

**Palliative and end-of-life care for Chinese immigrants:  
experiences of family caregivers**

by

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## **ABSTRACT**

Though Chinese immigrants constitute one of the largest immigrant groups in Canada, little research has been conducted to explore palliative and end-of-life care for this community. The purpose of this research was to learn about the lived experiences of Chinese family caregivers who have provided palliative and end-of-life care to their loved ones.

This qualitative study adopted hermeneutic phenomenology to understand palliative and end-of-life care for Chinese immigrants from the perspective of their family caregivers. Seven Chinese immigrants living in the Greater Toronto Area (GTA) were recruited and in-depth interviews were conducted with each participant using semi-structured and open-ended questions. Thematic analysis, guided by the Voice-Centred Relational (VCR) method, was employed to analyze the data. Five major themes were identified, namely, life as a family caregiver, Chinese cultural understandings of disease and death, interdependency in the Chinese family, experiences with Canadian health care services, and future considerations.

Understanding the lived experiences of Chinese family caregivers is an important first step in making healthcare providers aware of relevant aspects of Chinese culture so they may better provide palliative and end-of-life care to Chinese immigrants and their families in the future.

**Key Words** Palliative and end-of-life care, Chinese immigrants, family caregiver

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## **LIST OF ABBREVIATIONS**

CAM	Complementary or Alternative Medicine
GTA	Greater Toronto Area
VCR	Voice-Centred Relational
TCM	Traditional Chinese Medicine

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## **CHAPTER1 INTRODUCTION AND OVERVIEW**

### **1.1 Background**

According to the 2004-2008 mortality data from Statistics Canada (2011), the main causes of death in Canada are chronic diseases such as cancer, heart disease, respiratory diseases, stroke, diabetes and dementia. As patients progress through their disease towards the end of life, they require assistance and care from others. For many, the family will serve as the primary caregivers during their illness (Boerner & Schulz, 2009).

The World Health Organization (WHO) (2012) defines palliative care as that which aims to “improve the quality of life of patients with a life-threatening illness, through offering pain and symptom management, mental and spiritual support from diagnosis to end of life (para.3)”. The purpose of palliative care is to achieve comfort, guarantee respect for the person approaching end-of-life and enhance the quality of life for the patient and their family and loved ones (Health Canada, 2009). Palliative care not only deals with pain and symptom relief, but also provides social, emotional and spiritual support to patients and their families (Health Canada, 2009; World Health Organization, 2012).

Family palliative caregivers are traditionally defined as any relative, friend, or partner who has a significant relationship and offers care (physical, social and/or psychological) to a person with a terminal disease (Hudson et al., 2012). The care provided by family caregivers includes helping patients bathe, dress, use the toilet, eat,

and get in/out of bed, as well as helping with transportation, picking up medications and communicating with doctors about the patient's condition (Ghesquiere, Haidar, & Shear, 2011; McMillan, 2005). Providing care to a dying loved one is a significant burden on family caregivers, both physically and mentally, and family caregivers are found to be prone to high levels of physical discomfort, distress, depression and grief (Ghesquiere, Haidar, & Shear, 2011; Holtslander & McMillan, 2011). While some research investigates the difficulties and burdens that family caregivers encounter, very little is known about the experience of end-of-life caregiving for immigrant families. Due to different cultural norms and perceptions, and because immigrants face many barriers such as language incompetency, insufficient social support and limited health service access and utilization (Olson, 2001), it is not fully clear how end-of-life care for immigrants and the life of their family caregivers is different from those of non-immigrant Canadians.

Canada is home to one of the largest immigrant Chinese communities in the world. With a total population of over 1.3 million, Chinese immigrants now account for the second largest visible minority group in Canada (Statistics Canada, 2011). Furthermore, it is estimated the Chinese population will increase from 1.3 million to between 2.4 million and 3.0 million by the year 2031 (Statistics Canada, 2011).

Differences between Chinese and Western culture may result in a different palliative care experience for Chinese immigrants. For example, Chinese immigrants are usually faced with stronger family cohesion and mutual responsibility. In addition,

when seeking medical services, Chinese immigrants usually encounter challenges such as insufficient social support and a lack of culturally appropriate services (Lai & Surood, 2008; Sun, Ong, & Burnette, 2012). In brief, these all may make the palliative care challenging for both the patients and their caregivers.

With an increasing number of Chinese immigrants who live and will eventually die in Canada, it is important to explore the end-of-life care they receive and the support offered to their family caregivers. This study examined the lived experiences of Chinese family caregivers and attempted to identify the elements required to create culturally appropriate services and support for them.

## **1.2 Research Questions and Objectives**

The research questions of this study were as follows:

- 1) What are the experiences of family members who care for Chinese immigrants in end-of-life?
- 2) What are the barriers and challenges experienced by Chinese family caregivers?
- 3) What constitutes culturally appropriate care at end-of-life for Chinese immigrants?

Therefore, the objectives of this research were:

- 1) to understand the lived experiences of Chinese family caregivers who care for their loved ones with terminal disease; and

- 2) to propose culturally appropriate palliative and end-of-life care for Chinese immigrants and support for their family caregivers.

### **1.3 Rationale**

The current study is important for a variety of reasons. First, as an increasing number of Chinese immigrants move to Canada, they will eventually need culturally appropriate palliative and end-of-life care and support for their family caregivers. Thus, it is important to understand the challenges they encounter and their concerns, and these findings can inform health professionals and policy makers. Second, this study will contribute to cultural awareness in the Canadian health care system by enabling a deeper understanding of Chinese cultural perspectives towards death and disease. Lastly, the challenges experienced by Chinese immigrants might also serve as a valuable reference for understanding how palliative and end-of-life care is experienced by other Asian immigrants in Canada.

### **1.4 Thesis Organization**

This thesis is divided into five chapters.

Chapter 1, the current chapter, gives a brief introduction to the background and context of the study, as well as a presentation of the research questions, objectives and project rationale.

Chapter 2 contains a literature review of key concepts such as palliative care, Chinese immigrants and Chinese culture. The literature reviews explore the current state of knowledge on palliative care for Chinese immigrants and how traditional cultural values shape their perceptions of health and illness and their interactions with Canadian health care services. This chapter also identifies important gaps in the literature, emphasizing the need for this study.

Chapter 3 explains the methodology and methods adopted for this research. It begins with an introduction to qualitative research, the nature of phenomenology and the rationale for choosing phenomenology as a methodological framework. This chapter then describes how data was collected and managed. This is followed by a detailed explanation of my data analysis methods. Lastly, analytical rigor and ethical considerations are described.

Chapter 4 presents the study findings. Five main themes are identified and explored in order to deeply describe the lived experiences of seven Chinese family caregivers in Canada.

Finally, chapter 5 summarizes the key findings, and presents some recommendations for culturally appropriate care. This chapter also discusses the limitations of the study and possible directions for future studies.

## **CHAPTER 2 LITERATURE REVIEW**

This chapter provides a systematic review of the literature regarding the key concepts of this study. Accordingly, several questions guided the literature review: 1) What is palliative and end-of-life care? 2) What are the demographic characteristics of Chinese immigrants living in Canada? 3) What features of Chinese culture make the caregiving process unique for Chinese immigrants? 4) What is a family caregiver and what burdens does a family caregiver experience? And 5) what are the gaps in the literature concerning palliative and end-of-life care for Chinese immigrants?

Literature was retrieved mainly from PubMed and Google Scholar, and only articles published in English within the past 15 years were included. The key search terms used were: Chinese/Asian immigrants, Canada, palliative/end-of-life care, lived experience, and family caregivers.

### **2.1 Palliative and End-of-life Care**

#### **2.1.1 Definition**

Palliative care is a kind of health care provided to individuals who live with a life limiting illness. The purpose of palliative care is to offer the best quality of life for both the patient and his/her family members (Canadian Hospice Palliative Care Association, 1997). According to the WHO (2012), palliative care is defined as follows:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (para.1)”

End-of-life care, on the other hand, is provided when the condition of a patient with a terminal disease has advanced to the point that medical treatment can no longer cure the disease (Canadian Cancer Society's Steering Committee, 2012; National Cancer Institute, 2002). This care can be seen as a part of palliative care, which primarily focuses on making the patient feel comfortable (National Cancer Institute, 2002). The patient is provided with medications, treatments and services to control physical, psychological, social and spiritual pain, (Johansson, Henoch, Strang, & Browall, 2012; Rome, Luminais, Bourgeois, & Blais, 2011) and other symptoms, such as dyspnea, anorexia/cachexia, fatigue/weakness, agitation, nausea/vomiting, malignant bowel obstruction, delirium and breathlessness (National Comprehensive Cancer Network, 2011). Although it is usually believed that palliative care is practiced throughout the whole process of a terminal disease, while end-of-life focuses on its last stage, there are no universally accepted definitions for both terms; they are usually used interchangeably, sometimes confusing patients and caregivers (Hanks et al., 2009; Rome, Luminais, Bourgeois, & Blais, 2011).

### **2.1.2 Palliative and End-of-life Care in Canada**

The demand for palliative and end-of-life care is increasing because the Canadian population is rapidly aging . It is estimated that by 2036, the proportion of seniors will increase to approximately 24% (Statistics Canada, 2011). In addition, over 73% of deaths in Canada are due to chronic disease, such as neoplasms (about 30%), circulatory system diseases (about 20%), and respiratory system diseases (about 5%) (Statistics Canada, 2012); therefore, palliative and end-of-life care services will potentially benefit a great number of Canadians. However, a report from the Canadian Hospice Palliative Care Association (CHPCA) reveals that although Canada ranked ninth out of 40 countries in terms of quality and availability of palliative and end-of-life care services, less than 30% of Canadians who are dying of terminal diseases actually receive this form of specialized care (Canadian Hospice Palliative Care Association, 2012). Compared to other provinces, Ontario has the highest proportion of patients receiving palliative care assessment both in hospital and in ambulatory settings, at 26.7% and 17.9% respectively (Canadian Cancer Society's Steering Committee, 2012).

Previous studies suggest that while most seriously-ill patients prefer to die at home, nearly 70% of deaths happen in hospital, and most of these deaths occur in medical and surgical departments rather than palliative care beds (Barbera et al., 2010; Burge, Lawson, Johnston, & Cummings, 2003; Canadian Cancer Society's Steering Committee, 2012). Although this proportion does not necessarily mean that these



patients did not receive informal palliative care provided by family caregivers and primary care providers, it does reflect a lack of formal, patient-centered, community and family based palliative and end-of-life care service. In addition, because there is no universally agreed upon stage when palliative care should begin (Hanks et al., 2009; Rome, Luminais, Bourgeois, & Blais, 2011), it is difficult for health providers to decide when to initiate palliative care for patients instead of treatment; as a result, some patients receive treatment up until their death (Canadian Cancer Society's Steering Committee, 2012).

Caregiving in the final stages of life entails large financial expenses. It was estimated that the average cost per person for end-of-life care in Canada ranges from approximately \$20,000 to \$35,000 in health facilities (Canadian Cancer Society's Steering Committee, 2012). If the patient is cared for at home, additional money will be spent on providing medications and nutritious foods, and employing caregivers. Furthermore, some family caregivers experience a decrease in their income due to necessary limits on their working hours, which increases their financial burden.

## **2.2 Chinese Immigrants**

### **2.2.1 Chinese Living in Canada**

#### **2.2.1.1 General Demographic Characteristics**

Since the first wave of Chinese immigration to North America in the 1850s, Canada has become a destination attracting a large number of Chinese immigrants,

especially in recent decades. According to census data from 2006, over 1.2 million Canadians of Chinese descent constitute approximately 4% of the total population, and Chinese Canadians account for the largest non-European ethnic group in Canada (Statistics Canada, 2006). Statistics Canada (2001) reports that about 72% of all Chinese immigrants were born outside Canada: around 45% of foreign-born Chinese Canadians come from the People's Republic of China (mainland China), while 30% are from Hong Kong and 10% from Taiwan (Statistics Canada, 2001). More than half arrived in Canada between 1980 and 2000.

According to Statistics Canada (2001), Canadians of Chinese descent are much less likely to live alone (5.4 % compared to 12.5% of all Canadians), and are less likely to become a lone parent (4.3% compared to 5.5% of total population), suggesting that Chinese Canadians tend to participate in the Chinese tradition of living together and caring for elderly parents. Chinese Canadians are also characterized by the conventional emphasis on education; 27.1% of them hold a university degree whereas only 15.4% of the total Canadian population does. However, this may reflect Canadian immigration policies that show preference for well-educated immigrants. The employment of Chinese Canadians is noteworthy with only 55.5% being involved in the workforce, lower than the general population rate of 61.5%. Correspondingly, the average income for Chinese immigrants (\$25,018) is slightly lower than the average (\$29,769) (Statistics Canada, 2001).

### **2.2.1.2 Health Status of Chinese Canadians**

Previous studies indicate that Chinese immigrants in Canada, especially older Chinese immigrants, are physically healthier than Canadian-born residents. A recent study reports that the majority of Chinese immigrant seniors consider their health status as very good or good (Chow, 2010). Likewise, a study by Lai and colleagues (2004) suggests that the physical health status of senior Chinese immigrants is better than that of their Canadian counterparts. However, some studies suggest that senior Chinese immigrants suffer from poor mental health status; and a higher prevalence of depression was found among this population (D. W. Lai, 2004; McEwan, Donnelly, Robertson, & Hertzman, 1991). For specific diseases, Chinese immigrants are found to have lower cancer mortality in both sexes than that of non-immigrant Canadians (Hyman, 2001). A cross-sectional study on the health status of Chinese immigrants in Canada demonstrates that Asian immigrants were less likely to report chronic disease; and the prevalence of chronic diseases, such as diabetes, hypertension and cardiovascular disease is significantly lower than that of non-immigrant Canadians (Z. Y. Sun, Xiong, Zhang, Huang, & Wang, 2009). However, this might partially be attributed to the healthy immigrant effect, which means that recently arrived immigrants are usually healthier than residents in the host country, because younger and healthier foreign born people are more likely to be permitted to settle down in host country (Newbold, 2006).

### **2.2.2 Culture**

Culture is defined as a collection of beliefs, values, practices, and rituals shared by people from a particular ethnic group or geographic area and it affects how people behave and view the world (J. Anderson et al., 2003; Werth, Blevins, Toussaint, & Durham, 2002). Cultural beliefs and practices are also considered to have a significant influence on a patient's definition and understanding of illness, suffering and dying, their perception and feelings about treatment and care, and their processes of decision-making and emotional expression at the end of life (Anderson et al., 2003; Bowman & Singer, 2001; Kleinman & Benson, 2006; Valente, 2004; Werth, Blevins, Toussaint, & Durham, 2002; Wong-Kim, Sun, & DeMattos, 2003). Previous studies found that when cultural differences are neglected or not fully recognized, the care provided is usually inappropriate and ineffective (Bosma, 2011).

Chinese culture emphasizes the importance of family and collectivism. Greatly influenced by Confucianism, filial piety and family interdependence are highly valued (Olson, 2001). To investigate how culture may influence the experience of palliative and end-of-life care for Chinese immigrants, it is important to understand a number of specific cultural norms and values regarding illness, death, and the role and responsibilities of family members in the care process.

### **2.2.2.1 Family in Chinese Culture**

One of the most significant aspects of Chinese culture is an emphasis on creating and maintaining very strong bonds within the family. Togetherness, conformity and interdependence among family members is emphasized, resulting in a strong sense of obligation and responsibility for each member of the family (Olson, 2001). These emotional ties significantly influence people's behavior, life, and physical and mental status, especially during times of adversity.

Broadly speaking, Western culture emphasizes individualism, celebrates youth and denigrates the elderly, whereas Eastern cultures tend to embrace family interdependence and confer respect upon elderly family members (Chappell & Funk, 2011). This is not only embodied in decision-making processes, during which any significant treatment and/or care decisions are taken as the result of family consensus, but is also reflected in the traditional norm of filial piety, that is, the responsibility to care for aging parents (Anngela-Cole & Busch, 2011; Chappell & Funk, 2011). Higher rates of parents living with their children are found among Asian populations generally, who are also reported to provide more assistance to their independent elder parents than their non-Asian counterparts (Yu, Lai, Wen, & Liu, 2000).

Collectivism is a core value shared within Chinese families, and this is usually demonstrated by the family-centered decision-making process (Blackhall et al., 1999; Chow, 2010; Ngo-Metzger et al., 2003). Studies suggest that Asian Americans prefer to have the whole family involved in making decisions for a loved one. These studies

usually emphasize the significance of including extended family in end-of-life decision-making and care provision (Tong, McGraw, Dobihal, Baggish, Cherlin & Bradley, 2003).

#### **2.2.2.2 Filial Piety**

A traditional Chinese proverb reads: “among all the benefactions, filial piety must come first”. Filial piety is a moral principle and standard of conduct that is deeply rooted in Chinese culture, and which exerts substantial pressure on Chinese families to behave accordingly. Filial piety is not merely a practice of offering care when parents are sick, it also implies a sense of obligation, devotion and self-sacrifice (Kagawa-Singer & Blackhall, 2001; Olson, 2001).

Though filial piety is not exclusive to Asian cultures, there are general differences in how it is understood in the East versus the West. For example, in the East filial piety is largely regarded as an obligation, whereas in the West is generally considered more of an individual choice than a cultural requirement. While the essence of filial piety in Western culture is about respect and caring, in Eastern culture it also includes “obedience and unlimited responsibility” (Dai & Dimond, 1998, p. 13). Though it is not easy to explain what constitutes filial piety and good filial caring for the older family members, research conducted by Chappell and Funk (2011) suggested that filial caregiving should include: 1) basic daily activities such as bathing, dressing and feeding; 2) instrumental activities such as shopping, meal preparation and

discussion with doctors; 3) emotional support and companionship; and 4) financial support.

Norms of filial piety may prevent the use of palliative and end-of-life care services. Chinese may fear being seen as shirking their filial responsibility if they send sick parents to palliative care services, which would be socially regarded as “*diu lian*” or “losing face”, a Chinese concept of shame and dishonor (Kagawa-Singer & Blackhall, 2001; Ngo-Metzger et al., 2003; Olson, 2001). As a result, they usually try to act as their parents’ caregivers. However, if lacking in social support and caregiving knowledge, they may not only fail to provide competent care, but caregiving responsibilities may also affect their normal work and social activities.

### **2.2.2.3 Attitudes Towards Disease and Death**

Honesty is one of the most fundamental responsibilities of health care providers in the Western health system (Werth, Blevins, Toussaint, & Durham, 2002). In Western cultures, patients are usually informed of their terminal illness conditions (Marzanski, Jainer, & Avery, 2002; Tuckett, 2004). However, many non-Western cultures tend to avoid disclosure of critical physical conditions or the mention of death. For example, studies in Saudi Arabia, Japan and China all indicate that cancer patients either do not ask questions about cancer, or are not informed about their disease (Jiang et al., 2007; Kashiwagi, 1999; S. Y. Wang, Chen, Chen, & Huang, 2004; Younge, Moreau, Ezzat, & Gray, 1997). The reasons for this are multiple, predominantly

concerned with maintaining the patient's psychological well-being. In Chinese culture, disclosure can sometimes be seen as a violation of "non-maleficence" (Tuckett, 2004, p.508), for it potentially suggests death and thus increases patient's anxiety, distress, depression, pain and anger (Hancock et al., 2007; Tuckett, 2004). A study in the US demonstrated that discussion of end-of-life care for Chinese seniors is usually avoided in nursing homes because they may consider the discussion of death as a bad omen (Chan & Kayser-Jones, 2005). Similarly, a Canadian study on Chinese seniors suggested that talking about end-of-life planning and death is a bad sign that will disrupt "emotional harmony" and "affect their psychological state" (p. 458), provoking negative thoughts that may subsequently lead to negative outcomes (Bowman & Singer, 2001).

Such cultural beliefs, however, are usually not supported by health care providers, who claim that refusing to discuss death hampers planning for end-of-life care and limits the interaction between the health providers and their patients (Bosma, 2011; Kramer & Auer, 2005). When physicians are discouraged from talking about illness and palliative care plans with the patient himself/herself, they can only discuss with family caregivers, who will then make decisions on the patient's behalf. Therefore, Chinese family caregivers not only provide care to their dying family member, but may also be responsible for making all his/her palliative care or end-of-life decisions.



## **2.2.3 Experience with Palliative and End-of-life Care Services**

### **2.2.3.1 Language Barriers**

“Communication is the pinnacle of everything,” write Owens and Randhawa (2004, p.419). Language can be a barrier to good palliative and end-of-life care. First, the needs of patients and their families from ethnic minority groups may not be met if they are not fluent in the language of their host-country (Nyatanga, 2002; Owens & Randhawa, 2004), and this can result in extra physical and emotional stress and discomfort for patients (Kagawa-Singer & Blackhall, 2001). Second, health care providers cannot provide competent comfort, treatment, support and medical care if they do not understand the patient’s language and are unable to efficiently communicate with him/her (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004). Furthermore, lack of linguistic competency is usually the reason why patients are not aware of palliative and end-of-life services (de Graaff & Francke, 2003). Finally, given the high sensitivity of end-of-life planning and care, several studies indicate that some issues during the end-of-life stage are best expressed and discussed in the patient’s native language(s); otherwise, this process may be negatively influenced (Bosma, 2011; J. Chan & Kayser-Jones, 2005; McGrath, Vun, & McLeod, 2001).

Given that language barriers are a big challenge for Chinese immigrants in accessing and utilizing medical services, it is important to determine how language barriers affect the accessibility of palliative care services and communication between physicians, patients, and family caregivers.

### **2.2.3.2 Insufficiently Culturally Competent Service**

Acknowledging cultural diversity should be a priority in the Canadian health care system. However, although the importance of bringing culturally competent and sensitive practices into Canadian health services has been fully recognized, it is, in reality, limited by a variety of forces.

Cultural sensitivity or cultural competence is defined as "a process in which healthcare providers learn from and about different cultures" (p.153), and when such knowledge is acquired, it can be used to adjust health professionals' practices to better interact with patients from different culture background (Maddalena, 2009). In short, culturally competent services require that health providers can both understand the language and culture, and offer services accordingly. Such services usually consist of the inclusion of staff from the community served, the ability to speak their language and to act in ways consistent with their cultural norms (Anderson, Scrimshaw, Fullilove & Normand, 2003). The need to respect the cultural differences of patients and provide culturally competent and non-biased health care services has long been argued (Geiger, 2001; Lai & Chau, 2007a). Insufficiently culturally competent health services and providers continue to be one of the major complaints from many Chinese patients in Canada (Lai & Chau, 2007a; Lai & Surood, 2008; Wang, Rosenberg, & Lo, 2008).

However, there is limited literature examining how Chinese immigrants react towards the palliative and end-of-life care provided to them and what, from their perspective, would constitute culturally competent palliative and end-of-life care.

#### **2.2.4 Traditional Chinese Medicine**

Traditional Chinese Medicine (TCM) is an ancient medical practice that mainly includes herbal medicine, acupuncture, qi-gong, tai-chi, dietary therapy and massage (Ferro et al., 2007). TCM theory maintains that good health is achieved through the balance of flowing “qi”, or energy, and the harmony or “yin” and “yang” in the human body. The onset and development of a disease or pain is the result of the obstruction of “qi” and the imbalance of “yin” and “yang” (Smith & Bauer-Wu, 2012; Vanderploeg & Yi, 2009).

TCM is widely used among Chinese people both in China and abroad, especially among the elderly. Studies demonstrate that over half of older Chinese immigrants in Canada have used TCM or TCM combined with Western biomedicine conventional medicine in the past year (D. Lai & Chappell, 2007; Quan, Lai, Johnson, Verhoef, & Musto, 2008). However, little is known about the use of TCM for palliative and end-of-life care among Chinese immigrants and how patients and their family caregivers perceive TCM.

TCM is extensively utilized as a complementary or alternative medicine in the West (CAM) which is considered to be appropriate in dealing with chronic diseases,

in part due to its effects on relieving pain, managing symptoms and reducing side-effects (Liu et al., 2011). For example, acupuncture is found to be effectively in reducing chronic pain (Cho et al., 2012; Lee et al., 2013; Vickers et al., 2012) as well as cancer pain (H. Lee, Schmidt, & Ernst, 2005; Peng, Peng, Xu, & Lao, 2010).

Furthermore, numerous studies indicate that herbal medicine is useful in reducing the pain and side effects of cancer treatment. For instance, a review conducted by Xu and colleagues (2007) found that Chinese herbal medicines may be useful in managing pain in cancer, at least in the short term (Xu et al., 2007). In addition, several studies suggest the side effects related to chemotherapy and radiation therapy, involving vomiting, diarrhea, et cetera. were greatly decreased with the use of herbal medicine (Qi et al., 2010; Smith & Bauer-Wu, 2012; Wu, Munro, Guanjian, & Liu, 2008).

### **2.3 Family Caregivers**

A family caregiver is someone who provides continuous care and assistance without pay for a family member (or a close friend) who is in need of support because of their physical and/or mental health condition (Canadian Hospice Palliative Care Association, 2012). In 2006 and 2007, nearly one in every five Canadians cared for a family member who had serious health problems (Health Care in Canada Survey, 2007). While all caregiving can be tiring and demanding work, serving as a family caregiver for a family member with a terminal illness can include additional challenges.

### **2.3.1 Experiences of Family Caregivers**

Caring for a family member approaching death is never easy for family caregivers. On the one hand, they have to dedicate themselves to providing good care, reducing personal time for work and socializing. On the other hand, being too focused on the care process for dying patients, the caregivers usually neglect their own physical and mental health needs (Stajduhar, Fyles, & Barwich, 2008). A number of studies have illustrated that more than one third of family caregivers present with symptoms of depression and other mental and physical problems that would potentially hinder their long-term health and well-being (Stajduhar, Fyles, & Barwich, 2008). Another study by Funk and colleagues (2009) also suggested that the illness and suffering of a loved one is associated with uncertainty and fear among family caregivers as well as feelings of a loss of control. Furthermore, for caregivers providing care for a dying family member at home, they encounter additional uncertainty in their ability to offer adequate care (Funk, Allan, & Stajduhar, 2009). An integrative literature review done by Johansson and colleagues (2012) identified that when caring for a dying family member, family caregivers suffered from stress and vulnerability. They also complained about a lack of information concerning patients' condition and claimed they were unprepared for both the role as caregiver and the approaching death of the care recipient (Johansson, Henoch, Strang, & Browall, 2012).

Studies have found that often, caregivers gradually lose their social lives as the health status of their patients deteriorates; consequently, caregivers experience

difficulty in leading their previous lives (Adelbratt & Strang, 2000; Milberg, Strang, & Jakobsson, 2004). They find they have to abandon future plans involving the patient and often feel a reduced sense of autonomy and increased feelings of loneliness (Sand & Strang, 2006). With the declining health status of their loved ones, family caregivers not only feel powerless but may also suffer from physical problems such as pain, fatigue and breathlessness (Milberg, Strang, & Jakobsson, 2004; Sand & Strang, 2006). Some caregivers are reported to have experienced muscle tension, headache, loss of appetite and sleeplessness (Tsigaropoulos et al., 2009). Additionally, caregiving entails a great economic burden on the family. According to some caregivers, the economic expenses required selling off assets, spending savings and taking on extra jobs (McMillan, 2005).

Watching a loved one die is undoubtedly an experience that brings about great distress. Studies have shown family caregivers may live with constant fear and show high levels of depression and anxiety; but often have difficulties expressing these feelings (Adelbratt & Strang, 2000; Milberg, Strang, & Jakobsson, 2004; Tsigaropoulos et al., 2009). Caregivers may also suffer from a sense of insufficiency, powerlessness and helplessness when feeling there is nothing they can contribute to their patient's wellbeing (Milberg, Strang, & Jakobsson, 2004; Sand & Strang, 2006). When sick family members' illnesses advance, they may fall into a state of unconsciousness. At such time, caregivers have been reported to experience increased

loneliness and isolation, and to develop feelings of anger toward the disease

(Albinsson & Strang, 2003; Milberg, Strang, & Jakobsson, 2004).

In addition, it is very common for family caregivers to feel obligated to protect their dying loved one and to do anything possible to alleviate their distress; yet, they often find themselves trapped in their own suffering (Adelbratt & Strang, 2000). Some of them not only feel a sense of guilt but also blame themselves for not having done enough (Milberg, Strang, & Jakobsson, 2004). An Australian study found that family caregivers need: 1) to know the loved one will be cared for even when they are not available; 2) the availability of a phone hotline service; 3) respite time away from their caregiving duties; and 4) assistance to overcome stress and other feelings of being trapped (D. W. Lai & Surood, 2008).

### **2.3.2 Supports for Family Caregivers**

Several interventions have been proposed to assist caregivers, reduce their stress and to provide them with information and social support. First, conversations between the spouse and the ill loved one were assumed to be helpful in reducing the burden and finding new strategies for coping with daily life (Benzein & Saveman, 2008; Johansson, Henoch, Strang, & Browall, 2012). Second, retreat weekends have been suggested. In one study, caregivers were asked to participate in several weekend sessions involving stress reduction, relaxation, spiritual comfort, yoga and group therapy. These activities could heal the caregivers emotionally and spiritually, and

enhance their sense of involvement with a community (Arnaert, Gabos, Ballenas, & Rutledge, 2010). Third, a research study conducted by Ferrell and colleagues (1995) found that education on pain and symptom management for cancer patients not only resulted in better pain management for the care recipient but also improved the quality of life among the family caregivers (Ferrell, Grant, Chan, Ahn, & Ferrell, 1995). Finally, research has shown that caregivers felt a strengthened sense of inner power and well-being after receiving a massage. This might be an effective way to reduce worry, fatigue and stress among family caregivers (Cronfalk, Strang, & Ternstedt, 2009).

Research has documented that sufficient information and dialogue with physicians is vital to caregiver confidence (Johansson, Henoeh, Strang, & Browall, 2012). Another study found that for family caregivers, 55.8% rate confidence in their doctors and 44.1% rate the honest communication of patient information as extremely important in end of life care. (Heyland et al., 2006). Indeed, working with competent professionals, having timely, accessible care and services, and feeling a strong sense of self-worth is linked with feelings of security among family caregivers (Funk, Allan, & Stajduhar, 2009). It is unknown whether this communication would bring long-term benefits for the caregiver. What is more, there is little research examining if such interventions are feasible and applicable for culturally diverse populations (McMillan, 2005).



Although caring for a dying family member is valuable and meaningful, a large number of caregivers encounter intense and difficult emotions during bereavement (Holtslander & McMillan, 2011). Bereaved family caregivers suffer from a high level of depression and grief, especially during the first few months after death (Chentsova-Dutton et al., 2002). Therefore, palliative care also includes bereavement care and support for the family caregivers after their loved one dies. Bereavement support may start when the grieving process starts and even before the death of the family member. Bereavement support is an important part of palliative care for people who may have faced many losses over a short period of time (Canadian Hospice Palliative Care Association, 1997).

### **2.3.3 Difficulties Experienced by Chinese Family Caregivers**

Despite of some Asian cultural beliefs associated with positive caregiving experiences, such as increased closeness within family, filial piety norms may also be a source of stress. Many Chinese immigrants bring their parents to the host country to care for them, but thereafter attribute their parents' adverse health conditions to the migration (Holland, Thompson, Tzuang, & Gallagher-Thompson, 2010; Sun, Ong, & Burnette, 2012). Moreover, lack of family support does occur among Chinese immigrants, and some family members who are more acculturated to the West may not be willing or interested in sharing in caregiving responsibilities (Sun, Ong, & Burnette, 2012). Chinese immigrants are found to have lower health care utilization (F.

Sun, Ong, & Burnette, 2012). They face a series of barriers to accessing health care services including cultural and linguistic differences. There is either a dearth of awareness, or the quality of services are perceived negatively. Stigma and a lack of culturally appropriate services may also make Chinese immigrants reluctant to utilize services education and information (Lai & Surood, 2008; Sun, Ong, & Burnette, 2012).

Though the majority of Chinese immigrants in Canada are foreign-born, first generation and are strongly attached to the traditional values cultivated from their homeland, some research has found that the second or third generation may not place as high a value upon filial piety. It is shown that adherence to filial responsibility gradually erodes in later generations (Olson, 2001). In addition, a lack of social and community pressure also facilitates the loss of filial piety among the second and third generations of Chinese Canadians (Olson, 2001).

## **2.4 The Gap in the Literature**

Despite the fact that Chinese immigrants now account for the largest visible ethnic-minority in Canada, their health and health-related beliefs and behaviors are not sufficiently studied. On the other hand, although palliative and end-of-life care has become an increasingly popular research focus, little emphasis is placed on the Chinese immigrant population. As discussed above, people's cultural beliefs, values, and life experiences shape their attitudes towards illness, death and quality-of-life at

the end of their life. This then influences beliefs related to palliative and end-of-life care for both providers and recipients.

However, several gaps exist in the literature concerning palliative and end-of-life for Chinese immigrants. First, little is known about how palliative and end-of-life care is provided for Chinese immigrants in Canada and how Chinese culture influences the care provided. In addition, to date, no study has been conducted in Canada that examines the challenges for Chinese family caregivers caring for a family member living with terminal disease. Finally, few Canadian studies have suggested features for creating culturally appropriate palliative and end-of-life care for Chinese immigrants.

In response to these gaps, this study was conducted to understand the lived experiences of Chinese family caregivers who are currently caring for or had provided palliative and end-of-life care in Canada. Through their narratives, their challenges were recognized and aspects for culturally appropriate palliative and end-of-life care for Chinese immigrants are recommended.

In conclusion, the literature examined here provides some information on palliative and end-of-life care, Chinese immigrants and Chinese culture, and the role of family caregivers. However, when the information is reviewed as a whole, it fails to relate the specific experiences of Chinese immigrants receiving or providing palliative and end-of-life care in Canada. Therefore, the current study is crucial to add new knowledge to this area.

The next chapter will introduce the methodology and methods that this study to uncover the experiences of the Chinese family caregivers. It provides an introduction to phenomenology, a description of my recruitment strategy, and a discussion of the approach employed for data collection and analysis. Finally, the study rigor and ethical issues are explored.

## **CHAPTER 3 METHODOLOGY, METHODS AND DATA ANALYSIS**

This chapter begins with a description of the methodology used in this study, followed by an introduction to phenomenology and the rationale for choosing this approach. This chapter then details how the participants were recruited, and how data was collected, managed and analyzed. Study rigor and ethical issues are also discussed in this chapter.

### **3.1 Methodology**

#### **3.1.1 Qualitative Methods**

The purpose of this study was to learn about the lived experiences of Chinese family caregivers who provide care to a family member with terminal disease. It explores the kind of care they provide, how caregiving is conducted and why one type of care is chosen over another. It further examines caregivers' perceptions towards utilizing Canadian health care services, specifically palliative and end-of-life care. Quantitative studies are ill-equipped to adequately reflect an understanding and interpretation of human phenomena (i.e., behaviors and perceptions).

Quantitative study design embraces the idea that human behavior is a direct response to external stimuli (e.g., biological and physical), ignoring that humans are also meaning-makers, embedded in a social and cultural environment (Bowling, 2009). In addition, quantitative research adheres to the paradigm of positivism. Positivist

epistemology (i.e., “how inquirer creates knowledge through research (p.126)”), asserts the existence of a single, universal and value-free truth (Raphael, Bryant, & Rioux, 2006). This paradigm aims to objectively investigate cause-effect relationships, which cannot adequately answer questions involving human subjectivity and interpretation (Streubert & Carpenter, 2011). Therefore, it is not appropriate for the current study.

Instead of attempting to predict and control the findings, this study emphasizes the need to contextualize human behaviors and beliefs in a particular time and place in order to understand what they mean. Therefore, the nature of the study falls under the paradigm of idealism, which is concerned with understanding humans varied interpretations of their world (Raphael, Bryant, & Rioux, 2006).

Idealists hold the ontological stance that reality is multiple and shaped by an individual’s social, cultural and economic values. Thus reality is dynamic and specific (Streubert & Carpenter, 2011). That is to say, individuals tend to generate distinctly different perceptions and understandings towards life events according to their specific historical and cultural context. Moreover, in terms of epistemology, idealists believe that individuals’ ideas and perceptions are best collected through qualitative methods of observation and interview, rather than through empirical methods and mathematical formulas, as in quantitative design (Raphael, Bryant, & Rioux, 2006; Streubert & Carpenter, 2011).

Qualitative study follows ‘inductive reasoning’ that begins with the observation

and then builds up statements (Bowling, 2009, p. 131). In brief, the ontological and epistemological position implied in the study objectives dictate the choice of methodology. In this case, the study requires a method that is able to inquire into the ‘how’ and ‘why’ of participants’ social health context and health behaviors, rather than just the ‘what’ (Green & Thorogood, 2004). The methodology therefore must enable the inquirer to interact with participants in order to better learn about their lived experiences (Raphael, Bryant, & Rioux, 2006).

Consequently, phenomenology, one of the most common methodologies in qualitative research, was employed in this study because of its role in the exploration and understanding of human’s lived experiences.

### **3.1.2 Phenomenology**

Phenomenology means the study of phenomena (Annells, 1996). It explores the nature of a particular phenomenon, determining “that which makes a something what it is, and without which it could not be what it is” (Manen, 1990, p. 10).

Phenomenological study explores a deeper understanding of taken-for-granted experiences, and reveals new and/or forgotten meanings of these experiences (Koch, 1995; Lavery, 2003; Starks & Trinidad, 2007). According to Streubert and Carpenter (2011):

“Phenomenology is the study of essence...It is a transcendental philosophy

which places in abeyance the assertions arising out of the natural attitude, the better to understand them: but it is also a philosophy for which the world is always “already there” before reflection begins - as an inalienable presence; and all its efforts are concentrated upon re-achieving a direct and primitive contact with the world, and endowing that contact with a philosophical status. (p. 73.)”

Currently, two schools of phenomenology are widely practiced: Husserl’s descriptive phenomenology and Heidegger’s hermeneutic phenomenology.

### **3.1.2.1 Husserl’s Phenomenology**

Husserl, a German philosopher in the 19th century, believed that rather than simply responding to the outside world automatically, human beings react according to their subjective understandings (Lavery, 2003). In addition, these understandings, according to Husserl, are generally taken-for-granted and not critically reflected upon. Therefore, Husserl aimed to explore the meaning of human understanding and experience (Koch, 1995; Lopez & Willis, 2004).

The three central components of Husserl’s theory are “intentionality”, “essences” and “bracketing” (Lavery, 2003). The concept of intentionality suggests that consciousness is something that is deliberate and directed (Streubert & Carpenter, 2011). The process of intentional consciousness is the basis of phenomena (Koch, 1995; Lavery, 2003). Essences constitute the structure of consciousness, which



Husserl claims are the focus of any explanation of human experience (Koch, 1995).

The last core concept in Husserl's phenomenology, bracketing, is also known as phenomenological reduction. This requires that researchers suspend their own pre-conceived thoughts and presumptions regarding the phenomena in question .

Although Husserl admitted that humans cannot develop an understanding of the world free from the influence of their own social and cultural background (Lavery, 2003; Valle, King, & Halling, 1989), he insisted that the description of a phenomena must nevertheless attempt to be free from the interpretation of the researcher. Performing the above mentioned bracketing helps to generate a more neutral approach; therefore, Husserl's phenomenology produces thick and valid description (Koch, 1995).

### **3.1.2.2 Heidegger's Phenomenology**

Hermeneutic phenomenology, proposed by Heidegger, is an extension of Husserl's work, but presents a stark difference: it embraces personal interpretation. While Husserl emphasized descriptive phenomenon (Kvale, 1996), Heidegger emphasized 'Daisen': "the situated meaning of a human being in the world" (Lavery, 2003, p. 7), allowing the inclusion of personal historical, social and cultural influences.

Heidegger was dedicated to interpretation. As he stated, the aim of hermeneutic inquiry is to learn what the words of people imply about their daily experiences

(Lopez & Willis, 2004). Hermeneutic phenomenology transcends simple description. Heidegger believed that no human experience could be understood without considering the relevant context, and every event entails an interpretation from the person's own background (Koch, 1995).

It is also important to realize that because our cultural and social values are present before we come to understand the outside world, our understanding of outside is inevitably affected by our context, background, and related presuppositions (Koch, 1995). Therefore, bracketing is not only considered unnecessary, but also believed to be nearly impossible. In addition, presumptions are considered valuable in hermeneutic phenomenology. Background knowledge of the phenomena being studied is helpful in guiding the questions to be asked (Lopez & Willis, 2004). Researchers are thus encouraged to identify and incorporate their own presuppositions into their inquiries.

Of note, hermeneutics requires reflexivity, reminds process whereby the researcher remains aware of his/her location, and reflects upon how his/her assumptions and personal factors may affect his/her inquiries and interpretations (Cheng, 2010; Hertz, 1997).

According to Streubert and Carpenter (2011), the production of meaning in hermeneutic phenomenology is achieved through the analysis of texts in a cycle of readings, reflective writing and interpretations (i.e., hermeneutic circle), as stated below:

- 1). “During the naïve reading, the researcher reads the text as a whole to become familiar with the text and begins to formulate thoughts about its meanings for further analysis.
- 2). “Structural analysis, or interpretive reading, forms the second step...the text is divided into meaning units, which are transformed with the contents intact. Arising from every transformed meaning unit a number of labels are created to discover common themes.
- 3) “Interpretation of the whole follows and involves reflecting on the initial reading along with the interpretive reading to ensure a comprehensive understanding of the findings (p. 85).”

In summary, Heidegger’s phenomenology holds that it is unavoidable that the researcher will bring personal assumptions and interpretations from his/her social and cultural background into the study (Koch, 1995). Therefore, hermeneutic phenomenology embraces both descriptions and interpretations. In the present study, it can not only describe how the selected Chinese family caregivers provide care in Toronto, but can also explore how their caregiving behavior is influenced by their own social and cultural backgrounds, which in turn are understood through both their and my own interpretive lenses.

### **3.1.3 Rationale for Adopting Hermeneutic Phenomenology**

In this research, hermeneutic phenomenology was chosen as the methodology for several reasons. First, because the primary purpose of this research is to understand the lived experiences of family caregivers who care for their loved ones, hermeneutic phenomenology can reveal the essences of family caregivers' experiences. Second, ideal for examining unsaid meanings, hermeneutic phenomenology also attempts to interpret the caregivers' experiences in-depth, taking into consideration the influence of their particular historical, social and cultural backgrounds. Furthermore, because hermeneutic phenomenology welcomes the researcher's assumptions as part of the interpretation of the findings, my cultural background also makes hermeneutic phenomenology an appropriate choice (Cheng, 2010). As a Chinese student living in Canada who has been educated and instilled with traditional Chinese values from a very early age, it is helpful that I can understand, interpret and then explain the participants' experiences to a deeper level with my own cultural background.

### **3.1.4 Reflexivity**

In qualitative studies, it is vital to take into account the fact that the background and position of researchers can affect what they choose to learn, what methods they adopt and how they describe and interpret their findings (Malterud, 2001). In this study I assumed the role of research designer, interviewer, translator and data analyzer. Therefore, being reflexive is required at every step in qualitative study: from data

collection to interpretation of results. Reflexivity refers to “the responsibility of the researchers to examine their influence in all aspects in qualitative inquiry” (Streubert & Carpenter, 2011, p. 34). That is, the researcher should be conscious of the influence he/she has on the information provided by interviewees, and of how his/her position influences how he/she makes sense of the data.

In hermeneutic phenomenology especially, the role of the researcher is particularly important because his/her assumptions, preconceptions and biases are inevitably embedded in the every step of the study, which has the potential to greatly affect the interpretation of the results (Cheng, 2010). Consequently, acknowledging the location of the researcher should be clearly and continuously noted and discussed (Alcoff, 1991).

I recognize I am both an “insider” and “outsider” in this study. On the one hand, as a Chinese, I understand the traditional norms and expectations of a good family caregiver, which may have been neglected were the study done by a non-Chinese researcher. In addition, my background facilitated the comprehension of the participants’ caregiving beliefs and behaviors, and the interpretation of their lived experiences. Furthermore, my undergraduate training as a medical student enabled me to empathize with the participants regarding the medical conditions they and their loved ones might have experienced. Most importantly, being a Chinese national, or ‘one of them’, helped many of the participants to feel more comfortable disclosing their stories to me.

On the other hand, I have never cared for a family member with terminal disease, nor have I experienced a terminal chronic disease myself. Moreover, my limited experience in qualitative research and interviewing may have resulted in a failure to fully capture some of the key aspects of participants' experiences, especially the unspoken or inexplicit meanings. Furthermore, I am also fully aware that the role I played: an outsider, a younger person, and in most cases, a different sex, may have influenced how interviewees described their experiences to me. Lastly, being a Chinese national, it is also possible for me to generate take-for-granted thoughts on how culture can affect participants' life, neglecting the true experiences of them under particular circumstances.

In summary, I fully recognized that as both an "insider" and "outsider", my personal experiences, capacity in understanding Chinese culture and values, and limited knowledge of qualitative study influences the questions I asked, my understanding of the contexts and my interpretation of the findings (Cheng, 2010). Reflexivity is therefore vital in this study and is thus often discussed alongside the findings. It is critical to be aware that the findings of the study only reflect one angle of the complex lived experiences of Chinese immigrants who are caring/have cared for their loved ones.

## **3.2 Methods**

### **3.2.1 Inclusion Criteria**

At the beginning of my research, the participants had to satisfy the following criteria to participate in the study: 1) they are Chinese immigrants, either first or second generation, living in Canada; 2) they have lost their loved one in the past five years; 3) they have provided palliative and end-of-life care, either alone or with other caregivers; 4) their care recipients were also Chinese immigrants living in Canada; 5) they were at least 19 years old at the time of the study and willing to participate in a one-on-one interview; and 6) they speak either Mandarin or English.

However, three months after launching the call for participants I had not located any interested participants and I began to think the inclusion criteria might be too narrow. I then revised the inclusion criteria to include family caregivers who are currently caring for a loved one with terminal disease.

Notably, in some circumstances where seriously ill persons do not receive care from family members, his/her close friends take on the role of caregiver. Friends, serving as primary caregivers, were therefore also considered family caregivers for the purposes of this study and were eligible to participate. Therefore, family caregiver in this study is in fact a broader category, defined as anyone, family member or friend, who provides informal care to their beloved ones with terminal diseases.

### **3.2.2 Recruitment of Participants**

According to Statistics Canada (2001), the largest Chinese community in Canada is located in Ontario with around 500,000 people of Chinese descent, half of them being from mainland China, Hong Kong, and Taiwan. Most live in the Greater Toronto Area (GTA); thus, all data was collected in Toronto.

I used purposeful sampling for this study. Purposeful sampling selects appropriate participants with particular characteristics to collect information (Bowling, 2009; Fossey, Harvey, McDermott, & Davidson, 2002; Green & Thorogood, 2004). In this study, only those Chinese family caregivers who met the aforementioned criteria were selected for interview.

Several methods were initially utilized to recruit participants in Toronto: 1) a Chinese press release (Appendix 1), which explained the background and rationale of this study in detail, was posted on several Chinese forums and websites; 2) the news report, along with a brief Chinese-English advertisement (Appendix 2a and 2b) was also posted in several Chinese senior homes in the GTA. Contact information was attached in the news report and advertisement. Interested potential participants were encouraged to contact the researcher by phone or email.

However, only one interested participant contacted the researcher through the above strategies. This may have been related Chinese beliefs discouraging talk about death. Given the sensitivity of the research topic, the recruitment strategy was refined to include another appropriate Chinese context, “guanxi”, or Chinese social networks.



Guanxi, literally translated as “connections”, is one of the basic components in Chinese society/community. Different from the Western notion of ‘social network’, it does not simply reflect the personal relationship of one person to others; rather, guanxi is formed through reciprocal favors. One of my supervisors, Dr. Wang, has an extended guanxi network in the Chinese community in the GTA gained through his early volunteer work with Chinese immigrants. These connections significantly facilitated the recruitment of participants. He distributed the Chinese press release through email to the directors of three provincial associations, a Chinese volunteer centre, an organization for Chinese seniors in Mississauga, Ontario, and one Chinese social worker. The directors then shared this request with members who met the inclusion criteria. When one participant showed his/her interest, the directors sent his/her contact information directly to me to provide them with further information.

The recruitment process lasted approximately four months, and nine people showed interest in the study and provided their contact information during this period. I called the nine potential participants one by one to confirm their willingness to participate before I left for Toronto. During our phone conversations, each participant was again informed of the purpose, rationale and importance of the study. A time and location for the interviews was also decided during this conversation. Two current caregivers declined the interview for fear that discussing end-of-life care constituted a death omen. In the end, seven participants provided their verbal consent and participated in the study.

### **3.2.3 Data Collection Methods**

The face-to-face interview is the most widely used data collection method in qualitative research (Green & Thorogood, 2004). This study employed one-on-one, face-to-face interviews, mainly because the sensitive nature of the topic and the disclosure of personal experiences discourages the presence of a third party. In addition, interviews facilitate the exploration of perceptions and insight and, unlike surveys, enable the interviewer to probe for further information or clarification of answers (Barriball & While, 1994). One of the most common types of interview is the semi-structured, in-depth interview. In semi-structured interviews, there is no rigidly predetermined set of questions, but rather it is the interviewee's responses that determine how the interview flows. Interviews are 'in-depth' when they provide participants with enough time to fully describe events important to him/her in detail (Green & Thorogood, 2004). Furthermore, open-ended rather than closed questions offer participants the opportunity to fully describe their experiences in ways that are meaningful to them instead of simply responding 'yes' or 'no' to questions framed by the researcher (Streubert & Carpenter, 2011). Therefore, semi-structured, in-depth and open-ended interviews were conducted to collect data in this study.

### **3.3 Data Collection**

As noted above, face-to face interviews were conducted using semi-structured, open-ended questions to discuss the lived experiences of Chinese family caregivers

who have cared for or are caring for their loved ones. The interview guide borrowed ideas from a similar research project conducted by my supervisor, Dr. Maddalena, and was modified specifically for this research by, for example, adding questions regarding the use of Chinese medicine or about the barriers to accessing health care services in Canada. The interview guide was framed in English (Appendix 3a) and then translated into Chinese (Appendix 3b). The translated Chinese version was verified by my co-supervisor, Dr. Wang, a Chinese Canadian. The interview guide was piloted with a Chinese visiting scholar with a nursing background. A simulated interview was conducted with her, and she provided me with valuable suggestions on how to modify questions and appropriately probe on sensitive topics.

The time and place of each interview was decided by participants for their convenience. Most interviews took place in the interviewees' homes, and three interviews were conducted in quiet cafés. The duration of the interviews varied from 50 minutes to 90 minutes, depending on the information the participants wanted to share. The interviews were conducted solely in Mandarin.

Each interview was digitally recorded with the permission of the participants. Two recording devices were used in each interview, in case one should fail. At the end of the interview, each participant was given \$20 cash or gift card as reimbursement for parking or other transportation costs. All the interviews were completed during two weeks in March 2013, while I was in Toronto.

### 3.3.1 Interviews

Before the interviews began in earnest, the participants and I had several minutes of informal conversation. These included greetings and my introducing myself. Most participants were very surprised by my age: they did not expect to see a young man conducting this sensitive project; many of the older participants referred to me as a “kid”. Nevertheless, they expressed their willingness to “help” me complete this study. In addition, they were also interested in knowing my life in China and in Canada. By way of these informal conversations, the participants became comfortable with me and believed I was trustworthy, which greatly facilitated the interview process. Most participants welcomed me with some food and drink. I, at the same time, observed the home or apartment settings of the participants.

The participants were again informed of the background, rationale and importance of the study before the initiation of each interview. The interviews officially started after they signed the consent form. They were also informed of their freedom to terminate the interview at any time in the event they did not want to proceed.

The interview guide was followed for each interview. In accordance with the hermeneutic inquiry, the interview started with a very broad question about the general experience of caring for a seriously ill family member in Canada. This was followed by deeper questions regarding their concrete examples in order to further understand their experiences (Manen, 1990). Therefore, in every interview, the

conversation began with “can you please tell me about your loved one? The whole story from the day you came to Canada to his/her death or until now.” This question usually initiated a long monologue. These long, descriptive answers often addressed some of the questions that had been planned for later, so this was noted in the interview guide to avoid repetition. The next set of questions focused on how they decided upon treatment and care, the difficulties they faced during this process and their relationship with family members and medical professionals. Meanwhile, probes such as “can you tell me more?” and “can you give me an example?” were used to obtain more detailed information, gaining a deeper understanding of the family caregivers’ experiences. The last questions focused primarily on “what kind of help and/or support could have been offered to make your caregiving easier?” These questions were asked to help generate suggestions for what could enhance culturally appropriate care and services in the future. The interviews ended when the participants expressed that they could provide no more information.

During the conversations with participants, attention was not only paid to each individual’s direct answers to the questions, but more importantly, to the most significant and recurring meanings and statements that emerged among the ensemble of interviews. This was achieved by comparing interviews and focusing on the repetition of similar statements. For example, if one particular statement was repeated by several different participants, this would be especially attended to in the next

interviews. Furthermore, this method was also adopted to examine whether any new statements emerged in the interviews.

Although few notes were taken during interviews (so I could be fully engaged in the conversations) and during my interactions with participants, notes were made when the participants presented their medications, diagnosis reports, and when they revealed their emotions for the potential use in the later analysis stage. Three participants shed tears during the interviews, and most participants expressed some sadness or sentiment; for instance, a long sigh. These emotional moments usually occurred when participants were asked “how did you balance your life and caregiving?” and “what was the most challenging part of your caregiving?” These questions clearly reminded them of the sadness and difficulties they experienced in the past. It is of great importance in hermeneutic phenomenology to record the emotional expression in the conversations and capture the unspoken meanings held therein (Cheng, 2010).

Demographic information was collected using a short survey at the end of every interview. The demographic survey (Appendix 4a and 4b) collected socio-economic variables, age, sex, the time of the immigration, et cetera, for both the caregiver and the care recipient.

### **3.4 Data Management**

The recordings were transferred onto and stored in the researcher's computer after the completion of all interviews for further transcription, translation and analysis.

Data management consisted of transcription and translation.

#### **3.4.1 Transcription**

Transcripts not only served as the raw data for later analysis, but they can also be used for expert review to increase the rigor of the study (Sandelowski, 1994). All the recordings were thoroughly reviewed once before transcription so as to ensure the content of each interview was complete and coherent. Each interview was transcribed verbatim. Given the high volume of interview content, transcription was completed by me and a professional transcriber from China. Her work was checked by me to correct the medical terminology, names of places in Toronto and some English expressions occasionally used during the interviews. The transcripts also included non-verbal components, such as a pause, laughter, a sigh or cry.

Both the transcribers and participants speak Mandarin. The participants spoke very slowly in the interviews, greatly facilitating the work of transcription. However, due to the heavy dialect accent of one participant, some of her responses were very difficult to understand. Therefore, the recording of her interviews was listened to and transcribed twice by both transcribers. A comparison was made between the two transcriptions to clarify her answers.

### 3.4.2 Translation

The translation of transcripts was a challenging process. Shklarov (2007) suggests that translation is not a simple linguistic and technical issue; but rather, it can generate overreaching impacts on the quality of data and its later interpretation. In addition, the meanings of words must be carefully attended to, because they usually carry nuances and cultural connotations that evade literal translation (Cheng, 2010; Shklarov, 2007).

Translation was completed solely by me. According to Shklarov (2007), when the dual role of both translator and researcher is assumed by one person, critics might suggest this violates the requirement of objective translation without personal values. However, because pure objectivity is not an absolute concern in qualitative research, personal preconceptions being viewed as both unavoidable and even desirable, this dual role can engender greater sensitivity in the translation, and the 'researcher as translator' is thus currently generally accepted (Shklarov, 2007).

All the Chinese transcripts were literally translated into English. When expressions in Chinese could not be adequately translated using English words, the literal translation was followed by a short explanation.

Several challenges were noteworthy during the translation process. The first challenge came from the inability to identify parallel or equivalent words in English when attempting to translate some Chinese concepts. This might be caused by my limited translation skills, but also by inherent differences between the two languages. For example, when one participant wanted to express how he might bring trouble to



his friends if he asked for too much help from them, he said: “添麻烦” (literally means adding trouble or inconvenience). While ‘trouble’ in English can indeed be understood as “something that causes more than usual effect or inconvenience” (Longman Group, 2001, p. 1657), The Mandarin term it additionally implies that he owed his friends financially or emotionally for bringing trouble to them and he felt apologetic shame about it. Secondly, some idioms or proverbs in Chinese, even literally translated into English and explained by annotations, may be alien to Western readers and could thus not easily be understood in the English context. For instance, when talking about the notion of end-of-life care, one participant deliberately avoided the direct mention of death; instead she used “见马克思” (literally means meet Karl Marx), which is very commonly used among elder generation as a metaphor and periphrasis when referring to death.

The last challenge emerged due to the lack of clear tense in Chinese grammar. Unlike English, in which the sequential order is marked by past tense (e.g., did), and past perfect tense (e.g., had done), the concept of tense in Chinese grammar is achieved by the use of temporal adverbials (e.g., on that day), which are usually omitted in a conversation. Therefore, it is sometimes difficult to ascertain when events happened by transcripts alone.

These challenges could not be addressed without my engagement in the interviews. In other words, without having interacted with participants, these unsaid meanings would hardly be sensed, captured and included in the translation. Therefore, the

position of a double role to “see two parallel cultural meanings can meaningfully enrich the in-depth perceptions of the context and contribute tremendously to the quality of study” (Shklarov, 2007, p. 532).

All translated transcripts were then sent to the two Chinese scholars on my supervisory committee to ensure their accuracy.

### **3.5 Data Analysis**

While quantitative studies deal with numbers, qualitative studies focus on meaning, which is primarily mediated by language (Dey, 1993). Instead of measuring human phenomenon or behaviors via empirical observations, languages explain them, bringing in-depth information, because languages “teach and speak to the soul” (Krasner, 2001, p. 72). It is through language that we understand the world in which we live and then express these understandings to others; therefore, language is a central form of data in qualitative studies (Green & Thorogood, 2004). In qualitative studies, language does not only contains descriptive data (what they did) but also includes subjective, interpretive, and emotive content (how they did it, why they did it) (Green & Thorogood, 2004). Thus, this again demonstrates that understanding the lived experiences of these Chinese caregivers can only be achieved through an analysis of their language.

The purpose of data analysis is to “illuminate the experiences of those who have lived them by sharing the richness of lived experiences and cultures (Streubert &

Carpenter, 2011, p. 47). According to Green and Thorogood (2004), the research question and objectives of a study determine the style of data analysis, thus generating different outcomes. Given that this study is aimed at understanding the lived experiences of Chinese caregivers who care for their loved ones, the data analysis should focus on “developing explanations of phenomena” (Green & Thorogood, 2004, p. 176). Furthermore, due to the ontological, epistemological and methodological position of this study, apart from mere description or story-telling, the analytical method is also used to explore broader meanings beneath the descriptions.

The general procedure of data analysis in qualitative research consists of three steps: organizing the data, reducing the data into themes through coding, and representing the data (Bowling, 2009; Creswell, 2006). In hermeneutic phenomenology, particularly, data analysis follows a hermeneutic circle (i.e., naïve reading, structural analysis and interpretation of the whole), which was explained in detail in the previous section.

Of significance, however, data analysis is de facto an ongoing process which takes place throughout the whole study (Mauthner & Doucet, 1998; Streubert & Carpenter, 2011): it starts during the interviews by deliberately listening to the answers of the participants and then deciding what to probe for and what information should be closely attended to (e.g., repeated statements), as discussed above. Mauthner and Doucet (1998) further point out that analysis also happens in the

transcription phase when researchers “interpret and note areas of difference and overlaps with other participants’ accounts” (p. 7).

In this study, data analysis was achieved through coding and clustering of similar statements, also known as themes: they are the structured units of meaning in qualitative data (Streubert & Carpenter, 2011). This process was guided by the Voice-Centered Relational (VCR) method, which is detailed in a later section.

### **3.5.1 Before Data Analysis**

Before coding can begin, full immersion into the data is required (Cheng, 2010). Therefore, all the recordings were listened to in full again to remind me of the interview process. It is vital to gain a whole picture of the interview contents and treat the conversations as a fluid process, thus ensuring no information is neglected in later analysis (Cheng, 2010). In addition, special attention was paid to the attitudes, tones and pauses in the interviews, as these reflect emotional changes crucial to understanding the participants’ experiences.

The transcripts, both the original ones and translated versions, were also thoroughly read again. The purpose of the readings was to get familiar with the content and gain a general sense of it, stimulating thoughts and ideas for later analysis (Streubert & Carpenter, 2011). As discussed earlier, in hermeneutic phenomenology, in addition to the apparent statements, the unsaid meanings are also the focus of the study. Therefore, notes were made on the transcripts concerning the unsaid meanings

of a given statement, which was guided by the impressions gained from the recordings. Furthermore, repeated words and similar statements were underlined in each transcript, and comparisons were made among them. In doing so, the coding process was greatly facilitated.

### **3.5.2 Coding and Thematic Analysis**

Thematic analysis is the most basic and common approach to content analysis in qualitative study (Green & Thorogood, 2004). It is a process that identifies the themes embodied by and dramatized in the evolving meanings and imagery of the content (Manen, 1990). Generally, this method follows a linear sequence of thoroughly reading all the verbatim transcripts, coding for themes and then interpreting those themes.

Coding begins the data analysis process and is its fundamental element. According to Saldaña (2012), codes refer to reduced meaningful units, such as the key words/phrases in contents. Constant comparison, which means that a comparison should be made between new codes and previous ones, is then used to categorize codes sharing similar meanings into a single group (Taylor & Gibbs, 2010). These groups, identified through constant comparison, are then used to develop themes. In this study, the coding was first completed by me, and was then examined by my supervisor.

According to van Manen (1990), themes refer to simplified statements, aspects of the interviews to be captured, which are the outcome of coding (Ryan & Bernard, 2003; Saldaña, 2012). To be specific, when related codes are clustered into groups, they construct larger units, called themes (DeSantis & Ugarriza, 2000). A theme can also consist of several sub-themes.

When trying to identify a theme, two questions should always be kept in mind: one, would the phenomenon be the same were this theme changed or deleted? Two, would the phenomenon lose its fundamental meaning if this theme were retained (Cheng, 2010)? In order to extract themes from data, scholars pay attention to the repetition of words or phrases, indigenous typologies or categories, metaphors or analogies, transitions, and similarities and differences, among other things (Ryan & Bernard, 2003).

Although adequate for many qualitative studies that aim to describe a particular phenomenon, thematic analysis may fail to capture infrequent but nevertheless significant meanings. Therefore, more sophisticated methods may be adopted to guide this process, in which the researchers move beyond linear coding and extracting themes based on relatedness (Green & Thorogood, 2004). In this study, in addition to thematic analysis, the Voice-Centered Relational (VCR) method was employed to guide thematic analysis and explore the lived experiences of Chinese family caregivers.

### **3.5.3 Voice-Centered Relational Method: the Four Readings**

The Voice-Centered Relational method served as the guideline for the data analysis in this study. According to Mauthner and Doucet (1998), this method originated from a feminist psychology paradigm, and espouses the core idea of ‘relational ontology’. This posits the concept of “relational being, a view of human beings embedded in a complex web of intimate and larger social relations (p. 9).”

The VCR method aims to unveil the power, relationships and contexts of participants through a reading of their narrative accounts from different perspectives (Byrne, Canavan, & Millar, 2009; Hesse-Biber & Leavy, 2006; Mauthner & Doucet, 1998; Paliadelis & Cruickshank, 2008). That is to say, it is particularly interested in exploring the participants’ relationships to themselves, to the people connected with them and, in a boarder sense, to the social and cultural contexts in which they live. In addition, the VCR method, a feminist-oriented approach, is valuable in this study because the participants in this study were most females (6 out of 7). Though this method is not just designed to study women, it imply a world view.

Furthermore, Chinese culture emphasizes relationality and close personal ties in the family (Olson, 2001), thus requiring a method that places a greater emphasis on relations. In a word, whereas Western masculine epistemologies tend to value the idea of the detached, rational being, many feminists argue that a feminine world view values connection and sees the human as essentially relational. Therefore, because this study explores the aspects of filial piety and family interconnectedness as manifested

in end-of-life care, a more relational approach like VCR method is of interest.

Therefore, the VCR approach is perfectly tailored to this study, expressing and amplifying the voices of Chinese women and exploring social and cultural relationships.

Reflexivity remains a critical issue in the analysis stage, because I am expected to be not only an empathetic and responsive listener, but also an active one (Fairtlough, 2007). The VCR method emphasizes the interaction between the participants and the researcher; and the researcher needs to be reflexive about their theoretical, institutional and epistemological influences and subjectivity (i.e., beliefs, cultural and social location) in this approach (Fairtlough, 2007; Frost, 2008). In other words, by including the researcher in the analysis, it should be accepted that there is not only one way of doing research and that the results generated from the data only represent one interpretation of this study (Frost, 2008).

Different from traditional data analysis in qualitative research that follows a linear process, the VCR approach is proposed as a circular and hermeneutic process, consisting of four stages of reading, as Mauthner and Doucet (1998) describe:

1. Reading for the plot and for the responses to the narratives. This reading consists of two components. The first one is to read the overall story being told by the interviewees, including main events, the protagonists and subplots. The second one focuses on how the researcher emotionally and intellectually related to the participants,



enabling the researcher to examine how his/her assumptions and views might affect his/her interpretations.

2. Reading for the voice of “I”. In this phase, the reading centers on how the participants experience, feel and speak of themselves. The changes in how the interviewee perceives himself/herself can be usually observed from the shifts between ‘I’, ‘you’ and ‘we’. This step of reading encourages staying with the interviewees’ multi-layered voices, avoiding categorizing their words according to the researcher’s understanding.

3. Reading for relationship. The participants’ relationships with their friends, family and relatives constitute the focus of the third reading.

4. Reading for cultural contexts and social structures. As a cross-cultural study, it is always of interest to understand how participants’ cultural and social contexts influence their responses to an event and their decision-making process.

In a word, rather than creating a linear causal narrative, which takes the risk of neglecting significant single events, the VCR method embraces the notions that “narratives are polyphonic” (i.e., different voices can be heard concurrently) (p. 23) and that one statement can have different meanings when looked at through different lenses (Frost, 2008). In summary, the VCR approach brings to the fore unspoken cultural and social influences upon participants’ behaviors and beliefs.

### 3.5.4 Summary

With a knowledge of thematic analysis and the VCR method in hand, the concrete steps for the analysis of the interview transcripts were formulated.

1. Each transcript was read thoroughly four times, each time focusing on different aspects, as proposed by the VCR method's four readings. Four pens of different colors were used to highlight significant statements in each reading. These statements were reduced into a word or a phrase (i.e., codes), for instance "burden", "a sense of responsibility", which was useful for further multiple comparisons and the generation of themes.

2. When the readings of all the transcripts were completed, comparisons were made among the seven transcripts to form a sense of all the contents in their entirety. Codes with similar meanings were then grouped together. For example, "feeling sad", "feeling guilty" and "self-blaming" all represented similar negative emotions of participants, so they were grouped into one category.

3. These small categories were later grouped into a larger and more general categories. For instance, because "caring for other family members", "changes" and "emotional impacts" all reflected different aspects of the life as a family caregiver, they were categorized into one larger group.

4. Finally, the themes and sub-themes were organized and then checked by my supervisor for wording and consistency. Therefore, these themes and sub-themes, which will be presented in detail in the next chapter, formed the comprehensive

structure to understanding the lived experiences of the Chinese family caregivers in this study.

### **3.6 Rigor in Analysis**

Validity and reliability are important to reduce bias and errors throughout the qualitative research process, and are usually examined via notions of credibility, dependability, confirmability and transferability (Bowling, 2009; Streubert & Carpenter, 2011). Several criteria were followed to guarantee the trustworthiness of the results.

#### **3.6.1 Credibility**

Credibility includes the methods used to ensure credible findings will be produced, which is usually achieved by an activity called prolonged engagement (Streubert & Carpenter, 2011). At least two calls were made to each participant before the interviews. During the calls, the participants formed some understanding of the study and became familiar with the researcher. As discussed above, before the interviews, most participants welcomed me with food and drinks, and we had informal conversations about our lives. In addition, interviews in this study lasted quite long, around 1 hour for each participant.

### **3.6.2 Dependability**

Similar to reliability in quantitative studies, dependability in qualitative study is concerned with the extent to which the findings are dependable, which is assessed in part by triangulation (Sharts-Hopko, 2002). My supervisory committee consists of scholars from nursing, health policy and epidemiology, forming an interdisciplinary team. Triangulation was also achieved by having more people participate in the transcription process, and having scholars (i.e., members in the committee) to check the translation. Furthermore, the coding process was guided by the researcher's primary supervisor, assuring the verification of the codes.

### **3.6.3 Confirmability**

The way to record confirmability of the findings is to leave an audit trail, which documents the activities over time so that others can follow the research process (Streubert & Carpenter, 2011). In this study, research notes and memos were saved, so that the whole study can be traced and repeated.

### **3.6.4 Transferability**

Transferability is related to generalizability, which concerns whether or not the findings of this study can be applied to other populations (Green & Thorogood, 2004). Due to the nature of qualitative research and the sampling method of this study, however, the results should not be extrapolated to other settings. The findings

could nevertheless help inform strategies for health promotion. (Opala & Boillot, 1996)

### **3.7 Ethical Considerations**

The ethics approval (Appendix 5) for this study was obtained from the Health Research Ethics Authority (HREA) in Memorial University of Newfoundland before the commencement of the interviews.

#### **3.7.1 Participant Consent**

During the the conversations over the telephone before interviews, each participant provided their verbal consent at the end of the conversation. Prior to every interview, each of them was asked to read and sign a bilingual written consent form (Appendix 6a and 6b), which describes the aims and rationale of the study as well as the potential benefit and harms. During this time, I also carefully explained every part of the consent form and the participant was also advised to freely ask any question regarding the research. Each participant was also informed of their freedom to withdraw from the study at any time without repercussion.

#### **3.7.2 Confidentiality**

Each participant was assigned a number based on the date when they participated in the interview. No personal information of the participants was left in the recordings

or questionnaires. The transcription, translation and data analysis was conducted in Newfoundland; digital and printed transcripts were only accessible to the researcher and his supervisor. All the digital information is kept in the researcher's password-protected computer. Currently, all the data is kept in the office of Dr. Victor Maddalena and will be kept for five years

### **3.7.3 Risks and Benefits**

There were no known risks associated with participating in this study. However, because the topic of death of a family member can be very sensitive, the participant might, during the interview process, become upset. I planned that if a participant experienced a high level of distress, the interview would be suspended and I would assist the participant in accessing professional psychological care if he/she wished.

This research did not directly benefit the participants, but hopefully it will benefit those who face a similar situation in the future.

In summary, this chapter opened with an introduction to the methodology, which was followed by a detailed description of the data collection, management and analysis process.

This chapter explained the theoretical aspects of the methodology and how they guided the choice of hermeneutics phenomenology. Later, the chapter described how the transcription and translation work proceeded, as well as the problems

encountered therein. This chapter additionally emphasized the theories guiding the data analysis methods used, and brought theories into practice. By adopting these approaches, the specific and concrete lived experiences of Chinese family caregivers are revealed, as detailed in the next chapter.

## **CHAPTER 4 RESULTS AND FINDINGS**

The previous chapter described the methodology guiding the conceptualization of knowledge and the methods adopted to collect data. In this chapter, the findings of the study are summarized and then detailed. This chapter starts with the introduction of the demographic profile of the participants. It proceeds to a detailed description of the themes and sub-themes that emerged from the four readings per the Voice-Centered Relational (VCR) method. Therefore, this chapter presents a full review of the study findings regarding the lived experiences of Chinese family caregivers who care for their loved ones.

### **4.1 Introduction to the Participants**

As described in the previous chapters, seven eligible participants were included in this study. The sample consisted of six females and one male; three of whom were currently working while the rest had retired. The age of participants ranged from 50 to 85, with three of them in their 50s and the others over 65. All participants had quite high levels of education, reporting at least some college education. In addition, all the participants come from mainland China and have lived in Canada for at least 10 years. Most participants had an annual family income between \$50,000 – \$70,000, with one exceeding \$100,000. All the participants lived in Toronto or its surrounding areas. Five participants were currently providing or had provided care to their spouses, one cared for her parents and one cared for a friend. In addition, all participants lived with



their family: spouse and/or children. With the exception of one participant who self-described as Christian, the others did not disclose any religious affiliation.

Care recipients ranged in age from 65 to 85. Four were men and three were women. In addition, four have/had cancer; one has dementia, one had myasthenia, and one died of a disease that was not clearly identified.

#### **4.2 Emerging Themes**

Five main themes were identified through the four readings of the transcripts: life as a family caregiver; Chinese cultural understanding of disease and death; interdependence in the Chinese family; experiencing Canadian health care services and future considerations. ‘Life as a family caregiver’ focuses on the daily life of caregivers, including what activities caregiving entails and the impact that providing care had on them. ‘Chinese cultural understandings of disease and death’ explores how Chinese traditional beliefs affected their perceptions and behaviors at end-of-life. ‘Interdependence in the Chinese family’ emphasizes the importance of family as a collective for caregiving activities. ‘Experiencing Canadian health care services’ presents many differences Chinese family caregivers and patients experienced in the Canadian health care system. Lastly, ‘future considerations’ discusses the wishes and suggestions the caregivers had for future improvement.

In summary, the five themes, along with several sub-themes, frame my discussion of the lived experiences of Chinese family caregivers who provide care for their loved ones. The five themes are detailed in the following sections.

#### **4.2.1 Life as a Family Caregiver**

Caring for a loved one with a life-limiting disease is a challenging experience both physically and emotionally. Different from professional caregivers, who regard caregiving as a job, family caregivers are unavoidably involved with a deeper emotional response to their changes, resulting in more complex experiences. In addition, though many interviewed Chinese immigrants have lived in Canada for over 10 years, they may spend most of their time in the Chinese community, isolating themselves from mainstream residents. Therefore, patients and their family caregivers also have to deal with difficulties generated from adapting to the bigger non-Chinese environment. Therefore, exploring participants' lives as a caregiver allows us to observe not only the meanings concealed in their daily life, but also to understand how culture influences them and their loved ones in the caregiving process.

All participants either directly or implicitly considered their life as caregivers to be very difficult. They used words such as "hard", "sad" and "difficult" to describe their caregiving experiences. Caregiving increased their feeling burdened, added more tasks to their life, and shortened the amount of time that could spend doing other activities. They had to make changes in order to balance their family caregiver role

with their other roles, such as parent or employee. Nevertheless, all of them managed to fully dedicate themselves to caring for their loved ones. Moreover, living in a foreign environment, in addition to routine caregiving activities, they also assumed other responsibilities, such as translation. Lastly, providing end-of-life care to a loved one entails great emotional responses, and could have impacts on one's body and lifestyle.

#### **4.2.1.1 Full Devotion**

Most participants devoted themselves fully to caring for their loved ones. Caring for their loved ones became the main focus of life for many participants every day. Their caregiving usually included cooking, cleaning, and in most cases, just staying close-by to guarantee everything went smoothly. Caregivers described their life as very scheduled and they preferred to stay with their loved ones all the time:

We have to do everything together, I am just afraid of what may happen if I am not around. It feels like I could not leave the room already...I could not leave the apartment; and I cannot leave him alone here (at home).

I did not have any life myself then, no work, not at all; caring for her was my life...I could not imagine if she had survived for another 4 or 5 months.

Full devotion to caregiving also meant that the caregiver had to sacrifice other activities in order to better assume their caregiving duties. One participant said that she had to stop working for some time in order to be fully engaged in caring for her mother.

From that day on, I just told my company that I had something to deal with in my family...I then sent an email to my company as well, saying that my mother was seriously ill and she had to stay in hospital. I could not come to work for quite a long time...I was just every day (caring for her). I did not go to work for about 3 weeks. No, 4 weeks, totally 4 weeks.

For senior caregivers, sometimes they suffered from chronic disease themselves. Nevertheless, they chose to endure their physical condition and provide care to their spouses with more advanced illness:

I have osteoporosis, hypertension, and I have been coughing for over 10 years. In addition, I had my thyroid glands removed...You see, as for my age, I can handle myself, for example, I can take medications myself; but I also have to care for him, so it is not easy.

It is me who cares for him every day...I fell down some time ago. I stumbled. I sat on the floor and my head hit the door. My waist was not good, there was something wrong with my lumbar...I felt hurt even just lying on the bed, but I still endured the pain to cook for him...just endured the pain. Take pain killers, that's it.

It can be understood from these statements that these Chinese family caregivers assumed their caregiving role as a fulltime commitment. According to these participants, caring for the seriously ill one is regarded as a priority, and their personal life, work and physical conditions were likely to come second.

#### **4.2.1.2 Multiple Demands**

Apart from the aforementioned responsibilities, most participants indicated that the role of caregiver included additional tasks. According to them, caring for their loved one's daily life is the rudimentary part, and there were multiple other demands made upon them. For example, during caregiving, they usually needed to serve as a translator or messenger to enable communication with physicians. Therefore, from a broader perspective, being a family caregiver is a demanding role, consisting of a variety of tasks. In short, they had to consider and implement every possible means to assist the life of their patients and make them comfortable.

(1) Translator

A number of Chinese immigrants suffer from poor English language skills, especially those who are older. To communicate with physicians and nurses, one family caregiver mentioned that she had to take on the role of a translator for her parents:

Language is also a huge barrier; this is the most challenging thing for Chinese immigrants when they go to hospitals, because they cannot communicate with doctors and nurses. If she has something to say to the nurses, she just asked me to translate for her...I translated all these (her requests) to the doctors.

Her English was not very good. So I was with her every time we went there (to hospital)...I needed to first communicate with her and translate what she wanted to the doctor.

(2) Massager

Many participants mentioned that they tried to make their loved ones feel more comfortable by giving them massage. They thought massage could not only mitigate their physical pain, but also increase their physical activity:

I did not know what to do with it, I had no better choice and I just did some massage for her, and she felt relieved and better...I then used pillows, put the pillow under her body, raised her legs and then put them down, and then some massage, you know, just to reduce her pain and misery.

I just did my massage for him...I did not know if it worked. I just thought it was better than nothing.

(3) Entertainer

The caregivers in this study usually try to bring mental comfort to their ill loved ones by making them feel relaxed. Through small activities, such as playing cards and enjoying movies together, they tried to help their loved ones relax so they could be distracted from their illness a little bit. Some participants mentioned that they often served as entertainers to bring happiness:

Sometimes we would sing some songs or operas for her, tell her some jokes, and she became relieved and happier; so she was very grateful for what we had done for her.

(4) Secretary

Family caregivers also had to deal with the patients' personal documents. One participant stressed that it is of great importance to immediately send a death certificate to the government and other agencies after the patient's death:

When my father died, there were quite a lot of things to do for him; like informing his insurance company...when I got back from China, I had to write letters to the government that this person had died. I had to prepare his death certificate. Therefore, the Chinese immigrant here should be careful. If a family member dies in China, you should remember to have all the necessary documents from the hospital prepared, so that you can notify the government here in Canada that this person is dead.

In conclusion, to fully accomplish their caregiving role, Chinese family caregivers were engaged in a variety of diverse activities to manage the patients' daily life, improve their quality of life, and get them accustomed to the life in Canada.

#### **4.2.1.3 Multiple Roles**

In addition to the role of caregiver, many participants admitted that they had more "titles". That is, apart from caring for their loved ones, they also needed to look after other family members and go to work.



For instance, one participant indicated that apart from caring for her loved one, she also had to fulfill her responsibility as a parent:

I also had to care for my kids. It would be too difficult for me to care for him (her father) outside and care for the kids at home...when I got back home at 10, I had to do something else; sometimes cook, cook for myself, cook for my daughter as well, who was still at home.

Another participant revealed that he was experiencing a dilemma: he had to strike a difficult balance between caring for his wife and working.

It was just very hard for all of us, very difficult and very tiring, because you could not just leave her alone. She needed someone to be around, so we had to be with her, stay by her side. But you know, I could not just quit my job...I had my job, I had two jobs, I could not care for her all the time...I really needed more time; because I could not just give up everything to look after (her).

Apparently, the family caregivers wore several “hats” at the same time: as a caregiver, as a professional and usually as a parent. The obligation to serve as both a family caregiver and other roles simultaneously can quickly result in increased pressure in life.

#### 4.2.1.4 Consistency of Caregiving

As stated above, full engagement in caregiving can be very tiring and challenging, and it might have great impacts on caregivers' lives. As a result, physical and mental changes were quite common among participants. One participant mentioned that because she had to care for her mother all day long and usually experienced emotional unrest, she suffered from rapid weight loss and disordered sleep during the caregiving process.

Just caring for her, to tell you the truth, I had lost 15 pounds, and I have not gained the weight back since then. You could just see me lose weight every day...I could not sleep well, even until now from that time on. I wake up early in the morning, or I just cannot sleep in the morning.

Another participant revealed the compromise he had to make for his role in the family. He described his family as having a traditional Chinese style: the man was in charge of a business while his wife was responsible for household affairs. According to him, after he began to care for his wife, he had to undertake all the household affairs himself for the first time:

I have experienced many changes myself. You see, we are a very typical Chinese style couple. We have a very clear-cut division of labor. The man deals with

outside affairs while woman deals with affairs at home...I did not know how to wash dishes, not to mention how to cook...(But now) I have become very good at all the housework ... Now, I can do all these things, I had to learn these things.

#### **4.2.1.5 Emotional Impact**

Watching a loved one suffer from a life-limiting disease and dying is an extremely devastating experience; and sometimes, nothing can be done to relieve their pain or prevent their death. As a result, most participants said that they were greatly emotionally affected. They expressed that strong feelings emerged from their caregiving, such as sadness, regret and misery:

This experience (of caring for her) was really not a pleasant one. Because I was watching a person suffering in pain, (but) could do nothing to help her; she just waited for her death gradually, in despair. This feeling is just awful; this experience had a very bad influence on me.

Once we saw her in the hospital, I was extremely terrified...I felt very down and overwhelmed. I felt very frustrated...I became very scared.

Sometimes, I feel so sad, so bad at night, I cry. But I just cry underneath the quilt. I have to conceal my tears in front of him. I cannot let him see, let him know.

These feelings continued after the death of their loved ones. Apart from grief for the loss of a loved one, participants expressed self-blame and regret for not fulfilling what they felt should have been done:

When my brother hurried to Toronto, he only found his mother lying in the bed in ICU with her life supported by a breathing machine; no sense, no consciousness. I felt extremely guilty for this, that I did not let my brother see her for the very last time.

Now I am really regretful, I should not have persuaded her to take it (radiation therapy). If only we had not taken that. (Sigh)...I just regret letting her receive the radiation therapy. If she had not received it, nothing would have happened at all, nothing. If only I had listened to her words when the doctors recommended (radiation therapy). She did not want it at all. Now, if the same situation came to me again, I would not have all the therapies.

Caring for a seriously ill loved one can be a very emotional experience. All the participants revealed the sadness, sometimes helplessness, they experienced. It is noteworthy that the participant who had the strongest emotional outburst was he who lost his wife during his 50s. This is a reflection that in Chinese culture, the two most devastating events in life are “losing spouse in mid life, and losing a kid in old age.”

Despite the negative emotional impacts caregivers felt, several participants also mentioned that it was of great importance for them to maintain a good attitude and remain optimistic. They believed that having a positive attitude was beneficial for their caregiving and their patients. One participant commented that she always saw things in a positive way and tried to make her husband think that way as well:

I tried hard to make him think positively; tried to comfort him: “do not think badly of your daughter-in-law; do not think of the bad side of a person; you have to see the good sides of people.” I just wanted him to be relaxed and be open, and to not think too much. He said I did not take anything seriously. I said why take everything seriously; you get very tired if you do. “I do not care that much. If you do not do well this time, you can try next time. Why take everything so serious.” I just wanted to calm him down.

Another participant admitted that her husband’s dementia sometimes would irritate her, making her quite angry. However, she attempted to listen to the doctor’s suggestions and regard her husband as a child to care for:

I was so angry that I told the doctor that I did not want to live anymore. I cannot stand it. Once I was so angry, I just grabbed my clothes and bags, and shouted to him that I was leaving... The family doctor told me that I should act like this, and

I could just give him sweets. Just regard him like a two year old kid, use candy as a reward...Now, it is good now. No such things happen.

In summary, the Chinese family caregivers were fully dedicated to their caregiving role, fulfilling multiple demands in a foreign environment and managing to strike a balance between this role with other familial and social roles. Caregiving was also accompanied by physical and life changes as well as emotional impacts. Therefore, it can be concluded from the above themes that it is a very challenging task to serve as a family caregiver providing care to a seriously ill family member.

## **4.2.2 Chinese Cultural Understanding of Disease and Death**

### **4.2.2.1 The Chinese Custom of Truth Telling**

A huge difference exists between Chinese and Western health systems concerning how to disclose the truth of a disease and to whom that information is disclosed. In Chinese hospitals, it is quite common for the diagnosis of a terminal disease to first be revealed to direct family members in the absence of the actual patient. The immediate family members, usually a spouse, parents or adult children, collectively decided what treatment should be used. The disclosure of a terminal disease to the patients is usually only after the approval of family members. In contrast, health professionals in Canada act quite differently, according to a different interpretation that prioritizes privacy and autonomy and binds this in laws regarding patient confidentiality. They therefore

usually disclose diagnostic and treatment information to the patient. According to the participants, doctors tended to reveal the patients' physical conditions directly to them and sometimes without effective communication with family members.

Although it is understandable that doctors in Canada believe it is their responsibility to ensure patients' right to know their conditions, Chinese culture strongly rejects this idea, believing that it is very unkind to tell someone that he/she is dying. Chinese family caregivers fear that truth-telling will add an extra burden, both physically and mentally, to the patients, which can result in very serious outcomes:

(After discovering his cancer had metastasized), he just collapsed mentally. The acupuncture used to be very effective but now did not seem to work. It seemed he had no power at all...He could not eat anything. This lasted for a month, and I think he was mentally collapsed. He just thought he was over.

Instead, Chinese immigrants believe that the diagnosis of the patients' disease should be first communicated to the family, who then could decide whether to tell the sick family member:

In China, if someone is diagnosed with cancer, his/her family is the first one to be notified instead of the patient...However, here in Canada, it is different. The doctors directly tell the patients what is going on with their body. And I, as his

daughter, will be informed only after he has agreed so; otherwise, I won't know anything. Therefore, usually, the patients, the old people will feel very much pressured, because he is the first one who knows this. He did not know what the exams are, which are all in English. He just felt very afraid... The doctor just told me that the patient had to be present if he told us any of his conditions or the treatment. He thought the patient had to decide. So after he said anything to my father, he asked me to translate for him. This means that we cannot have anything concealed, we had to tell him everything. In other words, the patient knew everything about himself. This is very different from our own culture.

From the description, it can be seen that doctors in Canada wish to respect the autonomy of their patients; however, they sometimes neglect that it is culturally inappropriate to communicate information regarding serious disease directly to the patient. In addition, in Chinese culture patients usually do not make treatment decisions themselves, but concede those decisions to close family members.

Nevertheless, only one participant experienced this culturally competent way of truth-telling:

The doctor, he is a Chinese, but (he) does not speak (Mandarin), (he) asked us out (of the ward) and told my son, daughter and grandson that this (the patient's disease) was lymph cancer.



In Chinese culture, the family members expect to be updated on the condition of the patients in a timely manner. In other words, the state of the disease should always be promptly revealed to family members. For example, one participant criticized the minimal information she received concerning her mother's situation. In China, according to her, the patient's medical file is usually accessible to direct family members. If the patient's illness is getting worse, the family will be notified as a reminder to prepare for the next steps. However, in Canada, such notice is rarely issued. She mentioned that as she had no clue about how serious her mother's illness was, she was unable to make decisions about whether or not to summon her brother from China to visit her mother for the very last time, which, in Chinese culture, is considered one of the most significant events in one's life.

In Canada, they do not give you the pathological report. I asked whether her condition was so serious that I had to ask my brother to come (from China) to see her (for the last time). But no one told me anything about this... Since the doctor did not tell me how my mother's illness was, I could not decide whether to ask my brother to come or not. I think it is really a bad side (of the hospital here). Unlike in China, doctors here do not give the family a notice (that the patient is dying/the patient has limited time), they just do not give you any information.

It is so different in China... a notice (of dying) will be given to the family for the preparation for the next step. This is very important in China. The last time to meet, (it is) a very important thing for people. But doctors here do not take it (seriously). Without the notice, how could I make decisions?

Another participant also complained that the lack of medical reporting provided to the patient and his/her family is very different in Canada than in China, and resulted in her be worried and confused about the real condition of her husband's disease.

Also different in China, where I can just read the reports by myself, nothing was provided here... The doctors here would not give us the medical record of his... They just told you we are fine, nothing serious at all. Well, I had no idea whether he was really fine or not; I did not know what he is fine means. They just told me that he is fine, like: he is fine, very good.

In addition to confidentiality surrounding the patient's condition, Chinese health professionals and family caregivers tend to tell "white lies" to reassure patients, to help them remain comfortable and think positively. For example, physicians may disclose the truth about a less severe condition in order to reduce a patient's worries. It is the Chinese belief that no harm will be done in telling the patients a white lie as long as it means they can stay relaxed and happy. After all, the caregivers tend to believe

that because their loved ones will not have much time left, it is unnecessary to bring them further misery:

She once asked the doctor: “cannot I eat anything?” she wanted me to ask the doctor (in English), well, actually I know it was impossible for her to eat anything, and the doctor said “no, you cannot eat anything.” But I just I told her: “well, it all depends, of course you can eat whatever you want when your situation gets better, but if not, you cannot eat.” You know, I was lying, but I just did not want to put more pressure on her, you know, just did not want her to be more miserable.

They told him there are several patients with pancreatic cancer are cured. Well, actually, this is good for him mentally, just a kind of mental comfort...I think this can be told to the patient to make him feel better...telling them the cancer can be cured can really make the patient feel better, feel less pressured...Well, I think as long as they can provide very good service and a good environment, they can do it to make the older feel relaxed, to ease their pain.

To summarize, when it comes to truth-telling, the beliefs of Chinese family caregivers vary greatly from the Western tradition of full and private disclosure. They not only strongly discourage revealing the state of the disease to patients for fear of

adding extra pressure on them, but they also desire prompt and updated information regarding the patient's disease. Furthermore, in Chinese culture, telling white lies to patients is usually acceptable if it helps to maintain their well-being.

#### **4.2.2.2 Chinese Medicine**

It is widely observed that people tend to rely on their traditional cultural medications when they get sick. Accordingly, nearly every participant acknowledged that they tried Traditional Chinese Medicine (TCM) for their loved ones to ease their symptoms and improve their quality of life, although they mentioned that doctors strongly disapproved of the use of Chinese medicine. However, most of them admitted that the Chinese medicine they used was not effective in solving their patients' problems:

Me: So how was the Chinese medicine you tried?

Participant: It was not useful. We spent much money on Chinese medicine, including many folk medicines, but it was not useful.

One participant confessed that she spent a lot of money on Chinese medicine, but surreptitiously. She stopped giving her husband the Chinese medicine a few days before a medical exam for fear that the doctor might detect it.

We used Chinese medicine, acupuncture, everything and spent quite a lot of money...but there was nothing effective...they (friends) sometimes recommend some (Chinese) nutritious products to us, like ginseng...But you have to cease it two days before any examination, because the doctor will find out... The doctors examined and then asked the patient to be very cautious about what he eats and drinks...we just stop taking any Chinese medicine two or three days before any examination.

This participant's story reveals the situation of Chinese medicine in a society where Western biomedicine is dominant. According to her, Chinese medicine is of great significance and should be protected as a traditional asset. However, it is not properly practiced or respected in Canada. Therefore, she thought efforts should be taken to standardize Chinese medicine in Canada:

You know, Western medicine does not recognize Chinese medicine, and Chinese medicine does not recognize Western medicine here...we found Chinese medicine here has some problems...Chinese medicine doctors here are not like in China. In China, the Chinese medicine doctors have state-issued certificates, very standardized. But here in Canada, Chinese medicine is not so standard.

While the majority of participants held some negative perceptions towards the effectiveness of Chinese medicine, one participant relied heavily upon Chinese medicine and attributed the improvement of her husband's condition to acupuncture:

We found a doctor who could use acupuncture to treat liver cancer. He (her husband) said since he was treating liver cancer (with acupuncture), why he should take so many medications; these medications can be poisonous... So he just did not take medications. After three months, the doctor said his liver was okay after an exam. Well, maybe it was because of acupuncture.

His lung was hurt and he coughed for a month... finally it was acupuncture that cured his coughing.

To summarize, even though Western medicine has become dominant globally, Chinese medicine is still largely practiced by most Chinese immigrants as a complementary therapy. However, most participants doubted the effectiveness of Chinese medicine. In addition, the differences of opinion towards Chinese medicine further demonstrate that Chinese medicine in Canada is not standardized and not fully recognized by the mainstream health care system.

#### 4.2.2.3 Fallen Leaf Returns to the Root

One traditional teaching instilled in Chinese people is the concept of “luo ye gui gen” (落叶归根). It literally means that ‘no matter how tall the trees grow, the leaves finally return to the roots’. It suggests that however far you have travelled, eventually you will still want to return to where you were born. This concept is largely accepted by most care recipients. They expressed to their family that they did not want to die and be buried in a foreign land; they wanted to return home and be buried there:

My father did not want to be buried here at all, I always know it was against his will to have his last days here away from China, his root, (dying here was) not his will.

He could not be buried in Canada. He did not want it. He had long wished to die and be buried home. He had to go back, “fallen leaf returns to the root” (Chinese proverb: wherever you go, you still wish to come back home in the end). Well, (dying in Hainan, China) was one of his last wills.

Apparently, this traditional concept is prevalent among Chinese immigrants, especially among those who are older. To accomplish their wills, some family caregivers arranged the trip for their loved ones to go back to China in his/her last days,

and prepare for the possible funeral at home, which additionally brings more troubles for them.

#### **4.2.2.4 Avoiding Death at Home**

It is quite common in the West that the idea of dying at home is quite acceptable, even preferable however, in Chinese culture, having someone die at their house is traditionally avoided. Therefore, many participants accompanied their loved one during their last days at hospital. One participant mentioned that though her father preferred to spend his last hours at home, this was rejected by her mother, who believed it was highly inappropriate to let him die at home:

My father had a wish to die at home; but my mother, a very traditional Chinese woman, said he could not die at home; it is not good to have someone die at home. She asked me to rent a house somewhere else where we could live and care for him there.

#### **4.2.2.5 Accepting Disease and Death as a Natural Process**

In Chinese culture, disease and death are normally regarded as natural processes and unavoidable phenomenon; thus, human beings should accept them with a peaceful mind, especially when people get older.



However, discussion of death is usually discouraged and sometimes avoided. People tend to use euphemisms when referring to death. This was illustrated at the beginning of many of my interviews, for when I tried to explain to the participants what palliative and end-of-life care mean, the immediate response of several participants was usually a pause, followed by several seconds of pondering before they suddenly became solemn. Some of them then said: "okay, well, born, age, illness and death; just the natural law. It is okay for me to talk about this."

Accordingly, participants presented solemn facial expressions when talking about death or an approaching death. They mentioned that they could calmly accept disease and death. They felt quite content about themselves, for living long enough and enjoying a good quality of life. This was observed more in older participants:

End of life, we do not care much now. Chinese people say: you are born, then get old, become sick and die. (Death is) just a natural process, nothing, no big deal...after I die, just burn me and throw my ash anywhere they want. That is ok...you know, Chinese people always prepare for this (death).

I know this illness (cancer) will not just disappear. It cannot be cured easily. I also told him that we have to live with it for the rest of our life...we are not young anymore. The old man (her husband) is 75 and I am 72. I just wish for

several more years (of life), and then I will be content. I have made the mental preparation.

Though conversations about death were never easy, Chinese family caregivers admitted that they could peacefully accept disease and death as natural, which was seen as very beneficial for keeping a positive attitude in life.

In summary, the Chinese norms regarding disease and death greatly influenced participants' behaviors regarding end-of-life care, such as seeking treatment and care, and the afterlife plans and arrangements for the patients. Chinese family caregivers wished to be fully involved with the treatment and care of their loved ones. They preferred to be informed of the condition of their loved ones first and decide how to inform the patient. While they doubted the usefulness of traditional Chinese medicines, they were still eager to try. Furthermore, they considered disease and death as natural, and respected the wills of those who wanted to die in China.

#### **4.2.3 Interdependence of the Chinese family**

It is widely acknowledged that Chinese culture places enormous emphasis on family relationships and family values. Respect for hierarchical organization, filial piety and collectivism are some of the basic virtues inherited after a thousand years or tradition. Cultural norms produce the expectation among Chinese descendants to undertake the responsibility of respecting the elderly and caring for the young.

The family caregivers in this study claimed that they felt a strong sense of responsibility to undertake their caregiving tasks. They regarded caregiving as a obligation, for which family members must assume the primary role. They therefore usually rejected external assistance, either from friends or paid caregivers. In addition, some caregivers held that the reason they would assume the role alone is that they did not want to place more burden upon other people, such as their adult children.

#### **4.2.3.1 Family's Responsibility**

Most participants considered their role of a family caregiver as a way to fulfill their familial responsibilities. They directly stated that this sense of responsibility is what motivated their caregiving:

We are a couple, so it is my responsibility to look after him. That is okay. He is not very healthy now, so I will take my responsibility to care for him. That is it. I should care for him; we are a couple, and it is my responsibility.

I take care of the old man (her husband). I take my responsibility.

Some participants did not use words like “duty” or “responsibility”. They nevertheless expressed what they had to do for their patients in a way that reflected caregiving as an obligation they cannot shirk:

I worked hard and became very tired at night, but I still had to care for her... I had to care for her. You know, if the family member is not around, how can you trust the nurses? It makes a huge difference when a family member is present or not. Families are different, no matter how busy you are, you have to come.

These statements suggest that when someone in the family gets sick, the natural response of other family members is to immediately take on the responsibility to care for them themselves.

#### **4.2.3.2 Collective Decision Making**

Chinese family members tend to make decisions collectively. It is quite common that decisions are the result of unanimous family consent achieved through negotiation, rather than made by the patient himself/herself, especially when the patients were not able to do so:

In fact, he could not make any decision himself. He just listened to whatever we decided. So after we translated for him, he asked for our decision and then he agreed.

It is useless trying to save her. There was no way then. So my son and I discussed it and then decided not to use the breath machine any more...we made it (the decision) together.

We made the decision (of going back to China) together. He wondered if we should go back, I said since we have decided, we just go. Then we went back finally.

In a word, decisions concerning treatment and future plans were usually discussed among family members and then decided together. In general, the older generation usually holds a passive and submissive position and is more likely to depend on their adult children to make decisions.

#### **4.2.3.3 Dependency**

Within a Chinese family, middle aged members are usually regarded as the backbone of a family. They are the ones who primarily earn money, feed the younger and care for the older. It is a cultural tradition that when people get old, they depend on their children for support and care.

Many older participants admitted that they followed their children's advice and direction in most circumstances.

Because my daughter is a doctor as well, she told me this doctor is very good. So we just followed... Our daughter said it was unnecessary to do that (a surgery): he is very old now, and it is very dangerous to do surgery on him.

My son and daughter said they wanted to try chemo-treatment (for their father).

Then I also agreed to have a try.

One participant further pointed out that elders' dependency on their adult children is deeply rooted in Chinese culture, and is thus unlikely to change:

I can still remember how she looked at me; her eyes: dependency. Though she did not have to say it, I could read dependency in her eyes. You know, it's a tradition of the Chinese elderly. People usually say: 'raising a son to prevent aging' (Chinese proverb meaning people have kids so that they can care for them when they grow old). I could read that; it meant: then you just stay here, do not go to work. It was obvious, so I just stayed there without saying anything. This is our culture. There is nothing you can do to get rid of it; they have dependency, you cannot eliminate it.

Specifically, this participant stressed the elderly Chinese immigrants' helplessness and tendency to have their adult children to care and make decisions on their behalf. In

short, there is a strong sense of dependency especially among older Chinese immigrants. Given that they were living in an unfamiliar environment, it is quite understandable that they would strongly depend on their children. However, some of the participants tried to overcome this dependency and relieve the burden upon their children.

#### **4.2.3.4 Do Not Want to Be a Burden**

Although older Chinese often seek help from their children to become accustomed to life in Canada, many of them still tried to deal with caregiving on their own, reducing the trouble and burden they might bring to other family members. Many participants confessed that since they knew life was not easy for their children, they should be considerate and allow their children to save their time and effort for their own work and life:

He (my son) is working...he has his own family. He has kids himself and the kids are quite young. He has to work and then care for his own family. So you cannot spend too much of his time and energy. So for the most part, you have to rely on yourself. So I have to care for him (her husband) myself. So basically, if something happens, I will not ask them for help. I try to deal with everything just by ourselves.

Because I think acupuncture and all this stuff, these have been a big burden for my daughter already. I could not give her more burdens, right? She paid for everything...we cannot add more burdens to our children.

Realizing that their children are striking a balance between the duty to raise their own family and the will to fulfill filial responsibility, older Chinese caregivers tended to undertake the care for patients alone, avoiding bringing too much burden to their children.

#### **4.2.3.5 “Friends are Helpful but One Cannot Bring Them Trouble”**

Most participants expressed gratitude to their friends, who provided tremendous assistance when they were in need. According to them, their friends helped them prepare food and buy daily necessities, et cetera. However, they also indicated that they could not rely on friends, because they are not family. Participants believed that it was not appropriate to use too much of their time or bring them too much trouble:

My friends helped us a lot...For example; they would help me buy food or other stuff. Every time they go shopping, they will call us and ask if we need them to bring something; and they never even asked me to pay...They are very nice. (However), you know I could not depend on my friends for long; it is not good. You cannot cause much trouble to others; you cannot owe them too much.



The co-workers, friends, they were all very supportive... (But) you know friends are just friends. You can ask them to come to care once or twice, but for more than that, you just cannot ask them anymore. Friends are not easy as well, living here, they also have to work hard and they are also very busy. You cannot just use too much of their time.

Obviously, a very clear boundary exists between family and friends. Participants regarded care from friends as a favor, while they considered care from family as an obligation. They appreciated the kindness they received from friends, but usually felt uneasy when receiving such favors, fearing it might be an inconvenience to their friends' routine lives. Therefore, the Chinese family caregivers in this study rarely actively asked for help from friends.

#### **4.2.3.6 Rejecting Care from Outsiders**

Though it is quite common to hire paid care attendants in Canada, this idea was not welcomed by many participants. They believed that paid caregivers, who are in most cases regarded as outsiders, cannot be as reliable and responsible as family members. Some participants said they felt more comfortable and reassured when patients were cared for by family caregivers:

When my children see that it is very difficult for us, they once proposed I could just live my life and send him to the nursing house and let the nurses care for him.

But I said no... If I care for him, I will feel reassured. I just do not like having others care him. Well, even if it will be a little bit difficult for me, it is okay.

I then asked her (her mother) whether we could hire someone at home to care for him (her father). She said no, that would not be a solution; outsiders (are) not a solution.

Furthermore, one participant thought having a paid caregiver would affect her routine life, actually adding a burden to her family:

I said he did not need people all the time. He could help himself for many activities. If you hire someone here, after all, they are outsiders... (Non-family caregivers are) not convenient. So I did not do that. It was not about money. If you have someone in your room, they could not help much and sometimes is a burden to us.

In contrast, other participants believed it was fine to hire someone to assist their caregiving; however, the hired caregivers served merely a complementary role, shifting the work of the family caregiver.

Sometimes, you need to find someone to shift... If just one person could come to help me. So every day I just called the agency to find a good one to help me look after my mother. You know, if I cared for her for 24 hours a day, who would care for her if I became ill?

Later, I tried to hire a caregiver to help me. I managed to find someone in the Chinese community. And then she cared for my wife in the daytime, and I cared for her at night.

Paid caregivers were not heavily relied upon by Chinese family caregivers believing better caregiving comes from family members. In this sense, both friends and paid caregivers are considered outsiders who would not be considered for primary caregiving.

In summary, the Chinese immigrants in this study shared a strong bond among family members. They regarded providing care for family as an obligation, which should be actively and willingly practiced. Senior family caregivers often faced a more complicated situation: while caring for their ill spouse, they attempted to alleviate their dependency on their children, fearing it would increase their burden. Moreover, despite the fact that participants recognized the assistance from friends and paid caregivers, they did not tend to rely on them fully.

#### **4.2.4 Experiencing Canadian Health Care Services**

Providing palliative and end-of-life care requires frequent interaction with health care services. The majority of the study participants were satisfied with the medical service provided to their loved ones by their family doctors and specialists in the hospital. This is more often observed in older participants. They used words such as “nice” “trustworthy” and “convenient” to describe health professionals and the services they provided. When talking about their experiences with health providers and services, participants also tended to make comparisons between those in Canada and those in their homeland; and commented on how these differences had facilitated or hindered their medical utilization. Adherent to the preconceptions that I made during the literature review, participants complained about flaws in Canadian health care system, such as long wait times and insufficient cultural competence of health providers.

##### **4.2.4.1 Attitudes Towards Health Professionals**

Although most participants considered the health care system in Canada to be better than that in China, their attitudes towards health professionals varied. Some thought highly of the doctors and nurses for their politeness, carefulness, patience and dedication:

Everything is very standardized. For example, food would be sent to you upon your request...if you have anything urgent, you just press the button, nurses will come over very fast. Generally, the personal care attendants are also very nice and kind; you can feel this from their words and attitudes.

The doctors and nurses are just so good here, not like in China...as long as he is here, the nurses will help him wash his face and brush his teeth, they are very responsible. You know, regardless of whether they are male or female, the nurses will accompany the patient to the washroom... and the doctors are indeed very nice and helpful. They take care of bathing and feeding the patients, you don't have to care for them yourself actually. Some seriously ill patients require the company of family caregivers, just like what I was doing for him; the nurses would prepare a sofa for me to rest on.

In contrast, others were discontented with the doctors and nurses for their inexperience in dealing with emergencies and their untimely responses. One participant said the doctors treating her mother did not have any insight. She was uncomfortable that they failed to find out the cause of her mother's disease, who died very soon after admission. This greatly affected her impression of the doctors treating her mother.

The hospital made me feel they could do nothing at all. They did not tell me what her (her mother's) illness was, nor did they have a very good treatment plan. Did she need any rescue or did she need to be examined by more experts? Or they just thought everything was fine with her? I did not know. So the whole time, the hospital made me think they just had nothing to offer, no method to help her at all...The doctors, all of them, (are) inexperienced doctors trying to treat her. They had no personal suggestions at all; they just looked at the report, the data... They did not have any personal judgments. This made me feel very bad. It made you feel these doctors, without the data and report, they could not make any decision or any diagnosis at all...In addition, they did not even think about taking any risks or any responsibility.

Another participant also complained that the doctor who treated his wife was inexperienced:

He was not very experienced at all...I saw him change the plan so many times before he finally decided which one would be used. I saw him search online even, I was so surprised: he is a specialist, but he did not even know this. [Sigh] I was not very satisfied with that, so many changes in the treatment plan all the time...My wife's doctor was not a bad person at all. Maybe just not so experienced, and could not explain her illness very well.

This participant further criticized the nurses for not responding promptly when his wife was in need:

Though you could press the button to call for help, you had to press so many times. Sometimes they (the nurses) did not come. They don't come very immediately.

Interestingly, this statement was contradictory to other participants, who were impressed by the timely help from nurses. Obviously, participants' attitudes towards health professionals reflect their personal experiences with staff. It is also easy to understand how a caregiver's worry, fear and uncertainty may aggravate negative attitudes.

#### **4.2.4.2 Insufficient Interaction with Doctors**

Several participants complained of insufficient communication with doctors. According to their narratives, doctors in Canada are not frequently present and available to them. As one participant pointed out, in order to be fully updated on the patient's situation, she needed to interact with doctors but they were not usually easy to access:

Doctors there rarely showed up. They just did not come to have a look, they just gave her the prescription, medication and went away. They did not talk much with her and me. Yeah, this in Canada is different (than in China), patients like her were difficult for the doctors to see, it was mostly just the nurses. I rarely noticed any doctors come by, only the nurses cared.

I got to the hospital at 7 in the morning and returned home at 7 pm after he had supper. During those 12 hours in the day, the doctors and nurses only came three times. They never showed up at other times. So I did not like it there.

In brief, participants criticized what they felt to be insufficient interaction with health professionals in Canadian health care settings in this study. From a Chinese point of view, having a doctor around could reduce their worry for potential accidents.

#### **4.2.4.3 Wait Times Too Long**

Almost every participant complained of the long wait times required to receive medical service in the Canadian health care system. According to participants, they usually spent several hours to visit a doctor in the hospital, several months for an operation and up to years for admission to a hospital or nursing house. The long wait time usually made the caregivers feel worried and helpless, fearing unexpected events might happen during the interim.



We waited very long (for the operation). He was diagnosed in September, but we waited till November. This waiting time was very long, and we called so many times during this time. But they said they had no way to shift to an earlier date.

Despite the complaint of long wait times, participants understood the reasons for this problem. They admitted that having to wait a long time for medical service is indeed very common in Canada, and is an issue which is not easily addressed.

We said the wait time was too long, but that is not his fault. The wait time for the specialist is longer. Well, this is how the health care system works here. The number of patients increases but not the number of doctors. Also, (there are) more immigrants coming to Canada, but not enough doctors.

In brief, the participants complained of the long wait time for medical utilization. Nevertheless, they understood it is a common phenomenon in Canada.

#### **4.2.4.4 Language and Communication Incompetency**

English language incompetency has long been defined as an important barrier for immigrants who are trying to access health care services. Every participant identified language as the biggest barrier to accessing care for their loved ones. They claimed

that difficulties communicating in English prevented patients from seeking medical assistance. Only one of the caregivers spoke fluent English, the rest of the caregivers could not possibly take on the role of a translator and thus still depended on others to translate for them.

In addition, as the majority of participants stated, living in a non-Chinese cultural environment is very stressful for ill seniors:

She could not understand English, but English is the only language in hospital, she was helpless and had nothing to deal with it...language is a huge barrier, this is the most challenging thing for Chinese immigrants when they go to hospitals, because they cannot communicate with doctors and nurses... You know, if you do not know the language, your vigilance is strong; the alert is always on, and it is very difficult to trust them.

You see, if the older people were living in the all English environment in the hospital, they would inevitably feel very pressured and scared.

In addition to the language issue, some participants noted a lack of health professionals who have knowledge of Chinese culture. This led to a high degree of isolation and alarm among patients:

When my mother saw nurses of a different race, she became very vigilant. I feel reassured to have them help her. Well, there were nurses who were not so professional, like some could not inject well, maybe painful. My mother just thought they meant it, they wanted to hurt her.

The patient would be alarmed...I think if there were more nurses who are of Chinese cultural background, it would be much better, at least better. The patient would feel more comfortable, being cared for by people of the same (background).

Being unable to efficiently communicate with doctors and nurses usually renders the patients isolated and insecure. As the participants described, they could not clearly express their feelings, nor could they understand the physician's instructions. This has a great impact on the effectiveness of health care services. In addition, staying in an unfamiliar environment inevitably raises people's anxiety. People are naturally overwhelmed by a sense of not belonging. Therefore, it can be concluded that inadequate language and culturally incompetent health professionals in the hospital remains an enormous barrier for Chinese immigrants.

#### **4.2.4.5 Perceptions Towards End-of-life Care in Canada**

When it comes to end-of-life care, participants expressed different opinions. Some participants were unfamiliar with palliative care services. They admitted that they had no knowledge about what end-of-life care is or if any end-of-life care service is available:

Here in Canada, there would not be enough people caring for him. No end-of-life care service here, at least in the hospital...I do not know much. I do not know what kind of end-of-life care is provided there.

Well, end-of-life care, we do not know, we do not care much now.

Some participants had some knowledge of the end-of-life care provided in nursing homes. However, they preferred that these services be provided in hospitals rather than nursing homes, because in China patients are usually continuously cared for and spend their last days in hospital.

You know, her illness could not be cured, she was just waiting for her death, and there was nothing you could do, just hopeless. Well, when you have a disease like this: incurable, and you cannot have any operation, you just cannot stay in the

hospital, and it did not work this way in Canadian health care system. The hospital pushed her daughter to send her to the nursing home.

There is another very big problem, that when he becomes ill, approaching death, no hospital would take him. You know, cancer patients in their last stage will not be taken by hospital. He would be cared for at home or in a nursing home, I do not know; he just cannot go to the hospital. If he felt really in pain, you can send him to the emergency any time, but he just cannot be cared for there.

Furthermore, some participants also revealed negative perceptions towards the end-of-life care that they experienced or witnessed. For example, one participant criticized the care providers in one institution for being too cold:

One female patient, in the next bed, screamed every day, and no one even cared.

One day, she stopped screaming, and the nurses came and found out she was dead.

No one came for her later. Phlegmatic, apathetic, I find people are very cold here.

On the other hand, several participants attributed their negative attitudes to end-of-life care to the lifeless and hopeless environment of medical institutions. As they noted, they were surrounded by patients waiting for death and this was an emotional burden to both the patient and family caregivers:

I saw that the people living there were not healthy, and had a low quality of life. There was a medical room, where very sick people were just lying there; they could not do anything, could not eat; very sick and in very bad conditions. You know, just watching this kind of place will make you feel very sad. I do not like this kind of place; I told them that I would feel very bad if I stay there...that place is full of very sick patients; the situation there is really bad. You see, if you are in an environment where people are very energetic, you will feel very happy; but if you stay at a place where people are sick and lie in the bed, very lifeless, you will feel very terrible. Therefore, I just do not like this kind of place.

She did not like it (the nursing ward) there at all. That place was just like where you wait for death. You cannot do anything at all: just care giving, not treatment...she just did not like it. She could not stay there. There was no treatment at all and they did not do anything.

Apparently, end-of-life care is not fully and positively appreciated by participants. Some participants displayed a lack of knowledge concerning palliative and end-of-life care. In addition, apart from the care for their own condition, they also wished for a positive and pleasant environment for other patients.

In summary, most participants were satisfied with the health care system in Canada, appreciating the convenient service and nice health professionals, although some of them complained of the differences between Canada and China. However, many of them held somewhat negative perceptions towards end-of-life care services; a lack of information and the emotionally cold environment were the main reasons for these perceptions.

#### **4.2.5 Future Considerations**

Despite the different experiences of the Chinese family caregivers in this study, they all expressed wishes and suggestions, based on their own perceptions, that they felt could improve palliative and end-of-life care.

##### **4.2.5.1 Need for More Culturally Competent Health Professionals**

The most commonly expressed suggestion was to recruit more health professionals from the same (Chinese) cultural background. As the participants pointed out, having doctors and nurses from the same cultural background would improve communication with patients, and this in turn would help reduce patients' mental stress levels.

I hope that in the future, more Chinese health professionals can be sent to care for the patients. Yes, doctors and nurses from the same culture background would be

the best. Because using the same language to communicate is more comforting for us and the patients. Doctors and nurses are there to help people, and better communication (is key)...I think this is of great importance. I also think a lot of trouble will be solved if patients are cared for by people from the same ethnic background. You see, there is an increasing number of Chinese coming to Canada, many older people who cannot understand English at all, and it is very important to have people of Chinese background here to care for them.

I think if there were more nurses who were of Chinese cultural background, it would be much better, at least better. The patient would feel more comfortable, being cared for by people of the same (background)...Chinese nurses were so few in the past; there are more now, but (it is) still not enough. You know, but there are very few Chinese nurses in hospitals, most of them work in rehabilitation centers. It is very difficult to work in hospitals. There are not enough positions (for Chinese nurses).

#### **4.2.5.2 Need for Improvement in Facilities**

Participants also expressed a desire for more convenient facilities. Some participants complained of the long distance between the location of the senior's home and the nearest shops and hospital. Therefore, they expressed a desire for a Chinese senior's house to be equipped with a restaurant and primary health services:



They (the senior apartment) should have a restaurant here, so I would not have to make food for every meal, it would be more convenient. And (we should have) doctors living here. I think it would be perfect if we had a restaurant and doctor in this senior home.

#### **4.2.5.3 Need for Social Support**

Many participants admitted that caring for their loved ones alone in a foreign country was unavoidably a very difficult experience. They acknowledged a great need for social support. Participants expressed a desire to have more relatives and friends around who could provide assistance and mental support.

I wished I could have had some relatives here. They could have helped me a lot, you cannot always ask a friend to help you.

To tell you the truth, I need my relatives, even if only just one of them beside me. I sometimes need a friend who can just talk with me, simply talk with me. (There are) just some words hidden in my heart. These words are like jammed in my heart and it makes me feel really bad. I have no one to talk to about the words in my heart.

#### **4.2.5.4 Financial Assistance**

Although most of the treatment and care-related expenses were covered by the social and health insurance of the provincial government, many participants indicated that they also had to spend extra money for additional care. For senior caregivers who did not have employment income, this meant a greater financial burden on them or other family members. Therefore, they described their need for more financial assistance:

I wish for a lot, but firstly I wish I could have been given at least some financial assistance. You see, we spent a lot of money. Everything cost a lot of money, and all from our own money. I wanted to reduce some of my daughter's pressure.

In conclusion, the participants listed several strategies that could have better assisted families and patients. The most prominent need expressed was to have more health providers from the same cultural background. The participants also expressed the need for more social support and increased financial assistance.

### **4.3 Summary**

This chapter presented findings from the interviews with family caregivers. Through thematic analysis guided by Voice-Centered Relational (VCR) method, five main themes were identified in the study: life as a family caregiver, Chinese cultural

understanding of disease and death, interdependence of the Chinese family, experiencing Western health care services and future considerations.

To provide palliative and end-of-life care to loved ones, the family caregivers fully devoted themselves to caregiving. This involved striking a difficult balance between their role as a caregiver and several other roles. This was difficult considering they were emotionally affected by the fact that their loved ones were approaching death. This greatly increased their burden and negatively affected their own personal life. As immigrants, Chinese patients and family caregivers were further influenced by their traditional cultural perceptions and beliefs, especially those towards disease and death. They hold the view that it is inappropriate to disclose the disease prognosis to patients directly rather than to the family. They thought a doctor's priority should be to make patients relaxed and happy, thus necessitating certain "white lies". Chinese immigrants preferred to die and be buried back home and thus end-of-life care also typically included plans to send them home.

Chinese immigrants stressed the importance of family. Firstly, they considered it a responsibility to care for their loved ones, and that caregiving should not be assumed by outsiders, either friends or hired attendants. Secondly, how the treatment and care options were selected was usually the result of a collective family decision. Lastly, although family interdependency was welcomed, senior immigrants did not want to bring too much burden to their adult children.

Chinese immigrants embraced the Western health care system, though they still tended to use TCM when they became sick. Despite some of the widely recognized flaws in the health care system, such as long wait times and insufficient cultural competence among health professionals, they believed that Western health care had been beneficial to their situation. However, their perceptions of and interactions with end-of-life care services were quite negative: such service was either non-existent to them, or presented a sense of cold hopelessness, which potentially hindered their interest in accessing such services.

In summary, the five themes presented in this chapter express the lived experiences of the Chinese family caregivers involved in this study. The findings can bring insight not only to health policy-makers interested in bettering palliative and end-of-life care and services for Chinese immigrants, but also as preparatory information to provide to future Chinese immigrants. These implications, together with a discussion of the findings, will be presented in the next chapter.

## **CHAPTER 5 DISCUSSION AND IMPLICATIONS**

In the previous chapter, I presented the experiences of Chinese family caregivers who are caring for, or who have cared for, their loved ones with a serious illness. The five themes identified addressed the research questions proposed for this study. I will now explore how the findings echo those found in previous studies, but also fill a unique gap in the literature. This chapter then explores the possible implications these findings have for the public and health policy makers. The limitations and the impact for future studies are also included in this chapter.

### **5.1 Discussion**

There is little qualitative research that examines the lived experiences of Chinese immigrants caring for their love ones in Canada. This study serves as a first step in understanding palliative and end-of-life care for Chinese immigrants.

Previous studies focusing on family caregivers are primarily quantitative studies, which emphasized the exploration of predictors for caregiving difficulties and burdens, with the use of surveys and questionnaires, and statistical analytic methods. In contrast, the objectives of this qualitative study are to learn about the lived experiences of Chinese family caregivers and to investigate how Chinese cultural traditions influenced and shaped the caregiving process. Furthermore, this research aimed to explore what constitutes a culturally sensitive palliative and end-of-life care for Chinese immigrants in Canada.

To achieve these goals, I adopted hermeneutic phenomenology in order to explore daily caregiving activities, and to examine the experience of serving as a Chinese family caregiver in Canada. I conducted seven interviews to gain an in-depth understanding of participants' caregiving experiences. In addition, I bring to this research my own knowledge of Chinese culture, traditional beliefs and norms.

The narratives of these participants highlighted Chinese family members' willingness to assume caregiving duties and responsibilities. The participants experienced difficulties talking about death and dying; nevertheless, they shared what it was like accompanying their loved ones into their final days. These conversations were at times overwhelming and incredibly emotional.

The results generated from the data analysis are valuable for understanding the lives of the Chinese family caregivers in this study. The results not only reflected and further verified the findings of existing literature, but more importantly, add new knowledge about how Chinese immigrants spent their last days in Canada and how their family caregivers planned and provided their care.

Five main themes emerged in this study with four of them directly reflecting their current experiences as family caregivers and one reflecting the participants' ideas for how to improve palliative and end-of-life care services for Chinese immigrants.

### **5.1.1 Reflection on Life as a Caregiver**

The Chinese family caregivers in this study were fully engaged in caregiving; and caring for their loved ones was the priority in their life. The concept of caregiving as a way of expressing devotion to their family members was also found in many other studies on family caregivers, in which the caregivers reported that they regarded caregiving as an intense and continuous job where they were on duty 24 hours a day (Boland & Sims, 2007; Schulz et al., 2003). Similar to the participants in this study, these studies also found that family caregivers intentionally spent as much time as possible with the patients, thereby leaving little time for their own personal life (Boland & Sims, 2007; Chan & Chang, 1999).

Consistent with the findings in this study, previous studies also found that family caregivers provide a number of daily services to ill family members, such as preparing meals, shopping, transportation, providing companionship, and arranging outside services (Lai & Leonenko, 2007; Silverstein & Giarrusso, 2010). Also as found in the current study, Lai and Leonenko (2007) also suggested that the 79.4% of the Chinese Canadian family caregivers in their study had to provide translation/interpretations for the care recipients.

Other studies have found that caregivers wear multiple “hats” and experience difficulties balancing their life as a caregiver with their personal life (Shyu, 2008). Studies have observed conflict when caregivers were caring for their loved ones and also tending to their own family and work responsibilities (Kao & Stuifbergen, 1999).

This was verified by the two participants in this study who were caring for other family members and working and at the same time as providing care for their loved ones.

The emotional burden of caregiving is well documented in the literature. According to these studies, stress, anxiety, sadness, guilt, regret and helplessness were usually found among family caregivers (Milberg, Strang, & Jakobsson, 2004; Mok, Chan, Chan, & Yeung, 2003; Parks & Pilisuk, 1991). These same emotional burdens were also observed among participants in this study. Emotional impacts generated by caregiving also render the caregivers prone to physical problems, such as poor sleep and loss of appetite (D. W. Lai, 2007; Rabow, Hauser, & Adams, 2004; Tsigaropoulos et al., 2009).

In brief, life as a family caregiver often entails a full commitment that brings with it great burdens.

### **5.1.2 Reflection on Chinese Cultural Understanding of Disease and Death**

This study confirmed that Chinese immigrants are deeply influenced by their cultural conceptions towards disease and death, which are reflected in their beliefs and behaviors during end-of-life.

In this study, disclosure of diagnosis or prognosis directly to patients was discouraged by participants. In fact, influenced by the Confucian philosophy of beneficence, non-disclosure of terminal illness is largely practiced in hospital settings



by family members and physicians in China and many other Asian countries (Jiang et al., 2007; Wang, Chen, Chen, & Huang, 2004). It is sometimes believed that the diagnosis of cancer should never be told so as to help patients retain quality of life and reduce their despair and feelings of hopelessness (Jiang et al., 2007; Tuckett, 2004). In China, family members are the first ones to be informed of a patient's condition, and are then responsible for the decision to disclose that information to the patient (Tse, Chong, & Fok, 2003; Tuckett, 2004). In this study, the family caregiver participants preferred to be the first ones informed of their loved ones' condition and treatment options.

Furthermore, the study suggests that to comfort and avoid distressing their loved ones, participants preferred to tell "benevolent lies" or "white lies" in addition to nondisclosure of relevant information to their loved ones. Though deception is widely criticized in Western health care system, previous studies justify the use of benign deception, suggesting this behavior could potentially protect the patient from the fear of death (Tuckett, 2004). Moreover, the deceptive approach is also considered a compassionate course, and a natural response to the tragedy of illness ( Lee, 2007).

Regardless of the effectiveness of Chinese medicine, the study found that every participant tried TCM for their loved ones. This phenomenon might reveal two meanings. On the one hand, Chinese immigrants continue to rely on their traditional treatments when illness occurs. This has been repeatedly confirmed by a number of previous quantitative studies that demonstrated a wide use of Chinese medicine

among Chinese immigrants in Canada (D. Lai & Chappell, 2007; Lennox & Henderson, 2003; Wong et al., 1998). Stressing on yin-yang, energy flow and balance between human body and the outside world, TCM reflects an eastern perspective on health. Though some of its concepts are disagreed, it should be recognized and respected in the Canadian health care system. On the other hand, continuing to use Chinese medicine despite its slow effectiveness suggests caregivers have inappropriate expectations. While modern Western medical treatment and care are globally seen as standard, traditional Chinese medicine has been used as a complement; however, Chinese family caregivers have high expectations for its effectiveness. In addition, participants' knowledge of Chinese medicine usually came from anecdotal experience in the community. For example, several participants said friends suggested the use of various herbs, such as ginseng, because they had heard of its effectiveness "somewhere". This partially reflects the Chinese proverb: "treating the dead horse as alive", which refers to trying every last attempt to treat someone even when hope is slim.

Several participants in this study stated that their loved ones wanted to return to China to die. In other words, the sense of "leaf returning to root" became increasingly obvious as the patient's health condition deteriorated. Chinese culture suggests that the dying Chinese immigrant wishes to return to where they and their ancestors were born (Slote & De Vos, 1998).

According to traditional Chinese perception, death at home is greatly discouraged. It is often believed by many Chinese that the ghost/soul of the recently dead dwells wherever he/she died (Koenig & Gates-Williams, 1995), therefore, their preferred place of death is in the hospital. This partially explains why some participants, when unsatisfied with palliative and end-of-life care, complained of the hospital's refusal to admit the dying patients.

Traditional Chinese attitudes towards death are deeply influenced by Confucius' teachings. This study suggests that though the discussions about death were very solemn, participants could think about death peacefully. This is exactly what Confucius and later philosophers proposed in ancient China: "respecting life seriously and accepting death peacefully" (Tse, Chong, & Fok, 2003, p. 340), neither in despair nor to be presumptive (Lee, 2009).

### **5.1.3 Reflection on Interdependency of the Chinese Family**

Emphasis on family connection forms the basis of Chinese culture, and therefore family plays an important role in Chinese patients' care and treatment. The findings in this study demonstrate that participants directly or implicitly regard their caregiving as a way to assume their responsibilities to their family. Previous studies have indicated that caregiving is predominantly provided by adult children in Chinese context, which is driven by their sense of filial piety (D. W. Lai, 2007).

However, this study only included one adult child who served as the caregiver for her parents, therefore filial piety was not emphasized as much in this study. Instead, most family caregivers identified were spousal caregivers. Noteworthy, this does not necessarily mean that their children did not assume filial responsibility, because the senior participants explicitly recognized and appreciated the physical, emotional and financial supports from their children. Of significance, this study highlighted spousal responsibility, which is usually neglected and overshadowed by discussion of filial obligation when studying Chinese families. Similar to Western families, spouses (usually the female partners) are in most cases the major source of care and support (Mackenzie & Holroyd, 1996). The current study therefore serves as a reminder that care from spouses should not be neglected by overemphasizing filial piety in the Chinese context. In other words, this study suggests that filial responsibility and spousal responsibility are usually equally important in caring for a seriously ill family member, and both represent a certain consistency in the Chinese concept of familial responsibility.

One interesting finding discovered in the participants' narratives was that no patient chose his/her care or treatment plan on his/her own; but rather, his/her family made decisions as a whole on his/her behalf. Deeply rooted in Chinese culture, family interdependency is highly valued and a single member of the family usually does not place their self autonomy above the need for collective family determination (Tse, Chong, & Fok, 2003). According to Tse and colleagues (2003), very distinct from

Westerners, the family decision-making for a patient is usually classified into three levels: “1) the family takes part in decision making with the patient; 2) the patient asks the family to decide; 3) the family decides alone despite the patient’s wish to participate (p. 340)”. Therefore, when choosing treatment and care for a Chinese patient, family collectivism should always be acknowledged and respected.

Furthermore, one important perspective in the Chinese immigrant family is not frequently studied in the literature: altruism from parents. In China, older generations are always very concerned for the well-being of the children even when their kids reach thirty or forty. In this study, although senior Chinese participants inadvertently acknowledged their need to depend on their children, the majority of them declared that, realizing their children had to strive to raise their own family, they did not want to be a burden on their children. They persuaded their children to focus on their own life, assuring them that they could care for themselves. Indeed, considerable previous studies indicate that the fear of becoming a burden to the family is not uncommon among immigrant Chinese seniors (Mackinnon, Gien, & Durst, 1996; McPherson, Wilson, & Murray, 2007a). As a result, some Chinese seniors were found to conceal their needs and reduce treatment as a way to alleviate the burden to caregivers (McPherson, Wilson, & Murray, 2007a, , 2007b). These findings, together with the results from this study, suggest the possible request for emotional outlets to decrease this sense of burden among Chinese patients.

This study also demonstrates that the task of providing care to a family member is exclusive, and rejects the participation of outsiders in caregiving. This is also repeatedly confirmed by many related studies, in which providing care to family members with life-limiting disease is considered a family duty, thus refraining from seeking help from outsiders (Chee & Levkoff, 2001; Kung, 2003; Scharlach et al., 2006).

Three main reasons potentially contribute to the reluctance to seek outside assistance. First, as previously noted, a strong sense of family responsibility motivates Chinese immigrants to assume their role as a caregiver; second, some care recipients felt uncomfortable receiving care from someone outside the family (Spitzer, Neufeld, Harrison, Hughes, & Stewart, 2003). Third, the Chinese concept of “saving face” discouraged having too much involvement from outsiders for fear that this would lead to a leak of unfavorable information about the family, such as a stigmatized illness, to the outside world.

To sum up, this study concurred with previous studies in recognizing the great importance of family as a whole in decision making about care and treatment. This Chinese collectivism is also present in the family unit; one person is merely an element of the larger whole. Therefore, though health professionals can still recognize their patient’s autonomy, they should also respect the patient’s family (Tsai, 2006).

#### **5.1.4 Reflection on Experiencing Canadian Health Care System**

The utilization and experience of the Canadian health care system by Chinese immigrants has been widely studied; however, how they perceive palliative and end-of-life services provided in Canada is not fully understood. In this sense, the current study both verified the findings of previous studies and fills a gap in the literature.

Despite a few unfavorable perceptions, the majority of participants in this study held positive attitudes towards health providers in the Canadian health care system. Previous studies focused extensively on Chinese immigrants' negative experiences with the Canadian health system, neglecting the satisfactory parts. Actually, a large proportion of Chinese immigrants appreciate the convenience of health services in Canada. For example, a research conducted by Liu, So, and Quan (2007) suggested that although lower than their non-Chinese counterparts (92.8%), 73.7% of the Chinese Canadians in their study were satisfied with the general practitioners in Canada. This research further contributed some negative perceptions from Chinese immigrants to the distinctly different health care systems in the two nations. As they explained, because patients in China visit physicians in outpatient departments without appointments, Chinese doctors could attend to their patients in a more flexible schedule with more interactions. (R. Liu, So, & Quan, 2007). Consequently, with these expectations, Chinese immigrants might complain that the doctors in Canada are inexperienced and do not spend much time with them (R. Liu, So, & Quan, 2007).

This largely explained the participants' unfavorable perceptions towards health professionals in this study.

The participants also reported some challenges facing the Canadian health care system, such as wait times and the lack of culturally competent health providers. Long wait times have been identified as a barrier to accessing health services by Chinese immigrants (Asanin & Wilson, 2008; D. W. Lai & Chau, 2007b; Setia, Quesnel-Vallee, Abrahamowicz, Tousignant, & Lynch; L. Wang, Rosenberg, & Lo, 2008). The current study added new knowledge concerning the perceptions toward palliative and end-of-life care provided to Chinese immigrants in Canada. On one hand, the availability of palliative and end-of-life care service was not known to some of them. On the other hand, others held quite unfavorable attitudes to end-of-life care services in Canadian health care system. They did not like the depressing environments where their loved ones would wait for death; they described such places as full of a dying atmosphere with cold nurses. Indeed, dwelling in lifeless and hopeless places invariably increases anxiety and depression, posing an additional emotional burden on both the patients and family caregivers. This is against the Chinese belief of benevolence: family members are obligated to make the patients feel happy to bring them a "good death", which is particularly valued among Chinese people. Therefore, improvement for future end-of-life care service should consider adding emotionally positive environments.



## **5.2 Recommendations**

The objective of the current study was to understand the lived experiences of Chinese family caregivers, who have cared for, or are currently caring for their loved ones with terminal disease. This study also explores what constitutes culturally appropriate palliative and end-of-life care for Chinese immigrants. Thus, the findings of this study can inform culturally appropriate palliative and end-of-life care for Chinese immigrants.

### **5.2.1 Recommendations for Chinese Family Caregivers**

Family caregiver participants found that providing palliative and end-of-life care to a loved one is a challenging task. To ensure the quality of the care provided to their loved ones, family caregivers should also be aware of their own physical and mental well-being. Recommendations for family caregivers may include:

#### **(1) Focusing on the Mental Wellness of Their Loved Ones**

End-of-life care concentrates on providing mental comfort to the patient. First, a family consensus should be reached to determine what information can be revealed to their loved one, to avoid worrying him/her. Second, as a Chinese saying goes “the old is just like the kid”, family caregivers should be patient and bring happiness to their loved ones in their final days. For instance, telling jokes and teaching games can be very beneficial in maintaining mental wellness. Third, Chinese traditional art, such as

Peking Opera, and songs from the 1950s and 1960s are widely loved by Chinese seniors; therefore, playing music for them can bring back a sense of home. Lastly, because of the traditional Chinese family concept that encourages multiple generations living together, elder Chinese are particular fond of younger generations. Visits from their grandchildren are invaluable in making them happy; thus, younger generations should be encouraged to regularly visit their ill grandparents.

## (2) Providing Food for Love Ones

One of the most prominent features of the family caregivers was their dedication to make food for their loved ones. The participants complained of the poor quality of the food in the hospital, so they often made nutritious traditional food for their loved ones. Therefore, future family caregivers should consider consulting with Chinese medicine doctors on what foods to prepare.

## (3) Hiring Respite Caregivers from the Same Cultural Background

Though shirking family obligation to rely solely on paid caregivers is generally not encouraged, paid caregivers can be hired to assume a complementary role, such as providing respite for caregivers at night. Furthermore, the hired caregivers are sometimes indispensable. For example, given that most participants are older female caregivers, they usually require physical assistance, especially when bathing their husbands. Fortunately, the large number of Chinese immigrants in the GTA enables

families to avail of paid Chinese informal caregivers. According to the participants, an interview with the hired caregiver is always necessary and helpful to determine his/her cultural and care capacity.

#### (4) Ensuring Effective Communications With Doctors and Nurses

Effective communication with health providers is very important. At the initiation of the physician-patient interaction, Chinese family caregivers should always inform the doctors and nurses of their relevant cultural values, traditions and beliefs. For instance, it is important they share with the doctors that, in Chinese culture, diagnosis and treatment are, in most cases, based on a collective family decision. This should be discussed with the patient and the family. In addition, any plan to bring the loved one home to China should be discussed with the physician ahead of time, especially if his/her condition is deteriorating.

#### (5) Forming a Strong Support System

Mental and emotional support for family caregiver is very important. Several participants mentioned that their stress was greatly reduced after a talk with their close friends. Therefore, family caregivers should be advised to communicate more frequently with their family and friends. In addition, a support group consisting of Chinese family caregivers with similar situations can serve as a community support system. Though few participants mentioned the use of counseling or religious comfort,

future family caregivers might consider these alternatives for the mental wellness of themselves and their loved ones.

### **5.2.2 Recommendations for Health Professionals**

The health professional is invaluable in providing good palliative and end-of-life care to Chinese immigrants. The findings of this study can provide physicians and nurses with insight into how Chinese family caregivers provide end-of-life care to their loved one, but more importantly, they can inform physicians of cultural characteristics that they should be aware of when planning treatment and care for Chinese immigrants during the final days of their life. Furthermore, culturally competent physicians can influence fellow doctors and policy-makers in becoming more sensitive to cultural differences, thereby reinforcing cultural competence in the current Canadian health care system.

#### **(1) Being Culturally Sensitive**

Recognizing that patients and their families from different cultural backgrounds may require different types of health services forms the very basis of culturally appropriate palliative and end-of-life care services. It is the physician's responsibility to be aware of possible cultural difference when treating ethnic minority patients. Therefore, doctors should understand patient and family expectations in terms of their

care needs. For example, concerning truth-telling, doctors can ask “what the patient wants to know and is prepared to know” (Tse, Chong, & Fok, 2003, p. 342).

### (2) Being Supportive of Alternative Approaches to Health

Physicians, when treating Chinese patients, should be more aware of Chinese people’s commitment to TCM. Although it is almost impossible to request the doctors to obtain a full knowledge of Chinese medicine, when patients choose to use Chinese medicine close attention should be paid without making judgmental remarks.

Recommendations for continuing or ceasing Chinese medicine should be made after carefully referring to the literature and discussing treatment options with the family and the patient.

### (3) Technically Assisting Family Caregivers

The findings of this study suggest that Chinese family caregivers assumed their multiple caregiving tasks, and most of them trusted their physicians. Physicians and nurses should assist with educating family caregivers on how to care for their loved ones, e.g. teaching them how to assist with bathing, making healthy food, dealing with emergencies, et cetera.

### **5.2.3 Recommendation for Policy Making**

Although policy-makers are becoming increasingly aware of cultural diversity in the Canadian the health care system, many institutions have not been successful in developing policies, practices and procedures that address the needs of different cultures (Majumdar, Browne, Roberts, & Carpio, 2004). In addition, previous studies have established a positive association with racial concordance between patient and doctor and patient satisfaction (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003). Therefore, recommendations that emerged from this study for future policy-making include:

#### **(1) Recruiting More Culturally Competent Health Providers in the Health Care System**

A more culturally diverse workforce in the health care system is still highly requested. This is echoed by repeated complaints made by participants, stating that health providers from the same cultural background made a significant difference in the treatment they received. Policy-makers should consider recruiting more physicians and nurses of Chinese descent into the medical workforce to meet this request from the growing number of Chinese immigrants in Canada.

#### **(2) Simplifying the Visa Process for Family Members in China**

Providing palliative and end-of-life care is a family obligation and some of the participants wished for their relatives to share in the responsibility. Admittedly, it not practical to accept more Chinese immigrants simply so they may provide familial care. However, it is feasible to simplify the visa issuing process for relatives living in China, so that they can arrive in Canada promptly and share in the caregiving responsibility with Chinese Canadians.

### (3) Improve the Environment of Palliative and End-of-life Care Facilities

The availability of end-of-life care services should be communicated to Chinese immigrants once their loved one is diagnosed with a terminal disease. The most negative impression of end-of-life care service came from the depressing environment, greatly affecting the utilization of such service. Therefore, improvement should be made to transform these environments into places of hope and peace, full of positive energy and optimism. Instead of awaiting pending death with despair, it is beneficial to convince the patients that they are just about to commence another great journey in life, which can also reduce the burden on their family. This can be achieved through collaboration by physicians, nurses, social workers, mental counselors and religious professionals.

### **5.3 Limitations of the Study**

The current study has certain limitations, largely due to the sample selected. To begin, due to the non-random nature of this sample, the findings of the study cannot be generalized to other settings (Green & Thorogood, 2004). In other words, this study merely reflected the lived experiences of the selected Chinese family caregivers who participated in the study. In addition, because the sample was selected through the same social network, similar characteristics could be found among the participants; for instance, the sample consisted of Chinese immigrants with high education level and high socio-economic status.

Hermeneutic phenomenology enabled the inclusion of personal interpretation during the translation and data analysis. Assumptions were unavoidably brought into the results. However, this issue was addressed by ongoing reflexivity: by culturally and socially locating myself, I was able to be aware of how my background and knowledge influenced the study findings.

### **5.4 Direction for Future Studies**

The current study examined the lived experiences of Chinese family caregivers caring for their loved ones with terminal disease. This research further reveals how traditional Chinese concepts affect their decisions for treatment and care. However, this study is merely a first step, and further investigations are warranted to gain a



deeper and wider understanding of palliative and end-of-life care being provided to Chinese immigrants in Canada.

First and foremost, because this study included both adult children participants and spousal participants, future studies may consider distinguishing the different meanings between filial responsibility and spousal responsibility on caring for a dying loved one.

Furthermore, future studies may recruit Chinese immigrants from lower socio-economic status, whose experiences are likely significantly different due to limited social and financial resources. What is more, as this study was conducted in Toronto, which has the greatest population of Chinese immigrants in Canada, future studies should be conducted in other areas where there are fewer Chinese immigrants. Areas with fewer Chinese immigrants may be more vulnerable because of a lack of community support.

Last but not least, the participants in this study all originated from China, suggesting they were raised with Chinese traditional teachings. Future studies may consider including second generation Chinese immigrants. It is of importance to observe whether and how Western culture can affect attitudes and behaviors towards end-of-life care decision-making.

Quantitative studies can also be implemented to gauge the satisfaction of Chinese immigrants using the palliative and end-of-life care services in the Canadian health

care system. The combination of the findings from quantitative can be used to inform future improvements in these services.

### **5.5 Conclusion**

This study explored the lived experiences of Chinese family caregivers who provide palliative and end-of-life care to their loved ones; and some recommendations for improved care were also made based on the findings.

Deeply influenced by traditional Chinese concepts of family responsibilities and collectivism, Chinese immigrants assumed the challenging role of family caregiving. The findings of this study can serve as a valuable reference for health providers and policy-makers to formulate culturally appropriate and competent care for the well-being of both the Chinese patients and their family caregivers in Canada.

### **5.6 Personal Reflection**

Conducting this study was an exciting and unforgettable experience. This study offered me a unique perspective on the life of Chinese immigrants concerning their health and medical utilization, and more specifically, on their experiences when they or their loved ones were approaching death. I was frequently moved by the stories the participants told to me. This study greatly strengthened my capacity to conduct qualitative research and write an academic thesis. Through study design, data

collection and analysis, the knowledge I have gained in coursework was finally put into practice.

## REFERENCES

- Adelbratt, S., & Strang, P. (2000). Death anxiety in brain tumour patients and their spouses. *Palliat Med*, 14(6), 499-507.
- Albinsson, L., & Strang, P. (2003). Existential concerns of families of late-stage dementia patients: questions of freedom, choices, isolation, death, and meaning. *J Palliat Med*, 6(2), 225-235.
- Alcoff, L. (1991). The problem of speaking for others. Retrieved May 10, 2012, from <http://www.jstor.org/stable/1354221>
- Anderson, J., Perry, J., Blue, C., Browne, A., Henderson, A., K.B, K., et al. (2003). "Riting" cultural safety within the postcolonial and postnational feminist project: toward new epistemologies of healing. *Advances in Nursing Science*, 26(3), 196-214.
- Anderson, L. M., Scrimshaw, S. C., Fullilove, M., T, E, F. J., & Normand, J. (2003). Cultural Competent Healthcare Systems: A Systematic Review. *Am J Prev Med*, 24(3S), 68-79.
- Anells, M. (1996). Hermeneutic phenomenology: philosophical perspectives and current use in nursing research. *J Adv Nurs*, 23(4), 705-713.
- Anngela-Cole, L., & Busch, M. (2011). Stress and grief among family caregivers of older adults with cancer: a multicultural comparison from Hawai'i. *J Soc Work End Life Palliat Care*, 7(4), 318-337.

- Arnaert, A., Gabos, T., Ballenas, V., & Rutledge, R. D. (2010). Contributions of a retreat weekend to the healing and coping of cancer patients' relatives. *Qual Health Res*, 20(2), 197-208.
- Asanin, J., & Wilson, K. (2008). "I spent nine years looking for a doctor": exploring access to health care among immigrants in Mississauga, Ontario, Canada. *Soc Sci Med*, 66(6), 1271-1283.
- Barbera, L., Sussman, J., Viola, R., Husain, A., Howell, D., Librach, S. L., et al. (2010). Factors Associated with End-of-Life Health Service Use in Patients Dying of Cancer. *Health Policy*, 5(3), e125-143.
- Barriball, K. L., & While, A. (1994). Collecting data using a semi-structured interview: a discussion paper. *J Adv Nurs*, 19(2), 328-335.
- Benzein, E., & Saveman, B. (2008). Health-promoting conversations about hope and sufferings with couples in palliative care. *International Journal of palliative Nursing*, 14, 439-445.
- Betancourt, J. R., Green, A. R., Carrillo, J. E., & Ananeh-Firempong, O., 2nd. (2003). Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Rep*, 118(4), 293-302.
- Blackhall, L. J., Frank, G., Murphy, S. T., Michel, V., Palmer, J. M., & Azen, S. P. (1999). Ethnicity and attitudes towards life sustaining technology. *Soc Sci Med*, 48(12), 1779-1789.

- Boerner, K., & Schulz, R. (2009). Caregiving, bereavement and complicated grief. *Bereave Care*, 28(3), 10-13.
- Boland, D. L., & Sims, S. L. (2007). Family Care Giving at Home as a Solitary Journey. *Journal of Nursing Scholarship*, 28(1), 55-58.
- Born, W., Greiner, K. A., Sylvia, E., Butler, J., & Ahluwalia, J. S. (2004). Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos. *J Palliat Med*, 7(2), 247-256.
- Bosma, H. R. (2011). *Visioning whole-person care: an interpretation of the health care experiences of culturally diverse persons living with a life-limiting illness*. Unpublished Dissertation, University of British Columbia, Vancouver.
- Bowling, A. (2009). *Research methods in health: investigating health and health services* (3rd ed.). Berkshire, England: McGraw-Hill House.
- Bowman, K. W., & Singer, P. A. (2001). Chinese seniors' perspectives on end-of-life decisions. *Soc Sci Med*, 53(4), 455-464.
- Burge, F., Lawson, B., Johnston, G., & Cummings, I. (2003). Primary care continuity and location of death for those with cancer. *J Palliat Med*, 6(6), 911-918.
- Byrne, A., Canavan, J., & Millar, M. (2009). Participatory research and the voice-centered relational method of data analysis: is it worth it? . *International Journal of Social Research Methodology*, 12(1), 67-77.
- Canadian Cancer Society's Steering Committee. (2012). *Canadian Cancer Statistics 2010*. Toronto: Canadian Cancer Society.

- Canadian Hospice Palliative Care Association. (1997). Family Caregivers: Frequent asked questions. Retrieved April 17, 2012, from <http://www.chpca.net/family-caregivers/faqs.aspx>
- Canadian Hospice Palliative Care Association. (2012). *Fact Sheet: Hospice palliative care in Canada*. Ottawa: Canadian Hospice Palliative Care Association.
- Chan, C. W., & Chang, A. M. (1999). Managing caregiver tasks among family caregivers of cancer patients in Hong Kong. *J Adv Nurs*, 29(2), 484-489.
- Chan, J., & Kayser-Jones, J. (2005). The experience of dying for Chinese nursing home residents: cultural considerations. *J Gerontol Nurs*, 31(8), 26-32; quiz 52-23.
- Chappell, N. L., & Funk, L. (2011). Filial caregivers; diasporic Chinese compared with homeland and hostland caregivers. *J Cross Cult Gerontol*, 26(4), 315-329.
- Chee, Y. K., & Levkoff, S. E. (2001). Culture and dementia: accounts by family caregivers and health professionals for dementia-affected elders in South Korea. *J Cross Cult Gerontol*, 16(2), 111-125.
- Cheng, T. (2010). *"Continuing a normal life as a normal person": a hermeneutic phenomenological study on the reconstruction of self identity of Chinese women within the lived experience of breast cancer survivorship*. Unpublished Dissertation, University of Toronto, Toronto.

- Chentsova-Dutton, Y., Shucter, S., Hutchin, S., Strause, L., Burns, K., Dunn, L., et al. (2002). Depression and grief reactions in hospice caregivers: from pre-death to 1 year afterwards. *J Affect Disord*, *69*(1-3), 53-60.
- Cho, Y. J., Song, Y. K., Cha, Y. Y., Shin, B. C., Shin, I. H., Park, H. J., et al. (2012). Acupuncture for Chronic Low Back Pain: A Multicenter, Randomized, Patient-Assessor Blind, Sham-Controlled Clinical Trial. *Spine (Phila Pa 1976)*.
- Chow, H. P. (2010). Growing old in Canada: physical and psychological well-being among elderly Chinese immigrants. *Ethn Health*, *15*(1), 61-72.
- Creswell, J. W. (2006). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (2nd ed.). Thousand Oaks: Sage Publications.
- Cronfalk, B. S., Strang, P., & Ternstedt, B. M. (2009). Inner power, physical strength and existential well-being in daily life: relatives' experiences of receiving soft tissue massage in palliative home care. *J Clin Nurs*, *18*(15), 2225-2233.
- Dai, Y. T., & Dimond, M. F. (1998). Filial piety. A cross-cultural comparison and its implications for the well-being of older parents. *J Gerontol Nurs*, *24*(3), 13-18.
- de Graaff, F. M., & Francke, A. L. (2003). Home care for terminally ill Turks and Moroccans and their families in the Netherlands: carers' experiences and factors influencing ease of access and use of services. *Int J Nurs Stud*, *40*(8), 797-805.



- DeSantis, L., & Ugarriza, D. N. (2000). The Concept of Themes as Used in Qualitative Nursing Research. *Western Journal of Nursing Research*, 22(3), 351-372.
- Dey, I. (1993). *Qualitative Data Analysis: a user-friendly guide for social scientists*. London: Routledge Taylor & Francis Group.
- Fairtlough, A. C. (2007). Adapting the voice-centred relational method of data analysis: reading trainees accounts of their learning on a pilot programme for practitioners working with parents. *Learning in Health and Social Care*, 6(1), 2-13.
- Ferrell, B. R., Grant, M., Chan, J., Ahn, C., & Ferrell, B. A. (1995). The impact of cancer pain education on family caregivers of elderly patients. *Oncol Nurs Forum*, 22(8), 1211-1218.
- Ferro, M. A., Leis, A., Doll, R., Chiu, L., Chung, M., & Barroetavena, M. C. (2007). The impact of acculturation on the use of traditional Chinese medicine in newly diagnosed Chinese cancer patients. *Support Care Cancer*, 15(8), 985-992.
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Aust N Z J Psychiatry*, 36(6), 717-732.
- Frost, J. (2008). Combining approaches to qualitative data analysis: synthesising the mechanical (CAQDAS) with the thematic (a voice-centered relational approach). *Methodological Innovations*, 3(1), 25-37.

- Funk, L. M., Allan, D. E., & Stajduhar, K. I. (2009). Palliative family caregivers' accounts of health care experiences: the importance of "security". *Palliat Support Care*, 7(4), 435-447.
- Geiger, H. J. (2001). Racial stereotyping and medicine: the need for cultural competence. *Cmaj*, 164(12), 1699-1700.
- Ghesquiere, A., Haidar, Y. M., & Shear, M. K. (2011). Risks for complicated grief in family caregivers. *J Soc Work End Life Palliat Care*, 7(2-3), 216-240.
- Green, J., & Thorogood, N. (2004). *Qualitative methods for health research*. London, UK: SAGE publications Ltd.
- Hancock, K., Clayton, J. M., Parker, S. M., Wal der, S., Butow, P. N., Carrick, S., et al. (2007). Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med*, 21(6), 507-517.
- Hanks, G., Cherny, N. I., Christakis, N. A., Fallon, M., Kaasa, S., & Portenoy, R. K. (2009). *Oxford Textbook of Palliative Medicine* (4th ed.). New York, NY: Oxford University Press.
- Health Canada. (2009). Palliative and End-of-Life Care. Retrieved April 10, 2012, from <http://www.hc-sc.gc.ca/hcs-sss/palliat/index-eng.php>
- Health Care in Canada Survey. (2007). Health care in Canada survey: a national of health care providers, managers, and the public. Retrieved August 2, 2012, from <http://www.hcic-sssc.ca/english/Content.aspx?10=4&11=21&tid=24&l=1#t1>

- Hertz, R. (1997). *Reflexivity and voice*. Thousand Oaks, CA: Sage.
- Hesse-Biber, S. N., & Leavy, P. (2006). *Emergent Methods in Social Research*.  
Thousand Oaks, CA: Sage Publication.
- Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., et al. (2006).  
What matters most in end-of-life care: perceptions of seriously ill patients and  
their family members. *Canadian Medical Association Journal*, 175(4).
- Holland, J. M., Thompson, L. W., Tzuang, M., & Gallagher-Thompson, D. (2010).  
Psychosocial factors among Chinese American women dementia caregivers  
and their association with salivary cortisol: Results of an exploratory study.  
*Ageing International*(109-127).
- Holtslander, L. F., & McMillan, S. C. (2011). Depressive symptoms, grief, and  
complicated grief among family caregivers of patients with advanced cancer  
three months into bereavement. *Oncol Nurs Forum*, 38(1), 60-65.
- Hudson, P., Remedios, C., Zordan, R., Thomas, K., Clifton, D., Crewdson, M., et al.  
(2012). Guidelines for the psychosocial and bereavement support of family  
caregivers of palliative care patients. *J Palliat Med*, 15(6), 696-702.
- Hyman, I. (2001). *Immigration and Health*. Retrieved. from  
<http://courseweb.edteched.uottawa.ca/pop8910/Notes/Immigrant%20health%20in%20Canada.pdf>.

- Jiang, Y., Liu, C., Li, J. Y., Huang, M. J., Yao, W. X., Zhang, R., et al. (2007). Different attitudes of Chinese patients and their families toward truth telling of different stages of cancer. *Psychooncology*, *16*(10), 928-936.
- Johansson, C. M., Henoch, I., Strang, S., & Browall, M. (2012). Living in the presence of death: An integrative literature review of relatives' important existential concerns when caring for a severely ill family member. *The Open nursing journal*, *6*, 1-12.
- Kagawa-Singer, M., & Blackhall, L. J. (2001). Negotiating cross-cultural issues at the end of life: "You got to go where he lives". *Jama*, *286*(23), 2993-3001.
- Kao, H. F., & Stuijbergen, A. K. (1999). Family experiences related to the decision to institutionalize an elderly member in Taiwan: an exploratory study. *Soc Sci Med*, *49*(8), 1115-1123.
- Kashiwagi, T. (1999). Truth telling and palliative medicine. *Intern Med*, *38*(2), 190-192.
- Kleinman, A., & Benson, P. (2006). Culture, moral experience and medicine. *Mt Sinai J Med*, *73*(6), 834-839.
- Koch, T. (1995). Interpretive approaches in nursing research: the influence of Husserl and Heidegger. *J Adv Nurs*, *21*(5), 827-836.
- Koenig, B. A., & Gates-Williams, J. (1995). Understanding cultural difference in caring for dying patients. *West J Med*, *163*(3), 244-249.

- Kramer, B. J., & Auer, C. (2005). Challenges to providing end-of-life care to low-income elders with advanced chronic disease: lessons learned from a model program. *Gerontologist, 45*(5), 651-660.
- Krasner, D. L. (2001). Qualitative research: a different paradigm--part 1. *J Wound Ostomy Continence Nurs, 28*(2), 70-72.
- Kung, W. W. (2003). The Illness, Stigma, Culture, or Immigration? Burdens on Chinese American Caregivers of Patients With Schizophrenia. *Family in Society, 84*(4), 547-557.
- Kvale, S. (1996). *Interviews: an introduction to qualitative research*. Thousand Oaks, CA: Sage.
- Lai, D., & Chappell, N. (2007). Use of Traditional Chinese Medicine by older Chinese immigrants in Canada. *Fam Pract, 24*(1), 56-64.
- Lai, D. W. (2004). Health status of older Chinese in Canada: findings from the SF-36 health survey. *Can J Public Health, 95*(3), 193-197.
- Lai, D. W. (2007). Cultural predictors of caregiving burden of Chinese-Canadian family caregivers. *Can J Aging, 26 Suppl 1*, 133-147.
- Lai, D. W., & Chau, S. B. (2007a). Effects of service barriers on health status of older Chinese immigrants in Canada. *Soc Work, 52*(3), 261-269.
- Lai, D. W., & Chau, S. B. (2007b). Predictors of health service barriers for older Chinese immigrants in Canada. *Health Soc Work, 32*(1), 57-65.

- Lai, D. W., & Leonenko, W. (2007). Effects of Caregiving on Employment and Economic Costs of Chinese Family Caregivers in Canada. *J Fam Econ Iss*, 28, 411-427.
- Lai, D. W., & Surood, S. (2008). Service barriers of Chinese family caregivers in Canada. *J Gerontol Soc Work*, 51(3-4), 315-336.
- Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology a comparison of historical and methodological considerations. Retrieved April 21, 2012, from [http://www.ualberta.ca/~iiqm/backissues/2\\_3final/pdf/laverty.pdf](http://www.ualberta.ca/~iiqm/backissues/2_3final/pdf/laverty.pdf)
- Lee, H., Schmidt, K., & Ernst, E. (2005). Acupuncture for the relief of cancer-related pain--a systematic review. *Eur J Pain*, 9(4), 437-444.
- Lee, J., Choi, T., Lee, M., Lee, H., Shin, B., & Lee, H. (2013). Acupuncture for acute low back pain: a systematic review. *Clin J Pain*, 29(2), 172-185.
- Lee, S. C. (2007). *The Family, Medical Decision-Making, and Biotechnology: Critical Reflections on Asian Moral Perspectives*. Dordrecht, Netherlands: Springer.
- Lee, S. K. (2009). East Asian Attitudes toward Death- A Search for the Ways to Help East Asian Elderly Dying in Contemporary America. *Perm J*, 13(3), 55-60.
- Lennox, P. H., & Henderson, C. L. (2003). Herbal Medicine Use is Frequent in Ambulatory Surgery Patients in Vancouver Canada. *Canadian Journal of Anesthesia*, 50(1), 21-25.

- Liu, J., Li, X., Liu, J., Ma, L., Li, X., & Fonnebo, V. (2011). Traditional Chinese medicine in cancer care: a review of case reports published in Chinese literature. *Forsch Komplementmed*, 18(5), 257-263.
- Liu, R., So, L., & Quan, H. (2007). Chinese and white Canadian satisfaction and compliance with physicians. *BMC Fam Pract*, 8, 11.
- Longman Group. (2001). *Longman Dictionary of Contemporary English*. Beijing: The Commercial Press.
- Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. *Qual Health Res*, 14(5), 726-735.
- Mackenzie, A. E., & Holroyd, E. E. (1996). An exploration of the carers' perceptions of caregiving and caring responsibilities in Chinese families. *Int J Nurs Stud*, 33(1), 1-12.
- Mackinnon, M. E., Gien, L., & Durst, D. (1996). Chinese elders speak out: implications for caregivers. *Clin Nurs Res*, 5(3), 326-342.
- Maddalena, V. (2009). Cultural Competence and Holistic Practice Implications for Nursing Education, Practice, and Research. *Holist Nurs Practice* 23(3), 153-157.
- Majumdar, B., Browne, G., Roberts, J., & Carpio, B. (2004). Effects of cultural sensitivity training on health care provider attitudes and patient outcomes. *J Nurs Scholarsh*, 36(2), 161-166.

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines.

*Lancet*, 358(9280), 483-488.

Manen, M. v. (1990). *Researching lived experience: human science for an action*

*sensitive pedagogy*. London, Ontario: the Althouse Press.

Marzanski, M., Jainer, A., & Avery, C. (2002). What have you been told about your

illness? Information about diagnosis among psychiatric inpatients. *Int J*

*Psychiatry Clin Pract*, 6, 103-106.

Mauthner, N. S., & Doucet, A. (1998). *Feminist Dilemmas in Qualitative Research:*

*Private Lives and Public Texts*. London: Sage

McEwan, K. L., Donnelly, M., Robertson, D., & Hertzman, C. (1991). *Mental Health*

*Problems among Canada's Seniors: Demographic and Epidemiologic*

*Considerations Ottawa*.

McGrath, P., Vun, M., & McLeod, L. (2001). Needs and experiences of

non-English-speaking hospice patients and families in an English-speaking

country. *Am J Hosp Palliat Care*, 18(5), 305-312.

McMillan, S. C. (2005). Interventions to facilitate family caregiving at the end of life.

*J Palliat Med*, 8 Suppl 1, S132-139.

McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007a). Feeling like a burden to

others: a systematic review focusing on the end of life. *Palliat Med*, 21(2),

115-128.



- McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007b). Feeling like a burden: exploring the perspectives of patients at the end of life. *Soc Sci Med*, *64*(2), 417-427.
- Milberg, A., Strang, P., & Jakobsson, M. (2004). Next of kin's experience of powerlessness and helplessness in palliative home care. *Support Care Cancer*, *12*(2), 120-128.
- Mok, E., Chan, F., Chan, V., & Yeung, E. (2003). Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nurs*, *26*(4), 267-275.
- Morris, J. N., Suissa, S., Sherwood, S., Wright, S. M., & Greer, D. (1986). Last days: a study of the quality of life of terminally ill cancer patients. *J Chronic Dis*, *39*(1), 47-62.
- National Cancer Institute. (2002). End-of-Life Care: Questions and Answers. Retrieved April 17, 2012, from <http://www.cancer.gov/cancertopics/factsheet/Support/end-of-life-care>
- National Comprehensive Cancer Network. (2011). *NCCN Clinical Practice Guidelines in Oncology: Palliative Care*. Retrieved from [http://www.nccn.org/professionals/physician\\_gls/pdf/palliative.pdf](http://www.nccn.org/professionals/physician_gls/pdf/palliative.pdf).
- Newbold, K. B. (2006). Chronic conditions and the health immigrant effect: evidence from Canadian immigrants. *Journal of Ethnic and Migration Studies*, *32*(5), 765-784.

- Ngo-Metzger, Q., McCarthy, E. P., Burns, R. B., Davis, R. B., Li, F. P., & Phillips, R. S. (2003). Older Asian Americans and Pacific Islanders dying of cancer use hospice less frequently than older white patients. *Am J Med*, *115*(1), 47-53.
- Nyatanga, B. (2002). Culture, palliative care and multiculturalism. *Int J Palliat Nurs*, *8*(5), 240-246.
- Olson, L. K. (2001). *Age through Ethnic Lenses: caring for the elderly in a multicultural society*. Maryland: Rowman & Littlefield Publishers  
Incorporation.
- Opala, J., & Boillot, F. (1996). Leprosy among the Limba: illness and healing in the context of world view. *Soc Sci Med*, *42*(1), 3-19.
- Owens, A., & Randhawa, G. (2004). 'It's different from my culture; they're very different': Providing community-based, 'culturally competent' palliative care for South Asian people in the UK. *Health Soc Care Community*, *12*(5), 414-421.
- Paliadelis, P., & Cruickshank, M. (2008). Using a voice-centered relational method of data analysis in a feminist study exploring the working world of nursing unit managers. *Qual Health Res*, *18*(10), 1444-1453.
- Parks, S. H., & Pilisuk, M. (1991). Caregiver burden: gender and the psychological costs of caregiving. *Am J Orthopsychiatry*, *61*(4), 501-509.
- Patrick, D. L., Engelberg, R. A., & Curtis, J. R. (2001). Evaluating the quality of dying and death. *J Pain Symptom Manage*, *22*(3), 717-726.

- Peng, H., Peng, H. D., Xu, L., & Lao, L. X. (2010). Efficacy of acupuncture in treatment of cancer pain: a systematic review. *Zhong Xi Yi Jie He Xue Bao*, 8(6), 501-509.
- Qi, F., Li, A., Inagaki, Y., Gao, J., Li, J., Kokudo, N., et al. (2010). Chinese herbal medicines as adjuvant treatment during chemo- or radio-therapy for cancer. *Biosci Trends*, 4(6), 297-307.
- Quan, H., Lai, D., Johnson, D., Verhoef, M., & Musto, R. (2008). Complementary and alternative medicine use among Chinese and white Canadians. *Can Fam Physician*, 54(11), 1563-1569.
- Rabow, M. W., Hauser, J. M., & Adams, J. A. (2004). Supporting Family Caregivers at the End of Life "They Don't Know What They Don't Know". *JAMA*, 291(4), 483-491.
- Raphael, D., Bryant, T., & Rioux, M. (2006). *Staying Alive: Critical Perspectives on Health, Illness, and Health Care* (1st ed.). Toronto, Ontario: Canadian Scholars' Press Inc.
- Rome, R. B., Luminais, H. H., Bourgeois, D. A., & Blais, C. M. (2011). The role of palliative care at the end of life. *Ochsner J*, 11(4), 348-352.
- Rosenbaum, E., Garlan, R. W., Hirschberger, N., Siegel, A. L., Butler, L. A., & Spiegel, D. (2006). The Life Tape Project: Increasing family social support and symbolic immortality with a brief existential intervention for cancer patients and their families. *Journal of Death and Dying*, 53, 321-339.

- Ryan, G. W., & Bernard, H. R. (2003). Techniques to identify Themes. *Field Methods*, 15(1), 85-109.
- Saldaña, J. (2012). *The Coding Manual for Qualitative Researchers* (2nd ed.). Thousand Oaks: Sage Publications.
- Sand, L., & Strang, P. (2006). Existential loneliness in a palliative home care setting. *J Palliat Med*, 9(6), 1376-1387.
- Sandelowski, M. (1994). Notes on transcription. *Res Nurs Health*, 17(4), 311-314.
- Scharlach, A. E., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. J. (2006). Cultural attitudes and caregiver service use: lessons from focus groups with racially and ethnically diverse family caregivers. *J Gerontol Soc Work*, 47(1-2), 133-156.
- Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., et al. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *N Engl J Med*, 349(20), 1936-1942.
- Setia, M. S., Quesnel-Vallee, A., Abrahamowicz, M., Tousignant, P., & Lynch, J. Access to health-care in Canadian immigrants: a longitudinal study of the National Population Health Survey. *Health Soc Care Community*, 19(1), 70-79.
- Sharts-Hopko, N. C. (2002). Assessing rigor in qualitative research. *J Assoc Nurses AIDS Care*, 13(4), 84-86.

- Shklarov, S. (2007). Double vision uncertainty: the bilingual researcher and the ethics of cross-language research. *Qual Health Res*, 17(4), 529-538.
- Shyu, Y. L. (2008). Patterns of Caregiving When Family Caregivers Face Competing Needs. *Journal of Advanced Nursing*, 31(1), 35-43.
- Silverstein, M., & Giarrusso, R. (2010). Aging and Family Life: A Decade Review. *J Marriage Fam*, 72(5), 1039-1058.
- Slote, W. H., & De Vos, G. A. (1998). *Confucianism and the Family*. Buffalo: State University of New York Press.
- Smith, M. E., & Bauer-Wu, S. (2012). Traditional Chinese Medicine for cancer-related symptoms. *Semin Oncol Nurs*, 28(1), 64-74.
- Spitzer, D., Neufeld, A., Harrison, M., Hughes, K., & Stewart, M. (2003). Caregiving in Transnational Context: "My Wings Have Been Cut; Where Can I Fly?" *Gender & Society*, 17(2), 267-286.
- Stajduhar, K., Fyles, G., & Barwich, D. (2008). *Family caregivers coping in end-of-life cancer care (final report)*. Retrieved from [http://www.coag.uvic.ca/eolcare/documents/Coping\\_Report\\_Final.pdf](http://www.coag.uvic.ca/eolcare/documents/Coping_Report_Final.pdf).
- Stajduhar, K. I., Martin, W. L., Barwich, D., & Fyles, G. (2008). Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nurs*, 31(1), 77-85.

- Starks, H., & Trinidad, S. B. (2007). Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qual Health Res*, 17(10), 1372-1380.
- Statistics Canada. (2001). The Chinese Community in Canada. Retrieved April 17, 2012, from <http://www.statcan.gc.ca/pub/89-621-x/89-621-x2006001-eng.pdf>
- Statistics Canada. (2006). *Selected Demographic, Cultural, Educational, Labour Force and Income Characteristics (926), First Official Language Spoken (4), Age Groups (8A) and Sex (3) for the Population of Canada, Provinces, Territories, Census Metropolitan Areas and Census Agglomerations, 2006 Census*. Retrieved from <http://www12.statcan.ca/census-recensement/2006/dp-pd/hlt/97-562/pages/page.cfm?Lang=E&Geo=PR&Code=01&Table=1&Data=Count&StartRec=1&Sort=2&Display=Page>.
- Statistics Canada. (2011). Study: Projections of the diversity of the Canadian population 2006-2031. from <http://www.statcan.gc.ca/daily-quotidien/100309/dq100309a-eng.htm>
- Statistics Canada. (2012). Ranking and number of deaths for the 10 leading causes of death, Canada, 2000 and 2009. Retrieved September 2, 2012, from <http://www.statcan.gc.ca/pub/84-215-x/2012001/table-tableau/tbl001-eng.htm>
- Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing: advancing the humanistic imperative* (5th ed.). Philadelphia: Lippincott Williams & Wilkins.

- Sun, F., Ong, R., & Burnette, D. (2012). The influence of ethnicity and culture on dementia caregiving: a review of empirical studies on Chinese Americans. *Am J Alzheimers Dis Other Demen*, 27(1), 13-22.
- Sun, Z. Y., Xiong, H., Zhang, X. M., Huang, G. W., & Wang, P. Z. (2009). The health status of Asian immigrants and the associated factors in Canada. *Zhonghua Liu Xing Bing Xue Za Zhi*, 30(4), 360-364.
- Taylor, C., & Gibbs, G. R. (2010). How and what to code. Retrieved April 15, 2013, from [http://onlineqda.hud.ac.uk/Intro\\_QDA/how\\_what\\_to\\_code.php](http://onlineqda.hud.ac.uk/Intro_QDA/how_what_to_code.php)
- Tong, E., McGraw, S. A., Dobihal, E., Baggish, R., Cherlin, E., & Bradley, E. H. (2003). What is good death? minority and non-minority perspectives. *Journal of Palliative Care*, 19(3), 168-175.
- Tsai, D. F. (2006). Eye on religion: confucianism, autonomy and patient care. *South Med J*, 99(6), 685-687.
- Tse, C. Y., Chong, A., & Fok, S. Y. (2003). Breaking bad news: a Chinese perspective. *Palliat Med*, 17(4), 339-343.
- Tsigaropoulos, T., Mazaris, E., Chatzidarellis, E., Skolarikos, A., Varkarakis, I., & Deliveliotis, C. (2009). Problems faced by relatives caring for cancer patients at home. *Int J Nurs Pract*, 15(1), 1-6.
- Tuckett, A. G. (2004). Truth-Telling in Clinic Practice and the Arguments for and Against: a review of the literature. *Nursing Ethics*, 11(500-512).

- Turner, L. (2002). Bioethics and end-of-life care in multi-ethnic settings: cultural diversity in Canada and the USA. *Mortality*, 7(3), 285-301.
- Valente, S. M. (2004). End of life and ethnicity. *J Nurses Staff Dev*, 20(6), 285-293.
- Valle, R., King, M., & Halling, S. (1989). *An introduction to existential-phenomenological thought in psychology*. New York: Plenum Press.
- Vanderploeg, K., & Yi, X. (2009). Acupuncture in modern society. *J Acupunct Meridian Stud*, 2(1), 26-33.
- Vickers, A. J., Cronin, A. M., Maschino, A. C., Lewith, G., MacPherson, H., Foster, N. E., et al. (2012). Acupuncture for chronic pain: individual patient data meta-analysis. *Arch Intern Med*, 172(19), 1444-1453.
- Wang, L., Rosenberg, M., & Lo, L. (2008). Ethnicity and utilization of family physicians: a case study of Mainland Chinese immigrants in Toronto, Canada. *Soc Sci Med*, 67(9), 1410-1422.
- Wang, S. Y., Chen, C. H., Chen, Y. S., & Huang, H. L. (2004). The attitude toward truth telling of cancer in Taiwan. *J Psychosom Res*, 57(1), 53-58.
- Werth, J. L., Blevins, D., Toussaint, K., L., & Durham, M., R. . (2002). The Influence of Cultural Diversity on End-of-life Care and Decisions. *American Behavioral Scientist*, 46, 204-219.
- Wong-Kim, E., Sun, A., & DeMattos, M. C. (2003). Assessing cancer beliefs in a Chinese immigrant community. *Cancer Control*, 10(5 Suppl), 22-28.



- Wong, L. K., Jue, P., Lam, A., Yeung, W., Cham-Wah, Y., & Birtwhistle, R. (1998). Chinese herbal medicine and acupuncture. How do patients who consult family physicians use these therapies? *Can Fam Physician*, *44*, 1009-1015.
- World Health Organization. (2012). WHO Definition of Palliative Care. Retrieved April 13, 2012, from <http://www.who.int/cancer/palliative/definition/en/>
- Wu, T., Munro, A. J., Guanjian, L., & Liu, G. J. (2008). Chinese medical herbs for chemotherapy side effects in colorectal cancer patients. *Cochrane Database of Systematic Reviews* 2005(1).
- Xu, L., Lao, L. X., Ge, A., Yu, S., Li, J., & Mansky, P. J. (2007). Chinese herbal medicine for cancer pain. *Integr Cancer Ther*, *6*(3), 208-234.
- Younge, D., Moreau, P., Ezzat, A., & Gray, A. (1997). Communicating with cancer patients in Saudi Arabia. *Ann N Y Acad Sci*, *809*, 309-316.
- Yu, E. S. H., Lai, S., Wen, Z., & Liu, W. T. (2000). Caregiving survey in Guangzhou: A preliminary report. In W. T. Liu & H. Kendig (Eds.), *Who Should Care for the Elderly? An East-West Value Divide*. Singapore: Singapore University Press.

## APPENDICES

### Appendix 1 Chinese News Report On a Study of Palliative and End-of-life Care for Chinese Immigrants

#### 华裔学者将在多伦多地区展开华人移民的临终关怀的研究

当一些严重的慢性疾病，例如癌症，发展到晚期的时候，对病人救治护理的重心会转移到临终关怀上。通过缓解疼痛和症状，以及提供精神和心理支持，可以改善患有危及生命的疾病的患者及其家人的生活质量。一项针对华人移民临终关怀的研究将在多伦多地区展开。

该研究将从家庭料理者的角度了解在加拿大离世的华人，在生命最后一段时间里是否得到了最佳的照顾和护理；并将了解在这期间，病人及其家属遇到的困难；同时，该研究也会了解在病人生命的最后时刻，中华传统观念和价值，在加拿大这个新的环境中如何发挥作用。

由于文化差异，对加拿大医疗体制的不了解以及语言障碍等诸多因素，移民人群在加拿大使用医疗资源的过程中，会比本地人遇到更多的不便和困扰。与西方家庭不同，在华人移民家庭中，有关病人的救治和护理等重要抉择往往都是由其家人来决定的。并且，对病人的照料，常常也是由其家庭成员来担当。另外，当病人病情进入到晚期，其生命已经有限的时候，因为华人对生死的传统观念的不同，更是需要有不同的救治和护理的方案。然而，在加拿大，有关华人移民临终关怀的研究却极少。本研究将了解在加华人临终关怀的现状，并将结果以报告的方式发布，提醒有关部门注意，为日后将在加拿大度过人生最后时光的华人提供可靠，符合文化传统的临终关怀。

该研究由纽芬兰省应用健康研究中心和戴尔豪斯大学临终关怀基金资助，并得到了纽芬兰纪念大学伦理委员会的批准。研究人员将保证参与者的隐私。研究人员希望通过总结您的经历，更好地帮助未来面对同样问题的华人朋友。该研究将通过硕士研究生课题完成，指导委员会成员为 Victor Maddalena 副教授（纽芬兰纪念大学及戴尔豪斯大学），王培忠教授（纽芬兰纪念大学）及李从业副教授（约克大学）。

该研究的对象是在过去四年中照料和护理过，或者参与护理过病重亲人的家庭料理者（例如，配偶，子女等直系亲属）。研究人员将采访 7-10 个家庭料理者，倾听他们的心声和曾经的故事，包括在加拿大照料自己病重亲人及与亲人离别是怎样的经历，遇到过怎样的困难，曾经希望得到怎样的帮助等。采访大约需要一个小时，可在您认为方便的时间，地点进行。虽然鉴于伦理委员会规定，受访者无法得到经济补偿，但会收到一份纪念品及研究报告。另外研究人员将会支付由于采访所导致的停车费，及误餐补助。所有研究结果将以匿名方式报道。 希望符合条件的华人支持与参加本次项研究。

联系方式： 吴昊 (709)351-7096, hao.wu@mun.ca  
杨思奥 (Ryan Yang) (416)565-6587  
李妍 (647) 527-1840  
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李从业 副教授 (416) 736-2100 转 20071

## Appendix 2a Advertisement for Recruitment (Chinese Version)



您是否正照顾病重亲人/在过去四年中照顾过因病重而辞世的亲人？

纽芬兰纪念大学的研究者正在开展一项研究，旨在研究华人移民的临终关怀以及对其家庭照料者的帮助。

我们的研究题目是

### “华人移民的临终关怀：家庭照料者的经历”

该研究的目的不仅是为了了解华人的临终关怀情况，更是为日后在加华人制定符合中华文化的临终关怀的服务。

如果您对我们的研究感兴趣，我们将十分荣幸的邀请您加入本研究。您仅仅需要进行一个大概一个小时左右的面谈采访。参加采访的条件是您在过去四年中照顾或者参加照顾过你的病重亲人。

您的所有信息都会被严格的保密。

**如果您对我们的研究，或知道某人可能会对我们的研究感兴趣，请联系：**

吴昊 (709) 351-7096 hao.wu@mun.ca  
杨思奥 (Ryan Yang) (416)565-6587  
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**我们期望着您的加入！**

## Appendix 2b Advertisement for Recruitment (English Version)



**Are you a Chinese immigrant (1<sup>st</sup> generation or 2<sup>nd</sup> generation) who are caring for a seriously ill family member/has cared for a family member who died in the past 4 years but no sooner than 6 months?**

Researchers in Memorial University are working on a project learning the lived experience of Chinese immigrant who has served as a family caregiver for a family member with terminal disease, such as cancer and dementia.

### **“Palliative and End of Life Care of Chinese Immigrants: Perceptions of Family Caregivers”**

The aims of the research will not only learn the lived experience of the family caregiver but also propose culturally appropriate palliative and end of life care service for Chinese immigrants.

If you are interested in participating in our study, it would be our pleasure to interview you. The interview would probably last 1 hour. In order to participate, you have to be at least 18 years older and can join the interview independently.

Your privacy will be carefully protected.

**If you or someone you know may be interested please contact for more information:**

Hao Wu (Investigator) Tel (709) 351-7096  
Siao Ryan Yang (416)565-6587  
Yan Li (647) 527-1840  
Peizhong Wang (709) 746-2898  
Tsorng-Yeh Lee (416) 736-2100 ext 20071

**We look forward to hearing from you!**



### **Appendix 3a Interview Guide (English Version, for deceased)**

1. Please tell me about your loved one's illness.  
The whole story from the time of diagnosis until they died
2. At the time of diagnosis, what information was given to you?
  - (1). how did you feel when you heard the news?
  - (2). were treatment options offered? What were they?
  - (3). which treatment was chosen? Who made the decision for him/her? Can you tell me more?
3. Tell me about your encounters with the health care system.
  - (1). how did he/she use the health care service?
  - (2). how often and how long?
  - (3). what were the satisfactory aspects of the service and what were the unsatisfactory aspects?
  - (4). were you able to access any palliative care services?
  - (5). did your loved one use any kind of alternative healing practice or folk medicine, such as Traditional Chinese Medicine (TCM)? where did you learn about TCM? Were the TCM treatments effective? How was it?
4. Did he/she experience any symptoms? If any, what were his/her most miserable symptoms?
  - (1). How did it affect his/her and your life?
  - (2). were the symptoms well managed?
5. Would you describe your loved one's death as being comfortable?
  - (1). did they die in their place of choice (hospital/home)?
  - (2). Who made the decision? Tell me more
5. What was it like being the caregiver for your loved one?
  - (1). what were the differences before and after you offered the care?
  - (2). were you the only caregiver?
  - (3). did you feel comfortable in your role as a caregiver?
  - (4). how did your role as a caregiver shape your life?
  - (5). can you describe a typical day when you cared for him/her?
  - (6). what did you find most difficult as a family caregiver for your loved one?  
Can you tell me more?
6. Did any unexpected event happen during the care giving process?
  - (1). how did you feel?
  - (2). what did you learn from it?

7. Can you tell me the relationship between you and your family, friends?
  - (1). do you think the relationship changed?
  - (2). were they helpful or not? In what ways? Can you tell me more?
  
8. What would have made your care giving process easier?
  - (1). what help from other family member could be given?
  - (2). what help from the community could be given?
  - (3). what help from the health care service could be given?
  
9. Is there any one story you would like to share with me about your family member?
  
10. Is there anything else that you would like to tell me about your caregiving experience?

### **Appendix 3a Interview Guide (English Version, for alive)**

1. Please tell me what it is like caring for your family member.  
The whole story from the initiation of care till now.
2. Does he/she have any (chronic) disease or (or physical or mental) limitations that make it challenging to care for your family member?
  - (1) When did he/she have this disease and how did you feel about it.
  - (2). were treatment options offered? What were they?
  - (3). which treatment was chosen? Who made the decision for him/her? Can you tell me more?
3. Does he/she experience any symptoms? If any, what are his/her most miserable symptoms?
  - (1). How does it affect his/her and your life?
  - (2). Are the symptoms well managed?
4. Tell me about your encounters with the health care system.
  - (1). how did he/she use the health care service?
  - (2). how often and how long?
  - (3). what are the satisfactory aspects of the service and what are the unsatisfactory aspects?
  - (4). Does your loved one use any kind of alternative healing practice or folk medicine such as Traditional Chinese Medicine (TCM)? where did you learn about TCM? Were the TCM treatments effective? How was it?
5. What is it like being the caregiver for your loved one?
  - (1). what were the differences before and after you offered the care?
  - (2). Are you the only caregiver?
  - (3). Do you feel comfortable in your role as a caregiver?
  - (4). how does your role as a caregiver shape your life?
  - (5). can you describe a typical day when you care for him/her?
  - (6). what do you find most difficult as a family caregiver for your loved one? Can you tell me more?
  - (7). what do you find as the most rewarding aspects of caring for your family member?
7. Did any unexpected event happen during the care giving process?
  - (1). how did you feel?
  - (2). what did you learn from it?
9. Can you tell me the relationship between you and your family, friends?

- (1). do you think the relationship changed?
  - (2). were they helpful or not? In what ways? Can you tell me more?
10. What would have made your care giving process easier?
- (1). what help from other family member could be given?
  - (2). what help from the community could be given?
  - (3). what help from the health care service could be given?
11. If the family member is in good health now, do you have any concerns for the future as your family member's health deteriorates or is he/she becomes less mobile or incapacitated?
12. Do you have any plan for end-of-life for him/she in the future?
- (1) What is the biggest concern about end-of-life care in Canada?
  - (2) What do you think is necessary for a good end-of-care?
13. Is there any one story you would like to share with me about your family member?
14. Is there anything else that you would like to tell me about your caregiving experience?



**Appendix 3b Interview Guide (Chinese Version, for deceased)**

1. 请告诉我您去世亲人的疾病。  
从到加拿大，到诊断该疾病直到去世的全部过程。
2. 在诊断出该病的时候，您被告知了怎样的消息呢？
  - (1). 当您听到这个消息的时候是怎样的感受呢？
  - (2). 当时有些什么治疗方案呢？
  - (3). 最后采取了那种方案呢？是谁做的决定呢？（您能再说详细点吗？）
3. 您给告诉我您对医疗服务的使用情况。
  - (1). 请问他/她是否使用了医疗资源呢？
  - (2). 多久？经常吗？
  - (3). 您对这些服务感到满意的地方是哪些？不满意的呢？
  - (4). 他/她有没有接受临终的照顾和关怀服务呢？
  - (5). 他/她有没有有过其它的治疗手段呢？比如中医之类呢？您是从哪儿知道的？效果怎样？
4. 他/她最痛苦的症状是什么？
  - (1). 这个症状怎样影响到您的生活呢？
  - (2). 这个症状最后处理得好吗？
5. 您能不能说说他/她去的是否是否安详？
  - (1). 他/她是在哪儿去世的呢？（家还是医院）
  - (2). 谁做的决定？请说详细点。
6. 照顾他/她是怎样的经历呢？
  - (1). 在照顾之前和之后有些什么不同呢（影响）？
  - (2). 您是家里唯一一个照顾者吗？
  - (3). 您对您的职责（表现）满意吗？
  - (4). 您的照顾者身份有没有改变您的生活呢？
  - (5). 您能告诉我您照顾他/她的典型一天是怎样的吗？
  - (6). 您觉得在这个过程中最难的是什么？（请说详细些）
7. 在这个过程中有没有发生过什么意外呢？
  - (1). 您是怎样感觉的？
  - (2). 您从中学到了什么呢？
8. 您能说说您和家人朋友之间的关系吗？
  - (1). 您觉得你们的关系有变化吗？
  - (2). 他们是否很支持您。能举个例子吗？

9. 您觉得怎样做能让您当时更容易一些？
  - (1). 家人能帮助些什么？
  - (2). 华人社区能帮助些什么？
  - (3). 医疗服务能说明些什么？
  
10. 您还有什么其它的故事和我分享的吗？还有什么您愿意告诉我的吗？

**Appendix 3b Interview Guide (Chinese Version, for alive)**

1. 请您告诉我照顾这个病人的感受  
从移民到加拿大，到诊断这个病，再到现在
2. 你觉得他的什么病症或者症状让照顾他的过程变得比较困难呢？
  - (1) 他什么时候患上这个疾病的？您听到这个消息的时候是怎样的感受呢？
  - (2) 具体提供了哪些治疗方案呢？
  - (3) 最后哪种方案被采纳了呢？谁做的这个决定呢？您能再说详细一些吗？
3. 他有什么症状呢？其中最痛苦的症状的什么呢？
  - (1) 这些症状对他/她和您的生活有怎样的影响呢？
  - (2) 这些症状都有很好的控制吗？
4. 医疗资料的使用情况
  - (1) 是否经常使用医疗设施？
  - (2) 多久一次呢？
  - (3) 对这些设施满意的地方在不满意的地方分别是什么呢？
  - (4) 该病人是否有使用过中医药呢？从哪儿得到的这些知识，是否有效呢？
5. 作为照料者是怎样的感受呢？
  - (1) 在您照顾他/她之前和之后有怎样的变化呢？
  - (2) 您是唯一的照料者吗？
  - (3) 您对您照顾的这个过程满意吗？
  - (4) 您认为作为照料者怎样改变了您的生活？
  - (5) 您能描述一下您照顾他/她的一天吗？
  - (6) 您觉得作为照顾者最困难的是什么地方呢？
  - (7) 你觉得作为照顾者最有意义的地方在哪儿呢？
7. 在照顾的过程中有没有发生什么让您意想不到的状况呢？
  - (1) 您当时是怎样的感受？
  - (2) 您从中学到了什么？
9. 您能说下您和您和家人朋友的关系吗？
  - (1) 您觉得你们的关系有变化吗？
  - (2) 他们对您支持有帮助吗？从哪些方面呢？
10. 您觉得怎样可以让您的照顾的过程变得轻松点呢？
  - (1) 家庭成员可以给您提供怎样的帮助？
  - (2) 社区可以给您提供怎样的帮助？
  - (3) 医疗系统可以给您提供怎样的帮助？

11. 如果日后病人健康状况恶化，并且逐渐失去自理能力之后，您会有哪些的担忧呢？
12. 您对病人日后的临终关怀有什么打算吗？
  - (1) 您对他在加拿大接受临终关怀最大的担忧是什么？
  - (2) 您觉得一个好的临终关怀需要什么？
13. 您有什么故事要和我分享吗？

## Appendix 4a Demographic Survey (Chinese Version)

一般情况调查 # \_\_\_\_\_

### I. 照顾者情况

1. 性别: 男 女

2. 年纪: \_\_\_\_\_

3. 婚姻状况:

未婚

已婚

离婚

丧偶

其它

4. 教育程度:

初中

高中

专科

本科

研究生及以上

5a. 出生地:

中国大陆

香港, 澳门

台湾

加拿大 (您一般使用哪种语言\_\_\_\_\_)

其它, 请说明\_\_\_\_\_

5b. 如果您未在加拿大出生, 请问您何时移民来此: \_\_\_\_\_

6. 宗教信仰 \_\_\_\_\_ (请说明)

7. 家庭年收入 (\$):

30,000 及以下

- 30,000-50,000
- 50,000-70,000
- 70,000- 100,000
- 100,000 及以上

**8. 就业情况:**

- 全职
- 兼职
- 自主创业
- 休假中
- 其它\_\_\_\_\_ (请说明)

**9. 工作时间灵活度 :**

- 自己决定
- 可以调整的工作时间
- 固定工作时间

**10. 居住地:**

- 市中心
- 郊区
- 附近的城市
- 其它\_\_\_\_\_

**11. 居住情况:**

- 与家人同住
- 与朋友同住
- 独居
- 其它\_\_\_\_\_ (请说明)

**II. 被照顾者情况**

**1. 与照顾者关系: \_\_\_\_\_**

2. 性别: 男 女
3. (已去世的病人)去世时年纪:\_\_\_\_\_
4. 婚姻状况:
- 未婚
  - 已婚
  - 离婚
  - 丧偶
  - 其它
5. 教育程度:
- 初中
  - 高中
  - 专科
  - 本科
  - 研究生以以上
- 6a. 出生地:
- 中国大陆
  - 香港, 澳门
  - 台湾
  - 加拿大 (他/她一般使用哪种语言\_\_\_\_\_)
  - 其它, 请说明\_\_\_\_\_
- 6b. 如果他/她未在加拿大出生, 请问您何时移民来此:\_\_\_\_\_
- 7.宗教信仰\_\_\_\_\_ (请说明)
8. 他/她是否有子女: (是/否), 如果“是”, 有几个?\_\_\_\_\_
9. 他/她是否有收入: (是/否)
10. 医疗保险情况:
- 自己付钱
  - 社会保险
  - 商业保险

其它

**11. 居住地:**

市中心

郊区

附近的城市

其它\_\_\_\_\_

**12. 居住情况:**

与家人同住

与朋友同住

独居

其它\_\_\_\_\_ (请说明)

**13. 所患疾病:** \_\_\_\_\_

**14. 诊断时间:** \_\_\_\_\_

**15. (已去世的病人) 去世时间?** \_\_\_\_\_

**16. 被照顾了多久:** \_\_\_\_\_ (周/月/年)

**17. 照料地点:**

家里

普通医院

临终关怀医院

**18. (已去世的病人) 去世地点:**

家中

普通医院

临终关怀医院



**Appendix 4b Demographic Survey (English Version)**

**Demographic Survey # \_\_\_\_\_**

**I. Caregiver Information Part**

**1. Sex:** Male Female

**2. Age:** \_\_\_\_\_

**3. Marital Status:**

Not Married

Married

Divorced

Widowed

Other

**4. Education:**

Junior High

High School

College

Undergraduate

Graduate

**5a. Place of Birth:**

Mainland China

Hong Kong

Taiwan

Canada (what language do you primarily use) \_\_\_\_\_

others, please specify \_\_\_\_\_

**5b. If you were not born in Canada, when did you immigrate to Canada: \_\_\_\_\_**

**6. Religion \_\_\_\_\_** (Please specify)

**7. Family Annual Income (\$):**

30,000 or below

30,000-50,000

- 50,000-70,000
- 70,000- 100,000
- 100,000 or above

**8. Employment status:**

- Working full-time
- Working part-time
- Self-employed
- On leave
- Other \_\_\_\_\_ (please specify)

**9. Work Time Flexibility :**

- Flexible
- Adjustable work time
- Fixed work time

**10. Residence:**

- Downtown area
- Suburb
- Surrounding cities
- Other \_\_\_\_\_

**11. Living Arrangement:**

- Live with family
- Live with friend
- Live alone
- Other \_\_\_\_\_ please specify

**8. Care Recipient Information Part**

- 1. Relationship with the caregiver:** \_\_\_\_\_
- 2. sex:**  Male  Female
- 3. Age** \_\_\_\_\_ (age at death if deceased)

**4. Marital Status:**

- Unmarried
- Married
- Divorced
- Widowed
- Other

**5. Education:**

- Junior High
- High School
- College
- Undergraduate
- Graduate

**6a. Place of Birth:**

- Mainland China
- Hong Kong
- Taiwan
- Canada (what language does/did he/she primarily use)
- Others \_\_\_\_\_ (please specify)

**6b. If he/she was not born in Canada, in which year did he/she immigrate to**

**Canada:** \_\_\_\_\_

**7. Religion:** \_\_\_\_\_ (please specify)

**8. Did/does he/she have kids: (Yes/No), if “Yes”, how many?** \_\_\_\_\_

**9. Did/does he/she have income: (Yes/No)**

**10. Health Care Expense:**

- Self paid
- Social Insurance
- Insurance Company
- Other

**11. Residence:**

- Downtown area
- Suburb
- Surrounding cities
- Other \_\_\_\_\_

**12. Living arrangement:**

- Live with family
- Live with friend
- Live alone
- Other \_\_\_\_\_ please specify

**13. The disease he/she has or had:** \_\_\_\_\_

**14. (for deceased only) When did he/she die?** \_\_\_\_\_

**15. How long been cared by the caregiver:** \_\_\_\_\_ (week/month/year)

**16. Where was he/she cared:**

- at home
- general hospital
- Hospice/palliative care hospital

**17. (for deceased only) Where did he/she die:**

- at home
- general hospital
- Hospice/palliative care hospital

## Appendix 5 Ethics Approval



**Ethics Office  
Suite 200, Eastern Trust Building  
95 Bonaventure Avenue  
St. John's, NL  
A1B 2X5**

July 24, 2012

Mr. Hao Wu  
Community Health and Humanities  
Memorial University

Dear Mr. Wu:

**Reference # 12.126**

**RE: Palliative and end-of-life care for Chinese immigrants: perceptions of family caregivers**

This will acknowledge receipt of your correspondence.

This correspondence has been reviewed by the Chair under the direction of the Board. **Full board approval** of this research study is granted for one year effective **June 28, 2012**.

This is to confirm that the Health Research Ethics Board reviewed and approved or acknowledged the following documents (as indicated):

- Letter from Dr. Peter Wang, acknowledged
- Revised Consent Form dated July 10, 2012, approved
- Demographic Survey, approved
- Interview Guide, approved
- Research Proposal, approved

**MARK THE DATE**

This approval will lapse on **June 27, 2013**. It is your responsibility to ensure that the Ethics Renewal form is forwarded to the HREB office prior to the renewal date. *The information provided in this form must be **current to the time of submission** and submitted to HREB **not less than 30 nor more than 45 days** of the anniversary of your approval date.* The Ethics Renewal form can be downloaded from the HREB website <http://www.hrea.ca>.

*The Health Research Ethics Board advises THAT IF YOU DO NOT return the completed Ethics Renewal form prior to date of renewal:*

email: [info@hrea.ca](mailto:info@hrea.ca)

Phone: 777-8949

FAX: 777-8776

Mr. Wu  
Reference # 12.126  
July 24, 2012

Page 2

- *Your ethics approval will lapse*
- *You will be required to stop research activity immediately*
- *You may not be permitted to restart the study until you reapply for and receive approval to undertake the study again*

*Lapse in ethics approval may result in interruption or termination of funding*

It is **your responsibility to seek the necessary approval from the Regional Health Authority or other organization as appropriate.**

Modifications of the protocol/consent are not permitted without prior approval from the Health Research Ethics Board. Implementing changes in the protocol/consent without HREB approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendment form (available on the HREB website) and submitted to the HREB for review.

This research ethics board (the HREB) has reviewed and approved the research protocol and documentation as noted above for the study which is to be conducted by you as the qualified investigator named above at the specified site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Health Research Ethics Board currently operates according to *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*; *ICH Guidance E6: Good Clinical Practice* and applicable laws and regulations. The membership of this research ethics board is constituted in compliance with the membership requirements for research ethics boards as defined by *Health Canada Food and Drug Regulations Division 5; Part C*.

Notwithstanding the approval of the HREB, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,



Patricia Grainger, Acting Chair  
Health Research Ethics Board

CC VP Research c/o Office of Research, MUN  
VP Research c/o Patient Research Centre, Eastern Health  
HREB meeting date: August 9, 2012

email: [info@hrea.ca](mailto:info@hrea.ca)

Phone: 777-8949

FAX: 777-8776

## Appendix 6a Consent Form (Chinese Version)



Faculty of Medicine

Division of Community Health and Humanities

The Health Sciences Centre

St. John's, NL Canada A1B 3V6

Tel: 709 777 6652 Fax: 709 777 7382 [www.med.mun.ca](http://www.med.mun.ca)

### 参与研究知情同意书

**题目:中国移民的临终照料: 家庭护理者的经历**

**研究员: 吴昊, 硕士生**

**社区健康与人文系**

**医学部, 纽芬兰纪念大学**

**联系电话: (709)351-7096**

我们邀请您参与一项研究。这项研究的参与完全自愿, 参与与否完全出于您自己的意思。您完全可以拒绝参与。而且如果您参与了也可以在任何时刻退出。

在参与之前, 您需要知道这个研究的目的, 了解研究的风险和受益。该同意书将解释这一系列问题。

请仔细充分的阅读此同意书。您可以有充分的时间来思考。您可以在您不了解的地方标注, 然后在您阅读完毕之后, 可以向我询问任何不清楚的地方。

研究员将会:

- 和您一起讨论本研究
- 回到您的问题
- 将对您的个人信息完全保密
- 在研究的过程中解答您的一切疑惑

#### **1. 背景介绍:**

尽管在加拿大中国移民(华裔)占整个移民人口的很大的比例, 但是对于罹患绝症的病人所经历的挑战和困难以及照料他们的家属的生活经验却知之

甚少。因此，我们有必要首先去了解他们家属在照料过程中的所有经历。这项研究在这个领域十分新颖，并会对日后的研究奠定基础。

## 2. 目的:

本研究的目的在于了解照顾过罹患绝症家人的人群的照顾经历，从而为中国移民以及华裔人群构建适合中华文化的临终照料和护理并对他们的家人提供帮助。

## 3. 研究过程:

您将参加一个面对面的深度访谈。时间和地点都将视您的情况而定。访谈的问题将集中在您现在照顾的亲人/当时照料现已离世的亲人的整个过程。整个过程将会录音，然后被整理成手稿用于日后的分析。

## 4. 研究时间:

整个访谈时间将在一个小时左右。

## 5. 风险:

参与此项研究不会有已知的风险。但是有极少的人会对某一些问题感到难过。如果您感到不舒服的话，您可以在任何时候中止访谈，此刻，如果您愿意的话，研究员可以转介您至（情绪和心理方面）专业人员以获取帮助。

## 6. 受益:

尚不知该研究是否能让您受益。

## 7. 责任:

签署该同意书代表您愿意参与本研究。在此您已经完全了解了这些研究的信息。当您签署了该通知书不会免除您的法律权利。研究员以及参与到此研究的机构亦有他们的法律责任。

## 8. 保密

在该研究中保护您的隐私十分重要。我们将采取行动保护您的隐私。然而，这并不是绝对的。例如，如果法律要求您的信息可能会被其他的人看到。

当您签署该通知书后，我们将有权利：

- 收集您提供的信息
- 与共同研究的人员共享您的信息
- 与保护你安全的人员共享您的信息

记录的接触



参与此项研究的人员可以看到您的名字以及您提供的信息。其他能够看到的人包括：研究人员、伦理委员会。您可以要求了解这些能接触到您的信息记录的人员名单。但是他们只有在此研究的研究人员的监督下才能接触到您的记录。

### 您的信息的使用

研究小组将会收集您提供的情报，这些情报仅限于与研究目的有关。

这些信息包括

- 性别
- 采访中的内容以及来自人口学调查的信息

您的姓名以及联系方式将被严格的保存在位于纽芬兰的研究小组。这些信息在没有得到您的允许的情况下是不会被其他人看到的。您的姓名不会出现在该研究的报告以及日后的发表文献中。

您的信息将会被保存五年。

如果您决定在数据分析之前退出研究，到那个时候为止您提供的信息不会被销毁，但它们只会用于研究目的。

收集的一切信息将被存储于纽芬兰纪念大学医学部小区健康与人文系，Dr. Victor Maddalena 将会负责保存您的信息。

### 您对于信息的接触权

您可以向研究员请求以接触您自己的信息。

## **9. 疑问:**

如果您对于参与该研究有任何疑问，您可以与研究员见面询问。研究员是的联系方式为：

Dr. Victor Maddalena, 电话: 圣约翰斯 709-777-8539

王培忠教授, 电话: 多伦多 709-746-2898

或者，您也可以向其他该研究以外的人并了解您参与研究权利的人员询问。这个人可以通过以下方式联系：

伦理办公室

健康研究伦理管理处

电话: 709-777-6974 或者通过电子邮件 : [info@hrea.ca](mailto:info@hrea.ca)

在签署了此档之后您可以获得一份复印件



## Appendix 5b Consent Form (English Version)



Faculty of Medicine

Division of Community Health and Humanities

The Health Sciences Centre

St. John's, NL Canada A1B 3V6

Tel: 709 777 6652 Fax: 709 777 7382 [www.med.mun.ca](http://www.med.mun.ca)

**TITLE: Palliative and End-of-life Care for Chinese Immigrants: Experiences of Family Caregivers.**

**INVESTIGATOR(S): Hao Wu, MSc student**

**Division of Community Health & Humanities,  
Faculty of Medicine, Memorial University of  
Newfoundland**

**Tel. (709)351-7096 St. John's  
(416)655-3379 Toronto**

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

**1. Introduction/Background:**

Although Chinese immigrants are one of the largest immigrant and ethnic minority groups in Canada, little is known about what difficulties they have when caring for a loved one with a chronic or terminal illness or at end of life. We want to learn about the experiences of Chinese family caregivers who are providing or had provided care to their loved ones. This study will add knowledge in this area.

**2. Purpose of study:**

This research will increase our understanding of the experience of Chinese family caregivers who provide care to their loved ones with a chronic or terminal illness, and to propose culturally appropriate palliative and end-of-life care/service for Chinese immigrants and support for their family caregivers.

**3. Description of the study procedures:**

You will join in a face-to-face interview and complete a short survey. The time and place of interview will be at your convenience. The interview will focus on your experience as a family caregiver for your family member. The interview will be audio taped and then transcribed. The transcripts will be used for later data analysis.

**4. Length of time:**

The interview and completion of a short survey will last around 1 hour.

**5. Possible risks and discomforts:**

There is no known risk for being a part of this study, except some questions might make you uncomfortable and sad. If you get emotionally upset during the interview, you will be asked if you wish to stop the interview. The interviewer will refer you to a mental health service.

**6. Benefits:**

This research may not directly benefit you. However, it may benefit other Chinese patients with terminal disease and their family caregivers.

**7. Liability statement:**

Signing this form gives us your consent to participate in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

**8. What about my privacy and confidentiality?**

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records.

When you sign this consent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

#### Access to records

The members of the research team will see study records that identify you by name.

Other people may need to look at the study records that identify you by name.

This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

#### Use of your study information

The research team will collect and use only the information they need for this research study.

This information will include your

- Demographic profile
- information from study interviews

Your name and contact information will be kept secure by the research team at Memorial University in Newfoundland and Labrador. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will kept for five years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored at the Division of Community Health & Humanities, Faculty of Medicine, Memorial University of Newfoundland. Dr. Victor Maddalena is the person responsible for keeping it secure.

#### Your access to records

You may ask the researcher to see the information that has been collected about

you.

**9. Questions or problems:**

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is

Dr. Victor Maddalena (St. John's) 709-777-8539

Dr. Peter Wang (Toronto) 416-250-5894

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office

Health Research Ethics Authority

709-777-6974 or by email at [info@hrea.ca](mailto:info@hrea.ca)

**After signing this consent you will be given a copy.**

## Signature Page

**Study title: Palliative and End-of-life Care for Chinese Immigrants: Experiences of Family Caregivers.**

**Name of principal investigator: Hao Wu**

**To be filled out and signed by the participant:**

Please check as appropriate:

- |  |         |        |
|--|---------|--------|
| I have read the consent.   | Yes { } | No { } |
| I have had the opportunity to ask questions/to discuss this study.   | Yes { } | No { } |
| I have received satisfactory answers to all of my questions.   | Yes { } | No { } |
| I have received enough information about the study.  | Yes { } | No { } |
| I have spoken to Hao Wu and he has answered my questions   | Yes { } | No { } |
| I understand that I am free to withdraw from the study   | Yes { } | No { } |
| <ul style="list-style-type: none"> <li>• at any time</li> <li>• without having to give a reason</li> </ul> |         |        |
| I understand that it is my choice to be in the study and that I may not benefit.                           | Yes { } | No { } |
| I understand how my privacy is protected and my records kept confidential.                                 | Yes { } | No { } |
| I agree to be video/audio taped  | Yes { } | No { } |
| I agree to take part in this study.  | Yes { } | No { } |

Signature of participant	Name printed	Year Month Day
--------------------------	--------------	----------------

<i>Signature of person authorized as</i>	<i>Name printed</i>	<i>Year Month Day</i>
<i>Substitute decision maker, if applicable</i>		

<i>Signature of witness (if applicable)</i>	<i>Name printed</i>	<i>Year Month Day</i>
---	---------------------	-----------------------

**To be signed by the investigator or person obtaining consent**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator	Name printed	Year Month Day
---------------------------	--------------	----------------

Telephone number: \_\_\_\_\_