PALLIATIVE HOME CARE AND CHINESE IMMIGRANTS: 
THE MEANINGS OF HOME AND NEGOTIATIONS OF CARE

By

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A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy
Graduate Department of Lawrence S. Bloomberg Faculty of Nursing
University of Toronto

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ABSTRACT

Palliative care for non-dominant ethnocultural groups is problematized in the palliative care literature, which often presents essentialist conceptions of cultural beliefs on death and dying. Death is often portrayed as a taboo topic within the Chinese community, and thus, the assumption is that dying at home may not be the preferred option. Beyond these stereotypical representations, little is known about what it is like for Chinese immigrants with terminal cancer to receive palliative home care. Home is a complex site where cultural “difference” becomes contextually salient when home care providers introduce palliative care. More is potentially at stake than the violation of a taboo, as Chinese immigrant care recipients, their family caregivers, and home care providers negotiate changes to the existing routines of the home. The purpose of this study was to examine how meanings of home condition negotiations of care between Chinese immigrants with terminal cancer receiving palliative home care, family caregivers, and home care providers. Postcolonial theory provided a critical lens for this focused ethnographic study of palliative home care for Chinese Canadian immigrants. The analysis drew on postcolonial concepts such as Othering, subjugation, and hybridity. The methods included
interviews with 11 key informants, and observational visits and interviews were conducted in 4 cases of Chinese immigrant care recipients, their family caregivers, and home care nurses.

Two major findings emerged: 1) colonization and distancing and 2) negotiating hybridity. The meaning of home was deeply altered as palliative home care occupied care recipients’ and family caregivers’ everyday lives and represented a form of micro-colonization - the home was metaphorically invaded. The ambivalent relationship between care recipients and home care providers was characterized by a mutuality of need, but care recipients used distancing as a way to resist colonization. Palliative care presented its own unique cultural influence, which was imbued with meanings, beliefs, and practices. For care recipients, the meaning of dying at home was fluid, situational, and contextually informed. Subsequently, differences were created and highlighted in the confrontation between the meaning of palliative care for home care providers and the meaning of dying at home for care recipients. It was in the meeting, blending, clashing, and grappling of differences where participants had to negotiate and generate new, hybrid meanings and practices so that particularized, personal approaches to dying could be achieved.

The findings capture the realities and complexities of palliative home care, and highlight the sophisticated and evolving ways providers come to know and care for care recipients and families in their homes. Although culture was prominently featured in participant narratives, the pragmatics of dying at home were more pressing than was adherence to essentialized cultural beliefs of death and dying. A key implication is the need to move away from simplistic conceptualizations of culture to a critical approach that will enable providers to understand and find comfort in working with the fluid, dynamic, and contextually-driven nature of culture and dying at home.
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My family: Mom, Dad, Lily, Andrew, and Michael, thank you for always cheering me on, pushing me to pursue my passions, for being there, and keeping me grounded. If I ever took myself too seriously, you knew what to say to remind me of who I am and where I come from. From you, I learned compassion and caring.

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<tr>
<td>APN</td>
<td>Advanced practice nurse</td>
</tr>
<tr>
<td>CareFirst</td>
<td>CareFirst Seniors and Community Services Association</td>
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<tr>
<td>CCAC</td>
<td>Community Care Access Centre</td>
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<tr>
<td>CG</td>
<td>Caregiver</td>
</tr>
<tr>
<td>CHPCA</td>
<td>Canadian Hospice Palliative Care Association</td>
</tr>
<tr>
<td>CR</td>
<td>Care recipient</td>
</tr>
<tr>
<td>HCP</td>
<td>Health care provider</td>
</tr>
<tr>
<td>HPC Teams</td>
<td>Hospice Palliative Care Teams for Central LHINs</td>
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<tr>
<td>KI</td>
<td>Key informant</td>
</tr>
<tr>
<td>LHINs</td>
<td>Local Health Integration Networks</td>
</tr>
<tr>
<td>N/A</td>
<td>Not available or not applicable</td>
</tr>
<tr>
<td>PSW</td>
<td>Personal support worker</td>
</tr>
<tr>
<td>S.R.T.</td>
<td>S.R.T. Med-Staff</td>
</tr>
<tr>
<td>St. Elizabeth</td>
<td>Saint Elizabeth Health Care</td>
</tr>
<tr>
<td>TLCPC</td>
<td>Temmy Latner Centre for Palliative Care</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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I have always found it difficult to articulate how I became interested in palliative home care issues for Chinese immigrants. It is not easy to tell the story of how this topic has progressed into a research purpose that aims to examine the changing meanings of home for Chinese immigrants with advanced cancer, their family caregivers, and home care providers. I start the story of my journey by reflecting on the “cultural” assumptions about death and dying that underlie my doctoral work in this area.

For those who inquire, I tell them that my interest developed after I had worked at the Victorian Order of Nurses (VON) for my final practicum in the Master of Nursing program, where I became sympathetic to and privy to the experiences of caregivers providing care at home for family members. But I think my interests have always been there.

How do you tell people that you are afraid of death and of losing people close to you? How do you explain that you are very hesitant to talk about death and dying because you grew up feeling like you could not and should not say those words?

I have several memories from growing up within a Chinese immigrant household that highlighted the fact that death is not spoken about openly. One memory involved my father telling me that my piano teacher’s husband had passed away. In translation, my father had said literally that he had “gone up to the sky”. I confirmed by verifying that he had meant my piano teacher’s husband had “died”. My father corrected me by saying, “You do not say it that way. You say they went up to the sky”.

On another occasion, my mother was talking with an insurance agent, who was also Chinese, about life insurance policies, and again I tried to confirm by saying, “so when you die, the policy…” Immediately, my mother gave me a look, and the insurance agent stopped and explained to me that you never say “you die” to a Chinese person. He went on by telling me that it is not polite to talk about death to Chinese people or at least you never said the actual word. This was coming from a life insurance agent! I did not find it odd that he would reprimand me for using the word, and I actually felt bad that I had “slipped” up again. So as I was growing up, there was a silence around death and I understood that it was bad to talk about death. I had the sense that the silence was more than the normal anxiety and sense of loss that surrounds death,
but that it could be associated with bad luck. From these experiences I questioned whether there could be something different about handling death for Chinese immigrants.

What is most difficult to articulate is that although I find it difficult to talk about death, I sometimes think about it. I think about how difficult it will be to lose family members as they get older. I go to family gatherings and realize how my aunts and uncles, and with most difficulty, my own parents, are aging. I think about how difficult it will be to care for them when they are dying. Even as I write this, I feel guilty and almost fearful because I may be hastening death by writing about it. But as I get older, I realize that one day, I will have to take care of my elderly parents. There is a paucity of research examining the palliative home care experiences of Chinese immigrants to help guide care in this area. Part of my work is selfish in that I want to ensure that when the time comes for my family members to receive care, I want it to be well informed and sensitive to their needs rather than based on stereotypes of Chinese immigrants.

Initially when entering the PhD program, I wanted to examine preference for place of death among Chinese immigrants. In the beginning I thought there was something different about Chinese immigrants’ homes that would make them rich places to examine palliative care. The home could house multiple generations with different beliefs based on differing experiences of migration. How would these differences support or challenge palliative care at home? My topic evolved as I looked into the literature on preference for place of death. A study by Seymour, Payne, Chapman, and Holloway (2007) found that healthy Chinese immigrants were open to being cared for at home if they became terminally ill, but would prefer to die in a hospital.

As I reflect on my experiences and the questions that were emerging, I realize that this comes from my position as a first generation Chinese immigrant, a nurse, a daughter, a sister, and a partner. Although I was born in China, I immigrated to Canada with my parents when I was only one year old. I consider myself a Chinese Canadian and not an immigrant. Over so many years living in Canada, I have developed a sense of belonging. The reflection on my own positioning allows me to be aware of several assumptions I hold. One of the assumptions is that terminally ill Chinese immigrants may not want to die at home. Another assumption is that not all Chinese families may want to care for a dying family member at home, let alone have them die in the house because it may bring bad luck. Although I may find it difficult to talk about death, I believe that there are Chinese immigrants that are willing to talk about death. I began to
wonder, to what extent does death as taboo ring true for Chinese immigrants? Are there Chinese immigrants that are willing to have a family member die at home?

I realize that as I write this, my assumptions may be contradictory. I write about death as taboo, and as being a shared belief among Chinese people yet, I want to ensure that with my research, Chinese beliefs are not stereotyped. And this is where I connect with the concept of hybridity. The concept of hybridity explains that depending on situations, contexts, and circumstances, people may draw on beliefs, practices, and knowledges that come from being both “Chinese” and “Canadian” (Spence, 2006). I feel that I am a hybrid; my “Chinese” and “Canadian” beliefs flow into one another. I believe that I have a fluid ethnic and cultural identity that nuances my daily experiences. And this is partially what I want to examine in palliative home care experiences of Chinese immigrant families as they negotiate palliative care amongst themselves and with outside home care providers. Does hybridity play out in daily aspects of care that balance new and old beliefs and practices? If so, how? And how does a sense of belonging and citizenship play out in immigrants’ care decisions?

At one of my first committee meetings, it was pointed out that there seemed to be a bigger gap in terms of how palliative home care takes place for Chinese immigrants. What was the process of care like? The word negotiation came through as a word that was important in examining the process of palliative home care. I realize that the question of what is being negotiated in daily aspects of care is important to examining the experiences of palliative home care for Chinese immigrant families.

From there, the relevance of the home resurfaced again, not just as a place of death but theoretically as a place that has meaning for immigrants’ sense of belonging and ability to negotiate palliative care. There are few studies examining the meanings of home for immigrants using a postcolonial lens, specifically the notions of nationality, citizenship, and belonging. How does an immigrant’s sense of citizenship allow them to feel that they are able to rightfully access services, supports, and resources? Does one’s sense of citizenship provide entitlement to ask and negotiate for care or resources? Also the sense of belonging in the home can be seen at both the macro and micro levels that have political and structural implications for how Chinese immigrants engage in making decisions around their care at home.

If this story sounds confusing or illogical, it is because this journey has been so. It has been a long journey; I have come up with ideas, thrown out ideas, and revisited them once again.
But most importantly, this journey has allowed me to be reflexive about both the personal and professional experiences that constitute the reflexive background for my efforts to articulate what I want to understand about palliative home care experiences of Chinese immigrants. My experiences have played a critical role in drawing me to this substantive research area, and by reflecting on my journey, I am able to lay bare my personal and professional assumptions about this phenomenon, and begin to articulate the silences around death. This preface provides the reader with the context for my professional nursing inquiry. In the following introductory chapter, background information, problem statement, purpose and research questions will be presented.
CHAPTER 1
INTRODUCTION

Introduction

Population based statistics show an overall trend towards a decline of cancer deaths in hospitals and a gradual increase in home deaths across Canada (Burge, Lawson, & Grace, 2003; Neutel, Bishop, Harper, & Gaudette, 2005; Wilson et al., 2009). These figures appear to represent a shift to the home as a place of care and death at the end-of-life. Most studies examining place of death among terminal cancer patients indicate that between 49%-100% of respondents express a preference to receive palliative end-of-life care at home (Higginson & Sen-Gupta, 2000). The home is represented as the ideal place to receive palliative end-of-life care in the literature and media. However receipt of palliative care at home can shift or change the meanings of home, as a place of health, refuge, privacy, and security (Angus, Kontos, Dyck, McKeever, & Poland, 2005; Exley & Allen, 2007; Sorensen Marshall, 2008), to a home that has to accommodate and support dying. The home is a place that holds emotional connotations as well as vulnerabilities (Sorensen Marshall, 2008). Often home care is seen as an intrusion that disrupts routines, and is an invasion into private lives when “outside” health care professionals enter the home to provide care (Magnusson & Lutzen, 1999).

As “outsiders”, home care providers are often subject to the social expectations of being guests in care recipients’ homes as well as managing their roles as professional care providers (Magnusson & Lutzen, 1999; Oresland, Maata, Norberg, Jorgensen, & Lutzen, 2008). Although providers are guests in the home, the care recipient and family are dependent on their services; thus, there is a mutual sense of vulnerability (Oresland et al., 2008). There is a level of ambiguity in roles and social expectations that also must be negotiated between care recipients, family caregivers, and home care providers.

Palliative home care is socially negotiated because the care not only affects the dying care recipient but may affect the routines of others in the household as well. The home care provider may have different goals and interests than the care recipient and family, which may necessitate a process of negotiation (Oresland et al., 2008). Negotiating care may be further complicated by dissimilar ethnic or cultural backgrounds, especially if there are language barriers. It is important to examine the shifting meanings of home for advanced cancer patients,
their family caregivers, and home care providers to better understand the constraints and facilitators to negotiating palliative care in the home.

The home is a richly layered place to understand what is being negotiated in palliative care situations for immigrants. According to Dyck and Dossa (2007), everyday practices of migrants “are not best understood as simply local, but as intricately interwoven with material resources and/or cultural knowledge located and constructed within a context of transnational connections and memories of ‘home’” (p. 692). Immigrants must negotiate multiple meanings of home such as home as a place of origin, home as a form of shelter, and home as a place of belonging (Hayes, 2007).

The meaning of home may be even more significant for immigrant care recipients experiencing palliative home care because of the possible disruption to multiple meanings of home. Postcolonial scholars question how policies and structures influence immigrants’ sense of citizenship and belonging at the state-level and how that translates into agency within their everyday lives. And so in the context of palliative care, immigrants’ sense of belonging may have consequences for their ability to make decisions about care. Immigrants may feel a sense of isolation and alienation as they try to (re)build a sense of home and belonging. The existential anxiety associated with trying to (re)claim a sense of home may be evoked again when receiving palliative care at home. In this instance, the meanings of home may be contested as a succession of outside home care providers enter to provide care, and as the home becomes a site for death. There is a lack of research examining how meanings of home may change physically, socially, and spiritually over time for immigrant care recipients and caregivers when receiving home care (Sorensen Marshall, 2008). It is important for health care providers to appreciate the meanings of home for immigrant families because it provides an understanding of how the home environment can shape or constrain their practices as well as how they can empower immigrant families when negotiating palliative home care (Roush & Cox, 2000). There have been few studies examining the meanings of home for immigrants (Dyck & Dossa, 2007) and none that examine the meanings of home in relation to palliative care of Chinese immigrants.

**The Problem and Relevance**

In Canada there has been a shift in health care delivery from institutions to the home due in part to an aging population and an emphasis on fiscal accountability (Lilly, Laporte, & Coyte,
The growth in demand for home-based care has prompted a trend towards palliative care delivered in the home (Guerriere, Zagorski, Fassbender, Masucci, Librach, & Coyte, 2010; Lilly et al., 2010; Romanow, 2002). The impetus for death to return to the home means that most care for terminally ill patients may be provided in the home by unpaid family caregivers (Donovan, Williams, Stajduhar, Brazil, & Marshall, 2011). Since Canada is considered an ethnoculturally diverse nation, cultural considerations for care have been stressed in the delivery of palliative care. Despite this fact, there remain few studies examining how experiences of migration and the fluidity of beliefs can influence palliative home care experiences for immigrants.

Specifically, Chinese immigrants make up the largest minority group in the country and have a history of migrating to Canada for over 150 years. Yet there is little known about what it is like for Chinese immigrants with terminal cancer to receive palliative home care. Assumptions about Chinese beliefs around the process of dying fail to recognize the heterogeneity within the Chinese immigrant population. The Chinese belief system is often described in the literature as being influenced by Confucianism, Taoism, Buddhism, local folklore, and superstition (Yick & Gupta, 2002; Woo, 1999). Discussion often describes how Chinese beliefs influence health behaviour, but few pay attention to the fluidity of beliefs that come with migration and long-term re-settlement. Hence, examining the palliative home care experiences of Chinese immigrants is a complex endeavour because it means not only studying how beliefs can influence their views of the dying process but also acknowledging differences within the Chinese immigrant population.

Angus et al. (2005) found that home care can create ambiguities when the logics and practices of the health care system become superimposed onto the logics and practices of the home. Thus negotiating palliative care in the home involves not only dialogue between those involved in organizing care, but it is also a material and spatial experience. Care recipients and family caregivers must learn to negotiate through an altered space that becomes a site of health care with unfamiliar equipment and a succession of health service providers. Inhabitants must find places for medical equipment such as hydraulic beds and commodes (Exley & Allen, 2007), and these objects are also laden with social and personal meanings. Negotiations also centre on pain, symptom management, and the scheduling of care so that these activities minimally disrupt the normal routines of the home (Angus et al., 2005; Szeto & Cheng, 2006). The home care
provider deals with similar ambiguities in efforts to reconcile their own beliefs, habits, and routines of care provision with those of the family.

Just as migrants have negotiated through journeys that take them from one home to another in new countries, death is another journey that migrants must eventually negotiate as well. I focus on negotiations because there are multiple meanings. It can mean to bargain or make a compromise between individuals, but can also describe a way of moving through or managing a situation. Negotiating care involves a process of discussion or bargaining to agree or compromise on how care should take place (Piercy & Woolley, 1999; Spiers, 2002). Journeys also involve “negotiation” of unfamiliar terrain, as in the journey of life to death. What is negotiated in palliative care situations? In the case of Chinese immigrant families receiving palliative care at home, negotiation may occur between individuals who are differently positioned around the activities and meanings of care. There is not only a struggle to negotiate care but also to negotiate the process of dying.

**Theoretical Lens**

A postcolonial framework has helped to deepen my thinking and understanding of how Chinese immigrants diagnosed with terminal cancer, their family caregivers, and home care providers negotiate palliative home care amidst changing meanings of home. For Chinese immigrants, dealing with terminal cancer is layered and intimately connected with the meanings of home, past experiences of migration, and efforts to create a sense of belonging in Canadian society. Postcolonial theory is concerned with notions of home and belonging. Colonization and its continued ramifications in the present are central to postcolonial critique. Postcolonial theorists write about migrant experiences of displacement, diasporas, and migration, and examine the concepts of boundaries and nationhood. Bhabha (1994/2004) writes about migrants’ “unhomely” experiences. For Bhabha, the home can be a place where the “personal-is-the-political; the world-in-the-home” (p. 15). I interpret this to mean that the home is a microcosm in which the macro-politics of the nation-state are played out. Thus the macro-politics of nationalism and citizenship may have consequences for immigrants’ sense of belonging within their own homes and communities, and in how they negotiate palliative care at home.

Postcolonial theory is also critical of how certain knowledges are discursively constructed as culturally different and subject to a process of Othering. The dying person may
become the “other” in the physical re-organization of the home to separate spaces where activities of living and dying occur. Chinese immigrant families and home care providers are variously positioned in a dynamic relationship between “lay” and “professional” care providers. Central to their positioning may be how certain knowledges may be privileged over others (i.e. the medical knowledge of health care professionals over the tacit knowledge of Chinese immigrants). Through a postcolonial lens, the home and its meanings are seen as a place that can be taken over by home care and medicalized practices. Furthermore Chinese families may resist the colonizing effects of medical discourse to ensure that their care preferences are met. Postcolonial theory provides a lens to examine these aspects of negotiation of palliative care.

Culture is difficult to define. Many studies that examine palliative care and ethnicity take a traditional approach to defining the concept. These studies generally prescribe ways to provide care based on the assumption that culture is “pre-existing, discovered among a group of people, and can be written about in an allegedly neutral way” (Mohammed, 2006, p. 99). The nature of culture and how it is represented in research is central to postcolonial critique and the privileging of Western scientific knowledge (biomedicine). Therefore, a conceptualization of culture as a fluid and dynamic process would generate a better understanding of the meanings of home for Chinese immigrants with terminal cancer receiving palliative home care, their family caregivers, and home care providers. Although I am critiquing the use of culture, I understand that there is a historically based definition that aligns culture with race, ethnicity, ancestry, and religion. I reflexively work towards a way of engaging with culture that is conscientious of this historical definition, but also recognizes the fluid and dynamic nature of culture.

Purpose

The purpose of this study was to describe and examine how the shifting meanings of home for Chinese immigrants with advanced cancer receiving palliative home care, their family caregivers, and home care providers condition negotiations of care. A focused ethnographic study was conducted and drew on the tenets of postcolonial theory to examine the contextual, systemic, social, and material issues associated with palliative home care for Chinese immigrants.
Research Questions

The following research questions guided my exploration of the meanings of home and how it conditioned negotiations of palliative care in the home for Chinese immigrant families:

1. What are the meanings of home for Chinese immigrants with advanced cancer, their family caregivers, and home care providers?
2. How does palliative home care change meanings of home?
3. How is palliative care negotiated in the home?
4. What is negotiated in home-based palliative care?

These questions reflected the need to examine the everyday activities care recipients and their caregivers, professional and non-professional, engaged in to ensure that the daily care needs of the care recipient were met. A focused ethnographic approach was used to explore these experiences. Through this type of exploration, I examined how the palliative home care experiences of Chinese immigrant care recipients, family caregivers, and home care nurses intersected with experiences of gender, class, race, and culture.

Outline of the Dissertation

In total, the dissertation is divided into eight chapters, including this introductory chapter. Chapter 2 presents the relevant background information pertaining to the history of migration of Chinese people to Canada and the palliative home care landscape in Ontario, Canada. Chapter 3 explains the theoretical underpinnings of postcolonial theory and how it was used as a lens for examining the research problem. Because the study drew on a postcolonial theoretical lens, the key relevant concepts are discussed and defined. Chapter 4 presents a critical synthesis of the literature on palliative home care. Since postcolonial theory is a critical theory, it provided a critical lens to examine the current literature on palliative care in the home with Chinese immigrants. In Chapter 5, I discuss why a qualitative approach was taken to examine this problem as well as how a focused ethnographic approach was best suited for this study. The sample, sampling, data collection, data analysis, reflexivity, ethical considerations, and rigour are also outlined in this chapter. The findings for the study are divided into two separate chapters. Chapter 6 explores the meanings of home for participants and how meanings changed during palliative home care. In Chapter 7, negotiations of palliative home care are described through a
postcolonial lens. Finally, in Chapter 8, the contributions of the findings to existing research and the implication to practice, education, policy, and future research are discussed.
CHAPTER 2
BACKGROUND

Introduction

As will be further elaborated in the theoretical chapter, a postcolonial perspective contextualizes within a particular socio-historical moment the interconnections of gender, class, race, and other social location in health care experiences. This chapter provides background information pertaining to palliative home care in Ontario, Canada to better contextualize the palliative home care experiences of Chinese immigrant care recipients. Furthermore background on the Chinese Canadian population in Canada (specifically Toronto, Ontario), the historical context of Chinese migration to Canada, and recurring concepts on death and dying associated with the Chinese population are discussed.

Palliative Home Care Landscape in Ontario, Canada

Defining Palliative Care

The World Health Organization (WHO) defines palliative care as:

an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual (WHO, 2007)

Thus palliative care may start once the patient has been diagnosed with a life-threatening illness, and is primarily focused on supportive and not curative treatments. The goal of palliative care is to “relieve suffering and improve quality of living and dying” (Canadian Hospice Palliative Care Association [CHPCA], 2002). Some literature differentiates between palliative care and end-of-life care. Quality of life is emphasized in palliative care while quality of dying and death is the focus of end-of-life care (Hales, Zimmermann, & Rodin, 2008; Kaasa & Loge, 2003). End-of-life care is part of palliative care, and focuses on therapeutic interventions to improve quality of dying; thus, end-of-life refers to the phase of active dying (Aranda, 2003; Boyd & Murray, 2010). In this study, I refer to palliative care because the sample of Chinese immigrant care recipients recruited into the study was stable and not actively dying.
In a qualitative synthesis of official policies and guidelines for palliative care from representative health organizations in English-speaking countries, Barazzetti, Borreani Miccinesi, and Toscani (2010) found that most statements placed a higher emphasis on control of symptoms and psychosocial dimensions of dying. Guidelines from the CHPCA (2002) were included in this synthesis. The CHPCA identify 8 domains of issues for patients and their family receiving palliative care: disease management, physical, psychological, social, spiritual, practical, death management, and loss and grief (2002). While all the domains of issues are relevant to palliative care in the home, it is the practical domain of issues involved in the activities of daily care such as bathing, feeding, toileting, cooking, cleaning, etc., that may require significant negotiations around (CHPCA, 2002). Changes to these activities may shift meanings of home because these activities are part of the everyday routines of the home.

In Ontario, when care recipients are no longer responsive to curative treatments and actively dying, they are categorized as code 95 by the Community Care Access Centres (CCAC) and become eligible for palliative care (Seow, King, & Vaitonis, 2008). Code 95 is a client categorization code used by the CCAC that signifies the client as palliative. Although dying trajectories vary among patients and diseases, research has been conducted to examine the trajectory of dying for cancer patients (Costantini, Beccaro, & Higginson, 2008; Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; Teno, Weitzen, Fennell, & Mor, 2001). Several studies indicated that a sharp functional decline for cancer patients occurs in the last 2–4 months of life (Costantini et al., 2008; Lunney et al., 2003; Teno et al., 2001). Functional deterioration is defined as the point in which patients require assistance to perform activities of daily living, such as dressing, walking, and eating (Costantini, et al., 2008; Lunney et al., 2003). Thus palliative care begins as early as diagnosis, but family caregivers and home care providers may be much more involved and depended upon for care in the last 2–4 months of life, when there is significant decline. In terms of negotiating care, this means that there may be abrupt or gradual shifts in needs and demands during the trajectory of illness, and thus, negotiation is required on a continuous basis.

Home Care and Palliative Care

The push for care into the homes and out of institutions has historically been attributed to the health care “reforms” experienced in the 1990s (Randall & Williams, 2006; Williams, 1996; Williams, 2006). The motivation to shift care into the home has been characterized by fiscal
constraints, cost-efficiency, decline in the economy, and cost-saving attempts (Williams, 1996). Home care is one of the fastest growing components of the health care system (Romanow, 2002). This growth has been attributed to the changes in demographic and life expectancy rates of Canadians, and has resulted in an “aging in place” health services delivery policy (Abelson, Gold, Woodward, O’Connor, & Hutchison, 2004; Lilly et al., 2010; Masucci, Guerriere, Cheng, & Coyte, 2010). Due to these changes, there has been a need for greater intensity and range of services outside of hospitals, including home-based professional services such as nursing, physiotherapy, occupational therapy, personal care assistance, and home making (Abelson et al., 2004). In Ontario, home care is contracted out to a mix of for-profit and non-profit agencies based on a system of managed competition (Abelson et al., 2004; Randall & Williams, 2006). Home care delivery, under managed competition, has been criticized, and there is research evidence of poor continuity of care, no change in efficiency, human resource constraints, decreased access, and increased reliance on unpaid family caregivers (Abelson et al., 2004; Armstrong-Stassen & Cameron, 2005; Lilly et al., 2010; Randall & Williams, 2006; Williams, 2006; Woodward, Abelson, Tedford, & Hutchison, 2004).

In 1996, the Ontario Ministry of Health and Long Term Care developed an organization to coordinate home care services: CCACs. Currently, there are 14 regionally-based CCACs in Ontario whose mandate is to assess service needs, make referrals to services, and purchase home care services (Abelson et al., 2004; CCAC, n.d.; Randall & Williams, 2006). In 2006, the Ontario government enacted the Local Health System Integration Act, which established 14 Local Health Integration Networks (LHINs) across the province. The mandate of the LHINs is to integrate and fund local health services such as hospitals, CCACs, long-term care facilities, community health, and mental health services. Both the LHINs and CCACs are integral to palliative care delivery in the community.

Both fiscal restraints and the “aging in place” strategy have contributed to the trend towards home-based palliative care (Guerriere et al., 2010; Masucci et al., 2010). In Canada approximately 230,000 people die annually (Statistics Canada, 2008a). Only 5% of dying Canadians receives integrated interdisciplinary palliative care (Chochinov, 2001; Standing Senate Committee, 2000). In the Romanow Commission (2002) examining the future direction of health care in Canada, the lack of national policy on palliative care and home care was highlighted. Currently, there remains a lack of national policy on funding and standards for
palliative care delivery. In 2005 however, the Ontario Ministry of Health and Long-Term Care announced funding for the Ontario End-of-Life Care Strategy for a period of three years (Dudgeon et al., 2007; Seow et al., 2008). The main objectives of the Strategy were to 1) shift care of dying from acute settings to settings of individual preference, i.e. home, 2) enhance client-centred and interdisciplinary service delivery in the community, and 3) improve access, coordination, and consistency of services and supports (Seow et al., 2008). End-of-life care networks were developed to support and implement strategic priorities and service delivery models to integrate and improve palliative care service delivery (Dudgeon et al., 2007; Seow et al., 2008). Since the funding for the Strategy ended in the fiscal year 2007-2008, it still remained to be reported whether the initiative accomplished its objectives.

**The Chinese in Canada**

**Demographics**

In the 2006 census, there were over 5 million visible minorities living in Canada, and just over 1.2 million identified themselves as Chinese (Statistics Canada, 2008b). There were over one hundred thousand (129,740) Chinese Canadians over the age of 65 living in Canada (2008c). As this population continues to diversify, grow, and age, sensitive topics such as palliation and end-of-life care are becoming especially important to research among this population. In their population projections, Statistics Canada (2005) estimates that by 2017, the total visible minority population will increase to between 6.3-8.5 million. Approximately 3.2-4.4 million of these visible minorities will be South Asian or Chinese. This indicates that immigration of Chinese to Canada will only continue to increase in the years to come. Like many other immigrants that settle in Canada, Chinese immigrants also tend to settle in major metropolitan cities, including Toronto, Vancouver, Calgary, Edmonton, and Montreal (Li, 1998). In the Greater Toronto Area alone, there were approximately 2.1 million visible minorities and almost a quarter of that population were Chinese at 486, 330 (Statistics Canada, 2008c). Over fifty thousand (52,675) Chinese persons living in the Toronto area were over 65 years of age (Statistics Canada, 2008d). The risk of developing cancer increases with age (Canadian Cancer Society, 2011), thus it is important to examine the palliative care needs of this rapidly growing and diverse population.
The Chinese Diaspora in Canada: Historical Waves of Chinese Immigration

It is crucial to recognize the differences between Chinese Canadians’ experiences of migration and the historical, political climate toward Chinese immigrants because it demonstrates how differences in timing of arrival to the country could greatly contribute to what it means to live in Canada as a visible minority. The Chinese are a heterogeneous group. As a country, China is a very ethnically diverse nation with a population of over 1.2 billion (Can, 2004). There are 56 different ethnic groups officially recognized by the government and over 100 different dialects spoken (Can, 2004). Differences within the Chinese Canadian population have been influenced by changing immigration legislation related to changes in the political climate and acceptance of Chinese immigrants. The first large-scale migration of Chinese to Canada began in 1858 (Li, 1998; Liu & Norcliffe, 1996). Many of these Chinese immigrants had migrated to California in search of gold, but moved to the Fraser Valley in British Columbia upon hearing of gold being discovered there (Chui, Tran, & Flanders, 2005; Guo & Devoretz, 2007; Li, 1998; Liu & Norcliffe, 1996).

The second wave of Chinese immigrants came between 1876 and 1885 to construct the Canadian Pacific Railway (CPR) (Li, 1998; Liu & Norcliffe, 1996). Both the first and second waves of Chinese immigrants were predominantly young, poor men from the southern agricultural and coastal provinces of Guangdong and Fujian in Mainland China, who spoke mainly Taishan (Li, 1998; Liu & Norcliffe, 1996). Once the CPR was completed, Chinese immigrants were no longer welcomed in the country. Chinese immigrants were perceived as competitors for jobs that belonged to White people (Li, 1998).

Between 1885 and 1923, the Canadian government enacted several laws restricting the social and political rights of the Chinese in Canada (Guo & Devoretz, 2007; Li, 1998; Liu & Norcliffe, 1996). To control immigration, a $50 head tax was imposed on all incoming Chinese immigrants in 1885, which was subsequently raised to $100 in 1900 and $500 in 1903 (Guo & Devoretz, 2007; Li, 1998; Liu & Norcliffe, 1996). By 1923, the Chinese Immigration Act, or more commonly known as the Chinese Exclusion Act, prevented any further Chinese from entering Canada (Liu & Norcliffe, 1996). As a result, the Chinese Canadian population shrank from 46,519 in 1931 to 34,627 in 1941 (Liu & Norcliffe, 1996). The Chinese Immigration Act was repealed in 1947, but Chinese immigration continued to be restricted (Li, 1998).
The third major wave of Chinese immigrants did not occur until 1967 when Canada’s restrictive immigration policies were changed and a point-immigration system was introduced (Guo & DeVoretz, 2007; Li, 1998). Many of the immigrants who arrived after 1967 were from urban areas of Hong Kong and Taiwan, were generally well-educated, and spoke Cantonese or Taiwanese (Guo & DeVoretz, 2007). Many migrated from Hong Kong due to concerns about communist rule once the colony returned to the control of Mainland China (Chui et al., 2005). Between 1991 and 2001, almost 200,000 Chinese from Mainland China migrated to Canada, and many of them spoke Mandarin. The Chinese diaspora was significant as over 30 million ethnic Chinese lived outside of Mainland China and resided in other parts of Asia, such as Vietnam, Cambodia, Laos, and Philippines (Li, 1998). In the 1980s, a large number of ethnic Chinese refugees arrived in Canada from Vietnam, Cambodia, and Laos; thus, the Chinese diaspora came to Canada through diverse routes (Chui et al., 2005)

History of Discrimination: Institutional Racism

The early history of Chinese migration to Canada saw Chinese immigrants treated as second class citizens who did not have the same rights and freedoms as European-descended Canadians. Between 1884 and 1967, both the British Columbia and Canadian government passed legislation and created policies that greatly restricted the social and political rights of Chinese immigrants (Li, 1998). The *Chinese Immigration Act, 1923* is an extreme case of institutional racism. Institutional racism is the process whereby discrimination is both systematically and legally sanctioned based on “race” as a means of disqualifying certain members of society from equal participation (Li, 1998; Murji, 2007). Although these discriminatory laws and policies have been abolished, there remain many Chinese Canadian immigrants who still can recall times when the Chinese were not as welcomed to the country. The historical ramifications of Canada’s contentious history with Chinese immigrants should not be discounted in the present-day relationships that Chinese immigrants may have with home care providers. Chinese immigrants may see home care providers as representatives of a government that had enacted laws that discriminated against Chinese immigrants, and as such may feel discomfort in having them in their homes. Past experiences of marginalization may structure health care decision-making and influence how negotiations take place between Chinese immigrants, their family caregivers, and home care providers.
Chinese Worldviews on Death and Dying

Research on issues in palliative care of Chinese populations often includes background discussion on Chinese beliefs on death and dying. Chinese beliefs are often presented in the literature as heavily influenced by Buddhist, Confucist, and Taoist religion as well as local superstition and folklore (Braun & Nichols, 1997; Chow & Chan, 2006; Chan, Tse, & Chan, 2006; Martinson, Chao, & Chung, 2002; Neuberger, 2004; Yick & Gupta, 2002). Here I provide a postcolonial analysis of these representations of Chinese beliefs on death and dying, especially taboos about death and the concept of filial piety.

Postcolonial theory cautions the reader to be critical of how cultural beliefs are represented. It is important to understand that my descriptions here are not prescriptive of how we should understand Chinese people’s behaviours when confronting death, but that these beliefs may change with experiences, especially with migration. It is important to avoid using such literature to stereotype groups. Thus, I was careful to focus on how Chinese immigrants experience palliative home care, not only because they make up a large proportion of immigrants in Canada, but because there is so much written about Chinese health beliefs on death and dying. I was conscious that it may be difficult for home care providers to avoid the stereotypes associated with Chinese care recipients. Because there is ample literature on Chinese health beliefs, it may re-enforce the presumption amongst home care providers that they already know enough about this population’s health beliefs and practices. But in fact, literature on Chinese health beliefs may actually perpetuate stereotypes of Chinese immigrants. Thus I recognized the importance of remaining cognizant of the history of Chinese immigration to Canada, critical of the way Chinese immigrant beliefs are portrayed in health literature, and aware of and open to how migration can change beliefs. While it was not my intention to exoticize or maintain marginality in describing Chinese beliefs, it was useful to understand and know the literature that has been written from an “outsider” point of view to understand the dominant discourses describing Chinese beliefs on death and dying.

Death as a taboo topic

Many articles and studies examining Chinese attitudes toward death and dying generally describe taboos about openly discussing or mentioning death in conversation (Braun & Nichols, 1997; Woo, 1999; Mjelde-Mossey & Chan, 2007; Payne et al., 2005; Wong & Chan, 2007; Yick & Gupta, 2002). In a qualitative study conducted by Yick and Gupta (2002), focus groups were
conducted with Chinese immigrants in New York to learn about their attitudes and practices around death, dying, and bereavement. Participants indicated that death was a taboo topic and that when death was spoken about, it was usually in an indirect way, mainly through the use of euphemisms (Yick & Gupta, 2002). Mjelde-Mossey and Chan (2007) found in their telephone survey of Hong Kong Chinese on their attitudes and beliefs around death, dying, and end-of-life care that participants thought that talking about death to a dying person would hasten death. A study by Tse, Chong, and Fok (2003) examined Chinese perspectives of breaking bad news, specifically a prognosis of death. The authors differentiate the West’s emphasis on truth-telling as stemming from an ethic of autonomy while a Chinese perspective would emphasize the concept of non-maleficence. According to the authors, the principle of non-maleficence would argue that more harm is done in disclosing a terminal diagnosis because it may cause psychosocial and spiritual distress (Tse et al., 2003). In the latter two studies, the researchers concluded that speaking about death or disclosing a poor prognosis to a dying patient was harmful in the Chinese perspective because death is a taboo topic.

Filial Piety

The concept of filial piety, or honouring family, forms a common theme across articles and studies examining palliative care among the Chinese population (Kagawa-Singer & Blackhall, 2001). Filial piety implies deep loyalty, respect, and devotion of children to their parents (Ng, Phillips, & Lee, 2002). In their studies examining death and dying, both Braun and Nichols (1997) and Yick and Gupta (2002) found that respondents often associated Chinese cultural values with filial piety, importance of the family unit, and emphasis on hierarchical relations. Filial piety emphasizes the collectivist orientation to family as opposed to the individualist approach that is associated with North American (or Western) familial responsibilities.

In a phenomenological study by Wong and Chan (2007), the researchers examined the experiences of family members caring for terminally ill patients in a palliative care unit in Hong Kong. One key finding was the commitment to care family caregivers expressed. The researchers discussed how the prominence in the theme of commitment to care may be due in part to the value of filial piety, but most family members responded that caring was both natural and what a responsible person would do (Wong & Chan, 2007). A postcolonial stance challenges the
stereotype that Chinese families are committed to care only because of a sense of duty, and that there may be multiple and complex reasons why family members take on care responsibilities.

Although these concepts, death as taboo and filial piety, appear frequently in research findings and/or discussions about the death and dying experiences of Chinese people, it should not be taken for granted that these beliefs are held by all Chinese care recipients. It was important to take a critical view of how these concepts came through in the data, especially acknowledging the influence of migration and the context in which palliative care is delivered.

Conclusion

The history of migration of Chinese to Canada serves to provide the context of the experience of immigration and how it may shape negotiation of care in the home. The prevalent literature examining Chinese beliefs on death and dying do not take into consideration the experience of migration and how that may change health behaviour. And so health professionals are cautioned to use research findings that examine beliefs on death and dying in a way that does not generalize across ethnocultural populations. The complexities involved in delivery of palliative care in the home is important to understand because it highlights the challenges Chinese immigrant families may face when negotiating and organizing palliative home care.
CHAPTER 3
THEORETICAL FRAMEWORK AND KEY CONCEPTS

Introduction

My theoretical framework has played a central role in my research study from conceptualization, data collection, to data analysis. In this chapter, I will examine postcolonial theory and key concepts relevant to the research study, including Othering, culture, race, ethnicity, hybridity, nationalism, and belonging, and how these concepts provided a theoretical lens from which to examine palliative home care issues for Chinese immigrants, family caregivers, and home care providers. A postcolonial lens directs attention to the complexity and diversity of immigrant identities and experiences. In health care research, it is often assumed that studying Chinese immigrants means studying Chinese culture (Kao, Hsu, & Clark, 2004). Invariably, when examining Chinese immigrants and palliative care, cultural beliefs on death and dying are often sought or questioned; and as such, “culture” becomes a central concept. The focus on culture draws attention away from the multiple positionings, places, and knowledges that enter into palliative home care for Chinese immigrant care recipients. The process of migration may impact cultural beliefs and practices.

Theory helps to orient the researcher in the field to observe for particular activities, and to identify patterns within the data (Hammersley & Atkinson, 2007). Working from a postcolonial lens meant that data collection and analysis also took a critical perspective on negotiations of care that recognized the material and social circumstances of immigrant participants, and how it intersected with gender, class, race, and other social positions. I worked reflexively with theory and recognized my own positioning within the research process. Working reflexively required me to look at ways to become better aware of the assumptions I held, the locations I occupied, and the emotional responses I had that may have influenced my perceptions of the field (Hsiung, 2008). As a Chinese immigrant myself, I may share similar experiences with immigrant participants such as experiences of exclusion and finding belonging within a new community. These shared experiences provided me with background understanding of immigrant experiences. Working reflexively also means seeking awareness of assumptions and how these may facilitate or constrain analysis of data (Hsiung, 2008). I recognized that I was variously positioned in relation to my participants, in that I am a Chinese immigrant, I have aging parents,
I am a daughter, and I am a nurse. Some of these positions offered insight into what participants were trying to tell me, but may have also denied me access to experiences as well. I was careful to observe and listen to participants so that I was attuned to their particular ways of knowing, which may be different from my own, despite sharing relevant experiences.

Reflexivity was crucial to this research study because of the sensitive nature of examining the palliative home care experiences of Chinese immigrants, family caregivers, and home care providers. Chinese immigrant care recipients’ accounts of dealing with advanced cancer were layered and situational. Working reflexively was integral to unpacking these layers and understanding how each denoted a particular sense of home.

**Postcolonial Theory**

**Postcolonialism, Othering, and Dying at Home**

Postcolonialism is a critical theory that examines everyday experiences of marginalization based in political, structural, and historical developments of power originating from colonialism (Prasad, 2005; Reimer Kirkham & Anderson, 2002). Critical theory is focused on the interconnections between gender, class, race, location, and ideology (Holmes, Roy, & Perron, 2008). Thus, postcolonial theory is concerned with the effects of colonization, specifically critiquing the West’s relationship to the Other (defined below), either in former colonies or within its own geographical boundaries (Ashcroft, Griffiths, & Tiffin, 2006; Prasad, 2005). A postcolonial stance privileges a material-realist ontology that emphasizes how gender, class, race, and other social locations constitute circumstances that can shape real world experiences (Denzin & Lincoln, 2005). At the epistemological level, the theory aims to deliberately de-center or de-privilege the dominant culture so that the starting point for knowledge development becomes the voices, perspectives, and experiences of those that have been historically marginalized and silenced – subjugated knowledge (Anderson, Reimer Kirkham, Browne, & Lynam, 2007; Racine, 2003; Spivak, 1988). Bhabha (1994/2004) contends that postcolonial critique comes from the Third World or “minorities” that seek to dispel the division between East and West, North and South. These critiques bring attention to the differential and often disadvantaged experiences of nations, races, communities, and peoples who have been marginalized (Bhabha, 1994/2004). Therefore it is important to recognize the
continuing effects of these inequities on social experiences such as migration, uncertain and underemployment as well as unemployment, education, and health care.

The process of Othering is a central concept in postcolonialism. The Other has historically referred to non-European peoples that are positioned on the margins of society. Differences in positioning, such as gender, class, and race, are used as the basis for categorizing individuals as belonging or not belonging to a dominant group (Canales, 2000; Lynam & Cowley, 2007). Othering and marginalization are closely related concepts. Othering is a process of exclusion that stereotypes and stigmatizes individuals whereas marginalization is a sense of being overlooked, categorized, or misrepresented (Lynam & Cowley, 2007). The process of Othering can contribute significantly to the quality and extent of social participation for groups or individuals (Lynam & Cowley, 2007). As discussed in the previous chapter, Chinese immigrants were made marginal through legislation (i.e. Chinese Exclusion Act) that reinforced their position in Canadian society as second-class citizens or the Other. These historical experiences may linger in discourses about immigration and continue to influence Chinese immigrant perceptions of their legitimacy as equal citizens. The perception of inequality stemming from past experiences of marginalization may contribute to how Chinese immigrants with advanced cancer and their family caregivers are able to negotiate care.

While Othering refers to the systemic marginalization of groups of people, the concept of Othering may be applied to processes within the home as well. Chinese immigrants receiving palliative care may become marginalized within their own homes because they may no longer belong to the dominant household group - those that are actively living. Although most cancer patients prefer a collaborative approach to decision-making (Hubbard, Kidd, & Donaghy, 2008), often they may be silenced from making care decisions. This process of separating the dying from the living in the home may result in dying family members being gradually excluded from the normal routines of daily life (Exley & Allen, 2007). Finally home care providers enter the home as strangers or outsiders. Their position, relative to care recipients and family members, may be reinforced by professional knowledge, but lacks an insider’s perspective on the household, thus, their knowledge of the care recipient may be deemed marginal to those that live in the home. The concept of Othering brought attention to the need to be observant of how each participant was marginally positioned as the Other and how it shaped abilities to negotiate care.
Key Concepts: Hegemony, Race, and Ethnicity - Legitimizing Knowledge and Home Death

Hegemony often refers to the privileging of knowledge or the social dominance of one group over another, and can be in the form of cultural, ideological, and economic influences (Williams, 1983). Hegemony is power achieved “not by force or coercion alone, but also by creating subjects who ‘willingly’ submit to being ruled” (Loomba, 2005, p. 30). In Orientalism, Said (1979/2003) comments that binary divisions, enforced through discourse (media, images, and literature), between East and West, Occident and Orient, insider and outsider, creates categories of people. These categories are juxtaposed as favourable and unfavourable stereotypes that reinforce Western dominance. Thus hegemonic structures are kept in place based on the notion that legitimate knowledge can only come from Western economy, technology, ideology, and science.

Postcolonial theorists question the hegemony of Western ideology, including science, biomedicine, and the research enterprise (Tuhiwai Smith, 1999). They further question how these ideologies become dominant, and their impact on the everyday lives of marginalized groups (Xie, 1997). I realized that it was not always scientific or biomedical knowledge that would prevail in negotiations of care between Chinese immigrant care recipients, family caregivers, and home care providers. It was important to be aware of the situated realities of participants, the knowledges they possess, and how they use this knowledge to negotiate palliative care at home. For instance in the case of sharing a poor prognosis, most Western health providers would advocate for telling the patient the truth about their diagnosis based on an ethic of autonomy (Tse et al., 2003). On a pragmatic level, it may be easier for health care providers to care for a care recipient who understood his or her terminal diagnosis. In some cases Chinese families may keep the prognosis from the care recipient because they do not want their family member to be upset or lose hope (Tse et al., 2003). Consequently the beliefs of the family may prevail over Western biomedical ethics.

The hegemony of biomedicine, in particular its messages about home as the ideal place for dying, and the economic incentives for shifting health care delivery to the home have contributed to the recent resurgence in home as the site for palliative care. Postcolonial theory points out the need to understand how dying at home has become legitimized, gradually taken up by the health care system, and how it comes to shape Chinese immigrants’ experiences of dying at home. Home care providers may be well-intentioned in trying to help families maintain dying
patients at home, but they may also be unduly influenced by idealized understandings of home death. Home care providers may miss cues that families are not able to provide palliative care at home, and may have few alternatives to offer in any case. By adopting a postcolonial lens, I was sensitized to the generalizing effect of claims that the home is the best place to die, regardless of ethnocultural beliefs, individual care needs, contextual circumstances, or personal preferences.

The work of legitimizing subjugated knowledges involves being critical of how knowledge of the Other is represented, worked over through a Western lens, and then disseminated back to those it purports to describe. The concepts of race and ethnicity are seen as constructions that are active within marginalizing relations. Postcolonial theorists have argued that the use of race as a set of biological markers, such as skin colour, as the defining feature for cultural difference has historically been accepted without consideration of its social constructedness (Li, 1999; Loomba, 2005; Mohammed, 2006; Racine, 2003; Reimer Kirkham & Anderson, 2002). Cornell and Hartman (2007) acknowledge that race as a social category has exerted considerable influence through government policy and social interactions. Ethnicity, on the other hand, has become the preferred term to refer to groups. Spence (2006) distinguishes between race and ethnicity by explaining that “ethnicity [is] ‘socially defined but on the basis of cultural criteria’ whereas race is ‘socially defined but on the basis of physical criteria’” (p. 46).

I do not conceptualize science and biomedicine as solely oppressive institutions since research is often motivated to improve humanity. But in the absence of critical and conscientious thought regarding the conceptualization of race and ethnicity, the relevance to ethnocultural groups may be immaterial. For instance, the literature often states that the Chinese culture is family-oriented and so palliative care decisions are made as a family unit (Thomas, Wilson, Justice, Birch, & Sheps, 2008). Some health care providers may take this knowledge as rules for behaviour of cultural groups without accounting for individual experiences and preferences. A postcolonial framework encourages researchers studying immigrant experiences of palliative care to be critical of how race and ethnicity are conceptualized to avoid stereotyping groups, and to better understand individual needs and contexts of care.

**Belonging: Negotiating Care in the Home**

Dying at home is highly connected with the meaning of death and dying. What does it mean to die away from home? Home may mean more than a physical shelter; it may refer to a place in which one feels “at home” or a sense of belonging (Dyck & Dossa, 2007; Hayes, 2007).
For immigrants, there may be disagreement in the meaning of dying “at home” if there is no sense of belonging in their current surroundings. Postcolonial theory is concerned with ideas of nationalism and how these ideas contribute to a sense of belonging (Cornell & Hartman, 2007). Cornell and Hartman (2007) explain that a group’s claim to nationalism is generally based on a shared cultural heritage that sets them apart from others. These attributes include shared understandings, practices, language, history, and blood ties. While these attributes are seen as factors that constitute a nation, the solidarity of nations and claims to nationhood have been questioned within the context of globalization and migration (Anderson & Taylor, 2005). Globalization and migration blur the boundaries of nations, and challenge immigrants’ efforts to create a sense of belonging.

According to Anderson and Taylor (2005) discussions of nationhood, citizenship, belonging, and group membership have historically been embedded in national and international policy discourse, but these higher-level concepts have relevance in the everyday as they can “also be played out in the local spaces of lived experience” (p. 462). To be recognized as a citizen should mean that one belongs, has membership, and a voice (Anderson & Taylor, 2005). Within the context of palliative home care for Chinese immigrants, the macro-politics of nationalism and citizenship may have consequences for immigrants’ sense of belonging within their own homes and communities. Belonging may affect the extent of engagement in negotiation with providers over the particulars of palliative home care delivery.

Hybridity: Complicated Entanglements

My own interpretation of hybridity recognizes that immigrants’ individual and cultural identities are in flux depending on contexts and circumstances. The immigrant may draw on previous beliefs or adopt new beliefs as necessary to generate a blended understanding that draws on various sources of knowledge and experience. Hybridity is seen as a way to challenge essentialism and to think beyond stereotypes. Bhabha (1994/2004) writes that migrants negotiate their identity in-between the old and the new spaces. This in-between space is what he calls the Third Space where newness emerges (Bhabha, 1994/2004). This newness represents the hybrid of culture that emerges when the migrant’s cultural beliefs (old space) intermingle with the beliefs of the society they are now trying to integrate with (new space). Hybridity is a key theoretical concept in postcolonialism that represents ethnic and cultural identity as fluid and dynamic (Spence, 2006).
Adopting a lens of hybridity facilitated examination of Chinese immigrants’ beliefs on palliation, helped avoid stereotyping, and focused my analysis on individual preferences for care. The concept of hybridity offered a nuanced approach to exploring the multiple ways Chinese immigrant care recipients, family caregivers, and home care providers were positioned and how these positions intermingled with each other. When negotiating care, participants drew on a mixture of beliefs and experiences that resulted in personalized approaches to palliative home care.

While the concept of hybridity has been adopted by many postcolonial scholars, there are criticisms about the concept as well. Spence (2006) highlights some of the major critiques: 1) hybridity presupposes the existence of pure races; 2) hybridity is often romanticized in its discussions of migrants living in liminality or “in-between”; and 3) hybridity does not adequately address the social and political contexts that influence individual and group actions (Spence, 2006, p. 194). Spence (2006) warns against being carried away by the “anti-essentialist euphoria” associated with hybridity, but to recognize the “real-life experiences of living ‘between culture’, not as a romanticized concept but as a challenging and at times painful negotiation between attitudes and values that are resistant to merging” (p. 194). What is pointed out here in Spence’s comment is that immigrant efforts to straddle multiple cultures and grapple with cultural differences are difficult and complex.

Ang (2003) also addresses these critiques by advocating for the use of hybridity as an analytic tool:

Hybridity is not the solution, but alerts us to the difficulty of living with differences, their ultimately irreducible resistance to complete dissolution…

Hybridity is a heuristic device for analyzing complicated entanglement. (Ang, 2003, p. 150)

I believe Ang (2003) uses the term “heuristic” because hybridity offers a nuanced lens with which to explore how differences play out in daily lives of immigrants. As an analytic tool, hybridity encouraged me to learn from participants and be flexible in understanding the meanings embedded within their daily activities and interactions. It shed light on how living with differences can shape circumstances that, in turn, complicate negotiations of palliative home care. And so the concept of hybridity was not used to explain away differences between Chinese immigrant care recipients, family caregivers, and home care providers; instead the concept of
hybridity provided a way to better understand both the situational, contextual, and material circumstances that informed negotiations. Chinese immigrant care recipients, family caregivers, and home care providers all worked with hybridized perspectives, which drew on old and new beliefs (Chinese and Canadian beliefs), contextual knowledge, and past experiences (i.e. other experiences of death). Home care providers also drew on a professional culture. Thus the concept of hybridity facilitated my analysis of participants’ embodiment of multiple cultures and their subsequent efforts to negotiate palliative home care. Revealed was the entanglement of care practices and relationships within the home.

**Postcolonialism in Health Care**

Postcolonial scholars in health care critically examine culture and health care, and how Western ideology continues to marginalize ethnic groups’ access to health care (Anderson, 2000b; Reimer Kirkham, 2002; Mohammed, 2006; Racine, 2003). Scholars such as Anderson (2000a, 2000b, 2002, 2004), Reimer Kirkham (2002), Lyman (2005), Mohammed (2006), and Racine (2003) have argued the relevance of working with a postcolonial lens, specifically a postcolonial feminist lens, to expose the exclusionary and marginalizing effects of health care. Anderson et al. (2003) state that postcolonial theory challenges health providers to look beyond exotic belief systems associated with ethnocultural groups and to begin treating each individual as a distinct entity. Anderson et al. (2007) contend that cultural categories used in health care are not neutral descriptions of a culture. Cultural categories in health care tend to normalize Western biomedical beliefs and problematize health beliefs and practices that are “different”. However, differences among care recipients, family caregivers, and home care providers’ perspectives on death and dying may better account for challenges and opportunities in the process of negotiating palliative home care. Postcolonial theory provides a starting point from which to observe negotiations of care, one that does not problematize the beliefs and practices around death and dying based on so-called cultural difference.

**On Language – Colonization as a Metaphor**

In my findings, I chose to draw on the concept of colonization to describe how the home of a Chinese immigrant family becomes a place for dying after a family member is diagnosed with terminal cancer and given the option to die at home. The concept of colonization is closely linked with postcolonial theory, and it increasingly and iteratively aligned with my observations.
of palliative home care. But I also use the concept with caution. I recognize there are implications in using such a term to describe how the institution that is palliative home care may come to supplant home as a place for living. Colonization is associated with imperialism and imperialist endeavours, thus it elicits negative and traumatic images of historical processes of invasion and domination of countries and citizens (Loomba, 2005; Tuhiwai Smith, 1999). Often colonization included, in the name of empire-building, violent tactics such as “trade, plunder, negotiation, warfare, genocide, enslavement, and rebellions” to gain control over a people’s land and resources (Loomba, 2005, p. 8). It would seem harsh then to speak about palliative home care providers in a similar light, and I acknowledge this. Although I am aware of the violent and traumatic histories of colonization, I also recognize it as a concept that can simply encompass descriptions of how something (people, plants, animals, bacteria, organisms) comes to settle and establish itself somewhere else (Merriam-Webster, n.d.).

In Frank’s (1995) book, The Wounded Storyteller: Body, Illness, and Ethics, he described how his sick body became colonized by medicine through the processes of surgical and pharmacological treatment. Similarly, I use the term colonization as an analogy and metaphor to describe how a care recipient’s home becomes overtaken by the logics of palliative care. One of the main distinctions between using the term colonization as related to empire-building and as a metaphor for settlement is that there is a clear indication that care recipients, families, and home care providers have a mutual desire and need for each other. Neither can function without the other. Without the dying patient, the providers would not have anyone to administer palliative care. At the same time, care recipients and families express a desire and need for knowledge and guidance from providers about dying at home. This mutual need is a way to mitigate the anxiety and uncertainty of dying at home.

In that sense, colonization is mutual and happens at several levels. First, the care recipient’s body is literally invaded by cancerous cells. Malignant, foreign cells come to displace what was once normal, healthy tissue. As cancer changes a healthy person to a sick patient, the person is diagnosed or labeled; however, this facilitates access to a system set up to treat and help people with cancer. Frank (1995) describes how the sick person (in being labeled a ‘patient’) becomes vulnerable to medical colonization. The body becomes colonized by cancer, which manifests itself as pain, the need for medications, use of assistive devices, a change in
function, and in biographical accounts that tell the story of how the body has changed with diagnosis.

Once the person’s cancer is deemed terminal, he or she may be referred to a sub-system within the larger system of cancer care: the palliative home care system. This sets off a process in which the care recipient and family become drawn into and colonized by palliative home care. As professional providers establish their presence through home visits to care recipients’ homes, incremental colonization of the home occurs. Providers do not enter homes with an intention to colonize the home as a place for dying. Providers may not regard their home visits as a form of colonization because they themselves are also deeply and assumptively embedded within the system. I recognize that providers have good intentions; they are concerned with fulfilling their job role, which is to provide palliative and supportive care for dying care recipients and their families. Just as providers may not be aware of their roles in colonization, care recipients and families may also not be aware of the ways in which they are colonized and colonizing as well.

With that being said, I do not want to diminish the magnitude nor impact of colonization as an imperialistic endeavour. Nor do I want to trivialize colonization of Chinese immigrant care recipients’ homes as places for dying. My ethnographic observations and interviews do suggest that palliative home care is a kind of invasion into care recipients’ and families’ everyday lives, and so it represents a form of micro-colonization. As palliative care comes to displace the home as a place for living, it can be a traumatic and difficult experience for care recipients and families. Thus, I am sensitive to the gravity in using such a term to describe what is happening to the home of Chinese immigrant care recipients receiving palliative home care. Through the metaphor of colonization, I hope to show that micro-processes associated with colonization may still be at play, even if goals are not imperialistic and nationalistic in nature.

Since postcolonial theory is a critical theory, I am conscious of the inclination to examine how care recipients and families resist colonization, which in turn indicates an exertion of agency. All participants in the study exerted agency in some way as they dealt with receiving or delivering palliative home care. I use the concept of colonization as a metaphor – and with a view towards the power of the social impact of illness – and so I feel that resistance would not exactly be the right term to use. I do not feel that the care recipients in my study overtly resisted care, but rather they wanted to distance themselves from the constant message that they were going to die. This was in part because the care recipients in my study were stable and their
prognoses were not definitive; for example, one care recipient had been labeled palliative for the past seven years. Although palliative care philosophy would argue that palliative care is about helping patients live, there are very real and constant reminders of terminal illness. Often care recipients questioned why a home care nurse would come visit them if they were only coming to take their blood pressure? I have come to interpret this as a form of colonization. These visits were a way for providers and palliative care to establish presence and availability. Care recipients interpreted these visits as home care nurses monitoring their health for further deterioration, or waiting for them to be actively dying.

Although care recipients and families were not overt in their resistance to palliative care, there was still a passive form of resistance that strategically avoided damage to relationships with palliative care providers. This seemed better described by the term distancing, instead of resistance, because care recipients and families recognized they also needed palliative home care providers to help them navigate the system and negotiate dying at home. I conceptualize distancing, in counterpoint to colonization, to describe how care recipients and families engaged in passive resistance so that they could continue to live out the everyday. In their narratives, care recipients and families wanted providers to know that they continued to live outside of the once or twice weekly home visits.

**Postcolonial Critiques**

A central aspect to adopting a postcolonial lens was its ability to help me articulate my reservations about how culture is conceptualized in health care and health research. My discomforts with the concept of culture, acculturation, assimilation, and multiculturalism were analyzed and made transparent through a postcolonial lens. These postcolonial critiques were relevant because it enabled me to work reflexively and conscientiously with the data.

**The Culture Concept**

Culture is a widely used, but highly contested concept with a long and socially significant history (Agar, 2006; Anthias & Lloyd, 2002; Dorazio-Migliore, Migliore, & Anderson, 2005). Definitions of culture have been used to distinguish particular populations based on race and ethnicity (Ford & Harawa, 2010; Kao et al., 2004; Moscou, 2008). Anthias and Lloyd (2002) stated that the term culture in sociology has been used in three main ways: 1) as a set of cultural attributes, content, or product; 2) as a worldview, process, or mechanism; and
3) as a patterned way of knowing, form, or structure. Leininger (2001) asserted that culture “refers to learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular group that guides their thinking, decisions, and actions in patterned ways” (p. 47). From a postcolonial framework, it may be argued that culturalist conceptualizations of culture, such as Leininger (2001), offer a static and neutral view whereby the transmission of learned patterns from generation to generation is linear, rigid, unproblematic, and devoid of a history.

Agar (2006) argued that the traditional anthropological definition of culture as a closed system of meanings and actions shared by a group of people is insufficient to adequately represent what culture means in ethnographic research. For Agar (2006), culture is both translational and relational because differences only become visible when outsiders come into contact with cultures for which they do not have insider perspectives. Agar (2006) contends that “difference” is an artificial construct used by ethnographers to enable translation between researcher and subject, and to explain their own confrontations with novelty. Agar (2006) points out that it is from the ethnographer’s perspective that culture is defined and studied, and thus, ethnographies reveal as much about the researcher as they do about the subject.

Culture is studied from different paradigmatic positions and will differ in meaning based on the differences in foundational assumptions of each paradigm. In the positivist and post-positivist traditions, culture is seen as a concrete system of rules that exists in a group of people (Kao et al., 2004). In these paradigms, culture is operationalized and quantified to represent some “universal truths” about a group of people, which risks stereotyping (Moscou, 2008). Interpretivists, such as Clifford Geertz, have called for a move away from positivist approaches to the study of culture. To study culture is not an “experimental science in search of law but an interpretive one in search of meaning” (Geertz, 1973/2000, p. 5). The analysis of culture is about interpreting the subjective understandings of the signs and symbols that communicate culture (Geertz, 1973/2000; Roth & Mehta, 2002). Like Agar, Geertz (1973/2000) asserted that “what we call our data are really our own constructions of other people’s constructions of what they and their compatriots are up to” (p. 9).

Postcolonial theory has extended Geertz’s definition of culture by including a critical perspective on the socio-historical context in which culture functions. Postcolonial theory provides a framework to approach the use of research with culture. In using a reflexive definition of culture, my working understanding of culture was fluid and dynamic like culture itself.
Postcolonial theorists argue that health research that focuses on culture may direct analysis away from White-dominant culture, which implicitly positions it as the norm (Reimer Kirkham & Anderson, 2002). My continuing engagement with the work of postcolonial scholars helped me move away from essentializing notions of culture and recognize the social, historical, and political contexts in which the culturally different Other is constructed (Mohammed, 2006).

Acculturation, Assimilation, and Multiculturalism

A multicultural, acculturationist, and assimilationist perspective were not considered as conceptual tools because of the formidable postcolonial critiques leveled against these approaches. From a postcolonial lens, both acculturation and assimilation are critiqued for the insistence that minority groups or immigrants adopt the values and norms of the dominant group. Acculturation results from “overt or system pressures from the dominant group(s) to adopt, conform with, or adjust to majority values, customs, behaviours, and psychological characteristics” (James, 1996, p. 23). Assimilation on the other hand calls for minority groups to relinquish most if not all elements of their cultural values, customs, and behaviours in order to fit in with the dominant group (James, 1996). The definition of culture in acculturation and assimilation models tends to conflate culture with nation (Bhatia & Ram, 2001). It is argued by postcolonial theorists that nations are difficult to define, as boundaries become meaningless with increasing globalization and migration (Bhatia & Ram, 2001). Thus, acculturation and assimilation models were deemed inadequate to critically examine negotiation of care among Chinese immigrant care recipients, family caregivers, and home care providers.

In Canada, the concept of multiculturalism was adopted to represent the more tolerant aspect of Canadian society and to distance from the more assimilationist views of Americans (Li, 1999). Yet multiculturalism is also a contentious perspective. Multiculturalism is a difficult concept to define because of its lack of clarity in government policy, but it generally has to do with a set of principles, policies, and practices that supposedly aim to counteract cultural hegemony and cultural universalism (Li, 1999; Spence, 2006). Arguments have been made that multicultural policies are ineffective tools in opposing racism and unequal practices in the everyday lives of immigrants. Because a multiculturalist stance fails to explicitly confront power differentials and fails to address the inequalities faced by immigrants, it becomes a value-free term that is tolerated in policy (Bannerji, 2000). According to Bannerji (2000), multiculturalism is a term that re-centres issues of social injustice, unemployment, and racism onto the safer
ground of cultural diversity. She argues that this actually obscures the social relations of inequality, exclusion, and discrimination of immigrants (Bannerji, 2000). Some argue that instead of recognizing and tolerating difference, a discourse of multiculturalism actually further segregates ethnic groups and creates divisions based on language, traditions, and religion (Bannerji, 2000; Li, 1999).

**Conclusion**

A postcolonial perspective enabled me to see culture as more than actual differences between care recipient, family caregiver, and home care provider, but instead as constructed within particular historical (immigration policy) and experiential contexts (experiences of migration). The concept of hybridity was an analytic tool that allowed me to tease out the “complicated entanglement” of cultural identities and subjectivities. In reality hybridity is not always unproblematic and a romanticized living “in-between” but that cultural difference is negotiated in sometimes difficult circumstances, and thus, culture is always in flux. Although culture is difficult to define, it was clear that from a postcolonial perspective, its study demands a reflexive approach. Culture has come to mean different things within different paradigms and so I engage with it critically. A postcolonial theoretical lens makes aware the multiple complexities associated with negotiating and organizing palliative home care for Chinese immigrant care recipients, family caregivers, and home care providers.
CHAPTER 4
AN ENCOUNTER WITH THE LITERATURE

Introduction

A review of the literature was conducted to examine the current status of work on meanings of home and negotiations of care within palliative home care settings for Chinese immigrants. Rather than a conventional reporting of the literature, I present here a more reflexive approach to my literature review. I share in this chapter my encounter with the literature and the issues I faced in trying to combine different areas of literature (i.e. home care, negotiations of care, immigrant experiences of palliation, meanings of home, place of death, etc) together to support the rationale for this study. I had struggled with my literature review in part because I was combining multiple areas of the literature that had not been combined together previously. One of the major challenges had been conceptualizing a framework to present the literature that connected these areas together in a coherent and concise story. As discussed in my preface, my initial interest was in preferences for place of death of Chinese immigrants, so I will start with this area of research. However, my explorations of the literature gradually widened to include other areas, such as immigrant experiences of palliative home care, meanings of home for immigrants, and meanings of dying at home. These areas added to the depth of articulating the research purpose and questions.

The review of the literature was an iterative process which meant that the more I read, the more gaps I saw, and the more changes made to my research questions, which also meant further examination of literature. It was a vicious cycle. This initially led me down many possible different paths for my inquiry, but there were three clear points that consistently emerged. The literature indicated that 1) home is a rich and complex place to examine care practices; 2) there is little research describing the actual process of how palliative care takes place in the home, specifically how the care is negotiated; and 3) the meanings of home may have particular significance for immigrants.

The lack of research in examining the actual process of providing palliative care may be due to the complexities of the home as the nexus of social activities and co-constituted, situated meanings. The significance of “home”, both its physical structure and theoretical significance came towards the end of my review of the literature. I came to realize that the home and its
meaning was the central feature (with varying degrees) of all the research I had read on place of death and palliative home care. Magat (1999) astutely states that the home is a “simple, yet powerful idea” (p. 120). I acknowledge that this simplicity meant that I initially overlooked the meaningfulness of home to the experiences of palliative home care.

**Search Strategy**

Searches were conducted in CINAHL, MEDLINE, Scopus and Scholars Portal which includes Social Sciences and Natural Sciences Indexes (i.e. Social Sciences Citation Index, Psycinfo, Sociology, Science Citation, etc). Keywords were grouped into four main categories: 1) Chinese immigrant - Chinese, immigrant, migration; 2) palliative care - palliative care, end-of-life care, terminal illness, cancer, advanced cancer, prognosis, dying trajectory, death, dying; 3) home - meaning of home, place of death, home, home-based, home care; and 4) negotiation - negotiating. Keywords were combined in searches to identify relevant research. No studies were found that combined at least one word from each category. Studies were located that combined at least one word from at most three of the four categories. Titles and abstracts were screened for relevancy. Articles deemed relevant were retrieved. The reference list of articles was then hand-searched for further relevant research papers.

**Literature Review**

Currently there are few studies examining Chinese immigrants’ experiences or perceptions of palliative end-of-life home care (Payne, Chapman, Holloway, Seymour, & Chau, 2005; Seymour, Payne, Chapman, & Holloway, 2007), especially within a Canadian context (Feser & Bernard, 2003), and none specifically examining the meanings of home and negotiations of palliative home care. I reviewed the literature with a postcolonial framework in mind, and thus the literature was read with a critical interpretation.

**Place of Death: Preferences, Experiences, and Caregivers**

**Preference for Place of Death**

First I examined the literature around preferences for place of death. There are a number of studies conducted on preference for place of death and the majority of these studies indicate that patients prefer to die at home. The majority of studies examine preferences for terminal
cancer patients. Many studies examining preference for place of death constructed the home as the ideal place to receive palliative end-of-life care, and many did not question whether this was true for all cancer patients, regardless of types of cancer or ethnocultural beliefs. The presumption that home is the best place to die confuses home as a place of care and a place of death (Agar et al., 2008). There needs to be a clear distinction between understanding preferences for place of care and place of death; this is further discussed the literature review.

Higginson and Sen-Gupta (2000) conducted a systematic literature review on preference for place of death of cancer patients. The researchers identified 18 articles that met their inclusion criteria. The literature indicated that for those studies conducted amongst the general public (n=5), results generally found that between 49%-100% of respondents wanted to be cared for at home during terminal illness (Higginson & Sen-Gupta, 2000). The researchers also reported that in studies that examined patient and caregiver preferences, the majority found that both the patient and caregivers preferred a home death, but preference for home death declined as death came nearer (Higginson & Sen-Gupta, 2000). The reviewers also observed that preference for a home death appeared higher than the actual number of deaths that did occur at home (Higginson & Sen-Gupta, 2000). The reviewers were not explicit in identifying the homogeneity of the sample, or whether there was ethnocultural variation in preferences. The reviewers were unable to construct a comprehensive picture of preference for place of death amongst terminally ill cancer patients because the studies varied greatly in quality and perspective of preferences, for example, patients under existing circumstances, post-bereavement survey of caregivers, or nursing staff assessments.

Several quantitative studies using a prospective study design were located examining preference for place of death. All studies found that majority of participants preferred a home death (Dunlop, Davies, & Hockely, 1989; Fried, van Doorn, O`Leary, Tinetti, & Drickamer, 1999; Hinton, 1994; Townsend et al., 1990; Tiernan, Connor, Kearney, & O’Siorain, 2002). Although most patients indicated a preference to die at home, only a fraction actually did (Karlsen & Addington-Hall, 1998; Tiernan, et al., 2002). Karlsen and Addington-Hall (1998) reported from their post-bereavement study of 229 caregivers that 73% of care recipients had expressed a preference to die at home but only 58% did. Similarly, in their prospective study examining preferred versus actual place of death, Tiernan et al. (2002) found that of their sample of 191 advanced cancer patients, 63.4% (121) preferred to die at home, but only 44% (84) did.
The studies do not provide reasons why patients did not die at home even though they preferred it; therefore, a gap clearly exists in understanding how palliative care can best facilitate and support dying at home. Quantitative studies about preferences generally viewed the participants as a homogenous group and do not account for differences within the group, except mostly for age, diagnosis, and gender. These quantitative studies are generally unable to provide much detail about reasons for preferences, especially any ethnocultural influences on preferences.

Three qualitative studies were located examining preference for place of death (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004; Tang, 2003; Thomas & Clark, 2004). Tang (2003) conducted an exploratory, descriptive study in the US to explore the preferences for place of death among terminally ill cancer patients and to identify the reasons for their preference and the importance of dying there. A similar study by Thomas and Clark (2004) was conducted in the UK to examine preference for place of death of 41 terminally ill cancer patients and 18 informal caregivers. Gott et al. (2004) conducted focus groups and semi-structured interviews with males and females over the age of 55 years living in Sheffield, England. All of these studies found that most patient and their caregivers preferred a home death, but under ideal circumstances. Many care recipients expressed a concern for being a burden on family and requiring intimate care, and this would be the main reason they would want to be transferred to a hospital to die instead (Gott et al., 2004; Tang, 2003; Thomas & Clark, 2004). The qualitative findings indicate that many participants preferred a home death under ideal circumstances, but did not elaborate on how participants defined their ideal circumstances. There is an apparent need to examine the process of how palliative care is provided in the home to help further understand what care recipients and families consider favourable or ideal circumstances. Thus in studying the actual day-to-day process of negotiating and managing care in the home, attention to the interplay between care and context may illuminate optimal circumstances for dying at home.

Experiences of Home as a Place of Death

There is a major gap in the literature in that there are few studies that describe the daily aspects of palliative care or examine how negotiations of care take place in palliative situations. Most studies of North American experiences of place of death resulted in descriptions of the shift from death at home to hospital, and then back again to the home. Within the literature, one of the apparent main goals of palliative care in the past few decades has been to support people in dying at home (Cobbs, 2001; Dudgeon & Kristjanson, 1995; Stajduhar & Davies, 1998).
Stajduhar & Davies (1998) contend that the renewed interest for dying at home is based on three factors: 1) cost-effectiveness of dying at home, 2) end-of-life care in hospitals is dominated by life-prolonging treatments, and 3) dying at home is seen to contribute to overall quality of life for terminally ill patients and their families. Dying at home is seen to facilitate a sense of normalcy, security, and familiarity to patients and their family members (Stajduhar & Davies, 1998).

The experience of home as a place of death was examined by several teams of researchers (Appelin, Broback, & Bertero, 2005; Bray & Goodyear-Smith, 2007; Chan & Chang, 2000; de Graaff & Francke, 2003; Hinton, 1994; Luijkx & Schols, 2011; Peters & Sellick, 2006; Szeto & Cheng, 2006; Wong, Liu, Szeto, Sham, & Chan, 2004), but each varied in their approaches. Two focused on immigrant experiences (Bray & Goodyear-Smith, 2007; de Graaff & Francke, 2003), two teams studied a Chinese population in Hong Kong (Chan & Chang, 2000; Wong et al., 2004), one focused on perceptions of home and hospice of terminally ill patients and caregivers (Luijkx & Schols, 2011), and three examined quality of life of participants receiving palliative home care (Hinton, 1994; Peters & Sellick, 2006; Szeto & Cheng, 2006). Common domains explored by all who conducted quality of life studies were: physiological, emotional, and psychosocial. These researchers concluded that care recipients receiving palliative care at home experienced moderate to high levels of quality of life, especially in areas such as pain management and social support (Hinton, 1994; Peters & Sellick, 2006; Szeto & Cheng, 2006). There was great variability among other studies of palliative home care experiences with regards to focus, perspectives, and quality. Researchers focused on accessibility of palliative home care (de Graaff & Francke, 2003), managing caregiving (Chan & Chang, 2000), common health problems (Wong et al., 2004), and familial experiences (Bray & Goodyear-Smith, 2007). The variability made it difficult to draw any conclusive statements about palliative home care experiences.

In the research study by Chan and Chang (2000), the researchers used a cross-sectional, descriptive survey design to examine the relationship between caregivers’ age and managing caregiving tasks. They found that caregiver’s age was negatively correlated with difficulties in managing caregiving tasks (r = -0.38, p<0.05). They also pointed out that these findings are consistent with other research, and hypothesized that this may be due to the fact that older caregivers (>50 years) may have less role conflict than younger caregivers, such as parent,
employee, student, etc, and so may have more time to devote to caregiving (Chan & Chang, 2000). This pointed to the need to consider age of caregivers during recruitment and sampling.

Bray and Goodyear-Smith (2007) conducted a qualitative case study to explore the experiences of palliative home care for different generations of an immigrant family living in the same home. The family was described as an Indian Muslim family from Africa living in New Zealand for 3 years. Three generations of the family were included in the study: the care recipient (grandfather), his spouse, their son and daughter-in-law, and grandchildren. A key theme that emerged was family and how it influenced palliative care. Interestingly the respondents reported that a sense of filial duty was a prominent reason underlying their commitment to providing care at home for a dying family member. As discussed in a previous chapter, filial piety is often associated with Chinese populations. Bray and Goodyear-Smith (2007) demonstrated that filial piety may be a sentiment that goes beyond ethnocultural beliefs, and therefore it should be examined in the context of negotiations regardless.

Few studies report on terminally ill cancer patients’ perceptions and experiences of palliative home care, but a qualitative study by Luijkx and Schols (2011) interviewed 8 women and 5 men with a life expectancy of less than 3 months to examine their perceptions of home and in-patient hospice as places for dying. Four of the participants were at home and 9 were in an in-patient hospice. The researchers found that care recipients who were married, cohabitating, and whose partners were willing and able to provide the intensive 24 hour care needed at end-of-life were most likely to die at home (Luijkx & Schols, 2011). Regardless of where the participants resided, all expressed a need to “feel at home” with their surroundings (Luijks & Schols, 2011). The dimensions that constituted feeling at home included having control over their daily routines, continuation of important familial and social relationships, and maintaining privacy (Luijks & Schols, 2011). This study offered insights into how terminally ill cancer patients perceive caregiving and the circumstances under which they could feel at home.

Most studies used the perspectives of family caregivers to report on dying patients’ experiences of palliative home care (Chan & Chang, 2000; de Graaff & Francke, 2003). These studies cited ethical and practical limitations to collecting data from dying patients (de Graaff & Francke, 2003). While caregiver perspectives are important, the perspectives of actual dying patients receiving palliative home care are important as well. From a postcolonial lens, excluding the perspective of dying patients positions them as the Other, and subsequently their knowledge
is devalued or subjugated. This aligns with the postcolonial critique that argues the need to build knowledge from those that are experiencing the phenomenon; this perspective cautions against working from representations of these experiences (as in the case of Western representations of the East). Thus I was sensitized to the importance for my study of gaining the perspective of the dying care recipient.

Appelin, Broback, and Bertero (2005) conducted secondary analysis on three phenomenological studies that examined the meaning of palliative home care from the perspective of each group involved in care: care recipients (Appelin & Bertero, 2004), district nurses (Bertero, 2002), and next of kin (Broback & Bertero, 2003). Appelin et al. (2005) combined these three studies to build a comprehensive picture of palliative home care. I discuss here the findings from the secondary analysis of the combined studies. The researchers reported they re-analyzed the data using a hermeneutic approach guided by Gadamerian philosophy to understand the advantages and disadvantages of palliative home care. The researchers separated the findings into two categories: advantages and disadvantages. The advantages included striving for a normal life, safety, and resources/policies. Striving for a normal life was composed of four concepts: care in the home, physical care, mental/emotional care, and emotional experiences (Apellin et al., 2005).

The disadvantages were commitment and demands. Commitment meant that there needed to be adaptation to palliative home care which involved extra work. The elements of commitment were described as a feeling of obligation and engagement. I did not interpret commitment as a disadvantage for participants, but rather the sense of obligation was. Demands were plagued with feelings of frustration and uncertainty because they came from different directions and were both internal and external. For example, district nurses sometimes struggled physically to provide care, but also felt internal frustration when they could not provide the kind of care they wanted to provide. The researchers reported that the sense of uncertainty was related to cancer diagnosis, prognosis, expectations of care, and uncertainty about resources and knowledge (Appelin et al., 2005).

Although the researchers described how a hermeneutic analysis proceeded, it was difficult to evaluate whether their analysis achieved this interpretive goal, because themes seemed to stay close to the original descriptions of participant perspectives. The re-analysis did capture from the perspectives of those most closely involved in care the conflicted nature of
providing palliative home care. These studies also demonstrated the multidimensional experience of palliative home care. Highlighted is the need to focus deeply on a particular area of the palliative home care experience, such as meanings of home and negotiations of care.

Immigrant Perceptions and Experiences of Palliative Home Care

Ethnic variation in preference for place of death was reported in a number of quantitative studies examining place of death in the US (Bruera, Sweeney, Russell, Willey, & Palmer, 2003; Colon & Lykes, 2003; Enguidanos, Yip, & Wilber, 2005; Johnson et al., 2005; Weitzen, Teno, Fennell, & Mor, 2003) and UK (Coupland, Madden, Jack, Moller, & Davies, 2011). These studies generally used White ethnic background as the baseline from which other ethnic groups were compared. Studies conducted in the US indicated that African Americans were more likely to die in acute care settings than European Americans. Only one study was conducted with Asian Americans (Enguidanos et al., 2005). This study indicated that Asian Americans were less likely to die at home than European and Latino Americans (Enguidanos et al., 2005). In a retrospective study of UK cancer registries of South East England (including London, Sussex, Kent, & Surrey), Coupland et al. (2011) reported that Black and Chinese patients were less likely to die at home than White patients. No data on rates of home death among Chinese Canadians were found. I am conscientious and critical of how the findings from these studies may be interpreted, which may inadvertently blame culture for some people’s inability to die at home. Although it may appear that ethnocultural minority groups are less likely to die at home, it does not mean that culture or ethnicity is the cause of the phenomenon; thus, it is important not to attribute causality where at best an association can only be established.

Overall, the above studies did not provide details of immigrant perceptions of palliative home care and place of death. Only a few studies examining immigrant experiences of palliative home care were located in the literature. Two relevant studies were located examining immigrants’ experiences of palliative home care. Owens and Randhawa (2004) examined “culturally competent” palliative care for South Asian people living in the UK. Interviews were conducted with 10 health care professionals in palliative care to explore how these professionals address the difficulties and ambiguities of providing culturally competent care. The researchers found that health care professionals who used models of cultural competency had a heightened awareness of difference that often led to assumptions about South Asian care recipients’ expectations for end-of-life care (Owens & Randhawa, 2004). For example, some health care
professionals felt that family was a very important part of South Asian culture and so, they thought it was important for them to help maintain dying South Asian care recipients in the home.

The researchers indicated that the heightened awareness of difference also meant that health care professionals positioned themselves within an ‘us’ and ‘them’ binary. The health care professionals used this as a way to describe and differentiate themselves from their patients who did not share the same ethnocultural background. Although Owens and Randhawa (2004) did not explicitly use a postcolonial framework for their analysis, the researchers were sensitive to how difference was spoken about by health care professionals. Through a postcolonial lens, the way health care professionals talked about difference could be seen as a form of Othering. This study indicates the potential for home care providers to discursively position themselves in relation to care recipients and families.

As discussed above, the study by Bray and Goodyear-Smith (2007) was a case study conducted with a multi-generational Indian Muslim family in New Zealand experiencing palliative home care. The researchers followed Stake’s method for intrinsic case study. The researchers interviewed members of the household: the care recipient (grandfather), his spouse, their son and daughter-in-law, and grandchildren. Six themes emerged from analysis: family, community, culture and religion, communication, palliative care, and the migration process. The theme of migration is relevant because it showed how migration influenced the family’s experiences of palliative home care. The researchers reported that because the son and daughter-in-law had immigrated three years prior to the care recipient’s migration and illness, they were better socialized in their community. Their early socialization helped because they understood the health care system better and were able to assist the care recipient to access appropriate palliative care services (Bray & Goodyear-Smith, 2007). The researchers briefly discussed generational differences, which may contribute to differences in experiences of migration and role expectation in contributing to caregiving. They did not address gender difference, which could also contribute to experiences of palliative home care. This study points to the complex and multiple roles of those involved in caregiving.

One literature review and one study were located that dealt with Chinese immigrant preferences for place of death. In their literature review, Payne, Chapman, Holloway, and Seymour (2005), examined literature on Chinese cultural perspectives on end-of-life care. They
concluded that Chinese minority populations living in Western countries appear to adopt dominant preferences for provision of end-of-life care such as disclosure of diagnosis and treatment choices. The authors also stated that it appeared that Chinese patients value both Western and traditional Chinese medicine, but find them incompatible (Payne et al., 2005). The writers were conscientious of not perpetuating stereotypes of Chinese people and they began their literature review by stating that they recognized the Chinese as a heterogeneous group. The writers differentiated findings between Chinese peoples living in countries where the Chinese are the dominant culture from Chinese living as minorities in Western countries. This was helpful in understanding that migration may complicate Chinese immigrants’ beliefs on palliative care.

The second was a study of preferences for place of death among White and Chinese elders (Seymour et al., 2007). Focus groups were conducted with White and Chinese elders, separately. The participants consisted of both Chinese born in the UK and Chinese immigrants. There was no information regarding recency of immigration. Overall, Chinese elders expressed a preference for a hospital death, rather than hospice or home (Seymour et al., 2007). In the UK, the term hospice is more commonly used than palliative care, but only a few Chinese elders had heard of hospices and mainly associated it with imminent death. The researchers reported that the Chinese elders felt that hospices were not helpful to dying patients because it would discourage hope for recovery. The hospital was seen as a place where hope could be maintained and a sense of peacefulness (Seymour et al., 2007). These participants expressed a concern for contamination and cleanliness of the home when home became the site for dying. The study was conducted with mainly healthy respondents who were living independently. Thus, the study did not provide insight into how terminally ill Chinese immigrants regard home as a place of death.

**Family Caregivers**

Many studies have identified strong associations of place of death with the following factors: age, gender, availability of caregiver(s), living situations (living with a spouse), expressed preference for home death, registration in a palliative care program, and availability of medical support in the community as being highly associated with a home death (Brazil, Bedard, & Willison, 2002; Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005; Cantwell et al., 2000; Higginson, Jarman, Astin, & Dolan, 1999; Izquierdo-Porrera, Trelis-Navarro, & Gomez-Batiste, 2001; Karlsen & Addington-Hall, 1998; McWhinney, Bass, & Orr, 1995; Weitzen et al., 2003). The research clearly indicated that availability of caregivers and caregiving situations were vital
to delivering palliative home care and achieving a home death. There are a number of studies on the issues for family caregivers and their perspectives on providing palliative home care (Jo, Brazil, Hohfeld, & Willison, 2007; Stajduhar, 2003; Stajduhar, 2005; Tang, Liu, Lai, & McCorkle, 2005; Teno et al., 2004; Visser et al., 2004). Funk et al. (2010) conducted a comprehensive synthesis of qualitative research examining home-based family caregiving at end-of-life. Funk et al. (2010) reported on key findings in the literature highlighting the contextual experiences of caregiving, including decision-making, supports, meaning, and coping. None of these studies explicitly focused on the ways caregivers negotiated care in the home to meet the care recipient and/or their own care needs.

Visser et al. (2004) conducted a retrospective survey of family caregivers and found that family caregivers provide mainly three types of care: personal (e.g. bathing), household care (e.g. cooking), and management (e.g. doctor’s appointments). The family caregivers in the study tended to be female, usually a spouse, daughter, or daughter-in-law (Visser et al., 2004). Caregivers who resided with the care recipient were older and spent on average 7 days per week providing some type of care while non-resident caregivers tended to be younger and provided 5 days of care per week (Visser et al., 2004). While the authors described the tasks that were involved in caregiving, they did not provide further details about the process of care and how these tasks were negotiated between family caregivers. In summary possible aspects of care that may need to be negotiated include who does what types of care, when is care provided, when can caregivers take respite, where is care given in the home, and so on.

Stajduhar (2003) conducted an ethnographic study with 60 family caregivers (13 currently providing care for a dying family member and 47 who had previously provided care). A secondary sample included health care providers (13) and administrators (10). The purpose of the study was to examine the social context in which family members provide home-based palliative care (Stajduhar, 2003). Data collection included participant observation of the 13 caregivers providing care at home, and in-depth, open-ended interviews with caregivers, health care providers, and administrators. Overall, caregivers that spoke about caregiving as a life-enriching experience had a previously good relationship with the care recipient, felt well supported by health care providers, tended to have both time and financial resources, and had negotiated the decision to provide palliative care at home prior (Stajduhar, 2003). Some caregivers spoke about the guilt they felt in not being able to keep the dying family member at
The inability to provide care at home was seen as a failure to caregivers. The study points out that caregivers’ fear of failure may influence negotiations of care since they may feel pressure to maintain the care recipient at home. Thus there is a need to further examine how time and resources contribute to negotiations of care – in other words, the context of care.

The gendered division of labour in the home has been most often analyzed through a feminist lens. Previous studies indicate that family caregivers are more often women (Visser et al., 2004). Yantzi and Rosenberg (2008) examined the meanings of home for women caring for children with disabilities that had long-term care needs. Women reported they felt there was a disjuncture between the ideal of home and the reality of home. The ideal home was one that represented intimacy and belonging, but the women had to restructure their home to meet care needs. The women struggled to maintain a “homely home” but understood that public discourses would deem their homes “unhomely” (Yantzi & Rosenberg, 2008, p. 311). This study demonstrates that there are multiple, complex, and contested meanings to home as a site of care, especially for caregivers who are women.

MacKinnon (2009) examined the literature on the roles of ethnic minority women as family caregivers of palliative home care recipients. Drawing on the theories of feminism, multiculturalism, and social justice, MacKinnon (2009) identified a lack of research examining ethnocultural minority women’s caregiving experiences of providing palliative home care. MacKinnon (2009) recognized that the conceptualization of culture in palliative care literature has been simplistic, and conceded that women who belong to ethnic minorities may experience marginalization as caregivers due to unequal access to palliative home care resources. Although the review was aimed at examining the experiences of ethnic minority women, the findings spoke generally about women’s gendered socialization as caregivers at end-of-life. The first implication of this review is that there are shared experiences and issues of caregiving for women that go beyond ethnocultural background. The second implication is the need to be aware of how gender plays out in the everyday delivery of palliative home care for ethnic minority women caregivers.

**Home as a Place of Care and a Place of Death: Processes of Care**

After I examined the literature on place of death, the gap in research examining the process of care in palliative home care led me to look for literature on processes of care in long-
term, chronic home care and its issues. I suspected there were some similarities between the two areas. Within the literature there are many studies examining the problematics of providing care in the home. The issues faced by home care recipients and formal and informal caregivers when the home becomes a site for care have been explored extensively in the literature. The studies included in this review have taken a critical examination of home care.

The perspective of home care providers is also important to understanding how meanings of home influence negotiations of palliative care for Chinese immigrant families. In a study of home care for persons with mental illness, Magnusson and Lutzen (1999) focused on how home care providers interpreted and dealt with the principle of autonomy of clients. They problematized the conflicts for home care providers between respecting autonomy and protecting the client from harm, while simultaneously ensuring their own safety. The researchers reported that home care providers experienced many conflicted feelings: feelings of intrusion, fluctuating boundaries between friendship and professional relationships, a need to respect privacy, and an understanding of the mutual vulnerability of both home care providers and clients in home care situations. While the researchers focused on a mental health population, most of these issues were seen as relevant to providing long-term home care to other populations as well, including palliative.

The significance of the home to care recipients, family caregivers, and home care providers is an important aspect of providing home care. The disruptions to home when receiving long-term home care were also examined in the study by Angus et al. (2005). Using Bourdieu’s concepts of habitus and field to analyze the data collected through interviews with and observations of clients and paid and unpaid caregivers, the researchers found that the significance of home for care recipients was disrupted and reconfigured to accommodate both the aesthetics of health care and the aesthetics of home (Angus et al., 2005). The resulting changes to home care recipients’ relationship to their homes “produced an ambiguity of place” for them and meant that the relationship between their bodies, spaces, and meanings of home were altered (pg. 182). Thus from this study, it was evident that the introduction of home care can change meanings of home for care recipients and caregivers.

Negotiating Care

The word negotiation was mentioned in several of the reviewed studies (Magnusson & Lutzen, 1999; Stajduhar, 2003; Stajduhar & Davies, 2005), but it was apparent that the process
of negotiation did not receive sustained analytic attention or elaboration. Furthermore, no studies were found that examined negotiation in palliative home care settings. Studies were identified that examined end-of-life negotiation, but these focused on decision-making on treatment and disclosure of diagnosis (Bowman, 2000; Gabbay et al., 2005; Kagawa-Singer & Blackhall, 2001). I searched the literature for studies examining negotiation in long-term home care situations instead and found three groups of studies that either focused on negotiations between 1) care recipients and caregivers only, 2) home care providers and care recipients, or 3) care recipient, caregiver, and home care provider.

First, I will discuss the studies examining negotiations between care recipients and caregivers. Two relevant studies were located. In the study by Coeling, Biordi, and Theis (2003), the researchers examined how care recipients and caregivers negotiated rules that influenced the caregiving experience. Sixty dyads of care recipients and caregivers were interviewed for the study. Findings indicated that care recipients and caregivers negotiated, on an on-going basis, a set of rules that governed their behaviours. These rules were mutually developed and defined the care process (Coeling et al., 2003). For example, rules expressed by one caregiver included taking it one day at a time and prioritizing things. Negotiations were described by participants as a joint decision-making process that took into consideration the costs and benefits of both care recipients and caregivers (Coeling et al., 2003).

In the second study by Horton and Arber (2004), 35 older persons who had recurrent falls and their primary family caregivers (23 females, 12 males) were interviewed about actions taken to prevent falls. The care recipients did not live with their family caregivers. The purpose of the study was to examine how gender influenced negotiations of care. Using grounded theory, the analysis identified 5 distinct categories of actions caregivers took to prevent falls: protective, coercive, negotiating, engaging, and reflective mutual respect (Horton & Arber, 2004). In relation to the categorization of negotiating, it was found that 16 of the 23 female family caregivers used negotiating actions to prevent falls, while none of the male caregivers did (Horton & Arber, 2004). Negotiating actions for caregivers were seen as ways to deal and bargain with the older person. There was an element of compromise that was associated with negotiation; but, both care recipients’ and caregivers’ perspectives were valued and taken into consideration. Although acts of negotiation were classified into 5 distinct categories, it is possible that negotiations are not always straightforward, and cannot necessarily be
compartmentalized into neat categories. The potentially unruly nature of negotiation is further discussed below.

In the study by Coeling et al. (2003), negotiations between care recipients and caregivers were seen as on-going processes while Horton and Arber (2004) categorized negotiations into 5 distinct categories. The discrepancy in findings between the studies may be due to differences in the purpose of the study and conceptualizations of negotiation. Building on Morley (1986 in Coeling et al., 2003), Coeling et al. (2003) conceptualized negotiation as a process and thus, they focused on examining the process of negotiation between care recipient and caregiver. On the other hand, Horton and Arber (2004) did not refer to negotiation as a process, but rather that certain characteristics of negotiations resulted in particular outcomes. For example, Horton and Arber (2004) talked about anticipatory negotiations where caregivers anticipated future needs, which resulted in each party having input into the negotiations.

I questioned whether negotiations could be classified into distinct categories, as was found in Horton and Arber (2004). It may be positivistic to assume that negotiations can be classified, as though they were inherently categorical. Perhaps some aspects of negotiations may be invisible, and difficult to articulate as a category. A postcolonial lens, specifically the concept of hybridity, may offer a different view of negotiation. Hybridity is described as a complicated entanglement that engages both old and new beliefs (Ang, 2003). Perhaps this is the case with negotiations as well, where these categories are not mutually exclusive. These categories may be part of a larger process of negotiation, where for example, aspects of engaging and reflective mutual respect are drawn on to negotiate care.

One relevant study was found that examined negotiations between care recipients and home care providers. In the Spiers (2002) study examining the interpersonal contexts of negotiations in the home care setting, home visits between 3 home care nurses and their clients (8 home care recipients) were videotaped. Spiers (2002) identified areas that were negotiated between care recipients and home care providers, in addition to the outcomes of successful negotiation. Some of the areas identified were negotiating territoriality, perceptions of the situation, working relationship, role responsibility, knowledge, and taboo topics (Spiers, 2002). Spiers (2002) viewed negotiation as a necessarily mutual experience, where both parties were involved in the discussion and decision-making. When mutuality was achieved, successful outcomes resulted, such as patient autonomy and therapeutic communication. Similar to Horton
and Arber, Spiers conceptualized negotiation in relation to its outcomes. Thus it is important to recognize the different approaches to how negotiation is conceptualized in relation to home care.

One study examined all three perspectives: care recipient, caregiver, and home care provider. Piercy and Woolley (1999) interviewed 16 home health aides, 10 home care recipients, and 15 family caregivers. The purpose of the study was to investigate definitions of quality home care and how quality care was achieved. The main findings indicated that quality home care was obtained through a process of negotiation. Areas that had to be negotiated between care recipients, caregivers, and home health aides included tasks, closeness and involvement, client autonomy, and relationship beginnings (Piercy & Woolley, 1999). Similar to Coeling et al. (2003), Piercy and Woolley (1999) also found that good relationships had to be maintained through on-going negotiation. For instance, care recipients appreciated it when home health aides showed consideration of their time by maintaining regular visit times, but if this was not possible, telling them in advance. The outcomes of successful negotiation were trust and acceptance of the home health aide as an insider (Piercy & Woolley, 1999).

Taken together my view of these studies provided important insights into what can be negotiated in the home, and also who is involved in negotiations of care. Some of these studies were only focused on negotiations between dyads, but Piercy and Woolley (1999) emphasized the importance of examining all three perspectives, because home care usually affects others living in the home besides the care recipient. This further demonstrates the complicated entanglement of negotiating home care. In terms of this research study, the findings from these studies raised questions about whether there are differences between what is negotiated in long-term home care and palliative home care situations, and, since none of these studies indicated whether their sample included immigrants, how the experience of migration may influence negotiations of care. From a postcolonial perspective, it is important to examine negotiation in palliative home care because it may contribute to marginalization, or Othering. For example, if home care providers are only negotiating care with caregivers, then the care recipients’ perspective of and knowledge of their needs are excluded. This may be a mechanism through which knowledge is subjugated. Thus it would be important to examine if and how participants actively engaged in negotiations.
Place of Care versus Place of Death

One of the other problems in discussing palliative home care is the distinction between place of end-of-life care and place of death, which many studies on place of death do not make explicit (Agar et al., 2008; Brazil, Howell, Bedard, Krueger & Heidebrecht, 2005). Agar et al. (2008) examined longitudinal preferences for place of care and place of death among 71 care recipient/caregiver dyads. The researchers found that both preferences for home as the site of care and death were high when initially posed the question but declined over time. When first asked, 87% of care recipients and 85% of caregivers preferred home as a place of care, but changed to 71% care recipients and 66% caregivers when last asked (Agar et al., 2008). Similarly when first asked, 41% of care recipients and 42% of caregivers preferred home as a place of death, but changed to 35% patients and 30% caregivers when last asked (Agar et al., 2008). The important difference to note is between preference for place of care and place of death. It is clear that care recipients and caregivers make a distinction between place of care and place of death, yet previous research studies have been less adept.

Similarly Brazil et al. (2005) examined family caregiver perceptions about place of care and place of death by interviewing 216 bereaved caregivers. Most caregivers reported that they and the care recipient had preferred a home death (77% and 68%, respectively). Caregivers also had a greater preference for an institutional death (14%) than care recipients (5%). Although the study focused on place of death, the distinction was conceptually formulated prior to data collection to help organize analysis. There are other studies that have also found anecdotal evidence that Chinese patients want to be cared for in the home but wish to die in the hospital (Enguidanos et al., 2005; McGrath, Vun, & McLeod, 2001; Tang, Lui, Lai, & McCorkle, 2005). Tang et al. (2005) found similar findings among caregivers in a study examining differences in preferences for place of death between care recipients and family caregivers in Taiwan. The researchers found that more care recipients (61%) expressed a preference to die at home than family caregivers (56.9%) (Tang et al., 2005). The hospital was the second most common choice while only 5% stated hospice. These studies indicate the need to be attentive to whether questions around place of death recognize this differentiation because results may be skewed due to a misunderstanding of the meaning of place of death and place of care.
Meanings of Home for Immigrants

It became clear that the meaning of home was significant in how care recipients, family caregivers, and home care providers perceive and provide care in the home. Theoretically, I understood the meaning of home was important for immigrants because postcolonial theory is concerned with the concepts of nation, citizenship, and belonging at “home”. For immigrants, there may be multiple meanings to home, which may impact their experiences of home care, especially what it means to “die at home”. I examined literature on meanings of home for immigrants and the meaning of home and palliation. There were no studies examining meanings of home for immigrants receiving palliative care.

Magat (1999) conducted extensive interviews with 10 Israeli and 10 Japanese immigrants in Canada to examine and compare the meanings of home and identity. Magat (1999) argued that immigrants probably attach different meanings to the concept of home, which may have direct and indirect implications for how they perceive and interpret their daily lives. The findings supported the fact that some immigrants do have different notions of home, and they can be different between immigrants as well. Magat (1999) found that while both Israeli and Japanese participants varied in their view of Canada as a home, many made a distinction between Little Home and Big Home. Participants spoke about Little Home as the place where their daily activities occurred and Big Home as the place where they felt they belonged and would ultimately return (Magat, 1999). The Israeli participants held a strong sense of Israel as the Big Home to which they belonged and spoke about how this constrained what they perceived to be their responsibilities as a Canadian citizen. This research demonstrates that home does have special meaning and implications for immigrants’ daily activities. Thus it was important to examine whether Chinese immigrants also made a similar distinction between Little Home and Big Home, and how these meanings of home may influence negotiations of palliative care. Dying away from Big Home may be upsetting for immigrants, and so it was also important to examine what the meaning of death might hold in their image of the Big Home.

The meanings of home for migrants, and specifically with respect to home care and palliative home care, have not been well explored. Dyck and Dossa (2007) note that “migrants have been invisible in the ‘cartography’ of healthy spaces” and have received little attention (p. 692). Thus in their study, Dyck and Dossa (2007) examine how migrant women construct ‘healthy space’ through routine practices for their families. The study compared and interviewed
two groups of immigrant women: 10 South Asian and 10 Afghan women. Overall, the study took a critical examination of the women’s agency in producing ‘healthy space’ through the process of migration and re-settlement. The researchers acknowledged that the production of healthy space is “not simply locally constituted but involves relationship and materialities stretched over space” (p. 699). Despite differences in migration narratives of displacement and re-settlement, all women expressed that they were positioned in Canadian society as the Other (Dyck & Dossa, 2007). But regardless, women were still active in creating a ‘healthy space’ within their homes for their families even though they had to contend with the ambiguities of a migrant identity and marginal status.

Although Dyck and Dossa (2007) did not engage a postcolonial stance in their research, the use of the concept of Othering is indicative of their critical stance in examining meanings of home for immigrant women. Since the women spoke about being marginalized as immigrants or refugees, it was necessary to consider how a sense of belonging could influence agency in building ‘healthy space’ for their families. From this I surmised that a sense of belonging would be an important focus when examining meanings of home for Chinese immigrants receiving palliative home care.

Only one study was found that used a postcolonial lens to examine the concept of belonging in health care settings. The concept of belonging was a recurrent theme in a study by Reimer Kirkham (2003) that examined intercultural health care interactions between nurses, patients, and administrators in acute care hospital settings. The researcher conducted an institutional ethnography with the purpose of uncovering the social practices and processes that structure intergroup relations in health care provision through a postcolonial feminist analytical lens (Reimer Kirkham, 2003). The researcher found that the concept of belonging was operationalized at the macro, meso, and micro-levels of health care interactions. First, national discourses on “Canadianess” and the macro-policies of multiculturalism framed the context in which intercultural health interactions occurred. Second, the commitment and enactment of organizational policies such as anti-harassment policy, diversity training programs, and integration of alternative medicine practices, constituted the meso-level experience of belonging. Most importantly, the researcher found that constructions of Otherness dictated who “belonged” within micro-level nurse-patient interactions. The findings referred to the ways both dominant (Caucasian) and marginalized (ethnic) nurses and patients positioned each other in order to
negotiate health care provision. The importance of belonging in health care intercultural group interactions is highlighted in this study.

**Meaning of Palliation and Home**

It is clear that palliative care for non-dominant ethnocultural groups has been problematized in the palliative care literature. In a qualitative synthesis examining the conceptualization of palliative care among ethnoculturally diverse populations within the context of Western health care, Bosma, Apland, and Kazanjian (2010) found that palliative care needs cut across ethnocultural groups. The synthesis found that minority populations held consistent philosophies of palliative care that were advocated by mainstream palliative care organizations (Bosma et al., 2010). Three common themes emerged from the studies: 1) palliative care should address physical, psychosocial, and spiritual aspects of death and dying; 2) palliative care providers should demonstrate excellent knowledge and expertise, and convey respect and compassion; and 3) palliative care resources should alleviate burdens (Bosma et al., 2010). These areas also represent many of the principles of palliative care espoused in the policies and guidelines of palliative care organizations that were synthesized by Barazzetti et al. (2010); thus, showing congruency between diverse ethnocultural groups’ conceptualizations of palliative care and that of mainstream palliative care organizations. The researchers also pointed out the heterogeneity within specific ethnocultural groups’ understandings and expectations of palliative care (Bosma et al., 2010).

The complexity of home care and its challenges for care recipients, caregivers, and home care providers was evident in the literature. Exley and Allen (2007) conducted a critical analysis of home care by drawing on end-of-life care as an illustrative case. Using qualitative data collected from three studies interviewing terminally ill care recipients and caregivers, the research identified several themes that were also identified in other studies examining the sociological significance of home (Angus et al., 2005; Oresland et al., 2008). Similarly, home care was seen as an intrusion to the home, which frequently required that domestic spaces be re-configured to accommodate care (Exley & Allen, 2007). The significance of dying at home to the meaning of home as a social space was expressed as concerns over hospital beds in bedrooms. Participants spoke about how health care artifacts such as hospital beds that remained in the house after the death were painful reminders of loss. Similarly dying patients pondered
about the changes in the meaning of a room, specifically bedrooms, if they were to die in it. For example, one care recipient questioned whether her husband would want to sleep in their bedroom after she had died there. The care recipient was referring to the changes in emotional meaning attached to the bedroom once someone has died in it. The complexity of home care is illustrated here, especially the alterations to meanings of home for those that survive the death.

Stajduhar (2003) also found that caregivers experienced changes to their relationship with their home and family while providing palliative end-of-life home care. Caregivers remarked that the home environment became a hospital-like setting that disrupted normal home life routines. Caregivers expressed a concern for the invasion of privacy as a succession of home care providers entered the home to provide care. These findings were similar to other studies (Exley & Allen, 2007; Luijkx & Schols, 2011; Magnusson & Lutzen, 1999) but because the focus was not to examine meanings of home, there was little elaboration on the reasons caregivers experienced these changes.

Tang (2000) wrote about the meaning of dying at home for Taiwanese Chinese as being related to commonly held beliefs, but also shifts in meanings due to urbanization. Tang (2000) identified several benefits to dying at home for the Taiwanese culture which may contribute to a good death: 1) being in familiar surroundings, 2) security and continuity of the dying person’s identity, 3) high quality interactions with family, and 4) dying in a hospital can be unsettling. The meanings of dying at home for the Taiwanese Chinese were based in traditional feelings that death should occur in the home and the belief that if the dying person does not die at home, their spirit is left wandering because the spirit of the dead person cannot find a place to rest (Tang, 2000). Because the author is writing from the perspective of Taiwanese living in Taiwan, the discussion only provides a list of possible meanings for dying at home for Taiwanese care recipients. Experiences of displacement, diasporas, and migration may exert an impact on what the home means (i.e. Big Home and Little Home), and so it is necessary to specifically examine Chinese immigrants’ experiences. The findings from studies examining Chinese people where they are the dominant ethnocultural group should be applied to Chinese immigrants with caution because experiences of migration may change health beliefs.
Conclusion

My initial research questions had focused on preferences for place of death among Chinese immigrants but through a constant dialogue with the literature and my theoretical lens, they subsequently evolved to incorporate meanings of home and negotiations of care. This change came about because the majority of literature on preference for place of death indicates that the majority of participants prefer a home death. The presumption that people want to die at home remains an important consideration when studying meanings of home for Chinese immigrants with advanced cancer and their family caregivers. Also, what became apparent in the literature on place of death was the lack of research about the work that is involved in providing palliative care at home; therefore, negotiation of care was incorporated into the research purpose. My research purpose and questions also evolved to include meanings of home because they became theoretically significant to my study. The politics of nationalism and belonging in a “new home,” that contribute to a sense of self-determination and empowerment, were theoretical concepts that fit with examining negotiations of care among Chinese immigrants receiving palliative home care. Thus in reviewing the literature, I saw that there was a gap in research examining the palliative home care experiences of immigrants, and in particular the ways Chinese beliefs on death and dying were written about in the literature. The following chapter examines the tenets of ethnography, and in particular focused ethnography, which informed my methodological approach to answer my research purpose and questions.
CHAPTER 5
METHODOLOGY AND METHODS

Introduction

This chapter describes the rationale for a qualitative design based on the methodological tenets of ethnography, and more specifically focused ethnography. Ethnography aims to examine social phenomena, and describe and interpret social aspects of daily life (Hammersley & Atkinson, 2007). Increasingly, focused ethnographies have been utilized in health sciences research (Morse & Field, 1996). Focused ethnographies are more delineated than classical ethnographies as the topic and research questions are established before starting data collection, as was the case with this study (Morse & Field, 1996; Savage, 2000). A fieldwork protocol was developed and further refined during field observations of interactions between care recipients and a palliative home care nurse in Chinese immigrants’ homes. The resulting protocol is described in this chapter and includes the sampling strategy, sample size, recruitment, data collection, data analysis, and ethical considerations.

I chose a qualitative design for this study because of the exploratory nature of the research. The purpose of the study is to describe and examine the meanings of home for Chinese immigrants receiving palliative care at home, their family caregivers, and home care providers, and to understand how these meanings condition negotiations of care. As my review of the literature indicates, the lack of research in this area warrants a qualitative approach. Furthermore, the theoretical underpinning for this study is congruent with a qualitative approach to examining these issues (Reimer Kirkham & Anderson, 2002). Ethnographic methods are intended to examine and explore social life within particular settings or cultural contexts (Atkinson, Coffey, Delamont, Lofland & Lofland, 2001). Since ethnography is concerned with the interpretation of meanings, functions, and actions within people’s daily lives, this approach is well suited to researching the proposed questions: 1) What are the meanings of home for Chinese immigrants with advanced cancer, their family caregivers, and home care providers? 2) How does palliative home care change meanings of home? 3) How is palliative care negotiated in the home? and 4) What is negotiated in home-based palliative care?
Qualitative Inquiry

Qualitative research is a mode of inquiry that aims to understand “the unique nature of human thoughts, behaviors, negotiations, and institutions” within different historical and environmental contexts (Benoliel, 1984 cited in Munhall, 2001, p. 86). Overall, qualitative research incorporates the holistic context in which individuals assign meaning to experiences (Roper & Shapira, 2000). Denzin and Lincoln (2005) note that qualitative researchers turn the world into a series of representations, including field notes, interviews, conversations, recordings, photographs, and memos to the self…

This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. (p. 3)

Most definitions of qualitative research highlight similar characteristics: data is collected in the natural setting, the researcher is the key instrument of data collection, outcome is a process rather than a product, analysis of data is inductive, and the focus is on participants’ perspectives and their meanings (Creswell, 1998; Denzin & Lincoln, 2005).

Qualitative research provides not only a means of describing a phenomenon, but also involves the scrutiny of social phenomena (Esterberg, 2002). Meanings of home may change for care recipients because the home becomes a site of death. But for other inhabitants of the home, the meaning of home may shift because dying occurs in conjunction with activities of the living, and so the home may mean different things to different occupants. These differences in meanings also imply that occupants may have different goals, and negotiations may reflect this. In the case of Chinese immigrants, experiences of migration and achieving a sense of belonging are complex and embedded with memories of another “home”. There are multiple perspectives and contexts to consider when providing palliative care in the home, in particular the relationships between the care recipients, family caregivers, and home care providers. Qualitative data such as interviews and observational data would best capture the experiences of negotiating care within fluctuating meanings of home, living, and dying. Qualitative researchers try to understand social life in novel ways, and at the same time remain attuned to their own subjectivities. Thus, qualitative researchers may look to existing theory to help examine phenomena in a new way, and to also understand their own subjectivities. This is important because death, dying, and palliation are sensitive issues about which researchers may have strong feelings. Using a
postcolonial lens to guide my inquiry encouraged me to be reflexive, and a critical observer of participant experiences of home and palliative care.

**Ethnography**

Ethnography originated within 19th century Western anthropology and was seen as a “descriptive account of a community or culture, usually one located outside the West” (Hammersley & Atkinson, 2007, p. 1). The term ethnography is closely related to “ethnology” which is the study of non-Western societies and cultures (Hammersley & Atkinson, 2007). Since then, ethnography has evolved to examine more than just non-Western societies, but has moved beyond to examine more local cultures or communities. Under a postcolonial lens, the past use of ethnography can be seen as a method that enforced binaries between us and them, and East and West, thus it was a form of Othering. However, in its current usage in health research, ethnography goes beyond emphasizing binaries between East from West, and is focused on the activities and shared meanings of a group, which can highlight differences between and within groups. Ideologically, culture is difficult to define, and as indicated, postcolonial theorists seek to problematize how the concept of culture has been used in health research. I was mindful of this critique and considered that groups are bound by more than a shared ethnic culture, but also realized that they may share contextual experiences and beliefs that form the basis for group identity. For example, participants in the study all shared the experience of palliative home care, even if from different positionings.

Although ethnography has a tradition well rooted in anthropology and sociology (Wolf, 2001), other disciplines such as nursing and education use ethnographic methods to examine everyday behaviour in local contexts. Ethnographies aim to learn about people by learning from them (Roper & Shapira, 2000). Ethnographers examine the interactions between participants, the meanings of behaviour and language, and how they make sense of the social world (Creswell, 1998; Hammersley & Atkinson, 2007). There is a debate between uses of emic and etic perspectives in making sense of people’s actions. The emic perspective is the insider or participant’s perspective of reality (Boyle, 1994; Morse & Field, 1995). The etic perspective is what the outsider or researcher brings to the explanation of the phenomena (Boyle, 1994).

Although some ethnographers emphasize emic over etic perspectives, and vice versa, most ethnographers rely on both perspectives to help develop conceptual and/or theoretical
interpretations of people’s behaviours. As discussed, a postcolonial theoretical stance calls for the re-discovery of subjugated knowledges of those who have been historically marginalized (Anderson et al., 2007; Racine, 2003; Spivak, 1988). Thus postcolonial theory places an emphasis on emic or participants’ perspectives of reality for knowledge development. Both emic and etic perspectives are important to ethnographic work since participants’ perspectives are central, and researchers do not go into the field without some theoretical understanding of the world (Boyle, 1994; Geertz, 1973/2000; Hammersley & Atkinson, 2007). Thus a postcolonial stance calls for transparency in the use of emic and etic perspectives. It is necessary for the ethnographer to be clear that the findings are the researcher’s interpretations of participants’ behaviours, and that they are not represented as participants’ own perspectives of reality. I was conscious that it was important to avoid losing the perspectives of participants within my own interpretations so that participants’ knowledges were not subjugated or misrepresented.

When conducting ethnography, the researcher seeks to understand the perspectives of a group through interviewing, participant observation, and fieldnotes (Creswell, 1998; Hammersley & Atkinson, 2007; Morse & Field, 1995). Ethnographies involve the researcher participating in the daily lives of people for a certain amount of time, in their natural setting, observing what happens, listening to what is said, and asking questions, either in formal interviews or through casual conversations (Hammersley & Atkinson, 2007). Hammersley and Atkinson (2007) note that ethnographies may begin with a focused problem or issue. Ethnographers seek a holistic and contextualized perspective on the actions, knowledges, beliefs, and interactions of a group (Boyle, 1994; Roper & Shapira, 2000). In contextualizing the data, events, behaviours, and relationships within a group are analyzed for their meanings in conjunction with an understanding of the historical influences and circumstances that they take place (Boyle, 1994; Roper & Shapira, 2000). This fits well with postcolonial theory because it emphasizes the current circumstances of peoples’ lives and the historical contexts in which meanings are attached to actions. In my study, data analysis was undertaken with awareness of the historical ramifications of Chinese immigrants’ experiences of being Othered (i.e. Chinese Exclusion Act) to meanings of home and abilities to negotiate palliative home care.

differentiated between thin description and thick description. Thin description merely describes what a participant is doing whereas thick description, the goal of ethnography, illuminates the situated meanings. Patton (2001) also points out that thick description provides readers with a rich, detailed, and concrete description of the phenomena that allows for interpretation of the significance of meanings to participants’ actions. But he also emphasizes the need for careful separation of description from interpretation; and so good description comes first, that in turn allows for interpretation (Patton, 2001).

As for theory, Geertz (1973/2000) stated that ethnographers do not enter into thick description empty-handed, but may bring theoretical ideas from other related studies, applied and refined to interpret new problems. Theory provides a vocabulary with which to interpret and express the meanings of social actions (Geertz, 1973/2000). Thus Geertz’s formulation allowed ethnographers to enter the field with a theoretical framework in mind. In my case, I entered the field with a postcolonial theoretical lens. Theory, in ethnography, helps researchers attune to contextual factors and particular activities in the field, and to identify patterns within the data (Hammersley & Atkinson, 2007). As Boyle (1994) suggested, I engaged with the tenets of ethnography and postcolonial concepts to bring about more than a mere description of what was going on for participants, and provided a theoretical explanation that came through the inherent reflexive nature of the ethnographic process.

Focused Ethnography

I further classify my study as a focused ethnography. Focused ethnographies share many similarities to classical ethnographies, such as the principles and aims discussed above, but there are differences that make it a suitable alternative within health research. Muecke (1994) explains that focused ethnographies are time-limited and exploratory in nature, which calls for a more carefully defined approach to gathering data. Focused ethnographies are centred on a particular problem and are context specific, often concerned with a particular disease or other shared characteristics in health or illness (Morse & Field, 1996; Muecke, 1994; Roper & Shapira, 2000). Classical ethnographies seek to gain a comprehensive description of a group’s circumstances and perspectives, and so require the ethnographer to remain in the field for a prolonged period of time (Muecke, 1994). Due to time and resource constraints, a focused ethnography, in its bounded nature, may be adopted instead to work around these constraints (Savage, 2000).
Focused ethnographies collect data primarily from selected episodes of participant interactions, and entail interviews or observations of persons directly involved with the phenomenon being studied (Muecke, 1994). According to Morse and Field (1996), participant observations are generally restricted to particular events and times, and interview questions are based on the observed events and specified topic. In summary, focused ethnographies are time-limited; concentrated on a specific topic, place, and/or participant group; and directed toward examining a pre-defined issue within interviews. Thus, my research study is a focused ethnography because the inquiry had a pre-determined focus (meanings of home and the negotiation of care for Chinese immigrants), was context specific (palliative home care), included only those directly involved in the phenomenon (care recipients, family caregivers, and home care providers), and was time-limited (focusing on care interactions between participants).

Knoblauch (2005) recognizes that because focused ethnographies do not require the researcher to be in the field for extended periods of time in observation, the common critique is that focused ethnographies risk being “superficial”. Despite this, Knoblauch (2005) argues that because of the shorter time period spent in the field, researchers often collect a larger amount of data within a smaller time frame, making their data collection and analysis “experientially-intensive”. Some of the increase in data in focused ethnographies may result from the use of technologies that are incorporated with traditional methods of recording data, such as handwritten fieldnotes (Knoblauch, 2005). For example, digital technologies, such as digital audio and video recorders, are able to record a greater volume of data and may contribute to the intensive nature of focused ethnographies. Thus focused ethnography, while different and similar in aspects to classical ethnography, was an appropriate approach for this study.

Critical Approaches: Postcolonialism and Ethnography

To examine the shifting meanings of home for Chinese Canadian immigrants when receiving palliative home care, I used a postcolonial theoretical lens to provide grounding for the research inquiry. Like other critical theories, postcolonial theory shares a common commitment to social critiques, knowledge production that counters oppressive representations, and recognition of the social and historical context of power relationships (Denzin & Lincoln, 2005; Hesse-Biber & Leavy, 2006; Kincheloe & McLaren, 1998; Lincoln & Guba, 2000). According to Denzin and Lincoln (2005), critical theory privileges a material-realist ontology that recognizes
that the “real world makes a material difference in terms of race, class, and gender” (p. 24). As previously discussed in the theoretical chapter, postcolonial theory is concerned with social criticism and knowledge production that recognizes the continuing effects of colonialism in the production of unequal power relations and the subjugation of knowledges. Postcolonial theory also emphasizes the need to look at the social and historical contexts of peoples’ lives to better understand the barriers they encounter. Ethnographic tenets privilege participants’ experiences and knowledges (emic perspective); therefore, it is a methodology that is well suited to study the subjugation of knowledge of marginalized groups. Kincheloe and McLaren (1998) maintain that critical research is inherently political in that it is intended to expose contradictions of representations and question hegemonic structures. Part of the work required in understanding power relations and contradictory representations involves researcher reflexivity. Hammersley and Atkinson (2007) also emphasize the need for reflexivity in ethnographic research. I engaged in reflexivity throughout the process of the study because I recognized the importance in being critical of my own beliefs and acknowledging how my experiences may influence relationships with participants and interpretations of data.

Methods

Gaining Access

Both postcolonial theory and ethnography consider the positions of insider and outsider. Hammersley and Atkinson (2007) point out that depending on how an ethnographer is positioned as an insider or outsider, he or she will have access to different sorts of information. I recognize that I was positioned variously as an insider (being a Chinese immigrant) and also an outsider (not being part of the circle care); but in gaining access to the field of palliative home care, I was a veritable outsider. My initial foray into the field proved to be difficult, because I was an outsider who had to gain the trust of insiders working in palliative home care so I could obtain the information necessary to gaining access into the setting and to begin recruitment. There were administrative layers and practical considerations I had to penetrate before I could get in to the homes of Chinese immigrants who were receiving palliative home care.

Hammersley and Atkinson (2007) acknowledge that gaining access, or entrée, is a difficult task that must take into account contextual, ethical, and practical considerations. I had to learn which agencies had jurisdiction over providing palliative home care in the community and
the catchment areas; meet with and negotiate with gatekeepers at the agencies involved in providing palliative home care, including the CCACs and home care agencies; ensure I met their ethical requirements and received ethical approval at the various institutional levels; and develop strategies that were attentive to the ethical and practical implications for recruitment.

Hammersley and Atkinson (2007) state that “the discovery of obstacles to access… itself provides insights into the social organization of the setting or the orientations of the people being researched” (p. 41). Within my experiences of navigating the system for this study, the context of community care seemed fragmented as multiple agencies at varying institutional levels were involved in providing palliative home care and at different points. The study was reviewed at several ethics research boards as there was no one board that covered home care. Despite the fragmentation, it was evident that palliative home care patients were collectively regarded as an especially vulnerable group, and were closely guarded as research subjects. Thus, gaining access to the setting and field took several months to negotiate (June 2009 to March 2010). Because of the delay in gaining access to Chinese immigrants receiving palliative home care, the recruitment strategy and sample had to be modified. The sample was adapted from recruiting 5 cases of Chinese immigrant recipients of palliative home care, their family caregivers, and respective home care providers to also include interviews with 10-12 key informants. The following results section reflects these changes.

**Setting and Recruitment**

There were two main sites for recruitment of Chinese immigrants who were receiving palliative home care: 1) the Community Care Access Centre (CCAC) at the Toronto Central and Central regions; and 2) the Temmy Latner Centre for Palliative Care (TLCPC) at Mount Sinai Hospital. The Toronto Central and Central CCACs were approached to assist with recruitment because of the large Chinese immigrant population they served. As described in the background chapter, there are numerous home care agencies that have contracts to provide home care; thus, two home care agencies agreed to participate in the study: S.R.T. Med-Staff (S.R.T.) and Saint Elizabeth Health Care (St. Elizabeth). Recruitment strategies were negotiated with participating agencies and institutions to work through ethical and practical concerns, which are now described separately for each below: key informants and cases.
Key Informants

Preliminary interviews were sought with key informants and started with purposeful sampling for home care nurses, personal support workers (PSWs), case managers, palliative physicians, and other service providers who had been involved in palliative home care to Chinese immigrant care recipients. Palliative home care nurses and PSWs were recruited from S.R.T. and St. Elizabeth. S.R.T. and St. Elizabeth were also involved in recruiting nurses to build cases for the study. The advanced practice nurse (APN) at S.R.T. and the nurse research manager at St. Elizabeth approached nurses and PSWs known to have provided palliative home care to Chinese immigrant families to tell them about the study. The APN and nurse research manager provided my contact information to those who were interested in learning more about the study. If the potential participant consented, their contact information was forwarded to me so that I could contact them with further details regarding the study directly. Potential participants were given a telephone explanation of the study and an opportunity to ask questions. Interview appointments were arranged with those who indicated they wanted to participate in the study. Similarly, case managers were recruited directly from the Toronto Central and Central CCACs. I attended team meetings to inform case managers of the study and provide contact information should they wish to hear more about the study or to participate in the study.

As I became immersed in the field and came into contact with providers in various positions in palliative home care, some key informants were recruited through snowball sampling. I was also invited to attend team meetings with the community palliative nursing consultants from the Hospice Palliative Care Teams for Central LHIN (HPC Teams). Three community palliative nursing consultants were recruited as key informants. Part of recruitment and getting buy-in from providers of palliative home care was attending team meetings to inform providers of the study and to ask for assistance in recruitment. I attended several team meetings at the Toronto Central CCAC, S.R.T Med-Staff and the TLCPC to present my study proposal to case managers, home care nurses, and palliative physicians. During these meetings, I distributed a leaflet containing information about the study and my contact information (Appendix A). Requests to attend meetings for PSWs at the home care agencies were denied and so an amendment was made to the recruitment protocol. Advertisements, in the form of informational sheets for key informant interviews, were sent to CareFirst Seniors and Community Services Association (CareFirst) to distribute amongst their PSWs. CareFirst is a non-profit organization.
that provides home care nursing, personal support, and home making to Chinese clients in the Greater Toronto area and York region, and had a larger Chinese immigrant client base. It was likely that their PSWs may have worked with a Chinese immigrant receiving palliative home care. CareFirst was not approached as one of the home care agencies for recruitment of cases because they do not have contracts with the Toronto Central and Central CCACs to provide personal support or nursing care.

Cases

Recruitment procedures for cases were tailored for each of the CCACs and the TLCPC due to differences in resources, structure, and ethical considerations.

*Toronto Central CCAC*

The case managers at the Toronto Central CCAC identified Chinese immigrant care recipients that met the inclusion criteria for the study and who were receiving palliative home care services from the aforementioned home care agencies: S.R.T. and St. Elizabeth. I then notified the APN or research manager at the home care agencies who made initial contact with the home care providers to inform them of the study. If the home care provider agreed to participate, the Toronto Central CCAC case manager then made contact with care recipients and family caregivers to tell them about the study. To avoid unnecessarily burdening families, only the care recipients and family caregivers of home care providers who agreed to participate were approached for participation by the Toronto Central CCAC case managers.

The case managers, APN, and research manager provided my contact phone number to participants who were interested in learning more about the study, or if the participant consented, their contact information was directly given to me (see Appendix B for copy of telephone recruitment script). Those who contacted the researcher and those who had given permission to be contacted were given a telephone explanation of the study and an opportunity to ask questions. Observation and interview appointments were arranged with those who consented and were also sent a copy of the study consent form in the mail or brought to their first meeting so that they could review the contents prior to the interview. Information sheets/consent forms were translated to Chinese for care recipients and family caregivers (see Appendix C for copies of Information Sheet/Consent Forms).
Central CCAC

At the Central CCAC, it was the APN and research manager at the home care agencies who identified potential Chinese immigrant participants from their clients list supplied by the Central CCAC. The APN and research manager made initial contact with home care providers to tell them about the study. Similar to the procedure with the Toronto Central CCAC, only the care recipients and family caregivers of home care providers who agreed to participate were further approached for participation by the APN or research manager, and similar procedures were followed for contacting, informing, and consenting the care recipients, family caregivers, and home care providers for the study. I then notified the Central CCAC that the client was participating in the study. Since the home care agencies are contracted to the Central CCAC, the home care agencies were obliged to let the Central CCAC know if a client had been put in a study.

Temmy Latner Centre for Palliative Care

The TL CPC research coordinator identified potential participants who met the inclusion criteria and made initial contact with the home care providers. Similar to the procedures outlined above, only the care recipients and family caregivers of home care providers who agreed to participate were further approached for participation by the research coordinator. If the care recipients and family caregivers expressed interest, a letter of invitation and consent form were mailed to interested participants after the initial contact. The research coordinator then collected the participant’s contact information and forwarded it to me to follow-up on reviewing study details and obtaining consent.

Sampling, Sample Size, and Inclusion Criteria

Qualitative researchers use purposeful sampling as a strategy to select participants (Kuzel, 1999; Maxwell, 2005). One important goal of purposeful sampling, also known as criterion-based sampling, is to achieve a representative or homogenous sample that will provide information that will answer the research question. Specifically, criterion-based sampling selects participants based on one or more criteria that are relevant to the study (Kuzel, 1999). Postcolonial theory is concerned with the intersection of gender, class, race, age, location, and other social factors; therefore, these constituted some of the relevant criteria to select participants. Hammersley and Atkinson (2007) identify this method as strategic selection of
cases. Although there was snowball sampling with key informants, they also had to meet inclusion criteria so I could ensure they had relevant experiences of providing palliative home care to Chinese immigrant care recipients.

Patton (2001) contends that there are no rules to sample size but states that smaller sample sizes may allow for more depth in understanding the phenomenon. There is a basic assumption within qualitative research that between 5 and 20 units of analysis are sufficient to constitute a small sample (Kuzel, 1999). To build cases, the unit of analysis was households receiving palliative home care. A household consisted of a first generation Chinese immigrant with terminal cancer receiving palliative home care, at least one primary family caregiver, and a home care provider (all of whom were home care nurses in this study). In some Chinese immigrant care recipient homes, there were multiple generations living together. First generation immigrants refer to persons born outside of Canada (Statistics Canada, 2008e). Second generation immigrants include individuals who are born inside Canada but have one or both parents born outside of Canada (Statistics Canada, 2008e). Finally, third generation immigrants are persons born inside Canada with both parents born inside Canada as well (Statistics Canada, 2008e). For the purposes of this study, first generation immigrant care recipients with advanced cancer were sought while family caregivers could be first, second, or third generation immigrants. I chose to place this constraint because first generation immigrants may have very different experiences than second and third generation immigrants who are born and have lived in Canada all or most of their lives. Reconciling differences between generations when negotiating palliative care added another complex dimension to examining the palliative home care experiences of Chinese immigrant families. The following sections provide further details on sampling, sample size and inclusion criteria of key informants and cases separately.

Key Informants

As indicated, the recruitment strategy was amended to also include interviews with key informants: individuals knowledgeable about and having experience with providing palliative home care to Chinese immigrants. Purposive and snowball sampling were used to recruit key informants. Hammersley and Atkinson (2007) state that a “representative sample of informants is by no means what is required in ethnographic research” (pg. 106). Rather, the researcher should aim to target informants who have knowledge and experience with the phenomenon, and who are willing to speak with the ethnographer. To start recruitment of key informants, I purposively
chose and contacted through email and/or by telephone several individuals who were known to have worked extensively with Chinese immigrants at end-of-life. From these initial key informants, snowball sampling ensued as they suggested other knowledgeable individuals. Key informants were told to ask their colleague(s) for permission to pass their contact information to me before I contacted them about the study.

As mentioned, a qualitative sample of between 5-20 participants is considered sufficient because of the depth and large amount of data that can be obtained from hour-long interviews (Kuzel, 1999). In light of this, 11 key informant interviews were recruited. These 11 key informant interviews were then supplemented with the cases. Multiple perspectives were sought to build a broad but focused understanding of palliative home care experiences of Chinese immigrants. While saturation of data is commonly viewed as the point for stopping data collection, because multiple perspectives informed the analysis, saturation was not expressly sought. Rather, a sense that a cohesive and comprehensive view of the phenomenon had been gained signified when data collection would stop (Sandelowski, 1995).

The inclusion criteria for key informants included:

- home care nurse, PSW, palliative physician, CCAC case manager, social worker or any persons providing social services to and who has provided palliative home care to a Chinese immigrant with terminal cancer
- no more than 1 year since last relevant care experience
- consent to participate

Overall 11 key informants (see Table 1) were interviewed for the study. Interviews took place at a place and time that was convenient for the key informants. Place of interviews included key informant’s homes, offices, coffee shops, cafeterias, and at offices located at the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto.
Table 1

*Key Informant Positions*

<table>
<thead>
<tr>
<th>Key Informant</th>
<th>Position</th>
<th>Service Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>KI1</td>
<td>Case manager</td>
<td>Toronto Central</td>
</tr>
<tr>
<td>KI2</td>
<td>Home care nurse</td>
<td>Central</td>
</tr>
<tr>
<td>KI3</td>
<td>Social Worker</td>
<td>Toronto Central</td>
</tr>
<tr>
<td>KI4</td>
<td>Case manager</td>
<td>Central</td>
</tr>
<tr>
<td>KI5</td>
<td>Palliative nursing consultant</td>
<td>Central</td>
</tr>
<tr>
<td>KI6</td>
<td>Palliative nursing consultant</td>
<td>Central</td>
</tr>
<tr>
<td>KI7</td>
<td>Home care nurse</td>
<td>Central</td>
</tr>
<tr>
<td>KI8</td>
<td>Palliative nursing consultant</td>
<td>Central</td>
</tr>
<tr>
<td>KI9</td>
<td>Case manager</td>
<td>Toronto Central</td>
</tr>
<tr>
<td>KI10</td>
<td>Palliative physician</td>
<td>Toronto Central</td>
</tr>
<tr>
<td>KI11</td>
<td>Hospice volunteer/bereaved caregiver*</td>
<td>Toronto Central</td>
</tr>
</tbody>
</table>

*Note. *KI11 was recruited for her position as a Cantonese-speaking hospice volunteer; it was during her interview that she revealed and spoke about her experiences as a bereaved caregiver.*

**Cases**

For the purposes of this study, cases of households of first generation Chinese immigrants receiving palliative home care, their family caregivers, and home care providers were considered the unit of analysis. Five cases were initially sought for the study. Households provide multiple sources of information and can result in rich data through observations and interviews. Since a household can consist of more people than those listed above, i.e. multiple family caregivers, I was aware that a case could potentially be more than 3 individuals, and so only 5 cases were initially sought.

The inclusion criteria for *care recipients* included:

- first generation Chinese immigrant (including Hong Kong, and from other Chinese diasporas)
- aware of diagnosis of terminal cancer
- Service Recipient Code 95 (CCAC code categorization for palliative patients)
- adult (non-pediatric)
- recipient of palliative home care
• living with their primary family caregiver
• capacity to give informed consent (that is to exclude participants who are not oriented to person, place, or time); this was determined by the CCAC case manager or APN at initial recruitment; at the TLCPC, capacity was screened by the research coordinator in consultation with the physician responsible for the care recipient. Capacity to give consent was continuously assessed status could change
• consent to participate

A balance of male and female participants were sought. Chinese immigrants who spoke English, or dialects of Chinese, including Cantonese, Mandarin, or Taishan, were included in the study. Interviews with non-English speaking participants were possible through my verbal abilities in Taishan and Cantonese, and by access to professional interpreters for those participants who spoke Mandarin or other dialects. Maximum variation was not a goal of the sampling strategy because a more homogenous sample would enable better across-case comparison (Patton, 2001). Where possible, variation was sought in socioeconomic status, education level, fluency in English, recency of immigration, and type of living situation (i.e. house or apartment; multiple families in one home) to examine and explore analytical ideas as they arose during data collection.

The primary family caregiver was identified by the care recipient. Inclusion criteria for primary family caregivers included:
• first, second, or third generation immigrant
• living with the care recipient and providing care to the care recipient
• consent to participate

Where possible, variation was sought in the type of relationship between care recipients and primary family caregivers such as spouses, children, sibling, etc.

Inclusion for home care providers included
• being a registered nurse, registered practical nurse, or personal support worker
• providing palliative home care to these care recipients and primary family caregivers
• consent to participate

Four cases were recruited for the study. The home care provider recruited for each case was a home care nurse. A brief narrative description of each case and the sample characteristics of each case are presented in Table 2.
Table 2

*Case and Sample Description*

<table>
<thead>
<tr>
<th>Case</th>
<th>Role</th>
<th>Sex</th>
<th>Age</th>
<th>Cancer Site</th>
<th>Living Situation</th>
<th>Country of Origin</th>
<th>Languages Spoken</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Case 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CR1</td>
<td>Care recipient</td>
<td>F</td>
<td>68</td>
<td>Stage 4 Lung</td>
<td>Spouse</td>
<td>Hong Kong</td>
<td>Cantonese, English</td>
</tr>
<tr>
<td>CG1</td>
<td>Spouse</td>
<td>M</td>
<td>67</td>
<td>N/A</td>
<td>Spouse</td>
<td>Hong Kong</td>
<td>Cantonese, English</td>
</tr>
<tr>
<td>HCP1</td>
<td>RN</td>
<td>F</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>South Africa</td>
<td>English</td>
</tr>
</tbody>
</table>

**Case 2**

CR2 lived in a large single family home with his wife, CG2, and several other adult family members. Their bedroom was located on the first floor, but the kitchen and living room were considered communal spaces. CR2, who was formerly a small-business owner, was now unemployed and had been so for the past several years since being given a terminal prognosis. CG2 had to quit her previous manufacturing job to care for CR2 after he was hospitalized for several weeks and required her to care for him at home. She recently started a new manufacturing position and was doing shift work. CR2 immigrated to Canada over 20 years ago and CG2 immigrated over 10 years ago after marrying in China. Case 2 shared the same home care nurse as Case 3.

| CR2  | Care recipient | M   | 51  | Stage 4 Liver | Spouse; 6 adults | China              | Taishan, Cantonese, Mandarin |
| CG2  | Spouse        | F   | 39  | N/A           | Spouse; 6 adults | China              | Taishan, Cantonese, Mandarin |
| HCP2/3† | RN | F   | N/A | N/A           | N/A               | Taiwan             | Mandarin, English         |

**Case 3**

CR3 was an elderly man who lived with his wife, CG3W, in a single family home. CR3’s bedroom was on the second level, but when he was not well, he could not come downstairs. CR3 and CG3W immigrated to Canada together over 40 years ago. They had a son, CG3S, who lived in a separate home, but visited weekly to help run errands. Both CR3 and CG3W were retired and CG3S worked full-time.

| CR3  | Care recipient | M   | 77  | Stage 4 Brain | Spouse            | China              | Taishan, Cantonese, Mandarin |
| CG3W | Spouse        | F   | 65  | N/A           | Spouse            | China              | Taishan, Cantonese         |
| CG3S | Son           | M   | N/A | N/A           | Alone              | Canada             | Cantonese, English         |
### Case 4

CR4 and CG4 lived in a large single family home in a newly built subdivision in the suburbs. There was limited public transportation available in the area. The elderly couple lived with their two adult children. They arrived in Canada over 25 years ago from Vietnam. CR4 and CG4 were both retired. CR4 had a make-shift bedroom set up in the family room because she was no longer able to go upstairs.

<table>
<thead>
<tr>
<th>HCP2/3†</th>
<th>RN</th>
<th>F</th>
<th>N/A</th>
<th>N/A</th>
<th>N/A</th>
<th>Taiwan</th>
<th>English Mandarin, English</th>
</tr>
</thead>
<tbody>
<tr>
<td>CR4</td>
<td>Care recipient</td>
<td>F</td>
<td>72</td>
<td>Stage 4 Lung</td>
<td>Spouse; 2 adults</td>
<td>Vietnam</td>
<td>Cantonese, Chui chow</td>
</tr>
<tr>
<td>CG4</td>
<td>Spouse</td>
<td>M</td>
<td>74</td>
<td>N/A</td>
<td>Spouse; 2 adults</td>
<td>Vietnam</td>
<td>Cantonese, Chui chow</td>
</tr>
<tr>
<td>HCP4</td>
<td>RN</td>
<td>M</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>Hong Kong</td>
<td>Cantonese, English</td>
</tr>
</tbody>
</table>

*Note. † HCP2/3 was the home care nurse in both Case 2 and Case 3*

### Data Collection

In ethnographic research, data collection is inductive (Wolf, 2001). Ethnographic data collection involves the use of the researcher as an observer, entails prolonged engagement in fieldwork, and engages researchers in both informal and formal interviews with participants (Hammersley & Atkinson, 2007; Morse & Field, 1995; Wolf, 2001). All participants were interviewed once, individually in their homes or at a place that was convenient and afforded privacy for the participant. In-depth, open-ended interviews with participants were guided by a theme list (Appendix D) to ensure that relevant issues were discussed (Hammersley & Atkinson, 2007; Liamputtong & Ezzy, 2005). To engage in in-depth interviewing, Crabtree and Miller (1999) write that initial, “grand tour” questions should be posed that are open-ended and allow participants to provide accounts of not only their beliefs and values, but also their everyday routines and relationships. Because the study had a specific purpose, initial questions were designed to elicit the biography and descriptions of everyday life as recommended by Crabtree and Miller (1999), but to also stimulate participants to discuss their experiences within the scope of the study. Hammersley and Atkinson (2007) call this non-directive questioning where questions are open-ended, but also have purpose. I wanted to ensure that questions were not so broad and general that they overwhelmed the participants, and so interviews remained close to the purpose of the study.
Key Informant Interviews

Each key informant was individually interviewed in their own home or at a place that was convenient (i.e. work place, coffee shop), or at the University of Toronto. In-depth, open-ended interviews lasted between 60 to 90 minutes. Interviews were focused on key informants’ perception of palliative home care for Chinese immigrants. Key informant interviews were digitally audio-recorded and then professionally transcribed for data analysis.

Case Interviews

Interviews with care recipients and family caregivers were guided by three main themes as prompts: 1) experiences of migration; 2) experience of home and palliative home care; and 3) negotiation and management of palliative care at home. Open-ended interview strategies allowed questions to be altered to fit each participant and reformulated as new understandings surfaced during the interview (Liamputtong & Ezzy, 2005). Interviews were digitally audio-recorded and then transcribed for data analysis. Interviews with participants who spoke Cantonese or Taishan were verbally translated by myself to English using a digital audio recorder and then sent for transcription.

A translator was used during the interviews with CR4 and CG4, so only the English portions of the interviews were transcribed. Translators are better represented as interpreters, since word-for-word conversion is unlikely during real-time data collection (Esposito, 2001; Temple, 2002). I had instructed the interpreter to repeat word for word in English the interviewee’s comments, in hopes of minimizing interpretation. I was cautious of viewing the interpreter as a neutral transmitter of messages, and considered the positioning of the interpreter in the research process as well. Esposito (2001) also offered strategies for addressing potential threats to validity of translation of transcripts. Esposito (2001) recommends using credentialed interpreters and using back-translation to test the credibility of the translation process. For my study, I only used a credentialed interpreter. Esposito (2001) also suggested increasing credibility of transcripts through back-translation. I conducted accuracy checks on all transcripts by listening to the interview and reviewing the transcript for misspellings, missing words, and meaning. For those transcripts which I translated, I listened to the audio-file in Cantonese/Taishan and re-reviewed the English transcript for accuracy, as Esposito (2001) suggests.
I recognize that use of interpreters and translation of interviews are not as simple as suggested. Temple (2002) warns that interpreters, just like researchers, translate from their own perspectives; thus, interpreters are also active producers in the research process. As the researcher and interpreter for the interviews with care recipients and caregivers in Case 2 and 3, I realize that I may already be engaged in interpretation of meanings when I was translating these interviews. Since I occupied the position of interpreter and researcher, I was already in a position of actively producing meaning in those interviews, but I do not feel that this hindered rigour, but instead added to it. Since I understood Cantonese and Taishan, I had particular knowledge of some of the idiosyncrasies of the language, and may have a better understanding of its more nuanced usages. I tried to retain these unique meanings in my translations from Cantonese or Taishan to English. I was cognizant of being reflexive in how I positioned my translations and my interpretation of participants’ meanings.

Due to the vulnerability of participants, if care recipients or caregivers indicated that they required further psychosocial support, permission would be sought to make a referral through the home care agency, CCAC case manager, or TLCPC. As CCAC clients, participants had access to psychosocial support from social workers or psychologists. None of the participants expressed a need for further psychosocial support.

Case Observations

Direct observations of interactions between Chinese immigrants diagnosed with terminal cancer, their family caregivers, and home care nurses were conducted at the homes of participants during home visits. I conducted two visits with each case and spent between 75 to 90 minutes at each visit. Visits were pre-arranged with the home care nurse. I also pre-arranged with the care recipient and family caregiver to arrive 15 minutes earlier than the home care nurse to observe preparation and stayed after the home care nurse had left to continue observations. An observation guide was used to identify important areas to pay attention to while in the field (Appendix E). Four main observation roles are found in the literature: complete participant, complete observer, observer-as-participant, and participant-as-observer (Hammersley & Atkinson, 2007; Morse & Field, 1995; Roper & Shapira, 2000). Hammersley and Atkinson (2007) argue that there is minimal difference between the observer-as-participant and participant-as-observer roles, but I discuss the differences below, and the role I took in participants’ homes.
In the participant-as-observer role, participants in the field are aware of the researcher’s purpose and dual roles (Morse & Field, 1995). It is understood that the researcher is there to observe the setting, but he or she is also expected to work or participate in the setting. For example, as a participant-as-observer in care recipients’ setting, I would observe care provided during home visits, but would also be expected to help the home care nurse deliver care. There may be conflict when trying to engage in the two roles at the same time, especially in delineating how much time is devoted to observation and providing care. In the observer-as-participant role, the majority of the researcher’s time is spent observing and interviewing with less emphasis on participation (Morse & Field, 1995). The issue with the observer-as-participant role is that participants may consider the researcher an outsider, and thus may not include the researcher in certain activities.

For the purposes of the study, I took on the observer-as-participant role. Hammersley and Atkinson (2007) point out that deciding what sort of role the ethnographer adopts in the setting is dependent on both the purpose of the research and the nature of the setting. The purpose of the study and the setting lent well to the observer-as-participant role. Due to ethical and legal reasons as well, I was not covered for liability to provide direct patient care. The majority of my time was spent observing and interviewing, but I offered assistance with small tasks that were appropriate, such as handing over some papers, getting supplies, etc. Bogdewic (1999) recommends that when the researcher first enters the field, they should be unobtrusive and be observant to the routines and rituals of the home, and to determine what sorts of roles are appropriate for the researcher to take on. I entered care recipients’ homes more as an observer than participant at first to understand the routines of the participants’ homes. When I first entered the home, I was positioned as an outsider, and so offering assistance to the care recipient, caregiver, and home care nurse helped me gain acceptance in the household.

Fieldnotes

Along with observation, I transformed what was observed into written accounts and descriptions in the form of fieldnotes (Emerson, Fretz, & Shaw, 2001). Fieldnotes are representations of the just-observed events, persons, and settings as well as recordings of what has been heard (Emerson et al., 2001; Patton, 2001; Roper & Shapira, 2000). I recorded concrete descriptions of observed social processes and their contexts (Hammersley & Atkinson, 2007). Informal discussions elicited during observations were also recorded in fieldnotes. Silverman
(2000), based on Spradley’s work, suggested that researchers keep four types of fieldnotes: 1) jots made during observations, 2) expanded notes afterwards, 3) fieldwork journal recording problems and ideas, and 4) analytic and interpretative ideas. Fieldnotes may record the physical space, the participants involved, the actions of participants, sets of related acts participants are engaged in, physical objects in the setting, the sequence of things that take place over time, goals participants are trying to accomplish, and the feelings and emotions expressed by participants (Spradley, 1980 in Bogdewic, 1999). Hammersley and Atkinson (2007) pointed out that fieldnotes are selective as it is impossible to capture everything. When I was observing at participants’ homes, I concentrated on recording the above elements but as it related to meanings of home and negotiations of palliative care.

It was difficult to keep direct observations, emerging analytic ideas, reflexive notes, and personal emotional responses separate when making fieldnotes; indeed, Emerson et al. (2001) write about strategies to separate between these types of writings. In terms of the format for fieldnotes, I set up two columns to create some separation between the different types of fieldnote writings. Following the example from Roper and Shapira (2000), fieldnotes were formatted so that on the left-hand side concrete descriptions of what had been observed and heard were recorded as they occurred (see example in Appendix F). On the right-hand side, emerging analytic ideas, inferences, and personal emotional responses were recorded (Emerson et al., 2001; Roper & Shapira, 2000). Despite the separation, it was still challenging to separate the concrete from the analytic thoughts that emerged. Subsequently, initial fieldnotes were expanded upon on the computer using MSWord - within 24 hours after leaving the observational field (Roper & Shapira, 2000). It was necessary to further differentiate between observations, analytic ideas, and reflexions after writing these fieldnotes. I made jot notes while in the home observing visits, and then expanded these jots into more descriptive fieldnotes after I left the participants’ homes. A reflexive journal and analytic memos were kept and entries were made as reflexive thoughts came up after observations, interviews, and during analysis. Reflexive journals and analytic memos are further discussed below. Basic demographic information was collected from participants for sample description purposes (Appendix G).
Data Analysis

Data analysis was concurrent with data collection (Hammersley & Atkinson, 2007; Morse & Field, 1995). In ethnographic data analysis, there is a gradual shift from describing the social phenomenon and its processes to developing and testing explanations through progressive focusing (Hammersley & Atkinson, 2007). To analyze data and engage in progressive focusing, I conducted several careful readings of the data, reduced data through coding of concepts, generated concrete and analytic categories of the codes, and systematically sifted and compared categories for mutual relationships (Hammersley & Atkinson, 2007). To ensure that emerging themes were valid, I met regularly with my supervisor and advisory committee to gain input and consensus on the analysis (Giacomini & Cook, 2000).

Ethnographic inquiry is concerned with what people do and the meanings linked with these actions (Hammersley & Atkinson, 2007). This meant that analysis was focused on the shared meanings constructed by participants through engagement with the social world (Hammersley & Atkinson, 2007). The analysis focused on what key informants, care recipients, family caregivers, and home care providers actually do to negotiate and manage palliative care at home. Central to ethnographic research is the assumption that “in order to understand what people are doing and why, one needs to understand the meanings involved: how they interpret and evaluate the situations they face, and their own identities” (Hammersley & Atkinson, 2007, p. 168). The meanings of home were explored through careful observation and in-depth interviews in order to understand how the meaning of home conditioned negotiations of care. As previously discussed in the theoretical chapter, theory in analysis helps the researcher identify patterns. Working with postcolonial theory allowed me to see patterns that were critical to highlighting the subjugated knowledge and voices of participants.

Analytic Notes, Memos, and Fieldwork Journals

Analytic notes, memos, and fieldwork journals were kept to keep track of emerging analytical insights and theoretical ideas (Hammersley & Atkinson, 2007; Liamputtong & Ezzy, 2005). Analytic notes and memos help the ethnographer engage in an internal, reflexive dialogue (Hammersley & Atkinson, 2007). By keeping an on-going record of analytic notes and memos, this helped to point out important things to continue to observe or ask participants about during subsequent observations or interviews. The fieldwork journal was also used to record personal feelings such as comfort, anxiety, surprise, and shock. Since I was examining the sensitive issues
associated with death and dying, it was important that I kept a fieldwork journal to understand how my own feelings impacted my relationships with participants, how that in turn influenced the data, and how theory could be used to explain what I was seeing and hearing during fieldwork (Hammersley & Atkinson, 2007). These tools were also useful in keeping an audit trail of research activities, and added to the overall rigour of the study.

**Evolving Research Questions**

Sometimes in qualitative research, the initial or proposed research questions and purpose may change as data collection progresses (Bailey, 2007). Although the wording of the research questions and purpose did not change, my understanding of them did. The boundaries of my understanding of the research questions expanded as I delved deeper into the observations and interviews with key informants, Chinese immigrant care recipients, family caregivers, and home care providers. The purpose of the study was expressed as a need to describe and examine how meanings of home condition and shape negotiations of palliative home care between Chinese immigrants with terminal cancer, their primary family caregivers, and home care providers. This original purpose was based on experiences of immigration and postcolonial theoretical conceptions of home, belonging, and citizenship. While the meaning of home for immigrants remained significant and these macro theoretical concepts were expressed in the data, it became evident that there was a need to broadly describe what was happening to the home when Chinese immigrant families and providers negotiated the meaning of palliative care within this place that was usually reserved for living.

In essence, the meaning of home was being re-negotiated as it became a place for dying; and so the purpose remained the same. The related study questions that were originally posed were:

1. What are the meanings of home for Chinese immigrants with advanced cancer, their family caregivers, and home care providers?
2. How does palliative home care change meanings of home?
3. How is palliative care negotiated in the home?
4. What is negotiated in home-based palliative care?

When I first posed the purpose and these research questions, the emphasis was on the meaning of home. While conducting fieldwork and engaging in analysis, as both data collection and analysis were concurrent, the emphasis became the contentiousness of instilling and engaging in
palliative care in this place that is associated with living, routines, and relationships – the home. And so it became apparent that Chinese immigrant care recipients, family caregivers, and home care providers were each working with different meanings, sets of knowledge, and goals for palliation.

While the purpose and questions remained the same, I came to understand them differently from the way they were originally posed. Originally, I was focused on the meaning of home and how this was part of what care recipients and caregivers were able to negotiate with outside providers. As data collection and analysis progressed, I came to see negotiation as not just something that transpired between those living in the home and those that were outsiders to the home, but rather Chinese immigrant care recipients, family caregivers, and home care providers had to negotiate within themselves multiple meanings, layered experiences, and diverse knowledges along with meanings of home in order to conscientiously and purposely engage in palliative home care.

**Using Vignettes**

I have chosen to represent some findings in the form of vignettes. Vignettes are often used in ethnographies (Hammerlsey & Atkinson, 2007). Vignettes have been variously used in qualitative research (Ely, Vinz, Downing, & Anzul, 1997; Spalding & Phillips, 2007). In medicine, clinical vignettes are similar to case studies, which are traditionally used in medicine and nursing as educational and assessment tools (Wofford & Singh, 2006). In social science research, vignettes have been used as an aid to collecting data; vignettes are often shown to participants to elicit and prompt responses during interviews (Hughes & Huby, 2002; Spalding & Phillips, 2007). According to Ely et al. (1997), vignettes can convey the complexity of a phenomenon “in a brief portrayal [of] what has been learned over a period of time” (p. 70). Ely et al. (1997) state

vignettes are compact sketches that can be used to introduce characters, foreshadow events and analyses to come, highlight particular findings, or summarize a particular theme or issue in analysis and interpretation. Vignettes are composites that encapsulate what the researcher finds through the fieldwork. (p. 70)

By using data from each case, I constructed exemplar vignettes that illustrate the layered, entangled, and complex nature of palliative home care for participants. The vignettes are
different from those constructed for clinical teaching, as the purpose of these vignettes is to accentuate interpretations and findings. These vignettes may, in the future, be modified and used as clinical educational tools. The vignettes offer a way to present a cohesive and coherent rendition of the themes by avoiding the fragmentation that may come with only presenting quotes from multiple participants’ narratives to support an analytical point. Rather, by using the data from one case to compose an exemplar vignette, this may convey a sense of the complex predicament of palliative home care for Chinese immigrants with terminal cancer. Spalding and Phillips (2007) argue that vignettes constructed from primary data are trustworthy and representative. I acknowledge that, as Ely et al. (1997) express, vignettes, in their writing and construction, have undergone some level of interpretation. Other methodologists have also pointed out that writing is analysis (Atkinson & Delamont, 2005, p. 834; Hammersley & Atkinson, 2007). In this respect, I recognize that in writing composite vignettes, there has been a level of interpretation performed as well.

Establishing Rigour, Trustworthiness, Quality, and Credibility

It is difficult to select a common terminology for describing rigour in qualitative research because there are numerous and varied terms offered in the literature, such as trustworthiness, quality, and credibility (Corbin & Strauss, 2008). For example, Morse, Barret, Mayan, Olson, and Spiers (2002) argue that terms like reliability and validity should not be abandoned in qualitative research as criteria for discussing rigour even though they are terms commonly used in quantitative research. Lincoln and Guba (1985) established four parallel criteria for evaluation: credibility, transferability, dependability, and confirmability (Morse et al., 2002; Sparkes, 2001). Despite the variability in terminology, what all writers are addressing in rigour, trustworthiness, quality, and credibility is the soundness and worthiness of the research (Morse et al., 2002). Thus I have chosen to focus on the concept of transferability as the criterion for rigour and trustworthiness because of its fit with a postcolonial lens.

In quantitative research, external validity or generalizability is an important criterion for evaluation (Finlay, 2006; Polit, Beck, & Hungler, 2001). Generalizability refers to the degree that results from one study can be extrapolated to another setting or sample (Finlay, 2006; Polit et al., 2001). Although generalizability is not a goal of qualitative research, it is still important to consider how the findings or the knowledge gained could be critically applied to other samples
or settings. Transferability is often used by qualitative researchers as a parallel term for generalizability (Finlay, 2006). To ensure transferability of results or theories derived from analysis, I sought to provide extensive details about the setting and enough information so that the reader could judge how applicable the findings or generated theoretical explanations could be to other samples or settings (Finlay, 2006). From a postcolonial perspective, transferability is the preferred term because emphasis is placed on context, both social and material circumstances and historical context, which I have highlighted in my findings. Postcolonial theorists avoid making generalizing statements that would negate the particular experiences and knowledges of individuals. Through repeated engagement in participants’ homes and careful recording of fieldnotes and reflexive journaling, I was able to generate detailed accounts so that transferability could be judged.

**Strategies**

Despite the debates and lack of consensus between the writers discussed above, all do provide various and useful strategies for establishing rigour, quality, and credibility in qualitative research. I will speak to some of these strategies I undertook during my own research to ensure rigour, quality, and credibility: methodological coherence (Corbin & Strauss, 2008; Morse et al., 2002), identifying negative cases (Patton, 1999; Seale & Silverman, 1997), shadow data (Morse, 2000), and credibility of the researcher through reflexivity (Corbin & Strauss, 2008; Patton, 1999).

Establishing methodological coherence (Morse et al., 2002), also known as methodological consistency (Corbin & Strauss, 2008) entails ensuring that the research question matches with the methodologies, including types of data collected, process of analysis, and theoretical underpinning. Methodological inconsistency may occur when methodologies are mixed up (Corbin & Strauss, 2008). In designing the research, I was conscientious of making the link between ethnographic methodology and postcolonial theory. I collected both observational and interview data to answer my research questions because it is a fundamental aspect of ethnographic research which aims to understand meanings and everyday practices, and also postcolonial theory’s inclination to generate knowledge from participant experiences. Thus I maintained methodological coherence in adhering to the principles of both ethnography and postcolonial theory.
Looking for and explaining negative or deviant cases in datasets are important for establishing rigour and credibility (Patton, 1999; Seale & Silverman, 1997). Seale and Silverman maintain that identifying negative cases helps to develop a more inclusive theory to account for the data, which demonstrates rigour on the part of the researcher. Negative cases may help develop alternative explanations or explanations of why certain cases do not follow the main patterns seen between other cases (Patton, 1999). During analysis, I was mindful of being open to negative cases. The data did not explicitly identify negative case. Instead, the results, following a postcolonial lens, contextualize the different social and material resources participants had to demonstrate the variability in participants’ experiences of palliative home care. None of the cases were definitively a negative case, but by highlighting the contextual differences between cases, it enhanced transferability and credibility of the findings.

Vignettes derived from observations and interviews with cases are further supported and expanded upon from the narratives of key informants. Morse (2000) refers to this as shadowed data where participants may report on others’ social contexts and actions within interviews. These reports are useful because they help to expand and provide a range of perspectives from which to understand the phenomenon (Morse, 2000). I did not use the shadowed data as a means of triangulation because of the controversies associated with triangulation, especially the misconception that triangulating different sources of data, such as interview and observation, will provide a ‘truer’ representation of events (Barbour, 2001).

Sometimes it is falsely presumed that combining different data sources is unproblematic (Atkinson & Coffey, 2003). Problems arise when seeing “what people do” does not coincide with “what people say they do” (Atkinson & Coffey, 2003, p.120). In this case, Atkinson and Coffey (2003) argue that neither interview data nor observational data should be privileged over one another. Such may be the case when analyzing shadowed data – accounts of accounts. Instead, interview data and observational data are viewed as distinct and equally valued sources of data for analysis; thus adding to the rigour and credibility of the study. In working with both interview and observational data, analysis requires a reflexive approach in which a more comprehensive view is sought by paying “attention to the coherence and plausibility of accounts, their performative qualities, the repertoires of accounts, and moral types that they contain” (Atkinson & Coffey, 2003, p. 116; Barbour, 2001). Although the shadowed data is provided in interviews but not observed by myself, it was equally valued to observed data. The shadowed
data was analyzed as a distinctive form of social action that added to the complexity and diversity in understanding these etic categories and what was happening between providers and Chinese immigrant care recipients and family caregivers during palliative home care.

Corbin and Strauss (2008) and Patton (1999) see the credibility of the researcher as intrinsically linked to the credibility of the study itself. The researcher is an instrument of the qualitative inquiry process, and so it is fundamental for the researcher to demonstrate reflexivity to enhance credibility of the study (Corbin & Strauss, 2008; Patton, 1999). Patton (1999) advises researchers to report any background characteristics that may influence experiences in the field. Researcher characteristics include gender, age, race, and ethnicity. In this dissertation, I have been reflexive about how I may be positioned in the research because of the multiple roles I occupy. The following section addresses reflexivity and positionality and the implications to data analysis and relevance to the findings.

Reflexivity, Positionality, and Data Analysis

Reflexivity is an important part of ethnography which reminds researchers that they are part of the social world they study and that their values and beliefs orient them to the research problem a particular way (Hammersley & Atkinson, 2007). Boyle (1994) states that “ethnography has a reflexive character, which implies that the researcher is a part of the world that she or he studies and is affected by it” (p. 165). Because the researcher is the main tool in ethnographic data collection, it was important for me to be reflexive during data collection, data analysis, and generally throughout all processes of the study. I was conscious of the need to be reflexive in my use of the concept of culture and also my own assumptions regarding the meaning of home for immigrants because I myself am a first generation immigrant. Hammersley and Atkinson (2007) caution the researcher to be aware of how personal characteristics such as gender, class, age, and race may shape relationships with participants.

Because ethnographic research is a process that consists of participant observations, interviews, and conversations, the combination of these data types requires reflexive consideration for the mixing of insider/outside interpretations (Boyle, 1994; Hammersley & Atkinson, 2007). As Agar (2006) pointed out, what is reflexive about ethnographic research is that the interpretation of data can speak more about the relationship between the ethnographer and his/her participants than it does solely about the actions, or the meanings attributed to the
actions of participants. Maintaining a reflexive journal also added credibility to the study. Because of the lengthy amount of time immersed in the data, reflexive journals were practical and necessary as it allowed me to keep a record of analytic thoughts and insights. Part of my reflexive work was to explore how my own values influenced my theoretical assumptions. In the following, I share two important reflexive accounts that were crucial in my data analysis and development of the results chapters. These reflexive accounts demonstrate the complexity of putting it all together in data analysis, whilst acknowledging my own positioning in the research process.

**Reflexivity: A Unifying Discourse only Works in Theory**

There are challenges associated with using postcolonial theory to inquire, examine, and analyze the palliative home care experiences of Chinese immigrants, family caregivers, and home care providers. Postcolonial theory and its criticisms have mainly been applied to literary critiques of how binaries between the West and East have (mis)represented the East as primitive, uncivilized, and inferior (Ashcroft et al., 2006). Although works by postcolonial feminist nursing scholars, such as Joan Anderson, Sheryl Kirkham Reimer, and Annette Browne, have provided much guidance in applying postcolonial concepts to a health care context, the challenge persisted in my own efforts to capture and write a fixed account of “culture” while recognizing its dynamic and fluid nature. As Bhabha (1994/2004) reminds us

… it is from those who have suffered the sentence of history – subjugation, domination, diaspora, displacement – that we learn our most enduring lesson for living and thinking… It forces us to confront the concept of culture outside objects d’art [italics from author] or beyond the canonization of the ‘idea’ of aesthetics, to engage with culture as an uneven, incomplete production of meaning and value, often composed of incommensurable demands and practices, produced in the act of social survival. (p. 247)

I believe this quote succinctly points out the difficulties in trying to convey a complete and enduring picture of the ‘culture’ of palliative home care for Chinese immigrants, family caregivers, and home care providers. The ‘cultural’ meaning and value of home, death and dying, palliative care, cancer, Western medicine, Chineseness, immigration, and so on are uneven and incomplete, and are worked over in the face of incommensurable demands and practices that converge in everyday encounters between participants. Thus the complexity can be
overwhelming. What I also take from Bhabha’s quote is the acknowledgement that culture is complex, and that representations of culture are not solely based on finding a “unifying discourse of ‘nation’, ‘people’, or authentic ‘folk’ tradition,” but to examine how meanings are produced within “specific contextual locations and social systems of value” (Bhabha, 1994/2004, p. 247).

Being an immigrant, a caregiver, and a home care provider are subject positions that are particular to specific contextual locations; and just as homes are embedded within social systems of value, so is palliative care. From this, I realized that the results of my analysis could not be written as a fixed, essentialist descriptive account of the barriers, facilitators, and expressed needs of Chinese immigrants receiving palliative home care. While in theory, I should be able to articulate a unifying discourse, in consideration of the fluid and dynamic nature of culture, I could not arguably make claims to a universal understanding of Chinese immigrant experiences of palliative home care. Therefore, I had to reconcile with the fact that what I write today in these results chapters would and should change, because, as postcolonial theory poignantly points out, the (post)modern experiences of globalization, migration, and diaspora create the conditions under which “cultural” meaning and value is constantly in flux (Bhabha, 1994/2004; Loomba, 2005).

I also realized the analysis needed to take into account the situated subjectivities located in the specific contextual locations of being an immigrant, being displaced, and being part of a diaspora. These locations were not specific to Chinese immigrant care recipients, but to all participants. As such, I had to draw on postcolonial theory to grapple with what I mean by meaning. Bhabha views cultural meanings and identity as contingent, partial, transgressive, and indeterminate; as such, they are uneven, incomplete productions (Bhabha, 1994/2004; Spencer 2006). For immigrants, cultural meaning emerges in the confrontation of cultural differences, in the form of taken-for-granted knowledges, long-held assumptions, and conflicting values, which are negotiated in the Third Space, so that hybrid, new meanings can emerge (Bhabha, 1994/2004; McLeod, 2000). I draw from Racine’s (2003) research examining the caregiving experiences of Haitian Canadians to recognize that cultural hybridity acknowledges people’s multiple subjectivities or positionalities through processes of negotiation about cultural meanings. Racine (2003) noted that clinical encounters in the domestic sphere were privileged sites where cultural differences and contradictions were negotiated. As such, I similarly contend that the home, in this study, is the Third Space, in which subjectivities, knowledges, experiences,
interpretations, and assumptions of home, death and dying, palliative care, cancer, Western medicine, Chineseness, belonging, and immigration, collide and must be negotiated by Chinese immigrant care recipients, family caregivers, and palliative home care providers.

**Reflexivity: Re-engaging with Purpose, Theory, and Data**

In qualitative research, especially ethnography, the researcher is immersed in the field and submerged in the data and data analysis for a lengthy period of time (Hammersley & Atkinson, 2007). Admittedly I had lost sight of what originally brought me to this journey, and so I had to re-situate my prior experiences and assumptions with the knowledge and experiences gained through my readings, while in the field, and from subsequent review of my data. What had originally propelled me to research this topic were the tensions I held with my own experiences of death being a taboo topic, and the broader social, political, biomedical, and economic thrust for death to return to the home. Initially, I had the distinct impression that talking about death was taboo for Chinese peoples, and so felt that dying at home would be an uneasy option for this group. I have since had the opportunity to interact with different Chinese immigrant care recipients with advanced cancer, family caregivers, and home care providers, and through my observations and interviews, I became familiar with and privy to a multitude of different experiences of palliative home care. I observed wide variation in Chinese immigrant care recipients’ desire and ability to die at home.

Consequently, what became troubling to me was the expectation (and my lack of ability) to explicate definitively whether Chinese immigrant care recipients wanted to die at home, and how home care providers could support their preference. Again, I had to be resigned to my inability to elaborate a *unifying discourse* (Bhabha, 1994/2004) on dying at home for Chinese immigrants, because “cultural meanings permanently change” (Kalscheuer, 2009); thus, a generalizing statement was difficult to make because cultural meanings were in a constant state of flux. As I reconciled these two things together, I saw that I was again in a space of tension, and a place of struggle – I was in the in-between, the Third space trying to make sense of what I was seeing in my data. Like the participants in the study, I too was struggling to reconcile cultural differences. We were all trying to work through the cultural differences between home, death and dying, palliative care, cancer, Western medicine, Chineseness, belonging, immigration, and so on. I was also working within the confines of academic and scholarly assumptions of qualitative inquiry. We were all engaged in negotiating cultural differences to
generate new, hybrid forms of knowing, understanding, doing, practicing, and being. Thus, I saw that negotiation went beyond trading objects or positions (West & Olson, 1999) between care recipients and providers; negotiation became significant to understanding agency and resistance, and to illuminating the ways participants and I came to clash and grapple with cultural differences.

Although I had extolled the theoretical virtues of hybridity in my research proposal, I do not think I fully grasped its potential until I entered the field, re-read theoretical resources, and began an in-depth analysis of the data. I falsely assumed that my theoretical stance would explicate the phenomenon to me. Instead, what I feel now is that it truly was an iterative process, in that the data, what I saw happening and what I heard from participants’ narratives, also helped to refine my understanding of the theory. Although I am working from the concepts of hybridity and cultural transformation from the work of Bhabha (1994/2004), it was the continual engagement between the theory and the data that better elucidated how negotiation and hybridity appear in the everydayness of palliative home care for Chinese immigrants care recipients, family caregivers, and home care providers.

**Ethical Considerations**

Conducting research with terminally ill care recipients and their family caregivers meant there were many ethical concerns to consider (Bruera, 1994; Kristjanson, Hanson, & Balneaves, 1994). Although care recipients with advanced cancer are considered a vulnerable population and there are questions regarding whether it is ethical to conduct research with this population, I agree with Kristjanson et al. (1994) that dying persons are still considered autonomous beings that have the right to decide whether to participate in a study. Ethical approval was obtained from the Office of Research Ethics, University of Toronto; the Joint Research Ethics Review Board (JREB) for Bridgepoint Hospital–West Park–Toronto Central CCAC; and the Mount Sinai Hospital Research Ethics Board. Neither of the home care agencies had their own ethical review boards and accepted the ethical approval granted by the University of Toronto and the JREB.

**Informed Consent and Ongoing Consent**

As previously described in the recruitment protocol, informed consent from the key informants, care recipients, family caregivers, and home care providers were obtained prior to data collection (Appendix C). The purpose of the study was not withheld from participants; thus,
care recipients had to know of their terminal diagnosis. Consent was considered an on-going process as there may be changes to the physical and emotional well-being of the care recipients and family caregivers during data collection (Kristjanson et al., 1994). I asked participants on an on-going basis if they wished to continue to be in the study and allowed for ample time for participants to review the consent form and to answer any questions they had during observations or interviews.

Privacy and Confidentiality

Privacy for interviews was a challenge for care recipients and caregivers since they lived together and interviews were mostly conducted in their homes. I accounted for the fact that some homes may be small or there may be many people around, and so it may be difficult to maintain privacy. I anticipated making accommodations to meet participants outside of the home if necessary. I made every effort to ensure privacy by carrying out interviews in an enclosed room or asking other family members to leave the room. Most key informants were interviewed at their offices, homes, or at the Lawrence S. Bloomberg Faculty of Nursing, but some key informants wanted to be interviewed in a coffee shop and so I would arrive earlier to find a more secluded area in the coffee shop to ensure as much privacy as possible. I was able to conduct all interviews individually and in privacy except with CR4 and CG4. CR4 and CG4 were an elderly couple who spent much of their time together in the family room, where the interview took place. When I explained about privacy, the couple expressly stated that they wanted the other person in the room during their interviews so that they could refer to each other for support.

All of the data collected was kept strictly confidential. All hard copy data, such as fieldnotes and memos, were stored in a locked filing cabinet at the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto in an area that is protected by electronic key access. All electronic data and audio-recordings were kept on a password protected institutional server at the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto in an area that is protected by electronic key access. Participants were assigned a unique identifier code to ensure privacy, and transcripts were anonymized by removing identifying information such as people’s names and places. Audio-files were erased once they were transcribed.

Risks and Benefits

As in all research studies, there were inherent risks and benefits. It is possible that some participants found it enjoyable and helpful to talk about their experiences and may even have
developed a better understanding of how they negotiated and managed palliative home care. Participants may have derived satisfaction in the possibility that their contributions increased awareness of how the health care system might better support palliative home care for immigrant families. The potential risks in the study were minimal because it involved interviews and participant observation. Participants may have found it uncomfortable or upsetting to talk about their experience but every effort was made to ensure participants felt comfortable and safe. The participants were informed that they could skip any questions they did not want to answer, or if they did not want to be observed at any time during observation visits, this wish would be respected. They were also informed that they could withdraw at any time with no consequences to their care or employment. Language was an important consideration in the study, specifically around the use of the words death, dying, and cancer. I paid close attention to the language used by participants to talk about death and dying, i.e. euphemisms or avoidance if participants were actively avoiding those words.

**Compensation**

Because participants were likely inconvenienced by the need to arrange time, space and, possibly, child or family care for the interview, an honorarium of $30 was provided to key informants and home care providers, and a $30 gift certificate to Shoppers Drug Mart was provided to care recipients and family caregivers.

**Conclusion**

Focused ethnography is used to examine a specified social phenomenon, and the meanings of behaviour, language, and interactions embedded in daily activities. An ethnographic approach was well suited to examining how changing meanings of home for Chinese immigrants receiving palliative home care, their family caregivers, and home care providers came to shape the daily activities involved in negotiating palliative care at home. A key strength of this study has been the emphasis on positionality and reflexivity so that the knowledge of participants is not taken-for-granted or further subjugated. Thus the tenets of ethnography and the principles of postcolonial theory worked well together to highlight and give voice to participants’ experiences and knowledges.
CHAPTER 6
COLONIZATION AND DISTANCING: THE EVERYDAYNESS OF DYING AT HOME

Introduction

This chapter is the first of two results chapters. An in-depth analysis highlights the transposition of participants’ homes from what might be considered private spaces for living to less sequestered spaces, opened up for scrutiny as places for dying. This chapter addresses the first two research questions: 1) What are the meanings of home for Chinese immigrants with advanced cancer, their family caregivers, and home care providers? and 2) How does palliative home care change meanings of home? This chapter provides an analytic description of how the meaning of home shifts when a Chinese immigrant care recipient with terminal cancer receives palliative home care. The analytic description is interpreted and conceptualized under a postcolonial framework, using colonization as a metaphor (Refer to Chapter 3: On Language – Colonization as a Metaphor).

Organization of Results

The results have been divided into two chapters: 1) Colonization and Distancing: The Everydayness of Dying at Home, and 2) Negotiating Hybridity: Home as the Third Space. As Hammersley and Atkinson (2007) point out, “one of the major problems [of ethnographic writing] is that the social world does not present itself as a series of separate analytic themes… we have to disentangle the multiple strands of social life in order to make analytic sense of them, before we reintegrate them into the synthesis of an ethnographic account” (p. 193). Thus, in presenting the results, I recognize the complexity and entanglement of these themes, but for a clear, understandable ethnographic account, themes have been separated into two chapters to better expand, support, and describe what is going on in the household with study participants. These themes are based on ‘etic’ categories that reflect the theoretical lens (Hammersley & Atkinson, 2007). Analysis was inductive, but key analytic findings are organized and linked to significant theoretical concepts in postcolonial theory. Chapter 6 focuses on colonization and distancing while Chapter 7 focuses on negotiation and hybridity. I illustrate each category with a composite vignette (one from each case) to help describe, understand, and analyze the multiple layers of meaning and value embedded in palliative home care for Chinese immigrants.
It may seem in the first results chapter that instances of colonization and distancing may be no different from any patient, regardless of ethnocultural background or immigration status, with advanced cancer receiving palliative home care. And this is true. But it is important to remember that these interviews were conducted in the context of speaking about Chinese immigrants. The *incommensurability* that Bhabha (1994/2004) refers to was present in home care providers’ narratives as they struggled to reconcile what they thought were *demands and practices* that were distinctive of their Chinese care recipients with those that they saw as similar across palliative care patients in general. Often during interviews, key informants made comparisons and saw similarities between Chinese immigrant care recipients with other care recipients from different ethnocultural backgrounds, and were apologetic that they could not provide more specific examples. The blurring in the meaning of culture, palliative care, and home was a result of an integration of the different experiences and knowledges that providers could draw from. The complexity of integrating taken-for-granted knowledges, long-held assumptions, and conflicting values was evident and will be further discussed and elaborated upon in Chapter 7 on hybridity and negotiation.

Chinese immigrant care recipients and family caregivers spoke as individuals who were immigrants, who had been displaced, and were part of a diaspora; but were also now re-settled. They also spoke from the position of having cancer and being palliative, and many other positions such as spouse, immigrant, worker, host, citizen, etc. These Chinese immigrant care recipients were not only speaking as Chinese descendants, and so it was expected that the experiences of colonization by and distancing of palliative care could be applied to any care recipient receiving palliative home care. But there were experiences and ways of understanding palliative home care that could be particular for individuals who have experienced immigration, displacement, and re-settlement.

**Colonization and Palliative Home Care**

As previously discussed, colonization is used as a metaphor to describe what happens when Chinese immigrants with terminal cancer receive palliative home care. Colonization was a mutual process in that care recipients, family caregivers, and providers were all deeply enfolded in relations of palliative care. Palliative care is an institutional structure with its own set of values, norms, and functions. Gradually the values and norms of palliative care were introduced
to the occupants of the home. Ultimately, palliative care disrupted the norms and routines that care recipients and their family caregivers associated with living at home. As their bodies, homes, and needs changed, care recipients and family caregivers were often confronted with the fact that they could no longer go on as they had before, and they needed to re-write routines. In this sense, colonization and distancing went hand in hand and were fluid as needs changed.

Although all participants engaged in both colonization and distancing, I have chosen vignettes that are exemplars of each. As such, there may be overlap between vignettes. Distancing may be seen within this first vignette, but the focus will be to illustrate how colonization of the home by palliative care took place.

This first vignette is a composite of observational visits conducted during home care visits with CR1, CG1, and HCP1. CR1 and CG1, her husband and main caregiver, lived together in a newly built condominium. Both were recently retired. CR1 was diagnosed with stage 4 lung cancer and had been battling cancer for the past 8 years, but was only designated as needing palliative care within the last year. CR1 and CG1 had immigrated to Canada from Hong Kong over 30 years ago, and were proficient in English, but spoke Cantonese with each other. The couple received support from their grown children, who were married and lived close by. CR1 also had support from family members who were medical professionals. HCP1 had been visiting CR1 weekly for the past few months. Although HCP1 had previously cared for many palliative immigrant patients, this was the first Chinese family in her caseload.

Vignette 1: Case 1

The day before our visit, HCP1 gave me an approximate time of arrival, between 2:30pm and 3:00 pm, for her visit to CR1. On the day of the visit, I called HCP1 to get a closer estimate of her arrival time. She was running a little earlier and so would be arriving just before 2:30 pm. When HCP1 arrived, we (myself, HCP1, and her nursing student) called up to CR1 who buzzed us in. We were let in by CG1. CR1 was sitting in a cushioned chair facing the door at the other end of the apartment. We took our shoes off as we entered, and went to the living room to sit. Everyone seemed to have a designated seat. CR1 had stage 4 lung cancer. She was wearing nasal prongs that were fed by a long, clear, narrow plastic tube that snaked across the living room and disappeared into another room (probably attached to an unseen oxygen machine). There was a rhythmic, background hissing sound that pervaded the apartment from the oxygen machine. As soon as we came into the apartment, CR1 noticed that neither the nurse nor nursing
student was carrying any papers. She immediately asked the nurse if she had forgotten her chart as the nurse had taken it with her the last visit but promised to bring it back. HCP1 jokingly responded that she had forgotten and asked why didn’t CR1 remind her when she called last night to schedule her visit? HCP1 told the care recipient that between her and the nursing student, they’d be able to remember enough to chart it later; but CR1 was not satisfied and insisted her husband get paper for the nurse to write on.

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HCP1 told CR1 that she wanted to listen to her chest, and so CR1 automatically leaned forward from her chair to let HCP1 press her stethoscope on her back. HCP1 was surprised as she heard air sounds in the lower right lung. CR1 smiled at this and said coyly, maybe she’s doing better. CG1 sat silently and watched. HCP1 asked the student nurse to take CR1’s blood pressure while she asked her questions about her recent chemotherapy appointment. CR1 turned to face the student and rolled up her right sleeve; the nursing student placed the blood pressure cuff on and took the blood pressure. CR1 looked away and stayed silent as the student took her blood pressure. The nursing student stated that the blood pressure was 109/65. As the nursing student took the blood pressure cuff off, CR1 automatically extended her right hand out with her wrist facing up. The nursing student took CR1’s wrist and began to take her pulse.

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CR1 explained to HCP1 that she had asked her hospital social worker to arrange a tour of the palliative unit, but had not yet heard back. HCP1 suggested she book the tour directly with the palliative unit herself. CR1 questioned whether she could do this. HCP1 told her it wouldn’t hurt, and if they said no, then CR1 could wait for her social worker to do it. HCP1 explained that she encouraged clients to visit hospices and palliative care units for tours while they still could. CR1 looked at her husband and stated, “See, I’m not the only one.”

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CR1 stated that what she was really concerned about was if she deteriorated at home and required a PSW, could she get one that was Chinese so that she could speak with her in Chinese, and have her cook Chinese food? She asked if this could be pre-arranged with home care. HCP1 responded by saying that they could discuss this with her case manager when the time came, and explained that for palliative patients, they could arrange for a PSW or home-maker fairly quickly. HCP1 told CR1 to stop wasting her energy thinking about these things, and tried
to comfort CR1 by telling her that they would be there to help her. HCP1 said that for the duration, they will try to take care of CR1 at home as long as possible. HCP1 told CR1 to embrace her situation – that she was not dying now, and that she’s had lots of time to think about this. She needed to enjoy and celebrate the time that she had. CG1 smiled and nodded at HCP1’s comments. CR1 reluctantly responded, “I suppose so. But all I have now is free time to think and plan.”

Colonizing Forces

In the above vignette, there are several examples of how colonization of the home by palliative care can take place. These occurrences have been further divided into four thematic categories outlining the colonizing forces that allow colonization to take hold: 1) establishing the presence of palliative care in the home; 2) professionalized knowledge on dying at home; 3) organizing palliative home care; and 4) strategizing and positioning support. In the following sections, I will work with the vignette to illustrate how colonization may be subtle or overt, easy or difficult to identify, and mutual and fluid in how palliative care comes to take over the home.

Establishing the Presence of Palliative Care in the Home

Metaphorically, palliative care took over care recipients’ homes in varying and mutual ways. First and foremost, cancer infiltrated care recipients’ bodies, their space, and interactions. The care recipients became colonized by cancer as foreign cells invaded their body. As cancer cells grew and attacked a particular body system or ventured further and metastasized, the presence of cancer was evident in care recipients’ talk about pain and changes in their functioning or conduct of daily routines. For CR1, cancer was very present as she wore nasal prongs all the time to get enough oxygen to her lungs. Her laborious breathing was noted, especially when she spoke at length during our individual interview. She frequently paused mid-sentence to catch her breath. CR1’s body was physically colonized by cancer. In our interview, HCP1 noted the bodily changes in CR1 because of the lung cancer:

She (CR1) keeps telling me, “I function as half a person, I am not a full person.” Uh which is actually easy for her to see because her whole body shape is changing because the breathing, you know. Your body changes, your um, skeletal system changes to try and expand. It’s amazing the body, the whole, the body shape, the ribcage; everything changes as one side becomes more dysfunctional. It might be wasted more on the one side and you’ll see that the one lung is
working better. That side, her arm is stronger and thicker than the other side, she is more full on that one side. She really is like half a person. (HCP1)

HCP1 recognized that CR1 no longer felt like she belonged in her own body as it had significantly changed due to the lung cancer, and would continue to be less familiar as her disease progressed.

Other providers also saw how cancer changed care recipients’ bodies, especially when care recipients were in pain. This community palliative nursing consultant described meeting a client for the first time:

*You see a lot of head and neck cancers in the Chinese population. I had this one little guy, he was as cute as a button and his pain was really out of control... he was actually lying in the fetal position and curled up in bed with the sheets curled over his head.*. (KI6)

KI6 was a witness to the excruciating pain many cancer patients experience. The presence of cancer was expressed in physical manifestations of pain, fatigue, weight loss, difficulties breathing, etc. The resultant uncontrolled symptoms allowed for further colonization by palliative care. Often care recipients who experienced pain and symptoms wanted advice from providers on how to manage their symptoms. By allowing home care providers to help monitor and manage their pain and symptoms, this opened the possibility of personal and domestic colonization.

The home became colonized as home care providers, such as palliative physicians, home care nurses, PSWs, physiotherapists, hospice volunteers, etc. established a presence in the home. By establishing a presence, providers were claiming the home as a place for palliative care and dying. The constant presence of providers also acted as a reminder to care recipients that they were dying. Palliative home care providers’ claims to care recipients’ personal and domestic spaces were reinforced in the form of weekly visits and/or regular contact by phone. These interactions were inherent in the role of palliative home care providers to provide and do palliative care.

Care recipients’ homes were also noticeably altered when equipment and assistive devices were brought in to improve quality of life and help manage activities of daily living. The rooms inhabited by care recipients changed to adjust to their evolving needs, thus making these areas amenable for care provision as illness progressed. Often care recipients required hospital beds, commodes, and walkers, and space in the home was made to accommodate the new
equipment. CR1’s relationship with her living space was changed because she required an oxygen machine to breathe. Hidden in her bedroom was an oxygen compressor. She was connected to the machine by nasal prongs at the end of a long tube that snaked around her apartment and followed her wherever she went. The compressor created a constant background of hissing sounds that prevailed in every room. Although the oxygen machine was there to improve her quality of life, it was also a constant visual and auditory reminder of the cancer that occupied her lungs. Often, equipment changed the function of rooms, and how they were used. With Case 4, the care recipient was no longer able to go upstairs to her bedroom, and so her family had set up a bed for her in the family room. On an observational visit, I noted the equipment around her bed:

CR4 was sitting up in a make-shift bed (a twin mattress and box spring on the floor) that was pushed up against a wall in the family room. The bed fit nicely in between the couch and television... I noticed there was an assistive bar on the side of her bed to help her sit up and her pillow was propped up by a foam wedge... in the hallway I noticed the commode and a cane near the powder room. I learned that they were there to help her go to the washroom safely. (Case 4: November 17, 2010)

The assembly of equipment claimed the room, changing its purpose and arrangement, further embedding the presence of palliative care. The family room was now colonized and served the purpose of housing someone who was dying. The family room was no longer a place where the family congregated; regrettably, it became a lonely and isolating place for dying. CR4 explained that her adult children who lived with her rarely kept her company in the family room anymore; it was as though they felt that they did not belong there.

A reciprocal relationship developed as palliative home care providers routinely came to visit and interact with care recipients. As seen with CR1, her physical behaviours were adjusted to home care as she automatically reacted and performed what HCP1 and the nursing student needed her to do during the routine physical assessment. No instructions were required as the nursing student took CR1’s blood pressure and pulse. CR1 transitioned smoothly between procedures, and anticipated what was expected of her during the assessment, such as turning her wrist and presenting it for a pulse. Thus, the established and regular presence of palliative home care providers resulted in a coordinated exchange between the provider and care recipient. The insertion of palliative home care providers into care recipients’ domestic spaces and lives were
insidious and subtle; and so, care recipients and families may be initially unaware and slow to resist the colonizing effects of palliative care.

For many home care providers, caring for dying care recipients was different from caring for those who were receiving chronic non-palliative home care. Providers saw the demands of palliative care recipients as different and having greater priority in their caseloads. Thus, establishing presence was reciprocal. The demands of palliative care recipients weighed heavily on some providers, and claimed more of their time and space, even after they left work and went home. During our interview, HCP1 told me how all-consuming it was to be a home care nurse:

*My husband and kids will you tell this, that I give it all to my patients then I come home and I’ve got nothing left to give at home, when I come home. Um and being a community nurse means you are driving around on your own a lot so you might be seeing patients all day and talking, talking, talking, but you’re actually very lonely and on your own... I have to be sympathetic in that um, I am going through it [the dying] with [them] and I know the motions of how to support them through it, but I can’t get emotionally involved.* (HCP1)

HCP1 had to work at not getting too emotionally involved with dying patients because it could easily take over her home and family life as well.

A community palliative nursing consultant also shared how working with dying care recipients left deeply impressionable memories. The presence of these memories demonstrated the power of being part of someone’s dying experience. Her narrative illustrated how these experiences of caring for the dying remained in her memory and further embedded her in the system of palliative care. She recalled a chance encounter with the parent of a child she had cared for at end-of-life:

*... she [the parent] said, “You were one of two nurses that were the best nurses I ever had when my son was dying”... and we’re talking a long time, probably 20 years, it was over 20 years ago... I said, “Wow I can’t believe you can remember.” So she described because I was, “Oh no, I am not going to remember who her son is,” right? But I did remember, I did... it was mindboggling to me. I was so touched that first of all that I, you know, I had made that kind of an impact on somebody’s life, but that she could remember that. It’s outstanding.* (KI8)

KI8 was acutely aware of how providers could have a profound impact on how families remembered palliative home care for their loved ones; but also indirectly, demonstrated the persistence of memories for the provider as well. The presence of these memories had a
colonizing effect as she carried them forth in her care of other palliative home care recipients, and became mindful of the memories she would be leaving behind with families.

Visits by palliative home care providers were not seen as solely invasive and disruptive encounters. Care recipients and family caregivers were comforted by the fact that providers were watching over them and available for questions about care and the disease process. While the presence of palliative home care providers and the threat of mortality were established in care recipients’ homes, having the ability to contact and ask questions of providers gave care recipients, and especially family caregivers, a sense of relief. During home visits, home care nurses offered support by listening and talking with care recipients and family caregivers about their concerns. In her interview, CR1 recognized the benefits of working with the CCAC case manager and home care nurse in helping her stay in a familiar place:

*So they always say that it’s good to be at home. So I am grateful that the case supervisor A. and also HCP1 helped me to know more about palliative care at home. I know that it is true they have a very wide network of support, okay? And I was told that I could have 7, 8, 7 times 8 - 56 hours of support of PSW for a week. And then a nurse can come anytime, you know, and I have all sorts of equipment arranged to be at home. So I am grateful for all of this information.* (CR1)

Because the home care nurse visited on a weekly basis, CR1 felt that she could ask her to help her find resources and supports easily. HCP1’s routine visits and persistent presence was a comfort for this care recipient because she knew that there was a wide network of supports available to her.

Thus the established presence of palliative care staked a claim on care recipients’ homes. Colonization, in the process of nation- and empire-building, relied on settlers to stake a claim on lands, and make claims over the governance of the indigenous inhabitants (Loomba, 2005; Tuhiwai Smith, 1999). In staking a claim, settlers were establishing their presence in a foreign land, and making their intentions to stay known. Similarly, cancer physically staked a claim and occupied space in care recipients’ bodies, resulting in pain and other symptoms. The need for symptom management and guidance in dying at home enabled palliative home care providers to enter the home and gradually establish a presence. The data also pointed to how care recipients could also stake a claim on providers. Caring for the dying occupied and often remained on providers’ minds, even long after the death. Thus, colonization was mutual.
Professionalized Knowledge on Dying at Home

As palliative care staked a claim on care recipients’ homes as a place for dying, claims were also made on how dying at home could and should proceed. Palliative home care providers were seen as having expertise on dying at home. Their educational training, work with dying patients, and knowledge of the palliative care system was valued by care recipients and family caregivers, who had less experience with the system and death at home. In part, these claims were supported by lay people’s lack of experience with dying. KI8, a community palliative nursing consultant, questioned society’s overall lack of experience and comfort with death, especially in the home:

... for anybody they just don’t want to be associating the death process with home because it’s a difficult and unspeakable topic, and it’s traumatic.... The more society moves in that direction, the less comfort we have because you can live a long time and never see a dead body and never see a, maybe you don’t need to, I don’t know, but that is a fact of life... if we continue to always send everybody to hospital and not look at it, do we, do we ever get a comfort with that? I don’t know. (KI8)

In part, the lay discomfort with death may also stem from the lack of representation of “normal” deaths in the media. There may be over-exposure to gruesome deaths as portrayed in horror movies, or reported in the news. The lack of experience and comfort with death of care recipients and their families perpetuated the need for experts on dying at home, or a desire to remove death from the home entirely.

Assertions to professionalized knowledge on dying were associated with providers’ titles, and came in explanations of their defined roles, which were often set out in the introductory first meeting. As this palliative care physician indicated in his interview, first and foremost, he had to explain what his role was to care recipients in providing palliative home care:

So often for me it’s about explaining to people what my role is. That I am partly here to help with quality of life, and I’m partly here to help the team, who is trying to look after you, do their job, you know, well for you. And then part of my job is about helping make preparations for death. (KI10)

The professionalized knowledge that comes with such a specialized role had to be explained to care recipients and families so that they understood the goals and capabilities of palliative home care. Providers were there to provide care and to do their job by imparting information and
knowledge on palliation and the process of dying. The vulnerability of care recipients and the uncertainty of the time and circumstances of death positioned providers as experts on palliative care and dying, facilitated their access to care recipients’ homes, and enabled colonization of the home.

Professionalized knowledge was often sought by care recipients and families on many things, such as disease trajectory, available resources and supports, psycho-social support, treatments, pain management, and generally, what to expect at end-of-life. CR1, in the above vignette, wanted professionalized knowledge and advice from HCP1. In fact, CR1 legitimized her desire to tour palliative care units by having the home care nurse confirm, in the presence of her skeptical husband, that this was a valid activity at end-of-life. CR1 saw the home care nurse as having a specialized knowledge in this matter, and used this authority to validate her wish to tour hospices and palliative care units.

Having a claim on professionalized knowledge on dying at home meant that providers had a key role in educating care recipients and families. Providers demonstrated their professional knowledge by imparting information and educating care recipients and families on what to expect when the care recipient was actively dying. As this CCAC case manager explained:

... it’s a daughter and her father. And he’s been confused from time to time. He is getting weaker and I told her that it’s part of the disease. You will see that. So, I don’t want people to get surprises. Like I do tell them that, you know, this is normal during palliative care, end-of-life. So don’t be surprised. And I do tell them at some point, if they start to be more confused or they don’t recognize you, it’s the disease - the end is closer than it was like a week ago. (KI4)

By sharing with the caregiver what to expect with her father’s decline, the case manager was demonstrating she knew what the dying process looked like. KI4 educated the caregiver because she wanted the family to be prepared for the death and to anticipate it. She did not want the family to be surprised by it. Through judicious information giving and education, the principles of palliative care were conveyed to help coordinate the process of dying at home.

Despite efforts to educate care recipients about Western palliative approaches to cancer, some Chinese immigrant care recipients still sought other options or courses of treatment, such as the use of complementary or alternative therapies like traditional Chinese medicine. The care
recipient in Case 2 was diagnosed with liver cancer on a business trip to China, and had seen a Chinese and Western doctor when he came back to Canada. He acknowledged that:

Yes, I saw a Chinese doctor and then he cheated me out of $10,000 dollars, $20,000 dollars...

So, with this type of illness you shouldn’t go see a Chinese doctor because they’ll just trick you out of your money. Chinese doctors, they can’t cure you of this. So if I hadn’t gone to see a Western doctor, I wouldn’t be here. (CR2, translated)

CR2 had initially sought treatment from a Chinese doctor to cure his cancer, but it did not work. He expressed his anger at being cheated out of thousands of dollars, and acknowledged Western medicine’s role in keeping him alive thus far. For CR2, who had been labeled terminal for several years, he felt that Western medicine had a legitimate claim to professionalized knowledge on cancer care. Yet, he continued to use traditional Chinese medicine alongside his cancer medications. Although CR2 accepted and trusted his oncologist and the palliative home care providers that represented Western medicine, he proclaimed his own knowledge of his body and cancer as he continued to use traditional Chinese medicine. CR2 did not acknowledge any sense of precariousness owing to his prolonged assignment of a “terminal” status; instead, he expressed pride in surviving for so long. Perhaps he attributed his longevity to both Western and traditional Chinese medicine.

As seen, perceived knowledge imbalances supported palliative home care providers’ efforts to make recommendations and coordinate activities of palliative care because of their highly specialized knowledge and positions as gatekeepers to resources. In the colonization of nation-states, settlers proclaimed higher ideals and greater knowledge than indigenous inhabitants about how states and subjects should live and be governed. Likewise, palliative care providers were able to make claims to professionalized knowledge. Similar to the concept of medicalization, “experiences which were once seen as a normal part of life, such as pregnancy, childbirth, aging, dying and bereavement, have been deemed matters for medical concern and control” (Field, 1994). As discussed in Chapter 3: Theoretical Framework and Key Concepts, science and biomedicine profess legitimated knowledge claims related to palliative care and the processes of dying. Although Chinese care recipients wanted providers to educate them and share their knowledge on dying at home, they also made claims to knowledge as well, referencing their own experiences and bodies as evidence.
Organizing Palliative Home Care

Providers of palliative home care were seen as having things that were desirable to care recipients and could help prepare them for their journey in dying at home. Referral and assessment were key to getting Chinese immigrant care recipients connected to palliative home care. Once connected, palliative home care could be organized. This CCAC case manager explained what happened once a care recipient was referred for palliative home care:

*What we do, as a case manager, we do assessment in client’s home to determine their needs and um, services that they need. And then we’ll follow up with other service providers, with families, clients. We’ll also deal with medical supplies and your referrals to palliative specialty teams um, and like there’s also piece of education to families and clients. Why I like it? It’s rewarding. Like you do see families in distress, and they are quite vulnerable. And they don’t know what to do because like the system is so complicated.* (KI4)

KI4 illustrated how a complicated system sets up the conditions in which CCAC case managers and home care providers were needed to help organize and guide care recipients and families through the process of dying at home. Families were in distress and vulnerable, and were in need of case managers and home care providers. Immigrants may be even more vulnerable because they have not lived with an understanding of the Canadian health care system, but only came to learn about it after migration, and often only when it was needed. It was clear that providers were confident in the benefits of palliative care and were themselves colonized by palliative care. But again, the intent of the providers was to do their jobs, and to do it well. As KI4 indicated, she liked her work because she found it rewarding to help families navigate through the complex palliative care system.

Referrals and assessments often outlined what care recipients and family caregivers required to enable dying at home. Case managers were often the first to make contact with care recipients and caregivers. They helped to identify the supports and services that were needed and that could be provided. Palliative home care was socially organized so that offers were made and negotiated, based on the needs and wishes of the care recipient and family, and the needs anticipated by providers. The organization of palliative home care was never a simple matter of providing education and handing over equipment. There were levels of reading and reciprocation that were required from the provider. For this case manager, working with Chinese immigrant care recipients who did not speak English and having a family member translate, added an extra
layer of complexity in trying to determine if the care recipient understood their diagnosis, her role, the role of the CCAC, and how palliative care would proceed:

*So it could be very overwhelming to families uh, because they are entering a system of services and dealing often with a pretty recent prognosis... So, uh, I am letting them know about CCAC services, they may or may not have had CCAC services before. Who do we work with, like physicians, palliative care units, community resources... I always uh, involve the client in the conversation as much as possible. So sometimes that would be like, “Stop, please explain to her what I just said. Does she have any questions? Do you know why I am here?” Because the family member may be like 5 steps ahead of where the client is. So I have to make sure that I include them in the conversation.* (KI9)

For KI9, the initial assessment was layered and complex, especially with Chinese immigrant care recipients and families who struggled with English language proficiency. Within the initial assessment interview, the case manager was responsible for explaining what palliative home care entailed; figuring out whether the care recipient understood his or her terminal diagnosis; helping the care recipient and family develop a care plan; and setting up the appropriate services. Organizing palliative home care was challenging for providers, because they had to put all these things together on behalf of clients who were newly confronted with the complexities of both illness and terminal diagnosis.

Providers understood that a patient’s condition could change rapidly. Accordingly, providers had to stay in contact with care recipients, caregivers, and other providers to anticipate and negotiate the shifting needs of care recipients. The established presence of providers in homes allowed providers to monitor care recipients’ conditions. Providers had to anticipate and react accordingly to ‘crises’ that would challenge the intention to die at home, and steps would have to be taken if care needed to be re-organized. KI8, a community palliative nursing consultant, defined a crisis as:

*... a crisis in my mind [is when] somebody was dying and, and we weren’t allowing the death process to be peaceful. And I mean we were trying to bring back somebody that there was no chance of his recovery... just the lack of acceptance and knowing everybody not being on the same page.* (KI8)
The word “crisis” was often used by providers and referred to an incidence of chaos and confusion in which care recipients and families deviated from the plan of care and death, and threatened dying at home.

Deviation usually meant the care recipient’s condition changed drastically or unexpectedly for the worse and resulted in the family calling 911 or going to the Emergency, instead of calling a provider to guide them through the situation. Calling 911 or going to Emergency meant the care recipient was not able to die at home, in a palliative care unit, or hospice, which seemed to represent a failure to the providers. HCP4, a home care nurse explained:

*If the client [is] willing to stay at home to die so then there’ll be, the consultant will can come to see the client [at] home as well. So, no hurry to call emergency, go to emergency again. (HCP4 - English was his second language)*

Most providers stated that they tried to avoid a crisis moment at end-of-life by providing care recipients and families with supports and education, and setting up a plan of care and a plan for death. Consequently, attentive monitoring and coaching was important to avoiding a crisis. Home care providers made sure they kept in contact with the care recipients, caregivers, or other providers to monitor for signs of a crisis. Home care providers provided education to care recipients and families about what to do in case the care recipient’s condition changed, especially who to call. Thus establishing a presence and organizing care went hand-in-hand. Care recipients, caregivers, and providers at varying levels carefully monitored each other and worked collaboratively to ensure that the dying care recipient could be cared for and eventually die at home, or transitioned to a hospice or palliative care unit at the appropriate time.

And so the dependency was mutual between care recipients, family caregivers, and home care providers. Providers depended on care recipients and family caregivers to become knowledgeable and vigilant about monitoring their own progress or that of the dying family member. Thus an aim was to organize palliative care in a way that normalized it within the home for care recipients and family caregivers. Since providers could not be there all the time, they relied on care recipients, and most often family caregivers, to notify them when the care recipient’s condition changed, or when more palliative home care support was required, opening the home up to further colonization. With Case 1, CR1 demonstrated how she became socialized to palliative care as she became vigilant about her own condition and the potential future need
for a PSW as her condition deteriorated. She questioned whether a PSW would be available when she could no longer independently care for herself, and whether this PSW could be Chinese so that she could have Chinese meals cooked for her. She became active and vocal in organizing and planning her own death; in fact, she admitted that she was engrossed: *But all I have now is free time to think and plan.* Her socialization was fluid, and she continued to voice her preferences, despite the limited options offered by home care, so that she was not completely usurped and colonized.

As palliative home care providers staked and made claims to the home, palliative care was organized so that its presence was gradually taken-for-granted by all participants. Those invested in colonization were themselves colonized into an ideal of how nations and subjects should live and be governed. They were committed to the cause of expanding the empire, building wealth, and gaining governance over the indigenous inhabitants (Loomba, 2005). There is no doubt that colonizers benefitted, in wealth and status, from marginalizing indigenous inhabitants as intellectually inferior and lacking in civility (Tuhiwai Smith, 1999). Thus indigenous inhabitants became the Other in their own lands. Similarly, Chinese immigrant care recipients were positioned as the Other in their own homes as their lack of knowledge of the palliative care system and dying at home was highlighted by the need for palliative care providers. For immigrants, their knowledge gap was often heightened by a lack of English language proficiency, which also hindered their ability to navigate the system. Getting acceptance from inhabitants was crucial to colonization. Although colonizers created a separation between themselves and the indigenous inhabitants, there was still a need to get inhabitants to support the cause as well. In the case of palliative home care for Chinese immigrants, providers had to educate care recipients and family caregivers on dying at home so that this cause could be well organized and achieved. Establishing a presence and organizing palliative care allowed for palliative care to stake a claim on the home.

**Strategizing and Positioning Support**

Positioning support was a colonizing tactic that providers used to connect with Chinese immigrant care recipients and family caregivers. Providers talked about various strategies through which they positioned their support with care recipients and families so that they could gain acceptance as guests in care recipients’ homes and as representatives of palliative care. Providers had to sensitize themselves to multiple perspectives to position themselves on side
with care recipients, family caregivers, and other family members because each could be looking at a palliative care issue differently. Although Chinese immigrant care recipients and family caregivers could be positioned as the Other because of their lack of knowledge on palliative care and dying at home, providers could simultaneously be positioned as the Other because they were guests in the home (this is further elaborated upon when discussing distancing). As outsiders providers had to be strategic in the ways they positioned themselves, because support for one family member’s opinion could activate or reinforce power relations within the family. In a very subtle way, HCP1 positioned herself on side with CG1 when she told CR1 to stop worrying and over-planning her care and death. CG1 had nodded at HCP1’s comments; and so subtly positioned support with CG1. But in the same visit, HCP1 had also supported CR1 in visiting and touring palliative care units. Thus, supportive strategies were highly dynamic and fluid. HCP1 had to maintain credibility with the whole family. Although her comments may seem contradictory, it was necessary for her to adopt a balance in her relationship with both CR1 and CG1 to preserve her acceptance in the home by both.

Often the providers had to make a connection with the care recipient and caregiver to open up communication, as this CCAC case manager explained:

*I think the big thing is- the advantage is because I speak the language. It make a big, big difference, the comfort level. And I am also an immigrant here, here from 30 years ago. So like they feel some sort of connections, anyway, “Oh, you are speaking the same language,” you know. Chinese or if any people in any immigrant, whenever they see you and you can speak their language, they feel okay. It’s like they are back home, you know. (K11, English is her second language)*

The connection for this case manager was easy because she spoke Chinese. The case manager acknowledged that the ability to speak Chinese with Chinese immigrant care recipients brought them a sense of home and belonging. For this case manager, she saw that the meaning of home was significant for Chinese immigrant care recipients receiving palliative home care. The provider easily positioned herself as a support for care recipients and families by drawing on a shared cultural background and language. Hence, acceptance and colonization by palliative care was easier when providers were able to make the care recipients and families feel like they were *back home*, as K11 implied.

Although not all providers identified as being from the same ethnocultural group or spoke
the same language as the care recipients, there were other commonalities that providers drew on to make that connection with Chinese immigrant care recipients. Some providers identified themselves as immigrants from countries such as Europe, Eurasia, North Africa, and South Africa. These providers felt that their shared experience of migration made them privy to understanding the values and behaviours of Chinese immigrant care recipients and their families. This CCAC case manager, who had emigrated from Eurasia, talked about sharing similar beliefs on the importance of the family unit:

Well for me, I am half [Eurasian], half Jewish.... So and again, in today’s family, it’s very important. It’s like a core. So I do appreciate the Chinese families when they [are] all together, like I do understand that. (KI4)

This case manager felt that the Chinese families she worked with were very cohesive and they shared care between family members. She felt that her upbringing and background were alike in that respect, and so this was one way she could connect with Chinese immigrant care recipients and families. By building on these similarities, she was able to position herself as a support for Chinese immigrant care recipients and families.

Some providers were not first generation immigrants, but second or third. With this strategy, providers positioned their support with Chinese immigrant care recipients and families by talking about being a witness to and having a proximity to the struggles of immigrants in their families. In identifying with immigrants and sharing their experiences of migration in their own families, providers hoped to make a connection with the care recipients through this route:

So maybe it’s part of the, you know, the general immigrant experience. Myself- born here. My parents are immigrants, from the West Indies. But I realize it’s not part of the culture to tell everybody everything like we do here, you know, speak openly. I can respect that. It’s not the only families that I see it in. (KI9)

This CCAC case manager recognized that while it may be taboo to talk about dying amongst Chinese care recipients and families, this was not specific only to them. She acknowledged that within her background experience, there was a silence around death within her own family. By identifying this similarity, she positioned her support in the form of close knowledge and shared experiences.

A community palliative nursing consultant also wanted to acknowledge her immigrant background. She connected with immigrant families because she understood the struggles
immigrants had to go through to settle in a new country, which allowed her to understand the struggle with language Chinese immigrant care recipients faced when receiving palliative care: 

*Um, they’re still people, and you know what? They remind me of my grandparents. My grandparents were fruit and vegetable people; [they] were immigrants who were hard working labourers, and that’s what they did when they came into this country. So, it’s kind of like yeah, I know where they are coming from and they had to work hard… and I don’t need to be able to speak their language, to put a hand on them to say, “It’s okay.” It’s my face that they’re going to read. That’s the language. They know when people care, when you keep on going back, when you keep on checking in with their family… language isn’t so much the barrier. It’s the presence of being there. That’s what tells them that you care- is that you keep on going back.* (KI6)

For this community palliative nursing consultant, she was able to position her support not through language, but conveying a sense of caring through presence. KI6 felt that her facial and bodily expressions could convey just as much as language to her Chinese immigrant care recipients. Having grown up with immigrant grandparents, she had experiences that allowed her to understand the power of body language and gestures. And so she learned to position herself as a support through a different approach. Just as KI8 spoke about the lasting impressions of caring for someone that was dying, KI6 and KI9 also speak to the enduringness of the immigrant experience. For these two key informants, their immigrant experiences, although second hand, left indelible impressions on them. These familial histories impacted their practice and interactions with Chinese immigrant care recipients.

**Summary**

The colonizing forces, as discussed above, were the subtle forms in which colonization took place. These colonizing forces were set up as routine procedures and were often desired and rejected at the same time. (The ambivalent nature of the relationship between care recipients and providers is further elaborated when discussing distancing.) Routines become embedded, even if for short periods of time, and allowed the gradual invitation of palliative care into private, domestic spaces. For Chinese immigrants who had to re-settle in a new country and make new homes, the introduction of palliative care, disrupted and re-ignited efforts to make meaning of home again, but this time while facing a terminal illness. Colonization was significant for Chinese immigrants because they again had to re-establish belonging within their homes. The layered *meanings and values* of Chinese immigrants and family caregivers had to be re-worked
as a necessity of *social survival* because “outsider” home care providers established claims on the home as a place for dying. The dual desire for help in navigating their death, but also to maintain independence and control by care recipients and caregivers stirred up ambivalence toward palliative care and called forth strategies for resistance.

**Distancing as Resistance**

As the home became colonized by palliative care, care recipients and family caregivers engaged in efforts to distance themselves from providers and the anxiety of dying at home. Distancing could be seen as a form of resistance because it was an effort to exert agency. Care recipients and caregivers distanced themselves to maintain relations with providers, but still remain on their own terms. By distancing, care recipients and families were able to negotiate a sense of everydayness while living at home under the extraordinary circumstance of waiting for death. Care recipients and families were literally distanced from dying because they were not in the hospital, but at home, the place where living happened. And so distancing themselves from palliative care allowed them to continue on with daily routines. It was imperative that life continued for everyone in the home, and everyday activities did not stop because a family member was terminally ill. Instead, care recipients and family members adjusted and accommodated the illness, and continued on.

Resistance was also enacted by providers in that they tried to distance themselves to cope with their emotionally-draining work. Providers often asserted that they did not know much about the complementary and alternative medicines Chinese immigrant care recipients were using, and told them to use it cautiously. Indeed, providers expressed apprehension about caring for palliative care recipients who used traditional Chinese medicine. Providers advised care recipients to consult their oncologists, because they were not going to be monitoring this aspect of their care. The providers made it the responsibility of the care recipient to talk about complementary and alternative medicines with their oncologist, and in this way, were distancing themselves from a practice they knew very little about.

This second composite vignette is based on observational visits with Case 4. These visits usually involved the care recipient (CR4), family caregiver (CG4), and home care nurse (HCP4). CR4 was an elderly woman with stage 4 lung cancer. She was in her early-70s. Her cancer had metastasized to her right hip, and she recently had surgery. She had limited mobility and pain in
her right leg; she walked with a cane. Her main caregiver was her elderly husband, who was in his mid-70s. He also had mobility restrictions, walked with a cane, and had impaired hearing. On occasion, her son, who lived at the home as well, was present during visits. He appeared to be in his late-30s. When I asked if he would be willing to participate in the study, he declined to sign the consent form; although he did give me verbal consent to observe him and ask him questions. The family was part of the large Chinese diaspora that lived in Vietnam, and had immigrated to Canada in the early 1980s. Currently, they all lived in a newly built house in a sub-division in the suburbs. There was limited access by public transportation. The home was one block away from farmland, and was fairly isolated.

**Vignette 2: Case 4**

HCP4 and I both arrived at the house at the same time. HCP4 rang the doorbell and we waited for a little bit before CG4 came to the door to let us in. CG4 greeted us and directed us into the open concept kitchen/family/dining room. We took off our shoes before entering the home, and HCP4 put on white slippers he brought with him. There was another man sitting at the dining room table but he seemed to be reading something and did not acknowledge our arrival. I later learned that this was their son. CR4 was sitting up in her bed that was put into the family room. Her short salt-and-pepper coloured hair was matted at the back from lying down. HCP4 came into the living room and immediately asked how she was doing since she just had gone in for her chemotherapy. She told him that she was fine now, but vomited after having water and fruit the previous night. HCP4 asked if he could wash his hands in the powder room before he examined her? She nodded yes.

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HCP4 asked CR4 about her pain. She said that it was all right but the pain in her right hip felt stiff. HCP4 probed further about her pain and they discussed a recent appointment she had at the hospital. CR4 said that she was unhappy with her doctor’s visit because she was rushed through the appointment. She thought that the doctor did not check her properly, and told her that her pain was normal and that she needed to exercise more. CR4 explained that this was frustrating because they did not receive specific instructions on what type of exercise she had to do. She was also upset because her daughter had taken time off work to take her to the appointment, and they waited hours before seeing the doctor, but he barely spent any time with her. She felt he was rushed, “like he had water boiling”. HCP4 listened and tried to comfort and
rationalize with CR4. He suggested she massage her leg, and discussed her pain meds as a way to manage the pain. CR4 was upset because she thought she would be feeling better after the surgery, but instead was bedridden most of the time because it was too painful for her to walk. CG4 was sitting quietly during this whole discussion, but got up and brought a footstool for HCP4 to sit on as he was kneeling down to CR4’s level as she sat on the bed.

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Then HCP4 sat down at the kitchen island to do some charting. He told the family that he would not be visiting the next few weeks because he was going to be away taking care of some family matters. CG4 automatically asked if he was going on vacation and for how long? HCP4 answered again that he had family matters to attend to and there would be another nurse coming to visit them. HCP4 reassured them that he would be coming back. CR4 and CG4 seemed anxious and curious about where the nurse was going. Then CR4 asked again if HCP4 was going back to Hong Kong for a visit? HCP4 smiled again and said it was family matters. Finally HCP4 explained that he was going to Hong Kong, but not for vacation. He stood next to CR4 and placed his hand on her back reassuringly. As HCP4 began charting again, he asked the family if they had any other questions. Then the son joined the conversation and asked if he could take his mother on a trip? HCP4 answered that it would be best to consult their oncologist to see if it was a good idea. HCP4 explained that he knew that her chemotherapy was ending soon but depending on the CT scan, her treatment could change. HCP4 asked where they wanted to go. The son was thinking of going on a cruise. HCP4 suggested they might consider other types of trips. He suggested that a driving trip, or shorter trips might be better and that they had to remember to get his mom’s medications in order before going.

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After HCP4 left, I stayed to make an appointment for an interview with the family. I asked CR4 and CG4 if they liked to travel and where they were thinking of going? CR4 answered that they don’t really go anywhere, and weren’t really planning to travel, but just wanted to ask. I wondered if they were trying to hide something from the nurse, or did the question have another meaning?
Efforts to Distance

In the above vignette, there are several examples of how the care recipient, family caregivers, and home care nurse distanced each other. Their efforts to distance, along with the efforts exhibited by other participants in the study, have been further divided into four thematic categories outlining their efforts to distance: 1) expressing dissatisfaction; 2) positioning and repositioning: the ambiguous guest and host; 3) re-claiming the everyday; and 4) hiding and withholding. In the following, I will work with the vignette to illustrate how care recipients, family caregivers, and providers worked to distance themselves from palliative care in order to manage the everydayness of dying at home.

Expressing Dissatisfaction

Expressing dissatisfaction did not necessarily mean that care recipients and family caregivers were actually unhappy with palliative care and provider services, but rather that they wanted to maintain some distance. Care recipients and family caregivers scrutinized providers and the system, but also acknowledged the need for guidance in navigating death at home. Expressing dissatisfaction provided care recipients and family caregivers a sense of control over their own time and space, but was also a way to express an unmet need. Dissatisfaction was expressed in minimizing what providers did or how home visits disrupted their daily routines.

CR1 described home care visits as both a support and a nuisance:

*To be selfish, when you have so many questions to ask them and you find them very supportive then it’s okay, and you are not that- you don’t need to go out, you don’t need to moving around that much, then it’s okay to sit there and wait for them. But if you getting better and better, then it would be quite a, what is the proper word, gey ma fan (in Chinese - inconvenient)... It seemed to be quite inconvenient to be sitting there waiting, waiting for the nurse every day. So that’s why eventually we dropped to once every other day and then once a week. (CR1)*

Her expression of dissatisfaction was in the anticipation of visits that seemed to disrupt the flow of her daily routines. CR1 found it inconvenient to be waiting for home care visits, but she also recognized the need for visits as well. She weighed the support and knowledge offered by palliative care providers against the desire for normalcy in her daily routines. Such expressions of dissatisfaction were a way to distance providers and to express her unmet need to control the scheduling for her day. In the end, she was able to negotiate a visitation schedule that suited her better.
In the above vignette with case 4, CR4 expressed dissatisfaction with the care that was provided when she went in for a doctor’s visit. She noted that she and her daughter had to wait hours before seeing the doctor, the doctor was not helpful, and the visit was rushed. CR4 was very upset that her daughter had to take time off from work to take her to the appointment. During our interview, CR4’s dissatisfaction with the doctor could be explained as an unmet need:

*Oh right now I don’t know how people can help me at home, but what I need right now is uh, someone taking me to the appointments at the hospital. Keeping the medical appointments [are] difficult and I need transportation, and because I can’t speak English, I need a translator to help me there.* (CR4, translated)

The dissatisfaction she expressed in her visit with the doctor was broadly based on unmet needs: she required more time with the doctor, transportation to appointments, and translation. CR4 did not want her daughter to take time off from work to take her to her frequent and numerous doctors’ appointments. She hinted that her daughter’s employment was not secure, and was worried her daughter could lose her job.

Sometimes dissatisfaction with home care providers pertained to a tenuous understanding of the purpose of their visits. All of the Chinese immigrant care recipients in the study were considered stable and so they may have felt it unnecessary to have weekly home visits. CG2 acknowledged that her husband’s condition was stable and that was why she was able to take care of him on her own:

*Well, right now it’s okay. We don’t really need her [the nurse] to do more for us. Sometimes if I have a question, I can call her and ask her. So right now in his condition, I am able to still help him do most of his care so then I will do it... Well, right now I am still able to care for him, but later I don’t know how it will be.* (CG2, translated)

For this family caregiver, she did not feel a need for the nurse because her husband did not require that much care. But she did acknowledge the potential need for the nurse later on as his condition worsened.

Another way dissatisfaction with care came through was as a means of distancing the terminal diagnosis. By expressing dissatisfaction at provider care, care recipients could also distance identifying as a sick, terminal, dying patient. Sometimes care recipients rejected their terminal diagnosis initially, or did not believe they were actively dying. Expressing
dissatisfaction at provider care helped distance the label of being terminal. CR2 shared an anecdote in which his doctors told him they could not do a risky surgery to remove the tumor in his liver, but he was persistent and sought care elsewhere instead:

*I had a friend who had cancer in the liver too and he told me about going to see this doctor in [US city]... So then I went to [US city] to see if I could have tests done too. I went to have it checked to see if it was also a malignant tumour and they told me it was malignant. But they said that I could do the surgery, that he could also do the surgery so I thought I would do the surgery. So that was [year]. So they opened me up and saw that I had multiple tumours. It was too dangerous after all to do the surgery so they closed me up... Because at that time the meds couldn’t stop the cancer from growing. I couldn’t accept it so then I went to the US to see a doctor.*  

(CR2, translated)

His disagreement with his treatment in Canada and his need to distance the terminal aspect of his disease prompted him to see a doctor in the US for further, invasive treatment. His distancing allowed him to maintain a belief that there may be a provider somewhere who would be able to help treat his cancer. For this care recipient and the others, dissatisfaction with providers was often rooted in other reasons. Expressing dissatisfaction allowed this care recipient to maintain control over the interpretation of the severity of his illness, and to distance himself from an impending death. Although many of the care recipients and family caregivers expressed some dissatisfaction over provider care, they also still recognized the need for palliative care providers as well.

In colonial discourse, ambivalence refers to the simultaneous “attraction and repulsion that characterizes the relationship between colonizer and colonized” (Ashcroft, Griffiths, & Tiffin, 2007, p. 13). According to Bhabha, ambivalence disturbs the authority of colonization because the colonized are neither completely complicit nor resistant; rather, the relationship is in constant fluctuation (Bhabha, 1994/2004; Ashcroft et al., 2007). As illustrated, colonization of the home by palliative care is similarly situated in that *attraction and repulsion* are both present. Chinese immigrant care recipients and family caregivers expressed both a desire for help and an annoyance with the intrusions of palliative home care. Care recipients and family caregivers could engage in repulsion by expressing dissatisfaction with providers, lack of available resources, and difficulties accessing the system. In this form of distancing, care recipients and family caregivers were dually desirous of and indignant about palliative care at home. Thus, their
expressions of dissatisfaction could be simultaneously accompanied by statements of gratitude for palliative care. The fluctuations of ambivalence made it a complex, and not always evident, form of passive resistance.

**Positioning and Re-positioning: The Ambiguous Guest and Host**

As discussed above, Chinese immigrant care recipients and family caregivers were sometimes marginally positioned in their own homes based on their lack of knowledge of palliative care and dying at home. Conversely and simultaneously, Chinese immigrant care recipients and family caregivers could also differently position providers as outsiders and guests because they were strangers to the home. The ambivalence that characterized the relationship between care recipients, family caregivers, and providers was evident in the ways providers were positioned as guests. In this sense, providers could be positioned and re-positioned as welcomed friends, or unwelcomed strangers. Mostly, providers were temporarily allowed in the home, and were only welcomed when there was a sense of purpose for their visits. Even though care recipients in this study were receiving palliative services, they were in stable condition and so may not have wanted the constant presence of providers in their living space because it reminded them of their sickness and impending death. Accordingly, visits were bounded by time, purpose, and expectations. By positioning providers as guests in the home, care recipients and families were able to distance providers and normalize encounters within the social routines of etiquette.

As such, care recipients and family caregivers had specific expectations of what providers were allowed and not allowed to do in their homes. While some of these customs were based in social etiquette, others had to be learned by engaging with the care recipient and family, or were shared between providers. In the above vignette, when HCP4 and I first entered the home, we both took off our shoes automatically. HCP4 carried with him his own pair of slippers to he wear in the care recipient’s house, a practice he had acquired over time. Before HCP4 conducted his physical exam, he asked CR4 if he could use the powder room to wash his hands. Although HCP4 had been visiting this family for almost a year, and this may have been a routine that was performed every visit, he still asked permission each time. Both he and CR4 understood he was a guest, and this courtesy was expected of him. For almost all of the providers interviewed, taking off their shoes before entering the home was an essential aspect of being a guest in Chinese immigrant care recipients’ homes. Several providers relayed stories of having to take their shoes off outside before entering the domicile. While providers understood it to be a
form of etiquette expected of guests, they did not necessarily consider how care recipients positioned them as outsiders.

When I went for my first observation visit with Case 2, I had arrived earlier than the home care nurse, and was let in by CR2. These were my notes from that visit:

CR2 opened the door for me and he let me in. As I stepped in, I saw a pair of red slippers laid out. He seemed to wave his hand over the slippers to bring my attention to them. I took my shoes off and put them on. Then he led me to the living room. (Case 2: October 12, 2010)

As a guest in CR2’s home, I was subtly encouraged to take off my shoes and put the provided slippers on. In his motioning to the slippers, I was positioned as a guest, and he as a thoughtful host. As a guest, I quickly learned that my outdoor shoes were not permitted beyond the foyer. Simultaneously, I also knew that I was going to take off my shoes before entering. This was an etiquette I had learned elsewhere and practiced in my own everyday life. So some etiquettes of being a guest may be known or learned in situ, and refined according to situational variations.

Providers also understood that there was a difference between providing care in homes as opposed to hospitals. Providers acknowledged that the home was not their territory and so that made them a stranger in care recipients’ homes. When asked whether there was a difference to practicing in a hospital versus in care recipients’ homes, this palliative physician explained:

Yeah, I mean I think there’s a huge difference. Where to begin? I mean, I think the fundamental difference is whose space it is, right? In a hospital, it’s my space really. I mean, well not mine, but you know, it’s health care provider space, right? And so we have much more uh, control over what happens and doesn’t happen, and how it’s going to be. And I think, you know, one of the reasons I love home care is because, you know, I’m, I’m the guest in that setting and um, as the guest, I might be a respected guest, but I am still a guest. And so um, you’re much more acutely aware of the need that you’re negotiating, right? That this is a negotiated relationship. (KI10)

As KI10 points out, he was acutely aware of his positioning as a guest in care recipients’ homes, and understood there were differences in his ability to negotiate with care recipients and families compared with being in a hospital setting. He also felt that he was a respected guest and so he was favourably positioned with care recipients and family caregivers.

Over time, respected guests may transition beyond merely being a guest. Some providers felt that their relationship with care recipients changed and became familiar and closer. HCP4 noted that he had to build a relationship with CR4 at the beginning but now they were friends:
At the very beginning we had uh, to build a relationship. So right now like as a friend, not as a nurse. Usually now, okay I call like a friend, uh, Mr. so and so, no, maybe call his name. It depends, okay? But the better [the] relationship, they can work together better. (HCP4, English is his second language)

Although HCP4 acknowledged that he was now friendly with CR4 and CG4, he was still cognizant that this friendliness was intended to improve the working relationship. And so while he saw them as friends, he also positioned them as patients. Some providers recognized that they were positioned as unwelcomed strangers. This CCAC case manager commented:

The thing is they, they doesn’t want strangers, like any other one, because Chinese person especially in an older generation, they doesn’t want [a] stranger to get to know what’s going on in [their] home. They doesn’t feel comfortable... (KI1, English is her second language)

KI1 acknowledged that providers can be positioned as unwanted strangers that pry into care recipients’ homes, and may not be seen as friends.

When care recipients positioned providers as guests, it was a way to maintain a purposeful and professional relationship. This also meant that care recipients and families were held to the position of being hosts. As hosts, care recipients and families had to be prepared for home care visits. A home care nurse observed that when she went to visit one of her Chinese immigrant clients, the care recipient tried to be prepared and scheduled his activities around the home care visit:

... one time I visit a little bit earlier, like for example I was talking about 6:30pm but because [of] the schedule, then I come around 6:00pm. Then when I went there, they were having dinner so the client is really in a rush, like [to] finish his dinner. Then his daughter said, “Dad slow.” And then I sensed that right? So I said, “You know, take your time. I am not in a hurry.” So I guess they are prepare before I come.... If I am not coming she [the wife] may be always cleaning or doing cooking, but when I am there, they always seems like resting on the sofa. (KI2, English is her second language)

The home care nurse was astute in recognizing that while the care recipient and his wife may appear to be resting on the sofa when she arrived, she knew that they were possibly rearranging their activities to accommodate her visit. They actively prepared to host the nurse when she came to visit. In palliative home care, distancing through the guest and host positioning was complex and weaved together multiple positions held by care recipients, family caregivers, and providers.
Care recipients were not only seen as sick and dying, but were also held to the social expectations of a hospitable host. In this regard, care recipients had to straddle and balance these two worlds – one that was embedded in dying and the other in living. In the role of host, a care recipient could temporarily be excused from the position of someone that was dying.

Over time, care recipients, family caregivers, and providers got to know one another better, or became accustomed to each other. Thus, the host/guest relationship sometimes changed as well. Sometimes providers learned how to use their positioning as a desired guest to work to their benefit. This home care nurse illustrated how the social act of having tea with a care recipient could be used to accomplish care:

*I accept [coffee with] this client because I encourage her to sit with me. I always said that okay, she will offer me the coffee and I will say, “Okay, next week I visit you if you sit in the wheelchair and take the coffee with me, then I will take the coffee with you in the dining table, not you lying in the bed.” You know, I encourage her to get up, then next visit I will see her sit in the wheelchair.* (KI7, English is her second language)

This home care nurse wanted to encourage the care recipient to get out of bed and sit up, and so she offered to have coffee with her as a motivation. She was able to play on the hospitality of the host to accomplish care. There is a transposition in the guest/host relationship because of the ambiguous nature of their multiple positionings as both host and care recipient, and guest and provider. The care recipient occupies a host position when she offers tea, but is re-positioned as a care recipient when the nurse stipulates the conditions of this hospitality.

While care was negotiated, so were relationships; providers also positioned themselves in particular ways to distance themselves. Occasionally providers wanted to maintain a professional relationship and so rejected the positioning of guest to ensure that they did not become too close and friendly with care recipients and their families. One CCAC case manager explained:

*And people make you a tea or whatever, so you say you know, I am not- a nice way to say, “I am not your friend, I am your case manager.” I’ll be like, “You don’t have to prepare for my visit. You don’t have to whatever, let’s sit and talk about your needs and don’t make me lunch or whatever.”…they often offer you something and if you don’t take it, you’re not going to get out the door so whether it’s a bottle of water, a pear, some crackers, thank you.* (KI9)

And so the case manager made it clear that her visits were not social, but had a purpose. KI9 tried to pre-empt ambiguity in the relationship by specifying her role. Thus, the position of guest
was fluid and situational. Some providers were positioned as guests who were welcomed as friends, while others were positioned as guests who were greeted with reluctance because they were still considered outsiders. Providers were sophisticated and attuned to the various ways they were viewed by clients, and some used this knowledge to their advantage to accomplish care.

Palliative home care visits were socially and professionally layered in that multiple positions collided in these encounters, everyone (care recipients, families, and providers) was responsible to re-negotiate these positions as changes arose in the care recipient’s condition and needs. Care recipients and family caregivers were also variously positioned as immigrants. Thus, distancing was a fluid process and changed with time, familiarity, and needs. This ambiguity in positioning and re-positioning of the guest/provider, host/care recipient, and immigrant subjectivities drew attention to a hybrid that emerged from the ambivalent nature of relationships in palliative home care.

Re-claiming the Everyday

In their efforts to distance themselves from palliative care, care recipients and family caregivers sought to re-claim their everyday lives. Often care recipients passively resisted the possibility of dying by continuing to live and engage in everyday activities that were not constant reminders of their limited time. To oppose the colonizing forces of terminal illness and palliative care, care recipients and family caregivers re-asserted their agency by re-staking a claim on their home as a place for living in the face of dying. Care recipients and family caregivers lived beyond the weekly home visits from providers, and often described their daily engagement in mundane activities and routines. As the health of care recipients’ changed, sometimes for worse and sometimes for better, they and their families understood that the process of dying could take days, weeks, months, or years; and so, realized that all the while they were anticipating death, they still had to live out, no matter how limited, the days that were left. Some key informants related stories of working with palliative care recipients who died quickly, but the care recipients in my study were stable, and so had different experiences of re-claiming the everyday from care recipients who had poorer prognoses and were considered actively dying.

Care recipients and family caregivers continued to engage in everyday activities that existed prior to being labeled palliative. Often these activities had to accommodate the accouterments of cancer: pain, fatigue, chemotherapy schedule, doctors’ appointments, and home visits. Some activities were a return to past routines, and others were newly formed adjustments
to changes in health status and replaced past behaviours that were now difficult to continue. Care
recipients and family caregivers described these activities of daily living in detail, indicating that
they were occupying their time and continuing to live. Living out the everyday allowed care
recipients to distance themselves from death because life still held them responsible for
themselves and others. In that regard, care recipients remained firmly embedded in living. In
case 4, both CR4 and CG4 were elderly and required care, but CR4 felt that even though she was
sick, she continued to care for her elderly husband who had multiple health problems. She
explained that there were chores that she still had to do because there was no one else to do them.
When asked about what she did in a normal day, she replied:
... getting up, washing, dressing and cooking, a little cooking. (I: Did anyone in the family help
you?) Oh, when they come home from work in the evening, they help a little because they have to
work and don’t have a lot of time. (I: Okay, um, how has your husband been able to help you?)
Well he can’t manage himself actually. He can’t cook {laughing} .... even if there’s pain, I still
have to get up. (CR4, translated)
CR4 had to continue with previous domestic routines despite her terminal cancer diagnosis
because her husband also had health problems. She continued to do light cooking and cleaning
for her family because her children were busy and working. She had indicated that her children’s
employments were not secure because she worried about them losing their jobs when they took
time off to take her to her doctors’ appointments. The precarious and demanding nature of
employment for many immigrants (and non-immigrants) meant that there were no compassionate
benefits that would allow her children to take paid time off to care for her. CR4 re-claimed the
everyday because her daily routines firmly embedded her with tasks and responsibilities that
distanced her from being sick, palliative, and dying.
In contrast to care recipients’ descriptions of the flourish of daily life, a few providers
noted that palliative care recipients were different from other home care clientele because they
wanted visits to be quiet and respectful:
One thing is you don’t come into the house like hi everybody noise, noise, noise. They don’t like
noise. They like things to be quiet and calm so you’ll come in and you’ll talk in quieter voices,
more calm and relaxed. (HCP1)
But in their interviews, care recipients described the many daily activities they were engaged in.
While a desire for a quiet and calm environment may be true for palliative care recipients who
were actively dying; the care recipients in this study, who were stable, offered an alternative view. They were not merely sitting at home and waiting to die. Rather care recipients and family caregivers continued to engage in routines and activities that they enjoyed. CR3 expressed his desire to be active and social because it gave him a sense of life:

The one thing I try to get myself to do is, well when you’re at home, there isn’t a lot of places to go, but when you’re walking on the street, you kind of force yourself to keep walking and keep walking. So you have to get out there and kind of force yourself or motivate yourself to do exercise and keep doing activities… Being around other people is good. It gives you a sense of life. Well cancer is a condition that makes you very anxious and so you need to let go and be more carefree… So you don’t isolate yourself at home. (CR3, translated)

CR3 did not want to be isolated at home alone. He wanted to be around other people, around people who would motivate him to also live.

One way to re-claim the domestic space as a place for living was to socialize and entertain in it. When I arrived at CR3 and CG3W’s home one morning for an observational visit, the living room was filled with four women playing Mahjong:

The living room had an old brown couch pushed up against a wall but the space was mostly taken up by a Mahjong table with four lively women playing together, including CG3W.

... 

CR3 walked us [HCP2/3 and I] to the door and we waved good-bye to the women still playing Mahjong. They smiled and were cheery in their good-byes but did not stop their game. (Case 3: November 16, 2010)

The game of Mahjong required at least four people, which meant friends were invited to come and play. The lively activity of four women huddled around a small, square table chatting and playing Mahjong gave a sense of living, and marked the endurance of past social activities. Death was temporarily distanced as they socialized and talked about different things besides the illness.

Some care recipients believed that they were doing better and this sometimes confused providers. Although the care recipients were labeled palliative, they continued to act as though they were getting better and preparing for a full return to prior routines, such as going back to work. Sometimes care recipients over-extended themselves when engaging in daily routines. As this community palliative nursing consultant explained:
I always check reality. I ask what do you mean you want to get better? I am always asking this question when he says, “I just want to get better.” What do you mean by that? Because some of them they want to get better means they are cured. And now you have to get back and think what you are going to do about this... Many times they say that and they back up and say, “I just want to be free of pain and comfortable, and do not burden to my family.” (KI5, English is his second language)

KI5 made an important observation here that care recipients may have different reasons for thinking they were getting better, and it needed to be questioned in terms of meaning. Although re-claiming the everyday and engaging in routines gave care recipients a sense of getting better, providers needed to question what this meant, as expectations for a cure and a return to previous activities were not always possible. KI5 pointed out that while care recipients may hope for remission, it is possible they did not want to be a burden on family caregivers.

Gendering Roles

There was a gendered aspect to caregiving that allowed care recipients to re-claim the everyday. The gendered nature of caregiving was often observed by providers caring for Chinese immigrant families. Many providers admitted that it was normal for them to see a gendered division of caregiving in Chinese immigrant families. Most notably, some providers commented that women, either wives and/or daughters, were noticeably relegated to the provision of intimate, physical care to either husbands or fathers. KI5, a community palliative nursing consultant, shared this observation about Chinese immigrant care recipients:

And the husband, usually the man, usually this is very common, the man wants the wife to look after him – not somebody strange. (KI5, English is his second language)

A CCAC case manager had a similar comment:

So sometimes what we put in is caregiver relief, right? So like good gosh, lady you’re doing everything, taking care of your dying husband. What can we do to help you? So you may put in a block of PSW you know, on Thursday from 1 to 4 so she can go out and do groceries or get a haircut or do whatever. And they [PSWs] are actually not even doing any personal care. They are just there because the wife did everything before. (K19)

This case manager tried to work around a gendered division of care, but sometimes these habits were difficult to break. Even when she offered a PSW, the wife would still do the personal care and leave the PSW to simply watch her husband so that she could go out to run errands.
Two of the family caregivers in the study were wives taking care of their husbands. In both cases, the care recipient and their wives declined having a PSW come to the home to do personal care like bathing. When asked if he had a PSW, CR2 explained;  
*No, not right now. I don’t need anybody. I have my wife to help... I don’t want somebody to come, it’s so hard to watch, it’s so embarrassing so I don’t want. I have my wife so that’s all I need. (CR2, translated)*

The embarrassment of having an outsider provide personal care deterred this care recipient from seeking help from anyone but his wife. It was invasive to have his emaciated body exposed to a PSW - a stranger. He was simply not used to having his vulnerability made so visible. In expecting their wives to take on this intimate care, the male care recipients could limit their exposure and retain a sense of their dignity and personhood.

Partnered male care recipients could rely on their wives for intimate care, such as toileting and bathing; these activities became normalized and part of the daily routines of the home. CR2’s wife admitted that her husband had become dependent on her:  
*Well, let’s just say before, when he wasn’t sick, he did a lot for himself. But now I think when he was really sick, what happened was that he got used to depending on me, you know, like doing simple tasks. He still needs me now. For example, he will still call me over to pour him a cup of tea. He won’t do it for himself anymore, so sometimes I will say to him, “Well you can walk and you can run so why don’t you pour yourself a cup of tea?” So it forces him to have to do it himself…. Yeah, that’s how it was for him in the hospital too. If he needed to take a bath or go to the washroom, or change his clothes, he would always ask me to help. He wasn’t used to having a nurse help him either. (CG2, translated)*

This wife provided all of CR2’s care for him, even when he was in the hospital with nurses there to help. This gendering of care could be seen as a way to distance providers for men. Male Chinese immigrant care recipients who were partnered could reject care from outside providers by turning to their wives for care. The requirement of such intimate care from a PSW, such as bathing and toileting, could also signify to the care recipient that their diagnosis was terminal and that they were indeed dying. By relying on their wives for care, the male care recipients could mitigate the anxiety of dying.

Partnered women in the study did not seem to draw on their husbands for similar care. In fact, even though CR4 was sick and in pain, she still had to do light cooking and cleaning for her
family, and she continued to take care of her husband. While this was a feature that many care recipients and key informants shared in their narratives, it was not necessarily the case with all participants. CG1 took on more domestic duties when his wife became ill:

So she’s been so weak; she was on oxygen support, right. So um, she can hardly do any household chore, right so uh, everything would be on me. Yeah, okay. Buying grocery, okay? Taking her to the hospital for all type of medical appointments... Like I, I am not that kind of a man, who thinks might be the household works would be the job of the wife. No, I am not that kind of person, okay? Besides she, she cannot do it right? So, somebody has to do it okay, alright yeah. (CG1)

For CG1, taking care of his wife became a new job for him since retirement. In his statement, although he willingly became a caregiver and did household chores, he also categorized them as women’s work. He accepted his role in taking over domestic duties, such as cleaning and grocery shopping, but he was not at a stage where he was providing personal care such as bathing and toileting. These types of intimate care seemed to be in the domain of female caregivers. Thus the gendered nature of care allowed male care recipients to re-claim the everyday whilst distancing them from the embarrassment of exposing their bodies and vulnerabilities to outside providers. It appeared also that male caregivers could distance from the vulnerabilities of illness by maintaining an instrumental approach to their supportive work. They seemed more comfortable speaking about homemaking and meal preparation instead of physical care.

**Hiding and Withholding**

Hiding and withholding information and knowledge enabled care recipients, family caregivers, and providers to exert agency and control within palliative home care encounters. In the Case 4 vignette, there were several instances where information was being withheld. HCP4 told the family that he was going to be away and would not be visiting for a couple of weeks. CR4 and CG4 questioned him to find out where he was going and why. HCP4 resisted telling them and divulged only that he had to attend to some family matters. Through their persistent questioning, HCP4 finally admitted that he was going to Hong Kong. The reasoning for withholding this information could be that this was a personal matter – not professional – and so HCP4 did not want to share this personal information with a client. In this way, he was trying to distance himself from developing a social relationship, and tried to maintain a professional one. In their questioning, CR4 and CG4 initially appeared only mildly curious as to where HCP4 was
travelling; but their persistence may have been hiding something as well. Perhaps HCP4 finally relented because he could sense the gradual urgency in their need to know the details of his travels. What may have been hidden was the fact that CR4 and CG4 not only needed to know where he was going, but that he was going to return and continue to care for them. They needed confirmation that they were not going to be abandoned. In framing their probes as a polite inquisitiveness, they were able to hide their fear and anxiety of losing HCP4 as their primary nurse.

The other instance of hiding and withholding was in the family’s questioning around travelling. CR4’s son asked HCP4 about taking his mother on a vacation, but CR4 indicated to me that they had no actual intention of travelling. Although CR4’s son did not explain the purpose of this conversation with the nurse, it was an instance of hiding and withholding. Perhaps CR4’s son may have creatively used travelling as a way to get at CR4’s condition without explicitly asking. It may have been too difficult for CR4’s son to inquire outright about his mother’s worsening condition; instead, he framed the question as an innocent inquiry about travelling. In all of my observational visits at care recipients’ homes, I never observed the family caregivers alone with the home care nurse. Thus caregivers may rarely have the opportunity to ask private questions that they did not necessarily want to pose in front of the care recipient. While death may seem a taboo topic, it could also be that inquiring about the amount of time a family member had left or when the care recipient was expected to die were questions that were too painful and insensitive to pose with the care recipient present. Hence, caregivers may have to creatively devise ways to ask providers questions that met their need to understand the care recipient’s prognosis, but at the same time did not provoke anxiety. By hiding his real reasoning for his question, CR4’s son was able to get a sense of his mother’s condition in her presence whilst avoiding the difficult task of discussing death.

Three of the four care recipients in the study were using traditional Chinese medicines. While two discussed it openly with their providers, CR3 did not:

(I: Have you told any of your uh, Western doctors that you’re using Chinese medicines or making uh, Chinese soups?) No, no I haven’t told them. (I: So, when the doctor comes to visit you at home you don’t?) No, no I haven’t told them. He hasn’t asked me about it either. (CR3, translated)

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CR3 may have been reluctant to share that he was taking Chinese medicines because he did not feel his Western doctors knew enough about it, and so he kept this information to himself. He was able to distance the authority of palliative care by asserting his knowledge and exerting agency in continuing to use Chinese medicine to treat his symptoms. He felt that he knew his body and what it needed, and so took the allopathic medicines that were prescribed by his oncologist, but also sought the advice of traditional Chinese doctors and Chinese resource books on medicine. In a way, these Chinese immigrant care recipients were covering all their options. They did not take for granted that either Western or traditional Chinese medicine should be the only approach to treating cancer and related symptoms. Instead, the care recipients used both approaches to maximize benefit, if there were any.

A palliative physician discussed his observation that most of his Chinese immigrant care recipients were using some sort of Chinese medicine, and his lack of knowledge about it:

*I haven’t yet uh, cared for a Chinese patient who isn’t in some way shape or form using um, yeah, various forms of Chinese medicine, either you know, herbs and acupuncture and all sorts, like, like the whole ... Uh, I, guess I’m, I’m probably the least stressed about stuff like that and in terms of people you might meet. My only concern is that sometimes I am not sure what, what the heck they are taking and how it might interact with what I am giving them. My concern is more for the welfare... So I don’t, I mean I am comfortable with people utilizing it. My only concern is I say is really that I am not always sure what’s in what they’re taking and what would be the interactions.* (KI10)

This palliative physician did not want to discourage Chinese care recipients from taking Chinese medicines, but he also had to acknowledge his own knowledge deficits on it. He spoke with certainty that all of his Chinese care recipients used some form of Chinese medicine. Many providers expressed similar sentiments. In fact most providers spoke about the use of Chinese medicine and only attributed it to Chinese care recipients. Thus, the use of Chinese medicine was a signifier of “Chineseness.” Even though all patients with cancer, regardless of their ethnocultural background, have the option of using Chinese medicines, it was assumed that most Chinese care recipients partook.

Sometimes withholding or hiding the illness was a necessity for care recipients and family caregivers. CG2 did not want to tell her employer that her husband was sick because she worried it would affect the continuity of her employment:
Well, when it’s really busy, obviously, they don’t want you to take time off, but I would not tell him or my boss that um, my husband is sick. I would just tell them that I had an issue to take care of…. So, I was working in the factory. So, if you tell them that – if it’s really busy then they wouldn’t like it but there’s no other way. I would tell them that there really was an issue and I had to take the time off. (CG2)

CG2 did not want to tell her boss that her husband was sick because she was worried that she would get in trouble for taking time off when the factory was busy. She was worried about the implications it would have on her bosses’ perception of her work. She felt she had to hide her husband’s illness because she did not think they would support her. CG2 also went further to describe the extent to which her husband’s sickness was hidden:

So we will ask others for help and ask others for answers, and talk to other people about how to do it, but when we ask others or things like that, we don’t directly tell them that my husband is sick. We just usually say that we know somebody that is sick and so what would your advice be? Because he doesn’t want other people knowing that he has this particular illness and I don’t want others knowing either. A lot of our friends don’t know that he’s sick. (CG2)

The stigma around cancer was apparent for CR2 and CG2. Both did not want others to know that he was sick with cancer and developed strategies for asking for advice without divulging his illness. Withholding this information was a way for the care recipient and caregiver to distance others from finding out her husband was sick with cancer, and from the stigma of cancer.

Participants shared numerous instances of hiding or withholding: what they were hiding and who they were hiding it from. While it may appear that hiding and withholding could be a means of avoiding the taboo of discussing death, the actual reasons for doing so were much more fluid and situated. Care recipients, caregivers, and home care providers were keenly aware of the benefits of hiding or withholding information, mainly as a way to be sensitive to others’ possible inability to cope with the impending death. When hiding and withholding, participants were, unknowingly and variously, engaged in supporting each other through their silences.

Summary

Efforts to subvert and resist colonial rule were sometimes overt, vocal, and violent, or were covert and creatively hybridized (Loomba, 2005). Similarly, subversive tactics were seen with care recipients, family caregivers, and providers as a way to resist and distance palliative care and death at home. Distancing, as a form of passive resistance, was exerted in multiple ways
by care recipients, family caregivers, and home care providers to manage the encroachment of
and colonization by palliative care in the home. These approaches helped to maintain a
comfortable distance between care recipients and providers. The mutual need between care
recipients and home care providers meant that total resistance was not desired; instead, subtle
and creative strategies had to be devised to minimize colonization of the home by palliative care.
The ambivalent nature of the relationship between Chinese immigrant care recipients and home
care providers made it difficult for either to feel completely like they belonged in the home. Thus
the meanings and values of home and dying at home were in flux, and were dependent on
changes in conditions, different knowledges and experiences, and ‘cultural’ interpretations.

Conclusion

This chapter provided an analytic description of what happens to Chinese immigrants with
advanced cancer who receive palliative home care. Postcolonial theory provided a way to
articulate what I heard and saw during fieldwork. The meaning of home was changed as
palliative care colonized the home, but resistance was mobilized as care recipients and family
caregivers tried to preserve the home for everyday routines. Although Chinese immigrant care
recipients, family caregivers, and home care providers worked from different and often multiple
positions, all had to grapple and engage with the layered and complex meanings of home, death
and dying, palliative care, cancer, medicine, Chineseness, belonging, immigration, diaspora, and
so on. Chinese immigrant care recipients, family caregivers, and home care providers put
together multiple meanings, past knowledges, and experiences to generate hybrid negotiated
practices and exchanges that shaped palliative care in the home. This is further elaborated in the
next chapter.
CHAPTER 7
NEGOTIATING HYBRIDITY: HOME AS THE THIRD SPACE

Introduction

In this chapter, I address the last two questions: 3) How is palliative care negotiated in the home? and 4) What is negotiated in home-based palliative care? As discussed in Chapter 4, my approach to the study purpose and questions changed as I progressed with data collection and became immersed in analysis (See Chapter 4: Evolving Research Questions). I had originally viewed negotiation between Chinese immigrant care recipients, family caregivers, and home care providers as a process where exchanges are made to reach a consensus, a compromise, or a concession on palliative home care delivery and practices. What I gradually came to recognize was that negotiation was much more complex, especially when dealing with the cultural differences between the assumptions of palliative home care and the meaning of dying at home for Chinese immigrants. While postcolonial theory, especially Bhabha’s (1994/2004) work with hybridity, Third space, and cultural transformation, provided an apt lens to examine negotiation of cultural differences, it was, conversely, the data that refined my understanding of the theory to show how cultural transformation of the home took place. The ethnographic data illustrated how the home was the critical site (in-between, Third space) where meanings and subjectivities were continually translated, reconstituted, re-articulated, re-inscribed, and enacted (West & Olson, 1999).

Home as the Third Space

While I have drawn from postcolonial theory’s central concern with the power influences on the representation of those relegated to a marginal status, I also draw from Bhabha’s conceptualization of hybridity and negotiation in my analysis. According to Bhabha (1994/2004):

It is that Third Space, though unrepresentable in itself, which constitutes the discursive conditions of enunciation that ensure that meaning and symbols of culture have no primordial unity or fixity; that even the same signs can be appropriated, translated, rehistoricized and read anew… [Third Space] may open the way to conceptualizing an international [his italics] culture, based not on the
exoticism of multiculturalism or the diversity of cultures, but on the inscription and articulation of culture’s hybridity… it is the ‘inter’ – the cutting edge of translation and negotiation, the *inbetween* space – that carries the burden of meaning of culture. (p. 55-56)

It was these perceptive, hopeful statements that helped me to begin to question and clarify what I observed and heard from participants. But what I observed and heard also shed light on these statements. It is through hybridization, the creative recombination of cultural differences in the interstitial space between cultures, that negotiations take place and cultural transformations take form (Bhabha, 1994/2004; Kalscheuer, 2009). The ‘inter’, Third Space, at the cutting edge, has also been conceptualized as the border zone where migrants, between boundaries of here and there, must contend with cultural differences (Bhabha, 1994/2004; Kalscheuer, 2009). It is in the Third Space where cultural differences “‘contingently’ and conflictually touch” (Bhabha, 1994/2004, p. 296), and aim “to rearticulate the sum of knowledge from the perspective of the signifying position of the minority” (p. 232). Thus, it is through hybridity, in the Third Space, that those who have been colonized and silenced can question and disrupt colonial authority, and generate new cultural meanings (Kalscheuer, 2009).

I understand that the Third Space is not an actual physical place, but I conceptualize Chinese immigrant care recipients’ homes as the ‘inter’, the Third space, the border zone where, like migrants who straddle more than one home, care recipients occupy the space between living and dying. The cultural differences that collide in the domestic sphere during palliative home care must be negotiated so that new cultural articulations are made. As care recipients’ and family caregivers’ homes are colonized by cancer and palliative care, it is within the interactions between all participants that cultural transformation takes place. The negotiation of knowledge, which can be both consciously and unconsciously summed up, is expressed as new cultural understandings in the form of, for example, reformulated routines, rearranged use of space, and redevelopment of strategies for privacy. In this chapter, I hope to show how participants negotiated between knowledges, experiences, while generating hybrid ways of doing as they vacillated between living and dying at home.

In this vignette, I had the fortunate opportunity of visiting two different Chinese immigrant care recipients and their family caregivers with the same home care nurse. This allowed me to see how one provider adapted approaches between different care recipients. It was
in these interactions that the negotiated aspect of hybridity became most palpable. HPC2/3 identified herself as Chinese, but indicated that she was from Taiwan and spoke only English and Mandarin. CR2 and CR3 were from Mainland China, and indicated they spoke Cantonese, Taishan, and Mandarin. I spoke with the care recipients in Cantonese and Taishan and in English with the home care nurse. CR2 and CR3 spoke Mandarin with HCP2/3 on visits. Thus, during visits, we were not able to communicate all together in just one language; there was always someone excluded from the conversation and translation was needed. Although each of us was “Chinese”, there were differences in “Chineseness”, how each was positioned, and what each knew and brought to the encounter.

Vignette 3: Case 2 and Case 3

In her individual interview, HCP2/3 made striking comments, which prompted my attention to the negotiated aspect of hybridity. She stated:

For the old immigrant who has been here 40 something years, 30 something years, they are very easy. They open the door with you, they talk about everything. But for new immigrants somehow, they’re just so different. Yeah, you can’t really talk so much and they are very suspicious and they are um, not really friendly either.

*

CR3 is different. He has been here for 40 something years. He is more like a Canadian. He open up to you, he doesn’t, he’s not suspicious anything about it. I can go any room I want when I go there you know. I can go to the kitchen, he’s not suspicious at all for any reason okay, so I can go pick up the chart I want. CR2 he has to bring the chart to me. I don’t say, “Oh I will go get it.” CR2, no, he goes to get the chart for me. That’s fine with me.

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Case 2 Visit:

I arrived at CR2’s home just a little before 10am to see if there was any preparation he or his wife needed to do before the home care nurse arrived. When I arrived, I rang the doorbell and an older man in his mid-forties opened it. I did not recognize the man so I explained, in Cantonese, that I was coming with HCP2/3, the nurse, for a visit. He still appeared confused until CR2 came to the door saying that it was all right and that it was for him. The man left and
disappeared to the back of the house where I didn’t see him again for the rest of the visit. I took off my shoes and put on a pair of red slippers that had been put aside for me. CR2 let me in and asked me to have a seat. He pointed to a beige leather loveseat in the living room. CR2 and I spoke Taishan to each other during the visit.

I called HCP2/3 on my cell phone and she indicated that she was on her way and would be arriving in about 5 minutes or so. Since we were waiting for the nurse to arrive, I asked a few general questions. I asked him how he was feeling this week. He said he was feeling better. He told me that he was now on Morphine 15mg every 4 hours, and had tapered down to that from 20mg every 4 hours. I asked him if this was something his doctor told him to do or if it was something he decided to do. He said that he had decided to do it. I asked who else lived in the house with him and helped him bedsides his wife. He said his older sister, her husband, and their adult child lived at the home too. He said it was a good thing because they were there to help, and it wasn’t as boring with more people living in the home.

At that moment HCP2/3 arrived and she knocked on the door. CR2 got up to get the door. When HCP2/3 came in, she took off her outside shoes and put on her own shoes that she brought with her. CR2 directed her to come in and sit with us in the living room. He spoke to her in Mandarin. HCP2/3 and I spoke English with each other. She sat next to me on the loveseat closest to CR2. HCP2/3 asked CR2 about his pain. She asked me if I knew that CR2 had liver cancer, but that the cancer had metastasized to the bone now, and he was going to see his oncologist this afternoon to discuss chemotherapy. HCP2/3 stated that she had to keep an eye on him. As HCP2/3 spoke to me, CR2 got up and went into his bedroom. He quickly came back with a white binder and placed it on the coffee table in front of HCP2/3 – it was his chart. HCP2/3 took CR2’s BP and told him it was good. She began charting and asked CR2 questions from the ESAS (Edmonton Symptom Assessment System) and charted. As she charted, she asked CR2 to tell me about his trips to New York to have turtle soup. CR2 explained to me, in Taishan, that for the last couple of years, he had been eating a ‘water fish’ (which he described as a turtle). He went to New York to have it because it was not available in Canada. I asked him how he learned that this was good for cancer and he stated that in China, that’s what they do for cancer patients.
HCP2/3 spoke to me in English, which excluded CR2 from the discussion. She stated that lots of her Chinese patients with cancer used traditional Chinese medicine. She said that few of her Canadian or European patients used alternative medicines; they just followed what their Western doctors told them to do. But she acknowledged that mixing Western and Chinese medicine could be dangerous so she always told her patients to tell their oncologist if they were taking anything else. She looked at CR2 and giggled at the fact that he was drinking turtle soup. She said that that was even too much for her. She then explained that she could not tell CR2 for certain which Chinese medicines worked because she didn’t know. Also, she rationalized that these patients were palliative, “who knows, it may work”. She laughed again and said that she learned so much from her patients.

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Case 3 Visit:
I arrived at the home at 11am but HCP2/3 had not arrived yet. I could see through the front window four elderly women around a Mahjong table. CG3W looked up from the table and saw me and came to open the door for me. She let me in and quickly ran back to her seat at the table and told me to go upstairs to wait for the nurse because that’s where her husband was. I took off my shoes, and began to head upstairs, but before I got up, CR3 was slowly and cautiously coming down the stairs. He told me he wanted to go to the kitchen to talk. CG3W was preoccupied the whole time and sat in the living room playing Mahjong with her friends.

* 

HCP2/3 arrived shortly after and she came into the kitchen and sat down at the table with us. She had her ‘in-door’ shoes on and she carried a purple duffle pack with her supplies in it. Again she spoke Mandarin with CR3 and English with me. She told me that usually she saw CR3 upstairs in his room. HCP2/3 got out a measuring tape and went over to CR3. He automatically lifted his shirt up and she wrapped the measuring tape over his stomach, which was distended. She told him that it was bigger. He nodded and didn’t seem bothered by it. I asked him if he ever played Mahjong and he said that he knew how to play but hadn’t played lately. Then HCP2/3 took CR3’s BP. He pulled up his shirt sleeve and laid out his arm.

* 

HCP2/3 then started telling me that she liked visiting older or more long-term immigrants because they were nicer and talked more openly while recent immigrants were not as nice and
they were always suspicious of her. She felt that recent immigrants seemed to pressure her. I asked her to explain how they pressured her. She told me that she found recent immigrants more demanding and wanting more. She translated our conversation to CR3 in Mandarin. CR3 responded by acknowledging that newer immigrants were coming here with more education so maybe that was the reason they expected more. HCP2/3 thought for a moment and then said that she thought it was probably because recent immigrants had lived through Communist China and so were more suspicious. HCP2/3 asked CR3 if he lived under the Cultural Revolution and Mao [Tse-Tung]? CR3 admitted that he emigrated China soon after and so was not affected by it as much. HCP2/3 then went upstairs and came back with CR3’s chart. I noted that she went upstairs without asking CR3. HCP2/3 seemed comfortable going up whereas with CR2, she had to ask him to go to his bedroom to bring his chart.

Negotiating Hybridity

Hammersley and Atkinson (2007) point out that in writing an ethnographic account, the author is “always faced with choices” – the choice of themes, their priority, the order, and the amount of detail (p. 193-194). I have chosen to focus on three areas of concern that came up frequently amongst participants: 1) discursive tensions in working with culture and caring for the individual; 2) dying at home: death as taboo; and 3) more than a language barrier. The decision to examine these three areas in-depth was in part to demonstrate the fluid, dynamic, and context-specific negotiation of major concerns and issues to develop hybridized ways of knowing and doing. The above vignette is the starting point for illustrating these three areas and will help ground the analysis in the data.

Discursive Tensions in Working with Culture and Caring for the Individual

Key Informants and Home Care Providers

In provider interviews, discursive tensions emerged in narratives of caring for Chinese immigrant care recipients dying at home. All providers seemed to struggle to reconcile the discourses of multiculturalism, cultural competence, and patient-centred care. Providers had difficulties in explaining how these seemingly compatible discourses actually worked together in practice. Although they were colonized by and conduits of these somewhat contradictory discourses, by way of best practices, protocols, and guidelines, providers more often described
how these superficially neutral discourses collided. The collision of discourses acted to fragment their ability to provide care.

Providers often shared their knowledge and respect for care recipients’ cultural beliefs and practices, illustrating this with individualized stories of care recipients they came to personally know. The discursive tension was evident in the above vignette as HCP2/3 provided palliative care to two Chinese immigrant care recipients. She articulately explained her different approach to care with CR2 and CR3, and had to reconcile their differences with her own experience as a Chinese Canadian immigrant. HCP2/3 was eager to point out that she grew up in Taiwan and differentiated herself from the Chinese from Mainland China, but that did not mean she did not know something of their Chinese culture:

*I grow up in that culture, I mean it’s not a communist culture, but you tend to know about the way of Chinese thinking, you know?... especially because when I was younger they always say that um, because of uh, the Communist were fighting with Taiwan something, I guess but, it’s, it’s not really communist but you have that kinds, like uh, you know, be careful of what you say or something like that.* (HCP2/3, English is her second language)

What she experienced and learned during her upbringing in Taiwan was integrated with her knowledge and experience of Chinese immigrant care recipients in Canada. Her experiences informed her opinion that recent immigrants from China were more secretive because they grew up under a Communist regime, and so were not as open as long-term immigrants who were, in her view, more Canadian. This was different from the political climate within Canada. Her interpretation of immigrants’ different experiences and characteristics translated into her individualized approaches to caring for CR2 and CR3. She made a point not to pry too much with CR2; she did not probe into personal matters that did not pertain to his health, and she did not go to his bedroom to get his chart. Whereas with CR3, an immigrant of over 40 years, she felt more comfortable and talked more openly with him, even expressing her opinion on the differences between long-term and recent Chinese immigrants. She felt at ease moving between different rooms of the home to get CR3’s chart. HCP2/3 negotiated through the differences between CR2 and CR3, and varied her approach to palliative care in each case to take into account her own cultural meanings, along with the expressed needs and wishes of individual care recipients.
The navigation of cultural differences in this in-between space was most fraught when starting with a new care recipient and family. HCP2/3 talked about the ways she had to build trust with more recently immigrated care recipients:

But you have to break this wall. This wall is very thick, especially for the new immigrant. The wall is so thick you have to break it otherwise you can’t get through… you need to build up the trust. Um, I don’t ask them too much uh, [wait] for them to tell me. Like for CR2, I don’t really ask them too much. I don’t ask who is in the house? I don’t ask, you know, until he like to tell me. Recently the nephew has been in the house for a long time. I never knew until recently he told me, “Oh, my nephew is in the basement, lives in basement.” I say, “Oh really.” But that’s it, I don’t ask anymore. He will tell me if he feels comfortable, you know. But it’s not related to his disease so I don’t really ask... he has trust uh, in me now, okay? (HCP2/3, English is her second language)

Such articulations show the complexity home care providers encounter when they enter into care recipient’s homes. Providers must decipher and interpret ways of knowing to evolve an approach to care that takes into consideration each individual care recipients’ needs. It was through her experiences caring for many immigrant families that HCP2/3 observed and concluded that recently immigrated care recipients required more effort to break this wall so that a trusting relationship could be built. She was still engaged in the process of gaining the trust of CR2, and so she behaved differently between them.

A central topic that emerged early on in providers’ interviews was what they perceived as the cultural differences between Chinese immigrants and themselves, as Canadians. Subsequently a question was developed to explore how providers defined and worked with culture. When asked about how he worked with culture in his practice, this palliative physician explained:

... I can’t be a cultural expert in 40 different cultures. It wouldn’t be feasible. So I guess my own approach is to try and be aware of the culture I am bringing first of all to the table because I mean I bring, I mean I do bring a culture to the table and pretending that we don’t, which we sometimes do in medicine, that we’re just these objective, you know, objective creatures, it’s not true.... I also try as best I can to ask when I am not sure what’s going on, so listening to those uncomfortable moments which inevitably happen when you’re working cross-culturally and then trying to be honest and say, “I am sensing that there’s something we’re not, you know, we’re not
communicating about here or we're not connecting about, can you help me understand this better?” (KI10)

KI10 was cognizant that he too brought a culture to the medical encounter that needed to be acknowledged – the culture of Western medicine. Although KI10 did not identify as an immigrant himself, other providers did in order to position themselves as empathetic to the situational context of Chinese immigrant care recipients. This resonates with the colonizing forces discussed in the previous results chapter (Chapter 6: Strategizing and Positioning Support). Although KI10 adhered to a discourse of cultural competence, part of negotiating the hybrid was this ability to draw on different positions in varying degrees that suited a particular care goal with a particular care recipient.

KI10 also understood that he could not pretend to be an objective creature, but had to consciously listen for uncomfortable moments in his interactions with care recipients. These uncomfortable moments were the consequence of tensions in the Third space where cultural differences had to be negotiated. One way to work through cultural differences was to rely on the use of second generation immigrants/family members. KI10 commented:

*I think often it's second generation immigrants perhaps who are best positioned to help people, like me, understand what's going on. Sometimes, they often end up being the bridge.... I think in, in my role I am very much aware that there are multiple cultures. I think sometimes, it depends a lot on the family right, so some families have been able in, in certain places within certain cultural groups to, to actually interact fairly, in a fairly more, in a more closed way within their own culture, within a place like Toronto, right? So, maybe a Chinese family, you know, they can shop in a Chinese store and they can have a Chinese banker and, you know, buy their groceries, you know, so there isn’t the same um, they’re not forced in a way to sort of re-examine the culture because they can kind of operate within it a lot of the time. Whereas families I think where they’ve been, where they’ve had more external exposure, maybe there’s been intercultural marriage um, you know, I often find those families are perhaps a bit more aware of the bridging issues that are going on. (KI10)*

For KI10, second generation immigrants, and especially intercultural marriage, were a literal acknowledgment of the fluidity of culture. Second generation immigrants existed in the in-between space, bridging the gap between different cultural understandings. This perception also indicated that working with culture had to incorporate an understanding of context and
circumstance. KI10 acknowledged that he had to take into account how much *external exposure* families have had. The trickiness of working between culture and individual needs was evident as KI10 tried to make sense of it in his own practice.

When providers tried to reconcile working with culture and the disease trajectory of advanced cancer, they recognized that the basic needs at end-of-life were more pressing than cultural beliefs of death in shaping experiences of dying at home. When asked whether there were differences in working with Chinese immigrants and other ethnocultural groups, HCP1 was adamant in her response:

*There is no difference, that’s what I am really saying, but there is no difference. You’re dealing with a dying patient and in every community you’ve got the culture to consider so it doesn’t matter if they are Chinese, Jewish, Muslim, Catholic, Anglican uh, Baha’i... It doesn’t matter what religion they are, you have to take it into consideration when you are dealing with a dying patient, um, so it’s really no difference.* (HCP1)

In reconciling her knowledge of culture and her role as a home care nurse providing palliative home care, this participant implied there were prominent end-of-life care needs and concerns for care recipients that took precedence over culture. The shared experience of dying from cancer precluded culture, ethnicity, race, and religion. However, in this view, culture could be so subjugated and embedded in the work that it was difficult to separate one from the other.

Another provider also talked about strategies for negotiating through tense, often confusing encounters within palliative home care. This community palliative nursing consultant explained that she tried to come to know care recipients’ and families’ preferences and expectations, and how this aligned with her role as a home care provider. She recognized that, regardless of ethnocultural background, some issues at end-of-life were the same for most care recipients:

*Yeah, tough to talk about that [working with the Chinese community] generally because to me, I think that, I never as a Canadian, I never had a clear vision of what that was because I saw so many different variations. You know everything from the extreme example in my mind was a daughter, I actually was yelled at by a daughter on the telephone for talking openly in front of her dad who was the patient, “Don’t you know Chinese,” I still remember, “Don’t you know Chinese people don’t like to talk about dying?” To a family sitting around the table and welcoming and being very open in front, maybe not in front of the patient but uh, with me and*
doing very active decision-making and planning. So it was hard for me to get my head around what was, you know, so I learned very quickly to, to let, take my direction from the family and to see where they were at…. And I am always reluctant to make big statements about any culture because you see so much variation. (K18)

Her comments may appear contradictory, but that is an apparent property of hybridity. The aim of negotiation was to reconcile the irreconcilable, and providers had to rationalize and make sense of their struggles with this task. Although K18 acknowledged there were end-of-life issues faced by many people from different ethnocultural backgrounds, she could not help but comment on the similarities she did see. Her contradictory statements indicated the complexity for providers of blending together knowledges, experiences, perceptions, and assumptions to bring reason to their actions and approaches to care. These rationalizations were often messy because practice was messy.

Providers genuinely struggled to put together the discourse of multiculturalism, cultural competence, and patient-centred care. From their comments during interviews it appeared that they earnestly tried to avoid stereotyping because it was neither culturally sensitive nor best practice. At the same time, in their narratives, providers frequently shared the commonalities they did see within Chinese immigrant care recipients and families, such as the preference for being cared for at home, but wanting the actual death to take place in a hospital palliative care unit or hospice. There was a tenuous grasp on a generalized account of the cultural nuances of caring for Chinese immigrants because providers were attuned to the individual needs of care recipients; thus it was challenging to reconcile these elements in a fixed account. The discursive tension was apparent in providers’ interviews as they wavered between sharing how they developed strategies to tailor palliative home care to individual care recipients while remaining alert to cultural preferences.

Care Recipients and Caregivers

Evidently, the discursive tensions were not as apparent with care recipients and family caregivers because they were not working between the same practice discourses as providers, but they were working between cultural differences. In contrast to the struggles of home care providers, care recipients and caregivers were able to more seamlessly describe the reconciliation of cultural differences, especially combining traditional Chinese medicine with Western medical approaches to pain and symptom management for their advanced cancer. During one of my
observational visits, CR3 took me to his office and showed me his collection of books on traditional Chinese medicine. CR3 often referred to these books for remedies to his ailments. CR3 had explained that since the surgery for his brain tumour, he had difficulty remembering things:

*Right now my memory isn’t as good as it was before. Once I close the book, sometimes I don’t remember what it was that I just read... when I had my surgery they took a part of my brain out so I need to work on that, I need to make some soups that are going to help me with my brain. I am going to look at some Chinese medicine books and figure out what I need to take to help with my brain.* (CR3, translated)

His use of traditional Chinese medicine references gave him a wealth of information, which he happily shared with me during the interview:

*So I would have to go to the hospital and see the doctor for check-ups because there were a couple of things that I didn’t have: I wasn’t vomiting, I wasn’t dizzy, and I didn’t have pain. So, the doctor said, “Well that’s good,” because these are the things that they’re most concerned about and I didn’t have any of that. I didn’t vomit, because a lot of people who have chemo, they vomit but I wasn’t vomiting. Because you know what I did, I would take raw ginger. (I: Huh?) You know, the ginger that you cook with? Yes, ginger. I would take a small bag and keep small slices of raw ginger in it. As soon as I felt something in my throat, I would take a piece of raw ginger and put it in my mouth and chew. Ginger is very spicy. But once you chew a bit, it keeps you from vomiting. That’s why you need to listen and understand that sometimes there is good in this raw ginger. It is good for preventing nausea.* (CR3, translated)

CR3 seamlessly integrated this knowledge into his symptom management regimen. He had an air of authority as he shared this knowledge with me, and he was confident in the effectiveness of ginger as an antiemetic. This knowledge was pragmatically enfolded into his chemotherapy routine, and he did not ask his oncologist whether ginger was contraindicated with his chemotherapy or not. CR3 felt knowledgeable and comfortable with combining traditional Chinese medicine and his Western medical regimen to suit his symptomatic needs.

When care recipients indicated that they took complementary or alternative medicine, it was not always just a matter of integrating knowledge from the different approaches. Instead, care recipients had many things to consider before a hybrid approach could be negotiated. During our interview, CR2 talked again about his regular visits to New York to have turtle soup
and to visit his younger sister. I asked him how he knew that turtle soup was good for his cancer. He shrugged and answered:

Well in China people usually say that, like back then they just, they just said that sea turtle was good for cancer, it was good for your health, so I just knew that it was good for you... In general taking sea turtle is supposed to be good for you. Like in China, they say eating sea turtle once in a while is good for prevention. (CR2, translated)

Aside from the fact that this was knowledge that had been passed down to him, he also had to contend with the resources he had, and the availability of sea turtle for consumption. CR2 explained that he had to go to the US to have the sea turtle because it was less costly than in Canada. That meant that he had to go to the US, and specifically New York City, to have it because his younger sister lived there. It was evident that CR2 had to conscientiously combine his knowledges and resources to access this health routine.

CR2’s wife, his main caregiver, also demonstrated creativity in accessing information about her husband’s condition by employing an assortment of approaches. As previously discussed, this couple felt stigmatized by cancer and so did not openly share his diagnosis with co-workers and friends. Thus, CG2 was strategic in the ways she retrieved information about cancer:

Well because most of my friends in China are doctors, I can call them and ask for advice. (I: So your friends in China, are they considered Chinese medicine doctors or are they Western doctors?) Well, they’re Western doctors, but pretty much all the Chinese doctors there, they know a bit of both, they know Western medicine and then they know a bit of Chinese medicine as well.... if I can think of what I need to know then I just punch it into Google and then it gives me an answer. So if I have a question about what to do or for instance um, when he was going through chemo, I wanted to know what was good to eat, then I would just put it into Google and then it came out with some answers.(I: So, do you use, do you type in Chinese into Google?) Yes, uh, you can type in Chinese and it gives you the answer in Chinese. (CG2, translated)

CR2 demonstrated a level of sophistication in accessing information. She was able to connect with friends who were physicians in China by simply calling them, and she was able to maintain her anonymity by using the internet to look up information available in Chinese. CG2 tapped into pre-existing transnational linkages. Transnationalism refers to “the process by which immigrants build social fields that link together their country of origin and their country of settlement”
Often transnationalism is spoken of in conjunction with hybridity in that the exchange of goods, ideas, and people between host and sending countries may result in a mixing and blending of knowledges and cultural differences to generate “new” cultural meanings and practices (Yue, 2009). CG2 recognized that her physician friends in China were transnational in that they were versed in both Western and Eastern medicines. This met her particular need to make sense of and integrate what Canadian doctors were prescribing for her husband, and the traditional Eastern medical philosophy that she was familiar with. This way, she could work through the discursive tensions between Western and Eastern medicine, and approach care that integrated both.

The use of Google offered another way of accessing relevant information. Current technologies have offered immigrants more cost-effective and immediate modes of communication such as long-distance phone calls and email. The advent of these technologies supports transnational practices and enables immigrants to access information and resources that are available in their own languages and within familiar contexts. Both CR2 and CG2 blended their need for relevant and particular information available in Chinese along with their need for privacy. By accessing, and thus re-enforcing, existing transnational linkages, care recipients and family caregivers could avoid having their knowledge subjugated as they searched for and translated English medical terms to Chinese, and re-interpreted them within their own notions of palliative home care.

For immigrants, the connections between cultural identity and nationality were not always well articulated. CG2 also shared her dilemma in answering whether she thought she was Canadian now:

Well, if I were to say, I would say that I am of course a Chinese person. I am Chinese but um, of course I am Canadian but if somebody asked me what I was, I would say I was Chinese... for the time being, I don’t want to go back [to China] because um, I have gotten used to it here [in Canada], and the situation there is not as good. But if you want me to say where I would feel more happy or welcomed, that would be in China. I am used to it being more quiet now and I don’t like to go to places that are busy, so it’s better here in Canada for me. That’s why, because it is quieter here, it suits me better. Because in China, it’s so much more busy and there’s more of a night life there and going shopping, things like that and they like to play Mahjong all the time. I am not really interested in those things. (CG2, translated)
This quote demonstrated the complexity of hybrid identities and the continual shifting that can occur in relation to a sense of belonging. CG2’s quote demonstrates the complexity for immigrants of belonging to and identifying a single home. Only when I questioned her directly about her nationality, did she consciously have to make an effort to articulate an identity. Many of the Chinese immigrant participants seamlessly wove cultural differences together and did not necessarily emphasize their “Chineseness” as rationale for why and how they were going about their daily routines and their perception of palliative home care. This was important because Chineseness may be an identity that was being assigned to immigrants by providers, instead of immigrants expressly assuming and claiming this identity. Similarly Canadian could also be a category that was assigned. HCP2/3 differentiated between CR2 and CR3 by stating that because CR3 had been in Canada much longer and was more receptive to her being in his home, she characterized him as being more Canadian. Thus Chineseness and Canadianess were not identities immigrants outwardly worked through as provider narratives would seem to imply. What was evident is that hybrid identities and a sense of belonging are fluid, context-specific, and open for interpretation. Chinese immigrant care recipients and family caregivers were not necessarily forefronting their culture when trying to reconcile their different knowledges, experiences, and assumptions. It was their everyday material and social circumstances within the context of dying that shaped their experiences of being cared for at home.

**Dying at Home: Death as Taboo**

Like myself, many of the key informants and home care providers also held an assumption that death was a taboo topic and that dying at home was not the preferred option for Chinese immigrant care recipients. In the above vignette, HCP2/3 did not address dying at home with either CR2 or CR3. During the home visits, HCP2/3 mainly addressed and attended to the immediate pain and symptom management concerns of the care recipients. In the vignette in the previous chapter, HCP1 and CR1 were openly planning for end-of-life and were setting up tours of hospital palliative units and hospices. With Case 2 and 3, there was a silence around discussing and planning for a home death. HCP2/3 admitted that she did not believe that Chinese care recipients wanted to die at home:

*To die at home is not uh, a really Chinese culture. They usually let the patient stay in the hospital when he’s really sick. They never take them home, right? They don’t usually take them home. It’s not, not really a Chinese culture to die at home.* (I: Um hmm, have you had Chinese patients that
want to die at home?) Not yet... No I haven’t seen any Chinese wants, wants to die at home.
(HCP2/3, English is her second language)

Her silence and reticence could have been informed by 1) her own experiences as someone who identified as ethnically Chinese and also held the perception that talking about death was a taboo amongst Chinese care recipients and families and/or 2) a perceived reluctance to speak about death from care recipients and family caregivers. Another ethnically Chinese CCAC case manager held a similar sentiment:

... I would like to say for Chinese client nobody want to die at home. No one want to die at home, they wanted to have palliative care support services, they agree to have hospice support but nobody want to die at home, they always wanted to die in a hospital. They worry about the love one will be scare because of, they are very superstitious, and also they worry about if they die at home, their home cannot be re-sell. (KII, English is her second language)

Many key informants and providers shared similar stories and experiences caring for Chinese immigrants receiving palliative home care. Often they felt that Chinese immigrant care recipients wanted to be cared for at home until they were actively dying, at which time, they wanted to be transferred to a palliative unit or hospice where the actual death would take place. While some providers had a sense there was a negative energy (K14) associated with dying at home, others reported experiences with Chinese care recipients that demonstrated they did not want to die at home, implicitly inferring it was a cultural belief.

Although some providers shared the assumption that Chinese immigrant care recipients did not want to die at home, many also had experiences that challenged their belief. A community palliative nursing consultant expressed her perplexity when asked what her impression was of Chinese immigrant care recipients’ preference for place of death:

Um, I don’t know maybe because they are not as open discussing sometimes and that’s not the only culture that’s like that obviously. Uh, people that aren’t as open you know, maybe you think that, you get the impression when you’re a professional that they are um, that it’s a taboo subject and that it’s not something that they are going to be comfortable with at the end-of-life, and yet I saw people that did, you know, so. (K18)

Just like HCP1 and CR1 were openly discussing and planning where CR1 was to go when she was actively dying, K18 related a similar story of a Chinese immigrant family actively engaged in planning their mother’s home death:
Yeah, I am thinking of that family, it’s quite a while, but that family that I told you, that was probably about 4 kids and they were all professionals and they’d come in - a couple from Hong Kong, a couple from this, one from the States, I think. They were like literally around the table talking to me… I don’t know how else to describe them. They were professionals which is not uncommon either but they were really quite, I thought a bit unique that way, that they were really open… their goal, they were very clear with me that they were there to help and mom would die here [at home] and they just needed to know the details and they would ask very um, pragmatic questions, you know?... so I learned very quickly to take my direction from the family and to see where they were at. (KI8)

Providers often had experiences that challenged their belief that Chinese immigrants did not want to speak about death, or die at home. Providers had to be resolved that they could not strictly categorize preferences for place of death by culture; but, the lack of a prescriptive approach made it more complex when working with immigrant care recipients and their families at end-of-life.

The notion that death was taboo for Chinese peoples was also dispelled when a bereaved Chinese immigrant caregiver shared her experiences of caring for her elderly mother who was diagnosed with advanced metastatic breast cancer. She acknowledged that her mother’s decision was swift and resolute:

Yeah, my mom have uh, can-, uh breast cancer... and she doesn't want to treat it. So for, she last another 3 years at home, lacking of energy, support with transfusion. But we got lot of help from CCAC, from our family doctor and um, the doctor also do home visit... she make decision herself and she pass away at home. (KI11, English is her second language)

In her interview, KI11 spoke highly of having the opportunity to care for her dying mother at home, and planned openly with her. After seeing how KI11 cared for her dying mother, her father-in-law later approached her to provide palliative care for him at home as well. KI11 was able to provide palliative care for her father-in-law until he passed away at home as well.

Home care providers also shared comparable experiences of providing palliative home care to Chinese immigrant care recipients and helping them to achieve a home death, although admittedly, they felt that it was not the norm. Many of the providers felt that the lack of open discussion on death between the provider and family, and amongst family members hindered
palliation at home. Although HCP2/3 did not discuss with CR3 his preference for place of death, during our individual interview, she revealed that she had been discussing it with CR3’s son: ...
the family knows the progress and uh, I mean they know. I mean the son is looking into palliative care unit. (HCP2/3, English is her second language)
Although HCP2/3 was not talking directly with CR3 about his impending death, she was discussing it with his son, CG3S. CG3S shared with me that he had also discussed with his father where he wanted to go if his condition got worse:

... he spent most of his life in this neighbourhood, right? So he is very comfortable in this neighbourhood um, and he understands yeah, if there comes a time where he can no longer um, bathe himself, he can no longer um, you know, go to the washroom by himself, like he can no longer basically take care of himself then by all means send him to [Hospital name] basically, right? He’s got no problem with that, right, like he has no problem with that at all. (I: And you have had the discussion with him?) Oh yeah, I mean we walked all the way to [Hospital name] and he said, “Oh this is where, you know, I would like to go.”... if my mom obviously can’t carry him, if she can’t take care of him, by all means, he has basically got to go to palliative care. We don’t know how bad it can be. (CG3S)

While there may be an assumption that planning for end-of-life care was not taking place because death was a taboo topic, these discussions were taking place, but sometimes in roundabout ways. To work through actual and perceived differences in preference for place of death and willingness to talk about death, alternate routes were being negotiated. Hybridization came as the nurse considered the family’s level of comfort with broaching the subject of dying at home, and integrated it as a way to plan for end-of-life. HCP2/3 found a way to mitigate unnecessary stress and anxiety for CR3.

While many providers felt that Chinese immigrant families were not likely to openly discuss and plan for palliative care, a range of experiences were reported. Some Chinese immigrant families did so willingly and pragmatically, while others did so implicitly and circuitously. These discussions inevitably took place in a state of uncertainty because curative efforts were no longer effective, but the progress of terminal illness was indeterminate. CR1 had to reconcile her desire for a home death along with her understanding of the supports available to her, especially the strain it would place on her husband as her main caregiver. There were multiple intersecting considerations she had to take into account as she planned for end-of-life
care. She explained:

In fact at the very beginning, I don’t want to die at home. I want to go into the hospital to have palliative care. But my son and my daughter-in-law, they were so strong about being at home, the last stage. I think they don’t really know what it really involved... So, I do understand now that if I opt to stay at home, I will have all of this support. But still after I think about it, that is not enough. And I talk to my son and daughter-in-law, just me and dad in this apartment, even with all those support - that is not enough. I asked them whether they are willing to take no pay leave. We do need family members more than the old man, you know. There are so many little things: buying groceries. Okay, the PSW could prepare food, right? But still there are so many things: monitoring the medication. After thinking, anyway, I think that even with all of this government support, which is great okay, I think I still need a very wide network of support from family members. [It’d be] good if I live in a big house and have all sorts of relatives and family members pitching in on top of the government support. So anyway, I come to the conclusion that to spend the last days of life at home is not that easy. So my decision is that I will opt to spend my last days in the hospital, in the palliative care unit. (CR1)

Although her final decision was clear – she was not going to die at home – the hybrid and negotiated aspect of her decision was in her explanation of how she came to this decision. She recognized the multiple, and often competing considerations she held, and had to put it together in a way that would result in a satisfactory path to her last days. In her quote in the previous chapter, CR1 understood all the resources palliative home care could provide, but in her estimation and experiences with the services and with her husband, she decided that palliative home care was not enough. While her decision to tour palliative units and hospices may indicate an openness to discuss and plan for her death, there evidently was something that was not being discussed – she saw herself as a burden on her family members. In this sense she was silenced and there was subjugation of knowledge, fears, and anxieties.

A community palliative nursing consultant also speculated that some Chinese immigrant care recipients were silenced in expressing their desire to die at home because they feared burdening their family members. I had asked what his impression was of Chinese immigrant care recipients indicating that they didn’t want to die at home, he answered:

Almost all of them, they don’t want to be burden to the family, to the children, to the kids... (KI5)
KI5 attributed the preference to die in an institutional setting to the fact that Chinese immigrant care recipients did not want to be a burden on family members. Although providers conveyed a belief that Chinese immigrants did not want to die at home because of superstitions and negative energy being associated with the home, it may actually be that care recipients were choosing to die in hospitals, palliative units, and hospices to avoid imposing on family members. Thus, the belief that Chinese immigrants do not want to die at home may have been perpetuated by superficial observations and dominating cultural assumptions, rather than through a thorough examination for the reasons and logics behind the lack of willingness to die at home. Without probing further, Chinese immigrants may be silenced in expressing their real and underlying concerns for dying at home; thus, denying the agency of Chinese immigrant care recipients.

While care recipients must reconcile different knowledges, experiences, and beliefs, so too do providers as they plan care for palliative care recipients. Providers have also had to grapple with the institutional pressure for death to return to its historical place in the home. As a community palliative nursing consultant explained, her program’s performance was evaluated on how successful they were at supporting home deaths, and preventing costly emergency visits. She acknowledged:

*Because a lot of protocols that we are doing in our program now are supporting um, dying at home and avoiding emergency visits, that’s partly how our program is going to be graded is how we impacted those expensive emergency visits. Um, but it’s very important to establish that first where’s the place of preference for death and lots of people are not decided so then you have to kind of figure it out as you go. I think it’s always important to have a backup plan but they, they die at home if they want. That’s, that’s what I see as important.* (KI8)

Providers have had to reconcile that some Chinese immigrant care recipients may not want to die at home and some may be receptive to dying at home, along with the dominant medical impetus for cancer patients to die at home.

At the initial assessment, case managers often did not know whether care recipients knew their diagnosis, if they were open to speaking about death, and where they wanted to receive end-of-life care. When asked about talking about death and how she initially probed whether care recipients were willing to die at home, this case manager explained how she had to *test the waters* with each new care recipient and family:
Yeah, test the waters, drop a few words, or sometimes even on the phone you know, uh, I’ll ask, “What do they know?” ... I see how the conversation is going. So if say, if I have been warned about something, I am not going to bring it up, definitely not in my first visit. Um, if there is an adult child and the client steps out, I might say, “Do they know? Do they understand?” Do you know what I mean? So even if, you know, English is their first language, I might not just bring it up. But a common question is, “What do you know uh, or understand about your illness and your treatment?” And if they say, “I know I can’t be cured,” then I can talk openly, whereas if they are saying, “Well, I still have hope and I really don’t know,” then I am not going to be the one to uh, drop that information on them. (KI9)

Providers had to be sensitive, especially in initial visits. They explained that they tried not to push the care recipients too much because it could take time to understand and accept a terminal diagnosis.

As well, to negotiate the complexity and needs of each care recipient, providers described a hybrid approach – Plan B. Providers acknowledged that they often helped Chinese immigrant families develop a Plan B or a backup plan to dying at home. KI5, a community palliative nursing consultant explained:

So, there are many, many factors you have to take into consideration and then you can lay the whole information and it can try, so our goal is to honour the patient wishes number 1 and number 2 [is] to honour the family uh, wishes. Usually you will hear, “I want to stay at home as long as I can, until I cannot be able to be managed at home.” That’s the usual uh, that’s what they get about Chinese people. So, um, community and then we see how it will go and we are open for option, there is nothing written in stone. They can change the care plan, we have plan 1, plan 2, that’s why we do a backup application in palliative care units so the patient doesn’t stay in Emerg for 10 hours or 20 hours, or days. They go right away to the palliative care unit and we have the communication all the time so the hospital of the palliative care unit or the hospice, residence hospice. (KI5, English is his second language)

Through their extensive experiences providing palliative care, these providers devised a strategy, Plan B, which tried to account for the possible scenarios that come up when a care recipient is actively dying. Plan B was a safety net; it allowed providers to initially get care recipients to accept receiving palliative home care because there was a back-up plan to move care out of the home if desired.
Some providers also felt there was an inversion in understanding what palliative home care actually meant for Chinese immigrant care recipients. As HCP2/3 alluded to in her above quote, Chinese immigrant care recipients may not understand that they are terminal because they are able to stay at home, and are not sick enough to be admitted to a hospital. A home care nurse concurred with this understanding and explained:  

Yeah, I don’t think they would die at home, yeah. For my sense, I don’t think they 100% understand what is the palliative care for them... Because they, they at home yeah, they feel they are not so bad because if they get worse they will stay in hospital, you know what I mean?...

*In China or in Hong Kong we don’t have the home care. If you feel sick, you will stay in hospital. If you okay, you recover, then you go home.* (KI7, English is her second language)

These providers understood that there was a difference between the Canadian health care system and that of their country of origin. The understanding that illness was treated differently within the different health care systems resulted in an interpretation of what palliative home care potentially meant for some Chinese immigrant care recipients. The inversion of understanding contradicted the dominant Western ideal that the home was a peaceful place for dying. Instead, these providers took into consideration their knowledge, experiences, and beliefs of the health care system in China and Hong Kong to re-formulate a new understanding of why Chinese immigrant care recipients may be hesitant to receive palliative home care.

The initial and dominating assumption that Chinese immigrant care recipients do not want to die at home was continuously re-worked to develop hybrid understandings and approaches to understanding and engaging in palliative home care. Participants had to negotiate multiple, intersecting considerations to address the issue of dying at home. Providers indicated that they had experiences where they helped Chinese immigrant care recipients to plan for a death in a palliative care unit or hospice, and cared for Chinese immigrants who preferred and were able to achieve a home death. The variation providers experienced highlighted how the social, material, and contextual circumstances shaped dying at home for immigrants. The arrangements for dying at home were fluid and dynamic for Chinese immigrant care recipients, and *not written in stone*. What became apparent in providers’ narratives was that there was no *universal discourse* on this matter. Death was no more taboo than for any other cultural group, including Canadian-born care recipients. The contextual circumstances were the most significant consideration when approaching the topic with a family.
More than a Language Barrier

Care recipients and caregivers:

Although the participants and I identified ourselves as “Chinese” and spoke “Chinese”, we all did not speak the same dialects. This meant that during home observational visits, I spoke with HCP2/3 in English, HCP2/3 spoke Mandarin with CR2 and CR3, and I spoke Cantonese and Taishan with CR2 and CR3. Sometimes HCP2/3 translated her Mandarin conversations with CR2 and CR3 to me in English, or I translated my Cantonese and Taishan exchanges with CR2 and CR3 to HCP2/3. Invariably, there was a lot of translation going on despite all of us being “Chinese”. Although our communications required more work, we tried to include everyone in the conversation. There was extra effort involved when there was a perceived language barrier, and many participants spoke of these difficulties when delivering and receiving palliative home care. Most Chinese immigrant care recipients and their family caregivers who did not speak English well relied heavily on either professional interpreters or English-speaking family members to help them navigate doctor’s appointments. When asked what additional services she felt she needed, CR4 simply put it:

*I can’t speak English. I need a translator to help me.* (CR4, translated)

CR4 talked about the difficulties of going to medical appointments with her oncologist because she required an interpreter. Often, it was her daughter who translated for her, but again, she was worried about her daughter taking too much time off from work and the resultant potential to jeopardize her employment. CR4 felt that the formal services offered did not meet her need for transportation to medical appointments, and she needed an interpreter at these appointments. Some care recipients were fortunate enough to go to an institution that provided translation services for free. CR2 explained that he had formed a close relationship with a volunteer translator, who coordinated and went with him to most of his doctor’s appointments. CR2 explained:

*The translator and I are very good, she’s very good. Uh, she’s been helping me translate about 5 years... if I don’t bring a translator then the hospital doctors will go and find somebody to translate. So there’s always somebody there to translate.* (CR2, translated)

CR2 maintained personal contact with the volunteer translator and informed her of his appointments so that he could use her services when needed.
But where there was translation, there was also the potential for miscommunication and misunderstandings. When I asked CG1 if there were services he thought he required as a family caregiver, he explained that even though he spoke English, he would have liked services in Cantonese because there were things that he could not articulate and explain in English well:

Well, I guess for sometimes if for Chinese uh, whose mother tongue is Chinese, maybe a Chinese-speaking counsellor would be a, would be preferable. And sometimes maybe if your mother tongue is, is Chinese right, sometimes you might have difficulty in expressing... yeah, more eloquently, right? Without having to pause and think how should I frame my questions or how do I frame my answer, right? (CG1)

CG1 expressed the complexity of language and that not all things could be easily translated. He also spoke about the comfort of speaking in one’s mother tongue, and having confidence in what was being conveyed, but also how it was delivered with more conviction, and without pause. In spite of this, care recipients and families were resilient in the ways they addressed language barriers. They often developed sophisticated approaches to work around language barriers. This family caregiver quite simply recognized that she needed to learn English to better verbalize information during medical appointments:

What really prompted me to learn English was because you know, we would go to the doctors and then we would have to depend on a translator. I couldn’t even say the simplest things or ask questions. Like I couldn’t even say, “He was dizzy,” or things like that, so then I felt that I really had to go back and learn English to even say the most elementary things. Well, you know, it’s just that right now I am able to stay at home a bit, but really if I had to work, I wouldn’t be able to go to ESL classes. But at this ESL school they are pretty flexible. (CG2, translated)

Learning English was not as simple as just going to class though. As CG2 alluded here, considerations for time had to be taken into account. While she was fortunate to find an ESL program that was flexible, she still had to juggle this between everything else that was going on, such as caring for her husband and maintaining paid employment.

The ways in which care recipients and family caregivers addressed language barriers showed how tacit knowledge surfaced and was blended within the everyday. These hybrid approaches were borne out of necessity. For instance, this caregiver devised a way to help his father deal with the anxiety of filling out English-language forms at medical appointments so that he would not have to take time off work to accompany his father to every appointment:
But you know, I mean since my dad had cancer I’ve pretty much been um, you know, taking him to the hospitals because you know, his English is not that good. Which is the main thing, his English is not that good. He doesn’t know like the most simplest instructions, right? So, for example um, let’s say I have to take him to get an MRI, which was every month, he wouldn’t know how to fill out the form before going there, but it’s the same type of things, right? So to make it easier on him and my mom, I basically just go through it with him, check off the stuff that’s, that’s supposed to be checked off and then basically do another copy for him and then he can do it himself. (CG3S)

This form was meant to be filled out each time, but CG3S realized that it was the same form at each visit, and so made a copy for his father to refer to when filling out the form at the MRI appointment. He mitigated his parents’ anxiety by patiently explaining the form to them prior to the appointment, and then relied on their abilities to copy. Family caregivers, who spoke English and were depended upon as translators, felt the burden of being available to help interpret for their ill family member. This often put a strain on their employment or other commitments. Many of these family caregivers had to develop strategies that took into account competing demands so that the care recipient would not be abandoned due to lack of communication abilities, while at the same time fulfilling caregivers’ commitments to work and their own families as well.

Key informants and home care providers:

Most providers also talked about the issues of working with care recipients and families who did not speak English. HCP1 acknowledged that language barriers were a concern when providing palliative home care. She sympathized with her immigrant care recipients who could not communicate in English:

Well, I have worked with so many different immigrant families and the problem is, there’s a huge problem which I think you’ll understand that with a language barrier... just generally, the Chinese community, and I think this will probably obviously spill over to how you would deal with them palliatively, they’re treated with such disrespect when they come here, not knowing the language and I think this is not just Chinese. I think this across the board with foreigners who come here with a foreign tongue. They might be engineers, educated people, professors and things in their home country, in their home language. When they go to an English-speaking country and they don’t speak the language, people tend to think that you’re an idiot if you, or it’s
not even that, I mean even if I had to go to China they would probably treat me like an idiot. (HCP1)

HCP1 raised an important point that having a language barrier did not mean one was lacking intelligence. HCP1 recognized that many immigrants were highly educated but because they did not speak English well, they were often misunderstood in health care encounters, and this was a concern for her. Her ability to empathize came from her own experiences as an immigrant to Canada, but she emigrated from a British colony and so acknowledged her relative ease, in some aspects, in establishing herself in Canada.

Many providers implied that being able to communicate was crucial to providing good palliative home care. As KI1 previously explained, she felt that speaking Cantonese connected her with Chinese immigrant care recipients, and was beneficial because it gave her easier access:

... because I speak Cantonese, it make a big difference. When I call, they are not talking to a stranger, I don’t need to go through an interpreter in order to get the access to even speak to the person. (KII, English is her second language)

KII explained that her ability to communicate with Chinese immigrant care recipients in Cantonese meant that she did not face the same challenges as her English-speaking counterparts. Because of her ability to communicate in the same language, she felt that it made her less of a stranger to Chinese immigrant care recipients.

Providers who did not speak Cantonese or Mandarin explained the difficulties in providing palliative home care to Chinese immigrant care recipients who did not speak English. This palliative home care physician explained:

... I think when you then introduce a layer of linguistic or cultural difference into that mix um, you then have another layer of complications. So, again some agencies will try and make an effort for instance to have, if you have a palliative client and family who speak only Cantonese or speak only Mandarin, they will try and match the nurse or maybe some of the other people to that client. But sometimes their language capability doesn’t translate into their clinical capabilities so you might have a clinically more capable nurse in palliative care who can’t speak Cantonese or Mandarin or, you get a Cantonese-assigned nurse who has no interest or experience in palliative care. You can see sort of how that might, how that might complicate matters. I think the other thing is that when we’re really faced with situations where the, the,
translation piece is a huge issue, so, we often I think the default is that families get used for
translation, it’s not all bad but it has limitations. (KI10)

In his comments, KI10 brought up several issues related to language barriers. For KI10, providing palliative home care was challenging but adding cultural and linguistic differences only added to the complexity. He noted that there were limitations to using family members to translate, instead of a professional interpreter. While it seemed logical to match language capability between home care nurses and care recipients, this practice did not always result in the best care. As KI10 astutely pointed out, the ability to communicate in Cantonese or Mandarin did not necessarily translate to clinical capability or expertise in providing palliative home care.

KI10’s statements complicated the assumptions around language barriers. Like other participants, language barriers were seen as a real challenge to receiving and providing palliative home care; but, the assumptions were also worked over in participants’ narratives as they demonstrated tacit knowledge of language barriers. For instance, HCP2/3 explained that although she was Chinese and had been matched with CR2 and CR3, resolution of the language barrier was mostly assumed. The logics of matching for linguistic ability did not work in this case, and thus, the language barrier became silenced and subjugated. She admitted that communication between her and the care recipients was often difficult:

No, very difficult because you know, um, a lot of time is misunderstanding to each other and, and a lot of time, you can’t really explain things. They think they can speak Mandarin but the way he speaks Mandarin, I thought he was speaking Cantonese. Half the time I don’t understand. But now it’s better because I’m used to the way that he is talking but when I am explaining to him about - (I: Is this CR3 or both?) Um, both [CR2 and CR3]. But the thing is CR3 got a son. So son speaks English. So in this one, it’s easier to get them connected. Uh, for CR2, the wife speak Mandarin. She thinks she speak Mandarin, but she, I don’t know, it’s really a language barrier because when I explain something to her, she will say, “Yeah, yeah, yeah I know,” but in the end she would do something that’s different. (HCP2/3, English is her second language)

Adding to KI10’s observation about matching for linguistic ability and clinical capability, HCP2/3 was a clear example of how matching for linguistic ability, did not resolve the language barrier. What became clear was that home care nurses and care recipients were not necessarily being matched for linguistic similarities, but rather for assumed cultural and racial similarities. These complicated interpretations shed a critical light on the notion of matching for language. In
her statements, HCP2/3 was suggesting that language was not being adeptly matched. She acknowledged that she spoke with CR3’s son, CG3S, who spoke English, in order to help get CR3 connected to palliative resources. In this way HCP2/3 had to negotiate a different route for communication when she felt she was not able to appropriately convey her message to CR3 directly.

Relying on family members to translate could also be problematic, and had its drawbacks, as KI10 indicated. When questioned about using family members as translators, this CCAC case manager explained that there were cues and strategies she developed to understand because she felt she may be getting a diluted representation of the care recipient’s response and perspective from family members:

... so if you know, I ask a 3 word question and then they have like a 20 minute conversation and they only give me 3 words back then I will say, “There seems to be other things, what else did she say?” You know, you know what I mean? Or “Did she tell you how she is feeling?” Because they may only relay the facts but not all the other things that are, I am not understanding what they are talking about, um, but it is not the best system. The best is, the best is to have an interpreter. Uh, but often family want to be there so I will use them first and if that is not working uh, I’ll bring an interpreter. Or uh, often I may ask the client, “Can I come back and speak to you?” right, so I am losing the middle man and then I would bring an interpreter. (KI9)

Although KI9 noted that using a family member as an interpreter was not ideal, sometimes, there was no way around it. Instead, she blended these cues to navigate these home visits. She observed closely and developed a system of understanding whether translation with the family member was working or not. She sought the help of a third party professional interpreter when she sensed that the translation was not working with the family member. Thus, her hybrid approach was dynamic, as she had to look for signs and prompts that indicated translation by the family member was not adequate.

When there was a language barrier, providers often developed intricate, thoughtful, and blended ways of communicating that would help them make a connection with care recipients. Another home care nurse, who was matched with a Chinese immigrant care recipient, explained that she also spoke Mandarin and could not converse with her Cantonese-speaking care recipient. She explained that while at first she would request that English-speaking family members be present during home visits, soon she developed different ways of communicating:
Um, generally like we use the gestures and um, well certain key points, for example, I really want to know if the patient is, because the patient has hematuria so I was suspect if he is you know, CBC, like haemoglobin is stable those kind of information, so I really want to know if patient is dizzy or feel like really tired so I just uh, write down [in Chinese] on the paper like tired, dizzy, then they will say, “No” or “Yes,” right? So, it’s very clear... if I am talking this word, he really not understand this word so just write down or even sometimes draw a picture, right? If the client has pain then draw a face you know, really crying, like you know? (KI2, English is her second language)

KI2 worked with the care recipient to develop non-verbal ways of communicating. Although this provider spoke English, she was not fully fluent as she was an immigrant as well. This was also the case for some of the other immigrant home care providers in the study. Thus, immigrant home care providers caring for Chinese immigrant care recipients often had to work through multiple layers of their own and care recipients’ language barriers and cultural differences.

The need for a universal, non-verbal communication system was essential as English-speaking and immigrant home care providers had to creatively develop ways to communicate with care recipients. A community palliative nursing consultant described how she was able to communicate with her non-English speaking Chinese immigrant care recipients beyond relying on spoken language:

I never knew what ‘congee’ was, I never knew ‘tong’ was. I get them to teach me their language. I think it’s about being human um, it’s about, I think it’s about being human, it’s about being human. I think that you know, all culture aside, is it congee or chicken soup? It’s all about the same thing, we just call it something different. We’re all going to die. We all have the same fears, we all are just afraid to express them, and it’s a matter of taking the time to be and sit with somebody, and it doesn’t matter if we are Chinese, it doesn’t matter if we are black or, or if we’re white, we are all going to die.... we all get scared at the end.... and I don’t need to be able to speak their language to put a hand on them to say, “It’s okay.” It’s my face that they’re going to read, that’s the language. They know when people care, when you keep on going back, when you keep on checking in with their family... so sometimes language isn’t every, isn’t so much the barrier. It’s the presence of being there, that’s to, that’s what tells you, that’s what tells them that you care, is that you keep on going back. (KI6)
KI6 worked through language barriers so that subjugated anxieties and emotions around dying at home could be expressed, regardless of not sharing the same language. KI6 tried to be with Chinese immigrant care recipients in ways that eased their fears and anxieties. She learned important Chinese words, *congee* (Chinese rice soup = chicken soup) and *tong* (pain), to show her humility and language deficit, and she also shared the importance of non-verbal approaches to conveying care. She negotiated through the language barrier to develop a hybrid, non-verbal understanding of how to show caring and concern for care recipients. This was what Bhabha referred to as an *international culture* (1994/2004).

The effort that was involved in communicating when there was a language barrier also left silences. As discussed above, sometimes there was a hesitation in talking about death that was not due to the sole issue of differences in language, but that a silence was indicated and required by the family around discussing death and dying at home. Speaking about death required incredible linguistic sophistication in any situation, irrespective of a language barrier. A language barrier made planning end-of-life care that much more difficult because of the many euphemisms and metaphors to death that exist in the English language that were not available to providers. Thus, the silence may have persisted because of providers’ inability to speak euphemistically and sensitively about death when there was a language barrier.

Another issue that was not made clear in providers’ comments was that the professional language and jargon of providers formed an additional linguistic layer that needed to be negotiated by care recipients and families. Regardless of English-language proficiency, the institutional language of Western medicine and the medical jargon of palliative care was an added dimension to care recipients’ and families’ understanding and interpretation of palliative home care. Just as there are assumptions about cultures, the language of health also holds many assumptions. The assumption of the neutrality of health concepts and meanings was taken-for-granted by providers, and concealed the fact that palliative care and its meanings and practices were a Western notion. Care recipients and family caregivers may have perspectives on health and well-being that are based on Eastern understandings. Language is one way in which knowledge is conveyed, and so the inability to express their way of knowing in a mutually understood language meant that care recipients’ and caregivers’ knowledges were silenced or subjugated. Hence, the issues of communication went beyond just a language barrier.
Conclusion

The home was the in-between space, the Third Space where care recipients, family caregivers, and providers collided within the context of dying at home. Providers struggled to articulate best care practices for immigrants within the dominating discourses of multiculturalism, cultural competence, and patient-centred care. The discursive tensions permeated care as providers tried to make sense of it within the cultural meaning of dying at home, talking about death, and language barriers for Chinese immigrant care recipients. The variation they saw in their Chinese immigrant care recipients defied providers’ efforts to define a prescriptive approach to palliative home care for this population. Despite being baffling, the variation they saw also provided providers a repository of tacit knowledge from which to draw upon and consider as they negotiated the Third Space. Although providers tried to feature culture prominently in their narratives, the pragmatics of dying at home, regardless of cultural beliefs surfaced again and again. While I do not deny that culture exists and that there are shared meanings that can be imparted and passed on, what I hope these results show is that shared meanings go beyond ethnocultural affiliation. Palliative care itself is a culture and is imbued with meanings, rituals, beliefs, and practices that may have nothing to do with race, ethnicity, or culture. It is the meeting, blending, clashing, and grappling of differences that is being negotiated to form hybrid meanings, practices, and ways of being so that particularized, personal approaches to dying could be achieved.
CHAPTER 8
DISCUSSION, IMPLICATIONS, AND CONCLUSION

Introduction

As described in the prologue, the impetus for this study was the tensions arising with my own experiences of death being taboo within the Chinese community, and the broader social, political, biomedical, and economic thrust towards home as the place for death and dying to occur. The findings illustrate the tentative collision between the everyday routines of the home with the imposed practices of palliative care. Care recipients and family caregivers had to simultaneously accept the stranger that has arrived to provide palliation in their home, but also graciously delineate boundaries to maintain a semblance of home. Upon their arrival, home care providers had to try to seamlessly meld their clinical expertise and role with the available allocated resources and care recipients’ expectations of care. Although this study was focused on Chinese immigrant experiences of palliative home care, it became clear that as data collection and analysis progressed, the findings were not ethnic-specific, but specific to the circumstances of dying at home. While some providers related beliefs on death and dying and preferences for place of death to Chinese cultural beliefs, most also recognized that experiences of dying at home were situational, and shaped by many contingencies, such as the disease trajectory and the available social and economic resources of the family and of the home care system. Consequently the case of Chinese immigrants demonstrates the complexity of receiving and providing palliative home care. Thus this study provides only a small but important glimpse of the palliative home care experiences of immigrants.

Reflecting Back to Move Forward

Through the process of doing this study, I have gradually come to terms with the realization that this was not solely an altruistic endeavour, but that there were also self-serving reasons for engaging in this topic in that I wanted to find a place of belonging for myself. I wanted to know if others had thoughts and experiences similar to mine. Do others experience a silence around death? Are other providers struggling to reconcile their own immigrant experiences with practice expectations? Does anyone else feel that dying at home may be contentious? These were only a few of the questions that were raised in conceptualizing this thesis. By exploring palliative home care for Chinese immigrants, I wanted to be engaged in a
field where my experiences would resonate, and be immersed in a community that offered an outlet where I could begin to reconcile, translate, reconstitute, re-articulate, re-inscribe, and enact cultural differences in the meaning of dying at home as an immigrant. The possibility that I may have shared experiences and concerns liberated me from the isolation that comes from wanting to speak about the unspeakable. Here was a place where I belonged.

This PhD topic became a vehicle for me to actively speak about something that was formerly forbidden. I know that this desire to belong to a group, within a community, was antithetical to the variation I sought to uncover in Chinese immigrant care recipients’ experiences of dying at home. Ethnographies are concerned with gaining an in-depth understanding of the context of everyday social life (Hammersley & Atkinson, 2007). Although I sought to understand how different contexts contributed to variation in participant experiences of palliative home care, I was also challenged to reconcile the shared meanings that emerged from the data. This challenge speaks to the complexity of culture and mirrors the discursive tensions experienced by home care providers between the discourse of cultural competence and patient-centred care. The disjuncture between the universal and the individual may be a sign of our “post” modern times that emphasize the plurality or fragmentation of experiences (Bhabha, 1994/2004), yet we seem to try to find redemption and solace in commonality, like myself. This disjuncture is a key focus of my discussion chapter.

What also re-emerged as significant in this discussion was the translational and relational nature of cultural differences. Agar (2006) contends that culture is translational and relational in that cultural differences and stereotypes are constructions that only become salient when two or more perspectives collide, as with encounters between care recipients and providers. Thus observations of difference reveal as much about the observer as they do about culture. When participants discussed cultural differences and cultural stereotypes, they were speaking about it in relation to their own experiences, knowledges, and positionings.

The purpose of this study was to examine how meanings of home condition negotiations of care between Chinese immigrants with terminal cancer receiving palliative home care, family caregivers, and home care providers. Four research questions guided my exploration of meanings of home and negotiations of care. The first research question sought to illuminate meanings of home. The second asked how the introduction of palliative home care may change meanings of home. The third asked how palliative care is negotiated in the home. And the final question
pertained to what is negotiated. Palliative home care is profoundly complex. It is complex in its provision by providers, and in its ambivalent reception by care recipients and family caregivers. Culture, language, and immigration were extra layers for consideration in addition to examining death and dying at home for participants. The experiences of participants showed that these layers did not always stack up neatly. It is this lack of order and predictability that contributes to the complications of palliative home care, and will be further explored in this discussion. The discussion of the results will address three main points: 1) home as the first and final frontier for colonization; 2) de-centring and re-centring cultural differences during palliation; and 3) meaning of home and negotiation of care: a complicated entanglement.

**Theoretical Guidance: Balancing Theory and Data**

First and foremost, the findings aligned closely with the theoretical concepts of postcolonial theory. As a counterpoint to the highly emotive and divisive topics of palliation and dying at home, postcolonial theory offered an intriguing and alternative entry into exploring issues for Chinese immigrants. This critical stance shed light on the critiques of culture, race, ethnicity, and multiculturalism to enhance my analysis beyond merely a superficial re-telling of the barriers faced by participants. Instead, it propelled me to contextualize participants’ experiences, to speak of and value subjugated knowledges, and to become comfortable in those hybridized, in-between, grey areas that beset dying at home.

The context of participants’ experiences of palliative home care were elucidated through an intersectoral analysis that took into consideration their positioning of gender, class, race, culture, and other social relations (Anderson et al., 2009). According to Anderson et al. (2009), analysis “begins from [the] particular to [the] general, starting from the voices of the marginalized subject, connecting the micro- to the macro level” (pg. 286). My findings start from the voices of the participants and from the observations of the micro-interactions between participants. It is these observations and narratives that speak volumes about the macro-politics of culture and palliative care. The findings indicate that marginalization is fluid as care recipients, family caregivers, and home care providers were variously positioned as marginal. The context of these positions of marginalization were illustrated when highlighting the ways participants strategized and re-positioned themselves and others in the circle of care to distance palliation and the anxiety of dying. The rich details from participant observations and their
narratives offer “contextual knowledge”. Contextual knowledge is constructed through a critical lens and takes into account the intersectionalities of social positionings to allow the disruption of essentializing ideologies of the Other (Anderson et al., 2009). It is from this point that the findings give meaning to understanding the variation of experiences of dying at home for Chinese immigrants with advanced cancer.

Adopting a theoretical lens in this dissertation was also a way of opening the possibility to talk about death. Postcolonial theory provided a critical lens to facilitate examination of the palliative home care experiences of Chinese immigrants with advanced cancer, their family caregivers, and home care providers. This critical stance gave me a language to express my misgivings about how culture is conceptualized and used in health research, and it afforded me the means to reveal the discursive tensions providers were engaged in. As such, theory continues to be reflected in my discussion.

**Discussion**

As Silverman (2004) suggests, this discussion will focus on what has been accomplished in this study in relation to the research questions posed, theoretical stance, existing work discussed in the literature review, and new works appearing since starting the study.

**Home as the First and Final Frontier for Colonization**

The meaning of home and how it changed when receiving palliative home care for Chinese immigrant care recipients was metaphorically likened to colonization. The romanticization of home as an ideal place for dying was disrupted as it became a site for colonization. Through participant observations and individual interviews, it was clear that cancer and palliative care colonized care recipients’ bodies and homes when they received palliative home care. When invaders come to take over a land and its people, first and foremost, home was colonized. The sense of security, privacy, and identity are challenged as native inhabitants must re-envision how they are to continue to live within a context of home that is no longer the same. As postcolonial theory points out, the ramifications of colonization persist and we are all continually challenged to re-claim a sense of belonging in a globalized and fragmented world. Thus at end-of-life, those discontinuities may be highlighted again as the home becomes colonized by palliative care and the boundaries of the domestic sphere must be opened up to outside providers.
As Loomba (2005) explains, colonialism and capitalism were established in tandem as colonizers not only extracted “goods and wealth from the countries that [they] conquered – [they] restructured the economies of the latter, drawing them into a complex relationship” (9). As homes became colonized by palliative care, care recipients and families entered into a complex relationship with the home care system, and the economies of the home were restructured. In the current climate of health care restructuring, the shift of care to the home setting has been emphasized in policy (Guerriere et al., 2008). With this shift, governments are able to limit health expenditures by relying on family caregivers to provide care or pay out-of-pocket for care (Guerriere et al., 2008; Lilly et al., 2010). Although palliative home care is often offered as a peaceful, and often romanticized, alternative to dying in a cold, de-personalized hospital, what is hidden in this imagery is the fact that care and costs are being offloaded to family caregivers and to front-line home care providers. It is taken-for-granted that both family caregivers and home care providers are willing and able to extend themselves to meet the gaps in the home care system. It is important to acknowledge how fiscal and resource constraints shape the dying process at home. Providers spoke about how they were increasingly challenged to provide quality palliative care in the face of reduced times allocated for home visits, coverage of larger geographical service areas (further distances to travel between visits), and lack of funding for resources such as interpreters. The intersection of these constraints made it that much more complex and difficult for providers to provide quality palliative care in the home. As such, providers were faced with *incommensurable demands and practices* (Bhabha, 1994/2004, p. 247), such as not having enough time to spend with care recipients who had psychosocial needs that went beyond the allocated time for visits, or having to judiciously and discriminately decide if and when they could access resources such as interpreter services. Providers were forced to monitor how they used and spent health care resources. The partnership between colonization and capitalism was insidious and glossed over because of the persistent message that palliative clients were a special group that already received an exceptional amount of resource allocation in comparison to other types of home care clients, yet, it was evident that funding and resource allocation was still not enough.

As the final frontier for colonization, the displacement from home and belonging not only encompasses grander conversations of identity through citizenship, but also pertains to the close, intimate, and personal understandings of belonging within the everyday scope of a much smaller
and familiar home. In this sense, the findings support Quayson’s (2000) claim that the “post” in postcolonial does not signify the end of colonization, but instead, demonstrates that colonization persists, albeit on smaller scales. The analysis is in keeping with the assertion by Anderson et al. (2009) that these micro-interactions connect and shed light on the macro-politics of power, equity, and social justice in health care. It would be unconscionable to contemplate that, for care recipients receiving palliative home care, the last experiences of home would be home as a colonized space, but postcolonial concepts offered alternative ways of seeing, translating, and re-articulating the intricacies of how participants resisted colonization of the home. One such concept was ambivalence, which is further discussed below.

Home is a complex and powerful concept that encompasses physical, psychological, emotional, and spiritual aspects (Sorensen Marshall, 2008). A home becomes exceedingly more complex when palliative care is delivered to someone in that home. The sense of security and identity is jeopardized when the notion of home is changed and colonized by palliative care. The home as a milieu for dying is not straightforward, for there are many contingencies. Exley and Allen’s (2007) critical examination of palliative end-of-life home care revealed that palliative home care included “intrusions and re-ordering” where the domestic space was often re-organized to accommodate dying at home. This was similar to the findings in this study, but whereas Exley and Allen (2007) referred to it as an “intrusion and re-ordering”, it could be read as colonizing forces such as establishing presence and organizing palliative home care. Exley and Allen (2007) also accounted variability in contextual circumstances that would shape palliative home care experiences, but did not go so far as to conceptualize within their critical examination how care recipients and caregivers may resist these changes to the home. The participants in this study demonstrated a mutual, but ambivalent need for each other. Their ambivalence resulted in a form of resistance that could be more aptly described as distancing because there was a simultaneous repulsion and need between care recipients and home care providers. This type of resistance maintained at least partial agency and control over the meaning of home without giving in to complete colonization. Participants re-asserted the ownership of their home and took part in palliative home care in many different ways. By expressing dissatisfaction, maintaining daily routines, and hiding and withholding information, participants were engaged in distancing each other as well as the anxiety of death and an impending loss.
The findings from the study clearly indicate that the forces of colonization and efforts to distance were not ethnic-specific. Each of the four thematic categories of colonization by palliative care and distancing as a means of resistance were spoken of in the context of Chinese immigrants, but they were not exclusive to this particular group. In fact, often providers weaved experiences of caring for other ethnocultural care recipients and families into their discussions of Chinese immigrants. There were shared concerns and issues of dying at home that were not particular to an ethnic group, but were shared among care recipients and families facing death. Several points were constructed as distinctly Chinese issues at end-of-life: death as a taboo topic, preference for death to happen outside of the home, use of traditional Chinese medicines, and language barriers. However, the pervasiveness of these concerns did not overshadow the fact that they could be, more simply, the issues of people who were facing a terminal cancer diagnosis. Issues of place of death, use of complementary and alternative therapies, and barriers to understanding the home care system and medical jargon were not exclusive to Chinese immigrants. These are the concerns of advanced cancer patients, irrespective of ethnocultural affiliation (see Ernst & Casileth, 1998; Higginson et al. 2000; Purkis & van Mossel, 2008; Thomas et al., 2008; Verheof et al., 2005). Thus, according to Agar (2006), the fluidity of providers’ conceptions of Chinese cultural beliefs on death and dying is indicative of culture as relational and translational, and revealed more about providers’ own experiences of caring for palliative care patients in the community than the Chinese immigrant community as a whole.

During the study, providers talked about caring for Russian, Jewish, Italian, and other ethnocultural care recipients and families that seemed to have a similar silence around death. Providers did not discriminate that the taboo around death was exclusively a characteristic of Chinese immigrants with advanced cancer, yet that stereotype persisted strongly with reference to Chinese immigrants. At the same time, providers were conscious that end-of-life issues are just that, issues for people that are dying regardless of their ethnic background. In a qualitative synthesis conducted by Bosma et al. (2010) on cultural conceptualizations of palliative care, the authors concluded that the scope of palliative care was relatively generic across cultures. In fact, they found that there were more similarities than differences between ethnocultural groups’ understandings of what palliative care should address and entail (Bosma et al., 2010). In their synthesis, Bosma et al. (2010) found shared understanding of palliative care that included the need for pain and symptom management, support to family, friends, and professional care.
providers, death as a taboo topic, and a focus on hope. Similar to the narratives of participants in this study, Bosma et al. (2010) concluded that basic human needs at end-of-life were more pressing than adhering to static and essentialized information about ethnocultural backgrounds.

Home is a contentious site. It is not always a peaceful place, and it can be a battleground where there are competing interests (Douglas, 1991). According to Douglas (1991), home may be a constraining place because of its necessary routines to maintain a household. The emphasis on home as the ideal place for death is a complicating force when these routines must be disrupted to include care for a dying family member. In the study, care recipients were very aware of the disruptions and changes to the home due to their illness; but they continued to engage in daily routines and activities that were sometimes necessary (i.e. continuing to cook for the family) or sometimes desired (i.e. continuing to go out for walks). Invariably, there was change to these routines. Care recipients were especially conscious of the gradual decline of their abilities and dependency on family caregivers and from home care providers. Home care providers had made observations that they saw care recipients more willing to be transferred to a palliative unit or hospice when their care became more demanding on the family caregiver, such as requiring assistance with toileting and bathing.

Because of the changes in their bodies and their abilities, the desire to move death out of the home was not necessarily a function of being a “Chinese belief”. There were practical considerations voiced by care recipients, and some expressed an embarrassment over their sudden vulnerability. Care recipients did not want to be a burden on their family. Providers understood and were alluding to the fact that they were working within a culture of dying. Thus shifts in the meaning of and ability to die at home were shaped by these situational factors, rather than cultural beliefs. This was consistent with findings from studies examining preference for place of care and place of death (Agar et al., 2008; Brazil et al., 2005) and experiences of home deaths (Exely & Allen, 2007; Roush & Cox, 2000; Williams, 2004). The studies on place of care and place of death did not differentiate between ethnocultural groups. The preference for active dying to happen outside of the home had nothing to do with culture necessarily, but had more to do with the practicalities of dying. Thus colonization and distancing may not be specific only to Chinese immigrants, but the findings could be transferrable to people who are dying. This speaks to how the findings in this study may be relevant to people dying, and the inclusion of Chinese immigrants in this study served as a case for the complexity of providing palliative home care.
De-centring and Re-centring Cultural Differences during Palliation

Similar to other critical perspectives, postcolonial theory is also concerned with de-centring knowledge and power to re-centre and shift focus to those who have been historically marginalized and subjugated (Anderson et al., 2009; Narayan & Harding, 2000; Tuhiwai Smith, 1999). This re-shifting to the centre works to give voice to those who have been systematically excluded from full social participation and to expose the ways inequity and injustice work in health care (Anderson et al., 2009). Attention to the subjugated knowledges of the marginalized is a means of getting at what Anderson et al. (2009) theorize as contextual knowledge. As noted above, contextual knowledge is constructed in situ and informs us of how the social positionings of privilege and/or exclusion contribute to experiences of marginalization, inequities, and social injustice. By understanding the meaning and context of how inequities manifest in health care, we can begin to challenge cultural essentialism (Anderson et al., 2009). Rather than focusing on cultural beliefs, research with a critical framework seeks contextual knowledge in order to help transfer the gaze from cultural essentialism and stereotypes to illuminate the economic, political and socio-historical conditions that contribute to people’s experiences of health and illness.

The observation that matching care recipients and providers for language did not always benefit the care recipient shed light on how cultural essentialism worked in tandem with the conflation of culture, race, ethnicity, and language. Although care recipients may be matched with a nurse that spoke the same language, that nurse may not be as experienced with providing palliative home care. Within the home care system and for some providers, there seemed to be an infallible assumption of what being Chinese meant and what it looked like (i.e. skin colour). It is through a postcolonial lens that we can see how the interchangeable use of culture, race, ethnicity, and language has significant ramifications to the provision and receipt of palliative home care. By de-centering how culture has been traditionally used, we can re-centre practice on a more critical understanding and transparent use of culture that acknowledges the insidious persistence of race and racism in health care.

The cultural essentialist notion of Chinese that was at play in matching for language also appeared within perceptions that death was a taboo. These examples from my study and others re-centred understandings of palliative home care to the experiences of participants, rather than continuing to endorse the assumptions embedded within generic practice policies. Often standardized forms and practice policies do not account for the contextual variations between
care recipients and within practice settings, thus resulting in incongruous and misleading practices, such as matching for language/race. It was in participants’ narratives where they shared in great detail their immigration and illness biographies and individual circumstances that gave me an appreciation for the variation between palliative home care experiences. Their narratives highlighted the uniqueness of their circumstances. Participants tried to show me how they were already engaged in negotiating and hybridizing cultural differences. This was especially the case with immigrant care recipients who had to reconcile what they previously knew with what they learned through palliative home care, in terms of their own bodies and the meaning of home. Participants were engaged with transnational practices as they were informed by and accessed knowledge and resources from other countries and communities (Glick et al., 1992; Al-Ali & Koser, 2002; Vertovec, 2009), such as the caregiver who called her physician friends in China for medical advice. Negotiation and hybridization required knowledge from many different sources and places to engage with palliative home care. Consequently, in examining what is negotiated and how negotiation takes place in palliative home care for Chinese immigrants, negotiation is more than an exchange of goods or positionings. The hybrid emerges through judicious consideration of many things, such as varying meanings of home, the disease, daily routines, crises, relationships, cultural differences, sources of knowledge, and the multiple positionings of participants.

Participants were often negotiating decisions within themselves. Similar to Purkis and van Mossel (2008), participants showed me that negotiation took context and different sources of knowledge into consideration. This was evident in care recipients’ accounts of weighing their palliative home care decisions in terms of the potential ramifications for relationships with family caregivers and other family members. These decisions were not necessarily verbally negotiated between the care recipient and family caregivers. Instead, they were negotiations that had happened internally, and were made known through practices and decisions that circuitously directed care. Care recipients demonstrated how decisions on place of care and place of death were contextually informed and not based on stereotyped assumptions that Chinese people do not want to die at home; their narratives helped to re-centre the understanding to the contextual and the situational.

West and Olson (1999) call for an alternative view of negotiation that goes beyond navigating in order to reach a consensus, an accommodation, or a compromise. West and Olson
(1999) are mindful that negotiation “can act as a strategy of colonization disguised as civil interaction” (p. 241). They argue that a more critical perspective of negotiation is required to release it from merely being a superficially civilized way to maintain the status quo, so that it offers the liberating opportunity to grapple and work through cultural differences. Thus, West and Olson (1999) see negotiation as analogous to hybridity because both are related to cultural translation, re-articulation, re-inscription, and enactment of change. In my own study, participants exerted agency in negotiations that drew attention to their needs and knowledges. This critical and liberating conceptualization of negotiation highlights the complexity of hybridity and palliative home care, while remaining sensitive to participants’ efforts to re-position themselves to achieve their palliative care goals. Many of the care recipients used traditional Chinese medicine in conjunction with what was prescribed by their oncologists. Although the use of traditional Chinese medicine was a source of unease for providers, care recipients often spoke confidently and knowledgeably about the benefits of traditional Chinese medicine and Eastern philosophies of health and illness. In this way, care recipients negotiated a hybridized approach to pain and symptom management, and squarely re-centred knowledge of cancer and of their own bodies back within their own domain.

Negotiation was also integral to the ways participants worked through the cultural differences between home, death and dying, palliative care, cancer, Western medicine, Chineseness, belonging, immigration, and so on. Bhabha (1994/2004) advises that

the representation of difference must not be hastily read as the reflection of pre-given [his italics] ethnic or cultural traits set in the fixed tablet of tradition. The social articulation of difference, from the minority perspective, is complex, on-going negotiation that seeks to authorize cultural hybridities that emerge in moments of historical transformation (p. 3).

In this statement, Bhabha warns against cultural stereotypes as meanings and subjectivities are complex and continually transformed. Participants were negotiators, trying to navigate the difficult, contentious, and in-between space of palliative home care that was rich with meanings, normative values, and social relationships. In a description of the in-betweeness of negotiation, hybridity, and cultural transformation, Bhabha (1994/2004) describes a stairwell “as a liminal space, in-between the designations of identity… the interstitial passage between fixed identifications [that] opens up the possibility of a cultural hybridity that entertains difference
without an assumed or imposed hierarchy” (p. 5). This analogy is fitting for the palliative home care experiences of Chinese immigrants. The stairwell was symbolic of the liminality of care recipients’ predicaments. For many of the care recipients, the inability to physically go upstairs was a sign of their advancing terminal prognosis and also a change in their status in the home. Care recipients, along with family caregivers, had to re-negotiate to re-centre the meaning and routines of home to the ground level. For example, with one of the cases, the stairwell had to be given up completely; the move to a one-level apartment signified changing care needs of the care recipient.

Centredness has become a common term in health care, and has ideological and structural importance to how providers make sense of and value their practice (Hughes, Bamford, & May, 2008). There is a call for health care providers to re-centre care to those they are caring for (Hughes et al., 2008). There are several types of centredness found in the literature, including patient-centred, client-centred, family-centred, and person-centred care (Hughes et al., 2008). The significance of patient-centred care and cultural competence to quality palliative care has been noted in the existing literature (Feser & Bernard, 2003; Kemp, 2005; Ngo-Metzger, August, Srinivasan, Liao, & Meyskens, 2008; Owens & Randhawa, 2004; Payne et al., 2005; Yedidia, 2007). The emphasis on centredness, and specifically patient-centred care in palliative care was seen to be in conflict with a simultaneous emphasis on culturally competent care for providers in the study. The discursive tensions between culturally competent care and patient-centred care emerged as providers had difficulties in describing how they expressly accounted for the cultural beliefs and individual needs of their palliative care recipients. While the two discourses should, in theory, work together to get at the individual beliefs and goals of the care recipient, this was not necessarily how the combination played out in practice.

According to Beach, Saha, and Cooper (2006), at the core of both cultural competence and patient-centred care is the need to see the patient as a unique person, and in order to deliver care that recognizes the individuality of the patient, the cultural diversity of patients’ perspectives must also be accounted for. Their argument may seem logical enough, but it lacks critical interpretation of how providers interpret culture and how these interpretations manifest in practice. The difficulty lies in the fact that when we ask providers to be culturally competent, we are asking them to be knowledgeable and aware of a shared cultural belief system, whilst at the same time insisting that they be patient-centred and continually place the individuality of the
patient first. There is a mismatch between the discourses because categorizing and positioning a patient as having shared cultural beliefs is counterproductive to understanding and working with individuality. Hence, this may account for the discursive tensions providers were experiencing, and may refer to what Bhabha calls an *incommensurable demand and practice* (p. 247).

Providers in the study used multiple sources to inform their understanding of cultural beliefs of palliative care for Chinese immigrants: previous experiences of caring for Chinese immigrants at end-of-life, colleagues, textbooks, and their personal knowledge and experiences. Providers in the study found it challenging to talk about Chinese beliefs at end-of-life because of the fine line between culture and stereotyping. They had difficulties holding the two together for fear of seeming insensitive to care recipients’ cultural and individual needs. The critical question here is when does a shared belief become a stereotype? Is the perception that death is a taboo a stereotype? How does the individual and the universal come together? Similarly, in Owens and Randhawa’s (2004) study examining the experiences of community palliative care providers’ work with the South Asian community in the UK, providers also had difficulties talking about cultural differences and acknowledging individual care requirements. Like the providers in my study, Owens and Randhawa (2004) noted that providers also recognized that “many palliative care needs cut across ethnic or cultural differences, and that care should be provided on an individual basis” (p. 419). With a postcolonial lens, I was able to analyze and describe the discursive tensions encountered by providers in their efforts to provide culturally competent and patient-centred care.

Kemp (2005) argues that “applying generalizations to all people from a culture is stereotyping” (p. 45). While this may be a valid point, we cannot discount that stereotypes do exist and they may exist for no other reason than as a persistent shared belief among many people. If patient-centred care includes striving to understand the cultural beliefs of a care recipient, then we must acknowledge that part of our understanding may come from potentially stereotypical generalizations. It is only in the recognition that providers are not exempt from holding stereotypes that we can actually begin to deconstruct what a stereotype may look like in practice. It is not as easy as it may seem, because generalizations and standards are consistently used in best practice guidelines and sought in evidence-based practice. The discursive tensions between patient-centred care and cultural competence demonstrate the fine line between generalizations, standardization, and stereotyping and how providers had to negotiate within
these limits. Providers were challenged to re-centre care to the care recipient, but at the same
time acknowledge their own assumptions of palliative care for Chinese immigrants. Palliative
home care is complex as providers must put together many sources of knowledge and
experiences to navigate care encounters. It was not only providers that struggled with
contemplating what constitutes a Chinese belief. Whilst care recipients and family caregivers
talked about how individual circumstances shaped their current experiences of palliative home
care, they also made claims about their ethnocultural background that connected them to a larger
community (Chineseness), and so were also working with discursive tensions. By identifying
with a group, immigrant participants could potentially challenge marginalization (Ang, 1998).
This is further elaborated below.

Meaning of Home and Negotiation of Care: A Complicated Entanglement

Home is deeply intertwined with identity and belonging (Magat, 1999). Magat (1999)
differentiates between a Big Home, which relates to national identity and loyalty, and a Little
Home, where identity coincides with the daily routines and activities that bring about belonging
and comfort (Magat, 1999). It was evident in care recipients’ narratives that belonging and
finding a place of comfort, especially in their own homes, was central to being at ease with dying
at home. Care recipients and family caregivers wanted to maintain a sense of belonging in a
home that was no longer only a place for living. As care recipients’ disease progressed, or
stabilized in some cases, palliative home care had to be negotiated in ways that assured them of
their place in the home, despite the colonization of home by palliative care. In responding to the
overall purpose of the study, how meanings of home condition negotiations of care, there is no
simple description of how it all fit together because it was a complicated entanglement (Ang,
2003) that implicated hybridization and the Third space. Ang (2003) aptly warns against viewing
hybridity as a utopian approach to cultural difference. She describes hybridity as a complicated
entanglement because intercultural encounters are power laden and “not always harmonious or
conciliatory; often they are extremely violent, as the history of colonialism has amply shown”
(Ang, 2003, p. 147). Negotiations between the varying meanings of home, cancer, daily routines,
crises, cultural difference, sources of knowledge, and the multiple positions held by participants
meant that at any given point, there were many different things being “foregrounded” or
“backgrounded” in keeping with the context of the situation (Reimer Kirkham, 2003). I would
add to Reimer Kirkham’s statement that these are not only relegated to intercultural encounters,
but to health care encounters in general, where cultural beliefs were not always foregrounded in end-of-life decisions.

Belonging was jeopardized when palliative care colonized the home, thus one way to maintain and/or re-create a sense of belonging was to distance and to mediate cultural differences. The home became an in-between, Third space where new hybrid forms emerged to accommodate the uncertainty of cancer so that daily routines could continue. Although I have critiqued culture and its use in health research and have developed an academic/scholarly understanding of its collusion with race and ethnicity, I do not hold the false impression that it should be discounted in my examination of the everyday encounters between participants. Instead, it has become clear that culture has strong connotations and even in researching the misgivings in its usage, I realize that the lay association of race and essentialist assumptions cannot be ignored. As stated, cultural stereotypes are pervasive and insidious; they appear in professional providers’ accounts of working with Chinese immigrants, and racialized patients. Even for professionals, where discourses of cultural competence and patient-centred care infiltrate practice values, cultural stereotypes persist in the categorization of ethnocultural groups. Yet, providers also remain aware that stereotypes may be in play and that there is heterogeneity within cultural groups. Working in-between different sources of knowledge and knowing makes for complicated entanglements because providers must foreground or background stereotypes as they see fit to work effectively and sensitively with immigrant care recipients and families.

Care recipients and family caregivers were not oblivious to the importance of culture in their own experiences. Members of both groups talked about being part of the Chinese diaspora. Being Canadian and Chinese were not seen as mutually exclusive. All care recipients and family caregivers identified in some way as being Chinese and Canadian; these blended identities were not straightforward or static subjectivities. As one family caregiver noted, she identified as Chinese and felt a stronger sense of belonging to China, but at the same time, she called Canada home and was more accustomed to the quiet, predictable daily routines she was engaged with here. This finding was similar to the study by Magat (1999) and the distinction between a Big Home and Little Home. The ways in which immigrants in this study talked about their Canadianess and Chineseness may seem tenuous, but this demonstrates the in-between space and hybridized subjectivities that help immigrants to cope and create a sense of belonging after re-
settlement. Depending on the situation, immigrants draw more on their Canadianess or Chineseness as needed; thus belonging was fluid. The hybrid does not always predictably or consistently blend knowledge, context, and positionings in the same ways. It is not a mixture that draws equally on all elements, but is contextually based. Thus culture, negotiation, and hybridization are dynamic and fluid and may call for constant re-formulation and re-evaluation depending on the circumstances and desired goals.

All of the care recipients and family caregivers in the study were considered long-term immigrants because they have been in Canada for more than ten years (Picot, 2008). Despite being long-term immigrants, all still identified as Chinese in some way, and recognized themselves as being members of a larger community of displaced Chinese peoples: the Chinese diaspora. Ang (1998) also writes about the complex meaning of “Chineseness” and asks what individuals of the Chinese diaspora hold onto despite being displaced from China. Central to Ang’s (1998) discussion is her point that Chineseness is not a “category with fixed content – be it racial, cultural, or geographical – but instead it operates as an open and indeterminate signifier whose meanings are constantly renegotiated and rearticulated in different sections of the Chinese diaspora” (p. 225). This understanding of Chineseness then challenges cultural essentialism as it defies a fixed categorization. Despite this definition of Chineseness, some providers held the specific assumption that Chinese immigrants did not want to die at home. These opinions were most strongly held by Chinese providers themselves. And so this challenges us to reconsider the need for a stable Chinese identity.

Ang (1998) posits that the conditions of diaspora, “the scattering of seeds,” (p. 233) radically unsettle identity and belonging of immigrants. Claiming to be part of the Chinese diaspora and to be Chinese can lift that sense of displacement and rootlessness (Ang, 1998). Whereas immigrants are normally consigned to a minority status, identification with and acknowledgement of Chineseness instantly connects them and gives them membership in a larger group where they can affiliate and release themselves from marginalization (Ang, 1998; Ang, 2003). This was evident when care recipients described using traditional Chinese medicines and extolled the wisdom of practices that have existed much longer than Western medicine. Not only were care recipients wisely utilizing both allopathic and complementary and alternative therapies to derive benefits from both, but they were astutely re-centring subjugated Eastern forms of knowledge on cancer care. They cultivated a sense of belonging by drawing on the rich
knowledge of Eastern approaches to health and illness, and at the same time re-positioned themselves out of the margins.

Indeed, complementary and alternative therapies, such as traditional Chinese medicine, are increasingly employed by the general population and are often viewed as a more natural approach to supplement or replace conventional approaches to chronic health conditions (Verhoef et al., 2005). A systematic review of international studies, not stratifying for race or ethnicity, found that on average 31.4% of cancer patients used complementary and alternative therapies (Ernst & Cassileth, 1998). In my study, providers were troubled by the use of traditional Chinese medicines by care recipients, and held the stereotypical view that all Chinese immigrants used traditional Chinese medicine. This was worrisome for providers because they did not have a good grasp of the effect traditional Chinese medicine had on cancer and in conjunction with allopathic medications. While I found that oversimplified stereotypes can act to subjugate deeply meaningful health practices and understandings of the body that originate from Eastern philosophies, I also noted that care recipients and families held onto these health practices to find belonging, even at end-of-life.

Providers also engaged in hybridized subjectivities as they drew on their immigrant experiences to position themselves as supports to immigrant care recipients. The affiliation with larger communities was made evident as providers positioned themselves on-side with care recipients and family caregivers by drawing on their own or their own ancestral experiences of immigration and re-settlement. Providers drew on the larger community of immigrants to find a common ground from which to understand care recipients’ experiences of palliative home care. The comforts in drawing from a collective “we” – the immigrant - cannot be discounted. This may be especially significant when confronted at moments of isolation and marginalization, such as migration to a new country or at end-of-life. Bodily displacement, reconciliation of circumstances, and recognition of the continuation of everyday life are just a few of the parallels between migration and dying. Accordingly, finding belonging within a group may help ease the anxiety of being displaced from living. While hybridity is a complicated entanglement, providers found ways to make meaning of their socio-historical past to connect with the care recipients and families they care for.
Strengths and Limitations

This study addresses an important gap in the literature and provides a glimpse of the complexity of palliative home care for immigrants using a critical theoretical lens. The rigour of the study is evident in the findings, which capture the immense difficulties of palliative home care for not only care recipients and families, but also providers. The study strengths and limitations will now be discussed, keeping in mind how they may inform practice, education, policy, and future research.

One of the main strengths of the study was that it did not exclude individuals who could not speak English. As Hazuda (1996) and Lopez, Figueroa, Connor, and Maliski (2008) point out, by excluding participants who do not speak English from studies, we are contributing to the “invisibility [of] non-English speakers” (p. 58 & p. 1729, respectively) in what constitutes knowledge. Nursing scholars using postcolonial feminist theory, such as Anderson et al. (2009) are critical of research that is exclusionary, and reason that research with a social justice agenda must start from those who have been historically marginalized. The aim of this study was to examine the palliative home care experiences of Chinese immigrants and family caregivers, and so it was important that Chinese immigrants were not excluded based on English-language speaking ability. By including Chinese immigrants who did not speak English, I worked from the principles of postcolonial theory to avoid perpetuating subjugation based on language.

As previously discussed, the Chinese population is heterogeneous and language is diverse, with many dialects; thus, I was careful to avoid exclusions based on Chinese dialects. I conducted the interviews with case 1 in English; case 2 and case 3 in Taishan; and case 4 in Cantonese/Chiu Chow. While I was able to communicate with participants in two dialects: Taishan and Cantonese, I did not speak Mandarin, the official language of Mainland China. It was made known during recruitment that a translator could be used for interviews so that no participants were excluded based on language. For case 4, although the care recipient and family caregiver spoke Cantonese, they also spoke Chiu Chow (a dialect of the Chinese diaspora in Vietnam). I did not feel that my Cantonese was sufficient to conduct a full interview with them and arranged for a translator to help facilitate the interviews. This worked well as we all felt more comfortable articulating ourselves during the interview.

The challenges of recruiting palliative patients into research, and in particular home care research, has been noted in the literature (Ewing et al., 2004); thus, a strength of this study was
the inclusion of care recipients who were currently receiving palliative home care, rather than retrospectively interviewing family caregivers who had provided care to a dying family member. No other studies have gained access to this group previously within a Canadian context.

Although the care recipients in the study were classified as palliative, they were not actively dying; therefore, the findings from the study are particular to a group of care recipients who were considered stable despite being classified as palliative. As previously indicated, one care recipient in the study had been termed palliative for the past seven years and so this may not be representative of palliative care recipients who are actively dying and may require more involvement from family caregivers and home care providers.

A study limitation was that no Mandarin-speaking care recipients were identified during recruitment. While variation was sought to get a range of experiences, the feasibility and practicalities of a doctoral study meant that there was a limitation on time and resources to ensure that Mandarin-speaking participants were recruited. Efforts were made to recruit a Mandarin-speaking participant based on the understanding of the immigration patterns of Chinese to Canada in the last two decades. As discussed in Chapter 2: Background, points of origin for Chinese immigrants have changed over time as economic and political shifts have produced different push and pull factors for immigration to Canada. Mandarin-speaking immigrants from Mainland China are part of the most recent wave of migrants to come to Canada (Chui et al., 2005).

Again, most of the Chinese immigrant care recipients and caregivers in the sample were long-term immigrants because they had been in Canada more than ten years (Picot, 2008). As such, given the long-term immigrant status of the participants, their views may not reflect the experiences and concerns of more recent immigrants. Kuzel (1999) points out that the aim of sampling in qualitative research is not to generalize, but rather to get a range of data to uncover multiple realities and gain a deeper understanding of the phenomena. Thus, sampling is focused on gaining richness in information about the particular. The sample in this study was specifically selected for their experiences of palliative home care, but variation was still sought in the sample: two of the cases were from Mainland China, one from Hong Kong, and one represented the Chinese diaspora from Vietnam. As well, to gain a broader perspective of palliative home care for Chinese immigrants, questions were posed regarding differences to key informants. Their stories shed light on the range of experiences and added to the depth of understanding of
the palliative home care experiences of this immigrant population. Key informants could speak from different perspectives because of their different roles, such as home care nurse, community palliative nursing consultant, palliative physician, and case manager. While the goal of qualitative research is not generalization, these findings may be transferrable to care recipients with terminal cancer who have experienced immigration, displacement, and re-settlement.

The final limitation of the study was the inability to recruit PSWs into the study. All cases drew on interviews with home care nurses, and no key informants worked as PSWs. Active efforts were made to recruit PSWs. KI7 was currently working as a home care nurse but as indicated, she had worked as a PSW before getting her nursing degree. During our interview, I questioned her whether there were differences between working as a PSW and home care nurse, and she stated that indeed there were. PSWs provide intimate care and spend a considerable amount of time with care recipients. There is no research on the experiences of PSWs who work with Chinese immigrant care recipients in palliative home care and, overall, there is a lack of research on PSWs (Aronson & Neysmith, 1996; Church, Diamond, & Voronka, 2004). These limitations in the study offer insights into implications for practice, education, policy, and future research.

**Implications**

The findings, discussion, and limitations of the study point to several salient implications. The implications have been divided into four areas for discussion: practice, education, policy, and future research. Although all four areas are aligned in certain respects, the implications for practice and education have been grouped together because of how they work together to inform each other. Education is a key piece in improving practice. Knowledge that develops from practice are often integrated into education and training.

**Practice and Education**

The findings from this study highlight the complexity of palliative home care. Palliative home care represents the coming together of two very different worlds: the home and the hospital. Providers discussed the differences between providing care in the home and in a hospital. For providers, the home lacked the same sense of institutional backing as practicing in a palliative unit or a hospice. The difference in setting and how the home care system is set up meant that nurses working in the community did not necessarily have access to immediate
resources or collegial support, like in a hospital setting. While most of the home care nurses stated that they appreciated the independence that was afforded by working in the community, they also acknowledged that they often worked in isolation and did not often come into contact with other home care nurses, unless this contact was self-initiated. The nature of home care means that nurses are left alone to deal with the intense physical and emotional toll of providing palliative home care. The findings indicate that, in providing palliative care, home care nurses take in complicated sources of information from care recipients and family caregivers, other providers (i.e. PSWs, oncologists, family physicians, etc.), and experiential knowledge. They took all of this into consideration along with their understanding of the home care system and available resources. These are sometimes contradictory sources of information on which to base practice decisions and they must be thoughtfully evaluated.

Furthermore, practice-based decisions can be ethically challenging. Working in isolation means that home care nurses may not have a colleague to use as a sounding board or have access to a resource nurse or more senior nurse to help guide their decisions. Thus, the practice setting must be changed so that home care nurses providing palliative care can be better supported in the community. There need to be regular team meetings so home care nurses can discuss client issues together, and find opportunities to debrief and express the emotional aspects of providing palliative home care. There is also a need to develop a system where nurses can immediately access resources as crises emerge.

Additionally, home care nurses require more specialized education in providing palliative care. As indicated, some home care nurses may have more specialized skills in providing palliative home care than others. Not all home care nurses are experienced in providing palliative care or have a special interest in the area. In that case, it may be important to identify and support home care nurses who have a special interest in becoming more specialized in providing palliative home care. Those home care nurses with particular interests in palliative care may be offered specialized courses or certification so that they can become mentors or resources for other home care nurses in the community. While community palliative nursing consultants are available to provide education and mentoring to providers in the community (HPC Teams, n.d.), they are limited to certain geographical areas.

If only specially trained home care nurses can provide palliative care, only a small group of home care nurses may be versed in providing palliative end-of-life care. This may not be ideal
since, as the population ages, more and more people will require palliative home care and there will be a lack of specialized palliative home care nurses available to dispatch to homes. The implication is then that all home care nurses should receive some palliative care training. Thus, it may be more effective to have all home care nurses receive foundational education and training to provide palliative end-of-life care in the community. More broadly, it would be important to incorporate palliative end-of-life care into undergraduate nursing curricula so that all graduating student nurses demonstrate beginning competencies in palliative end-of-life care (Canadian Association of Schools of Nursing, 2011).

As indicated in the discussion, the discursive tension between cultural competence and patient-centred care is another area that could be addressed in education for home care nurses. As Owens and Randhawa (2004) explain, training on cultural competence needs to move away from rigid models that portray cultural beliefs and practices as shared, fixed patterns, and take into account the messy reality of everyday care provision. Engebretson, Mahoney, and Carlson (2008) also contend that clinical application of cultural competence to care is difficult for nurses because of the lack of conceptual clarity, especially “essentializing culture to race and ethnicity” (p. 172). The findings from this study point to the need for a critical perspective in cultural competence that acknowledges that providers may hold assumptions and that these assumptions are best worked through when they are transparent and openly discussed. Admittedly, this is difficult because most people are not usually aware of their assumptions. By bringing a critical perspective to culture, home care nurses may become aware of their assumptions and sensitized to the ramifications of conflating culture with race and ethnicity.

Educational workshops can help nurses engage a critical lens to understand culture within the context of palliative care. The workshops may include case studies or vignettes to show nurses how immigrants may variously experience palliative home care. The vignettes in this dissertation could be further developed as educational tools for home care nurses to dissect and analyze during workshops. The workshops should encourage discussion and reflection amongst home care nurse. Home care agencies might offer workshops as part of professional development and quality care improvement initiatives, and could be mandated by the CCACs. In addition, a critical perspective to culture and the implications to palliative care should be taught in undergraduate programs to introduce nursing students to the challenges they may face in practice and to provide the tools to think about culture as a dynamic and fluid concept.
Policy

Many organizations have values statements pertaining to the type of centred care that has been adopted, and often this may include a statement recognizing the cultural needs of its patient population. Organizational policies are often informed by values statements. At the practice level, policy is needed that clearly explicates how culture is conceptualized in terms of practice so that home care nurses can understand its applicability to situations they encounter in palliative care provision. Home care nurses must have a clear policy and values statement from which to evaluate and integrate an understanding of culture into practice. As suggested above, a values statement on cultural competence needs to include a critical perspective in order to empower nurses to critically reflect on their assumptions of culture in practice.

In Decolonizing Methodology by Tuhiwai Smith (1999), the author presents a critical discussion of the way research has been applied to indigenous peoples, and describes twenty-five strategies to re-claim research for indigenous groups in the pursuit of decolonization, self-determination, and social justice. I believe these decolonizing strategies offered by Tuhiwai Smith (1999) may be useful in addressing critical conceptualizations of culture in policy. One such strategy is envisioning. Tuhiwai Smith (1999) describes envisioning as a strategy that brings people together politically, and asks individuals to “imagine a future, that they rise above present day situations” (p. 152). In the articulation of a critical perspective on culture and cultural competence in organizational policies and values statements, it would be imperative to ask front-line providers (those who carry forth and represent the organization’s values) to envision how they see culture working better in their practice. To help providers begin envisioning a better way to incorporate cultural competence, critical questions should be posed: How do I define culture? What are my assumptions about ethnic-specific groups? How did I come to know this about these groups? How can I be open to and support difference in my practice? Who am I and what is my culture? How can I value what the care recipient knows/expects of care and what I know/expect of care? These are some of the questions providers may begin to think about in articulating a critical understanding of culture, and ask themselves to critically reflect on when engaging in intercultural exchanges. Some of the providers in this study were intuitively already asking these critical questions.

Furthermore, many of the provider narratives emphasized individualization in provision of palliative care in the home, and this was echoed in the findings from Bosma et al. (2010) and
Owens and Randhawa (2004). Perhaps the emphasis should not be on an essentializing notion of cultural beliefs at end-of-life, but to seamlessly integrate individual beliefs which may be informed by culture (among other things) into a philosophy of patient-centred care. In the literature review conducted by Hughes et al. (2008), several themes emerged. The theme of “respect for individuality and values” was based on recognizing individual differences, values, culture, strengths, needs, and rights (p. 458). This theme is also a key feature in definitions of cultural competence (Beach et al., 2006). Given this overlap, it would be prudent to amalgamate and better specify how the two discourses may work together within a critical definition of culture. A policy and values statement on practice that incorporates the principles of these two discourses and an explicit critical definition of culture would help to possibly dispel the discursive tensions between the discourses, and enable providers to find comfort in practicing a type of centredness that focuses on individual context, rather than static and essentializing cultural beliefs. The framework for person-centred nursing by McCormack and McCance (2006) provides a good starting point to build on such a values statement and adequately inform organizational policies and practice protocols, and from which to build in a critical cultural competence perspective.

I am conscious that there are many different types of centredness that exist in health care, i.e. family-centred, patient-centred, person-centred, etc. Like Hughes et al. (2008), I am not advocating for the adoption of one definition of centredness, but agree that the type of centredness adopted should reflect the practice setting that it serves. In the conceptual review conducted by Hughes et al. (2008), the authors identified significant commonalities between the different types of centredness; hence, it may be debatable whether there are major differences in calling it patient-centred or person-centred. I would suggest that in particular practice settings, such as home care, where families are seen as an integral part to care, family-centred care may be the appropriate term to include in conjunction with patient-centred care in the policies or values statements of that particular practice setting. To re-affirm my point above though, it would be important to find ways to seamlessly incorporate a critical cultural perspective within the centredness policy or values statement that an organization mandates for its providers. I recognize that there is ambiguity to the terminology of centredness; therefore, a clear and consistent statement on centredness that reflects the practice setting should be the first step to helping home care nurses begin to recognize and work with the discursive tension. Just as culture
is fluid and dynamic, this centredness statement should be re-evaluated and reflect the complexity of the practice setting, which helps to re-affirm to home care nurses the immensity and difficulty of their work.

One of the immediate policy changes that must take place to positively affect practice is to address and reconsider the matching of home care nurses and care recipients based on what appears to be language, but in actuality, is race. Matching for language/race did not necessarily result in the best practice scenarios for non-English speaking care recipients and families. The Chinese diaspora in Canada is a heterogeneous group, representing many different geopolitical areas, generations, dialects, timing of immigration, immigration statuses (i.e. family class, refugee), and routes of entry to Canada (i.e. China to Vietnam to Canada). The current approach to matching oversimplifies culture and Chineseness and does not always result in matching that recognizes the heterogeneity of Chinese immigrants. Matching for language/race also ignores the significant point that in spite of ethnocultural background, care recipients and family caregivers wanted home care nurses who were proficient and knowledgeable about palliative care. As Bosma et al. (2010) pointed out, the basic needs at end-of-life cut across assumed cultural beliefs, therefore matching for language/race may not always result in optimal care being offered to Chinese immigrant care recipients.

It is recognized in the literature that the work of home care providers is often undervalued, and is represented by disproportionate funding in comparison to acute care settings (Aronson & Neysmith, 2006; Purkis, Ceci, & Bjornstoddir, 2008). The ramifications of a lack of funding to home care services, and by default palliative home care, were apparent in this study as providers talked about rationing of services. Providers often discussed language barriers and would discriminately evaluate whether a translator was necessary; they would exhaust different forms of communication (i.e. using a family member; non-verbal cues) before bringing in a paid third-party interpreter to home visits. Matching for language/race could also be viewed as a policy that results from a limitation to resources. The rationing of access to interpretation services places a constraint on home care nurses’ ability to provide quality palliative care to care recipients who do not speak English. Thus, funding for translation services in the community needs to be increased to meet the demand. Rather than match a Chinese home care nurse with no expertise or experience in providing palliative care with a Chinese care recipient, a Chinese care recipient may be better cared for by a home care nurse who does not speak Chinese but has
training and expertise with providing palliative home care, and has access to an interpreter when required.

Another decolonizing strategy described by Tuhiwai Smith (1999) is reframing, where the purpose is to take “greater control over the ways in which indigenous issues and social problems are discussed and handled” (p. 153). Reframing may be a useful strategy for providers and researchers to consider when supporting policy changes. It is important to be critical of the way culture is framed in evidence to support policy changes to palliative care delivery for immigrants so that we avoid blaming culture or ethnic-specific groups for not being able to die at home. The findings from this study showed the variation in experiences of palliative home care and surfaced contextual issues with dying at home that informed immigrant care recipients’ decision to die at home or elsewhere. Decision-making on place of care and death should not be articulated as based on cultural beliefs, but rather, the contextual and situational aspects to preference for place of death must be accounted for in supporting policy changes. Some care recipients understood that a home care nurse or personal support worker could not be present all the time to relieve family from caregiving duties; thus, these care recipients struggled with the notion that they may be a burden to their families, which informed their decisions to die in a hospital palliative care unit or hospice. By presenting culture or ethnicity as a determinant of place of death, we risk blaming ethnocultural groups for taking up limited beds in emergency rooms for dying and burdening the health care system. In actuality, this type of framing deflects blame from and obscures the fact that there is inadequate funding for home care. Reframing offers providers an alternative approach to articulating the issues and representing the complexity of home care to policymakers to advocate for increased funding.

The findings from this study indicate that the work of palliative home care providers is complex, but it is not reflected in the allocation of funds to home care. Home care providers must contend with numerous practice and contextual issues that are very different from acute care settings. Home care providers must negotiate and seamlessly put together their clinical expertise and role with the available allocated resources, and care recipients’ expectations of care. The gravity of what home care providers do within the constraints of how home care is structured and the demands of practicing in patients’ homes must be acknowledged. The silences and failure to adequately fund home care constitutes an implicit rationing of health care services through inequitable distribution of resources between home care and hospital-based acute care. As noted,
palliative home care providers work in relative isolation and lack resources to support their efforts, given the intense physical and psychological toll of palliative care in the community. Therefore, funding should be increased to home care, especially for additional palliative home care training. These policy recommendations are not new and have been discussed in the Commission on the Future of Health Care in Canada: The Romanow Report (Romanow, 2002) and advocated by the Canadian Hospice Palliative Care Association. It is recognized that funding policies at the government level are subject to changes in political agendas and reflect trends in society. The lack of change in funding to home care programs and palliative care may reflect the taboo of discussing death within society in general. As the population ages and becomes increasingly diverse, and the demand for palliative home care increases, it is inevitable that studies like this will lift the silence from death and put the issue of palliative home care on the public agenda.

Future Research

There are three future research recommendations that have arisen directly from the limitations of this study. First, as indicated, all of the care recipients in this study were fairly stable, and so may represent a particular type of palliative cancer patient living in the community. Although the care recipients were labelled palliative and receiving palliative home care, they were not actively dying. The findings demonstrated that care recipients were engaged in re-claiming the everyday, and firmly embedded in living with an incurable but treatable disease. In their illness biographies, care recipients talked about remissions, crisis moments, hospitalizations, near-death experiences, subsequent discharges back to the home, and current understandings (or lack of understandings) of their terminal diagnosis. It was evident that these care recipients had been living with cancer for some time, and their disease trajectories were not always straightforward. Through advancements in treatment, there is a growing gap between time of cancer diagnosis and actual death (Phillips & Currow, 2010). There is an increasing awareness that there may be more people living with cancer for longer in the community, which supports a re-interpretation of cancer as a chronic disease (Berlinger & Gusmano, 2011; McCorkle et al., 2011; Phillips & Currow, 2010). Because of the relative stability of the care recipients in this study, they may be considered to be living with chronic cancer. Thus, future research needs to examine how these long-term palliative care recipients living in the community may benefit from care that adopts a chronic disease model in comparison to a palliative care
model. Lanoix (2009) introduced the concept of the chronic-palliative interface and conducted a comparison between chronic care and palliative care models in relation to Parkinson’s disease. Lanoix (2009) acknowledged some similarities between the models, mainly an emphasis on supportive rather than curative care and a concern with quality of life. Although her comparison is related to a condition that is accepted as chronic, her concept of the chronic-palliative interface may be important to explore further in relation to cancer. If we are going to treat cancer more like a chronic condition, it would be important to explore how we could integrate the two models to better help cancer patients transition from chronic to palliative care in the community.

Second, the inability to recruit PSWs into this study means that the findings may not reflect their experiences in working with Chinese immigrants at end-of-life in the community. Although this is the only study known to examine the palliative home care experiences of Chinese immigrants, their family caregivers, and home care nurses using a critical lens within a Canadian context, the absence of PSW participants is noteworthy because of their integral involvement in providing palliative home care. Postcolonial scholars such as Said (1979/2003) and Tuhiwai Smith (1999) are critical of representation of the Other in research. I am conscientious that it is important to be transparent that the findings from this study do not represent the experiences of PSWs. I do not want to silence or misrepresent their experiences, or further subjugate their knowledge. PSWs are often women and immigrants themselves and may potentially occupy a position of marginalization (Aronson & Neysmith, 1996; Church et al., 2004). Their experiences may be very different from other providers, such as home care nurses, case managers, and palliative care physicians. PSWs may spend more time with care recipients who are actively dying at home and provide more intimate care. Their relative positioning as outside care providers may be more tenuous in the home because of their closer proximity to care recipients and marginalized professional status. Research should seek out their experiences, and a critical theoretical lens would facilitate understanding the ways PSWs may negotiate care with immigrant care recipients.

Finally, future research should be extended to include immigrants in general to emphasize the material and socio-historical-political-economic conditions that shape dying at home, rather than continue to focus on ethnic-specific experiences. The current study only looked at Chinese immigrants and did not include any Mandarin-speaking care recipients. Future research should include variation in the sample to draw a larger picture of the palliative home
care experiences of immigrants to build a better critical conceptualization of culture in palliative home care. Such a study would help inform a framework for palliative home care that is inclusive of immigrant experiences and contexts, whilst remaining attuned to the basic human needs at end-of-life. This framework may then be introduced to a group of home care providers and evaluated upon on its feasibility and utility in working with immigrant care recipients at end-of-life. The systematic review conducted by Bosma et al. (2010) points to the fragmentation of current studies that narrowly focus on distinct ethnocultural groups, and as such, a study examining immigrants more broadly would be warranted.

**Scratching the Surface…**

This study has offered a glimpse into the complexity of palliative home care and merely scratched the surface to the immense meanings associated with dying at home. The Chinese immigrants in this study served as a case to show this complexity. The findings may be used by home care providers to begin advocating for increased funding to home care to adequately support and recognize the challenging work that they do in patients’ homes. Postcolonial theory offered a critical and reflexive approach to understanding how meanings of home conditioned negotiations of care between Chinese immigrants with advanced cancer receiving palliative home care, family caregivers, and home care providers. Findings were similar to those of other studies in that they clearly indicated that the home was a contentious site for death and dying where meanings of home changed as it became a site for providing and receiving palliative care. However, postcolonial theory offered a uniquely nuanced lens to explicate the complexities of palliative home care. The metaphor of colonization and distancing proved to be an insightful way of articulating how the home changed for Chinese immigrants receiving palliative home care. The ambivalence between colonizer and colonized was a strong metaphor for describing and understanding the complicated relationship between care recipients and professional providers.

It was clear that providers struggled with stereotypes and wanted to talk about the tensions they held in working with the discourses of cultural competence and patient-centred care. Neither discourses worked smoothly in practice. It was apparent from providers’ narratives that an essentialized approach to culture was a disservice to practice because it did not reflect the complex ways in which providers worked with immigrant care recipients at providing palliative care. Providers had to contend with different sources of knowledge, including contextual
knowledge that informed how they negotiated care with care recipients. Providers did not have a forum to express and share their diverse experiences of caring for immigrant care recipients. While this study provided an opportunity to talk about experiences of providing palliative home care to Chinese immigrants, a safe, informative space is needed so that providers can begin to acknowledge and work through their cultural and practice assumptions. Workshops would create designated spaces that are all the more important for home care providers, who often work in isolation and travel to different homes. Rather than suppress the tensions that arise in practice and placate them with discourses that fail to adequately address racism, a critical perspective on culture could be added to policies and values statements on cultural competence.

For care recipients, the meaning of dying at home was fluid, situational, and contextually informed. Subsequently, differences were created and highlighted in the confrontation between the meaning of palliative care for home care providers and the meaning of dying at home for care recipients. It was in the meeting, blending, clashing, and grappling of differences where participants had to negotiate and generate new, hybrid meanings and practices so that particularized, personal approaches to dying could be achieved. The findings capture the realities and complexities of palliative home care, and highlight the sophisticated and evolving ways providers come to know and care for care recipients and families in their homes. Although culture was prominently featured in participant narratives, the pragmatics of dying at home were more pressing than was adherence to essentialized cultural beliefs of death and dying. A key implication is the need to move away from simplistic, essentialist conceptualizations of culture to a critical approach that will enable providers to understand and find comfort in working with the fluid, dynamic, and contextually-driven nature of culture and dying at home.
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APPENDIX A

Information Sheet

Information Sheet:
Palliative Home Care and Chinese Immigrant Families

**Purpose of the Research:**
This research study is part of a PhD thesis (Lisa Seto, RN, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto).

The purpose of this research study is to gain a better understanding of how Chinese immigrants with advanced cancer, their primary family caregivers, and home care providers negotiate palliative home care with each other, specifically the daily care practices. The study is also interested in looking at how experiences of migration and meanings of home shape negotiations. This research is aimed at understanding and improving palliative home care for immigrant families.

**What is involved with participation?**
- Key informant interview
  - One individual interview, approximately 45mins-1.5hrs

**Inclusion Criteria:**
The inclusion criteria for **key informants** include:
- someone who has worked with Chinese immigrants around palliative home care, such as a registered nurse (RN), registered practical nurse (RPN), personal support worker (PSW), case manager, social worker, etc.
- providing home care to or having provided care in the past year to Chinese immigrant care recipients and their primary family caregivers

**Principal Investigator Contact Information:**
Lisa Seto, RN, PhD(Candidate)
Lawrence S. Bloomberg Faculty of Nursing
University of Toronto
155 College Street, Suite 130
Toronto, ON M5T 1P8
(t) 416 978 1578
(f) 416 978 8222
(e) lisa.seto@utoronto.ca

Please contact me if you have any questions or comments. Thank you!
APPENDIX B

Telephone Recruitment Script

1. Initial recruitment by CCAC case manager (for care recipients and family caregivers) or advanced practice nurse (APN) at home care agency (for home care providers):

Hello, [name of potential participant] my name is [insert recruiter’s name] and I am a [insert position title] at [insert CCAC or home care agency name]. I am currently recruiting participants for a research study on palliative home care and Chinese immigrants being conducted by Lisa Seto, a doctoral student from the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto.

This research involves interviews with care recipients, family caregivers, and home care providers to understand their perspectives on palliative home care. Interviews are flexible and will be conducted at a place and time that is convenient for you. Interviews may be broken up to accommodate your needs. As well, the researcher will be making observations of the care being delivered at your home. The researcher will make 2-3 visits to your home for observations and stay no longer than 3 hours at a time. On average, observational visits take approximately 1½ hours. If you are interested, may I pass on your contact information to the researcher so that she can contact you to further explain the details of the study?

*** If no, thank them for their time.

*** If yes, proceed to collect contact information.

2. Background information provided by researcher

Hello, [name of potential participant] my name is Lisa Seto and I am a doctoral student at the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. I am currently recruiting participants for a research study on palliative home care and Chinese immigrants. Is this a convenient time to talk to you about the study?

***If no, ask if there is a better time to call back.

***If yes, proceed to provide background information.

Background Information –

For the study, I will be conducting interviews with each participant starting [insert date]. The interview would last about 45 minutes to one hour, and would be arranged for a time and place that is convenient to you. The interview can be conducted in English, Cantonese, Taishan, or Mandarin. I am able to speak Cantonese or Taishan but will use a professional interpreter if you speak Mandarin. Involvement in this interview is entirely voluntary and there are no known or
anticipated risks to participating in this study. The questions will be around your experiences of palliative home care. You may decline to answer any of the interview questions you do not wish to answer and may terminate the interview at any time. You may withdraw from the study at any time. With your permission, the interview will be tape-recorded to facilitate collection of information, and later transcribed for analysis. I will also ask you basic demographic questions such as age, marital status, etc to get an overall picture of the sample but no individual participants will be identified specifically.

I will also come to your home to make observations starting [insert date]. Observations will be at the same time of visits from your home care provider. Observation times will depend on these visits but should last between 1 to 3 hours at a time. I will observe approximately 2-3 visits at your home. I may arrive a little earlier (at most 15 minutes) before your home care visit starts and stay a little later (at most 15 minutes) to make observations about the your preparation for and settlement after home care visits.

All information you provide will be kept confidential. The data collected will be kept in a secure location and disposed of in 7 year’s time.

If you have any questions regarding this study later on, or would like additional information to assist you in reaching a decision about participation, please feel free to contact me at 416 978 1578. The final decision about participation is yours.

I would like to assure you that this study has been reviewed and received ethical approval from the University of Toronto Research Ethics Board and the Community Care Access Centres. Should you have any comments or concerns resulting from your participation in this study, please contact Jill Parsons at the Ethics Review Office, University of Toronto, at (416) 946 5806, or Tim Pauley, Manager, Research & Evaluation, West Park Healthcare Centre, and Toronto Central Community Care Access Centre at 416 243 3600 x2628.

After all the data has been analyzed, you will receive an executive summary of the research results.

With your permission, I would like to mail/fax you an information letter/consent form, which has all of these details along with contact names and numbers on it to assist you in making a decision about your participation in this study.

Thank you very much for your time. May I call you in 2 or 3 days to see if you are interested in being interviewed? Once again, if you have any questions or concerns, please do not hesitate to contact me at 416 978 1578. Good-bye.

3. Initial recruitment by advanced practice nurse (APN) at home care agency for homecare providers

Hello, [name of potential participant] my name is [insert recruiter’s name] and I am a [insert
position title] at [insert home care agency name]. I am currently recruiting participants for a research study on palliative home care and Chinese immigrants being conducted by Lisa Seto, a doctoral student from the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto.

This research involves interviews with care recipients, family caregivers, and home care providers to understand their perspectives on palliative home care. Interviews are flexible and will be conducted at a place and time that is convenient for you. Interviews may be broken up to accommodate your needs. As well, the researcher will be making observations of you providing care to care recipients at their homes. The researcher will make 2-3 visits to observation care and stay no longer than 3 hours at a time. On average, observational visits take approximately 1½ hours. If you are interested, may I pass on your contact information to the researcher so that she can contact you to further explain the details of the study?

*** If no, thank them for their time.

*** If yes, proceed to collect contact information.

4. Background information provided by researcher

Hello, [name of potential participant] my name is Lisa Seto and I am a doctoral student at the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. I am currently recruiting participants for a research study on palliative home care and Chinese immigrants. Is this a convenient time to talk to you about the study?

***If no, ask if there is a better time to call back.

***If yes, proceed to provide background information.

Background Information –

For the study, I will be conducting interviews with each participant starting [insert date]. The interview would last about 45 minutes to one hour, and would be arranged for a time and place that is convenient to you. Involvement in this interview is entirely voluntary and there are no known or anticipated risks to participating in this study. The questions will be around your experiences of providing palliative home care to Chinese immigrant families. You may decline to answer any of the interview questions you do not wish to answer and may terminate the interview at any time. You may withdraw from the study at any time. With your permission, the interview will be tape-recorded to facilitate collection of information, and later transcribed for analysis. I will also ask you basic demographic questions such as age, marital status, etc to get an overall picture of the sample but no individual participants will be identified specifically.

I will also come with you to the care recipient’s home to make observations starting [insert date]. Observation times will depend on these visits but should last between 1 to 3 hours at a time. I will observe approximately 2-3 visits at the home. I may arrive a little earlier (at most 15 minutes) before you do at the home and stay a little later (at most 15 minutes) to make observations after you leave.
All information you provide will be kept confidential. The data collected will be kept in a secure location and disposed of in 7 year’s time.

If you have any questions regarding this study later on, or would like additional information to assist you in reaching a decision about participation, please feel free to contact me at 416 978 1578. The final decision about participation is yours.

I would like to assure you that this study has been reviewed and received ethical approval from the University of Toronto Research Ethics Board and the Community Care Access Centres. Should you have any comments or concerns resulting from your participation in this study, please contact Rachel Zand, Director, Office of Research Ethics, University of Toronto, at (416) 946 3389 or by email: rachel.zand@utoronto.ca. Also, you can contact Dr. Ron Heslegrave, Joint Research Ethics Board Chair for Bridgepoint-West Park-Toronto Central CCAC, at (416) 461 8252 ext.2343 or at Mount Sinai Research Ethics Board at 416 586 4875. These people are not involved with the research project in any way and calling them will not affect your participation in the study.

After all the data has been analyzed, you will receive an executive summary of the research results.

With your permission, I would like to mail/fax you an information letter/consent form, which has all of these details along with contact names and numbers on it to assist you in making a decision about your participation in this study.

Thank you very much for your time. May I call you in 2 or 3 days to see if you are interested in being interviewed? Once again, if you have any questions or concerns, please do not hesitate to contact me at 416 978 1578. Good-bye.
APPENDIX C

Information Sheet/Consent Forms

Care Recipient (English)

Research Title:
Palliative End-of-Life Home Care and Chinese Immigrants: The Meaning of Home and Negotiations of Care

Principal Investigator & Co-investigator:
Lisa Seto, RN, BScN, MN, PhD candidate, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, (416) 978 1578.

You are being invited to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study. The following information describes the purpose, procedures, benefits and risks of this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is called informed consent. Please ask the investigator to explain any words you don’t understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

Summary and Purpose of the Research:
Chinese immigrants make up the largest minority group in Canada, but little is known about what happens when they are diagnosed with advanced cancer and go home to receive care. The primary purpose of this study is to describe and examine how meanings of home enter into and shape negotiations of palliative home care between Chinese immigrants with advanced cancer, their primary family caregivers, and home care providers. Five families will be asked to participate in the study. The principal investigator will interview participants and observe care practices at their homes. This study is part of a PhD thesis.

Description of the Research:
Approximately 15 participants, that is 5 care recipients, 5 family caregivers, and 5 home care providers, will be included in the study. If you agree to participate in this study, we will ask you to take part in an interview and 2-3 observation visits. The principal investigator will come to the home to observe care between care recipients, family caregivers, and home care providers. The principal investigator may observe what type of care is given, who is giving the care, and how decisions about care are made. The principal investigator may also take notes of what you are doing. These visits may vary from 1-3 hours long. The principal investigator will arrive approximately 15 minutes before and leave 15 minutes after each home care visit to observe how you may have to prepare for home care visits and what happens after the home care provider leaves.

The interviews will be between 45 minutes - 1½ hours long and will be done by the principal investigator. The interview can be broken up into a few sessions if you find it difficult to sit through an entire interview. Interviews will be audio-recorded so we will not miss any of the
information that we talk about. You will be able to decide on the place and time of the interview, such as your home or at the University of Toronto. During the interview, we may ask you about:

- your experience with cancer and receiving home care
- your home and daily care routines
- how it is to be an immigrant in Canada
- how you manage at home
- the care you receive at home

You will also be asked to complete a personal questionnaire about information such as your living situation, employment, education level, language, whether you were born in Canada, and resources for health care.

**Potential Benefits, Harms and Inconveniences:**
You will not benefit personally from participating in this study. You may find it enjoyable and helpful to talk about your experiences and may have a better understanding of how you negotiate and manage your care at home. Your contributions may increase awareness of how we might better support palliative home care for immigrant families. In reports about the study, your ideas and experiences will be grouped together with other participants to develop conclusions that could be used to improve palliative home care so that it takes into consideration experiences of immigration. Although there are no obvious harms associated with taking part in this study, participating will involve some of your time, and may inconvenience you. You may find it uncomfortable to talk about some of your experiences. You may skip any questions you do not wish to answer.

**Participation:**
Your participation in this study is voluntary. It is important that you understand that if you change your mind and want to withdraw from the study at any time, you may simply inform the principal investigator. There will be no negative consequences whatsoever. If you decide not to participate, it will not affect the health care you receive or access to home care.

**Confidentiality:**
Every effort will be made to safeguard your privacy. We will not share the information you give us with anyone involved in your care. No information that could reveal your identity will be given to anyone unless it is required legally. All information that is collected for the study, including audiotapes and transcripts, will be kept in a locked filing cabinet that can only be accessed by the principal investigator. To further protect your confidentiality, your name will be replaced by a pseudonym on the file. Your identity and any identifying characteristics will not be revealed in publications that report on the findings of this study. Transcripts, journals and fieldnotes will be retained for seven years and then destroyed.

**Audio-recording:**
As mentioned above, individual interviews will be audio-recorded. The audio-recordings will be transcribed by a professional transcriptionist. The audio-recording will only be heard by the principal investigator and professional transcriptionist. The digital audiofiles will be kept on a secure server that can only be accessed by the principal investigator. Audio-recordings will be erased on completion of the data analysis.
Compensation:
You will be provided with a gift card for Shoppers Drug Mart worth $30 for the interview. The gift card will be given to you regardless of whether you complete the interview. Costs, such as parking or childcare, will not be reimbursed.

Questions:
If you have any general questions about the study, please call the principal investigator in charge of this study, Lisa Seto, PhD candidate, (416) 978 1578 or her supervisor, Dr. Jan Angus, (416) 978 0695.

If you have any questions about your rights as a research participant, please call Rachel Zand, Director, Office of Research Ethics, University of Toronto, at (416) 946 3389 or by email: rachel.zand@utoronto.ca. Also, you can contact Dr. Ron Heslegrave, Joint Research Ethics Board Chair for Bridgepoint-West Park-Toronto Central CCAC, at (416) 461 8252 ext.2343; or at Mount Sinai Research Ethics Board at 416 586 4875. These people are not involved with the research project in any way and calling them will not affect your participation in the study.

Consent:
I acknowledge that the research procedures described above have been explained to me and that any questions that I have asked have been answered to my satisfaction. I have told the researcher what it is I think I am being asked to do in this study. I have been informed of the alternatives to participation in this study, including the right not to participate and the right to withdraw without compromising health care services that are received now, or at any time in the future. I have been informed that I have the right to refuse to answer questions posed during the interview. In addition, the potential harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I know that I may ask now, or in the future, any questions I have about the study or research procedures. I have been assured that all information pertaining to me will be kept strictly confidential and no information will be released or published that would reveal my personal identity.

Signature:
I acknowledge that I have been provided with a copy of this consent form and description of the study. Having thoroughly read, understood and had full explanation of this consent form, I voluntarily consent to participate in this research study.

_________________________  ______________________  ______________
Name of Participant        Signature of Participant  Date

I confirm that I have explained the nature and purpose of the study to the subject named above. I have answered all questions.

_________________________  ______________________  ______________
Name of Person              Signature                  Date

Obtaining Consent
Care Recipient (Chinese)

资料书同意书 – 护理病人

（中译本：译文与原文如有差异，以英语原文为准。）

研究题目：
家中临终关怀护理与华人移民：家庭的意义及护理服务的选择（Palliative End-of-Life Home Care and Chinese Immigrants: The Meaning of Home and Negotiations of Care）

首席研究员：
司徒丽莎（Lisa Seto），册护士，护理学士，护理硕士，护理学博士生，多伦多大学护理系，（416）978-1578。

我们诚意邀请您参与一项研究计划。在您同意参与该项研究计划前，请阅读以下有关资料，以便了解研究计划的主旨、程序及对您本人的好处和风险。您有权在任何时候拒绝或终止参与该研究计划。在您决定是否参与该研究计划之前，您应充分了解研究计划所包含的风险及对您本人的好处，避免草率作出决定。这叫“经充分考虑后的允许”（informed consent）。在签署同意书之前，若有不明白的地方，请向研究员查询。请您务必在所有问题都得到完满的解答后才签署该同意书。

研究计划主旨与简介：
华人移民是加拿大最大的少数民族社群。一些华人移民在被诊断患上末期癌症后，便开始在家接受临终关怀护理服务，可是随后发生什么事，一般人所知甚少。该项研究主要探讨“家庭”这个地方和概念怎样影响患有末期癌症的华人移民与提供护理的主要家庭成员及专业家中临终关怀护理服务提供者在护理服务提供方面所进行的商讨和互动。我们将会邀请五个家庭参与我们的研究计划。首席研究员将会对参与者进行采访，并对家中临终关怀护理的实践方法与惯常做法进行观察。该研究计划是本人博士论文的一部分。

研究方法：
研究计划将会有十五位参与者（五位护理病人，五位提供护理的家庭成员及五位专业家中临终关怀护理服务提供者）。如果您同意参与该项研究计划，我们将为您进行一次采访，并邀请您参与两至三次的“家中观察访问”（observation visits）。首席研究员将会造访您家中，观察护理病人的家庭成员和专业家中临终关怀护理服务提供者怎样为护理病人提供护理服务。首席研究员可观察：

- 护理病人接受什么样的护理服务；
- 某些护理服务由谁来提供，以及
- 有关护理服务的决策过程。

首席研究员在观察过程中可能会记下您的言行，每次造访大约为时一至三小时。首席研究员每次会早于预约时间十五分钟到达您家中，观察护理服务之前的工作；同样，首席研究员每次亦会比预约时间后十五分钟离开，以便观察家中护理服务完毕后护理病人的状况。

除了“家中观察访问”之外，主要研究员会为您进行一次为时四十五至九十分钟的采访。如果您需要，我们可以把采访时间分为几个部分在不同的时间进行。采访时，我们将进行录音，以确保所有资料都被收录。您可以选择采访的时间和地点；地点包括阁下家中及多伦多大学等地。
采访进行时，首席研究员可能会问您有关以下内容的问题：

- 患癌经历和在家中接受护理服务的经验
- 日常家务程序及家中护理的例行工作
- 身为加籍移民的感受和感想
- 在家生活安排
- 您在家中所接受的护理服务

除此之外，首席研究员会请填写一份有关您个人资料的表格，资料包括您的生活与就业状况、教育水平、日常使用语言、医疗保健，以及您本人是否出生于加国等。

潜在好处、坏处与不便：
您不会从这项研究获得个人好处，但可能会从讲述自身经验而获得满足，同时亦可能对如何编排护理工作有更透彻的了解。除此之外，您的意见将会帮助我们就如何更有效地支援以家庭护理服务方面提供参考。在研究中，我们将把您和其他参与者所讲述的经验作综合分析，从而确定怎样提高家中临终护理服务的质量。您可能会为您的经验而感到不便，但亦可能会为您带来不便。“家中观察访问”进行时，您可以选择不回答您不想回答的问题。

参与：
您的参与出于自愿。即使您已答应参与但在随后不想继续，您仍可告知首席研究员您想退出。退出研究并不会为您带来任何负面后果，亦不会影响您家人所接受的护理服务。

私隐：
我们会全力保障您的私隐。我们不会将您提供给我们的资料给予任何护理人员，包括为您提供护理服务的家庭成员。除非法律规定，我们不会在没有您的允许下把任何可能透露您身份的资料给予任何人。所有资料，包括录音带和手抄笔记，会被锁在档案箱里，只有首席研究员才能打开这个档案箱。为了更妥善保障您的私隐，我们在档案中将不会使用您的真名。您的个人身份及身份特征，均不会发布在任何与该项研究成果有关的出版物上。该项研究计划的笔记以及有关资料，在保存七年后将会被销毁。

录音：
如上所述，采访将会进行录音。一位专业转录员会把录音转化成书面文字。录音只有首席研究员和专业转录员才能听到。所有数码录音档案会被存放在设有安全屏障的服务器内，只有首席研究员才能启动及使用这个服务器。数码录音档案在用于资料分析后会予以删除。

酬劳：
为酬谢阁下参与采访，我们将送上一张价值$30元的Shoppers Drug Mart礼品卡。不管您是否完成整个采访过程，这张礼品卡都会送给您。但请注意，我们并不会报销您其他的支出，如停车费及日托服务费用等。

查询：
如果您对这项研究有任何疑问，请致电首席研究员及博士生司徒丽莎或其指导老师安格斯珍(Jan Angus)。
详细联络资料如下：

司徒丽莎：416-978-1578
安格斯珍：416-978-0695
如果您对作为研究参与者应有的权益有任何疑问，请致电或发电邮给以下人士：

1）多伦多大学研究道德办公室总监瑞吉儿·瑞（Rachel Zand）：
   - 联络电话：416-946-3389
   - 电邮地址：rachel.zand@utoronto.ca

2）Bridgepoint-West Park-Toronto Central CCAC之联合研究道德委员会（Joint Research Ethics Board）和Mount Sinai Research Ethics Board署长思素古瑞夫·谦教授（Ron Heslegrave）：
   - 联络电话：416-461-8252 转接2343
   - 联络电邮：416 586 4875

瑞吉儿·瑞及思素古瑞夫·谦教授均没有以任何形式参与该项研究。联络他们并不会影响您参与该项研究计划。

同意栏
我确认，研究人员已向我解释上述有关研究的步骤和程序，并回答了本人所提出的所有问题。我已认为自己在该项研究里要做什么告知研究人员。研究人员已告知我，对该项目计划的参与并不是强制性的。本人有权终止参与，而终止参与并不会影响本人于现在或未来任何时候所接受的护理服务。我已被告知在采访时可以拒绝回答任何不感兴趣的问题。除此之外，研究人员已告知我参与该项研究的潜在风险及可能引起的人类与不便。研究人员并已告诉我参与该项研究计划的好处。我知道我可以于现在或未来对该项目的进行或内容提出任何询问。研究一方已向我保证，有关我本人的所有资料将受到严格保密，并会被禁止发往外界和刊登在任何出版物上。

签署栏
本人确认已获发此同意书及研究计划资料说明副本一份。在经详细阅读和理解该同意书的内容后，并且在获得充分说明和解释下，本人同意参与该项研究计划。

参与者姓名

参与者签名

日期

本人确认已向参与者说明上述研究计划的目的和本质，并已为其解答所有问题。

研究员姓名

研究员签名

日期
Family Caregiver (English)

**Research Title:**
Palliative End-of-Life Home Care and Chinese Immigrants: The Meaning of Home and Negotiations of Care

**Principal Investigator:**
Lisa Seto, RN, BScN, MN, PhD candidate, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, (416) 978 1578.

You are being invited to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study. The following information describes the purpose, procedures, benefits and risks associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is called informed consent. Please ask the investigator to explain any words you don’t understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

**Summary and Purpose of the Research:**
Chinese immigrants make up the largest minority group in Canada, but little is known about what happens when they are diagnosed with advanced cancer and go home to receive care. The primary purpose of this study is to describe and examine how meanings of home enter into and shape negotiations of palliative home care between Chinese immigrants with advanced cancer, their primary family caregivers, and home care providers. Five families will be asked to participate in the study. The principal investigator will interview participants and observe care practices at their homes. This study is part of a PhD thesis.

**Description of the Research:**
Approximately 15 participants, that is 5 care recipients, 5 family caregivers, and 5 home care providers, will be recruited in total for the study. If you agree to participate in this study, we will ask you to take part in an interview and 2-3 observation visits. The principal investigator will come to the home to observe care between care recipients, family caregivers, and home care providers. The principal investigator may observe what type of care is given, who is giving the care, and how decisions about care are made. The principal investigator may also take notes of what you are doing. These visits may vary from 1-3 hours long. The principal investigator will arrive approximately 15 minutes before and leave 15 minutes after each home care visit to observe how you may have to prepare for home care visits and what happens after the home care provider leaves.

The interviews will be between 45 minutes - 1½ hours long and will be conducted by the principal investigator. The interview can be broken up into multiple sessions to accommodate your schedule. Interviews will be audio-recorded so we will not miss any of the information that is discussed. You will be able to decide on the place and time of the interview, such as your home or at the University of Toronto.
During the interview, you may be asked about:
- your experience and role as a caregiver
- your home and daily care routines
- any changes to your home since becoming a caregiver

You will also be asked to complete a personal questionnaire about information such as your living situation, employment, education level, language, whether you were born in Canada, and resources for health care.

**Potential Benefits, Harms and Inconveniences:**
You will not benefit personally from participating in this study. You may find it enjoyable and helpful to talk about your experiences and may develop a better understanding of how you negotiate and manage caregiving at home. Your contributions may increase awareness of how we might better support palliative home care for immigrant families. In reports about the study, your ideas and experiences will be grouped together with other participants to develop conclusions that could be used to improve palliative home care so that it takes into consideration experiences of immigration. Although there are no obvious harms associated with taking part in this study, participating will involve some of your time, and may inconvenience you. You may find it uncomfortable to discuss some of your experiences. You may skip any questions you do not wish to answer.

**Participation:**
Your participation in this study is voluntary. It is important that you understand that if you change your mind and want to withdraw from the study at any time, you may simply inform the principal investigator. There will be no negative consequences whatsoever. If you decide not to participate, it will not affect the health care you and your family member receive or access to home care.

**Confidentiality:**
Every effort will be made to safeguard your privacy. We will not share the information you give us with anyone involved in your care. No information that could reveal your identity will be disclosed to anyone unless disclosure is required legally. All information that is collected for the study, including audiotapes and transcripts, will be kept in a locked filing cabinet that can only be accessed by the principal investigator. To further protect your confidentiality, your name will be replaced by a pseudonym on the file. Your identity and any identifying characteristics will not be revealed in publications that report on the findings of this study. Transcripts, journals and fieldnotes will be retained for seven years and then destroyed.

**Audio-recording:**
As mentioned above, individual interviews will be audio-recorded. The audio-recordings will be transcribed by a professional transcriptionist. The audio-recording will only be heard by the principal investigator and professional transcriptionist. The digital audiofiles will be kept on a secure server that can only be accessed by the principal investigator. Audio-recordings will be erased on completion of the data analysis.

**Compensation:**
You will be provided with a gift card for Shoppers Drug Mart worth $30 for the interview. The honoraria will be provided regardless of whether you complete the interview. Costs, such as parking or childcare, will not be reimbursed.

Questions:
If you have any general questions about the study, please call the principal investigator in charge of this study, Lisa Seto, PhD candidate, (416) 978 1578 or her supervisor, Dr. Jan Angus, (416) 978 0695.

If you have any questions about your rights as a research participant, please call Rachel Zand, Director, Office of Research Ethics, University of Toronto, at (416) 946 3389 or by email: rachel.zand@utoronto.ca. Also, you can contact Dr. Ron Heslegrave, Joint Research Ethics Board Chair for Bridgepoint-West Park-Toronto Central CCAC, at (416) 461 8252 ext.2343; or at Mount Sinai Research Ethics Board at 416 586 4875. These people are not involved with the research project in any way and calling them will not affect your participation in the study.

Consent:
I acknowledge that the research procedures described above have been explained to me and that any questions that I have asked have been answered to my satisfaction. I have told the researcher what it is I think I am being asked to do in this study. I have been informed of the alternatives to participation in this study, including the right not to participate and the right to withdraw without compromising health care services that are received now, or at any time in the future. I have been informed that I reserve the right to refuse to answer questions posed during the interview. In addition, the potential harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I know that I may ask now, or in the future, any questions I have about the study or research procedures. I have been assured that all information pertaining to me will be kept strictly confidential and no information will be released or published that would disclose my personal identity.

Signature:
I acknowledge that I have been provided with a copy of this consent form and description of the study. Having thoroughly read, understood and had full explanation of this consent form, I voluntarily consent to participate in this research study.

_________________________  ______________________  _____________
Name of Participant     Signature of Participant     Date

I confirm that I have explained the nature and purpose of the study to the subject named above. I have answered all questions.

_________________________  ______________________  _____________
Name of Person     Signature     Date

Obtaining Consent
Family Caregiver (Chinese)

资料书/同意书---提供护理的主要家庭成员

（中译本：译文与原文如有差异，以英语原文为准。）

研究题目：
家中临终关怀护理与华人移民：家居的意义及护理服务的选择（Palliative End-of-Life Home Care and Chinese Immigrants: The Meaning of Home and Negotiations of Care）

首席研究员：
司徒丽莎（Lisa Seto），册护士，护理学士，护理硕士，护理学博士生，多伦多大学护理系，（416）978-1578。

我们诚意邀请您参与一项研究计划。在您同意参与该项研究计划前，请阅读以下有关资料，以便了解研究计划的主旨、程序、及对您本人的好处和风险。您有权在任何时候拒绝或终止参与该项研究计划。在您决定是否参与该项研究计划之前，您应充分了解研究计划所包含的风险及对您本人的好处，避免草率作出决定。这叫经充分考虑后的允许“（informed consent）。在签署同意书前，若有不明白的地方，请向研究者查询。请您务必在所有问题都得到完满的解答后才签署该同意书。

研究计划主旨与简要：
华人移民是加国最大的少数民族社群。一些华人移民在被诊断患上末期癌症后，便开始在家接受临终关怀护理服务，可是随后发生什么事，一般人所知甚少。该项研究主要探讨“家居”这个地方和概念怎样影响患有末期癌症的华人移民与提供护理的主要家庭成员及专业家中临终关怀护理服务提供者在护理服务提供方面所进行的商讨和互动。我们将邀请五个家庭参与我们的研究计划。首席研究员将会对参与者进行采访，并对家中临终关怀护理的实践方法与惯常做法进行观察。该研究计划是本人博士论文的一部分。

研究方法：
研究计划将会有十五位参与者
（五位护理病人，五位提供护理的家庭成员及五位专业家中临终关怀护理服务提供者）。如果您同意参与该项研究计划，我们将为您进行一次采访，并邀请您参与两至三次的“家中观察访问”（observation visits）。首席研究员将造访您家中，观察提供护理的家庭成员和专业家中临终关怀护理服务提供者怎样为护理病人提供护理服务。首席研究员将可能观察

- 护理病人接受什么样的护理服务，
- 某些护理服务由谁来提供，以及
- 有关护理服务的决策过程。

首席研究员在观察过程中可能会记下您的言行，每次造访大约为时一至三小时。首席研究员每次会于预约时间前十五分钟到达您家中，观察护理服务之前的准备工作；同样，首席研究员每次亦会比预约时间晚十五分钟离开，以便观察家庭护理服务完毕后护理病人的状况。

除了“家中观察访问”之外，主要研究者亦会为您进行一次时间为四十五至九十分钟的采访。如果您有需要，我们可以将采访时间分为几个部分在不同时间进行。采访时，我们将会进行录音，以确保所有资料都被收录。您可以选择采访的时间和地点。地点包括阁下家中及多伦多大学等。
You may be asked about the following:

- Your role as a caregiver and your experience
- Your daily routine and the care you provide
- How your family has changed since you became a caregiver

In addition, the principal researcher will ask you to fill out a personal profile form, which includes your living and working situation, education level, daily use of language, health care, and whether you were born in Canada, etc.

Potential benefits, drawbacks, and inconveniences:

You will not receive any personal benefits from this research, but you may gain satisfaction from sharing your experiences, and you may gain a better understanding of how to arrange care. Furthermore, your opinion will help us achieve better support for end-of-life care services for immigrant families. In the research report, we will combine your and other participants' experiences for comprehensive analysis to better support end-of-life care services. Although participating in this research will not bring you any obvious drawbacks, it may bring you inconvenience.

Home observation visits will be conducted when it is convenient for you. You can choose not to answer any questions you do not want to answer.

Your participation is voluntary. Even if you agree to participate but later decide not to continue, you can inform the principal researcher that you want to withdraw. You will not affect the health care services you and your family receive.

Confidentiality:

We will protect your confidentiality. We will not share your information with any caregivers, including family members who provide you with care. Unless required by law, we will not provide any information that may disclose your identity to anyone. All materials, including recordings and note-taking, will be stored securely. We will not use your real name in the report. All research data and notes, including recordings, will be destroyed after seven years.

Recording:

As mentioned above, the interview will be recorded. A professional transcriber will transcribe the recording. The recording can only be accessed by the principal researcher and professional transcribers. All digital recordings are stored on a server with security measures, and only the principal researcher can access it.

Compensation:

As a thank you for your participation, you will receive a $30 Shoppers Drug Mart gift card. Regardless of whether you complete the entire interview process, you will receive this gift card. We will not reimburse you for any other expenses, such as parking fees and day care fees.

Inquiries:

If you have any questions about this research plan, please contact the principal researcher, Lisa S. or her supervisor, Jan Angus.

Contact information:

Lisa S.: 416-978-1578
Jan Angus: 416-978-6095

If you have any questions about your rights as a research participant, please contact or email the following person(s):
1）多伦多大学研究道德办公室总监·瑞吉儿（Rachel Zand）:
   - 联络电话：416-946-3389
   - 电邮地址：rachel.zand@utoronto.ca

2）Bridgepoint-West Park-Toronto Central CCAC之联合研究道德总署（Joint Research Ethics Board）和Mount Sinai Research Ethics Board署长·思素古瑞夫·龙教授（Ron Heslegrave）:
   - 联络电话：416-461-8252 转接2343
   - 联络电邮：416-586-4875

瑞吉儿与思素古瑞夫·龙教授没有以任何形式参与该项研究。联络他们并不会影响您参与该项研究计划。

同意栏
我已经向参与者说明上述研究计划的目的和本质，并已向其解答所有问题。我已告诉参与者，对该项研究计划的参与并不是强制性的，参与者有权中止参与，而中止参与并不会影响参与者于现在或未来任何时候所接受的护理服务。我已告知参与者在采访时可以拒绝回答任何不想回答的问题。除此之外，我已告知参与者该研究计划的潜在坏处及可能会引起的焦虑与不便。研究一方已向我保证，有关我本人的所有资料将受到严格保密，并会被禁止发放外界或刊登在任何出版物上。

签名栏
本人确认已获得并签署此同意书及研究计划资料说明副本一份。在经参与者详细阅读和理解并签署同意书的内容后，并且在获得充分说明和解释下，本人同意参与该项研究计划。

_________________________________________  ______________________________________  ____________
参与者姓名                                      参与者签名                                      日期

本人确认已向参与者说明上述研究计划的目的和本质，并已向其解答所有问题。

_________________________________________  ______________________________________  ____________
研究员姓名                                      研究员签名                                      日期
Home Care Provider (English)

Research Title:
Palliative End-of-Life Home Care and Chinese Immigrants: The Meaning of Home and Negotiations of Care

Principal Investigator:
Lisa Seto, RN, BScN, MN, PhD candidate, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, (416) 978 1578.

You are being invited to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study. The following information describes the purpose, procedures, benefits and risks associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is called informed consent. Please ask the investigator to explain any words you don’t understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

Summary and Purpose of the Research:
Chinese immigrants make up the largest minority group in Canada, but little is known about what happens when they are diagnosed with advanced cancer and go home to receive care. The primary purpose of this study is to describe and examine how meanings of home enter into and shape negotiations of palliative home care between Chinese immigrants with advanced cancer, their primary family caregivers, and home care providers. Five families will be asked to participate in the study. The principal investigator will interview participants and observe care practices at their homes. This study is part of a PhD thesis.

Description of the Research:
Approximately 15 participants, that is 5 care recipients, 5 family caregivers, and 5 home care providers, will be recruited in total for the study. If you agree to participate in this study, we will ask you to take part in an interview and 2-3 observation visits. The principal investigator will come to the home to observe care between care recipients, family caregivers, and home care providers. The principal investigator may observe what type of care is given, who is giving the care, and how decisions about care are made. The principal investigator may also take notes of what you are doing. These visits may vary from 1-3 hours long. The principal investigator will arrive approximately 15 minutes before and leave 15 minutes after each home care visit to observe how families may have to prepare for home care visits and what happens after the home care provider leaves.

The interviews will be between 45 minutes - 1½ hours long and will be conducted by the principal investigator. Interviews will be audio-recorded so we will not miss any of the information that is discussed. You will be able to decide on the place and time of the interview, such as your home or at the University of Toronto.
During the interview, you may be asked about:
- your experience providing home care to this patient and his/her family
- your experience providing home care to other patients and families
- any changes to the home while you have been providing care to this patient and his/her family
- your perspective of differences between providing care in hospitals and homes

You will also be asked to complete a personal questionnaire about information such as your living situation, employment, education level, language, whether you were born in Canada, and resources for health care.

**Potential Benefits, Harms and Inconveniences:**
You will not benefit personally from participating in this study. You may find it enjoyable and helpful to talk about your experiences and may develop a better understanding of how you negotiate and manage care with patients and their families. Your contributions may increase awareness of how we might better support palliative home care for immigrant families. In reports about the study, your ideas and experiences will be grouped together with other participants to develop conclusions that could be used to improve palliative home care so that it takes into consideration experiences of immigration. Although there are no obvious harms associated with taking part in this study, participating will involve some of your time, and may inconvenience you. You may find it uncomfortable to discuss some of your experiences. You may skip any questions you do not wish to answer.

**Participation:**
Your participation in this study is voluntary. It is important that you understand that if you change your mind and want to withdraw from the study at any time, you may simply inform the principal investigator. There will be no negative consequences whatsoever. Your employment will not be affected in any way by participating in this study, and if you decide not to participate, it will not affect your employment either.

**Confidentiality:**
Every effort will be made to safeguard your privacy. We will not share the information you give us with anyone at your work. No information that could reveal your identity will be disclosed to anyone unless disclosure is required legally. All information that is collected for the study, including audiotapes and transcripts, will be kept in a locked filing cabinet that can only be accessed by the principal investigator. To further protect your confidentiality, your name will be replaced by a pseudonym on the file. Your identity and any identifying characteristics will not be revealed in publications that report on the findings of this study. Transcripts, journals and fieldnotes will be retained for seven years and then destroyed.

**Audio-recording:**
As mentioned above, individual interviews will be audio-recorded. The audio-recordings will be transcribed by a professional transcriptionist. The audio-recording will only be heard by the principal investigator and professional transcriptionist. The digital audiofiles will be kept on a secure server that can only be accessed by the principal investigator. Audio-recordings will be erased on completion of the data analysis.
Compensation:
You will be provided with a honorarium of $30 for the interview. The honoraria will be provided regardless of whether you complete the interview. Costs, such as parking or childcare, will not be reimbursed.

Questions:
If you have any general questions about the study, please call the principal investigator, Lisa Seto, PhD candidate, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, (416) 978 1578 or her supervisor, Dr. Jan Angus, (416) 978 0695.

If you have any questions about your rights as a research participant, please call Rachel Zand, Director, Office of Research Ethics, University of Toronto, at (416) 946 3389 or by email: rachel.zand@utoronto.ca. Also, you can contact Dr. Ron Heslegrave, Joint Research Ethics Board Chair for Bridgepoint-West Park-Toronto Central CCAC, at (416) 461 8252 ext.2343; or at Mount Sinai Research Ethics Board at 416 586 4875. These people are not involved with the research project in any way and calling them will not affect your participation in the study.

Consent:
I acknowledge that the research procedures described above have been explained to me and that any questions that I have asked have been answered to my satisfaction. I have told the researcher what it is I think I am being asked to do in this study. I have been informed of the alternatives to participation in this study, including the right not to participate and the right to withdraw without compromising health care services that are received now, or at any time in the future. I have been informed that I reserve the right to refuse to answer questions posed during the interview. In addition, the potential harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I know that I may ask now, or in the future, any questions I have about the study or research procedures. I have been assured that all information pertaining to me will be kept strictly confidential and no information will be released or published that would disclose my personal identity.

Signature:
I acknowledge that I have been provided with a copy of this consent form and description of the study. Having thoroughly read, understood and had full explanation of this consent form, I voluntarily consent to participate in this research study.

_________________________  ________________________  ________________
Name of Participant        Signature of Participant      Date

I confirm that I have explained the nature and purpose of the study to the subject named above. I have answered all questions.

_________________________  ________________________  ________________
Name of Person              Signature                      Date

Obtaining Consent
Key Informant (English)

Research Title:
Palliative End-of-Life Home Care and Chinese Immigrants: The Meaning of Home and Negotiations of Care

Principal Investigator & Co-Investigator:
Principal investigator: Dr. Amna Husain, Temmy Latner Centre for Palliative Care, (416) 586 4800 x 6721 and co-investigator: Lisa Seto, PhD(c), Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, (416) 978 1578.

You are being invited to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study. The following information describes the purpose, procedures, benefits and risks associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is called informed consent. Please ask the investigator to explain any words you don’t understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

Summary and Purpose of the Research:
Chinese immigrants make up the largest minority group in Canada, but little is known about what happens when they are diagnosed with advanced cancer and go home to receive care. The primary purpose of this study is to describe and examine how meanings of home enter into and shape negotiations of palliative home care between Chinese immigrants with advanced cancer, their primary family caregivers, and home care providers. Preliminary interviews will be conducted with key informants and five families will be asked to participate in the study. The principal investigator will interview participants and/or observe care practices at their homes. This study is part of a PhD thesis.

Description of the Research:
Approximately 12 key informants will be recruited for a one-time interview. Key informants may include palliative home care nurses, personal support workers, palliative physicians, and community workers. Approximately 15 participants, that is 5 care recipients, 5 family caregivers, and 5 home care providers, will be recruited in total for observational visits and interviews.

The key informant interview will be between 45 minutes - 1½ hours long and will be conducted by the principal investigator. The interview will be audio-recorded so we will not miss any of the information that is discussed. You will be able to decide on the place and time of the interview, such as your home or at the University of Toronto.

During the interview, you may be asked about:
- your role
- your experience working or caring for Chinese immigrant families receiving palliative home care
• how you negotiate and manage care with Chinese immigrant families receiving palliative home care

**Potential Benefits, Harms and Inconveniences:**
You will not benefit personally from participating in this study. You may find it enjoyable and helpful to talk about your experiences and may develop a better understanding of palliative home care for Chinese immigrants. Your contributions may increase awareness of how we might better support palliative home care for immigrant families. In reports about the study, your ideas and experiences will be grouped together with other participants to develop conclusions that could be used to improve palliative home care so that it takes into consideration experiences of immigration. Although there are no obvious harms associated with taking part in this study, participating will involve some of your time, and may inconvenience you. You may find it uncomfortable to discuss some of your experiences. You may skip any questions you do not wish to answer.

**Participation:**
Your participation in this study is voluntary. It is important that you understand that if you change your mind and want to withdraw from the study at any time, you may simply inform the principal investigator. There will be no negative consequences whatsoever. If you decide not to participate. Your employment will not be affected in any way by participating in this study, and if you decide not to participate, it will not affect your employment either.

**Confidentiality:**
Every effort will be made to safeguard your privacy. We will not share the information you give us with anyone involved in your care. No information that could reveal your identity will be disclosed to anyone unless disclosure is required legally. All information that is collected for the study, including audiotapes and transcripts, will be kept in a locked filing cabinet that can only be accessed by the principal investigator. To further protect your confidentiality, your name will be replaced by a pseudonym on the file. Your identity and any identifying characteristics will not be revealed in publications that report on the findings of this study. Transcripts, journals and fieldnotes will be retained for seven years and then destroyed.

**Audio-recording:**
As mentioned above, individual interviews will be audio-recorded. The audio-recordings will be transcribed by a professional transcriptionist. The audio-recording will only be heard by the principal investigator and professional transcriptionist. The digital audiofiles will be kept on a secure server that can only be accessed by the principal investigator. Audio-recordings will be erased on completion of the data analysis.

**Compensation:**
You will be provided with a honorarium of $30 for the interview. The honoraria will be provided regardless of whether you complete the interview. Costs, such as parking or childcare, will not be reimbursed.
Questions:
If you have any general questions about the study, please call the principal investigator, Dr. Amna Husain, Temmy Latner Centre for Palliative Care, (416) 586 4800 x 6721; or co-investigator, Lisa Seto, PhD candidate, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, (416) 978 1578 or her supervisor, Dr. Jan Angus, (416) 978 0695.

If you have any questions about your rights as a research participant, please call Rachel Zand, Director, Office of Research Ethics, University of Toronto, at (416) 946 3389 or by email: rachel.zand@utoronto.ca. Also, you can contact Dr. Ron Heslegrave, Joint Research Ethics Board Chair for Bridgepoint-West Park-Toronto Central CCAC, at (416) 461 8252 ext.2343; or at Mount Sinai Research Ethics Board at 416 586 4875. These people are not involved with the research project in any way and calling them will not affect your participation in the study.

Consent:
I acknowledge that the research procedures described above have been explained to me and that any questions that I have asked have been answered to my satisfaction. I have told the researcher what it is I think I am being asked to do in this study. I have been informed of the alternatives to participation in this study, including the right not to participate and the right to withdraw without compromising health care services that are received now, or at any time in the future. I have been informed that I reserve the right to refuse to answer questions posed during the interview. In addition, the potential harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I know that I may ask now, or in the future, any questions I have about the study or research procedures. I have been assured that all information pertaining to me will be kept strictly confidential and no information will be released or published that would disclose my personal identity.

Signature:
I acknowledge that I have been provided with a copy of this consent form and description of the study. Having thoroughly read, understood and had full explanation of this consent form, I voluntarily consent to participate in this research study.

_________________________  ______________________  ____________
Name of Participant        Signature of Participant        Date

I confirm that I have explained the nature and purpose of the study to the subject named above. I have answered all questions.

_________________________  ______________________  ____________
Name of Person            Signature                  Date
Obtaining Consent
APPENDIX D

Interview Guide

Initial questions posed will be “grand tour” questions that are open-ended and allow participants to provide a biography of beliefs, values, and everyday routines and relationships. Although the questions may be broad, they will still be related to the research purpose. In-depth, open-ended interviews (approximately ¾ - 1½ hrs) with participants will be guided by a theme list to ensure that relevant issues are discussed.

Key Informant Interviews:
The interviews for key informants are divided into two main groups: 1) those representing ‘professional’ care providers such as nurses, PSWs, physicians, social workers, etc., and 2) ‘lay’ care providers including bereaved caregivers and other key informants such as community workers.

“Professional” Care Providers:
The main prompt for ‘professional’ care providers is what is the experience of working with Chinese immigrant care recipients?

Prompts for interviews with key informants:
1) Please tell me about your work and how you are involved with the care of Chinese immigrant families receiving palliative home care.
2) Please tell me about your experiences working with Chinese immigrant families receiving palliative home care.
3) Please tell me about one particular Chinese immigrant family that was significant to your practice or work.
4) What are some of the issues encountered in developing a plan of care?
5) What concerns arose in the time you were providing care?
6) How did you and the family problem solve?

“Lay” Caregivers”
The main prompts for ‘lay’ caregivers include 1) what was it like to provide care for a Chinese immigrant care recipient at home, and 2) what is the experience of negotiating and navigating care at home?

Prompts for interviews with key informants:
1) Please tell me about your experiences caring for your family member at home.
2) How did it come to be that you came to take care of your family member at home?
3) Please tell me about a typical day when you first started taking care of your family member at home. How about later on?
4) How did you work with other health care providers around your family member’s care needs? And your own?
5) How was it to work between your family member and the care providers?
6) Has your home changed since caring for your family member? How?
Cases:
The 3 main themes as prompts: 1) experience of immigration or as an immigrant; 2) experience of home and palliative end-of-life home care; and 3) negotiation and management of palliative end-of-life care at home. With qualitative interviewing, questions may evolve as analytic ideas develop.

Examples of initial questions include:
1) Please tell me about how you came to receive or provide home care?
2) Please tell me about a typical day at home.
3) Please tell me about a typical visit with the home care provider.

Prompts for interviews with Chinese immigrant receiving palliative end-of-life home care:
1) Please tell me about what happened after your diagnosis and how it is to receive home care.
2) Tell me about your home, how did you first come to live in this home?
3) What has changed in the home since your diagnosis?
4) What is it like to be at home now?
5) Tell me who takes care of you at home?
6) What do you do when you need something?
7) How did you immigrate to Canada?
8) What has it been like to be an immigrant in Canada?

Prompts for interviews with primary family caregiver:
1) Please tell me about what it’s like to be at home and take care of someone?
2) What kinds of things do you do to take care of the care recipient?
3) Tell me about your home, how did you first come to live in this home?
4) What has changed in the home since you became a caregiver?
5) When you think of home, what do you think about?
6) When you need help with care or care done, how do you get it done?

Prompts for interviews with home care providers:
1) Please tell me about going to this patient’s home to provide care?
2) For you, what are the main differences between home care and hospital care?
3) How long have you been coming to this home?
4) Have you noticed any changes to the home?
5) How do you make decisions about care with the recipient and family?
APPENDIX E
Observational Guide

Observations will be around activities within the home that pertain to care for the care recipient. Observations will be centred on home care visits by the RN, RPN, or PSW. The researcher will arrive approximately 15 minutes in advance and stay 15 minutes after the home care visit. The researcher will conduct approximately 2-3 observation visits per household. Observational visits will range from 1-3hrs long.

Things that will be observed include:
- Interactions between care recipients, family caregivers, and home care providers
- Activities before home visits from home care providers
- Activities after home visits from home care providers
- Discussions between patients and family caregivers
- Interactions between patient, family caregivers and other family members
- The home itself: layout, positioning of furniture and equipment, where care takes place, where other household activities take place, uses of particular rooms, etc.

Researcher in participant-as-observer role:
- Observe activities of care recipients, family caregivers, and home care providers
- Take fieldnotes during observations
- Ask and answer questions during observation, i.e. engage in informal conversation
- May assist in appropriate tasks, i.e. passing a glass, help make lunch; tasks involving nursing care or tasks deemed beyond scope of researcher observation role will declined
**APPENDIX F**

**Fieldnote Template**

<table>
<thead>
<tr>
<th>Date/Time:</th>
<th>Participant code:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Observed Event/Conversations</th>
<th>Analytic Thoughts/Emotional Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example:</td>
<td></td>
</tr>
<tr>
<td>Caregiver puts home care nurse’s purse in closet.</td>
<td>Caregiver may be trying to keep home in order or sees caregiver as guest and so places purse in closet.</td>
</tr>
</tbody>
</table>
APPENDIX G
Demographic Form

Participant code: ________

1. Birthdate ________
   Year

2. Gender
   □ Male  □ Female

3. Living situation (check all that apply)
   □ Alone
   □ Spouse/partner
   □ Child(ren) under 18, if yes, number of children under 18: ________
   □ Other adult(s), if yes, number of other adults: ________
   □ Common law
   □ Divorced/separated
   □ Married
   □ Single
   □ Widow
   □ Other, specify _____

4a. If care recipient or caregiver, relationship between each other ________________

4b. If home care providers, type
   □ Registered Nurse (RN)
   □ Registered Practical Nurse (RPN)
   □ Personal Support Worker (PSW)

5. Language(s) spoken
   □ English
   □ French
   □ Mandarin
   □ Cantonese
   □ Other(s), please specify: ____________________________
Participant code: _______

6. Language(s) spoken at home
☐ English
☐ French
☐ Mandarin
☐ Cantonese
☐ Other(s), please specify: ________________________

7. Born in Canada?
☐ Yes  ☐ No
If no, where? ________________________________
If no, year of arrival/immigration to Canada? ____________

8. Education
(highest level of education completed)
☐ < High school  ☐ Some post secondary education  ☐ Completed high school
☐ College diploma  ☐ Undergraduate degree  ☐ Graduate degree

9. Current employment status:
☐ Full-time  ☐ Part-time  ☐ Casual  ☐ Unemployed  ☐ Disabled
☐ Homemaker  ☐ Retired  ☐ Sick leave  ☐ Compassionate Care Leave
☐ Other ________________________________
If currently employed, list occupation: ________________________________
If you are not currently employed, list previous occupation: ________________________________

10. For Care recipients and caregivers, types of health care resources:
☐ Family physician
☐ Specialist, if yes list:
_____________________________________________________________
☐ Other, if yes list: _____________________________________________