audits would address this gap in knowledge.

Lastly, although THtD is more common in China than in Western countries, findings from this study have shown that improvements could be made to the transfer practice in China, especially to meet the needs for information and support as well as address the barriers to transfer identified by this study. Further investigations are needed to establish an evidence base for the implementation of THtD, particularly enhance the support to families. This could be achieved through intervention and evaluation studies to examine how the process of THtD can be improved. Evidence-based guidelines need to be generated based on findings from this study and further studies and consensus approaches are useful.

8.3 Study limitations and challenges

This study was undertaken in a single setting in China, however the clinical setting shared similarities with other ICU care settings in China in relationship to the range of patients admitted and the staff to patient ratio. The participant group only included family members who were involved in the THtD. Challenges to decision-making at the time of WLST may have been further illuminated by including family members of patients who died in the ICU. This study did not include HCPs as the aim of the study was to understand the experience of family members in the decision to transfer home to die. This decision was based on most current knowledge base from Western HCPs' perspectives. However, insights from doctors and nurses from critical care in China could have provided a further lens through which to explore the factors influencing the culture of ICUs that provide no support for the transfer process.

This study only included two family joint interviews and in the future, family joint interviews on family events like THtD in this study should be a methodological consideration. Different patterns might be identified from more family joint interviews by investigating the co-construction of the shared experiences within a family. However, family joint interviews can increase, not only the number of participants at one interview, also the complexities of interaction which require higher levels of research skills in guiding the interview and subsequent data analysis.

Another potential limitation of this study was that the participants were self-selected and represented specific demographic characteristics: most had low education attainment and financial status and were sons of the patient. This resulted in the patterns identified by this study might only exist in these groups of people. Family members with higher education level (college, university and above), higher socioeconomic class and spousal relationship might have different experiences, attitudes, views about THtD. For example, if the family were affluent they may be able to have private nurses and afford more resources needed at home such as private family doctor, expensive equipment for sustaining life, which may have made the process of THtD less challenging.

This study included the family members of one patient who died in the ICU but was transferred home. The reason for their inclusion was that the family experienced the decision-making about whether or not to take the patient home, even though the patient already died. Taking the deceased relative home was also part of the cultural expectations despite it breaching the cultural norms that the last breath must be exhaled at home. The mix of cases in this study comprised three subgroups of place of death: death occur at home, in the ambulance and in the ICU so the decision-making process of them shared similarities but also had differences because of the different patient's condition and needs. Furthermore, it also reflected the complexities of decision-making situations for THtD in China.

I encountered some challenges in the research process. A challenge of including bereaved family members within three months after death in this study was that some of them were still in a vulnerable state of grief and therefore felt distressed when recalling some detail of the difficult experiences of THtD and their stories contained profound feelings such as sorrow and regrets. If the invitation of study was made at a later stage, participants might tell a different story that contained less emotional and descriptive expressions but more reflections and deep interpretations for meaning making.

Most of the interviews were carried out in a quiet environment. Only one interview in a cafe had noise from the background occasionally and this resulted in some words said by the participant could not be heard clearly. However, this had little influence on the understanding of the data because it was a story with continuity and coherence, and the words or meaning could be identified from the surrounding contexts of story. However, in future research, the influence of public place on data should be taken into account and a quite environment is essential for quality of data.

A challenge for data analysis was translation. Chinese is a very different language from English and the data in this study contained many cultural and social meanings that are difficult to translate directly from Chinese to English. For example, "it's a breakpoint" was a quote from one participant that was used to name a theme initially. The word "breakpoint" was said by the participant to indicate the lack of transfer service in the healthcare system. However, it had different meanings to English speakers and therefore was revised to "gap in the care", according to a meaning-based rule for translation after discussion with my supervisory team and a linguistic expert. In addition to an expertise demand, translation was also time-consuming.

8.4 Reflections from my PhD journey

It has been a very long path since I started my PhD study in 2014 but it is an interesting and beautiful journey for me. I reflected on the challenges, opportunities and gain from this doctoral study journey.

8.4.1 A challenging but meaningful study

I spent nearly two years on developing the research questions, literature review and the research proposal. This was challenging to me because it is rare for a PhD study in China and I was concerned I was behind my peers and sometimes doubted on my research ability, competence and intelligence. The hardest time was when I became emotional at the supervision meeting because I was told by supervisors that further revision on the research design was needed and other PhD students started their data collection. However, when the study was finished and the thesis was drafted I am so grateful for what I invested to the research. The study I conducted is rigorous, the data and analysis are trustworthy, and the findings are powerful.

A well-designed study is meaningful for this challenging research area. THtD is a sensitive topic related to death and dying, within a particular cultural and social context of China, when existing knowledge is mainly derived from the West. Investigating topics which are sensitive in nature can present challenges for qualitative researchers particularly those who are less experienced (Fahie 2014). Managing emotions is identified as a key challenge when undertaking this type of research (Dickson-Swift et al. 2007) and attention needs to be paid to protecting the researcher from harm and anticipating potential problems before they manifest. I became emotional when hearing some participants’ stories and when reading their transcripts and deeply influenced by their painful experiences. For instance, a ‘painful’ and ‘helpless’ feeling was incorporated into my understanding of the experiences. My participants were in a ‘vulnerable’ position and support was needed. These situations, emotions and my reflections on them were written in the field notes and discussed at supervision meeting and debriefs with colleagues and friends.

The best outcome of this challenging study is the novel and meaningful findings that can be used to inform clinical practice, research and policymaking in China. I perceive that the stories I obtained from interviewing the thirteen family members were very powerful and compelling. I enjoyed the process of hearing their stories and analysing, or even re-analysing these stories even though this took a long period of time (three years). The data revealed very essential areas that need further improvement and reform by Chinese governmental policy, hospitals and HCPs to improve the practice of THtD, meet family members’ care needs and support their decision-making. From my perspective this thesis presents a very useful doctoral study and the process enabled me to grow up to be an independent researcher.

8.4.2 Developing as a researcher

My theoretical understanding of academic research and practical skills of doing research have been developed throughout the PhD journey. The most important personal gain is that I understand about methodology and its importance to a research study. I now know how to select the most appropriate methodology for a similar research area and the methods for data collection and data analysis. This has ensured I am confident in designing future research projects. I have gained knowledge and the practical skills for conducting qualitative interviews, and thematic analysis in an original research study.

I have learned how to carry out a literature review, and know the role of a literature review in a study. This enhances my ability of mapping the context of study, summarising the existing evidence and identifying gaps in knowledge. What most inspired me is the ethical practice in the conduct of a bereavement research, the ethical approval process, how to protect your participants and doing research in an ethical manner. Also, I obtained the dissemination skills for research. I learned how to write up a chapter-structured thesis, publication for academic journals, and oral presentation of my work at international conference. Finally, I learned how to work with my English supervisors on this study dealing with data in Chinese provided by a Chinese population and telling stories about a clinical and social problem in China. Teamwork and communication skills have been developed and applied.

If I was asked “would you do the PhD again?” my reply would be “yes”. I have gained meaningful personal growth through my PhD study which has transformed me in terms of experience, thinking, and biography. My understanding about the phenomenon of THtD shifted from a superficial level (prevalence) to a more in-depth level (assumptions, cultural values, and worldviews). I now feel prepared to publish my work, drive practice change, look for post-doctoral opportunities, and start an academic career.

8.5 Conclusion

This is the first in-depth study seeking the experiences of family members who transferred a patient home to die from a Chinese ICU where a home death is culturally expected. This detailed exploration has demonstrated the lack of evidence-based guidance and formal transfer service to support family members navigating this process, and has illustrated the influence, roles and responsibilities of different stakeholders (patients, family members, and HCPs), the means of communication and interaction, and what information and support should be provided and how. This study has provided insight into the importance of developing evidence-based guidance and standardised transfer service to support the end of life option of transferring patients home to die from Chinese ICUs.

Appendices

A.1 The databases and websites searched and rationale for inclusion

Database/ Website	Rationale for selection
MEDLINE (EBSCO)	MEDLINE is the world's best-known medicine and clinical science database, covering literature in the fields of medicine, nursing, dentistry, as well as coverage in the areas of allied health, biological and physical sciences, humanities and information science from 1950 to the present. As the work of transfer related to clinical science and nursing it should be included in MEDLINE.
CINAHL (Plus with Full Text)	CINAHL (Cumulative Index of Nursing and Allied Health Literature) provides authoritative coverage of full text literature related to midwifery, nursing, occupational therapy, physiotherapy, podiatry, health education and other related subject areas. As transfer practice involved nursing practitioners, this database was chosen.
EMBASE	EMBASE covers human medicine and related biomedical research including drugs, toxicology, clinical medicine, biotechnology, health affairs, psychiatry and forensic medicine. This database was selected because THtD was related to human medicine and biomedical research.
AMED	AMED (Allied and Complementary Medicine Database) covers a selection of journals in complementary medicine, palliative care and several professions allied to medicine including physiotherapy, occupational therapy, podiatry and rehabilitation. As transfer involves palliative care, this database was selected.
PsychINFO	PsycINFO is the key database for psychology and related subjects. It contains references and abstracts for journal articles, books, book chapters and dissertations. This database was included as literature regarding the experiences and psychological aspects in the process of transfer were targeted by this review.
Web of Science (core collection)	Web of Science provides references, and in many cases abstracts, for peer-reviewed scholarly journal articles in the sciences, social sciences, arts and humanities. It was chosen because of such a comprehensive coverage of literature.
Scopus	Scopus is the largest abstract and citation database of peer-reviewed literature in the fields of science, technology, medicine, social sciences, and arts and humanities. This database was included as it would cover literature about transfer in relation to medicine, social sciences and humanities.

Database/ Website	Rationale for selection
NICE	Evidence search provides access to selected and authoritative evidence in health, social care and public health, including guidance, systematic reviews, evidence summaries and patient information. NICE was chosen as there might be evidence-based sources concerning THtD practice.
The British Library	The 'Main catalogue' has records for circa 80 million items of books, journals, newspapers, conferences, webpages, database records, research datasets records, sound archive items, maps, scores etc. This was chosen for grey literature.
Open Grey	An open access to 700,000 bibliographical references of grey literature (paper) produced in Europe including technical or research reports, doctoral dissertations, conference papers, official publications, and other types of grey literature. This website was chosen for grey literature.
The Cochrane library	The Cochrane Library is a collection of databases that contain different types of high-quality, independent evidence to inform healthcare decision-making. This online library was selected for grey literature.
Google Scholar	Google Scholar is a freely accessible web search engine that indexes the full text or metadata of scholarly literature across an array of publishing formats and disciplines. It was included to search for any types of sources regarding THtD.
CNKI	CNKI (China National Knowledge Infrastructure) is the largest and mostly-used academic online library in China. It is a comprehensive integrated knowledge resources system in China, including journals, doctoral and masters' theses, proceedings, newspapers, yearbooks, statistical yearbooks, e-books, patents, standards and other types of knowledge material in Chinese and other languages in a variety of fields. CNKI was included for publications about THtD from critical care in China.
WanFang Data	WanFang Data is another large database in China covering similar types of sources with CNKI. This database was also selected for publications about THtD from critical care in China.
Baidu Wenku	Baidu, like Google, is a dominant internet search engine in China and Baidu Wenku is an online library created by Baidu for sharing academic and many other types of documents between users from any backgrounds. This website was selected for grey literature about THtD from critical care in China.

A.2 The search strategy in MEDLINE

Database: MEDLINE (EBSCO)

Date of search: 23 January 2019

#	Query	Records retrieved
S1	"dying patient*"	
S2	(MH "Terminal Care") OR "end of life care"	
S3	"terminal care"	
S4	"end of life"	
S5	(MH "Terminally Ill") OR "terminally ill patient*"	
S6	"Terminally ill"	
S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6	
S8	(MH "Patient Transfer") OR "Patient transfer"	
S9	"Transfer"	
S10	"Transfer* home"	
S11	"Transfer* home to die"	
S12	"Transfer* patient"	
S13	(MH "Patient Discharge") OR "Patient discharge" OR (MH "Patient Handoff")	
S14	"patient handoff"	
S15	"discharge"	
S16	(MH "Discharge Planning") OR "discharge planning"	
S17	(MH "Continuity of Patient Care") OR "continuity of care"	
S18	(MH "Transitional Care") OR "Transition of care"	
S19	"discharge home"	
S20	S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19	
S21	"withdrawal of treatment"	
S22	"treatment withdrawal"	
S23	"withdrawal of life sustaining treatment"	
S24	S7 OR S21 OR S22 OR S23	
S25	"die at home"	

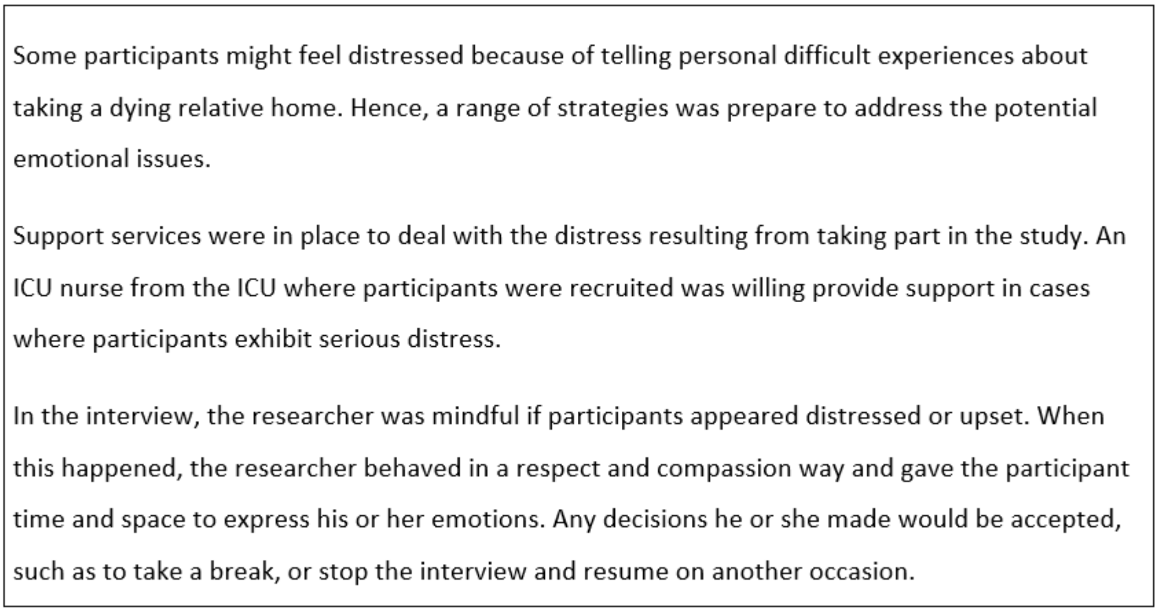
S26	"dying at home"	
S27	"place of death"	
S28	"site of death"	
S29	"location of death"	
S30	"home death"	
S31	"death at home"	
S32	"home hospice"	
S33	"home palliative care	
S34	S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33	
S35	(MH "Home Care Services") OR "home care service*"	
S36	S34 OR S35	
S37	(MH "Intensive Care Units") OR "critical care unit*"	
S38	"Intensive care unit*"	
S39	"critical care setting*"	
S40	"ICU*"	
S41	CCU*	
S42	S37 OR S38 OR S39 OR S40 OR S41	
S43	S20 AND S24 AND S36 AND S42	19

A.3 Full text papers excluded from review

No.	Database	Paper (Author(s), Year, Title)	Reasons for exclusion
1	MEDLINE	Digwood et al (2011) The impact of a palliative care unit on mortality rate and length of stay for medical intensive care unit patients. Palliative & supportive care 9(4): 387-392	No information on THtD from CCUs
2	EMBASE	Kaasa et al (2011) Challenges related to palliative care. The Lancet Oncology 12(10): 925-927	No information on THtD from CCUs
3	EMBASE	Meert and Sarnaik (2010) Choosing between death at home or in the hospital: Respecting the principle of autonomy. Pediatric Critical Care Medicine 11(3): 438-439	THtD of children
4	EMBASE	Vettese (2018) Note to an oncology fellow. Annals of Internal Medicine 168(5): 371-372	going home to die from oncology settings rather than CCUs
5	PsycINFO	Jeitziner et al (2015) Healthcare resource utilisation by critically ill older patients following an intensive care unit stay. Journal of Clinical Nursing 24(9-10): 1347-1356	Discharge home from ICU not for death
6	NICE	Rogers (2011) Role of the BHF heart failure palliative care specialist nurse: a retrospective evaluation. British Heart Foundation.	Discharge home to die from hospital in general rather than CCUs
7	NICE	RCGP (2012) Matters of life and death: helping people to live well until they die. General practice guidance for implementing the RCGP/RCN end of life care patient charter. Royal College of General Practitioners (RCGP).	No information on discharge home for death from CCUs
8	NICE	Gaughan et al (2013) Long term care provision, hospital length of stay and discharge destination for hip fracture and stroke patients (CHE Research Paper 86). Centre for Health Economics (CHE).	Discharge home alive not from critical care, not dying patients
9	NICE	Canadian Institute for Health Information (2018) Palliative Care in Canada. Canadian Institute for Health Information.	Discharge home to die from hospital in general rather than CCUs
10	NICE	Costa et al (2016) The determinants of home and nursing home death: a systematic review and meta-analysis. BMC Palliative Care 15: 8	Only place of death, nothing on discharge home for death
11	NICE	Wahid et al (2018) Barriers and facilitators influencing death at home: A meta-ethnography. Palliative medicine 32(2): 314-328	No specific transfer cases but discussion on the discharge home practice from hospital rather than specific CCUs
12	Google Scholar	Adams et al (2014) Nursing strategies to support family members of ICU patients at high risk of dying. Heart & Lung: The Journal of Acute and Critical Care 43(5): 406-415	A case was mentioned be discharged home to die but little about the transfer process

13	Google Scholar	Faber-Langendoen and Lanken (2000) Dying patients in the intensive care unit: forgoing treatment, maintaining care. Annals of Internal Medicine 133(11): 886-893	Nothing about THtD
14	Google Scholar	Kross et al (2011) ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. Chest 139(4): 795-801	No information on the practice of THtD
15	Google Scholar	Saydain et al (2002) Outcome of patients with idiopathic pulmonary fibrosis admitted to the intensive care unit. American Journal of Respiratory and Critical Care Medicine 166(6): 839-842	No information on THtD although death after hospital discharge was mentioned but the destination of death is not sure
16	Google Scholar	Schenker et al (2012) I don’t want to be the one saying ‘we should just let him die’: intrapersonal tensions experienced by surrogate decision makers in the ICU. Journal of General Internal Medicine 27(12): 1657-1665	Nothing on THtD
17	Google Scholar	Tang et al (2010) Propensity for home death among Taiwanese cancer decedents in 2001–2006, determined by services received at end of life. Journal of Pain and Symptom Management 40(4): 566-574	No information on THtD from CCUs (There are sentences about going home to die in Taiwan but not specified the CCU setting)
18	Google Scholar	Vitacca et al (2010) Last 3 months of life in home-ventilated patients: the family perception. European Respiratory Journal 35(5): 1064-1071	No information on THtD from CCUs (home-based patients admitted to ICU and died there)
19	Baidu Wenku	Shen and Li (2010) A literature review on treatment withdrawal in ICU dying patients. Nursing Journal of Chinese People's Liberation Army 27(21):1643-1644+1659.	No information on THtD
20	Baidu Wenku	Shen and Li (2013) The influence factors of the family members' decisions about whether to withdraw the life sustaining support of patients at terminal stage in ICU. Nursing Journal of Chinese People's Liberation Army 30(21): 1-3	No information on THtD

A.4 The supporting strategies for participants

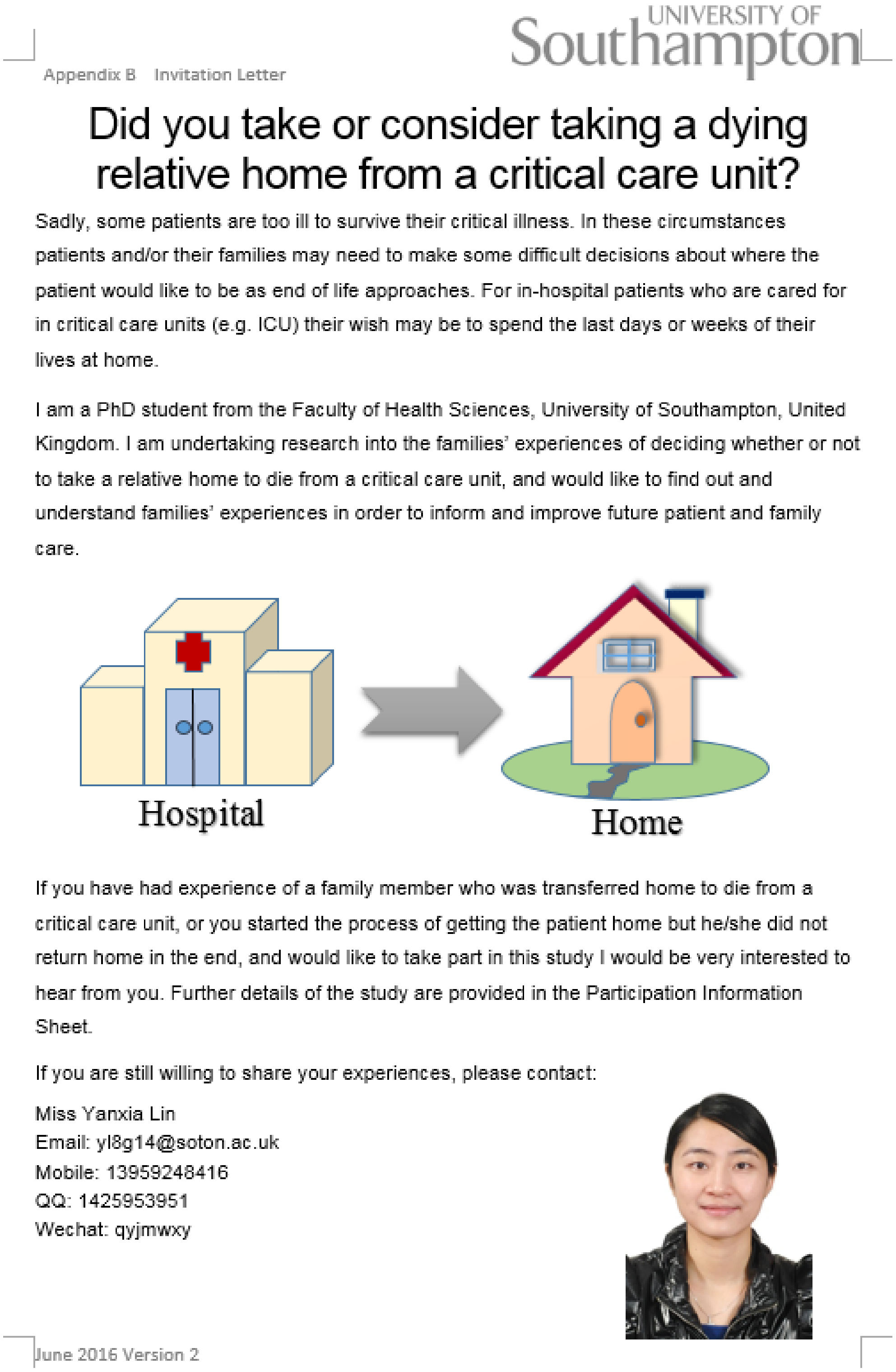


Some participants might feel distressed because of telling personal difficult experiences about taking a dying relative home. Hence, a range of strategies was prepare to address the potential emotional issues.

Support services were in place to deal with the distress resulting from taking part in the study. An ICU nurse from the ICU where participants were recruited was willing provide support in cases where participants exhibit serious distress.

In the interview, the researcher was mindful if participants appeared distressed or upset. When this happened, the researcher behaved in a respect and compassion way and gave the participant time and space to express his or her emotions. Any decisions he or she made would be accepted, such as to take a break, or stop the interview and resume on another occasion.

A.5 Invitation letter



UNIVERSITY OF Southampton

Appendix B Invitation Letter

Did you take or consider taking a dying relative home from a critical care unit?

Sadly, some patients are too ill to survive their critical illness. In these circumstances patients and/or their families may need to make some difficult decisions about where the patient would like to be as end of life approaches. For in-hospital patients who are cared for in critical care units (e.g. ICU) their wish may be to spend the last days or weeks of their lives at home.

I am a PhD student from the Faculty of Health Sciences, University of Southampton, United Kingdom. I am undertaking research into the families' experiences of deciding whether or not to take a relative home to die from a critical care unit, and would like to find out and understand families' experiences in order to inform and improve future patient and family care.

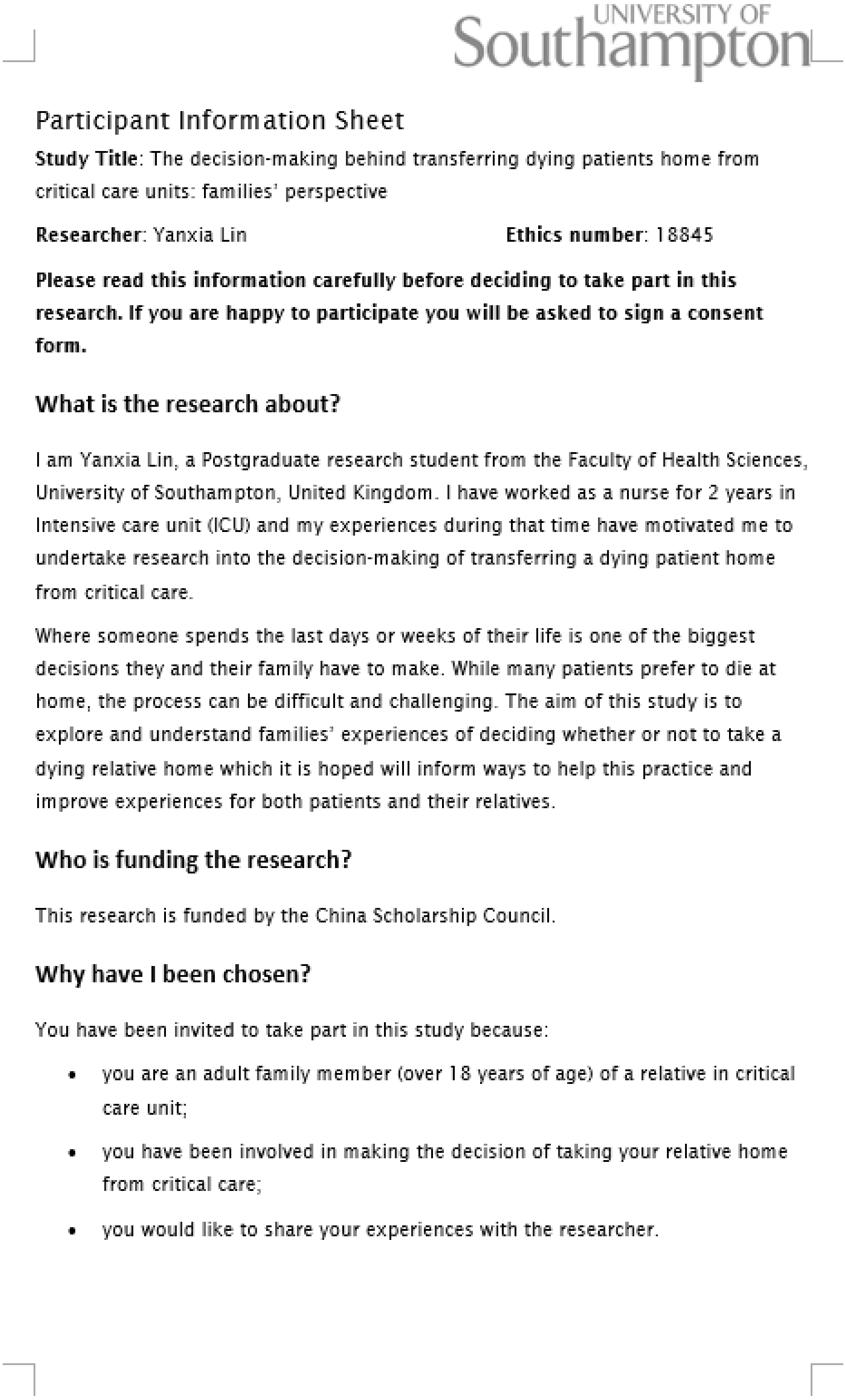
If you have had experience of a family member who was transferred home to die from a critical care unit, or you started the process of getting the patient home but he/she did not return home in the end, and would like to take part in this study I would be very interested to hear from you. Further details of the study are provided in the Participation Information Sheet.

If you are still willing to share your experiences, please contact:

Miss Yanxia Lin
Email: yl8g14@soton.ac.uk
Mobile: 13959248416
QQ: 1425953951
Wechat: qyjmwxy

June 2016 Version 2

A.6 Participant information sheet



UNIVERSITY OF Southampton

Participant Information Sheet

Study Title: The decision-making behind transferring dying patients home from critical care units: families' perspective

Researcher: Yanxia Lin **Ethics number**: 18845

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

I am Yanxia Lin, a Postgraduate research student from the Faculty of Health Sciences, University of Southampton, United Kingdom. I have worked as a nurse for 2 years in Intensive care unit (ICU) and my experiences during that time have motivated me to undertake research into the decision-making of transferring a dying patient home from critical care.

Where someone spends the last days or weeks of their life is one of the biggest decisions they and their family have to make. While many patients prefer to die at home, the process can be difficult and challenging. The aim of this study is to explore and understand families' experiences of deciding whether or not to take a dying relative home which it is hoped will inform ways to help this practice and improve experiences for both patients and their relatives.

Who is funding the research?

This research is funded by the China Scholarship Council.

Why have I been chosen?

You have been invited to take part in this study because:

- you are an adult family member (over 18 years of age) of a relative in critical care unit;
- you have been involved in making the decision of taking your relative home from critical care;
- you would like to share your experiences with the researcher.

Do I have to take part?

No. You can choose whether or not to take part in this study. If you decide to take part, you are free to leave at any time. If you do not want to take part you do not need to do anything more.

What will happen if I take part?

The process of taking part in the study is showed in Figure 1. If you would like to take part in the research, please contact me, and I will explain the study in further details and give you the opportunity to ask any questions. If you are still interested in being involved you will be asked to give your consent by signing a Consent Form.

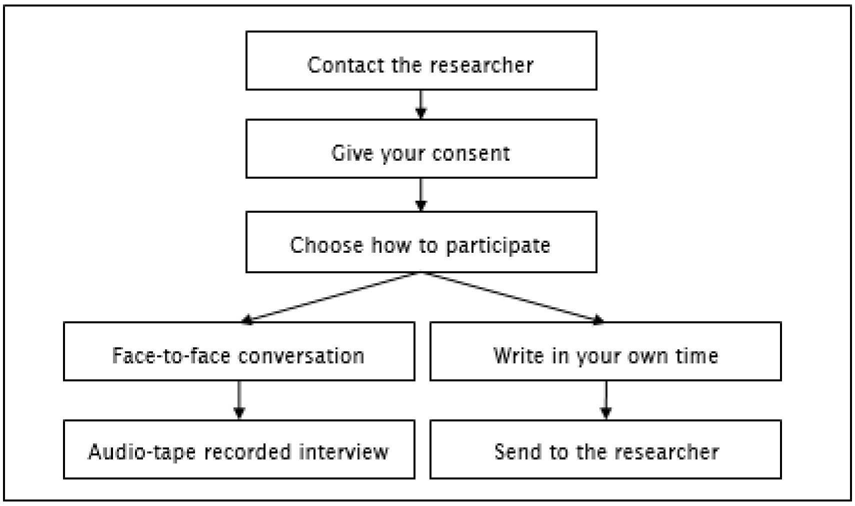
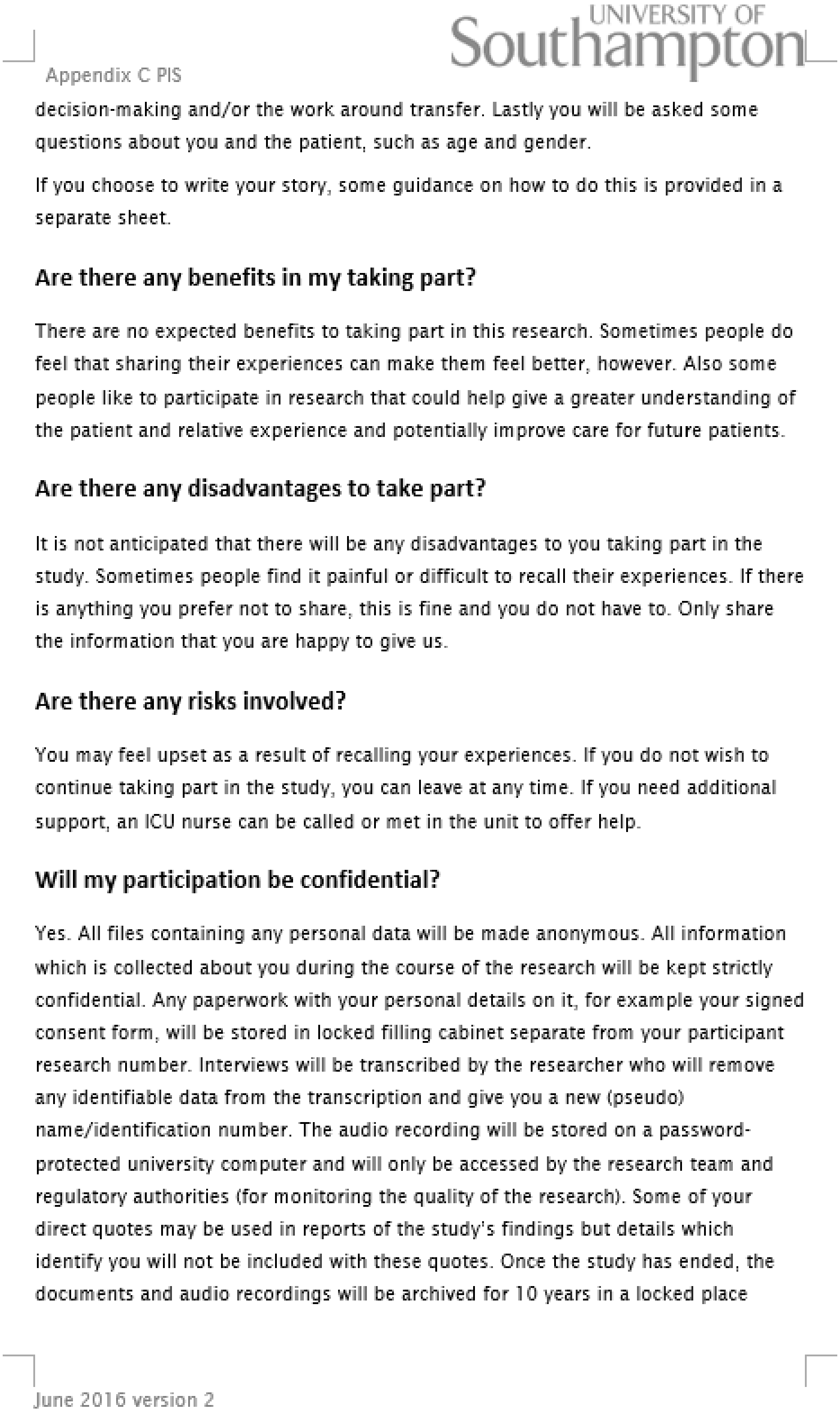


Figure 1 The process of taking part in the study

You can choose to share your experience in either of two ways: 1) by taking part in a conversation with me (interview), 2) or by providing a written account which can be done in your own time.

If you choose the conversation, you can discuss with me the time and place you would like to meet up. It is anticipated the conversation will last about an hour, although this could depend on how much you have to say and could be shorter. With your permission the conversation will be audio-recorded.

Firstly, I will invite you to talk about how you made the decision of taking your relative home. Then you will be asked a few questions about more details of the



decision-making and/or the work around transfer. Lastly you will be asked some questions about you and the patient, such as age and gender.

If you choose to write your story, some guidance on how to do this is provided in a separate sheet.

Are there any benefits in my taking part?

There are no expected benefits to taking part in this research. Sometimes people do feel that sharing their experiences can make them feel better, however. Also some people like to participate in research that could help give a greater understanding of the patient and relative experience and potentially improve care for future patients.

Are there any disadvantages to take part?

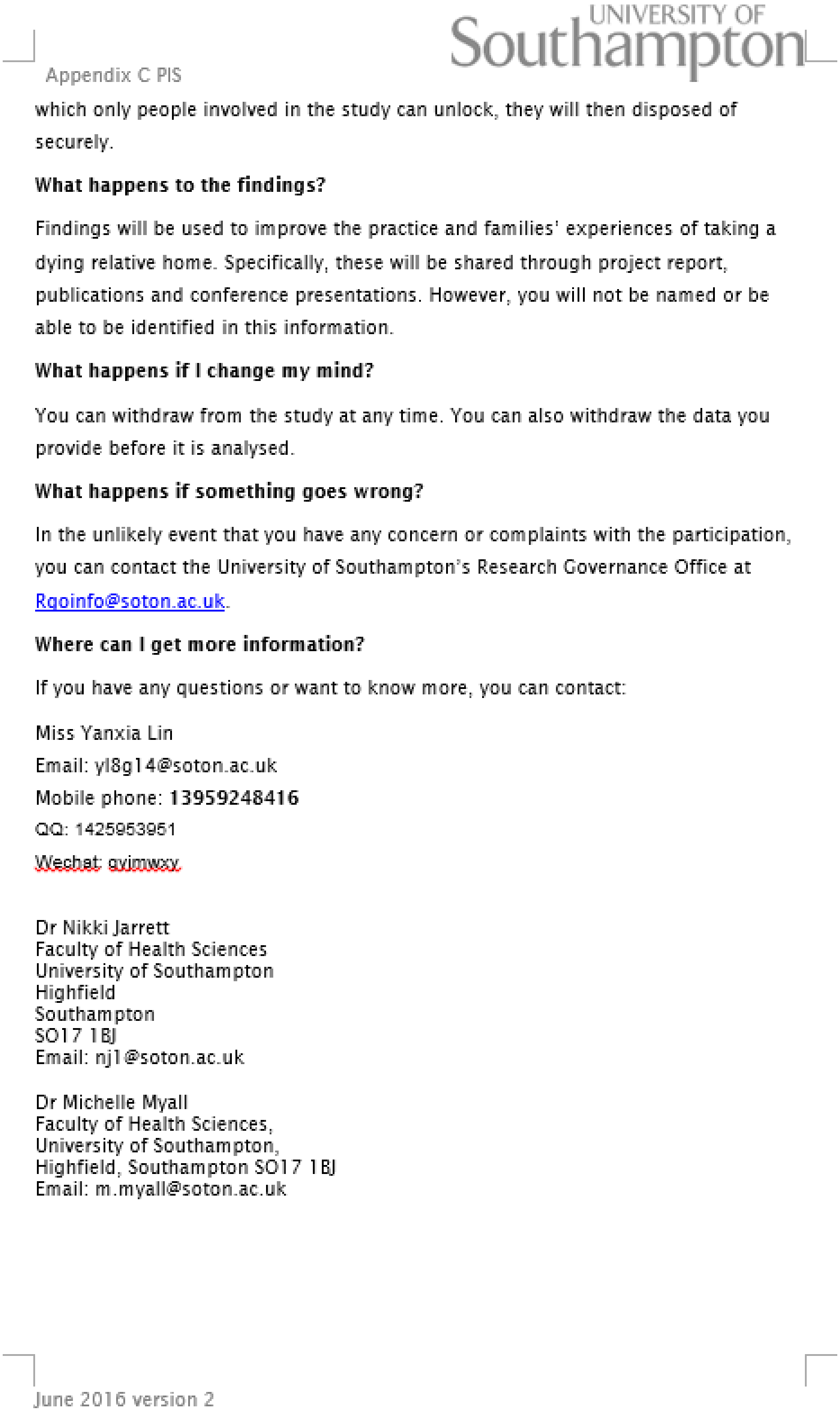
It is not anticipated that there will be any disadvantages to you taking part in the study. Sometimes people find it painful or difficult to recall their experiences. If there is anything you prefer not to share, this is fine and you do not have to. Only share the information that you are happy to give us.

Are there any risks involved?

You may feel upset as a result of recalling your experiences. If you do not wish to continue taking part in the study, you can leave at any time. If you need additional support, an ICU nurse can be called or met in the unit to offer help.

Will my participation be confidential?

Yes. All files containing any personal data will be made anonymous. All information which is collected about you during the course of the research will be kept strictly confidential. Any paperwork with your personal details on it, for example your signed consent form, will be stored in locked filling cabinet separate from your participant research number. Interviews will be transcribed by the researcher who will remove any identifiable data from the transcription and give you a new (pseudo) name/identification number. The audio recording will be stored on a password-protected university computer and will only be accessed by the research team and regulatory authorities (for monitoring the quality of the research). Some of your direct quotes may be used in reports of the study's findings but details which identify you will not be included with these quotes. Once the study has ended, the documents and audio recordings will be archived for 10 years in a locked place



which only people involved in the study can unlock, they will then disposed of securely.

What happens to the findings?

Findings will be used to improve the practice and families' experiences of taking a dying relative home. Specifically, these will be shared through project report, publications and conference presentations. However, you will not be named or be able to be identified in this information.

What happens if I change my mind?

You can withdraw from the study at any time. You can also withdraw the data you provide before it is analysed.

What happens if something goes wrong?

In the unlikely event that you have any concern or complaints with the participation, you can contact the University of Southampton's Research Governance Office at Rgoinfo@soton.ac.uk.

Where can I get more information?

If you have any questions or want to know more, you can contact:

Miss Yanxia Lin
Email: yl8g14@soton.ac.uk
Mobile phone: **13959248416**
QQ: 1425953951
Wechat: qyjmwxy

Dr Nikki Jarrett
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University of Southampton
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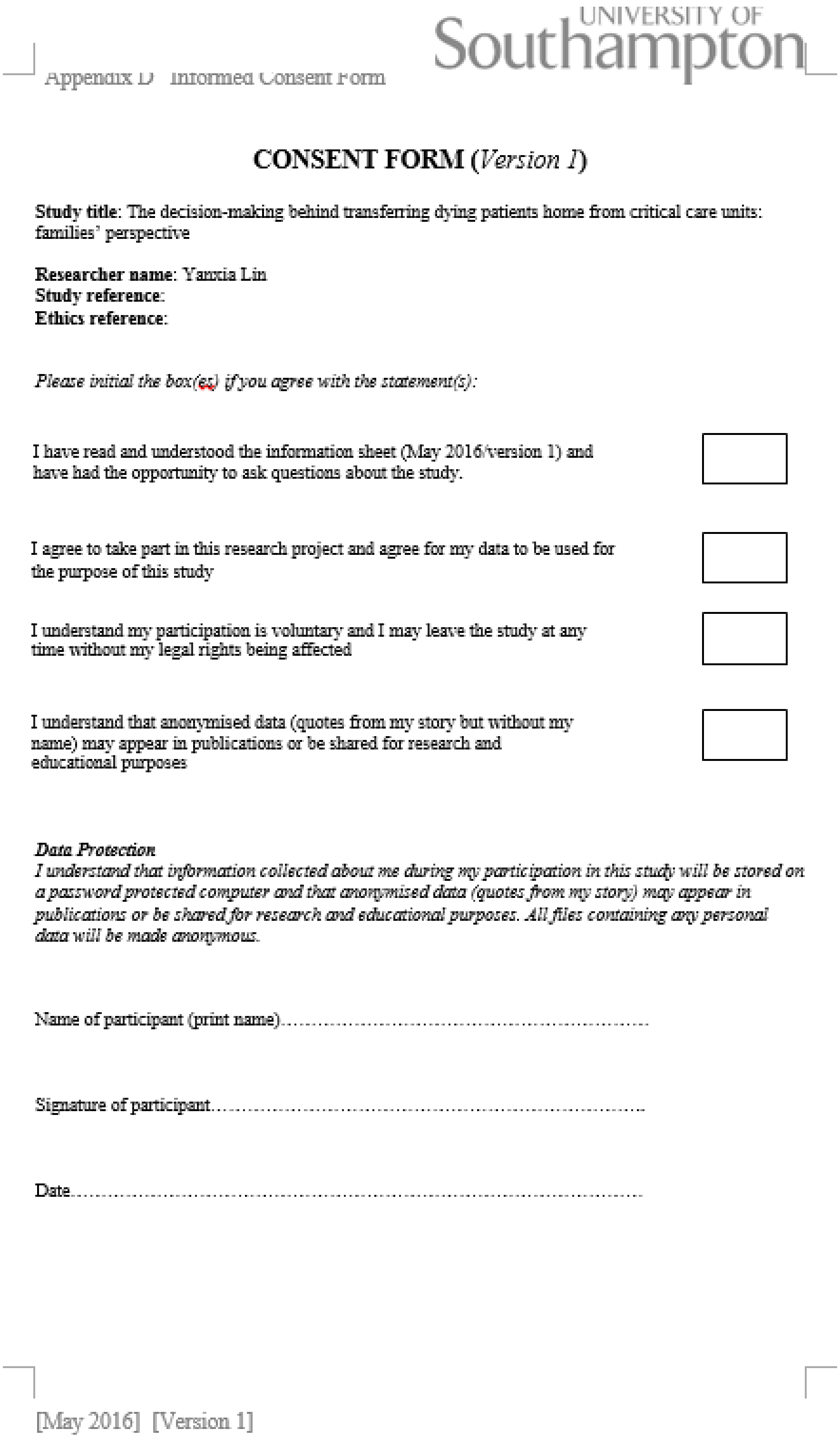
Email: nj1@soton.ac.uk

Dr Michelle Myall
Faculty of Health Sciences,
University of Southampton,
Highfield, Southampton SO17 1BJ
Email: m.myall@soton.ac.uk

A.7 Informed consent form



Appendix D Informed Consent Form

UNIVERSITY OF Southampton

CONSENT FORM (*Version 1*)

Study title: The decision-making behind transferring dying patients home from critical care units: families' perspective

Researcher name: Yanxia Lin
Study reference:
Ethics reference:

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (May 2016/version 1) and have had the opportunity to ask questions about the study.	☐
I agree to take part in this research project and agree for my data to be used for the purpose of this study	☐
I understand my participation is voluntary and I may leave the study at any time without my legal rights being affected	☐
I understand that anonymised data (quotes from my story but without my name) may appear in publications or be shared for research and educational purposes	☐

Data Protection
I understand that information collected about me during my participation in this study will be stored on a password protected computer and that anonymised data (quotes from my story) may appear in publications or be shared for research and educational purposes. All files containing any personal data will be made anonymous.

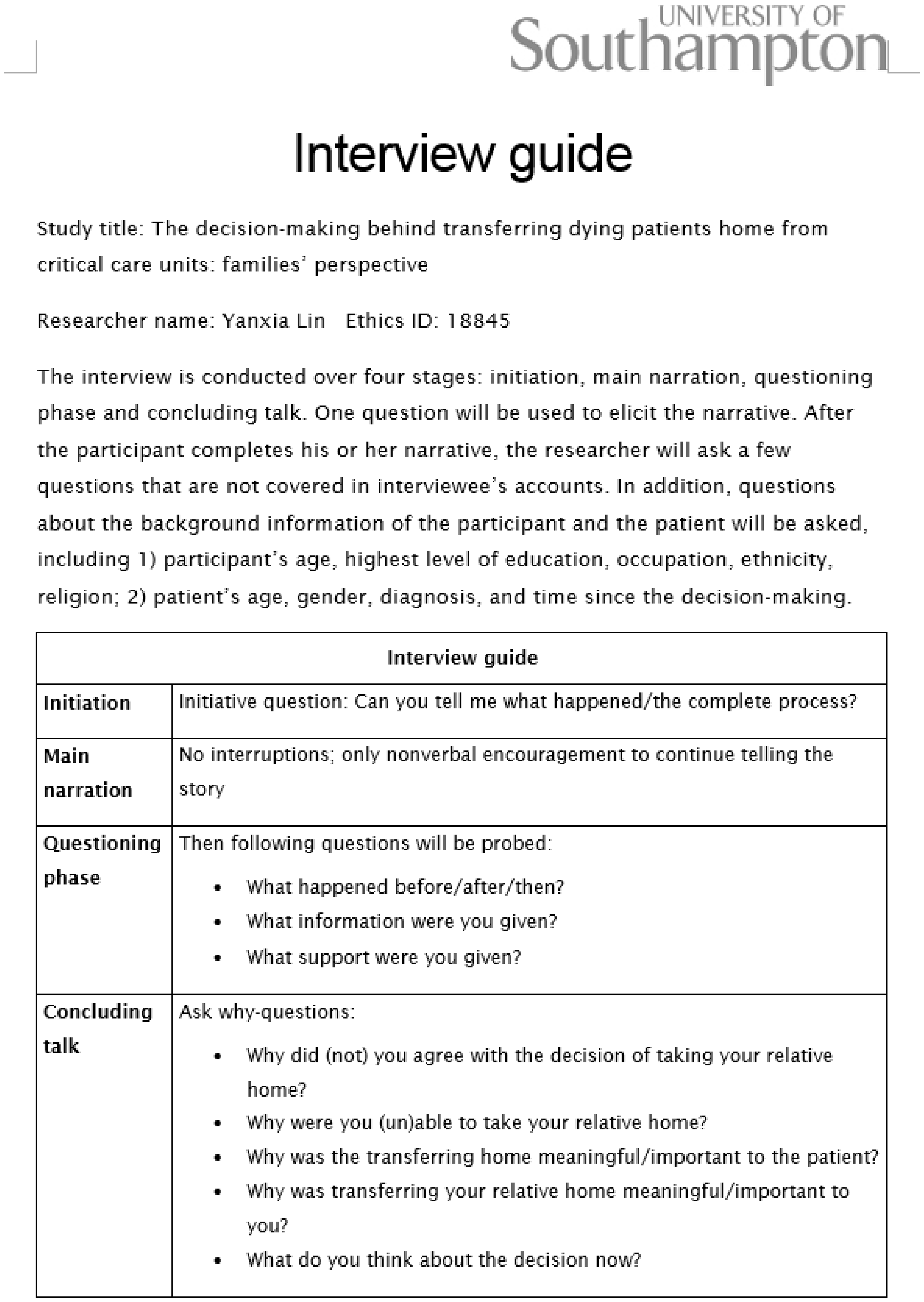
Name of participant (print name)……………………………………………………

Signature of participant……………………………………………………………..

Date…………………………………………………………………………………

[May 2016] [Version 1]

A.8 Interview schedule



UNIVERSITY OF Southampton

Interview guide

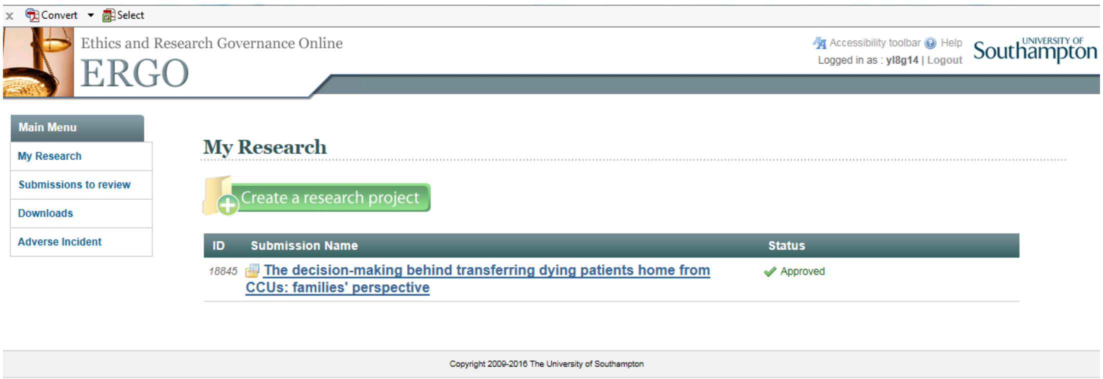
Study title: The decision-making behind transferring dying patients home from critical care units: families' perspective

Researcher name: Yanxia Lin Ethics ID: 18845

The interview is conducted over four stages: initiation, main narration, questioning phase and concluding talk. One question will be used to elicit the narrative. After the participant completes his or her narrative, the researcher will ask a few questions that are not covered in interviewee's accounts. In addition, questions about the background information of the participant and the patient will be asked, including 1) participant's age, highest level of education, occupation, ethnicity, religion; 2) patient's age, gender, diagnosis, and time since the decision-making.

Interview guide	
Initiation	Initiative question: Can you tell me what happened/the complete process?
Main narration	No interruptions; only nonverbal encouragement to continue telling the story
Questioning phase	Then following questions will be probed: • What happened before/after/then? • What information were you given? • What support were you given?
Concluding talk	Ask why-questions: • Why did (not) you agree with the decision of taking your relative home? • Why were you (un)able to take your relative home? • Why was the transferring home meaningful/important to the patient? • Why was transferring your relative home meaningful/important to you? • What do you think about the decision now?

A.9 Ethical Approval



My Research

ID	Submission Name	Status
18845	The decision-making behind transferring dying patients home from CCUs: families' perspective	✓ Approved

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A.10 Translation of the first interview

Transcript in Chinese	Translation
Wei:我先泡点茶再那个，你先放下，你会喝茶吧这一个？ YL: 恩，会，铁观音是吧？绿茶。 Wei:我是说你进来打一下电话，我就会知道。啊前面那个，额，啊前面那个，额，	Wei: I will make some tea first. You put it (my bag) down. Do you drink tea, this one? YL: Yes, I do. Tieguanyin, green tea, isn’t it? Wei: I mean you ring me when you come to let me know (you are here). Ur at first, ah, at the beginning (he started to talk about what happened to his father)…
YL: 他是从别的科转过来的，对吗？ Wei:对，就是...，因为我现在主要有点恼火就是..., 我是应该讲就是说我老爹他身体也有点...，年纪大了，他现在八十，八十岁了吗哦，就是说年纪也八十一岁，那年纪也大了。然后他，这个就是说，人可能也就是比较急，一个是年纪大，一个就是说他那个一些体质有点那个嘛。那然后，他是 12 年，12 年来这边做那个，做一个那个支架。	YL: He (the patient) was transferred from other department, right? Wei: Yes, he was. Now I am basically a little annoyed for…. I should say my old dad was a little … because he’s old, 80 years old. Well his age was 81 so he’s old. And his personality was a little impatient. One is his age, and the other is his health status. Then, it’s in (20)12, he came here to do, to do a stent in (20)12.
YL: 在哪里做的？ Wei:就在 A 医院，就在旁边那个心血管那个五号楼那个，就是 12 年五月份嘛，来做了一个支架。那然后是今年，我想一下 15 号，6 月 15 号，那个，给我打电话，他说那个脚肿，因为好像是 9 号，是相当于是，那时我回家反正还说话、走路这一些都是很正常的嘛，那因为他这两年就是走路比较慢，走路比较慢，但实际上都，就是说都没什么问题。那到那个 15 号，15 号给我打电话不是讲说，14 号，应该是 14 号打电话，讲说脚肿，然后就变成肿的确实是有点厉害，然后就走路就非常缓慢，就没什么能走那个脚嘛。那然后我 15 号下午回去，那确实看他走路呢就是说非常费劲，就是上一个楼梯，因为我们家那个是那个三层楼嘛，那他又很固执，就是说反正就这样三楼,那然后就走了差不多有二十分钟，就我们给他搀扶着，走了差不多二十分钟。那那个，就 16 号早上就来这边，因为那就有点冷嘛，他是想说哎是不是这个吃药，因为每天不是	YL: Where (did he) do that? Wei: It’s right in Hospital A, the Cardiovascular, Building 5. (He) came to do a stent in May (20)12. Then in this year, let me think about it, he rang me on 15th, 15th of June. He told me that his feet were swelling. Because it seemed to be on 9th, when I went home, he still could speak and walk, and all these were very normal. He walked slowly in recent two years. (He) walked slowly, but actually, there was no problem at all. Then on 15th June, he rang me and said, 14th June, it should be 14th, he rang me and said that his feet were swelling. Well it became really serious. So he walked very slowly and he hardly could walk. Then I went home in the afternoon of 15th. I did see he was walking upstairs, very strenuously, for one floor. Because our house has three floors, and he was very stubborn, (and wanted to climb up because he thought) anyway just three floors. Then he walked nearly 20 minutes, with our help. Then he came here (Hospital A) next morning. He thought ‘well is it (feet problem) because of the medication?’ because he felt a little cold. He took heart medication every day. ‘Is the feet swelling caused by the

Transcript in Chinese	Translation
心脏那边都要吃药嘛，那是不是吃药引起这个脚肿，他是自己在猜测，所以说一开始还是往那边去检查。那去检查然后那个医生反正检查也是说反正心脏这一个指标呢跟12年做完那个手术手术做完以后没什么，就指标都差不了多少，意思就是说你这三、四年还是那个，那你应该是别的病因就是引起这个脚肿。那反正就在那边，后来就住下来，来治疗嘛.	medication?' He was guessing on his own. So at the very beginning we chose to go there (cardiovascular department) for examination, and tests. Then, the doctor examined and he said "the heart indicators are not…, compared to those after the surgery in (20)12, they changed little, which means that his heart is still (alright) in these three or four years. So, there should be other causes for the feet swelling." However later we decided to stay there, for treatment.
YL:在心内科住下来？ Wei:对，在五楼那边嘛。那住下来，那个，住了两三天，就吃那个，那个他就每天都点滴什么的。那脚脚肿是好了，但是走路还是，就是说还是差不多，都是很缓慢，根本都不像说以前说，以前走慢一点，反正这样子慢慢走还那个，那就是从13、14号那时候就开始走就这样子，就根本走不太动的样子，但是反正吃什么的都是正常就是了。那到现在16号，进那个医院，然后好像是20号左右，发烧，发烧，就高烧到38、9度，就那发烧就应该是，我个人的猜想了，就是说医生他，说不好听点，他也不会跟我说这个实话，就是说我猜想说到底是比如说他年纪大了，感染了，还是说是那个，比如说是点滴那个过头，因为这个也是我后面26号那天我才知道的。就是那个不是一直就变成一直高烧嘛，那高烧，他就开始那个医生就是叫我说，已经11点多嘛，我去找他，晚上11点多，我去找他，他说那他们那边也没退烧药，叫我说去对面那个药店买那个小孩子吃的那种退烧药。	YL: He was hospitalized in cardiovascular ward? Wei: Yes, at fourth floor there. Then my dad stayed, for two or three days. He took a (medication), and received IV drips of something every day. His feet, feet swelling, was better but his walk was still, nearly the same, still very slow, which wasn't like before at all. In the past he walked a little slowly but he was still able to…. Since 13th or 14th of June he started walking like this and nearly couldn't walk at all. But eating such kind of thing was all normal. Then it's 16th June he was hospitalised. Then it was like on 20th June he had a fever, a fever high to 38-39 degrees Celsius. I personally guess that the doctor wouldn't tell me the truth about what caused the fever. I guess that it's actually because, for example, my dad was old, and got infected, or something else, for example, the treatment of the IV drips was over which I didn't know until 26th June. Because the fever lasted the doctor asked me to…. I went to see the doctor at about 11pm, at night. He told me that they didn't have antipyretics and asked me to buy the antipyretics for children from the pharmacy at the opposite.
YL:谁让你去买退烧药？ Wei:医生嘛，那值班医生嘛，叫我说去吃那个小孩子那个退烧药，那个是叫什么？我一下子没想起来，反正，噢不是，那个我想起，那个，对，那我就跑出来，跑出来后来人家药店都关门了，十二点多就都关门，后来他就又叫我说那你就到A医院，它因为它是两家医院，严格讲是应该是算两家嘛，那就叫我到A医院那边去挂个号，去拿个	YL: Who asked you to buy antipyretics? Wei: Well the doctor. The attending doctor asked me to give my father antipyretics for children. What is the medicine called? I don't remember it suddenly. Oh no, I remember it. That is, yes, I ran out, but the pharmacy was closed already. All (pharmacies) were closed after 12am. So he [the doctor] said 'you go to Hospital A to have a look', which is another hospital. Strictly speaking they should be counted as two hospitals (although they

Transcript in Chinese	Translation
药。也是一样的，也是他们也都是就是估计都一样的做法就是了，都是就是开那种小孩的那个那个退烧的那个，因为我查可以查的到，那个发票还有在嘛。那那个后来吃了，反正就流汗什么的就是会退下来，那退下来就是说那个，但是会反复，就是变成在 20 号左右，21、22 这样子就是说一天差不多一次高烧，或者说到后面就变成两次，那到那个 25、6 号就变成三、四次。就是变成高烧药那个退烧药吃下去，就满头大汗，然后全身流汗，那就退下去。也放了冰块那一种的。那那个，后来他也其中就是说每天都还是在一直在点滴，点滴，然后点的那个叫什么，泰能还是什么？你应该认识吧？亚培什么那种，他说这种药是算最好的，他那个医生那个姓 M 的，跟，姓 M，还有一个是，那个是叫什么？(他在回忆细节)	located on one site). So he asked me to get the medication from Hospital A. It was the same that the doctor there also, it was estimated that he prescribed the same, kind of (medication) to for children fever. If I check, this can be checked as the receipts are still available. Later he [my father] took the medication, and sweated, and the fever was controlled. The temperature was brought down, but it increased again. It became that he [my father] fevered once a day on 20th, 21st, and 22nd (of June). Then it became twice a day, and three to four times on 25th and 26th. After he took the medication, the antipyretics, he started sweating, from head to whole body and the fever was relieved, with the use of ice cubes and something like that. In addition, he was also dripped every day. He was dripped with, what is the name of the medicine dripped? Taineng or something? You should know that, right? Yapei or something. He [the doctor] said this was the best. The doctor, whose name is M, and another one is, what name is that doctor? (He was recalling the detail)
YL:这个时候还在心内科？ Wei:还在那边，对。那然后我也跟 ta 讲说那找，你看看别家去，因为 ta 也有讲说请人家来会诊，请别的那个，后来 ta 们就是请 A 医院那个 N，N 那个医生过来会诊，呼吸科的那个，那会诊呢就是说在 ta 那个，反正会诊这个过程我们前面是没接触啦，不知道他过来嘛，那 ta 就是说讲完就是这个，过来会诊的，他也是倾向于说还是用 ta 那一种方法，就是继续在那边点滴什么的嘛。那到，应该是 25 号，我又跑去 A 医院问了一下，还有一个是 B 医院，我过去问，他们也那边都没有床铺位，那没有床铺位，后来我就没有说那个。因为大部分 14 号看一直一直在那边反复，脚是已经正常的，但是一直没力气，然后呢变成 ta 一直讲说这里肺部感染了，现在是肺部感染，那你最少我，我是倒没有讲什么，我是我哥哥他是有点生气，然后我是心里面是有在想，我说你这个在医院这边都弄到那个感染了，然后你变成是一开始又没叫我们说要转院，	YL: Was this when your father was still in Cardiovascular ward? Wei: Yes, it was. At the time I also told him [the doctor] ‘you consult other doctors.’ Because he also mentioned consultation with others. So later they invited N (a doctor) from A Hospital for consultation. N was from respiratory ward, and he came but the process of which [the consultation] didn’t involve us at first. We didn’t know when he came (for consultation). He just said that, the doctor N, he also agreed with the treatment (the doctor in used by the doctors in Cardiovascular ward, and therefore (recommended) to continue the drips here. Then it came to, it should be on 25th of June, that I went to Hospital A again for help, and also went to Hospital B (another large hospital in the city). However they both didn’t have a bed available for my father. So I didn’t (transfer my father to other hospitals). Because since 14th his feet were normal but the fever recurrent and he was very weak. Then it became that he [the doctor] said that my father’s lungs got infected, and “now it’s lung infection”. Well at least I/we… I didn’t say anything but

Transcript in Chinese	Translation
然后到 26 号 ta 才在讲说‘哎那你要去转院或者说干嘛，你们自己要那个，因为我们也只能是用这个药，’所以我，就那时候 25、6 号，我就心里面就很不高兴，就是说你这个医生就，我说不好听点就是说，有点，你一个是，几个方面，我刚才就在讲说，我老爹他那个年纪大可能也是一个方面，比如说，我个人的猜想说，有可能占 50%的这种可能，那你这边医院应该是也有占 50%的可能，因为这个比例到底是多少比较合适，我是不好讲，但我内心的想法就这样的，我说应该他个人的体质还有我们年纪大他比如说体质比较差，这个有点引起感染或者什么，那你最起码你在这个医院，我进来的这两、三天是没有这种病状嘛，而且进来检查的时候也没有发现说肺部感染，那好，你到了 20 号以后发烧，21 号发烧的时候，才讲，过后，比如说，我具体忘记哪一天，比如说 22 号或者 23 号，才给我冒出来说是要感染，然后继续加大这个泰能的这个用量，他因为他一直讲说，这个是最好的药，都已经用到，然后一天还两次嘛，然后也有吃那个，吃一种，就补钠的那一个，有点苦嘛，有点咸嘛，然后就还吃了一天还吃了，三餐都吃，还吃了几瓶，那，你最起码在医院那边，ta 就变成大部分 ta 觉得说哎没办法，ta 才叫你说转院，到 25、6 号才一直想说那你再转院，因为我当时就想说 ta 会诊的时候到底，那个会诊过来 ta 也是讲说，就是倾向于他们这种治疗方案，认可 ta，我说那你能不能再找别的医院来会诊一下是不是，因为后来 ta 说也叫不到，而且也没那么快，ta 要去按那个流程，他到 25、6 号 ta 就给我讲说‘那你如果有熟悉的，你自己去找’，我说那你现在人已经这么厉害了，你才给我讲说这样的，因为到 25、6 号是变成每天三、四次的那个高烧，那吃完药退下来一会儿，然后就又高烧，然后就，我是一直在想说，你这样子烧烧烧，脑袋瓜会不会就讲话都那个。那所以到二十，应该是 26 号早上，因为我 25 号来两边跑，医院都没有，后来我就 25 号下午在 A 医院就挂了一	my older brother was a little angry. Then I reflected, that the lung infection was caused in the hospital but the doctors didn’t tell us to transfer to another hospital until 26th and he said, ‘if you would like to transfer or whatever, you yourselves need to do it, because we only have the medication to use.’ So I was very unhappy on 25th or 26th. To be honest, the doctor was a little... There might be several factors. One was that I have just talked about my father was old and for instance, I guess it may account for 50% (of cause for the death) and the other 50% was because of the hospital, because I cannot easily tell what the actual proportion is appropriate. But these are my thoughts. I mean his own wellbeing and his age should be… For example, his wellbeing was relatively poor which resulted in a bit of infection or something. However, at least in the first three or four days of stay in the hospital, there were no these symptoms. Moreover, the results of body tests at the beginning didn’t suggest lung infection. Well, the doctor didn’t tell us until the fever started on 20th or 21st (of June), and later, I forget when, probably on 22nd or 23rd, he suddenly said it’s infection. So he increased the dose of Taineng medicine and he always said ‘its the best’, which was already used twice a day. And (my father) also took the, the kind of (medication) to add sodium, which was a little bitter, a little salty. And he took it three times one day, and a few bottles of the medication in total. So, the hospital at least, it became that he [the doctor] felt ‘well there is nothing to be done’ and told you to transfer to other hospitals. He did not tell us to transfer until 25th or 26th. Because I was wandering about the doctor consulted actually…the doctor came for consultation also said he agreed with their treatment. He agreed with him [the doctor complained by Wei]. I had said to the doctor that ‘could you get someone else from other hospital for help?’ However later he said he couldn’t find one and it also could be time-consuming because of a procedure was to follow. He [the doctor] told me that ‘if you know some doctor personally, go for him’ on 25th or 26th. I mean that the doctor didn’t tell me about this until my father was so ill, because the fever occur three or four times on 25th-26th and the temperature decreased after he taking the medication but it rose again after a while. So I was always

Transcript in Chinese	Translation
个那个主任的那个那个号，门诊，那26号早上过去给ta看。	concerned about that the repeated fever would damage may father’s mind, and his speech. So, it should be in the morning of 26th, that I went to see a director doctor in Hospital A. I travelled between the two (Hospital A and Hospital B) on 25th, and both didn’t have beds available (so that I could not transfer my father to any of the two) so I went to consult the doctor at outpatient in Hospital A.
YL:是哪一个科？哪个主任啊？哪个科室？ Wei:就消化科的，那个呼，就是，应该是... YL:呼吸科是吧？ Wei:对对，那个应该是那个姓O吧，好像是姓O，后来说，在当时他坐门诊的时候，还是挂在那个呼吸科这一边，但是实际上他可能已经转到ICU那个主任还是什么的，具体他们是过后他有在讲，他说这个人已经在ICU了，就是，那在于他一听说还在点滴那一些，我说在那边住院嘛，他就在讲说，各个医生的那个看病的方法，在于他他是不需要点滴，因为点滴对他心脏也不那个，他这个医生是这样，那所以他也开了药，开了药后来我去拿，就反正拿了三百多块钱嘛，那实际上这三百多块钱的药后来根本都没吃啊，就是因为就是到10点多，买好药，然后去去那个，又回5号楼那边，心脏的那一边的时候，那这个医生好像是叫P还是什么，我想一下，这个这个久没有那个，就是那个医生，也是东北的，那个，还是还是叫Q，反正这个人就都名字都可以看到，主治医生可以看得到，ta不认可这样子，ta说在ta那边ta肯定还是要用点滴，就是ta一直延续的这一个多礼拜的这种那个做法，ta说除非这个O主任，就是A医院的这个人，他给我写这个字条过来，有问题他承担，然后ta才会去让我们吃这个药，我说那你们，反正都是医生，你应该是沟通一下，你们，就是说，因为，你，我采用你这个方法已经一个多礼拜，但是没有好转的这个那个，就变成是一直更反复的在发烧，你应该是要听一听那个，或者是你们再去组织会诊一下，这样子可能会比较好一点，是不是啊？因为确实医院不知道说是你这个方法	YL: Which specialist? Ah which director? In which department? Wei: Gastroenterology, oh Respire…Well, he should be… YL: Respiratory? Wei: Yes, right. He…his name might be O. He’s a respiratory specialist at the outpatient at the time. But actually he’s the director of ICU or something (the ICU where the patient was admitted later). The point is that after he [the ICU director] learned that (my father) was treated with IV drips he said to me different doctors use different treatment, and for him, IV drip is not needed because it’s not good for his [my father’s] heart. This was what he said. So he prescribed some oral medications for my father. Then I went to buy these medication which cost me 300 yuan. Actually my father didn’t take these medications because, after I returned to the heart ward in Building 5 at about 10 am with these medications, the doctor, called P or something. Let me think about it. The doctor, also from northeast, or called Q, anyway the name of this doctor can be seen (in the public place of hospital). He didn’t agree with him [the doctor in Hospital A Wei just consulted]. He [the doctor in heart hospital treating the patient at the moment] said IV drips must be used which had been used for more than a week. He said he could allow us to take the medications only unless this director, the doctor in Hospital A, wrote a note to say that he took responsibility for the change of treatment. I said ‘you, both are doctors, you should communicate with each other.’ Because I had adopted your treatment for more than a week, but my father had no improvement and the fever became repeated. ‘You should listen to the doctor’s suggestion, or organize another consultation meeting.’ It would be better if doing so, wouldn’t it? Because it’s true that the hospital, and it’s not sure

Transcript in Chinese	Translation
对还是要他的办法才是对的，是不是？那 ta 就是不愿意，那不愿意，后面，又可能讲了大半个小时，她就出了一个单子，然后 ta 说那不然就叫这个 A 医院这个医生这个主治医生嘛就是说他再签他的意见嘛，签在下面，后来就我就又去跑了一下，那人家这个人后来也签了，他意思就是他还是认为说吃药就行了。那到后面就回去就中午了嘛，就回去中午，那然后到下午的时候，那个值班的那个，它五楼有一个值班的主治医生嘛，姓 M 的，M 那个 ta 就又给我讲说 ta 已经去协调了这个，A 医院这边有一个床位，那 ta 说留一个床位给我，还是专门来这边，比较那个专业比较对口嘛，讲难听点，专业比较对口嘛，然后来这边治疗看看，那就 26 号下午就转过来这边，那转过来，反正也就是一直是这样子，反正我老爹讲话还，就是说，就比较声音就比平时就应该是减少 30-40%那种力气的样子，但是就是说，讲还是比较正常，反正就除了说走路就走不动，一直反复发烧这样子，那 26 号，26、27，反正就到 3 月 2 号，2 号，应该是 2 号晚上，2 号晚上，他那个 N 就是主治医生嘛，这个这个一个床位它有一个固定的医生嘛，那个就给我讲说抽血，因为每天都抽很多血去检查，去化验，你包括在心脏的这边也是这样子，那去化验完呢，就是说，给我讲是说，那时候是 5、6 点吧，我刚好要回来拿饭，因为平时我老爹还是正常都是吃干饭、稀饭这一些的，那然后就是，说血红，那个是什么？叫，那个血红蛋白还是什么的那个偏低，不是要去买一瓶那个四、五百块钱嘛，那种你应该知道，我就叫名...	whether your treatment is right or his is right, isn’t it? He’s just unwilling, unwilling (to adopt the suggestion by the doctor in Hospital A). Later, after we probably talked for more than half an hour, he wrote a note and said ‘go to ask the doctor’ in Hospital A, the attending physician, ‘to write his advice below.’ Then I ran there for this again. Actually the doctor also signed it later on. He [the doctor in Hospital A] said he still believed that only oral medications would be useful. Then I went home at noon, at noon. In the afternoon, a doctor on duty, the attending physician on duty on the fourth floor, called M, told me that a bed was available for my father in Hospital A. He said there was a bed for my father and ‘you [my father] should go there as the speciality is more matched,’ frankly speaking, the speciality there is more matched. So later we transferred here [Hospital A]. We transferred here in the afternoon on 26th (of June). My father was still the same (had little improvement in clinical condition). Basically my old father still spoke…, well, his voice volume reduced like 30%-40% of usual. But he still spoke normally, despite that he walked little and always in fever. So from 26th, 26th or 27th… to 2nd of July. It should be at night of 2nd, he, the doctor N, an attending physician. There was one doctor in charge of each bed. He [Doctor N] told me to draw (my father’s) blood. Actually a lot of blood was drawn every day to be examined, and tested, including the time in the Heart Ward (the ward before transferred to Hospital A). Later, it was 5pm or 6pm when I was about to coming home to get food as usually my old father ate normal rice or porridge etc., he [Doctors N] told me (my father’s) hemo-… what was that? the term… haemoglobin or something was low, and asked me to buy some medicine which cost about 400-500 yuan per bottle, which you should know about. I just (don’t remember) the name of it.
YL:白蛋白吗？ Wei:对呀，对对对，没错，就是那个去看发票就知道，我是品名没记住，那去陆陆续续也去买了几瓶来点滴就是了，每天反正点两瓶嘛，就是说在可能 27、28 号就开始点。那到 2 号那个 5、6 点的时候，我出来，我	YL: Albumin? Wei: Yeah. Yeah, yeah, yeah. Exactly. That’s it and it’ll be sure if to check the invoice. I just didn’t remember its name. So I bought a few bottles and two were used per day, which should be started from 27th or 28th of June. Then around 5pm or 6pm on 2nd (of July), when I was

Transcript in Chinese	Translation
要回来拿饭的时候，那个医生就给我讲说，那个检查就是说有发现什么病菌，还因为他讲的比较专业，我也听不懂对不对？他说，但是这一种就是说抢救的概率就是比较低，30-40%这样这个可能性，那然后他有去，那个又一种药，就是要来，也是来输液的，来点滴的，就是说，那个一瓶可能是2000块钱左右，他给我讲这样子，那我说，反正，因为他是在跟我探讨，你能不能报销这一些的，反正异地保，因为我老爹是在B那边老师嘛，就D的嘛，不是A本地人，那我说那反正没关系啦，报多报少这另外一回事，就是说有这个30-40%的可能，那反正就是说当然就当着100%这种去抢救啊，是吧？他说那可以，他就去申请，那就明天开始点滴这种药嘛，因为他就是说这个药，就是这种病情，那就是说要再去用另外一种药，就是讲是这个意思，那后来就2号，因为2号的那天，我就很有印象，就3号就出院了嘛，所以我很有印象，那结果讲完，然后...	about to coming home to get meal for my father, the doctor told me some bacteria was found from the blood test. I couldn't understand it because he spoke in medical terms. He also told me that "the probability of survival is low, which was about 30% - 40%, and there is another medication to be used for IV drip, which is about 2000 yuan one bottle". He told me like this. I said, well…because he was discussing with me 'could you be reimbursed' something like that. The health insurance was off-site because my old father was a teacher in D, of B (another city near City A), not a local one in A. I said 'Well it doesn't matter because it's not important how much can be reimbursed. Because there is 30% - 40% probability (of survival), it's certain that we'll save him as there's 100% (of probability), isn't it?' He [the doctor] said "Okay, I will apply for it [the medication] and use it from tomorrow".' What he said meant that "the medication, for such a condition, another kind of medication is needed." This's what he meant. Then on 2nd (of July), because I remember the day 2nd, because (my father) was discharged home on the 3rd (of July), I remember it clearly. Then after the talk…
YL:3号出院？	YL: (Your father was) discharged on 3rd?
Wei:3号早上就---	Wei: In the morning of 3rd (of July).
YL:为什么要出院？	YL: Why (was he) discharged?
Wei:不是，你听我讲完。就是，因为这个中间就是我老爹就是反正有时候就变成白天睡，然后晚上呢就经常有时候要起来这样子，有时候一会喝水或者干嘛，所以我哥哥就那个，1号晚上就，就折腾的都没什么睡嘛，所以说，2号早上就有点生气嘛，在跟我老爹讲说，哎，你昨晚一直起来，那我根本都没怎么睡嘛，那在我老爹就变成有点，可能有点，是不是发烧一直有点糊涂了，他就讲说，现在，因为早上7点多我拿稀饭过去嘛，他讲说现在是晚上嘛，那我就在跟他讲说，不是啊，现在才刚刚早上，所以，那旁边的那个人家也过来就是用本地话在跟他讲，他说，哎呀，昨天晚上确实你一直起来，然后也吵了你儿子干嘛干嘛的，就讲这一些嘛，那我哥哥就是可能有生气几分钟，	Wei: No. Let me continue. Well in the middle (of the illness) my old father sometimes slept during daytime but got up at night, drinking water or something else. So during the night of 1st (of July) my big brother was waken up (by my father) and didn't sleep well. So he was a little angry (with my father) next morning and said to my old father, 'last night you always got up which made me not sleep at all.' My old father became a little, perhaps a little…was he confused due to the constant fever? He said 'it's night now' when I brought him the porridge around 7am. I told him, 'no, it's early morning now.' And, the person in next bed also came and said in dialect, 'Ah, you did get up many times last night and woke up your son' such and such. He said so. My brother was angry for a couple of minutes, and I also said to him, 'It's not easy for him [our father], for such an old man, and he didn't mean

Transcript in Chinese	Translation
那我就有在跟他讲，我说，哎，老人家也不容易，他也不是故意的，我是听到后面，听了七八分钟，我就跟我哥哥讲，就是说不要去再去一直生气了，反正确实晚上连续几个晚上没睡上火，这个因为我前面也有两三个晚上没什么睡我也上火，我也是这样，牙齿都疼起来，那我2号上午还在跟我哥哥，好话在跟他讲，也在跟我老爹讲。那个，到下午，那个医生就跟我讲，有查出什么病菌，那然后要弄这种药，那我说我马上就在跟他讲说，那可以，那赶紧申请吧，他说这个还要单独提出申请，那他那个医生也讲说，那明天就开始用这个，那所以我就去外面去买了那些面巾纸什么的，回来的时候我还在跟我哥哥讲这件事情嘛，那讲完，然后我就回来，因为晚上都是我哥哥在那边的嘛。那到3号早上过去的时候，哎，我感觉就声音就比那个1，2号，不是，比29号、1号那时候就更弱了，就是比如说我们如果正常就这样子10分的话，那当时变成差不多比如说2、3分的这个声音，就讲起来就很不清晰，就是的，很小声的，它也是一个过程，也是慢慢，就跟刚才发烧我讲的一样的，就是一开始一天是发烧1次，到后面1、2次，到后面2、3次，3、4次这种，就是那声音马上明显就看得出来，3号早上就完全不一样了，吐痰，因为他也一直有痰嘛，就是说有叫他吐痰，前面那个27、8号那个在吐，还就是正常这样子吐出来，还比较有力气的吐，那到3号早上就吐不太出来，甚至就是就是变成有点那个吐不出来的这个感觉嘛，所以那个医生刚好在9点多过来，他在巡病房，他也感觉哎很弱的样子嘛，那所以他就在讲说那可能要转那个ICU。就9点多，开始在操办这一些，然后到10点多，那个他说叫一个人过来插那个氧气在那边嘛，要转移到那个是3号楼还是几号，还是1号楼，我忘记了，应该我们住的那个是3号楼，然后要转到5号楼后面的那个可能是1号楼，要转到那边。那那个人呢他就说像他这样子呢，就是说，那个管子插进去，有可能都不行，就那个女的嘛，后来那个插管的他说我跟在旁边，万一呼吸不舒服，我马	it.' Because I listened them to the end, for about 7 - 8 minutes. I told my brother not to be angry anymore, and actually he's Shanghuo (a term from Chinese medicine which means exhausted and anxious) after a couple of sleepless nights (caring for my father). Because I was also felt Shanghuo after having no sleep for two or three nights before, and my teeth also ached. So I was talking to my brother in the morning of 2nd like this, to persuade him, and my old father. Then, in the afternoon, the doctor told me some bacteria was found from the test and a medication was needed. I said okay right away and told him to apply for it as soon as possible, because he said the medicine required a separate application. The doctor also said that 'it would be used from tomorrow'. Then I went to buy tissues etc., and I told my big brother about this when I returned. Later I came (home) because my brother stayed there [in the hospital taking care of my father] overnight. Then I went there again the next morning which was 3rd of July. I perceived that (my father's) voice was much weaker, compared to yesterday and the day before, no compared to 29th and 1st. For example, if it's 10 for the normal speech, then my father's was like 2 or 3, his voice. He couldn't speak clearly, and his voice was very low. It's a process, gradually, just like the fever I have talked about, which was once per day at first and later it's once or twice, and then twice or three times, three or four times at the end. It's very easy to tell that his voice, was totally different in the morning of 3rd. He spitted... because he had sputum, and was asked to spit (by the doctor), and he was able to spit on 27th - 28th, when he still could spit normally and had strength. However, he was unable to spit in the morning of 3rd. I felt that he was unable to spit at all. Then the doctor happened to come over around 9am, doing ward rounds. He also felt (my father was) weak, and so he said 'perhaps he [my father] needs to be transferred to ICU'. So (we) started to arrange the transfer at 9am (on 3rd of July). Then he [the ICU doctor] told me a person [another doctor] was called to insert oxygen (endotracheal tube) around 10am, and was going to transfer (my father) to Building 3 or somewhere, or Building 1. I forget it. The one we stayed should be Building 3 and we were going to the one behind Building 5, which might be Building 1,

Transcript in Chinese	Translation
上再插管嘛，那医生也说可以啊。那反正就，后来就两三个医生跟那个护工总共连我们加起来，就总共7、8个人，11点多就给他送到ICU这一边嘛，那ICU办完手续，反正他也想说就3点，还能去探望，那当时就3点进去，反正管子什么的就都全部都插在里面，因为他11点多、12点人是就是那个叫什么，就是说，就带那个氧气进去嘛，那到后面他到里面他就是要插那些那个呼吸管，它就又插法不一样嘛，还有一个是可能打针还是什么，反正有几个管子，嘴巴这边也弄管子，然后那个大小便的那边也插管子嘛，因为到那个4号我给他拔出来的时候，这边也有插了几根管子，那到那个3号，相当于3点能进去，它那边的ICU只能下午3点进去看一次，一天只能这样子，那其他的都不能那个，那我进去在跟他讲，就我跟我哥哥两个人进去，反正他也没办法讲话了，因为管子都插在嘴巴，我不知道你知不知道那样子，那没办法讲话嘛，那反正跟他聊天的时候，我哥哥是有在跟他讲说，你如果说听得懂，你就眼睛眨一眨，听得知道，也没办法怎么点头嘛，就眼睛眨一眨嘛，那他也听得懂，那反正到时间到了，所以我后面我也一直在后悔就是这样的，到后面我要出来的时候，因为一开始我是站这边，后来我就站过去他那个右手边嘛，就有跟他，他手就一直抓着我的手嘛，就也，怎么讲，就是可能也是过后我自己想法，就是他是不是也感觉说那个反正，这个怎么讲，有时候变成完全陌生的那样子，也没办法讲话什么的啊，就那，反正意思就抓住我的手就是了，那到后面我也一直在跟他讲，我说反正我们明天下午就又会进来那个，也是一直在安慰他这一些话，那反正他听得到，他就眼睛眨一眨他也是这样子，那就出来，那出来到后面那个5点多，那里面的医生，就是ICU的这个医生，就那个给我打电话，他说那个指标不是很好，就说各种指标，他说看起来检查不是很好，他说需要，那个好像说，那个过程应该是说抽血起来消毒那样子的嘛，有这样子一个，一个步骤嘛，他说这个差不多，如果说做完几天，那差不多要10万块钱的费	where (my father) was going to be transferred. The person [doctor], a woman, said (my father) probably was not okay (means die) even when the tube was inserted in his current (critical) condition. Then she said ‘I will follow the trip and will insert the tube immediately if he breathes difficultly.’ The (ICU) doctor also agreed. Then two or three doctors, and (unqualified) support workers, seven or eight persons in total including us [family members], sent (my father) to the ICU around 11am. All procedures for admission were went through, and (we) thought that we could go into the ICU to visit him at 3pm. So we went in the ICU at 3pm. (We saw that) tubes or something all were inserted in (my father’s body). Because around 11am-12am he was, what’s that called? He went into (ICU) with an oxygen (tube) but he was inserted another tube for breathing, in a different way. And he had IV drips or something. Well there were some tubes, in his mouth, and in his urethra, because when I removed the tubes on 4th (of July, after my father died at home) I found some tube in there. So it’s when we went into the ICU at 3pm on 3rd because the ICU there only allowed one visit a day at 3pm. Only once a day and no other time (was allowed). I went in and told him…Only I and my older brother went in. Well he’s unable to speak because of the tube in his mouth. I don’t know whether you know about this or not, that he was unable to speak. And we were chatting with him, and my brother was telling him, ‘if you can understand us, you just blink.’ He could hear us but couldn’t nod his head so only blinked. He could understand us. Then the visit time ran out. So I, I always regret about this later. When I was about to leaving, I stood by his bed at one side at first and then changed to stand at his right hand side. I had (told) him. His hand grabbed mine all the time and also…how to say? Perhaps he’s…, these were my personal thoughts afterwards, that he’s also, how to say? I think that he felt completely strange (with the ICU), and couldn’t speak or something, just that… so he just seized my hands. Before I left I told him, ‘anyway we will come in again tomorrow afternoon.’ I said these words to comfort him, because he could hear me and blink. That’s all. Then we went out the ICU. Then the doctor inside, the ICU doctor rang me around 5pm (on the same day), and said my father’s

Transcript in Chinese	Translation
用，那我说，那反正，那既然这个是有一种办法，那能做的就尽量去试喽，去做喽，那所以到讲完，他说那你要去交钱，要去那个预交那个费用，我说那可以啊，那你们就做手续，他说他还要启动这个机子什么的也可能要那个大半个小时、一个小时，不是说马上做就可以做的，而且他也讲了，他说在这个做的过程中也有可能引起老人家更不好的这种可能性，因为做这一种确实我也知道不可能百分百的那个，那我也能理解，那然后他就是，后来到6点多，我就去交钱嘛，那交钱，他7点多就变成给我们又打电话讲说，可能那个指标更差，更不能做，他不敢做，就从5点多一开始是给我解释了这一个变化，那然后就是说要做，那后来反正我也跟我哥也商量一下，因为这个我就有和我哥讲一下，说哦他是，就是有这种可能，而且费用比较多，那你像2号晚上那个药的那个，反正我说，该点滴就点滴，那个钱比较少，那个反正我说能做就做，那3号5点多，那个医生给我们讲的这一些话，那我们就开始去弄。然后到7点多，就给我讲说，那个指标更差了，越来越差，越来越差，所以他也不敢做，那你们看是要住在这一边，还是说要先送回家。	condition was not good, in every indicator. He said the test results looked not very good. He said, sounds like, that a procedure [therapy] is needed to draw his blood, and disinfect the blood, something like that. There was such a, a step. The doctor told me that the cost about… if use it [the treatment] for a few days, then the cost would be about 100,000 yuan. Then I said, 'well, since there's such a treatment, and try everything possible, so just do it.' So he said, 'okay you need to pay for it, pay for it in advance. I said 'okay and you just prepare for it.' He told me he would prepare the machine etc. first, which would take more than half an hour or an hour. So it takes time.' And he also talked about the risk that it might cause something bad in the course of treatment. Because indeed such kind of treatment, I also know, could not be 100% of (safety). So I can understand it. Then I went to pay for it around 6pm, pay for the treatment. At about 7pm, he rang us again saying that perhaps it's not able to done because my father continued to decline, and he didn't dare to do it [the therapy]. At first he explained such change to me and said to do it (a treatment) at 5pm. Anyway I also explained this to my brother later. Because for this I had discussed with my big brother. I said it was, there was such possibility and the cost would be much more. The medication is similar to the one used at night of 2nd which I said 'anyway use it if necessary.' It cost less. I said 'do it if possible.' The doctor told us about this around 5pm on 3rd (of July) and so we started to (arrange) it. Then around 7pm, he [doctor] told me my father's condition was getting worse, worse than ever. So he didn't dare to do it [dialysis]. 'So you see if to stay here, or go home now'.
YL:当时医生有这样提出来吗？ Wei:对，他就是有讲这个，他，因为他再一个明显的讲法，他肯定不会说，哎你们一定要，他是说你们考虑一下你们自己的风俗习惯嘛，还有你们家庭的那个决定嘛，那这个事情我就，我听完，因为如果说按他这样子讲，他肯定是倾向于说基本上没希望的这种，他才会去跟我们讲这个说你要么就是说还在这边，或者说你根据你们的习惯如果说	YL: Did the doctor raise this at the time? Wei: Yes, he did. He…, because he wouldn't say it explicitly, 'well you must.' He said 'you think about your own customs, and your family's decision'. Then I, I heard this… because if he said so, he's certainly inclined to mean definitely there was no hope. So he told us 'you stay here, or go home according to your custom.' Later I discussed with my brother, and also with my family. My family also would like... Because I don't dare to tell my mum what

Transcript in Chinese	Translation
要回去，那那个，后来我就跟我哥商量了一下，然后也跟家里面那个商量了一下嘛，那那个就是说，我家里的人他也是想说那个，因为这些事情我都不敢跟我妈妈讲嘛，那就跟我那些堂哥什么的，他反正他们也反正比较有那个，那我哥哥听完，跟我堂哥听完，也是讲说，那如果是这样子，那可能还是要回来嘛，回家，因为就是说按这边的习惯，因为那，还是回老家那边嘛，回来嘛。那所以就那时候就8、9点的时候，8点多，那就在找那个救护，那个120的那种送回去的那种车子嘛，所以说这个哦，还有个问题，你看那个，那个有一个电话，我打120，那120是告诉我说，哦你打那个有一个是什么，52多少然后尾数是120，那个电话，那个有点，我后面在想有点类似说医院的那个商场的那种，可能它也是120下面，有一个，但是不是专门的这一种平时市里面接送的这一种的，就是它可能又多延伸出来的一种，一个科室吧，一个小科室，专门在送外地的这一种的，那打电话问，他说要那个2000块钱嘛，送回B那边，B你知道吗？	happened, I just told my cousins (male) such and such. My brother and my cousin heard that, and they also said, 'in this case, perhaps we should go back, go home. Because according to the customs here, because of that, we should go home, come back.' Then at 8pm or 9pm, around 8pm, we were looking for an ambulance, 120 (a number for emergency, like 999 in the UK) which can send patients back home. So as for the ambulance, there was a problem. Look, there was a telephone number, 120, I rang it, but a person [an unqualified support worker in the ICU] told me, 'you call another number, 52 or something with a tale of 120', such a number, which was a little bit. I was thinking afterwards it's like the shops in the hospital, and it may be also a (department) in 120 [emergency] but it's not specially for transferring within the city (A) usually. It may be an extended department, a small department, which specially transfer patients to other areas. So I rang this one, which said a price, 2000 yuan, for sending us back to D (a county in another city). Do you know D? (Wei asked me)
YL:嗯，我知道. Wei:你老家是不是这边的？ YL:我在这生活了10年。 Wei:哦，那应该知道，就对面那边嘛。那就是说那个就讲说2000，那后面那个我也是听了一下，那反正也觉得说同意，那就要定，那结果那个护工呢，又打电，又给我电话拿过去，他说你要问清楚他有没有氧气什么的，因为说难听点，这些都没接触过，也没经验嘛，他就拿过去，然后就又问了半天，又跟他唠叨了半天，然后给我讲说，这个它是没有氧气瓶的，什么的，然后就一个司机，那你可能还是要叫那种，上面还一个牌子，一个小的明信片，有一个那个人的电话，他说你可能还是要叫一种，他们比较专业，我就打电话去问这个人，他给我讲说要3000多块钱嘛，3800还是3300，我忘记了，反正是多了1000多块钱就是了，那后来我是觉得说那也可以啊，那既然他这一个	YL: Yes, I do. Wei: Is your home here? YL: I had lived here for 10 years. Wei: Oh, so you should know. Just at the opposite (of City A). That is, he said 2000 yuan, and I heard that, and I also agreed with him. So I was going to book this one. Then a support worker took my phone away and said 'you have to ask him (ambulance service staff) clearly if he has any oxygen'. To be honest, I hadn't been involved in this and had no experience for it. He [the support worker] just took my phone and talked to him for quite a while, and nagged with him for a long time. Then he told me 'it doesn't have oxygen bottle, etc., and only a driver. So you probably have to call another one. There is a (business) card up there, a small card, with a person's telephone number.' He said 'you probably still need to call that one which is more professional.' So I did what he [the support worker] told me and that one charged more than 3000 yuan. 3800 or 3300, I forget. Anyway it's 1000 more. But I thought it's alright if it's more professional and could ensure one-stop, had all (resources), and the ambulance

Transcript in Chinese	Translation
比较专业，比较能保证都都一条龙的，都有那个，而且他说他车子也比较大什么的，讲了一大堆，那我说那不然可以啊，那不然就叫这个3000多的，因为他那个护工又讲说，前面有几个人也叫他送走的嘛，那结果那个，过了一会，尾数120的那个人打倒打给我，他说，我们这个也都是有正规的，不是这个，而且也是经常在接送的，我们也都是有氧气瓶，有什么什么，反正他也是讲了一大堆了，担架什么的，点滴这些嘛，那我说刚才怎么会讲没有，那个你跟那个护工讲那个没有，那如果你也是跟他们都一样，那我肯定是要叫这个2000多的，而且又是你这个120的人给我推荐的，我当然，因为我也知道说那一个就跟送快餐的一样的，肯定也是先吃我们公司的食堂，不行再去吃外面的快餐，是吧？那后来我就给那个那个小卡片那个人退掉，我先不回去了，你先不要过来了，那就叫这个尾数尾数120的这个电话这个人叫他过来。那就，他一看，他说那如果说这个如果搞不好路上就不行，他也在讲说这个这个话嘛，你如果说路上就不行，到时候就，（他电话响起，接电话，讲闽南语，时间短）那后来就我也跟这个医生讲，不是，跟这个那个司机讲，我说反正，因为他说2000块钱要先给他嘛，那然后我说，那如果说确实半路不行了，反正我到家该给你红包，那我，就是他的习俗嘛，就是说那就，我说那给他红包嘛，那如果说没事，那就不需要，人家他也是讲这样子嘛，那后来...	was bigger etc. He [the ambulance staff] said a lot. So I said 'well it's okay'. So (I) chose the one cost 3000 yuan, because the support worker continued to persuade me and said that the driver had transferred several patients back home. After a little while, the number with a tale of 120 rang, called me back, and said 'we are also formal and aren't … and also transfer home very often. We also have the oxygen bottle, have such, and such.' He also said a lot, stretcher, etc., drips, etc. So I said 'Then why didn't you say so last time? And you told the support worker that you don't have those. If you are the same as them for sure I will use the one cheaper, 2000 yuan. Moreover, you are recommended by 120.' I certainly, because I know it's like (the food) take away. I certainly eat in our company's canteen first. If it's not good, I go to eat fast food, right? So later I cancelled the one on the small card. I said 'I won't go now and you don't need to come.' Then I rang the number with the tale, the tale 120 and asked him to come over. He came and took a look, and said 'he [the patient] probably will not be okay [survive] even on the road (the patient may die in the ambulance)'. He said, 'If he wasn't okay [alive] on the way, then… (His phone rang and he answered the call. He was speaking in dialect of the AA.) Later I also said to this doctor, no, this driver. I said 'well', because he said 'I need to give him 2000 yuan [the cost of the transportation] first, I said 'if he wasn't okay on half way, I will give you a red pocket (for tips) after reaching home.' Then I, which is just his custom, said 'I would give you a red pocket. If my father was alright, no need to pay you more. He also agreed with me. So later…
YL:为什么要给红包？ Wei:他的意思就是这个习俗，就是说人如果说，说土一点，死在他车上，那就给他一个红包，那个这个一个心理作用，借口是这样子，反正他没有讲说钱多跟少嘛，不在意这个多跟少，他那个，那后来那个10点多，因为很快嘛，就我们这边回去，然后他开车也熟，他路也熟，然后那个开车他也快，他就都就差不多还1个小时不到，就到我家了嘛，那反正就抬进去，还好好的，那反正我	YL: Why did you need to give him a red pocket? Wei: He meant it's a custom, which is, if someone, frankly speaking, died in his car, (the family) need to give him a red pocket. It's a psychological effect, an excuse (for tips). Anyway he didn't say how much. He didn't care more or less. He… Later around 10pm, because it was very fast to go back home from here. He [ambulance driver] knew the roads. He was familiar with the roads and he also drove fast. It took less than an hour to get to my home. We carried him [my father] inside (our house) and he's fine,

Transcript in Chinese	Translation
也有给他 20 块钱包一个红包嘛，我也给他一个意思嘛，因为毕竟那么晚了，他也辛苦，他也是在路上，他一开始有在发牢骚，他说这么晚了，他一般也不爱出来。	but I gave him [the driver] 20 yuan, wrapping in a red pocket. I gave him some tips because it's so late (in the night) and he also worked hard. He's also, on the way, at first he was complaining that usually he wouldn't go out (to transfer patients) when it's so late.
YL:那时候几点了？ Wei:9 点多嘛。 YL:晚上 9 点多？ Wei:对对对，因为因为从那个 7、8 点一直折腾，一直联系这一些，就弄到那个，因为具体，查电话通话记录就那个就可以知道说具体的时间点嘛，但是我是记得当时还不到一个小时就到我家了，就从这边，那个医院它病人又要把衣服弄掉，然后穿我们的衣服回去嘛，不然他在 ICU 的这里面，衣服都换掉，都换那个，当时也，那个一进去，他也叫我们说买那个什么氨水垫，垫在那个，买了 5、6 个，那然后纸巾也买了，反正几百块钱就是进去，进去结果到 5 点多说要做这个清理的、这个消、那个洗液的，这个应该你专业的你怎么讲就是说...	YL: What time was it? Wei: Later than 9pm. (YL: 9 at night?) Yeah, yeah, yeah. Because because we had been very busy since 7pm - 8pm, contacting the ambulance, etc., until... Because I can check my call history for the detail, for the specific time points. But I remember that it took less than an hour to get my home, from here. In the hospital, the patient's clothes were removed, then he wore his own clothes to go home, because he [my father] had been taken off all the clothes and changed all in the ICU. The ICU asked us to buy a type of water pad, placing under my father, at the time of entering the ICU. We bought five or six pads and some tissues as well. Anyway we spent several hundred yuan for entering the ICU. Later around 5pm, he [the ICU doctor] said a treatment was needed to clean, disinfect, wash the blood (of my father). What's, you are professional, how do you call it?
YL:我猜是血液透析是吗？血浆置换，血液透析。 Wei:但是他不是讲透析这个字样，我忘记了. YL:CRRT？ Wei:我忘记是什么了，反正就是他讲，因为我也问他了具体的，他说反正就是大概就是血液里面的病菌，检查出来这种病菌，要给它消毒一下就是了，而且他说那个管子，一套那个管子 3000 块钱，有可能，因为做这一个循环做一次就是要 6、7 个小时嘛，那有可能，比如说那个管子不能用，那还要再再换一组，那这样子一个小时是好像说 1000 还是多少，反正他算起来就是说一天要万把块钱嘛，那这样全部做几天以后就是要 10 万左右，就是在 5 点多意思在跟我解释这一些，那解释完也同意要做，那要做	YL: Wat it haemodialysis? Plasma exchange? Haemodialysis? Wei: But he [the doctor] didn't say the word dialysis. I forget. YL: CRRT? Wei: I forget about it. He just said, because I also asked him for the detail, he said roughly there's bacteria in his [my father's] blood, a bacteria was found, and disinfection was required. And he said the tubes (for washing blood), a set of tubes cost 3000 yuan. It's probably, because doing a cycle (of washing blood) took 6-7 hours, and it's probably that, for example the tubes could not be used any more, then another set was needed. So it would cost like 1000 yuan or how much for an hour (of washing blood). The cost that he calculated was 10,000 yuan per day, which would be 100,000 yuan for a few days. He was explaining these to me around

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呢，然后到7点多，又说哎指标越来越差越来越差，他也不敢做，那所以那到后面7点多，那我就听那样子感觉，因为那个就是结合我们的感觉嘛，而且跟我老爹讲话的那个早上讲话的那个声音，确实是越来越差的那个感觉，那所以也跟我哥哥、跟我堂哥那些讲完，他们也是觉得说，哎那如果是这样的，那还是回来算了，那所以就后面这个也没做嘛，像你刚才讲的那个根本也没做就是了。那到到家里面就那个还不到11点就是了，晚上嘛，那因为AA习惯反正就是说，那后来就我们也就说在那个老房子那个那个大厅那边就是说摆一个床铺嘛，小床铺，那就，因为人如果是活活人，那反正就是说正常这样子头朝这个外面这一边嘛，那如果说人如果说去世了，是要掉过头来这样子摆放的，那反正就我们也是按这个习俗，因为有很多病人就是说那个人家那一边的习惯就是也有很多病人，他也知道快不行了，他也就是说反正在大厅旁边靠墙壁这一边嘛，就是搭床铺，然后在那边，有的照顾几个月也有，这个就是说那边的一个习俗就是了，应该是G应该也是这样子，也是有这种习俗，那反正就，所以我们会。这个是我心里面在想的，没有跟我老娘讲这些，就也在后悔说，到底当时比如说把那些管子给它拔出来，有时候还能跟他讲几句话，那也不敢拔，因为那个而且他那个挂氧气什么的也都变成都没办法讲话，那后来到应该是变成是4号1、2点，2、3点的时候就人就，就走掉了，就这样子，因为我们坐在旁边，那他有时候眼睛有睁开，有时候又没有那个睁开，是变成很不好那个，那包括到那个3、4点，叫也都没反应，我手在摸他这边也是感觉温温的，但是是明显感觉说没有没有跳动的迹象（他喝了一口茶）。所以我就在，医生昨天在一开始在打电话，我心里面，我以为是说是那一边的医生在正常回访，所以我也是有点不高兴这样子，我是说你这个A医院这边，你，就心脏的这一边嘛，你既然，我也没有怪你说你一定要治好或者什么的，但是你如果说已经出现这种症状，后面他自己在讲的说，哦泰能是在他所用的算最	5pm. (I) also agreed to do the treatment after his explanation. Then around 7 pm he said my father's condition was getting worse, worse than before, and he didn't dare to do it. So when I knew about this and felt that, because it's consistent with our intuitions, that my old father's voice, the voice sounded in the morning, was really bad. So I told my older brother, and my cousin about it and after hearing this, they also felt that 'ah in this case, then he should come back.' So the treatment wasn't done at the end. The one as you just mentioned wasn't done at all. Then we reached home before 11pm, at night. In the AA (the local area) the custom and habits are that, so later we also placed a bed in the hall in the old house. If he is alive, for an alive person, normally his head is placed toward this side. If he passed away, his head is placed toward the other side. We also complied with the custom. Because the custom is that many patients are, he [family member] knows the patient is dying, and he builds a bed next to the wall in the hall, and some (patients) are cared for a couple of months in the hall. This is just a custom there. G should, should also has a same custom (a city near A, in the area of AA). There is also such a custom. This is what I wonder but have not told my mum, that I regret that, for example, what if I had pulled out those tubes at the time. Sometimes we might be able to say a few words to him. But I did not dare to pull it out because that... and he also had oxygen (tube) etc. hung on him so he's unable to speak. Then maybe around 1-2pm or 2-3pm on 4th of July, he had, had gone [passed away]. Just like this. Because we were sitting around him and he sometimes opened his eyes, and sometimes didn't. So it was uneasy to (tell the exact time). Around 3-4pm, he was irresponsive when we called him. I touched him and he was warm but obviously there was no no sign of beats (He sipped tea). So I was, when the doctor rang me yesterday, I thought he was following up and so I was a little unhappy at first, because the Hospital A, the heart ward. I am not blaming them that they must have cured my father or whatever. But the doctor, if the symptoms [fever] had already appeared. He also said later Taineng was the best (treatment) in his options, the effect of which was the best. Would you like

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好的药，就是说效果也最好。你要不要坐这边才不会一直晒太阳？（太阳透过窗户照在我的脸上刺眼， 我说‘哦，没关系。’）	to sit here so that you will not bask in the sun? (The sun shone on me through the window. I said 'No worries.')
Wei:那然后那个泰能点滴的时候，一直讲说在他自己称说是最好的那个药，那你既然说没有看到效果，而且他一直又讲说这个药 2、3 天然后才来看那个药效怎么样，那你既然又没有好转，你应该是最起码抑制住，我们说难听点，你比如说你一直发烧，说就是说一直一天 1、2 次，那反正也就是说最起码有抑制住、控制住，那也还好讲，那你变成是，一直变成加重的这个感觉，那到后面，好，你到 25、6 号了，发现说不行，那你 ta 才在讲 ta 去联系了那个这个 A 医院这边一个床铺位，那然后就过去，已经 4 点多了嘛，所以说才赶得 5 点多要去办入，那个，叫做入院手续嘛，那办完，然后那边反正也变成意思是点滴的这个，因为它又是，我们一开始我也是认为说它比较专业，它毕竟它是专门呼吸科的，那比较专业，那也，怎么讲，就是哎呀，讲迷信的，就是说反正就是这样子。那如果说分析一下，我心里面在想说应该是我们老人家他肯定也有他的体质啊，或者说病况这一种，应该也有，比如说，我刚才就在举例，有可能 50%我们的可能性，有可能 50%应该是医院这边耽误了，或者说用药不那个没有对症下药，这一类的，那种可能性，但是说不好听一点，我这个门外汉，我也没办法说去判断说，哦到底主因是哪哪个地方，因为你就按一个一个正常的想法，你说我人 16 号进来，是没有发烧这一些，没有肺部感染这个，因为他一进来都是有抽血有化验什么的，一开始进来都有整套的这个，那好，你到，而且还有做 CT，还有去做磁共振什么的。那然后，相当于 26 号晚上去 A 医院这边，那到 3 号早上，也变成也是一直往下，反正发烧也是一直这样子，一天 2、3 次，3、4 次这样子的，那也是一直吃那个小儿的那一种那个，然后就也是药，就是也是继续用这个泰能这一个，反正所以我刚刚就在讲说，那个那个门诊的那个，那个是应该是原来它这一边消	Wei: So he always said this was the best medication when Taineng was dripped. Well we didn't see it's effective, and he always said the effect would be seen after two or three days. However, there was no improvement, and he should at least have suppressed it, or controlled it, to be honest. For example he had a fever repeatedly, which was once or twice every day and the doctor at least suppressed or controlled the symptom. In contrast, it became aggravated. Then, the doctor didn't tell me to find a bed in Hospital A until he found my father wasn't okay on 25th and 26th. So later we went to Hospital A, at about 4pm, and we rushed to do admission procedures. Well Hospital A also used IV drips as what (the heart ward did). At the beginning we also thought they should be more professional, as the respiratory department it should be professional. However, how to say? just ah, persuade or comfort ourselves, frankly speaking. It's just like this. If to think about it, in my mind I believe that our old father's wellbeing should be an issue, or the illness conditions such kind. For example, I just give an example, perhaps fifty percent (of the death) was because of my father himself, while the other fifty percent should be due to the hospital, or the treatment was not the right one, such kind of thing. However, to be honest, I am a layperson. I cannot judge what the main cause was. Because, let's just think about it normally. Look my old father didn't have a fever and such, didn't have lung infection, when he first admitted on 16th (of June), because his blood was drawn and tested etc., at admission. At first an entire set of examination was done, including CT as well, and MRI etc. Then, we transferred him to Hospital A in the evening of 26th (of June). Then he [my father] deteriorated in the morning of 3rd (of July). Anyway the symptom of fever remained the same, which appeared twice or three times, three or four times one day. And (my father) still took the (medication) for children. The (treatment) remained dripping Taineng. So I just said that the person at outpatient of Hospital A, who

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化科的可能主任，那后来现在是转到 ICU 这一边的主任.	probably was the director of digestion department, or the director of ICU later on.
YL:那整个治疗过程你母亲她是她是一直在家里吗？ Wei:她都在家里面，都是，就这一边，因为我家在这边嘛，那我哥哥是住在 B 嘛，那就相当于就是我们两个轮流在照顾。 YL:你家只有你跟你兄弟两个人吗？就是小孩有几个? Wei:还有一个姐姐嘛。 YL:但是你父亲住院，就是你和... Wei:就我跟我哥哥在这边照顾嘛，那因为我白天我，我当时我也请公休，一开始我请公休，那请公休呢，一个是这边根本事情，我们这个这种单位就是说挺糟糕的，请公休是请公休，你没办法是全部撇开，那反正一天呢，也是几十个电话，那所以我在跟我哥哥讲，那算了，白天我去照顾，因为白天电话也非常多，白天你回去睡觉，因为他睡眠也比较好，他白天他能睡得着，那我是睡眠比较差，我是，有时候晚上都不是很好睡，所以我在跟他讲，我说那他也认可，他说那行，他就变成他白天睡觉，那晚上他去照顾，就是有几天是这样子，那前面有几天是晚上我去照顾，牙齿马上就痛起来，是这样子。	YL: So had your mum been at home throughout the course? Wei: Yes, she had. She had stayed here (City A) all the time because my home is here, and my big brother lives in B. Therefore we two brothers took care of (my father) in turn. YL: So only you and your brother your family? How many children? Wei: I also have a big sister. YL: But when your father was hospitalized, only you and you brother (was around)? Wei: Only I and my brother cared for him in City A. For the daytime I… during that time I applied for leave. At first I applied for leave, but the business, of our company is very bad, because I couldn’t ignore everything (about the work) even on leave. There were tens of phone calls every day. So I said to my brother, ‘alright, I take the day shift to take care of father, because I have so many calls, and you go home to sleep during daytime.’ Because he could sleep well even in daytime, while my sleep was poor. I am, sometimes sleepless. So I discussed with him. He also agreed with me. He said ‘okay.’ So he slept during the daytime and took the night shift of caring for our father. We followed this for for a few days. Before that it’s me who took the night shift, and my teeth ached immediately. That’s it.
YL:那当时在 ICU 的时候，就是医生他其实也就是暗示说没有希望了，可以回家了？当时你们--- Wei:对，因为他想说那个指标都非常差，他这个，不然他那个 5 点多一直跟我解释的那个，就你讲的当做你讲的说透析的这个嘛，就是说他都已经要做了嘛，他决定说要做，所以他就跟我讲说，我就要问他清楚说大概多少钱，然后概率有多高嘛，那然后，我们说句很不好听点的，如果说基本上都没概率，那我们就没必要去花费这个 10 万块	YL: So in ICU, the doctor actually hinted you that there was no hope and (your father) could go home (to die)? Wei: Yes. Because he [the ICU doctor] said my father’s condition was very bad. He had explained me about the dialysis as what you said, around 5pm, and he had decided to do it, so he told me, I need to ask him about the cost and the risk (of the treatment). Then, frankly speaking, if the probability (of survival) was nearly zero, we didn’t need to spend the 100,000 yuan (for the treatment). If there’s a probability of 20 - 30%, which is in 100 patients, there would be 20 - 30 that can be cured.

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钱，那如果说有 20-30%的那种可能性，100 个有治疗的 20-30 个好的，那我们就赌一把了，说不好听点就是这样子，那所以也同意，那反正也去马上去 1 楼那边交钱了嘛，那结果就不行，不行就后面到 7 点多，7 点半左右嘛，那个医生就就又给我打电话，不然我们就在门口而已嘛，他就又讲说，还是要讲这些事情，因为指标越来越差他现在也不敢做这个那个，这种治疗的那个手术，那就是你们自己那个喽，有的那个就是说习惯要回家，就是不愿意说在医院那边走掉，就就 AA 这边的习惯，就是反正各个地方，各个地方，有的不讲究这一种，那有的就说比较那个，所以他也在讲，说反正他不可能明着讲说你们赶紧就回家去，肯定是没希望了，他没有讲到斩钉截铁的这种话，但是讲的那个话肯定是说，哎基本上是没什么希望，那你们要住这边也行，要回去也行，那要回去呢就是说还要签一个就是说我自愿放弃治疗那个手术，他就省得去起纠纷嘛，说不好听点。那在于我不是说怪后面这个 7 点多来跟我讲这个话，因为我心里面一直在怪就是说，哎你那个 25、6 号，我们也一直在跟他讲说，你应该，他既然这个那个会诊的是这个说法，你能不能说，比如说病情一直不行，你能不能再请别的医院的来，毕竟每个医生，他的经验，他的水平，或者说治疗的方法不一样，你治疗的这个方法，有可能适用，有可能不适用，那，因为我为什么一直讲这个事情呢，就是说我们旁边两个村，就我们旁边两个村（电话铃响起，他按掉）这个村呢有个赤脚医生，那个土医生叫赤脚医生嘛，这个医生就是说本村的人都说他水平不行，非常差，治得根本不行，隔壁村的呢就都说他非常好用，药到病除，那所以我刚才就在讲说，实际上就是心理作用的这个概率非常高，就是这样子，医生，因为你毕竟他同样开这个药，对我不适用，对你有时候适用，就同样的病，因为毕竟每个人的病况、体质什么的，我是从这边这样子在想嘛，那所以回去有在跟我老娘在解释这些，我也不敢说，医生哦，这些事情我都不敢跟她讲，不然她心里面更不舒服，因为在我们	Then we would bet on it, to be frank. So we agreed with him, and went to Building 1 to pay for it [the dialysis]. However, it turned out no way. Later that doctor rang me again and I was just outside the door (of the ICU) around 7pm, at about 7:30pm. He said that, just what I said, because my father's condition became much worse and now he didn't dare to do the treatment, or the operation. (The doctor said) 'It's up to you.' Some have the customs of going home rather than passing away in the hospital. This is the custom in AA (the local area). It varies in different places. Some do not take it seriously while others do. So he [doctor] did talk about it. Anyway he wouldn't say obviously that 'You hurry home. There is definitely no hope.' He did not say it so clear-cut. But what he said definitely meant that 'Ur, basically there is no hope. You can stay here or take him [my father] home. If you take him home you need to sign on a form [consent form] to indicate that you give up the operation yourself.' This is to avoid a dispute, to be frank. To me, I don't blame the doctor about telling me all these around 7pm but I blame for what the doctor told me on 25th - 26th of June, because the doctor consulted said so [using oral medicine only], and could you [the doctor], for example, because my father's condition wasn't okay, could you consult doctors from other hospitals? Because every doctor, his experience, skills, or treatments are different. Your treatment may be applicable, may be not. So, why I keep saying this? There are two villages near us (His phone rang and he hang up). In one village there is a barefoot doctor. The rural doctor is called barefoot doctor. People in the same village say his skills are not good, very bad, and his treatments are not okay. In another village next to this, people say he (another barefoot doctor) is very good, can treat patient. So this's why I have just talked about, actually it's probably the psychological effect. Just like this. Doctors who prescribe the same medicine, which isn't applicable to me, but sometimes applicable to you, for the same illness. As anyway everyone has different conditions and physique. I am thinking from this respect. So I went back and explained to my old mother. I don't dare to say, say something about the doctor o about these stuff, I don't dare to tell my mum because she would be more

Transcript in Chinese	Translation
那边，反正，那些亲戚朋友给她解释说，哦毕竟年纪也这么大了，而且我也是一直跟她讲说，反正走的时候不是很难受，就也算一种解脱，对他也解脱，他也是知道说我们在这边照顾也辛苦，也是那个...（停顿）	uncomfortable. The relatives and friends at our place explained to her that, ‘Oh, well he’s so old.’ I also had told her that ‘anyway he wasn’t suffering when he left [died] which is also counted as a relief, a relief for him. He also knew that we were tired as result of caring him, also that…’ (long pause)
YL:那当时从ICU回家的时候，你觉得ICU的医生啊，包括你说的救护车啊什么，你觉得这些安排，有没有什么安排你不满意的，或者你觉得...？	YL: So for going home, what do you think about the ICU doctors, the ambulance you just talked about, the arrangements for discharge? Was there anything that you were not satisfied, or you felt not good?
Wei:那我刚刚不就是在讲这个事情，就是你这个最起码，我们是没有，没有证据马上就是说你这个护工，因为说难听点，当时也没这个心情，也是过后在想，才再那个嘛，但是我是后面那个人给我倒打回来的时候就是120的，因为这个通话记录都可以查得到的嘛，就是他那个，我给他打，第一次我给他打，他讲完，那个护工就给我接过去讲，就是讲说哎呀他的，后来就挂完电话给我解释说，这个人设备没那么齐全，什么什么乱七八糟的就讲了一大堆，后来我才决定说那就给这个人打这个电话，那这个就是说开口要3000多，我忘记了是3800还是3300就是，反正肯定是3300以上的就是了，因为3000多，所以我心里面想说贵了将近翻倍，那这个人他人家一开口就是说2000，但是就是说，在后来在车上就一开始，他也有在讲，哎我们科长有没有跟你讲说，这么晚了要给个点心费什么的嘛，我说没有，他没有讲那个，他只是说2000块钱，那后面他讲完呢，又过了一会，才冒出一个说，那如果说人真的不行，就是说要给个意思一下，红包，意思一下，他就讲了，那我是心里边我有在马上在跟他讲说，反正，那个我会会这个，既然你这个这个，这个也不是什么坏事情，毕竟，后来，就是，因为在这边马上就拿2000块钱给他了嘛，就运费就给他了，那到家里面，抬进去以后，我就包了20块钱，因为人都好好的嘛，我就说你也挺辛苦的，就买个面包，我是这样子跟他讲的嘛。	Wei: As I just said, it’s, at least, I don’t have evidence to show immediately that the support worker (who introduced an expensive ambulance for Wei) because to be honest, I didn’t have the mood at the time. I just thought about it afterwards. But I was…when the driver called me back, the 120 driver, which can be checked in my call history. I called him up at first and after he finished, the support worker took my phone, and told me ‘ah, his…’ The support worker hung up the phone and explained to me, ‘this one doesn’t have all the equipment, etc., etc.’ He [the support worker] talked a lot. So I decided to choose the one (the support worker recommended), which charged more than 3000. I don’t remember 3800 or 3300 yuan but it’s definitely more than 3000, so I thought it’s nearly doubled (than the 120 ambulance), and the 120 driver only required 2000 yuan. However, later in the 120 car (which I finally used) he [the driver] said at first ‘ah, did our Chief tell you that it’s better to provide some tips for snacks as I work so late?’ I said ‘No, he didn’t. He only said 2000 yuan. After this, after a while, he said again ‘if (your father) isn’t okay [dead],’ He meant ‘just for a little tips, a red pocket, like tips’. He said so. Then I said to him immediately ‘anyway I will, will… since you said so. This isn’t a bad thing since...’ Later, because I gave him 2000 yuan at once, for the transport fee, after we reached home and carried (my father) in, I gave him another 20 yuan in a red pocket as (my father) was okay. I said ‘You are also laboured. Go buy a bread.’ I said so to him.

Transcript in Chinese	Translation
YL:那当时回去的时候，他身上还是有输液的管子，是吧？插着气管插管？ Wei:有有，那个就是氧气管，氧气管--- YL:是插在气管里的，对吧？ Wei:对对对 YL:很长的一根 Wei:对对对。 YL:那你们是回家以后，是自己拔出来的吗？ Wei:没有，就是隔天那个早上早上7、8点了，我才给他拔起来的。 YL:是你拔的吗？ Wei:对。 YL:那你知道怎么拔吗？当时医生有告诉你怎么拔吗？ Wei:没有，就是所以我就说，一个是我们也没经验，那所以我刚才不是还在讲，我也是在后悔，有时候，这个就是说很矛盾一个心态啦，因为你这个肯定是已经是已经是这种症状，就是管子插那么多了，你给它拔起来，就是像早上10点多那个那个女的专门在插管子的，她也在讲说，我这个管子给它插下去，有可能病人不死也马上就当场就去掉的，也有这种，那个，所以那个她才讲说先不插，我就陪在旁边，送到那个送到哪个ICU这个路，我陪你走到那一边去，那如果说发现有那个不好的，我就马上就，就省得你一叫，起码有几分钟，如果说没过去，她这个医生倒是可以，我们凭良心讲，人家也主动说过去，那至于说，我们再说自私一点，至于说有没有算钱，我们也不知道，因为那些药单，都算钱，因为我还有一个就是不高兴的就是在那个心脏的这一边，可能24、5号，有一天，就是说那个泰能，一下子算了7瓶的钱，那正常每天都是2瓶，因为那一瓶是好像是250还是350，我忘记了，就几克嘛，就一点点，然后是参在那个什么那个什么钠，500的参在那里面嘛，这	YL: Your father had IV infusion set and endotracheal tube when going home, right? Wei: Yes, an oxygen tube. YL: It's inserted in his mouth, right? Wei: Yeah, yeah yeah YL: Is it very long? Wei: Yeah, yeah yeah. YL: Was it pulled out by you after going home? Wei: No, it wasn't until 7am or 8am in the next morning. YL: You pulled? Wei: Yes. YL: Did you know how to pull it? Had the doctor told you how to do? Wei: No. So I say, one is we don't have any experience and I just said that sometimes I still regret until now. It's very contradictory because with such a certain symptom and so many tubes inserted, if I pulled them out, (my father would die soon). Just as the woman, the specialist for inserting the tube, said around 10am that morning, 'if I inserted the tube, the patient, would leave [die] immediately, and sometimes it happens.' So she said 'I will not insert the tube now but I will accompany you on the way to the ICU. I will go with you. If I find anything bad happen, I will (insert) immediately, because if I don't go with you and you call me for this it may take me at least a couple of minutes to come. This doctor is good, to be honest. She would like to go with us voluntarily. As for whether this charged me or not, we had no idea. Because those medications were charged, and I am also not very happy with another event, which took place in the heart ward. One day, probably on 24th or 25th, seven bottles of Taineng were charged. Normally two were used per day. One was like 250 or 350 yuan, I forget, and weighs just a few gram, just a little. It's mixed in the the Sodium, mixed in 500 (ml) to drip. As I saw previous all were two bottles per day, why 7 bottles were charged that day? I was talking to the nurse about this. Then I forgot this afterwards. She said she would go to check it. Later I was

Transcript in Chinese	Translation
样子在点，那因为我是看前面的那一个都是两瓶，那怎么那一天是算了七瓶，我还在跟那个护士讲，那讲完过后也忘记了，她说她去查一下，那过后也就，在着急着跑B医院，跑到那边去找医生找床位嘛，就也忘记，那然后26号早上又在忙去门诊，然后又下午又转院，所以就没去较真这一些。所以刚刚在讲说，你在讲说（管子啊），对管子的事情，所以我们也变成很冲突，就没有去问，我后面我也在想说，有可能给他拔起来，是过后了，已经是过后我才在想这个事情，有可能还跟他讲几句话，他变成比如张开嘴巴，虽然声音很小，但是有可能还讲几句，听一听，他的那个最后讲什么，变成是一直都没有讲上话，就变成我们讲，他反正到底有没有听进去，我们什么的，就没有没有很明显的那个，但是如果是在3点，我进去跟他探视，我不是讲说后来我走到他的那个，我是前面，差不多我们进去就是十分钟左右，探视的就，那个我一开始站这边，站他的左手边，那我哥站右手边，后来在跟他讲，然后就是他会眨眼睛，就有在跟他讲说，反正不能讲话你就眨眼睛，然后到后面医生叫我们出来，那我就站到他那个右手边，然后就抓住他的手，他也抓住我的手，就抓的很紧，就我说我要出去...	rushing to Hospital B looking for doctors and bed. So I forgot it. Then I was busy with going to the outpatient in the morning of 26th and then transferring my father in the afternoon. So I had no chance to figure it out. So you were just saying, you were saying… For the (endotracheal) tube, I became struggled and did not ask (the doctor) about it. I reflected afterwards, perhaps he could be able to open his mouth if I pulled it out. I was thinking about it afterwards. He could be able to speak even though his voice was low, and we might hear what he would say at the end. It turned out we had no talk. It's just we said to him and there was no obvious (sign) about whether he could hear us or not, but when I went in (ICU) to visit him around 3pm (he could blink). I just told you that at first I was at this side and later I moved to the other side. We only had about 10 minutes for one visit. At first I was standing at this side, at his left hand side while my brother was standing at his right hand side. We talked to him and he could blink. We told him 'if you cannot speak just blink.' Later when the doctor asked us to go out, I was standing at his right hand side and holding his hand. He was also holding my hand tightly. I said I need to go.
YL:他是清楚的？ Wei:很清楚，因为我在跟他讲，他眼睛有相当于说听完了有眨眼睛，那然后我还在跟他聊...。包括到6点多，我还在跟医生，就是说决定说要做那个透析那种，那个手术，我还在跟那个医生交代，我说你等下如果进去再碰到我老爹，再跟他多鼓励一下，讲一讲，就是说那个因为我那个侄儿也还结婚，相当于他那个孙子嘛，也还没结婚，还在那个，我说那个跟他讲一讲这些事情，就是说也希望说，因为人有一个这个求生的意识，你如果说有一个什么，他就那个...。因为我当时的内心有一个什么，一进去看，那个ICU的那个，我第一个感觉就是说什么，人有时候正常人有时候真的进去就会，都会受	YL: Was he clear? Wei: Very clear. Because when I was talking to him he blinked his eyes, and I was chatting with him about…. And I was telling the doctor around 6pm when we decided to do the the operation dialysis that 'If you see my old father later please encourage him a little more, tell him that my nephew, his grandson, is still unmarried, and…' I said 'you tell him this.' I was hoping that, because people have the desire to survive, If you say something... When I saw the ICU at the first time. My first feeling with the ICU was that even normal people in there, would not be able to bear it. Why? Once he entered there, all his clothes were removed, tubes were inserted everywhere, in his nose, in his mouth, then, in his urethra too. And he was bound on the bed. Normal people, for example, at least can get up

Transcript in Chinese	Translation
不了，为什么，一进去它就变成给你全部，衣服全部换掉，管子，这边也插管子，鼻孔也有插，嘴巴也有插，那然后，大小便这边也有插，然后就又绑在床铺上面，都绑着，他怕你去弄这一些嘛，那你然后又没办法讲话，没办法交流，那你最起码，比如说我们正常人还会起来走一走，或者说走不动，还会做起来看一看，而且我老爹又比较性急，所以我是，这个是我内心自己的想法，我就不敢讲，我是心里面在想说，他妈的这个，我是心里面在这样子讲粗话，我心里面，内心自己在讲，我说‘他妈的，这种治疗的这一种方法，好好的都会吓死掉’，我是心里面是这样子，但是不敢表露出来，也不敢讲，因为你毕竟人家这样子做，肯定有它医生的这一种方式方法嘛，我们既然来这边，肯定是要遵守这样的一个规则，那因为他那个12年当时在做支架的时候，他也是进那边的ICU，但是就没有这样子，他是三餐都可以送餐进去，然后人也是整天是坐在床铺上，但是就没有像这样子管子所有的都穿到位，然后就绑在那里，那个一个感觉，所以我是印象，因为我也是第一次进那一种ICU，所以我的感觉说，我心里面第一感觉说，这个好好的人有的心理素质真的受不了都，而且变成是一整天都没办法那个讲话，就是到3点，家人有进来探视一下，可以讲一下，那你如果说指望那些医生或者护工就跟他讲，也不可能跟他去拉家常，去纾解他的那个。所以到那个7点多他，因为我不是跟你说5点多，我们决定要做，我还在跟他讲说，你有进去再跟我老爹讲讲这些，拉拉，拉一两句家常，因为我是一直在讲说哎我3点多忘记跟他讲这些话，我过后我也一直在后悔这个，所以有时候人，怎么讲，就是说有时候，所以我到5点多，我就有拖那个医生，我说我能不能再进去跟他讲一下话，他说不行，那不行，我说那不然你就帮我那个跟他讲一下，哎我那个，他那个孙子也在讲说那个反正这一两年，他因为也24、5岁，反正他说要结婚这样，老人家毕竟有这么这么一个心态嘛。反正后面到7点多，那个医生就一直讲那两个医生就一直讲	and walk, or cannot walk but get up and look around. Moreover my old father was impatient. So I… which is my persona thought, I didn’t dare to say, and I just thought about it in my mind, ‘Damn it, such a kind of treatment, even healthy normal people could be scared to death.’ I was thinking about this in my mind but did not dare to express, to tell the doctor, because anyway they did this, because they had their own way. Since we came here, we must comply with these rules. In (20)12 when he [my father] was doing the stent, he was also in ICU but it wasn’t like this. We could take three meals into the unit, and patients were also sitting in the bed everyday but wasn’t inserted tubes everywhere and bond there, that kind of feeling. So I was impressed, because it’s also my first time seeing such kind of ICU. So my feeling was, the first feeling in my mind was that even healthy people couldn’t bear it. Patients cannot speak for an entire day until 3pm their family come in visiting them, and then can chat a bit. If we count on those doctors and support workers to talk to them [patients], they will not give a family talk, to relieve their (fear or pain). So as I have told you I decided to do the dialysis treatment around 5pm. Then around 7pm I told him [the doctor] ‘if you go in please tell my dad, giving him a chat about his family.’ I said ‘I forgot to say these to him’, which I always regretted later. So people sometimes, how to say? Sometimes …. So I dragged the doctor around 5pm, and said ‘Can I go in and talk to my father again?’ He said ‘No, it’s not allowed.’ I said ‘so please tell him for me, that his grandson is also saying that well he is already 24-25 (years old) and he will get married just in one or two years’ which is a wish of this old man. Later around 7pm, that doctor said, the two doctors said, my father’s condition was getting worse, much worse than before and they couldn’t do the treatment any more.

Transcript in Chinese	Translation
说那个指标越来越差，那没办法做，那没办法做，越来越差。	
YL:那后来回到家里面，你觉得你父亲有难受啊，或者说就是最后他走是不是你觉得是不是？ Wei:没有，就是很平祥，因为就那些管子什么都，就都还插在那边，那除了没有拔嘛. YL:那输液管也是你拔掉的吗？ Wei:对，就是都是隔天 7、8 点. YL:可是那些管子有的是缝着的啊，还有的像气管插管都是固定的，你怎么把它们拔掉的？ Wei:我就是慢慢这样子硬拽出来的啊，那至于你刚才讲的--- YL:那你在 ICU 出去的时候，医生和护士没有交代给你这些管子回家要怎么处理吗？怎么拔掉？并没有交代对吗？ Wei:没有，我印象中没有讲，因为，因为说难听点，我说，我当时没有想到说这么复杂，那个管子啊，因为那到后面我要拔得时候，才发现说这个还伸得很长，这个好好拉的时候就是说还发现说还伸的很长进去嘛，那然后这一边它是有线缝住，我又那个线我有给它剪掉，然后我有慢慢那个，因为线这边可以看得到，那大小便那边，就没有，没有全部拉出来，因为就是说，凭我感觉啦，应该是说还有一点点在里面，因为一直到后面一直拽不出来嘛，那我就就不敢非常那个使劲那个，我就是说已经使到一定的力了，有慢慢慢慢出来，但是没有全部出来，我就说那我就说算了，反正也没有跟我妈妈他们讲这个事情了，我就有跟她讲说哦已经都弄干净了，因为老家还有个习惯就是说要给他擦洗干净嘛。	YL: What do you think about your father's life after going home, uncomfortable, and his leave (death)? Wei: No. it's [the death] very peaceful. Because he had all those tubes, all were there. YL: Did you also remove the infusion set? Wei: Yes, I removed all at 7am or 8am the following day. YL: But some of them were sewed, and some were fixed such as the endotracheal tube, so how did you pull them out? Wei: I just pulled them slowly like this. YL: Did the ICU doctor or nurse tell you how to handle the tubes? Wei: No, I remember no. Because, to be honest, I did not expect the tubes to be so complicated at the time. Because I didn't find the tube was so long until I was pulling it. I found it extended very long, and was sewed at this side and I cut the stitch then I pulled it slowly, because I could see the stitch at the site. Then for the tube in the urethra I didn't get the whole of out because I felt that a little bit was left inside. Because I couldn't pull all of it out and I didn't dare to pull it hard. I had pulled it hard and it came out slowly but not the whole. I said let it alone but I didn't tell my mother about this, I just said 'Oh everything has been cleaned up' as there was another custom in my hometown that the deceased body must be cleaned up.

Transcript in Chinese	Translation
YL:那后来你父亲是火化了还是？ Wei:啊，都是火化，这边 AA 的都是，现在可能全国都是要求火化了。就相当于也都是，相关于 4 号早上嘛，4 号早上那确定说，因为到底是 1、2 点还是什么的，我也搞不懂，就是因为我们说实在话，毕竟那个，就是在不可能，也不敢说一直去摸他心脏，摸这些的嘛，那到那个 2、3 点的时候，那感觉就是基本上是没有那个气息，跳动的气息，但是摸那些身体，摸这边还是感觉就是说有那个温度嘛，所以后面他们也在讲说有的人还好几个小时呢，5、6 个小时才体温才完全那个。那当时 10 点多，11 点到的时候，因为我们那个旁边有一个卫生所嘛，就是镇上的那个卫生所，还有给他拿两袋那个氧气袋嘛，就是跟枕头那个一样的，拿两袋过来换嘛，因为我们说实在话就是，在当时的心态就是认为说哎呀应该是没希望，反正就是说能多活一会就是了，所以又去跟医生拿了两袋氧气的那个。（停顿）	YL: Was your father cremated? Wei: Sure, every deceased is cremated in the AA, and maybe the cremation is required in national wide. It [death] was confirmed in the morning of 4th because I don't know exactly, it was 1am or 2am. To be honest, since it was impossible, I didn't dare to touch him, his heart [chest], etc. Around 2pm-3pm, I felt that basically he had no breathe, heartbeat, but we touched his body, touched here and still felt warm. So later they [other family members] also said that some people would last for a few hours, 5-6 hours, before the body temperature decreased. Around 10pm-11pm (post transfer), there's a clinic near us, in the town, and we took two oxygen bags [a soft bag filled with oxygen for short-term life support] from there which was like a pillow. We got two. Because to be honest, we knew that there was no hope but just prolong his life for a little while, we just got two bags from the doctor (in the town clinic). (Pause)
Wei:这个医生我就是所以就是很也很矛盾啊，因为我们说难听点，我的想法也应该也不能说全怪医生，但是我内心我一直在想说，肯定是最起码你那个病我觉得说没有抑制住，没有往好的这边好转，变成是一直是，从 16 号到 26 号转院，然后到 3 号去 ICU，就一直是往下的这个一个那个，然后你最起码比如说，因为每个人的治疗方法肯定是，有的人完全一样，有的人可能还不一样，那就我刚才就在讲说，她就到跟这个 O 的这个他的做法就完全不一样嘛，O 他的想法说你越点滴，后来我确实也在看那个百度，也不知道是准确还是不准确，我是说他们也是在讲说点滴确实是更不好，就跟那个癌症那个化疗一样，网上传的不是也是在讲，国外的都很多都不去化疗，因为化疗就是变成有点那个好的细胞杀了，坏的细胞杀了也是那个，就是有这个说法，到底你敢不敢跟我说这个你真实的想法，我也不知道（他笑着在问我），就是我后面我自己也在想说，也确实有这个可能，你毕竟人身体如	Wei: To be honest, I feel conflict. My thoughts are we shouldn't completely blame the doctor, but in my mind I would like to say, it must be… at least the illness wasn't controlled, or wasn't improved. Rather, my father declined all the time, from 16th to 26th, and then to 3rd (July) when my father was admitted to the ICU. At least the doctor, for example, his treatment for people should be, for some people it's totally the same, but some it may be different. As I just said, his treatment was completely different from O [the doctor who advised oral medication rather than IV drips]. O said if the more you dripped, I actually searched on Baidu (a main search engine in China, like Google) that I don't know if it's accurate or not, people say IV drips actually are worse, just like the chemotherapy in foreign countries. A hearsay online is that many people in other countries don't receive chemotherapy because it kills the the bad cells and also the good ones. This is the debate. Do you dare to tell me your real thoughts? I don't know (He is asking me with laughing). Afterwards I am thinking this is possible. Because if the body is healthy, the cells will be removed

Transcript in Chinese	Translation
果健康，那些细胞几天自然那个新陈代谢掉，是不是，好坏应该也是都是。那你国内的就是一直在传，因为毕竟也对这个医生有点偏见，就是认为你这个就是一直要想多赚钱，你毕竟国家医改有点糟糕，就是把你们推向说赚钱的一个渠道，是不是？然后你这个医生就是最起码给我的感觉应该是一大半想着去赚钱，而不是像以前说确实是要救死扶伤，存粹就是说，或者说像现在，因为我也是没出过国，也只是说了解，网上那边来评价说评价国外确实还是比较，像最起码我们刚解放医生的那种心态来救死扶伤的，那现在，你说不好听点，很多就是没病，就我那个侄儿，另外一个，一个小感冒，结果去那个就我们那个旁边那个卫生所，去住院，治疗了 4、5 天，然后花了 2000 多块钱，那那个医保报了 1000 多块钱，自己再花一个可能 7、8 百，就跟那个网上调侃的那个不是一样，说本来 100 块可以治好的那个病，那你现在呢反而，这个医改以后，要 1000 块钱，给你报了以后，自己掏 400 还很高兴，说还可以报大部分，那实际上你看那些钱变成给那些医生呐，给医院那，给药，然后给政府。(停顿示意故事结尾)	naturally through metabolism, won't they? both good ones and bad ones. Domestically an opinion is spread out that people have a little prejudice on doctors. One is that they just want to earn money because the national medical reform is a little bad, which pushes the doctors to make money, doesn't it? Then the doctors at least, I think that more than the half of them want to make money rather than truly save lives like before. Purely, or like now, as I have never gone abroad, just learn the comments online, that other countries actually are much (better), because the doctors at least saved lives like the ones when we were just liberated (when new China is constructed). Now, to be frank, many have no illness… My nephew, another one, had a cold so he went to the clinic near out home. He was hospitalized and treated for four to five days which cost him more than 2000 yuan, of which 1000 was refunded by insurance. So he spent probably 700-800 yuan out-of-pocket. Isn't it the same as what has been ridiculed online? Such an illness which would have been cost about 100 yuan but now it cost 1000 after the medical reform. Even he got part of it reimbursed he still needed to pay for 400 yuan. People are still very happy as most of it is refunded. Actually look the extra paid money is given to doctors, hospitals, medications, and then the government. （A pause indicating the end of the story）
YL:你还有什么想补充给我的吗？觉得还有什么想跟我分享的吗？ Wei:就是就是大概是这样子了，因为这个也是有点矛盾，我这个这个--- YL:但我特别感激，因为你今天跟我说了很多你心里的想法，所以我觉得，特别好，我想可能对我的研究帮助特别大。 Wei:哎，你如果说，反正我刚才不是也在讲说，如果说真的你如果说在国外，如果说按网上传的那样，你说确实，在我们这种环境，确实，有可能你也想做好，但是又没有这个又没办法去改变这个制度这个现况，你也只能随波逐流，变成说难听点，说就是近墨者黑了对不对？你也变成一直是，你一开始你出来，如果说你回来，你在这边上班，	YL: Is there anything else you would like to tell me? Wei: Generally that's all. I just feel a little conflict. I, I… YL: I am very grateful as you told me a lot of your personal thoughts. So it's very good and this will be very helpful for my research. Wei: Ah, I just talked about it, if in other countries, as those said online, actually in our context, maybe you also want to do it well but you don't have, you cannot change the regulations, the current situation. You will only follow the crowd. Frankly speaking, you touch pitch and you will be defiled, right? You will also become, when you start work, after you come back, you may be thinking to save patients' money or what, but finally you may be blacked

Transcript in Chinese	Translation
你有可能一开始想节约患者的钱，或者什么，到后面你可能也被动的黑掉了，就是说这个大环境就是这样子的。 YL:我相信有一部分医生可能像你说的这样，他会那个，但确实也有一部分医生还是好的。	down passively, because the broader context is just like this. YL: I believe some doctors may be like what you talked about, but indeed some doctors are still good.
Wei:那肯定是有，这个因为毕竟我们怎么讲，就包括我们公司一样的，有的很多人就存粹这个，这个怎么讲，就跟现在不是共产党一直讲，在吹这个那个抓这些人的素质什么的，你说当官的，你看得到，是不是？医改，还有这个教改这一些确实是，那教改有时候，你毕竟也有帮到穷孩子，比如说还有他通过高考的，那你这个医生确实是很糟糕。我们，我老爹一个同事，他是老师嘛，也是退休了，然后到 D 跟他女儿住，那早上不是出去散步要去买菜吗，那人感觉就不舒服，就马上去医院，到医院呢就给他诊断，马上要住院，要交 3000 块钱，那你早上出去买菜，肯定没带那么多的钱，他可能就是，他女儿估计就是我才两个人，就是比如说带 100 块或是多少，那就又不行，又跑回去拿钱嘛，结果来的时候他老爹就死掉了，可能也就是 70 几岁这样子的一个，应该是 70 岁左右，因为这个事例是真实的，然后也是几年前。 YL:那这个家属有跟医院怎么样吗？ Wei:那这个我是没打听我是没打听，我只是知道有这么一回事说，送去，那然后就回家去拿钱这个过程，然后到死掉嘛，那可能是不是也是心肌梗塞或者什么的反正，就是很多种病因，那所以我刚刚一直在讲说我们这个医改就是很那个... YL:很多问题哈。 Wei:恩。	Wei: Of course. Because we, how to say? like many people in our company only, how to say? like the Communist Party, is currently boasting to improve people's ethics, but look at the officers, you can see how they are, can't you? The medical reform, and the educational reform, are actually... The educational reform sometimes can still help the poor children. For example, it helps through Gaokao. As for doctors, they are really bad. One of my old father's colleagues, who was a teacher and retired as well, went to D and lived with his daughter. One day they went for a walk and buy some food in the morning, he [the patient's colleague] suddenly felt uncomfortable so went to the hospital immediately. He was diagnosed in the hospital and needed to be treated immediately. The hospitalisation required 3000 yuan. If someone goes to buy some food he will not take so much money with him. It's probably his daughter, I guess only the two persons, for example, just had 100 yuan or so, which wasn't enough, and so she went home to get money. However, when she returned to the hospital, she found her old father died there. He might be just 70s, about 70 years old. This is a true story, and just happened a couple of years ago. YL: Did the family do anything to the hospital? Wei: I didn't inquire about this. I didn't ask about it. I just know there was such an event that he was taken there, and died when his daughter went home to get money. It may be Myocardial infarction or something, or could be many causes. So I just talked about our medical reform is (bad). YL: There are many problems ha? Wei: Yes.

Transcript in Chinese	Translation
YL:那行，今天我们聊的就差不多，非常感谢你能跟我聊这么多，然后我能问一下你的基本情况吗？ 年龄：44，学历：大专，父子关系，已婚。 YL:行，那基本的情况就这样，然后如果你要是随时有什么想聊的或者补充的，都可以给我打电话，或者发信息也行。 Wei:行啊行啊，反正就是你这个就是说，我也不知道，说难听一点，反正怎么讲，就是说对你个人有一点点启发。 YL:哦，有很多启发。 Wei: 这个就是说，怎么讲？因为说实在的，最起码我到目前我也不是说非常偏激的一个，我是说我的做人也不是非常偏激，所以我是，社会确实有很多不公平的，或者说，很黑暗面的这一种的，那你也只能去适应，所以包括这一些话有时候我也一直在跟我老爹在争吵，就是这样的，那现在想一想，就是说，他也是很固执一个人，那就是说，那你不能改变这样的社会，你也没办法，你也只能去就这样，所以我刚才不是在随便开玩笑说，这些医生也大部分，有些是变得是主动、被动地去变坏掉，是不是啊？那你，包括我公司也是，包括领导当官的这些还不是一样，所以他们不是也在调侃，很多人宁愿去拜见那个，居住在那种环境可能相对会公平一点，是不是，哎呀，唠唠叨叨也不知道，我是自己…（录音结束）	YL: Alright. Today our chat is nearly finished. I am very grateful that you told me so much. Then may I ask you some basic information? Age… Okay. If you have anything else you want to share with me later, you can call me, or message me. Wei: Okay, okay. Well to be honest, I don't know how to say. I hope what I said is a little inspiration for you. YL: Oh, yes, a lot of inspiration. Wei: Well, how to say? To be honest, at least I am not a very extreme person to date. So I am, there are actually many unfair things, or very dark sides. You can only get used to it. So I always argue with my old dad about these. Now I think about it [the death or the event], he [my father] was stubborn. I mean we cannot change such a society, we have no choice and so it can only be like this. So I am not joking, right now most of the doctors are also… some become bad actively or passively, don't they? So is our company, in which the leaders, officers, are also the same. So they are ridiculing that many people would rather go to visit… It may be fairer to live in that environment, isn't it? Ah, I don't know I'm nagging… I am…myself. (The interview finished)

A.11 Vignettes for interview 02-10

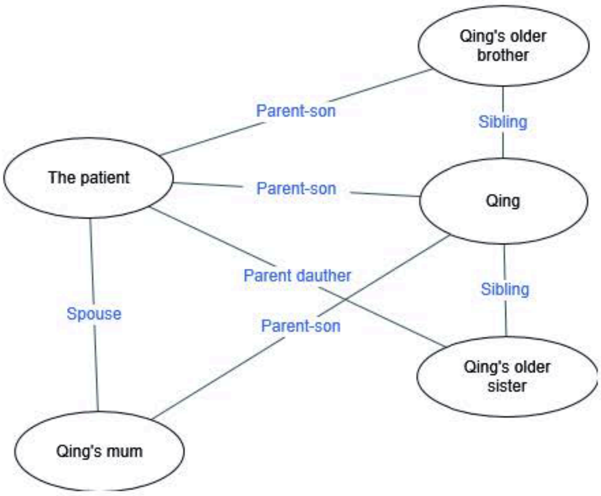
Textbox 1 A vignette developed for Qing's story

Interview 02 Pseudonym: Qing

Qing was a 48 year old man, married and worked as a business manager. The interview took place 36 days following the death of Qing's father. The interview was undertaken in a quiet room at a restaurant and lasted one hour and three minutes. Qing's deceased father was 89 year of age and had lived about 0.2 mile from the hospital in which he was treated and died. Qing's father fell into a coma at home at midnight and was admitted to the ICU directly from emergency at about 8am next day. About two hours later the ICU doctor told Qing and his siblings that their father had little hope to recover. Because the family had no pressure with the cost in ICU Qing and his siblings decided to continue the ICU treatment for their father. However, Qing's father did not wake up after one week of ICU stay and then Qing realized that there was no hope at all. The family was in a dilemma between giving up and sustaining life. About 20 days after admission, the ICU doctor recommended the family to take the patient home to die. However, Qing and his siblings could not transfer their father home because they could not deal with the intensive and painful home care after discharge. Qing's father was sustained in the ICU for another 20 days. In the morning of the last day in the ICU the doctor told Qing and his siblings that their father's organs started to fail and he was dying. Qing recognised that it was the time to take his father home because in their custom the elderly should pass away at home. So Qing and his older brother transferred their father home in the afternoon on the same day.

Qing's father survived a night at home and died at noon the next day. Qing emotionally described that he pulled the feeding tube and others for his father after death. At the end of his story, Qing made negative comments on doctors and the healthcare practice system.

The figure below shows the family structure of Qing according to the individuals and their relationships mentioned in his story. The relationship between them is marked. The centre is Qing because he was the person told the story and all the relationships were unfolded around him.



Textbox 2 A vignette developed for Jun's story

Interview 03 Pseudonym: Jun

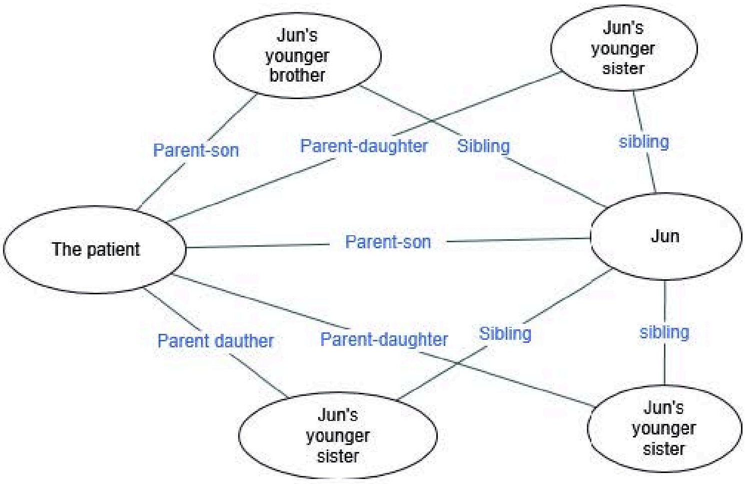
Jun was a 63 year old man who was married and retired. We met in a Café. The interview lasted 51 minutes and took place 38 days following the death of Jun's father. Jun's deceased father was 91 year of age and had lived about 20 minutes' drive from the hospital in which he was treated and died.

Jun's father was admitted due to stomach perforation at about 3am. He received a surgery at about 10am after Jun and his younger brother signed it. Jun's father was sent to the ICU post operation.

Jun's father declined. Jun and his siblings agreed with the use of dialysis. However, the treatment was not effective and the doctor informed Jun that his father's condition was critical. Jun decided to take his father home but his younger brother raised to continue the dialysis. The further treatment was still futile. An ICU nurse recommended Jun to take his father home soon. In the early morning of the fourth day in the ICU, the doctor called Jun to decide the discharge because the patient was dying.

As the oldest child, Jun decided to take his father home immediately. One of his younger sister supported Jun's decision but his younger brother and other two younger sisters disagreed with Jun because they preferred to let their father die in the hospital. Jun insisted because of the village custom of a funeral at home. Finally Jun's brother also agreed with the decision and the siblings took their father home successfully. Jun's father died shortly after his oxygen support was withdrawn by the ambulance service providers.

The figure below shows the family structure of Jun according to the individuals and their relationships mentioned in his story. The relationship between them is marked. The centre is Jun because he was the person told the story and all the relationships were unfolded around him.



Textbox 3 A vignette developed for Hui's family story

Interview 04 Pseudonym: Hui, Ling, and Dong, Family joint interview.

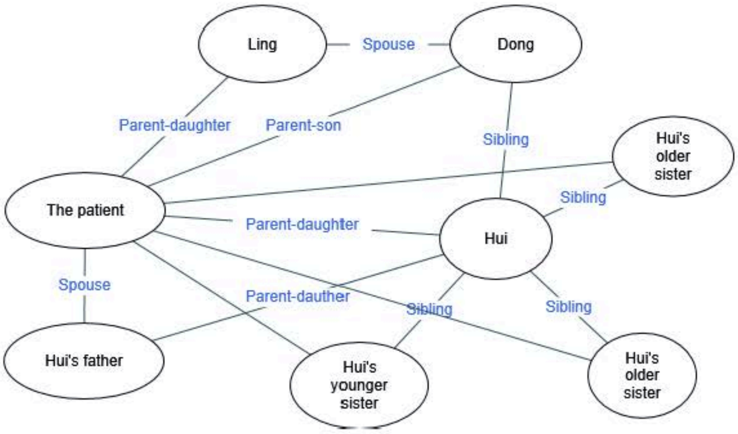
Hui was a 50 year old woman who was married and worked as a temporary worker. Hui's younger brother Dong and his wife Ling also took part in the interview. We met in a quiet room at the place where they worked. The interview lasted 1 hour and 14 minutes and took place 28 days following the death of Hui's mother. Hui's deceased mother was 75 year of age and her hometown was about 15 hours' drive from the hospital in which she was treated and died.

Hui's mother was admitted to a general ward due to a fever and stomach ache. She was not allowed to eat and drink since admission. One morning at about 8am right before the doctor's daily visit, Hui's mother suddenly lost her consciousness with unknown reason. Soon she was transferred to the ICU.

At about 11pm on the same day, the ICU doctor discussed with the family about the use of an expensive lifesaving treatment and he also told the family that the patient might die at any time. Dong said: "Is there a little hope to save my mum? Money is not a problem." The treatment was applied. However, at about 6am next morning, the doctor informed the family that their mother died. Hui and other siblings held their mother in the car drove by Dong and took their deceased mother's body home.

Throughout the story, Hui and her siblings complained that the doctors failed to diagnose and treat their mother.

The figure below shows the family structure of Hui according to the individuals and their relationships mentioned in her family narrative. The relationship between them is marked. The centre is Hui because she was the dominant person told the story and all the relationships were unfolded around her.



Textbox 4 A vignette developed for Ying's story

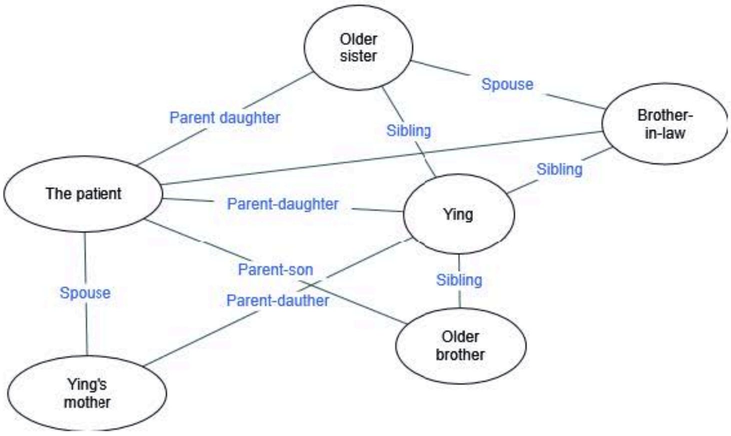
Interview 05 Pseudonym: Ying

Ying was a 37 year old woman who was unmarried and worked as a hotel manager. We met at a Café. The interview lasted 57 minutes and took place 56 days following the death of Ying's father. Ying's deceased father was 66 year of age and lived about two hours' drive from the hospital in which he was treated and died.

Ying's father was initially treated in their local hospital because he was unable to eat. After the problem lasted for about 30 days Ying and the local doctors persuaded Ying's father to go to a better hospital. He finally agreed with a transfer to Hospital A which was in a different city but he had fear of death. He had been improved after treatment in Hospital A. However one day he suddenly lost his mind. He could not breathe on him own so was intubated and transferred to the ICU.

On the first or second day of the ICU stay, Ying visited her father who was in coma and she promised her father to take him home soon. When the ICU doctor told Ying that her father was dying on the third day in the ICU, Ying contacted an ambulance and the family transferred the patient home. During the journey the patient was sustained on a portable respirator by the family which was continued after reaching home at about 11am. Ying's father survived about four hours post transfer and died at home at about 3pm. Ying did not know the cause of her father's death but she had the peace in mind as she took her father home.

The figure below shows the family structure of Ying according to the individuals and their relationships mentioned in her story. The relationship between them is marked. The centre is Ying because she was the person told the story and all the relationships were unfolded around her.



Textbox 5 A vignette developed for Lili's family story

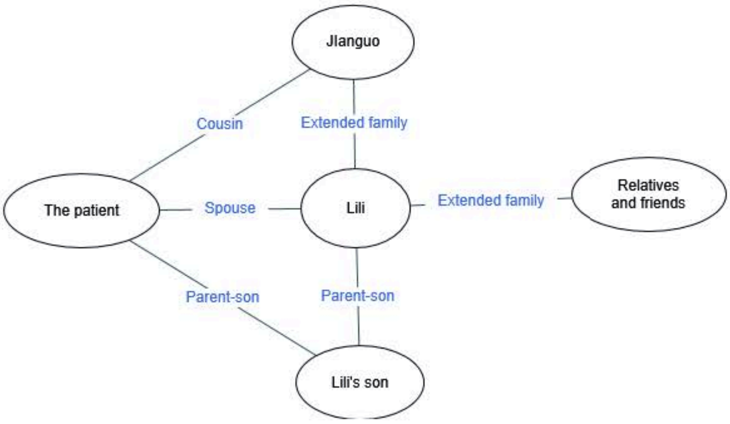
Interview 06 Pseudonym: Lili, Jianguo Family joint interview

Lili was a 52 year old woman who was married and worked as a housekeeper in the hospital where her husband was treated. Jinguo was a cousin of Lili's husband. Jianguo was 53 year old man, married and also worked as a temporary worker. We met in a quiet room in the hospital where Lili worked. The interview lasted 62 minutes and took place 49 days following the death of Lili's husband. Lili's deceased husband was 51 year of age and their hometown was about 15 hours' drive from the hospital in which he was treated and died.

Lili's husband was admitted to the emergency room after he lost consciousness and fell his bike on his way to work. Lili and Jianguo rushed to the hospital after the emergency doctor called her about her husband's accident. The doctor told Lili that there was little hope of recovery. Lili requested the doctor to make all efforts to save her husband no matter how much to pay. Lili's husband was transferred to the ICU as recommended by the doctor. However there was no improvement at all. A doctor and a support worker in the ICU suggested Lili to take her husband home if dying at home was their custom. Then Lili and Jianguo made the decision to transfer Lili's husband home to die. It was a long trip and Lili's husband died on the half way home.

Lili was emotional when telling that her husband did not speak to her before death. She was also sad because her husband was so young and she felt life was meaningless.

The figure below shows the family structure of Lili according to the individuals and their relationships mentioned in her story. The relationship between them is marked. The centre is Lili because she was the dominate person told the story and all the relationships were unfolded around her.



Textbox 6 A vignette developed for Zhi's story

Interview 07 Pseudonym: Zhi Telephone interview

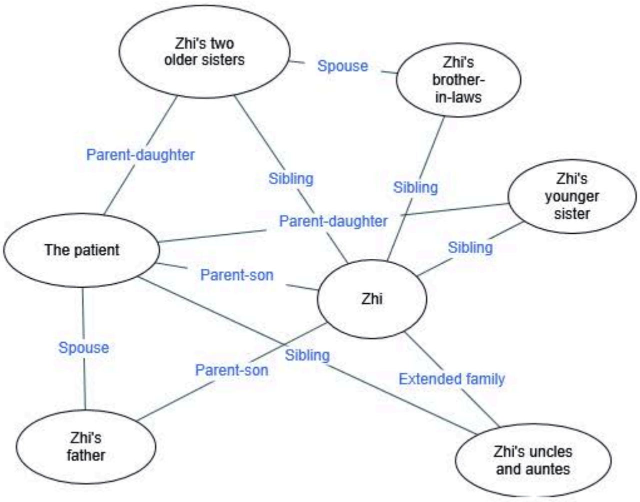
Zhi was a 45 year old man who was married and was a private business owner. He told me the story about his mother's transfer over the telephone because he preferred a telephone interview than a face-to-face interview. The interview lasted 45 minutes and took place 52 days following the death of Zhi's mother. Zhi's deceased mother was 67 year of age and had lived about 10km from the hospital in which she was treated and died.

Zhi's mother was admitted for a surgery with a diagnosis intestinal fistula. However Zhi's mother received four repeated operations due to the post-operative complications. She was transferred to ICU due to the infection after the last operation. One day Zhi's mother was resuscitated in the ICU. Then Zhi and his sisters decided to take their mother home to die because it was their custom and a demand by their mother's siblings.

Zhi and his family were very certain that their mother's death was caused by the unsuccessful four repeated operations which meant the doctors killed their mother. However the choice of transfer was against to suit the doctors because it required to leave the patient in the hospital to receive post-mortem. Zhi and his family struggled with the decision of transfer but they had no choice.

Zhi's mother died at home shortly after the ambulance service providers extubated her half an hour after reaching home.

The figure below shows the family structure of Zhi according to the individuals and their relationships mentioned in his story. The relationship between them is marked. The centre is Zhi because he was the person told the story and all the relationships were unfolded around him.



Textbox 7 A vignette developed for Kai's story

Interview 08 Pseudonym: Kai

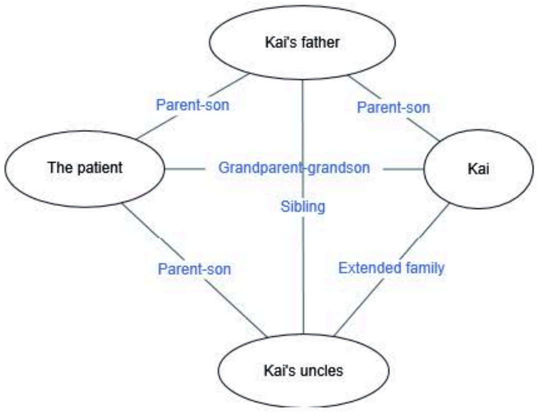
Kai was a 28 year old man who was married and was a private business owner. We met at a Café. The interview lasted 62 minutes and took place 45 days following the death of Kai's grandmother. Kai's deceased grandmother was 77 year of age and had lived about two hours' drive from the hospital in which she was treated and died.

Kai's grandmother was transferred to Hospital A from his hometown to receive a surgery due to a brain tumour. However, a vessel near the tumour was not detected until the operation was carried out and another small operation was needed which had to be signed by the family at the time. Kai's grandmother was sent to the ICU following the operation.

On the third day in the ICU, the doctor informed Kai that his grandmother was only maintained on the machine and had no hope to recover. Then Kai's father and uncles (the patient's sons) made the decision to withdraw the patient from the ICU and take her home taking into account the further cost in the ICU, the custom of dying at home, and the doctors' advice. Kai had different opinions from his father and uncles because he perceived that his grandmother's death was a result of the surgeon's malpractice. However, he did not have the right to make the decision for his grandmother because he was the younger generation. He commented the decision of transfer was to "sentence her to death".

Kai's grandmother died at home shortly after the ambulance service providers extubated her immediately after reaching home.

The figure below shows the family structure of Kai according to the individuals and their relationships mentioned in his story. The relationship between them is marked. Kai was the person told the story and all the relationships were unfolded around him.



Textbox 8 A vignette developed for Siming's story

Interview 09 Pseudonym: Siming

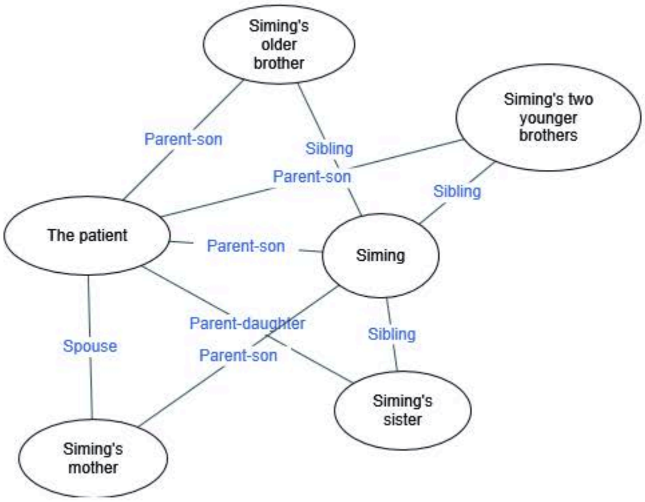
Siming was a 47 year old man who was married and was a private business owner. We met at a Café. The interview lasted 1 hour and 25 minutes and took place 58 days following the death of Siming's father. Siming's deceased father was 75 year of age and his hometown was about 13 hours' drive from the hospital in which he was treated and died.

Siming's father was admitted due to a fever. Some bacteria was found in his blood and an expensive treatment "washing blood" was used in the ICU. Siming signed the treatment representing all his brothers. However, Siming's father started to deteriorate from the second day of using the treatment. The ICU doctors arranged a family meeting to explain the changes to Siming and his brothers, without his mother and sister. The decision by the family was to continue "washing blood".

Then it was about 2am the next early morning, the ICU doctor called Siming that his father was dying. Siming rushed to the hospital and decided to take his father home because their home custom required to die at home. Siming and his three brothers took their father home immediately. However, Siming's father died on the way about three hours after departure.

Siming blamed himself that it was he who killed his father because he signed the treatment "washing blood" which killed his father.

The figure below shows the family structure of Siming according to the individuals and their relationships mentioned in his story. The relationship between them is marked. Siming was the person told the story and all the relationships were unfolded around him.



Textbox 9 A vignette developed for Quanxin's story

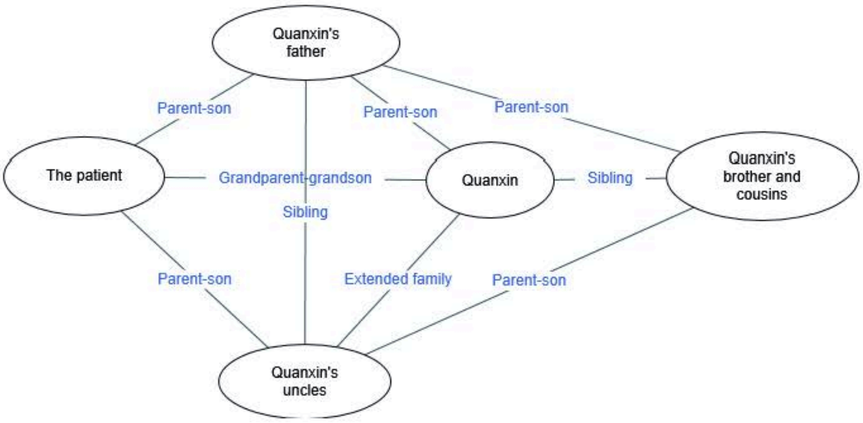
Interview 10 Pseudonym: Quanxin

Quanxin was a 35 year old man who was married and was a private business owner. We met at a Café owned by him. The interview lasted 75 minutes and took place 43 days following the death of Quanxin's grandfather. Quanxin's deceased grandfather was 88 year of age and had lived about two hours' drive from the hospital in which he was treated and died.

Quanxin's grandfather was admitted due to haemoptysis and was diagnosed with lung cancer. Supportive care was used. An early morning at about 3am he was transferred to ICU due to breathing difficulty. Taking into account the incurable cancer, the dying condition, and their custom of dying at home, Quanxin's father and uncles (the patient's sons) decided to take his grandfather home to die. The decision of transfer was not because of financial pressure but their custom of going home to die.

Quanxin's grandfather was happy to be at home surrounding with his sons and grandsons. Quanxin paid two carers to offer help and invited a private clinic doctor coming to visit his grandfather for home care. He died at home about a week after discharge.

The figure below shows the family structure of Quanxin according to the individuals and their relationships mentioned in his story. The relationship between them is marked. Quanxin was the person told the story and all the relationships were unfolded around him.



A.12 Initial codes generated from the first interview

Codes	Definition
Abnormal appearing	Abnormalities appeared including various symptoms and signs of illness.
Ascribing the death to malpractice	The abnormal appearing, death or other reverse outcomes were ascribed to the malpractice by the doctors: improper, illegal, or negligent professional activity or treatment.
Assessing the occurrence of death	Description about how the participant determining the occurrence of death through some symptoms or signs.
Constructing the causes of the abnormal appearing	Attempt to explain the reasons why the abnormal symptoms or signs appeared.
Constructing the decision on giving tips	Describing and explaining how the decision was made to give tips or a red envelope requested by support workers or drivers of ambulance.
Constructing the ICU as not a life encouraging place	The care in ICU and the environment was conceptualised as a location that was not encouraging the patient to survive but destructing the patient's mind.
Constructing the identity of patient	Portraying the characteristics of a person that resulted in a certain group of behaviours or outcomes of actions. The participant explained why the death happened and part of the reasons was the patient’s characteristics and personality.
Constructing the identity of self	The description of self to explain the logic of what the participant decided or did.
Constructing the logic: caring for the patient	Describing how the patient was cared for and explained why.
Constructing the logic of decision: cost	Describing and explaining the consideration and attitudes of cost in the decision-making.
Constructing the logic of decision: dying condition	A reason for the decision was the condition of dying that was hinted or confirmed by the doctor or other staff.
Constructing the logic of decision: hospitalisation	Explaining or justifying why a particular choice was made in terms of seeing a doctor or hospitalise in a hospital or unit.
Constructing the logic of decision: risk	Explaining or justifying that a decision was made because of risk of death

Codes	Definition
Constructing the logic of decision: standard	Describing and explaining the consideration of the official, professional and standard option, for example, the hospital' ambulance with sufficient resources and good service rather than private ones.
Constructing the logic of decision: time	The consideration of time about its influence in decision-making.
Constructing the logic of decision: unreasonable treatment by the doctor	The choice of treatment plan made by the doctor was not appropriate in the participant's view.
Convergent views on treatment	Close to or agreement on the choice from possibilities.
Custom oriented decisions	The reason for the decision was the custom, including THtD, giving a red envelope for the death, and the way of dying at home.
Decision assumption: trying another option	Assuming that choosing another option might generate a better consequence and should have been used.
Decision assumption: what if making a different decision	Assuming if a different option was chosen, the outcome might be different or better.
Divergent views on treatment	Different or contradicting opinions or decisions about the treatment
Gender authority based family decision	Male family members rather than female family members had the right to make the decisions that need to be shared responsibility.
Hinted the death: no hope	The doctor implicitly rather than explicit or openly told the family that the patient was dying and there was nothing to do.
“I am a lay person”	An in vivo code. Describing that the participant was not professional and might not have the necessary knowledge in making decisions.
Impressive event: the family talk	A detailed talk between the family and the patient that was stressed by the participant.
Negative evaluation: additional money was paid or charged	A negative experience with that the family paid for treatment or medication that was not used at all.
Negative evaluation: malpractice	Negative views toward the care practice by the doctors.

Codes	Definition
Negative evaluation: pretence and complaint	A negative description about the transfer care or service: the individuals requested for tips with excuse and complaint.
Negative evaluation: profit-driven health system	An over negative views on the health care system and the doctors to show the participant's opinions on the broader context: pursuing money.
Negative evaluation: unjust society	The view towards the entire society was negative, for example, unjust to the family and other similar ones.
Normal appearing	Normalities appeared or maintained such as eating, speaking etc.
Positive evaluation: good practice	Giving a good evaluation on what is done to show that what is right and what is not right in care practice.
Powerless people	Describing and discussing that the individuals had no power to change or make other choices.
Professional needs: consult/ transfer	Seeking information or advice from other professionals, or transferring the patient to another setting for a better treatment by competent doctors.
Decision regret for what was chosen in decisions	Negative meanings such as regret or guilty were generated from the decisions that were made by the family: having no talk or conversation between the family and the patient before death, deciding not to remove the tube.
Decision regret for what was chosen from contradicting options	Negative meanings from the decisions made by the family from two contradicting options and only one choice could be made.
Shared decision between male family members	Decisions needed to be made jointly with other male family members.
Decision struggling: accepting the death caused by the malpractice	Struggling and pain was described to the death which was believed to be a result of the doctor's malpractice: improper, illegal, or negligent professional activity or treatment.
Taking the responsibility of decision	The family members who made the decision had to take the responsibility for any consequences of the decision including death, by signing the consent for the discharge.

Codes	Definition
Decision power: rules, standard and authority	Family respected the standard and followed the rules in decision-making even though they might have different thoughts or opinions. Rules were a set of explicit or understood regulations or principles governing conduct within a particular activity or a setting. Standard: a level of quality or attainment. Authority: the power or right to give orders, make decisions, and enforce obedience, for example, the doctors' prescriptions, requirements or demands.
The strategies to encourage life: talking about family	Describing and explaining how to encourage the patient to survive in the ICU, for example, telling the patient something about the family events.
“There was a problem”	An in vivo code, a negative description on the options available for making a decision and the behaviours of the individuals involved (in the transfer service)
To gain peace of mind	The logic or purpose of making a decision was to obtain peace of mind, for example, using oxygen therapy before death.
Using futile treatment	The treatment used was ineffective or useless.
Views on the death	Expressing the views about whether the death was good or acceptable.

A.13 Mast codes across all interviews

Name of code	Definition
A profit-driven health system	A view about that the main goal of the healthcare system is to pursue money
“A red envelope”	An in vivo code. A custom that becomes an excuse for tips. A red envelope containing money for good luck according to the Chinese custom of death
Attitude: cost - medical malpractice	Description and discussion about the opinion on payment of treatment or services to indicate the underlying meaning to the participant: the doctors’ and other staff’s improper, illegal, or negligent professional activity or treatment.
Attitude: cost - virtuous family	Description and discussion about the opinion on payment of treatment, transport, funeral or any cost related to the transfer to show the Chinese family virtue.
Availability of caregiver	The quality of a family member or paid helper being able to be used or obtained to regularly look after a patient
Avoid death talk	The communication between patient and family was, or should be about life rather than dying or death, which reflected a taboo culture about death.
Context: unjust society	A negative view on the society that was experienced in the transfer event: the decision was not based on or behaving according to what is morally right and fair.
Decision assumption: cultural expectation	The underlying reason for a decision was the cultural expectation on the family and if not, the family would be blamed by the public, relatives and friends.
Decision assumption: circumstance specific	Explaining and assuming that a different decision would be made under a particular circumstance that was different from what really happened.
Decision barrier: time pressures	Decisions were made when there was limited time.
Decision facilitator: the staff acknowledged the decision	HCPs clearly recommended or agreed with the choice of going home to die according to families’ custom.
Decision influence: rule, policy, and law	What informed the decision was a rule: a set of explicit or understood regulations or principles governing conduct within the event; a policy: a course or principle of action adopted or proposed by a government, party, business, or individual; a law: the system of rules that a particular country or community recognizes as regulating the actions of its members and may enforce by the imposition of penalties.

Name of code	Definition
Decision influence: patient identity	Constructing the identity of the patient to explain or justify some decisions: education, occupation, personality.
Decision influence: family self-image	Constructing the identity of the participant him or herself or other family members, or the entire family, to explain or justify some decisions: education, occupation, personality.
Decision influence: family finance	The ability of the family to, successfully or efficiently, pay for the cost involved in THtD.
Decision influence: family intimacy and affection	The closeness and bond of love between family members that influenced the decision-making.
Decision influence: unspoken rules	Some behavioural constraints imposed in organizations or societies that were not voiced or written down
Decision influence: violating the local custom	The concerns or outcomes of the decision that break or fail to comply with the custom about dying at home, for example, the patient died before or during transfer.
Decision needs: standard and professional care	Constructing the logic for decisions were to seek a level of quality or attainment and related to the medical profession.
Doctors “shirked” responsibility of decision to families	A perception by participants that the doctor’s responsibility of decision was transferred to family through requirement on written consent for the decision.
“Falling leaves return to their roots”	An in vivo code, which was a Chinese proverb said by participants. The reason for the transfer was to respect the Chinese custom that a person should die at home rather than the hospital or other places, including all related activities, procedures such as funeral, burial.
Family shared rather than individual decision making	The responsibility of some critical decisions, including transfer were made by the joint family rather than a single member, including share of the cost and any outcomes of the decision.
Fear of death	Description of the anxiety of death or presaging that the patient will die.
Filial piety	In Confucian, Chinese Buddhist and Taoist ethics, filial piety is a virtue of respect for and taking care of one's parents, elders, and ancestors and this is a concept shaping families’ decision-making.
From divergent to convergent decision through negotiation	Individuals had different choice on a decision and agreement was achieved through discussion and communication
Futile treatment	The treatment given to the patient serving no useful purpose in attaining a goal of recovery
Gap of care	Discussion about the lack of standardised transfer service, the problematic ambulance available for transfer, and lack of

Name of code	Definition
	information, resources for the family to transfer the patient home to die.
Gender based authority in family decision	Decisions were shared by family members but there was a selection based on gender that male family members, especially the sons of patient had more authority in decision-making.
Good death	A positive attitude or view to the death. For example, a successful transfer for achieving a death at home was lucky.
Grieving the loss	Emotions about the loss of the relative reflected in the story.
“Parents’ heart of healers”	An in vivo code, describing the doctor’s attitude to the patient is the same as the attitude of the parents to the child which is the basic professional activity that doctors and hospitals should abide by.
Hope and hopelessness	From a desire accompanied by expectation or a belief in fulfilment of recovery to losing such a desire, expectation and belief.
“I am a lay person”	An in vivo code, illustrating that families lacked the information, knowledge, skills, experiences and resources needed for transfer decision making.
ICU is a place between hope and hopelessness	A conceptualisation about the place of ICU in family’s decision making from hope to hopelessness of recovery.
ICU is a place destructing people's mind	A conceptualisation about the place of ICU: traumatic, not encouraging life, suffering.
Illness trajectory	Description and explanation about the process and pattern of illness development towards death.
Irrational decision making culture	Discussion and ascribing the not logical or reasonable decision making to the broader culture and the society of China
Medical malpractice	The family attributed the abnormal appearing, decline and death to the doctors’ improper, illegal, or negligent professional activity or treatment decision making.
Meaning of telling the story	Participants made sense of their participation of interviews.
Meaning of treatment decisions	Justifying and explaining why a decision was made in terms of which hospital, which ward, and whether a treatment was used.
“Nowhere else to go”	An in vivo code, a metaphor for the difficult choice: falling into desperation, with no other way out.
Patient's wish: go home	Conveying that the decision was the patient’s wish regarding going home to die.
Poor death	A negative attitude or view to the death, for example, the death caused by malpractice.

Name of code	Definition
Powerless family	A helpless experience without the strength to make changes confronting the illness, treatment and death, in the context of the culture, society, healthcare system.
Regret in decision-making	A strong feeling in reflecting the decision-making and the participant experience better when realizing or imaging that the situation might be better, had they decided differently.
Risk of death	A situation involving exposure to danger of death
Seeking answers to death or abnormalities	Attempts to find out the causes for the death or abnormal appearing
Senior authority in family decision making	The right for decision making within the family was defaulted to a senior family member, generation, or relationship to the patient, such as the oldest, the richest, the adult sons rather than the adult grandsons of patient.
“Sentence to death”	An in vivo code, a metaphor to explain the deep guilt feeling of the decision: it was the family who decided the transfer killed the patient.
Style of communicating death	The way of talking about the dying condition or the death was ambiguous, implicit, and indirect.
Struggling with contradictory choices	The difficulty in selecting or making decision when faced with two mutually opposed or inconsistent possibilities.
Peace of mind	The purpose and outcome of the decision making was to be free of worries, regret, and guilty.
Torture on family	Family’s dilemma and pain in decision making.
Virtuous family	A virtuous family behave in a moral and correct way and making right decisions in moral criteria.
Witnessing the death	Description about watching a family member dying, assessing the occurrence of death, deciding the removal of tube before death, and removing treatment from the body after death.

A.14 The quotes and translation

Translation	Original quote
Theme 1: "Stay here or go home?": two steps to decide transfer	
Wei: Then around 7pm, he [doctor] told me my father's condition was getting worse, worse than ever. So he didn't dare to do it [dialysis]. (He said) 'So you see if to stay here, or go home now'. (…) He…, because he wouldn't say it explicitly, 'well you must' (…) He said 'you think about your own customs, and your family's decision'. Then I, I heard this… because if he said so, he's certainly inclined to mean definitely there was no hope. So he told us 'you stay here, or go home according to your custom.' (01: 200-208)	Wei: 然后到7点多，就给我讲说，那个指标更差了，越来越差，越来越差，所以他也不敢做,'那你们看是要住在这一边，还是说要先送回家?'(…) 因为他再一个明显的讲法，他肯定不会说，'哎你们一定要'，他是说'你们考虑一下你们自己的风俗习惯嘛，还有你们家庭的那个决定嘛'，那这个事情我就，我听完，因为如果说按他这样子讲，他肯定是倾向于说基本上没希望的这种，他才会去跟我们讲这个说'你要么就是说还在这边，或者说你根据你们的习惯如果说要回去'。
Zhi: At the time, we told the ICU doctor 'if my mum is really not right (dying), in our AA (the local area), my mother's siblings all required us to bring her home with her last breath'. (07: 39-41)	Zhi: 那当时我们就有跟ICU要求说有跟医生说，'如果我妈妈我老妈如果确实真的不行的话，我们AA这边，'因为我老妈她，她娘家她一些兄弟姐妹都要求说要给她留一口气回来嘛。
Lili: However, the doctor shook his head. He said that 'you should know that there is only 0.5 percent of the hope (of recovery)'. Then I thought there must be no hope and he was embarrassed to tell me the truth, so he said 'only 0.5 percent'. Because his heart beat declined rather than increased when they resuscitated him. (06: 58-62)	Lili: 但是医生就摇头，他说'最多自己做好心理准备，只有0.5%的那个希望，'就这样子，那我就决定那个肯定是没希望，他是不好意思跟我说0.0%的希望，他就说只有0.5%，他说，因为当时看他的心跳就一直往下往下往下，就没有往上的那个意思，就是他们抢救的时候，
Siming: Because (my father's) elderly, and my hometown has a custom, that the elderly are not allowed to old [die] outside [not at home] which means he couldn't be left outside, we considered if we could take him home before death. (09: 65-67)	Siming: 因为老人家嘛，我们老家有个风俗，就是说老人家不能叫老外面，就是不能就是说不能叫丢到外面嘛，因为我们，意思就是说要在看他活着之前看能不能把他送回家。
Qing: At about 10 o'clock. Was it 10 o'clock that day or the next day? The doctor said when communicating with us, that '(my father's) condition isn't optimistic, the rate of cure is very low, and there is basically no hope'. Well for our family members, we considered my father's physical condition was still good at the time. We still held a glimmer of hope, held a glimmer of hope, and then (the patient) entered the ICU. (…) But when my old father didn't wake up after a week, we felt a dilemma, because we already believed that the hope of waking up was no longer there. Was it beneficial or not that my old father lay still in the ICU and was maintained on those machines? It's painful to us. (…) Forty days later, the doctor said there was no hope, because the organs were beginning to fail. So in the custom of our AA, it's better for the elderly to pass away at home. (02: 4-7, 9-12, 14-16)	Qing: 那大概在10点，是当天的10点还是隔天啊？医生跟我们沟通的时候就说了这个，说'病情很不乐观呐，治愈率是非常之低的，基本上没什么希望，'那对于我们家属来说，当然额，看到老人家这个身体状况当时还是不错，我们还是抱着一丝的希望，抱着一丝希望，那就进ICU，(…)但是过了一个礼拜以后老人家还没醒的时候，我们就感觉这个很为难了，因为，我们认为已经是，唤醒的那个希望已经不存在了，那老人家躺在医院里动弹不得，就依靠那些设备来维持，到底是好，还是不好？对我们来说是很痛苦的，(…)40天后，医生说没希望了，因为器官已经开始衰竭了，那我们在AA的这个风俗里面是，老人家在家里面过世是比较好。
Qing: I used to think that ICU was a place to save the critically ill. When a patient came, he was cared for in a particular environment, which was in hope [of recovery]. (...).So you asked me how about the ICU, I don't think	Qing: 以前我认为ICU就是一个重症救护室，病人来了，他要在特殊的环境下进行重病看护，它是有希望的，(…)所以你说ICU的怎么样？我认为没什么亮点，就是高级病房，对

Translation	Original quote
there is any specialty. It’s just an advanced ward. For me, it’s an advanced ward. For my old father, this state is only an advanced ward. Nothing else (02: 395-398, 462-464)	我来说就是高级病房，对老头老爷子这种状态就是高级病房，没了。
Ying: It’s the first time or the second time (day in the ICU) I already planned to take him back. By the third day, I had decided to contact the ambulance and take him back. (…) I think dying people all go there [ICU]. (...) I always believe that people going to the ICU have no way to come out again, and all come out to die. (...) I think the door is exactly the same as what I watched on the TV. When the door is closed, I feel that there is no hope at that moment. There is no hope in the ICU. (05: 86-87, 491-497)	Ying: 第一次，还是第二次，那时就计划着把他带回去，应该到第三天的时候，已经确定帮他联系车，把他载回去。(…) 我觉得人快要死了都是要往那边。(…) 我始终觉得进了 ICU 出来都是，没办法再出来，出来都是走。(…) 我觉得那个门跟我在电影电视上看的简直是一模一样，门一关那以瞬间，我就觉得好像没什么希望了，那就是到了那儿更没希望了。
Wei: He [doctor] said ‘you think about your own customs and habits, and your family’s decisions’. (…) ‘It’s up to you.’ Some have the customs of going home rather than passing away in the hospital. This is the custom in AA (the local area). It varies in different places. Some don’t take it seriously while others do. So he [doctor] did talk about it. (01: 205, 376-378)	Wei: 他是说‘你们考虑一下你们自己的风俗习惯嘛，还有你们家庭的那个决定嘛，’ (…)‘那就是你们自己那个喽，’有的那个就是说习惯要回家，就是不愿意说在医院那边走掉，就就 AA 这边的习惯，就是反正各个地方，各个地方，有的不讲究这一种，那有的就说比较那个，所以他也在讲，
Lili: It’s [transfer] up to you. It’s your family’s business. It depends on how you treat it. There are still such fellows who don’t take [the relative] back and choose cremation. We’re different. (…) If he died in the hospital, if we still had the chance to take him away we would try our best. If they [the hospital] didn’t allow us to take him away, and no way, then went for cremation. (06: 353-355, 366-367)	Lili: 那个事情是看你自己，你自己家里人处事情，看你怎么去处事情, 还是有这种老乡烧灰不带回去，我们就不一样，(…)如果在医院就走了的话，如果我们尽量带得走我也要带走，如果说实在说这边不让我们带走，实在没办法的情况下，你就火化了。
Jun: I have three younger sisters and one of them supported me to go back. The younger brother, and another two younger sisters suggested to let him [my father] pass away in the hospital, in the morgue. I said ‘(he’s) so old, and I feel it’s very unworthy (if he) passed away silently there’. (…) Well, my younger brother (laughing) didn’t want my father back as well. Because it (hospital death) saves time, costs less, isn’t it? If we take him back we have to do the funeral. Ah, there is a lot of etiquette, too much. And we have to guard him for three days and three nights. We cannot sleep, and just close eyes for a little while. (03: 60-65, 129-132)	Jun: 我三个妹妹，一个妹妹让我回支持我回去，因为我那些，一个弟弟、两个妹妹意思是说不行在医院送天马，太平间那边，我说那么老了，这样无声无息过去，觉得很不值得. (…)我还有个弟弟（笑）也不想让老人家回来。因为省事啊，花钱少啊，是不是？那如果回来我们这个要办事啊，哎哟那礼节七七八八的很多啊，太多了，还要守三天，守三夜，不能睡觉的，最多就眯一下。
Zhi: If she [my grandmother] really died in the ICU, we wouldn’t take her back. We would do what we should. We would hire a lawyer to have a look at how the doctors did the surgery. We would just give the relevant documents to the person who knew medicine. (…) If we were not native, she was absolutely placed in the hospital, to see how to deal with it [the suit], isn’t it? (07: 103-106, 278)	Zhi: 如果真的死在 ICU 的话，我们也不会回来的啦，就是这样啦，就是该怎么样的我们会，该给院方好，反正他怎样做手术的我们就会那个请律师会怎样的，就是就是要懂得医那个医疗的人，我们会把那一些相关手续给他看，(…) 如果是我们是外地的话，绝对是放放医院里面的，看这个事情要怎样处理，是不是？
Lili: A person working inside, among the doctors, said that he had seen a lot of such cases and most died. ‘You are only waiting here’ he said, ‘and it’s useless.’ He said ‘if you have the custom to take him home, you’d better	Lili: 他医生里面的人，就是经常在里面那个，他就说，这种情况他看到很多，‘反正就是死的多，你在这边也是熬时间，’他说，也没有用，他说‘如果说你们老家有那个风俗，要拉

Translation	Original quote
do it quickly. It's better to go earlier.' So I decided to go.(06: 434-436)	走，你还尽，应该是早一点走，比较好，'就是这样子，我才走。
Kai: So why we took her away? Based on the advice of the doctor, what the doctor said, and all sorts of our own reasons we made the decision. It wasn't that we sensed that she had no hope (of recovery). It wasn't our own decision. Instead we were forced to accept (the death), forced to decide (to transfer), against our intentions, to be honest. (08: 306-308)	Kai: 所以我们为什么带她走？就是根据这个他医生的建议，医生讲的话，还有总总我们自己的原因，才下了这个决定，不是说，不是说我们自己觉得她没希望了，给她那个，不是我们自己决定的，就是说被迫接受，被迫决定，出于无奈也是，只能这样讲。
Hui: (The doctor) talked about the treatment and cost at about midnight. He said the money wasn't enough. Then we asked "how is my mother?" He shook his head like this. He said 'if you pay, if you pay 1,000 or 2,000 yuan today, the money will be run out tomorrow but your mother wouldn't (survive), wouldn't be saved.' (04: 130-133)	Hui: 那12点多讲那个，晚上12点多，就是说是看病花钱，就是那样，说钱不多了，他说，我们问'老人的病怎么样？'他说，就这样摇摇头，他说他说没，花钱可能是，'你今天扔进去1万2万，明天就没有了，好像是老人也不会那个，也不一定命能救得过来'，就这样的。
Siming: At about one o'clock in the morning, (the ICU doctor) called me. The attending Dr H, said 'your father isn't alright (dying). What's your plan?' Then I said if he's dying, we cannot do anything, right?' So we hurried to take him home. (...) He wasn't clear at the time. He's already on the ventilator. The (endotracheal) tube, everything was already there and we were about to go. (…) The doctor told us, 'drive fast, see if he can get home and will not (die) on the road.' (...) I mean let's see if he could reach home because the elderly are not allowed to old [die] outside (home). (...) We went home on a high speed road. All of us four brothers were in the ambulance. (...) and then suddenly we saw his breath stopped. He passed away at the time. He passed away when we just arrived at City G. (...) Well we were only crying in the ambulance at the time. (09: 112-115, 119-120, 271-271, 277-278, 126-133, 280-281)	Siming: 然后到晚上，到凌晨一点，就打电话给我，就那个主治医生，姓H的，他说'那你老爸不行了，'这个他说'那你准备要这个这个叫什么，这个看看有什么打算，'那我说那如果不行了，因为当时我们就是一个，那我说不行了那也没办法，不行了，是不是？这个我们就赶紧拉回家，拉回家，(…)那时候没那时候已经不是清楚了，那时候已经已经那个就是呼吸机都上好了，那我们，那个时间他管子，那已经所有的一切都那个了，那我们就准备拉走了。(…)就是说医生给我们讲了，他说'你开快一点，看能不能坚持到家，路上才不'，(…)我是说看能不能坚持到家，如果坚持到家，走了，反正我们，这怎么讲？因为老人家不能老老在外面，就是这个意思。(…)我们走高速，因为我们兄弟四个都在这个那个那个救护车后面，(…)然后就突然就看到这个呼吸的这个好像是比较这个，没有那个嘛就是，就是那个时间就没有了，他就没有了，就刚到City G就没有了。(…)那是，哎哟当时我们只有在车里面都哭哭啼啼的。
Zhi: If we were not native, she was absolutely placed in the hospital, to see how to deal with it [the suit for medical malpractice], isn't it? (…) For a non-native who live far away how could she be taken home? Impossible. Just because we are the local residents in City A, where we were born and raised, right? We must take her home for the funeral. (07: 278, 286-288)	Zhi: 如果是我们是外地的话，绝对是放放医院里面的，看这个事情要怎样处理，是不是？(…)你说如果是一个外地人，那七远八远的他哪里会带回去？不可能的，只是说我们本City A人，在这里土生土长的，自己地方地方也有，是吧？再怎样也要带回家里操办后事。
Quanxin: It isn't that we give up the treatment. It's really a tumour, which was impossible to cure. Under the circumstances, we took (my grandfather) back. After we went back the outpatient clinic nearby came over to give the general IV treatment. Because it's impossible to cure in the hospital and the critical notice has been issued, and we only took him back when the phlegm (symptom) couldn't be resolved. (10: 45-48)	Quanxin: 那不是说我们放弃治疗，这个是真的是说已经是肿瘤了，那根本不可能治愈的情况下，所以说我们会回去，回去的话，我们就是说家里面的那个门诊，还是会会来大概的点滴治疗，因为在医院是不可能治疗好的，那病危通知书已经下发了，已经是化痰已经化不过的情况下，我们才接回去的。

Translation	Original quote
Hui: She didn’t breathe at all. She was dead. She was dead when we took her out of the ICU. Ling: She was already dead. Hui: She didn’t (breathe at all). It’s not that she was so ill and couldn’t be cured so we took her home. No. She was dead. She was dead in the ICU. (04: 232-236)	Hui: 那时候都没气了，一口气都没有了，已经是不在了，出病房的时候人就不在了， Ling: 已经不在了。 Hui: 已经没那个，不是说病重了看不好我们要走，不是这个意思，就是已经不在了，在病房已经不在了。
Lili: If he hadn’t been resuscitated here in the morning and had been taken away he might have got home (alive). With the oxygen, and he might have got home counting the time assumed (for the journey). However, how could we bear not to save him here and directly take him home? We must save him and if there was any hope (of recovery) he would survive. (06: 514-516)	Lili: 如果是在这边，早上我们不在这边抢救就拉走的话，可能到得到家，那个氧气戴起来哦，按时间来算，可能到得到家，那我们怎么忍心说不在这边抢救就拉走啊，是吧？我们肯定要在这边抢救下，如果有希望就在这边医了就好了。
Quanxin: We took him back, as I just said, because it’s impossible to cure. If it’s possible to cure him, we would save him regardless of how much we had to spend. The reason we took him back isn’t the medical expenses that we cannot afford. It’s purely the custom that he must go home. (10: 96-99)	Quanxin: 因为我们接回去的情况下，就像刚才我讲的那样，这个已经是不可能的治愈的，你如果说有可能治愈的情况下，花再多的钱我们也是会治的，这个我们接回去，不是说因为医疗费用这一块，有什么负担接回去的，这个存粹就是说，我们的这里的一个习俗，一定要回去。
Jun: Two or three days after using the albumin (an expensive medication paid by out-of-pocket), it seemed not useful for (my father who) was old. My siblings said that since (our father) was in the hospital, we should be filial and apply the second operation, dialysis, use dialysis again. (…) Doctor Fu said ‘if you want to do dialysis again, then let’s do it. It might work or there is nothing to do’. The dialysis is to exchange the blood of the whole body, isn’t it? However it didn’t work, didn’t work. (03: 44-46, 147-148)	Jun: 点滴蛋白以后，过两三天，看年纪大了哦，滴好像没什么用，没什么用处，那我们兄弟姐妹说，‘既然来医院了，尽点孝道，要做第二次手术，’透析，再透析啦，(…)那个 Fu 医生说，‘如果你要就是再做透析，再做透析，透析做了，能行就行，不行就没办法了，’透析全身换血什么的，是不是啊？还是不行，不行，医生又五点左右给我打电话，“你要赶快决定啊，不然，看没什么用啊。”
Lili: It’s the way when we really had nowhere else to go. It’s the way when he could not be cured. We really didn’t have any choice. (06: 516-517)	Lili: 是实在没办法走投无路了，医不好我们才是才回去那一条路，是实在没办法的情况下才才回去，就是这样。
Kai: Because we had no choice. If we hadn’t taken her [my grandmother] home and left her here [in the ICU]. Then a lot of expenses were also (…) because we are limited in money. (…) Due to economic reasons, due to such and such reasons, we agreed to take her out. If, for example, the actual situation wasn’t so bad as the doctor said, but he told us like that, or what miracle there would be later, but now we, we gave her up first and took her out. It meant that there was no hope at all. Then as her family we are very sad. (08: 63, 102-105)	Kai: 不然你没办法，你不带回去只能在这边，然后七七八八花费也，因为我们经济也比较有限，(…) 因为经济原因，因为这些这些原因，你们，我们同意把她接出来了，如果说比如说像医生，实际情况没那么严重，他给你说成那样，或者说后面还有什么奇迹，然后我们现在就，我们自己先放弃了，给她接出来了，等于说一点，就真的一点希望都没有了，我们作为家人肯定也很难过啊。
Jun: I was informed for the first time, that (my father) was critically ill. I (said to) my siblings ‘since the doctor said so, let’s (take father to) go home soon. It would be useless, or meaningless, to stay’. (I have) four little siblings and the little brother said to try another course of treatment. (03: 143-145)	Jun: 第一次给我通知，意思是病危了，我给那那些兄弟姐妹都，‘既然医生说这样，不然早点回去，反正如果这样，再拖也没什么用，没意思，’那四个兄弟姐妹，弟弟说‘再做一个疗程看一看怎么样’。
Zhi: What I’m most tangled about is the (doctors’) medical skills. I think it must be a problem of medical skills, then how could it always be like this (four surgical operations)? (…) We definitely struggled. Why wouldn’t	Zhi: 我就是纠结，最纠结的就是在这里，如果是医术，肯定，我认为肯定是医术的问题啦，那不然怎么会老是这样？ (…)纠结是肯定有纠结的啦，哪里没纠结，是吧？如果放

Translation	Original quote
we struggle, right? If we left (my mother) there (in the ICU), we could sue the hospital that it's a medical accident. I'm sure the hospital absolutely had a little responsibility for it [the death], didn't it? (…) But what we struggled with was that if she was left in the hospital, if we did not take my mother home, our town folks would scold us, right? And my uncles and aunts (the patient's siblings) would also blame us. (07: 162-163, 276-277, 289-291)	着，我们还可以告个医院说那个这医疗事故啊，那肯定的，那再怎样你院方绝对有，再怎样也有一点责任那，是不是？(…) 但是我们当时的纠结就是怎样，如果说给她丢在医院，我们没办法给我老妈带回来，在我们这边人家乡里乡亲的也会说，是不是？然后一些我一些舅舅阿姨他们也会说。
Kai: She already passed away. If I raised this (malpractice complaint) she would be dissected. We don't want her to experience this suffering after she died. I mean this. If I requested for this it (the hospital) would go through a procedure and dissect her, and such and such. Then I couldn't take her home. (08: 160-163)	Kai: 你已经去世了，我再提出这个，他还要解剖还要干嘛干嘛的，所以一个出于对，我们本身也不愿意她去世了之后再受这个苦，就是这个意思，你提出来之后，他肯定走程序啊，还要解剖啊，还要干嘛干嘛，然后你人肯定是带不回去啦，就是这样讲。
Theme 2: "His sons discussed and others were not involved": the decision-makers in the process of deciding to transfer	
Ying: He's [my father] completely unclear. Only on the first…one day I went in (the ICU), and told him I would take him home. I could say he grabbed my hand. Actually he couldn't speak at all because a tube was inserted in his mouth. (…) YL: How did you know he wanted to go home? Ying: I don't know, I just knew he wanted to go home. YL: Had you talked about this before? Ying: No, we hadn't. (05: 80-82, 284-287)	Ying: 完全完全不清楚，只有第一，有一天进去的时候，跟他说我一定带他回去的时候，他有，应该说他手抓了我一下，其实他也不会说话，嘴巴也是插着管，什么都没有。(…) YL: 你怎么知道他想回去呢？ Ying: 不知道，我就知道他想回去。 YL: 你们之前有沟通过这个事情吗？ Ying: 没有啊。
Quanxin: No, it's impossible to communicate with him (my grandfather) about the fact he was dying. (...) We may not be like the European and American countries. Because you are still studying in the UK, your thinking is avant-garde since you had contact with the European and American countries, where perhaps the patients know all the diseases and pathologies. In China, not just City A, across the country, I don't dare to say a hundred percent but 98 percent (of families) will not tell the patients about such a critical illness [lung cancer]. (10: 267, 339-350)	Quanxin:对，这个不可能跟他沟通的。(…)我们可能不像欧美国家，那你还在英国留学，那你接触欧美国家会会比较前卫，那可能所有的病情病理，当事人都会知道，那在中国这个国情，不只是 City A，你在全国各地，应该还是说百分之，不敢说百分之百吧，百分之九十八，这种重大病情还是不会跟当事人说。
Jun: When (my father) was critically ill, I don't know how to say, his body showed that 'go home, go home'. (...) On the way home, he opened his eyes wide and looked at me. I was in the ambulance and held the oxygen for him. He looked at me with his eyes opened. Haha. (…) He was very happy being sent back. (03: 257-263, 352)	Jun: 在那病重的时候，反正讲不来，一直比，给我比：回去，回去，(…) 在路上眼睛睁大大一直给我看，因为救护车我坐在这边，帮他拿那个嘛，拿那个氧气那那个，帮他拿氧气，他就眼睛睁大大，他就看，哈哈（笑） (…)送回去他很高兴啊。
Lili: I rushed (to the hospital), cried while walking, and called them [relatives]. Later my relatives and friends, my family all came over. I had no idea what to do on my own. My child (son) wasn't here and there was only we couple. (06: 56-58)	Lili: 赶过来，那我就边走边哭啊，边跟他们打电话，然后他们亲戚朋友啊自家人就全部过来了，过来了，我一个人也没什么主意，小孩也不在这边哦，就我两夫妻在这边。
Ying: We negotiated, because every one of us had to. Everyone was his child. Everyone had to decide, and (we) also asked my mother. (05: 231-232)	Ying: 我们商量的，因为我们每个人都是他孩子啊，每个人要决定的，也要问我妈妈。
Jun: Anyway, 10,000 or 20,000 yuan isn't a burden to five siblings. (...) Everyone took a share which was more	Jun: 反正五个兄弟，一两万块也不算负担啊，（…）兄弟一人出一点就这样，一万

Translation	Original quote
than 10,000 yuan. The funeral cost more. The home funeral cost about 100,000 yuan. (...) Our (funeral) is the cheapest. This is the case in the countryside. Now this is universal in our countryside. If the (family's) economy is better, they spend two to three hundred thousand to (celebrate with) the relatives and friends. (03: 93, 96-97, 109-112)	多，丧事花的比较多，回家丧事花了十来万。(…) 我们是算最差的一个，农村就这样，现在我们农村的国情就这样啊，人家如果经济好一点的，花了二三十万，来亲戚朋友。
Wei: Later I discussed with my brother, and also with my family. My family also would like... Because I don't dare to tell my mum what happened, I just told my cousins (male) such and such. My brother and my cousin heard that, and they also said, 'in this case, perhaps we should go back, go home. Because according to the customs here, because of that, we should go home, come back.' (01: 208-212)	Wei: 后来我就跟我哥商量了一下，然后也跟家里面那个商量了一下嘛，那那个就是说，我家里的人他也是想说那个，因为这些事情我都不敢跟我妈妈讲嘛，那就跟我那些堂哥什么的，他反正他们也反正比较有那个，那我哥哥听完，跟我堂哥听完，也是讲说，'那如果是这样子，那可能还是要回来嘛，回家'。
Qing: There are a lot of different opinions in treatments among the patient's family, especially for our generation with many siblings. (…) When we siblings were discussing, I could say this to my brother, but I couldn't say this to my sister, because this is different, because my sister had a very good relationship with my father. What I mean is this was also a torture, because there was really no hope. I couldn't see any hope. To cut him and he might go (die) earlier. We couldn't do the job after death. So we (reached agreement) through communication, and we are relatively rational. (02: 24-25, 96-100)	Qing: 对病人家人来说，特别是说以前我们这一代的有很多兄弟姐妹，在治疗上也有些分歧，(…) 我们兄弟姐妹在探讨的时候，我跟我哥可以这样说，我跟我姐就不可以这样说，这个因为是不一样的，因为我姐跟我爸的感情是非常非常好，那我是说，这也是折磨，因为没有真的没有希望，看不到希望，你开了一刀，可能更早走，你后面的工作你还做不了，哎我们通过不断的沟通，而且都比较理性。
Jun: I said 'I will take (father) home even though you don't agree'. Later my little brother also agreed with me. Because we brothers matter the most, if we both agreed, my sisters didn't have any choice. So we took (father) home. (03: 193-194)	Jun: 我说'你不同意我也要带回去啊，'后来我弟弟也同意，因为主要是我们兄弟嘛，我们兄弟同意了，那妹妹那就就没办法了，就带回去。
Quanxin: My uncles and my parents made the decision. My father and his siblings, six siblings made the decision. (…) I couldn't make the decision and only took him [my grandfather] to see doctors. I have no right to decide because I'm his grandson. My senior generation have. (…) His sons discussed it and others were not involved. Others, we just gave some advice. (10: 94, 101-102, 279-280)	Quanxin: 我上面伯伯，我父母亲，我父，父亲的兄弟姐妹六个人决定的. (…) 我没办法做这个决定，我只是能负责带他来看病，带他来治疗，我没办法决定，我是孙子辈，我上面。(…) 他的儿子商量，其他的是不参与的，其他的，我们只是说给点建议。
Kai: I was against it (the decision to transfer) at the beginning. I said 'let's have a look before 8am.' My father and his brothers are not rich. One of them is better off but he couldn't make the decision. I don't know whether he wasn't willing to spend money, or something else. He was able to afford for (my grandmother) to stay (in the ICU) for a few days longer. However, my grandmother was in such a condition (dying) and they have so many siblings that he didn't want to spend so much money alone (because other siblings couldn't afford the share). I think so. So I have complaints with him and furthermore he is the oldest. (08: 371-376)	Kai:当初我本来就是反对，我说在 8 点前再看一下，然后因为他们几个兄弟，我老爸他们几个兄弟经济都不是很好，有一个比较好的，他又做不了（主），他又，怎么讲？他不舍得花钱还是怎么样？我也搞不懂，如果按照他是有能力再再住个一小段时间，但比如，毕竟说老人这个情况嘛，然后他兄弟又那么多个，所以他不想一个人出那么多钱，就是这个意思，所以我也有点抱怨那个人，他还是排老大。
Theme 3: "Falling leaves return to their roots": the meaning making of transfer	

Translation	Original quote
Quanxin: Why did we go home later on? Because first, in our AA area (locality), I don't know where you are from. In our AA area, when the elderly person is in critical condition, we have to take him home. (...) It may be a culture of thousands of years, in our City A. We belong to the rural area of City A. Falling leaves return to their roots, so he must go home. (10: 31-32, 42-43)	Quanxin: 那在后期的话，你说我们为什么会回家？因为第一，我们AA地区，我不知道你是祖籍哪里，我们AA地区，老人家病危的情况下，我们是都要接回去的。(...) 可能几百年上千年的文化，我们CityA，我们属于CityA的农村，我们的，我们的，就是说落叶要归根，一定要回家。
Wei: In the AA the custom and habits are that, so later we also placed a bed in the hall in our old house. If he’s alive, for an alive person, normally his head is placed toward this side. If he passed away, his head is placed toward the other side. We also complied with the custom. (01: 279-282)	Wei: 那因为AA习惯反正就是说，那后来就我们也就说在那个老房子那个那个大厅那边就是说摆一个床铺嘛，小床铺，那就，因为人如果是活活人，那反正就是说正常这样子头朝这个外面这一边嘛，那如果说人如果说去世了，是要掉过头来这样子摆放的，那反正就我们也是按这个习俗。
Jun: Because we are in a village, and this (going home to die) is the custom. The relatives and friends would scold us: ‘(Your father) has sons and daughters, so many (children) and you let him (die in the hospital)’. It’s [death] quiet in the hospital and nobody knows when we send him there. He will be burned there quickly [cremated]. Because he’s so old we should send him away with a big celebration [funeral]. If it’s quiet, and far away (from the village), nobody would go (to the hospital). So usually (the funeral) is celebrated at home. (03: 187-190)	Jun: 因为我们农村的，这个礼节是这样，‘你有子有女的，这么多，你竟然把他弄去，’亲戚朋友会骂，是不是啊？你静悄悄的有知道你医院什么时候弄到那边去啊？弄过去肯定很快就完就烧掉了，因为我们一个老人家，要给他送终，办热闹一点，就这么回事，静悄悄，这些亲戚谁要去啊？到那么远谁要去啊？一般都在家里办这个事情。
Lili: We brought the corpse (of my husband) back so that relatives and friends could have a look and we felt a little rest. (…) If I brought his ash back, what did they look at? Nothing. We have a good relationship with relatives and friends and the doctor agreed with us to bring him home so that everyone took a look. Then we also felt peace of mind and everyone felt peace of mind. (…) As a couple, he passed away before me so I did his things well based on my own conscience. I’m also relieved. In short, when he’s alive, he was kind to me. When he died, I was kind to him. (06: 385-363)	Lili: 我们捆尸带回去亲戚朋友看一样，好像觉得心安一点这个意思。(…) 那你把灰带回去人家看什么？没什么看了，就是说大家亲戚朋友全部关系那么好，他就是，医生同意我们带回去，人家看一眼，那我们我也觉得心安，大家都觉得心安嘛。(…) 反正我自己就是意思就是，我自己凭我自己的良心，夫妻之间他走前面，我得把他的事情给他办好，就这个意思嘛，我也安心了就是这个意思，总之来说，在生他对得起我，他死了我也对得起他。
Ying: We must take him [my father] home and let him sleep in his own bed. (…) Then I felt peace of mind. Otherwise I would feel very restless. (05: 305, 307)	Ying: 一定要让他回到家里，然后睡在自己的床上。(…) 然后然后我才会觉得我很心安，不然的话我会觉得心很不安。
YL: Did you worry about that, if your father would pass away on the way? Jun: Yes, I did. I did ask (the doctor) whether my father could survive the trip. He [doctor] said “Yes”. I stressed whether he could reach home, because if he stopped breathing before reaching home, he wasn’t allowed to enter the village. If others knew that he returned to the village (after death) they would scold and spit on us. (03: 237-241)	YL: 那你当时有没有担心在路上万一老爷子不行了怎么办？ Jun: 有啊，有啊。我都问‘能不能坚持到回家？’他说没，可以，我一直强调能不能到家，因为我们那边，如果不能到家就断气了，进不了村，进到村知道会给人家骂死，吐口水，就这样。
Qing: Because in China, a society emphasizing relationships between people, it’s very difficult to do this (transfer). Because the Chinese people prefer to die naturally than to take some more active and effective measures to alleviate or slow down anything. Because	Qing: 因为在中国这个人情社会当中，要做到这一点，非常之难。因为，怎么说呢？中国人就是说，情愿这样顺其自然的死，而不愿意采取一些比较积极的有效的手段，去减轻或减缓任何的事情，因为总有些人会指指点

Translation	Original quote
there are always some people who will point at you. If you aren't prepared psychologically that you are going to do these things… Or you think 'oh why am I doing this?' (…) To my children, telling them what I want is only to reduce their psychological burden. As for whether they will do it or not, because I will be lying there, how can I supervise them to do it? There is no way. (02: 227-230, 236-237)	点，你没有这种思想准备，你要去做这些事情，或者说你认为是说，我干嘛要这样呢？(…) 你说我的子女，你跟他表达这个意思，其实只是让他承担的减少心理负担而已，至于他做不做，你躺在那边，你怎么会监督他做不做？这没办法。
Theme 4: "It's a gap in the care": the unmet information and support needs	
Zhi: At the time, we hurried to get my mother home with her last breath. So we signed all that the hospital and the ICU required us to sign. We didn't have the mood to check them and just signed everything, because it's important to come back soon. We signed all that were given to us, because if we didn't sign them they [doctors] wouldn't let us go. (07: 106-110)	Zhi: 当时我们就急于说要回来回来，要赶快让老人家回来，让她最后一口气回到家里面，所以说就院方，那 ICU 里面叫我们要，反正当时的心情也没有去看那一些啦，就是就是能签的就签，人赶快回来要紧啊，是这样啦，反正，所有拿给我们该签的，我们都，我都我都有签，因为如果不签的话，他们也不会让我们走就是了。
Kai: Now its common in China, if there is any emergency in clinical treatment, he [doctor] will not resolve it until you sign it first. (…) The signature, actually I cannot say all of them. In fact, a large part of it is suspected to shirk responsibility. I think so, because most of us don't understand (risk), and only listen to what he [doctor] says. Well, we can only say roughly. For example, he said how much risk the operation is. We can only believe how much risk he said. We don't have, we don't have the ability to judge it. (08: 25-26, 234-238)	Kai: 然后现在中国这边都这样，一到临床有什么紧急啦，反正你要先签字，他才做，(…) 这个签字那个签字，其实不能说全部，其实有一大很大一部分是有在推卸责任这个嫌疑，我是这么觉得，因为像你说的我们大部分都不懂，只能听他怎么样讲就怎么样啊，我们只能说大概，比如说他，说这个要做手术，有多大风险，他他说有多大风险，我们就我们也只能相信啊，我们没有，我们也没有那个判断的能力啊。
Ying: To be honest, there is no data or report showing what cancer it was. Nothing. I forgot to take a look at the cause of my father's death (in his medical record) because he left the hospital and I took him back to C [hometown] using an ambulance. He died at home. So there isn't any proof about what his disease was. I'm also very, I'm also confused. (05: 71-74)	Ying: 治疗其实说实话，没有任何数据报告显示说得了什么癌，得了什么啊，都没有。然后后面就是，我都忘，我连去看我父亲是因为什么死亡的都没有，因为他从医院出来，我用救护车拉回 C 的时候，是在我们自己家走，所以说任何证明也没办法证明他那种疾病是什么，我也很，我也自己也一头雾水。
Siming: Because (my father's) an elderly, and my hometown has a custom, that the elderly aren't allowed to old [pass away] outside [not at home] which means he couldn't be left outside. So we considered if we could take him home before death. (...) We prepared for it (risk of death on the way home) at the time. We already prepared for it. (...) The doctor told us, 'Drive faster, see if he can get home and will not (die) on the road.' (...) I mean let's see if he could reach home because the elderly aren't allowed to old [pass away] outside. (09: 65-67, 271-271, 277-278)	Siming: 因为老人家嘛，我们老家有个风俗，就是说老人家不能叫老外面，就是不能就是说不能叫丢到外面嘛，因为我们，意思就是说要在看他活着之前看能不能把他送回家，(…) 因为当时我们有，当时我跟你讲，我们也有准备了，已经有准备了，(…) 就是说医生给我们讲了，他说'你开快一点，看能不能坚持到家，路上才不…'，(…) 我是说看能不能坚持到家，如果坚持到家，走了，反正我们，这怎么讲？因为老人家不能老老在外面，就是这个意思。
Wei: Perhaps fifty percent (of the death) was because of my father himself, while the other fifty percent should be due to the hospital, or the treatment wasn't the right one, such kind of thing. However, to be honest, I'm a layperson. I cannot judge what the main cause was. (…) Then a support worker took my phone away and said 'you have to ask him (ambulance service staff) clearly if he has any oxygen'. To be honest, I hadn't been involved	Wei: 有可能 50%我们的可能性，有可能 50%应该是医院这边耽误了，或者说用药不那个，没有对症下药，这一类的，那种可能性，但是说不好听一点，我这个门外汉，我也没办法说去判断说，哦到底主因是哪哪个地方，(…) 那结果那个护工呢，又打电，又给我电话拿过去，他说'你要问清楚他有没有氧

Translation	Original quote
in this and had no experience for it. (…) It's [death] confirmed in the morning of 4th (in July) because I don't know exactly, it's 1am or 2am. To be honest, since it's impossible, I didn't dare to touch him, his heart (chest), etc. (…) (YL: Did the ICU doctor or nurse tell you how to handle the tubes?) No, I remember no. Because, to be honest, I didn't expect the tubes to be so complicated at the time. (01: 308-311, 224-226, 505-508, 493-495)	气什么的'，因为说难听点，这些都没接触过，也没经验嘛，(…) 相关于 4 号早上嘛，4 号早上那确定说，因为到底是 1、2 点还是什么的，我也搞不懂，就是因为我们说实在话，毕竟那个，就是在不可能，也不敢说一直去摸他心脏，摸这些的嘛，(…) (YL: 那你在 ICU 出去的时候，医生和护士没有交代给你这些管子回家要怎么处理吗？) 没有，我印象中没有讲，因为，因为说难听点，我说，我当时没有想到说这么复杂。
Qing: It wasn't that we didn't want to give up, but we didn't know what to do. There was no such information to tell us what to do. (…) If my father, like what they [doctors] said, had exited the ICU 10 or 20 days earlier, and returned home, the doctors at least should have told us what we should try to prepare at home. If they didn't even tell about these, or perhaps because we didn't agree (to transfer), he did not say anything. We don't know. (…) We couldn't even get a simple medication in time or he [doctor] couldn't prescribe more to us. (02: 128-129, 290-292, 294)	Qing: 不是不想放弃，我们不知道要怎么做，没有这种（话）没有这种信息告诉我们说'你可以怎么做'，(…) 像我老爷子如果像他们所说的早个 10 天 20 天的出 ICU，如果是回到家里，你医生至少说'你家里尽力所能及的要增加一些什么设备'，如果你们这样子都没说，还是我们没同意，他就没说，这我们不知道，是不是？(…) 最简单的一个药，你都不能很及时的，他也不可能多开给你。
Kai: So in order to take her [my grandmother] back. At the time there were many 'black ambulances', which were fake ambulances. They hung the patient on a ventilator, to show that she was still alive so that we could take her back to our hometown. So we hired a black ambulance. (…) they (ambulance service staff) shouted out the price randomly. How to say? It's like an unspoken rule that its existence is known to everyone, the insiders (in the ICU) all know that they are fake ambulances. I mean the ambulance is from an external, private-owned company rather than the hospital, but it's marked as an ambulance. (…) They charged thousands (Chinese yuan) for only about 100km. The trip they charged thousands for is only hundreds or about a thousand yuan by a routine ambulance. (…) YL: Who pulled the ventilator tube out when you got home, your family or the people in the ambulance? Kai: The guys in the ambulance. Only they knew how to pull them out. YL: Was he a doctor? Kai: He wasn't a doctor but just did the business. Frankly speaking, they just earned the money. (08: 43-46, 52-54, 58-59,113-116)	Kai: 所以说为了把那个骨灰运回去，当时这边的很多那个嘛黑车嘛，就是假的急救车嘛，就是说给你挂上这个呼吸机，然后就证明说你还有一口气还没死，就是说可以运回去运回老家自己自己疗养，自己什么，所以就雇那种黑车回去。(…) 那些人都是乱喊价的，怎么说？它这个像像那种潜规则一样的，它的存在别人都知道，但是就是这个我也，反正内部的人都知道是黑车了，就是说它这辆车是外部，外面人家私家的，不是医院的，但是它挂的是那种急救车。(…) 反正一百一百多公里，他就喊那个时候是几千啊？就是说你普通的急救车才几百块上千块，他都是喊到几千上万的，(…) YL: 哎那回家的时候是谁拔掉呼吸机管道呢？是你们家里人还是跟车的人？ Kai: 那个跟车的人，他们才会拔啊。 YL: 医生是吗？ Kai: 那个也不叫医生啊，他们就是做那个生意的，说直白一点，他们就是专门赚这个钱的。
Zhi: We couldn't get the internal ambulances of the hospital and only called for an external ambulance. We had no choice at the time because the hospital's ambulances are regulated to transport in rather than transfer out. (07: 123-126)	Zhi: 里面的，医院里面的救护车，我们是请不到的啦，只能只能叫外面的那些那些救护车，没办法那当时，那医院医院不是有规定只能进不能出嘛，它是它医院的救护车只能送进去啊，没有载出来的啦。
Qing: We think it (ambulance) wasn't specialised. We also think it's a gap in the care between the hospital and the social security agencies because they never take into account that this is a custom in A or AA, that people	Qing: 说专门的我们认为也达不到，就是说这一个我们认为也是说医院或者是说社会保障机构之间的一个断点，因为他们从来都没想过就是说 A 或者 AA 都有这些个风俗，就是

Translation	Original quote
wish to go home (to die). So there is a lack of a controller. (02: 60-63)	都很希望回家，所以说这一点，就是说变成没有一个控制者。
Quanxin: His breath had been, due to the tumour, half of his lungs weren't working. (…) With the mask, he couldn't even breathe at all because he's so uncomfortable. (…) We took shifts for 24 hours. Both the older generation and us were around during the day time and two or three of us took the night shift. We also paid for two carers. One was hired before and the other was a full-time carer we used after discharge. We had two paid carers. (…) YL: Who gave him the medicine at home? Did he have IV infusion? Quanxin: The medication was prescribed by a community outpatient clinic (...) He [the clinic doctor] came to our house and reviewed (my grandfather's) medical records. YL: Was he a doctor? A community doctor? Quanxin: No, no, it's a private, privately licensed clinic. (...) It's impossible for us to get those doctors (community public doctors) to our home. (…) In terms of medicine, only IV medicine was provided. Perhaps because we didn't request, no other medicine was prescribed. So I suggest for the similar patients in the future, (the ICU doctors should) ask the family whether they should prescribe all the medicine needed. I couldn't get medicine the next day. (…) He [doctor] said the patient had been discharged, so any medicine couldn't be prescribed. (10: 82-83, 88, 154-156, 159-168, 394-397, 399-400)	Quanxin: 他就说呼吸已经说，肿瘤，肺已经一半不工作了，(…) 因为你如果那个口罩的话，根本连呼吸已经呼吸不了了，已经太难受了。(…) 二十四小时轮流啊，长辈我们都有在，就基本上白天大家都在，那晚上的话就两到三个人，那还请了两个，一个之前的护理，还有一个后面请回去的一个专职护理，有请两个护理。(…) YL: 那他在家里面的用药是谁给他的呢？就是他还有在点滴是吗，一直在点滴？ Quanxin: 用药呢，那我们当时就是说社区的一个门诊，门诊开的药。(…) 他有到家里，病历都要看一下，所有病历他都要看过. YL: 他是医生对吗？是社区的医生? Quanxin: 不是，不是，是私人的，是私人有有牌照的诊所。(...) 那个那个他不可能会到我们那个去。(…) 药物，当时可能我们也没给他要求，他只能提供点滴的药物回去，那没给提供其他的药物，那我是建议就是说，以后如果说有其他的老人家或者说其他病患，给他问一下家属，要不要一并给开出去，那隔天我又想去开药开不出来。(…) 他说已经办理出院了，开不出。
Kai: What he [doctor] said was to sentence to death. Nobody was willing to withdraw (her) out (the ICU) if there was hope (of recovery). (...) It's on the day when withdrawing her out, (...) I was worried about the sun burning her eyes and so blocked it for her. It's the moment when my heart was broken. At the moment it meant that we were pushing her on the way (to die), completely ruining hope. (08: 64,365, 367-369)	Kai: 他那句话说了都已经等于说判死刑了，那如果说有希望,谁愿意撤出来，(…) 就是就是那天给她撤出来之后，(…) 我还怕她怕她眼睛晒到太阳，给她挡了一下，就是那一刻，心里是崩溃的，就那一刻，就是说等于等于像我们给她推到这一条路上一样的，完全完全断送了希望。
Wei: This is what I wonder but haven't told my mum, that I regret that, for example, what if I had pulled out those tubes at the time. Sometimes we might be able to say a few words to him. But I didn't dare to pull it out (...) For the (endotracheal) tube, I became struggled and didn't ask (the doctor) about it. I reflected afterwards, perhaps he could be able to open his mouth if I pulled it out. I was thinking about it afterwards. He could be able to speak even though his voice was low, and we might hear what he would say at the end. It turned out we had no talk. (01: 285-287, 441-444)	Wei: 这个是我心里面在想的，没有跟我老娘讲这些，就也在后悔说，到底当时比如说把那些管子给它拔出来，有时候还能跟他讲几句话，那也不敢拔，(…) 对管子的事情，所以我们也变成很冲突，就没有去问，我后面我也在想说，有可能给他拔起来，是过后了，已经是过后我才在想这个事情，有可能还跟他讲几句话，他变成比如张开嘴巴，虽然声音很小，但是有可能还讲几句，听一听，他的那个最后讲什么，变成是一直都没有讲上话。
Qing: Was it beneficial or not that my old father lay still in the ICU and was maintained on those machines? It's painful to us. (...) Because he [father] was a vegetative person, 88 years old and couldn't undergo the surgery, and there was no further treatment. To be frank,	Qing: 那老人家躺在医院里动弹不得，就依靠那些设备来维持，到底是好，还是不好？对我们来说是很痛苦的，(…) 因为一个植物人，88 岁了，又不能做手术，后续也没有治疗过程，说白了，中国人就说等死嘛，(…) 就是说

Translation	Original quote
Chinese people say that he’s waiting to die. (...) I mean, the ICU resources are so scarce but it seems a ward waiting for death. Why? My father occupied a place there. (…) The doctor, I don’t know if it’s after about 20 days in the ICU or when, said that ‘your father is declining.’ But we said ‘what could we do if going home?’ To be frank, if he went home, we didn’t have the good equipment as they [doctors] did, did we? We aren’t as professional as they are, right? Then he’s maintained at home for five or six days long, who were available to take care of him? (...) He [doctor] also advised us to return home as soon as possible, but we, from our consideration, we still think that it’s better to place him [father] in the ICU than in our home. (…) We wouldn’t take him home until he was in a critical status. (02: 11-12, 33-34, 116-117, 131-134, 238-240, 256-257)	哎呀你这个ICU资源本来那么稀缺，好像是等死病房一样，干嘛？ 老人老人家躺在那边是占一个位置。(…)医生，就是说我不知道是20多天还是什么，他说老人家已经有点衰竭了，但是我们说‘回家我们怎么办？’说白了，你一回家，我们比你这边设备更不好，是不是？更不专业，是不是？那好啊，你你拖个5、6天，说实在的，在家里放个5、6天，谁来照顾？(…)他也建议我们尽早回到家里，但是我们，从我们的考虑来说，我们还是认为放在ICU比放在我们家里好，倒不是说他们没有建议我们，他是有建议我们。(…)那你老头子当时的身体状况还没达到那一种紧急状态下，我们认为拉回来肯定是，肯定也不会拉，对我来说，我肯定也不会拉。
Wei: The ICU there only allowed one visit a day at 3pm. Only once a day and no other time (was allowed). (…) My first feeling with the ICU was that even normal people in there, wouldn’t be able to bear it. Why? Once he entered there, all his clothes were removed, tubes were inserted everywhere, in his nose, in his mouth, then, in his urethra too. And he was bound on the bed. (…) And he couldn’t speak and communicate. (…) I said to myself in my mind, ‘Damn it, such kind of treatment, even healthy normal people could be scared to death.’ (…) around 7pm I told him [the doctor] ‘if you go in please tell my father, giving him a chat about the family.’ I said ‘I forgot to tell him these’, which I always regretted later. (01: 175-177, 458-465, 476-478)	Wei: 它那边的ICU只能下午3点进去看一次，一天只能这样子，那其他的都不能那个。(…)那个ICU的那个，我第一个感觉就是说什么，人有时候正常人有时候真的进去就会，都会受不了，为什么？一进去它就变成给你全部，衣服全部换掉，管子，这边也插管子，鼻孔也有插，嘴巴也有插，那然后，大小便这边也有插，然后就又绑在床铺上面，(…)那你然后又没办法讲话，没办法交流，(…)我心里面，内心自己在讲，我说他妈的，这种治疗的这一种方法，好好的都会吓死掉。(…)所以到那个7点多，我还在跟他讲说，‘你有进去再跟我老爹讲讲这些，拉拉，拉一两句家常’，因为我是一直在讲说哎‘我3点多忘记跟他讲这些话，’我过后我也一直在后悔这个。
Qing: In fact, a doctor should take the responsibility in his professional role and can’t say, ‘oh, it might be like this or like that.’ They should be responsible for it. Why? Doctor, in the past, people called a doctor Mr, and teacher, only the two (professions) can be called Mr. Doctors have been looked down. (...) Seriously, I look down at the doctors. I really look down at them. From my point of view I really look down them. First, they aren’t responsible. Second, they aren’t dedicated. (...) If they [doctors] are wrong, the patients sue them. They receive the red envelope [tips] given (by patients/family members) (laugh) (...) Chaos, it’s really chaotic. The medical reform is a failure. So we don’t know how to face the doctors. (02: 435-441, 462-465)	Qing: 其实，医生你专业方面你就要做起担当，你不能说，‘哎呀可能会这样这样’，那这一份东西你要负责任，你们要担起来，为什么要这么做？医生，以前以前人家叫先生，跟教书的，只有两个人才能叫先生啊，其他人不能叫的，你现在落魄成这种。(…)真的，我看不起医生，我真的看不起，对我的性格来说，我真的看不起，第一没担当，第二不敬业，(…)他们错了，病人闹，是不是？塞红包你就收，（笑），(…)乱象，真的是乱象，医疗医改是很失败的医改，所以说我们不知道怎么面对医生。
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