EXPLORING DEMENTIA CARE IN CHINESE IMMIGRANT FAMILIES
IN GREATER VANCOUVER, BRITISH COLUMBIA, CANADA

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ABSTRACT

Three aspects of dementia caring in the everyday life of Chinese immigrant families are not well understood: First, the notion of Chinese family or filial norm, in particular the key component of love and affection largely missing from the literature; second, the pathways between cultural beliefs and the actual caring practices of partners in care; and third, the Chinese person with dementia and the relationship with her or his carer, and their relationship within larger care contexts and structures. Borrowing notions from Buber, Bourdieu and Liang, the purpose of the study was to explore these gaps and uncover the connections between culture, emotions, and practice in Chinese families. Using the case study method and guided by principles of hermeneutical interpretation, four families comprising two or more family members and/or a service provider participated in in-depth interviews and observation sessions. Data were analyzed using ATLAS.ti to develop a holistic picture of each case situated in the particular and complex person-circumstance-time contexts of each family. Whereas the ‘story’ of each case, in its rich in-depth and contextualized details, was different and unique, cross-case analysis showed several themes that cut across all cases. First, routine caring practices are a culturally adaptive device as the routine practices embody the history, preferences and emotional investment of individuals. Second, the families draw on the cultural value of a Chinese relational self as reference for understanding family or filial obligation. Within the obligation are two aspects of responsibility and affection that co-exist and co-constitute each other. Third, in practice, participants draw on different cultures from their family, social, religious, and other life experiences in fluid and non-thinking ways that often introduce contradictions and tension between their thoughts and their actions. These non-thinking ways in between cultural spaces
and dualities suggest alternative ways of knowing and being, such as emotional rationality or intelligence. Study findings on dementia care practices of Chinese immigrant families have important research and practice implications.
PREFACE

Ethics approval for this research was received from the University of British Columbia Behavioural Research Ethics Board (BREB): BREB number: H08-02178.
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Caring for a person with dementia is difficult and demanding. McCurry (2006) likens dementia caring to the Greek myth of Sisyphus pushing his rock:

They are doing the best they can, yet they feel like Sisyphus pushing a rock up a hill, pushing against the progressive deterioration in someone they love, only to have their efforts come crashing back down each time a new problem emerges or a previously effective intervention no longer works. (p. 2)

Sisyphus is aware of his torment but continues in his toil, day in and day out, “stronger than his rock” (Camus, 1942/1955, p. 109). He must know why he is doing so. Like Sisyphus, many dementia carers face their situation with the same resolve and resilience (McCurry, 2006), doing their ‘36-hour day’ (Mace & Rabins, 1999), giving her or his best in order to be stronger than the rock they are pushing. Carers too must know why they are doing so.

In my research experience with Chinese families in similar or less challenging or rock-like situations, I often heard from participants that the reason for caring for an elderly family member is: “I’m Chinese,” that the Chinese tradition is so. This affirmation of ‘Chinese-ness’ behind caring always intrigued me. I’m Chinese too, born and raised in a Chinese family and lived and worked in Hong Kong for the first 2 decades of my life. However, if someone had asked me the reason why I flew back and forth between Canada and Hong Kong during the last 2 years of my father’s life to give a hand to my mother and siblings in caring, I wonder if I would have related it to my Chinese origin or tradition. Interestingly, my husband, who is Italian, with whom I emigrated from Italy to Canada almost two decades ago, did the same for his parents in Italy in order to provide occasional relief for his sister, the primary carer.

Every now and then, I would think about the relationship between caring and culture
by resorting to my teaching, research and community experiences. I have been conducting research with ethnic minority seniors for the last 12 years. For 4 years in early 2000, I also taught a family studies course at the University of British Columbia (UBC) that included components on ethnically diverse as well as elderly families. My understanding then on elderly care in ethnic minority families was firmly grounded in the body of literature that usually approached elderly care from one of two broad conceptualizations: Objective structures and subjective experiences. The first mainly held a ‘cultural deficit’ lens (Este, 2007) that focused on how structural barriers render the ethnic minority elderly as a disadvantaged group. The second conceptualization of elderly care approached understanding mainly through the subjective values and beliefs of the ethnic minority elderly or their family.

What the two conceptualizations and the literature did not always capture well were my personal experiences of caring for my parents when they lived with us in Canada for many years, or those of my Chinese friends who were also caring for parents here. Neither did the two conceptualizations capture well the many tales and experiences ethnic minority seniors told me in their anecdotes in interviews and more formal discussion or casual conversations at community forums, festivities and events. These tales and experiences told me, for example, how these seniors understood themselves as elderly persons and not solely disadvantaged persons or persons with certain cultural values and beliefs; about the relationships they could count and draw on to navigate and negotiate with objective structures; and finally how some elderly managed disadvantage to overcome structural barriers. These experiences confirmed that, rather than the kind of static culture found in ‘recipe books’ of cultural knowledge, often abstracted and essentialized from the experiences
or characteristics of an ‘Other’ (Este, 2007), their ‘culture’ was multifaceted and full of the kinds of complexities, nuances and tensions (Yan, 2008) that defied fitting the seniors or their experiences into neat categories.

The present study on dementia care practices of Chinese immigrant families provided me the opportunity to explore the intricacies between dementia caring and culture. In fact, the literature review for this study on dementia caring confirms how little understanding there is around elderly care in Chinese communities, particularly where the more complex and nuanced aspects of culture and caring in Chinese families are concerned. In the next sections of this first chapter, I will elaborate on the main areas of available information relevant to dementia caring of ethnic minority groups, including cultural values and norms around family and caring, conceptualizations of dementia, use of services and support, and finally, dementia caring with a personhood orientation. As I do so, I will highlight important areas and gaps of knowledge that helped me build my conceptual frame for this study.

Chapter 2 provides theoretical concepts for the conceptual frame. I borrowed notions from three theorists, namely Buber (1947), Bourdieu (1977) and Liang (1987), who all drew attention to the importance of relationship, emotion and practice. Together, the notions form an integrated framework for formulating the study design and research questions.

Chapter 3 describes the methodological orientation of this study based on an existential hermeneutics approach. I chose the case study method (Stake, 1995, 2005) as it is conducive to in-depth understanding of complex and nuanced phenomena of multi levels and layers such as in the practices and relations of dementia caring. In addition, the various data generation strategies and sources in case study research particularly favour the exploration of the uniquenesss, particularities and complexities of each case.
Chapters 4 to 7 are individual case studies depicting each of the four families in their uniqueness and particularities. Details include: How family members take care of each other; how the persons with dementia participate in caring; what, how and why care-partners do to, with, and for each other; and what their practices tell us about their relations with each other, family members and larger care structures.

Chapter 8 discusses three major thematic areas across all cases: The importance of routines; the Chinese cultural value of a relational self whereby filial or family norms comprise both responsibility and affection in unison; and the complexity and fluidity of cultural understandings and expressions which often introduce contradictions and tensions in caring. The three areas are interrelated in terms of how routine practice, culture and emotions implicate and co-constitute each other in everyday caring. In particular, findings on the importance of emotions in beliefs and practice suggest an alternative way of knowing and being, such as through Liang’s (1987) emotional rationality.

The overall findings of this study are then discussed in Chapter 9. First, compared to research with families and children, the importance of routines as an adaptive device is not adequately explored in elderly or dementia caring research. Second, the notion of relational personhood emerging from this study adds usefully to the ongoing dialogue on a person-centred and relationship-centred approach to dementia care. Third and finally, the emotional nature of thinking when family members care for and relate to each other urges further research on different ways of knowing and being for better understanding and supporting dementia caring. Important implications on policy and practice of the findings are highlighted.
Background Literature

Family caring involves broadly six areas of assistance provided to an elderly person: personal care, household activities, transportation and shopping, financial management, emotional support, and managing their care (Dupuis, Epp & Smale, 2004). Understanding family care for the elderly in and of itself is important due to its monetary, physical and other costs to families and society. That the family carer is the centerpiece of the health care system has been recognized since the 1970s (Kane & Penrod, 1995). The family provides around 80% of the care to seniors in the community (Chappell, Reid, & Dow, 2001), with significant cost-savings to the government (Chappell, Dlitt, Hollander, Miller, & McWilliam, 2004) of approximately $30 to $60 per day, or $17,000 per year per family (Hebert, Dubuc, Buteau, Desrosiers, Bravo, Trottier et al., 2001). The significant monetary savings to the government associated with family care come, however, at the cost of increased health risks and decreased well-being of carers (Schulz, O'Brien, Bookwala, & Fleissner, 1995; Vitaliano et al., 2002). With population aging, the involvement and importance of families in the care of an older relative will continue to grow (Chappell, Gee, McDonald, & Stones, 2003). Recognizing the costs, research has focused on trying to understand and find ways to ameliorate the repercussions associated with family care for over 3 decades.

Caring for a person with dementia is even more important because the challenges for dementia carers are more acute. Research indicates that dementia carers tend to experience more stress and negative health outcomes (Brodaty, Thomson, Thompson, & Fine, 2005; Mittelman, Roth, Coon, & Haley, 2004; O'Rourke, Cappeliez, & Guindon, 2003; Yee & Schulz, 2000). According to the 1994 Canadian Survey of Health and Aging, approximately half of the population with dementia lives in the community. As well, the survey showed that
family or friends care for almost all (94%) of these seniors with dementia in the community, often up until they can no longer care for the person with dementia because of deterioration of the condition of the care-recipient or of the carer’s own health (Dupuis et al., 2004).

The prevalence rate of dementia at 8% in Canada (Peacock et al., 2010) is expected to increase due to the longer life span of the Canadian population (Alzheimer’s Society of Canada, 2010). The illness affects 35% of seniors 85 years of age and above, and this age group is growing four times faster than any other age group in the Canadian population (Canadian Mental Health Association, 2006). The importance of understanding and supporting dementia care in creative and innovative ways is urgent.

This understanding is important for the Chinese population as well because little is known for this very large ethnic minority group in Canada. To begin, there is general agreement in the literature that research on dementia care has focused predominantly on mainstream populations, resulting in a dearth of information on ethnic minority groups (Aranda, 2001; Downs, 2000; Dupuis et al. 2004; Forbat, 2003; Gallagher-Thompson, 2006; Radebaugh & Ward-Robinson, 2002). Furthermore, while there is concern that ethnic minorities in general are an understudied group, “among the minority groups, the paucity of dementia information is most noted for the Chinese” (Mahoney, Clutterbuck, Neary, & Zhan, 2005, p. 784). Specifically, the Chinese group makes up a quarter of the total ethnic minority population in Canada (Statistics Canada, 2006). With the majority of immigrant groups settling in the three metropolitan areas of Toronto, Vancouver, and Montreal, the concentration of ethnic minorities is much higher in these cities. Whereas Chinese seniors make up 35% of all ethnic minority seniors in the country, the percentage goes up to 56% and 60% in British Columbia and Vancouver respectively (Statistics Canada, 2006). The
proportion of Chinese elderly on one hand, and the dearth of information on dementia care of
the Chinese group on the other, makes better understanding of the group a priority,
particularly for an area like Greater Vancouver.

I began the search for a better understanding of dementia caring of the group in the
available literature on caring in Chinese families, first in the broad areas of assistance
described in Dupuis et al.’s (2004) review, such as personal care, household activities,
transportation and shopping, financial management, emotional support and managing the
care of the elderly person. Importantly, these researchers (Dupuis et al., 2004) reported that
their “review found no literature pertaining specifically to ethnicity and caregiving tasks (p.
11). In fact, there is still very little information on the minutiae of family caring of ethnic
minority groups. This information is important because the practices of people and groups
can be useful entry points to understanding the way people work with their environment.

In the following literature review, although I draw as much as I can on studies with a
focus on dementia care in ethnic minority families, their numbers are limited. It is, therefore,
necessary to place these studies within the larger context of other studies on general care
provision of minority and/or other ethnic groups that can add light to the caring phenomenon.
The literature review describes some of the main areas of available information relevant to
family dementia caring of ethnic minority groups. These include cultural values and norms of
caring, conceptualizations of dementia, use of services and support, and finally, dementia
caring with a personhood orientation. As I elaborate on this body of literature, I will highlight
important areas and gaps of knowledge that helped me build my conceptual frame for this
study.
Cultural Values and Norms

I join the group of researchers working with different ethnic communities in their common assumption that cultural contexts influence family care of the elderly. Nevertheless, it must be noted that ‘cultural contexts’ can have very different meanings among researchers. A common definition or reference for ‘culture’ in the family care literature is the quote from Dilworth-Anderson and Gibson (2002) that states that culture is “a set of shared symbols, beliefs, and customs that shapes individual and/or group behavior” (p. S56). This emphasis on the uniqueness of a group sharing symbols, beliefs and customs, inevitably highlights its difference from ‘Other’ groups with another set of references (Este, 2007). This focus on difference can inadvertently exaggerate the homogeneity within and heterogeneity between groups (Iliffe & Manthorpe, 2004). Nevertheless, the definition is commonly used as a heuristic in research on caring in ethnic minority communities, specifically how different groups hold distinct norms and beliefs about the person and the caring relationship.

In Japan for instance, researchers reported beliefs that situate the responsibility of care in the individual family or societal member. Specifically, Japanese carers follow ‘gaman’, the indigenous belief to avoid imposing oneself on others (Daire & Mitcham-Smith, 2006), and the call on the individual to be personally responsible for keeping ‘boke’, or the frailty of elderly people, at bay (Henderson & Traphagan, 2005). As well, Japanese carers who place strong emphasis on what other people think of them and their actions in caring are more likely to refrain from seeking support for their elders (Arai, Sugiura, Miura, Washio, & Kudo, 2000). Likewise, research has identified how a number of populations—Indians in India (Gupta, 2009), Koreans in South Korea (Chee & Levkoff, 2001), Egyptians in Cairo (Sinunu, Yount, & El Afify, 2009) and Australia (Endrawes, O’Brien & Wilkes, 2007),
Bangladeshi in London, United Kingdom (UK) (Ahmed & Jones, 2008), Asian Americans (Yeo & Gallagher-Thompson, 1996), Latinos (Losada et al., 2006) and African Americans (Daire & Mitcham-Smith, 2006; Hinton, Fox, & Levkoff, 1999)—emphasize filial and family norms in the care of their elderly within the immediate or larger family. Different words are used to reference this value: For example, within Asian family groups this is commonly referenced as filial piety but in Spanish-speaking groups, it is referenced as familism. Some Mexican American female carers, however, equated caring to reciprocity and a point of reckoning for them that went beyond family responsibility and obligation (Clark & Huttlinger, 1998). Interestingly, although there is assumed meaning to the words of filial or family norms, there is actually no consistent definition of what the notion of filial or family norm and obligation comprises. For example, the notion of filial norms was defined as an ‘altruistic motive’ in one study that examined the motivation of adult children to help parents in Norway, Spain and Israel (Katz & Lowenstein, 2010), whereas the norms were defined as the ‘moral duty’ to provide care for an elderly parent in another study in India (Gupta, 2009). A group of researchers (Schwartz et al., 2010) even tested how some concepts such as communalism, familism and filial piety, that are according to them very similar, could be clustered into a single new factor which they named family/relationship primacy, and in doing so, fortify the collectivist-individualist binary. Whether and how such collapsed binaries are conducive to better understanding of individuals and families is not clear.

Regardless of the definition of filial or family norms, a common issue that emerges across the studies is that, albeit for different reasons, this locus of responsibility within the individual or family derived from traditional filial or family norms may discourage the carers from seeking help and support (Daire & Mitcham-Smith, 2006).
Specific to the Chinese notion of ‘filial piety’ or ‘xiao’ (Tsai, 2001), one common understanding is to set the notion within the context of Confucius’ five basic human relationships (‘wu-lun’) within the family and state. The five relationships are those between father and son, husband and wife, brothers, ruler and official, and between friends (Tsai, 2001). These are hierarchized by age and gender, with a set of prescribed rules on obligations and duties as well as guidelines for proper behaviours between individuals (Holroyd, 2003; Tsai, 2001). For example, where children are concerned, they should respect, obey, love, be loyal to, please, devote themselves to, and support, by providing materially and caring physically for, parents in old age (Chou, 2010; Lai & Surood, 2009; Leung, Wong & Wong, 2010). Findings on Chinese families suggest strong cultural sentiments about obligations to care (Chung, 2001; Dilworth-Anderson & Gibson, 2002; Ho, Friedland, Rappolt & Noh, 2003). In particular, filial piety was found to act as a protective buffer against negative stressors as well as reduce the carer’s burden (Lai, 2010). As well, roles and responsibilities may look somewhat different in Chinese families in comparison to mainstream carers. For example, in contrast to the more general notion among mainstream populations that it is daughters who are the first line of carers (Grant, 2004), it is expected in Chinese families that the eldest son and his wife take care of the parents (Effiott & Minno, 2006).

Studies on mainstream groups show that the more time-consuming ‘provisioning’ or caregiving tasks such as housework, food preparation and the more physically challenging personal care fall mainly on female carers (Neysmith & Reitsma-Street, 2009; Peacock et al., 2010). As well, research shows that there are more adverse effects for women, including for example, increased burden (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002), stress in managing the care (Rosenthal, Martin-Matthews, & Keefe, 2007), depression, anxiety as well
as decreased life satisfaction (Lee & Schulz, 2000). Furthermore, the general literature points to differences in kin or role relationships within gender. For example, male participants attending an adult day centre entered long-term care earlier if the carer was his daughter than if the carer was his wife (Cho, Zarit & Chiriboga, 2009). In their examination of intergenerational conflict and solidarity with relationship quality, Van Gaalen, Dykstra, and Komter (2010) reported a higher probability of a negative relationship between aging parents and daughters providing care. In Dunham and Cannon’s (2008) exploration of power struggles between dementia care-partners, the daughters, not wives, were the most vocal about how the person with dementia is actually in control. Expression of stress also came predominantly and in greater intensity from daughter-carers attending Chinese dementia support groups (Chan & O’Connor, 2008). While these findings hint that there may be important dynamics related to how gender, role relationship and power relations actually play out in dementia care, this body of research is still relatively small, particularly in relation to ethnic minorities, and requires further investigation.

In regards to roles and expectations within Chinese groups, some researchers argue that changes in the social and cultural contexts inevitably change how filial behaviours take place (Chappell & Kusch, 2007) and urge for a more social constructionist understanding of the concept of ‘filial piety’ (e.g., Zhan, Feng & Luo, 2008). Take China, for example, where the population is aging rapidly and policy makers are looking for ways to enhance the delivery of services to the elderly in changing contexts (O’Connor & Chan, in press). Specifically, the country’s demographics and changing economic and social organization pose challenges to the upholding of filial piety. Changing economic and societal conditions necessitate a high participation of women in the labour force (Liu, Dong & Zheng, 2010),
and move huge populations of migrant adult workers to cities and away from elderly parents (Zhang, 2005; Giles & Mu, 2006). Rapid population aging that is particularly acute in highly urbanized cities (Chou, 2010a), like Shanghai (Zhang & Goza, 2006), continues to accelerate and the full force of the one-child policy on family caring will be felt in the coming decades as these children are responsible by law to take care of their parents (Zhang, 2005). A 4-2-1 ratio of caring is likely to result where every child could potentially be taking care of two parents and four grandparents in families whose members enjoy a long life-span (Ikels, 2006).

While the tradition of caring for the parent is strong in Chinese families (Whyte, 2003) and most elderly still reside with a family member or relative (Ikels, 2006), the larger picture of caring meets with many challenges and has to evolve with changing conditions. The notion of filial piety thus takes on new meanings in China, for example, in modified expectations of both children and parents as to the necessity and feasibility of co-residence for fulfilling filial duties (Li, Hodgetts, Ho & Stolte, 2010). While those elderly with more resources can plan for their own future in retirement so as not to burden the children (Zhang & Goza, 2006), those with fewer resources, such as elderly women who are poor and childless, and urban and rural elderly people without pensions, may have to look to the community and government when care is needed (Ikels, 2006). Not surprisingly, the reluctant attitudes of some Chinese elderly towards institutionalization are slowly beginning to shift. Institutionalization is becoming more and more a viable option for both rural and urban seniors, although this growing body still constitutes only a small proportion of Chinese seniors (Zhan, Liu, Guan & Bai, 2006).
A more complex picture has meantime emerged outside of China, and the general agreement among researchers that Chinese carers ascribe strongly to the norm of filial piety and family obligation in the provision of care has been challenged. For example, Chinese carers are beginning to report family tension in Canada (Ho et al., 2003) and Hong Kong (Holroyd, 2005) as well as intergenerational conflict in the US (Dilworth-Anderson & Gibson, 2002) when adhering to filial norms. Gender roles and expectations are likewise changing. Where in the past, the role of the eldest son was that of primary decision-maker, the decision to institutionalize a parent in Chinese-American families is becoming more a family decision (Hicks & Lam, 1999). In more recent Canadian studies, Chinese daughters and sons, rather than the daughters-in-law, are increasingly taking over the primary carer role (Chappell & Kusch, 2007; Lai et al., 2007), a finding similar to that reported for family carers in China (Li & Lemke, 2004). However, in rural China, the ill health of a parent still affects the access to the migrant labour market for a son but not for a daughter (Giles & Mu, 2007). Besides gender and role relationships, the nature of caring in a rural or urban setting in China seems important.

Whether or not the changes could be a practical or philosophical issue is not always clear. Despite possible philosophical adherence to notions of filial piety, cultural practice is affected by societal change in different countries. For example, Korean carers are also beginning to report difficulties living up to the cultural ideal of filial norms (Chee & Levkoff, 2001). As well, Bangladeshi women carers in the UK find themselves isolated in keeping up the norm of caring within the family without familial or structural support (Ahmed & Jones, 2008). Some Japanese carers even coin the responsibility as ‘caregiving hell’ (Nakane & Farevaag, 2004) as public resources and services are not always able to keep up with one of
the fastest-aging populations on the globe. The same difficulty associated with providing care at home is seen as far as Cairo, Egypt, where families are placing their frail older relatives into long-term care despite norms of family care (Sinunu et al., 2009). The Egyptian researchers consider the placement within the context of societal changes, similar to how researchers working with Chinese carers in Hong Kong specifically cite the lack of resources or care infrastructure (Fung & Chien, 2002; Holroyd, 2003; Holroyd, 2005) as possible explanations.

However, neither global change (Chiu & Tsoh, 2009) nor lack of resources could explain why, in the study of Ho et al. (2003), even Chinese Canadian carers who held strong filial beliefs and had plenty of services and support were, nevertheless, ready and willing to institutionalize their relatives with Alzheimer’s disease as soon as a placement became open to the senior. The nature of filial and family norms, as well as whether, when and how family members adhere to their values and beliefs in actual behaviour and practice, seem more complex than current ways of understanding are able to explain. In this regard, Flores, Hinton, Barker, Franz, and Velasquez, (2009) suggest the importance of distinguishing the difference between ideology and practice. Based on a case study of a Latina dementia carer, the authors illustrate how, in nuanced and complex ways, the participant’s actual care practices involved both cultural prescriptions of familism and personal engagement aligned with an ethic of care. In other words, in caring practices, the carer oriented herself based on cultural beliefs as well as her emotional connectedness with the care-partner and their relationship.

The study of Flores et al. (2009) is a reminder of how current notions of filial and family norms may be restrictive in ways that hinder deeper understanding. For example,
descriptions of filial piety or norms can include the provision of living arrangements, support, respect, ancestral worship and gender norms (Li et al., 2010), a duty-bound obligation to support parents (Holroyd, 2003), or the strong obligation of children to repay the parents (Schwarz, Trommsdorff, Zheng & Shi, 2010). In fact, in the body of literature on Chinese family caring, filial piety or norm is almost exclusively examined or explored in terms of responsibility or obligation of children to provide and care for parents. Although affection (e.g., Chou, 2010) and love (e.g., Lai, 2010) are key elements integral to the concept of filial piety or norm, there is little literature on this affectionate component of the concept. Opening up the concept of filial piety or norm for exploring how carers actually practice, perform, express and construct the notion of obligation in everyday life, could enrich understanding of both family caring and the cultural references people make.

Beliefs About the Illness

According to the literature, the way carers conceptualize the illness also influences their caring and interactions with the person with dementia (Dilworth-Anderson & Gibson, 2002). In this regard, the literature reveals that people in different parts of the world conceptualize dementia differently. For example: Cohen’s (1995) fieldwork in India shows how carers relate Alzheimer’s disease to a ‘hot brain’ of anger; Henderson and Traphagan (2005) suggest that American Indians value the hallucinatory symptoms positively as communication with the ‘other side’; Lee and Bronstein (2010) noted how Koreans treat dementia as part of normal aging; and several studies examining Chinese conceptualizations suggest that they variously attribute dementia to a biomedical disease (Hinton et al., 1999), normal aging (Dilworth-Anderson & Gibson, 2002; Hinton, Guo, Hillygus, & Levkoff, 2000; Mahoney et al., 2005), and folk models (Hinton, Franz, Yeo, & Levkoff, 2005) including
superstition (Levkoff, Levy & Weitzman, 1999). Understanding how carers conceptualize dementia is important because different conceptualizations may lead to different care strategies and trajectories (Gaugler & Teaster, 2006). Those who use a biomedical approach and view dementia as a disease may seek medical attention earlier, and others who adopt a folk model of dementia or normal aging may not see any need for help (Dilworth-Anderson & Gibson, 2002).

At times, carers may feel “misunderstood, scrutinized and judged” by friends because of the diagnosis (Carpentier & Ducharme, 2005, p. 305). Chinese carers who associate stigma or shame with the illness may feel they have to hide the fact from the community (Mahoney et al., 2005; Zhan, 2004) and some may shun the diagnosis altogether (Hinton et al., 2000). Shame (Lee, 2003; Leung & Gallagher-Thompson, 2005; Smith & Koyabashi, 2002) and stigma (Chiu & Tsoh, 2009; Liu, Hinton, Tran, Hinton, & Barker, 2008; Mahoney et al., 2005) have been identified as common responses among populations of Asian ancestry. Importantly, understandings and conceptualizations are not always straightforward or intuitive. For example, some research suggests that attributing dementia to normal aging can persist even in light of a medical diagnosis (Dilworth-Anderson & Gibson, 2002; Hinton et al., 2000). At times, simplistic understanding of the conceptualizing of the illness may even create stereotypical assumptions and beliefs about ethnic groups. For example, Asians are often reported to conceptualize dementia in ‘folk’ ways (e.g. Braun & Browne, 1998; Yeo & Gallagher-Thompson, 1996). Yet, in a small non-random study, Hinton et al. (2005) found that most of their Asian sample, of which three-quarters were Chinese, actually drew on a combination of biomedical explanations with folk or cultural meanings to make sense of the illness.
Different ways of conceptualizing the illness have important consequences. For example, conceptualizing the illness as a stigmatized condition can delay diagnosis and the connection of dementia care-partners to services (Hinton et al., 2000). Zhan (2004) pointed out how the lack of knowledge and awareness of Alzheimer’s disease in her Chinese American participants played an intricate role with stigma that delayed carers’ seeking of service. With the objective of understanding early detection and treatment that is conducive to early planning and connection of clients to services, Ayalon and Arean (2004) evaluated the knowledge of Alzheimer’s disease among Anglo, Latino, Asian and African American older adults. The authors reported that Anglo participants were more knowledgeable about Alzheimer’s disease among the four groups, even after accounting for age and level of English. Similarly, a study conducted in Japan (Arai, Arai, & Zarit, 2008) evaluated the knowledge of Alzheimer’s disease among Japanese adults, and identified specifically a lack of knowledge on the biomedical aspects of dementia among the Japanese public. According to the authors, this lack of biomedical knowledge could pose problems to the planning of social and financial challenges accompanying the illness. The authors urged for more education so that the public is able to distinguish, for example, senescence forgetfulness from dementia, in order to ensure early detection and treatment. The authors did not, however, articulate whether and how such sophisticated distinction of terms might be possible among the general public.

Other researchers and clinicians suggest looking for symptoms of memory loss as early as possible, such as at the onset of mild cognitive impairment (MCI), which could be precursors to dementia. However, there is a debate around the benefits and implications of consolidating this transitory phase into clinical existence (Moreira, May & Bond, 2009), particularly when there is a lack of clarity around its diagnosis and prognosis as well as the
actual conversion rate from MCI to dementia (Bleizner & Roberto, 2010). Naue and Kroul (2009) specifically draw attention to the implications of a premature label of dementia and the irreversibility of the disease trajectory once the label and medical gaze are applied. An additional reason for their caution is the inadequacy of effective intervention practices to back up early screening procedures. Carpentier, Ducharme, Kergoat and Bergman (2008) echo this concern, citing the dwindling of resources for services.

There is no clear agreement as to an optimal time lapse between initial noticing of symptoms and diagnosis that would constitute timely diagnosis and treatment. In a study with 60 dementia family carers in Montreal, Quebec (Carpentier, Bernard, Grenier & Guberan, 2010), the authors reported an average of 21.5 months from initial noticing of unusual behavioural symptoms to diagnosis. With the various arguments put forth in the debate on the benefits and risks of early screening, one agreement among researchers is that the objective of a diagnosis is to connect the care-partners to services in a timely manner.

**Connecting to Formal Services and Support**

The preceding sections describe how family norms and conceptualization of the illness can influence family caring and its trajectory, including their use of services. The connection to services is important given the positive effects of service interventions through education and support that provide dementia carers with a better understanding of the illness and the caring process. For example, Gallagher-Thompson et al. (2003a) studied female Anglo and Latino dementia carers in the US and found that the skill-building aspect of intervention increased the adaptive caring strategies and reduced the distress level of carers in both groups. Other studies with mainstream carers showed how interventions and education reduced the negative reactions of carers to the problematic behaviours of the
partner with dementia (Mittelman, Roth, Haley & Zarit, 2004; Lavoie et al., 2005). The positive effects of interventions such as prolonged counselling and support of the carers in particular, reduced the depressive symptoms of carers even after placement or death of the partner (Mittelman, Roth, Coon & Haley, 2004).

Understanding the use of services of ethnic minority groups is an especially important item on the agenda of policy decision-makers and service providers given the assertion of some researchers (e.g., Gallagher-Thompson et al., 2003; Manly & Mayeux, 2004) that ethnic minority groups tend to underutilize formal services when compared to their mainstream counterparts. Whether or not ethnic minorities utilize services more or less than mainstream carers is not the focus of this review. Without making comparisons, this review focuses on the accessing of services and support by different ethnic or racial groups.

Some studies of mainstream groups are relevant and could be useful for setting the background for understanding formal and informal services and support of ethnic minorities. The use of informal support of mainstream carers is often discussed alongside the use of formal services and support. For example, after diagnosis the network of carers begins to extend beyond the single primary carer (Van Dussen & Morgan, 2009) and network compositions of dementia carers transform to include both formal and informal support (Carpentier & Ducharme, 2005). Apart from those carers who really feel they can manage the situation on their own (Carpentier, Pomey, Contreras, & Olazabal, 2008), many care-partners begin to venture into the community for services and support, or let services come into their home. In the process, private and public boundaries become more blurred (Martin-Matthews, 2007; Sims-Gould & Martin-Matthews, 2010). With time, care-partners can become savvy service users. For example, carers in one study (Sussman & Regehr, 2009) reported their
preference for adult day programs compared to in-home services because adult day programs offer both respite for the carer as well as opportunities for social interaction for the person with dementia. Other carers make new bonds in new spaces of care, such as when previously unfamiliar co-workers find out they now share the same caring experiences and can support each other (Vickrey et al., 2007).

Where Chinese dementia carers are concerned in terms of access to formal services and support, the literature focuses more on barriers, including those cultural values and beliefs about the illness described earlier. As well, they face similar as well as different structural barriers when compared to other ethnic minority groups. For example, Chinese carers face language barriers and culturally insensitive services (Zhan, 2004). In one study, these barriers were common to both Chinese and Puerto-Rican carers (Levkoff et al., 1999). However, carers reported unique experiences in another study. Unlike African American carers who reported racism, Latino carers who reported professional inadequacy of the doctors, Chinese dementia carers expressed disappointment in the lack of cultural knowledge and sensitivity of their clinicians (Mahoney et al., 2005). In instances where carers meet with structural barriers, Chinese carers seek help at ethnic-oriented sources and organizations (Mahoney et al., 2005) or churches (Wong, Yoo, & Stewart, 2005), African American carers go to their church ministers, and Latina carers instead seek out friends for help (Mahoney et al., 2005).

Understanding the use of formal services often draws on Andersen and Newman’s (1973) model of service use (e.g., Geerlings, Pot, Twisk, & Deeg, 2005; Lai, 2007). The model highlights predisposing factors such as socio-demographic variables, enabling factors such as resources and support available, and need factors such as physical and mental health status that would motivate the carer to seek help and support. Some findings on ethnic minority carers
seem compatible with and could support the postulate of need factors. For example, severe stressors or the declining health of the carer caring for a frail elderly relative (Gonzalez, 1997) or a relative with dementia (Cox, 1999) were overall associated with increased use of support. As well, Bowen and Gonzalez (2008) confirmed the higher use of health care services by American Blacks and Latinos than Whites, and that the higher use was associated with the level of daily living disability of the minority groups.

Some researchers suggest that effective informal care networks can reduce the need and use of formal services (Li, Edwards & Morrow-Howell, 2004; Raina et al., 2004). Where the use of formal and informal support of ethnic minority groups is concerned, compared to their White counterparts who usually prefer formal services and support, there is general preference by Japanese American (McCormick et al., 2002), Mexican American (Min & Barrio, 2009), Asian and Pacific Islander and African American (Chow, Auh, Scharlack, Lehning & Goldstein, 2010) care-partners to use informal rather than formal support. Other studies, however, indicate that issues surrounding informal support or service use of ethnic minority groups are not always straightforward. For example, Latina carers in Valle’s (2004) study surprisingly used less informal social support than their White counterparts even though the Latina carers reported higher distress levels. In terms of formal support, Black carers who had more unmet service needs than White carers had less desire to institutionalize their relatives with dementia (Hinrichsen & Ramirez, 1992). In this regard, O’Connor (1999) pointed out that mainstream Canadian carers with demonstrable needs are often reluctant to utilize formal services. She showed how the subjective systems of assumptions, values and beliefs of mainstream carers helped to define the self and the perceived needs of the carers.
This definition then positioned the carers differently in the continuum of use of formal support.

Together these studies suggest a possible gap between normative needs and service uptake. The significance of this gap between the normative evaluation of needs on one hand, and the appraisal of needs on the other, could be particularly important for understanding caring in ethnic minority groups whose appraisal may be shaped by worldviews that may be different from those envisioned within mainstream structures and services.

To summarize, there may be general agreement among researchers that there are unique as well as common beliefs and structural barriers to dementia caring in ethnic minority groups. For example, language barriers and cultural distance in services discouraged immigrant women carers from accessing healthcare and other services in Alberta, Canada (Stewart et al., 2006). Beyond this general agreement, the pathways between their conceptualization of illness or their cultural values and norms, and their use of formal and informal support are, according to Janevic and Connell (2001), not clear. In fact, in their review of dementia care studies between 1996 and 2000, the authors call for more research on the pathways between health care structures and the care provision and experiences of different ethnic groups, without which understanding of the dynamics of care will always be wanting.

The Persons and the Relationship

Whereas conceptualizing the illness as a stigmatized condition can delay diagnosis and the use of services, some researchers propose that conceptualizing the illness as a biomedical disease also has its setbacks (Kitwood, 1997). Specifically, Kitwood contends that the disease discourse reduces the person with dementia to an organic pathology, and in the process, negates that the person with dementia is still there! Whereas the disease discourse focuses on
the growing disabilities of the person with dementia and turns her or his existence into a process of the fraying of the self and an ambiguous drifting towards death (Davis, 2004), the personhood approach resists such “malignant social psychology” that is the nemesis to good dementia care (Kitwood, 1997, p. 45).

Many scholars and researchers attribute the personhood approach to dementia care (e.g., Hellström, Nolan, & Lundh, 2005; Whitlatch, 2001; Woods, 2001) to Kitwood. Kitwood advocates for a personhood approach to care that emphasizes not only the inherent value of persons regardless of their cognitive abilities, but also the importance of the relational aspects and contexts to people’s existence (Kitwood & Bredin, 1992; Beard, 2004). The focus on the disease, therefore, negates not only the person with dementia and her or his qualities and capacities, but also the caring relationship itself (Herskovits, 1995; Kitwood, 1997; Kitwood & Bredin, 1992; Nolan, 2001). Most studies initially have focused exclusively on the dementia carer and this focus suggests a one-way relationship that risks pitting the interests of the carer and her or his well-being against that of the person cared for (O’Connor, 2007). Approaching dementia care this way may encourage antagonistic relations between carer and person cared for, an antagonism that could be incompatible with the kind of relational emphasis likely to characterize some ethnic minority families such as the Chinese (Holroyd & Mackenzie, 1995; Tsai, 2001).

Kitwood’s own writings are replete with illustrations of the importance of intersubjective experience, and the myriad ways that the person with dementia and the carer exist in reciprocity and interdependence inherent in the symbiotic relationship that often occurs in dementia care-partnerships (Baldwin & Capstick, 2007). The relational aspect of personhood is deeply ingrained in Kitwood’s writings and in the spirit of his work.
Furthermore, much as his writings are filled with examples of interactions and relationships in formal care settings, Kitwood (1990, 1990a) always emphasizes the applicability of his ideas to family settings and relationships.

Furthermore, for better facilitating relational caring, Kitwood advocates the importance of a more fluid way of knowing different aspects of persons and caring. This includes knowing an individual’s history (Baldwin & Capstick, 2007), the possibility of “doublethink” (Baldwin & Capstick, 2007, p. 22), and a human capacity “grounded in emotions and feelings” for “feeling-knowing” (Kitwood, 1988, p. 88) in relational and social experiences. “Doublethink” is a notion that came out of Kitwood’s (1990) research when he observed how carers fluidly upheld the ‘standard paradigm’ of the disease as well as operated “intuitively [with] a more optimistic and less deterministic theory…that informs their practice” (Kitwood in Baldwin & Capstick, 2007, p. 36). In other words, professional carers in the facility did not use only their expertise and medical knowledge to take care of dementia residents. The carers also relied on their own personal in-depth knowledge of the residents from their close contact and involvement in their everyday work with them. This personal in-depth knowledge can come from the kind of human capacity for “feeling-knowing” (Kitwood, 1988, p. 88), something that the carers themselves “cannot articulate clearly” (Baldwin & Capstick, 2007, p. 36).

Knowing and recognizing these elements facilitates professional and relational caring that can help carers to enable the person with dementia “to continue, as far as possible and for as long as possible, in familiar roles…[on] a ‘beaten track’, where a way of being and doing has been deeply learned” (Kitwood in Baldwin & Capstick, 2007, p. 241). Of particular interest for this study is Kitwood’s drawing together of history, emotions and the
fluidity and dualities in practice, specifically his emphasis on the capacity of “feeling-knowing” and the importance of ‘beaten tracks’ of ‘ways of being and doing’. Ortiz, Simmons and Hinton (1999) used a similar lens of historical and geographical ties to explore caring of Irish and Puerto-Rican seniors with dementia in Boston, US. Through this lens with an emphasis on history and contexts, the authors were able to uncover very complex contextual dynamics and layered meanings in the caring of the families that facilitated or constrained the maintenance of personhood of the seniors. A space that accommodates history, emotions and practice holds promise to open up new possibilities for understanding dementia care in populations with different notions and knowledge of illnesses, relationships, and ways of ‘being and doing’.

Encouraged by the work of Kitwood and others that promote the personhood approach to dementia care, there is now a sizeable body of research that includes the perspectives of persons with dementia in mainstream populations. Researchers showed how, for example, contrary to earlier beliefs, persons with dementia in mainstream groups can participate in research and manage their identities after diagnosis (Beard, 2004), preserve their identities such as through clothes (Twigg, 2010), communicate other than verbally (Sabat, 2006; Small, Geldart, Gutman & Clarke Scott, 1998), and accept their own condition and make the best of things (Clare, Rowlands, Bruce, Surr & Downs, 2008). Even in moderate to severe dementia, Black Caribbean and White British seniors hold onto valued elements in life such as independence, self-reliance, a good brain and the ability to help others, whereas the ability to help others and a happy and supportive family characterized South Asian seniors in the study (Lawrence, Samsi, Banerjee, Morgan & Murray, 2010). In clinical settings, Kontos (2004, 2005) shows how practitioners can more fully honour the
personhood of residents with dementia when they recognize and support the embodied self-expression of the residents.

There is documentation on persons with dementia from other ethnic groups as well. For example, studies describe how Japanese (Fukushima, Nagahata, Ishibashi, Takahashi, & Moriyama, 2005) and Hong Kong Chinese (Mok, Lai, Wong, & Wan, 2007) elderly persons with dementia both point to the importance of the family. However, while Japanese seniors mentioned ‘cooperating and living together’, ‘living ordinarily’, ‘living quietly’, and ‘living gratefully’ as indicators of quality of life (Fukushima et al., 2005, p. 35), Chinese seniors expressed the wish for more supportive communication from the family and desire to simply continue living by adapting strategies and routines that would help them do so (Mok et al., 2007).

Whereas a personhood or person-centred approach focuses on the person with dementia (Bastings, 2003; Beard, 2004) in its attempt to separate her or him from the illness and rediscover the person through a friendly interpersonal, social and professional environment of care (Kitwood, 1997), the relational focus or relationship-centred approach emphasizes paying attention to all partners in care and fostering the relationships between the client or patient and the family carer as well as their relationship with professionals and clinicians in an equally friendly and respectful social and clinical environment (Keady & Nolan, 2003; Davies & Nolan, 2003). Specifically, researchers advocate putting the person with dementia and the carer at the centre of their working relationship (Cohen-Mansfield, Parpura-Gill, & Golander, 2006; Keady & Nolan, 2003; Nolan, Davies, Brown, Keady & Nolan, 2004) and emphasize finding ways that empower the service users (Greenwood, Loewenthal, & Rose, 2001) by giving the clients an active role to help practitioners identify
and better manage their care needs (Nolan, Ingram & Watson, 2002). Health care professionals are in fact in a strategic position to provide information and support that would foster better care as well as empower service users along various transitions until placement (Davies & Nolan, 2003) or otherwise.

Despite his emphasis on the importance of the relational aspects of dementia care, Kitwood’s (1997) own empirical research was limited to person-centred care due to his untimely death (Baldwin & Capstick, 2007; Greenwood et al., 2001). Other researchers, however, fine-tuned the relational aspects of the personhood concept. Perry and O’Connor’s (2002) study is one of the first to demonstrate how carers work to preserve the personhood of the partner with dementia. Other studies also focused on the daily interactions and activities in the everyday caring of care-partners (Hellström, Nolan & Lundh, 2005a; Kirsi, Hervonen, & Jylha, 2004; Phinney, 2006) with a view of understanding the persons as well as the relationship. In the case of spouses, Hellström et al. (2005) propose how the notion of personhood could be extended to couplehood given how couples ‘work together’ in varied ways to maintain the involvement of the person with dementia and create a ‘nurturative relational context’ (Hellström et al., 2005) or loving environment (Keady & Nolan, 2003) for meaningful activities (Phinney, 2006). In their study (Hellström et al., 2005a), couples no longer considered caring as work, but a way of continuing their established ways of being together. Some couples went to the extent of not talking about the illness but simply continued with their way of life that they found meaningful and offered them quality of life.

Another group of clinician-researchers explored the dynamics of relationships in terms of how care-partners work together, separately or apart in their relationships (e.g., Keady & Nolan, 2003; Nolan et al., 2004) in the family as well as in clinical and institutional
settings (Davies & Nolan, 2003; Nolan et al., 2002; Nolan et al., 2004) for better understanding of the dynamics between persons in relationships or ethical issues in care for the different players (Hughes, Hope, Reader & Dee, 2002). Researchers contributing to this dialogue bring their views that usually give more weight to either the person-centred side or the relationship-centred approach to caring. While many professionals advocate for partnerships within families and between families and professionals (e.g., Nolan et al., 2002, 2004; O’Connor et al., 2007), Kontos (2004) cautions, specifically with regard to working with a clinical population, that a focus on the relationship can dilute or divert attention from persons with dementia who are important informants and agents towards good caring practices. What is important to keep in mind about this dialogue among researchers is that the person-centred and relationship-centred approaches are not mutually exclusive. Like Kitwood (1997), these researchers (e.g., Greenwood et al., 2001; Nolan et al., 2003; O’Connor, 2007) usually remind readers the importance of both the person and the relationship in dementia caring.

The relational approach could be a useful approach to shed light on important aspects and complexities of dementia care in Chinese families, complexities such as the quality and textures of the actual everyday care practices and experiences, agency of people and meanings of the caring relationship. At present, there is relatively little information on the person with dementia in ethnic minority groups, and no information on the Chinese person with dementia and the carer together, in interaction with each other. The relational approach is particularly relevant as knowledge of the relationship is considered by researchers working with Chinese families to be important for understanding care provision of this group (Chung, 2001; Holroyd & Mackenzie, 1995; Wong & Chau, 2006).
To summarize, I have illustrated in this review that despite the information available about important aspects of general as well as dementia caring in ethnic minority groups, there are also major gaps. First, the literature available around the notion of Chinese family or filial norms is restricted, lacking the key element of love and affection in this body of research, when this affectionate component is an integral part of the notion itself. Opening up the notion of family or filial norm for exploration is opportune. Second, the information available provides facts about the groups rather than in-depth knowledge about them. These facts include, for example, information about Chinese cultural values and norms or conceptualizations about the illness, and how these norms and conceptualizations are shifting. Missing, however, are the relationships and links between these facts that are crucial for understanding the people and their actions, and how they make sense and meaning of their everyday lives. To begin, whether and how the shifting norms and beliefs are actually put into or affect practice (Flores et al., 2009) is seldom known. Similarly, whereas ethnic minority groups commonly confront structural barriers such as the lack of knowledge, language gaps and culturally insensitive services, the pathways (Janevic & Connell, 2001) or coincidence between objective norms and barriers on one hand, and the subjective or personal strategies and experiences on the other (Bourdieu, 1990), are not well established. Third and finally, there is extremely little information on the Chinese person with dementia, and even less on her or his relationship with the carer. The tenets of a personhood approach with a relational emphasis to dementia care (Kitwood, 1997) holds promise for revealing the relationship of the Chinese care-partners through their actual interactions with each other in their everyday life. Specifically, the accommodation of history, emotions and practice of Kitwood’s (1997) approach may open up new possibilities for understanding a complex
phenomenon like dementia caring in immigrant populations such as the Chinese, who may hold different notions and knowledge of illnesses, relationships, and ways of ‘being and doing’ things (Kitwood in Baldwin & Capstick, 2007) within the conditions of possibility of their existence (Bourdieu, 1990).
CHAPTER 2.
CONCEPTUAL FRAME: RELATIONS IN CARING

The major gaps in the research on understanding dementia caring in Chinese families revolve mainly around relationships: First, the Chinese filial or family relationship; second, the missing links, pathways or relationship between facts or knowledge around the objective beliefs of caring and the illness on one hand, and the actual caring that put the beliefs into action on the other; and third, the partners in care and the caring relationship itself, particularly how the latter is situated within larger care structures.

One way to close the gap between the separated pieces of information is to look at their actual practices of caring (Flores et al., 2009). Practice offers the possibility to link together the partners in care, their thoughts, beliefs and ideologies for their caring, as well as the structures or contexts within which caring takes place, and in the process, reveal the persons and the relationships between them as well as those with the larger society. To help think about issues from this perspective, this study employed a conceptual framework drawing on notions and concepts of three scholars: Martin Buber (1947, 1970), Pierre Bourdieu (1977, 1990), and Xiao Meng Liang (1987). All three emphasize the importance of relations in the everyday practices of people, albeit each places different emphasis on the interpersonal, social or cultural level.

**Buber’s I-Thou Relationship**

At the interpersonal level, understanding how care-partners relate with each other required a relational framework that could capture aspects of affective and intimate ties and interactions. Buber’s (1947) I-Thou relationship emphasizes the importance of relational connectedness for meaningful existence. Specifically, Buber (1970) depicts relationships as
moments of genuine meeting, encounter, actuality and presence between two persons in their everyday interactions. Buber’s relational emphasis was particularly pertinent as it was pivotal in informing Kitwood’s (1997) notion of a personhood that has a focus on the emotional or affective aspects of dementia care.

Buber (1947) describes two primary attitudes with which people live their existence: an ‘I-Thou’ (interchangeable with ‘I-You’), or an ‘I-It’ approach to life. The I-Thou relationship emphasizes the moment of encounter between two persons, that moment when the being and presence of two individuals for each other is actualized in a genuinely caring and inclusive way. This happens when they meet in a dialogic mode of openness, directness, mutuality and trust, fully participating in the being and existence of each other in reciprocal ways (Buber, 1970). In contrast, an I-It relationship runs on monologic mode in which the dialogic components are absent, such as when people are not mindful that “human beings we confront are persons” (Buber, 1970, p. 30), and treat them as objects instead.

A crucial element in the I-Thou relationship is, therefore, that of being mindful and inclusive of the other person. Of specific relevance to families with a member with dementia, Buber (1947) advocates for the active person in the relationship, if there is only one participating actively in an event, to be able, without forfeiting one’s own standpoint and reality, to live the event or experience “from the standpoint of the other” (p. 115). Where the meeting of two persons entails more or less the characteristics of inclusion, the meeting can be considered a dialogical or I-Thou relation. Without inclusion, the person is reduced to an object in an I-It relationship (Buber, 1947).

The dialogic principles of trust, presence, responsibility for and acceptance of another human being are applicable to all kinds of meaningful relationships. Specific to professional
care relationships, Buber has the following to say: “Consider, for example, the relation of doctor and patient. It is essential that this should be a real human relation experienced with the spirit by the one who is addressed” (p. 113). In other words, in relationships where one party may have more power such as can happen in doctor-patient relationships, the doctor should exercise “inclusive power” (Buber, 1947, p. 114) in order to understand the spirit of the patient as well as respond with an open heart to the uniqueness of the patient as a human person. This way, the doctor takes a caring and inclusive approach.

The drive for relational connectedness commences from the time of birth and lasts a lifetime (Buber, 1947). ‘Encountering You’, however, is about the here and now. Genuine encountering as described by Buber (1947) implicates a sense of the spiritual. However, it is more than this: Buber is not just speaking to a religious audience about an afterlife or world. He makes it very clear that dialogic interaction is not a mystical event. Buber (1947) emphasizes: “I possess nothing but the everyday out of which I am never taken” (p 16). The meeting is actual and factual. It is not divorced from everyday life, or ethereal, because it takes place in the common human world (Murphy & Buber, 1983). Unlike many philosophers musing at the more abstract levels of being, Buber is interested in people in their “activities that constitute everyday existence, in the everyday occurrences of life” (Murphy & Buber, 1983, p. 102).

Further, Buber (1947) acknowledges the importance of context in the practice of dialogic encounters. He notes that “responding when addressed, requires the right circumstance” (p. 40), and one should recognize what s/he is “able and unable to give of what is needed—and what he can give now, and what not yet” (p. 120). In other words, the person is not always in control of whether s/he engages in I-Thou or I-It relationships. Buber
emphasizes how meanings and structures within a society are important conduits for the generation of attitudes and responses to I-Thou or I-It relationships (Avnon, 1993). It is important, therefore, to consider whether and how the continuous change in circumstances or contexts in the flux of modern day society are conducive to the formation of one kind of relationship rather than the other (Avnon, 1993).

In discussing the importance of taking context into consideration, Buber (1947) does not seem to be emphasizing any one category determining another. In fact, he refuses to discuss the subjectivity of individuals or objectivity of structures. Buber (1947) contends that individualized or objectivized processes represent a small and fragmented piece of the person, whereas for him the subject has to be considered “in his wholeness” (p. 147), in which his actions are necessarily and naturally connected to his feelings and circumstances. Buber (1947) reminds readers that man and his circumstances are very complex. Man lives in a confusing world of multiform, full of conflict and contradictions. According to Avnon (1993), mutually exclusive and dichotomous forms of conceptualizations such as individualism or collectivism would be of no help to Buber for understanding human beings. The former sees only the personal through his actions and the latter effaces the individual altogether. Rather than treating humans as two kinds of beings that can be categorized neatly into one of the slots of a dichotomy, Buber would prefer to see duality and polarity as “intrinsic humanity” within one person (Avnon, 1993, p. 58). Avnon suggests probing into spaces within the dualities, spaces that can allow for alternation between inner unity and fragmentation, where there is fluidity and the capacity to capture intersubjectivity. This space is the “real place and bearer of what happens between men” (Murphy & Buber, 1983, p.
104), the place of actual human action in relating to another, where meanings come alive in practice.

The notion of Buber’s (1947) I-Thou relationship provides an interesting lens for considering everyday activities as the departure point for understanding the partners in care and the nature of their caring relationship. Specifically, the relational and affective processes of partners in everyday practice might illustrate whether and how they ‘meet’ and ‘encounter’ each other in mindful and inclusive ways. Yet, daily interactions and practices between care-partners do not occur in a vacuum. In fact, Buber urges the consideration of contingencies and multiplicities of context of such ‘meeting’ in “in-between” spaces (Buber, 1947, p. 241). While this lens is useful, Buber’s formulation of the I-Thou relationship remains largely at the interpersonal level, without much provision as to how to embrace complexities beyond the interpersonal level to the in-between spaces of practice or research. As a response to this gap, some ideas from Bourdieu’s (1990) ‘logic of practice’ may provide a useful lens for moving relational and affective processes beyond the interpersonal into the social relational realm and situate the processes within larger multiple contexts.

**Bourdieu’s Logic of Practice**

Bourdieu’s logic of practice (1977, 1990) offers a potential social relational lens with which interpersonal dementia care practices and meanings can be situated within larger care contexts and structures. There are many useful ways of applying Bourdieu’s (1977, 1990) logic of practice in research. Of particular relevance to this study is the application of some of his ideas to research with immigrants (Bourdieu et al., 1999; Sayad, 2004). Bourdieu (1977) extends Buber’s (1947) emphasis on complexity and duality in that in Bourdieu’s
logic of practice, there is duality and coincidence between the objective and the subjective, cognition and affect, and the mind and the body in everyday practices (Bourdieu, 2000).

For better appreciation of this duality or coincidence, it is important to understand an important notion around which many of Bourdieu’s ideas revolve, that of dispositions. Bourdieu (1977) describes dispositions as a kind of “tendency, propensity or inclination” (p. 214, n. 1). Although there are many approaches to understanding Bourdieu’s notion of dispositions, the one more relevant to this study is Bourdieu’s (2000) interest in the duality of the mind and the body: “The world is comprehensible, immediately endowed with meaning, because the body, which, thanks to its senses and its brain, has the capacity to be present to what is outside itself” (p. 136); and how he describes the acquisition of dispositions as a body-mind matter: “To deny the existence of acquired dispositions, in the case of living beings, is to deny the existence of learning in the sense of a selective, durable transformation of the body through the reinforcement or weakening of synaptic connections” (p. 136).

According to Bourdieu (1990), the system of dispositions is a “self-regulating mechanism” that works according to a ‘fuzzy’ logic (p. 62). This mechanism is highly adaptive with its “system of cognitive and motivational structures” (p. 54) made up of “schemes of perception, conception, and action” (p. 60) because of the duality of dispositions. Broadly defined, schemes are “organized ways of making sense of experience” (Berk, 1996, G-11).

There is duality in these dispositions or system of cognitive and motivational structures as these structures are both ‘structured’, in the sense of being socially constructed, and ‘structuring’ at the same time (Bourdieu, 1990). In other words, as individuals internalize objective structures, or their social conditions, into their internal dispositions, the dispositions
become ‘structured structures’. In turn, the individual’s actions and behaviours feed back into the structures, thereby ‘structuring the structures’ as they maintain, resist or transform the structures themselves (Calhoun, LiPuma & Postone, 1993). Given that any action no matter how small, even inaction itself, feeds back into the structures, all individuals are agents in terms of their potential to alter the structures (Bourdieu & Wacquant, 1992).

According to Bourdieu (1990), a person’s social conditions position the agent within a network of social and power relations within society, and the agent’s position or positions within this network of relations are largely based upon the various capital or resources with which the agent operates in the different areas of everyday life. Bourdieu (1990) terms an area of operation the ‘field’. In each field, agents are positioned in relation to each other and the field itself according to her or his capitals or resources.

The basic kinds of capital or resources are economic, social, cultural and symbolic capital (Bourdieu & Clough, 1996). Economic capital refers to material and financial resources, social capital to social and support networks, and cultural capital to education and information. All of these three forms of capital can be converted into symbolic capital, which refers to the status, privilege and authority from which an agent can derive the ability or power to negotiate. The capital and power can facilitate or constrain an agent’s entry to and ways of participating in the field (Bourdieu, 1996).

Agents are aware of their social conditions and positions in the field. According to Strauss and Quinn (1997) in their discussion about Bourdieu, even though schemes are “internalized (…‘incorporated’ or ‘embodied’)” (p. 44), the uptake and externalizing of the schemes are nevertheless not static and mechanical. Rather, quoting Bourdieu (1977), “the schemes enabl[e the person] to generate an infinity of practices adapted to endlessly
changing situations” (p. 16). Instead of fixed rules, the person acquires a cognitive-emotional “‘sense’ of the situation” (Strauss & Quinn, 1997, p. 76), or what Swartz (1997) describes as a “practical sense” of what works (p. 115). In other words, this system of embodied cognitive and motivational schemes and structures has a generative capacity to produce behaviours in complex and fluid ways that are suited to a person’s circumstances and time in an intuitive and adaptive way (Strauss & Quinn, 1977).

Similar to dispositions and their inherent duality and fluidity, capitals, positions and fields are also not deterministic or static. The field is actually a space of the possible, a space of social positions in designated social spaces and structures in relation with each other, a space made of a ‘bundle of [these] relations’, with some positions more dominant and others more subordinate (Angus, Kontos, Dyck, McKeever, & Poland, 2005). Finally, social mechanisms are in place to help individuals comply with the social order of a field (Bourdieu, 1990). Social mechanisms can include, for example, public institutions such as education, health-care, labour, and all kinds of community and social organizing policies and procedures.

That positions are never fixed in the bundle of relations in the field (Bourdieu, 1990) provides an interesting lens for considering the positioning of care-partners. On one hand, Bourdieu (1979) draws attention to how the positions are not fixed because the attendant power to any position fluctuates according to the constant combination and conversion of various capitals between fields as each field establishes ‘exchange rates’, in tension or competition with other fields, for converting the various capitals into power. On the other hand, agents act, or refrain from acting, within these socially structured spaces, in improvised and practical but not mechanical ways, when they strategize how to maintain or better their
positions or life chances. Although somewhat regulated, agents’ actions, inactions and strategies change their positioning and relations in some way. As a result, the structures and relations are always fluid and dynamic when agents inject duality into structures with their actions. Agents always have the potential to change the structures and the ‘relational configuration of the field’, albeit in the slightest ways. Although somewhat patterned, the field is thus always variable and varying, one of probabilities and indeterminacy, a relational structure that constantly reconfigures itself (Bourdieu & Wacquant, 1992). This is one understanding of Bourdieu’s (1990) explications about his ideas around his fuzzy logic of practice. This practical logic comes out of the workings of a system of cognitive and motivational structures or dispositions that are always structured and structuring at the same time, and has a generative capacity that is highly adaptive for the agent in optimizing his position and life chances in the fields within which the agent operates in practices of everyday living.

Another aspect of Bourdieu’s (2000) logic of practice is his emphasis on the role of affectivity in the mind-body nature of practice, a notion very likely related to the cognitive-emotional structures Strauss and Quinn (1997) described in their discussion of Bourdieu. Bourdieu (2000) asserts that exchanges “involving the whole person of two [or more] partners…[that are] highly charged with affectivity” (p. 167) consolidate the cognitive and motivational structures, particularly those “from the earliest experiences” of agents, a period that has “particular weight” (Bourdieu, 1990, p. 60). The inherent affectivity and long history render the cognitive and motivational structures to become deep-seated in a person. Agents take for granted the schemes of perception, thought and action in these structures. They draw from them as “the basis of perception and appreciation of all subsequent experiences”
(Bourdieu, 1990, p. 54), often without thinking about them because this “network of [neural] pathways are maintained and used, ‘beaten tracks’ that are really practicable for a particular agent” (p. 35). Schemes and structures become “internalized as a second nature and so forgotten as history” (p. 56). At this point, agents tend to do the familiar that requires the least thinking and effort, resulting in a kind of comfortable inertia (Bourdieu, 1990).

History and life experiences can thus function as an “accumulated capital” (Bourdieu, 1990, p. 56) among the other capitals or resources that can help agents optimize their life chances in everyday life. Nevertheless, Bourdieu reminds readers that the taken-for-granted ways of practice, which require little effort and thinking as they have been consolidated by test and time in the history of an agent, is only “one modality of action” (Bourdieu & Wacquant, 1992, p. 131). Non-thinking practice can take place alongside other modalities such as conscious thoughts and deliberations. The latter occurs when “rational choice” takes over, for example, when “the routine adjustment of subjective and objective structures” (Bourdieu & Wacquant, 1992, p. 131) no longer works.

Individual and collective practices are thus a product of history in accordance with the schemes generated by history, as well as the source of history-in-the-making. Bourdieu (1990) emphasizes how this duality of practice is an adaptive and practical response to the environment because it is logical and reliable: “…ensures the active presence of past experiences which, deposited in each organism in the form of schemes of perception, thought and action, tend to guarantee the ‘correctness’ of practices and their constancy over time” (p. 54). In other words, according to Bourdieu (1990), there is constancy and reliability in practice because the practices of an agent within a field are usually ‘correct’, meaning they are “objectively adjusted”, or adapted, to the field (p. 56).
It is when there are drastic changes in the field or in the circumstances of the agent that the importance of history within practice is particularly noticed. At such times, the customary relations between the person and the field, between subjective and objective structures, become threatened, and agents have to break out of the familiar and inertia in order to work out new practices that would be adapted to the new circumstances. Bourdieu (1990) terms this “the hysteresis effect”: “The presence of the past… is, paradoxically, most clearly seen when the sense of the probable future is belied…[when] the environment they actually encounter is too different from the one to which they are objectively adjusted” (p. 62).

To illustrate this effect, Bourdieu (2000b, 2004) uses documentation from his anthropological studies conducted in the 1960s and 1970s on the challenges and changes of two peoples in two different parts of the world that accompanied the restructuring of their local economic and social systems. In the first, he recorded how Kabylian peasants struggled with two sets of social conditions when new economic structures were introduced towards the end of the colonial period in Algeria. In the transition, the habitual cognitive and motivating structures of the old peasant economy, based on a long history of the honour system, had to incorporate the new economic structures based on a market economy (Bourdieu, 2000a). In a parallel study, he observed how changes in the economic structures in France reduced the traditional privileged status of primogeniture bachelors in rural Bearn to that of ‘unmarriageable’ peasants, and the consequent discord between the capital and status of these bachelors and a new set of conditions in the new social and economic order (Bourdieu, 2004). He demonstrates how Kabylian peasants and ‘empeasanted’ Bearnian bachelors had to find strategies to adapt to new conditions when their taken-for-granted
ways, practices and relations no longer worked. Changing taken-for-granted ways was not simple or straightforward as “what is taken for granted has a history behind it” (Bourdieu, 2000, p. 86) and the disconnect between the taken-for-granted practices of Kabylian peasants and Bearnian bachelors and their new structures became “the source of misadaptation as well as adaptation, revolt as well as resignation” (Bourdieu, 1990, p. 62). The Kabylian peasants and Bearnian bachelors then had to resort to her or his agency and strategies to adjust to the changed or new social order. Such adjustments and adaptation are often in “‘practical’ rather than conscious” ways (Swartz, 1997, p. 105).

The duality in Bourdieu’s (1977, 1990) notion of dispositions can be particularly useful for understanding how the subjective experiences of agents are related to the larger social contexts, and how the subjective and objective might co-constitute each other in practice in taken-for-granted ways. Particularly relevant is Bourdieu’s (2000) emphasis on the role of affectivity and history, specifically how the affective and historical components might play a role in the construction and maintenance of cognitive and motivating structures and schemes in times of stability or change. In the case of significant changes to the agent or her or his environment, such as entry into a new country or other new fields of everyday practice, the affective and historical components may shed light on the maintenance and/or adaptation or adjustment of some cognitive and motivating structures and schemes that could provide a better fit with the conditions of possibility of the agent’s existence (Bourdieu, 1990).

Liang on Chinese Wu-Lun (五倫 The Five Relationships)

Larger social contexts include the cultural history and experiences of an individual deposited in the form of cognitive and motivating schemes and structures (Bourdieu, 1977,
1990). It is from these that the individual draws frames and lenses of reference in intuitive ways to view the world and carry on ‘beaten tracks’ as well as open new ones suited to one’s environmental conditions. Bourdieu offers useful understanding at a conceptual level, but for the schemes and structures from the Chinese cultural history and experiences of individuals relevant to caring, Liang’s (1987) notions of relationship of the wu-lun provides important guidance.

The concept of xiao 孝 or filial piety that often appears in the care literature for Chinese groups pertains, according to Liang (1987) and Tsai (2001, 2005), to Confucius’ framework of wu-lun or ‘the five relationships’ formulated in the period around 500 B.C. According to the wu-lun, every Chinese person is a person-in-relation. A person is born into relationships and life itself occurs within relationships (Liang, 1987). The five relationships are those between father and son, husband and wife, brothers, ruler and official, and between friends (Liang, 1987, Tsai, 2001). Relationships start with the family but do not end there. This is seen in how three of the relationships are direct family relationships, yet the ruler is like a father to his people and friends are to be treated like brothers (Liang, 1987).

Importantly, because every person is naturally endowed with feelings and compassion (qing 情), an affectionate relationship is presumably born at the meeting of persons, such as happens between father and son at the birth of the child (Liang, 1987). Worthy of note is that according to Liang’s interpretation, feelings come first. Because there are affectionate feelings, the sense of responsibility follows naturally. Liang (1987) further asserts that it is feelings that render a person humane (ren 仁), lets her or him know shame and evil (yi 義 or righteousness), helps a person learn propriety and etiquette (li 礼) and enables her or him to tell right from wrong (zhi 智 or wisdom).
Feelings and the ‘heart’ or *xin*  have a special place in the Chinese culture of relationships. According to Sun (1991), the Chinese concept of ‘heart’ is complex. It is the part of the body that “covers both ‘heart’ and ‘mind’ in the Western sense” and denotes “a unitary concept of body and mind” (p. 3). Similarly, Ikels (1998) conveys that the ‘heart’ or “‘xin’ represents the fundamental deep mental processes (thoughts, will and emotion)” that suggests “an affective pre-rational self…more reflective of human nature than the rational self” (p. 242). Although lodged in the body of one individual, the heart is there to unite two persons “by the exchange of ‘hearts’ (xin) between two ‘bodies’” (Sun, 1991, p. 2). This emphasis on affection and relationship recalls Buber’s (1947) ‘meeting’ and ‘encounter’ between two persons in I-Thou relationships.

Furthermore, Liang (1987) describes how according to *wu-lun* (the five relationships), responsibility is the responsibility of a person’s position in a relationship. Within Chinese culture, taking responsibility of one’s position or positions by working hard and with discipline is a virtue that gives a sense of spirit and purpose as well as fulfillment in life. With the emphasis on responsibility, the concept of rights, according to Liang (1987), is not a relevant one.

Liang (1987) describes how occupants of positions in relationships are facilitated in carrying out their responsibility by *li* (propriety and etiquette), or the proper conduct consonant with the kind of affection and responsibility congruent to each position. Whether through book learning, tales, rites and rituals, or everyday comportment, children see that father shows kindness, son shows *xiao* (filial piety), older brother treats younger one with friendship and younger brother treats older brother with respect. Husband and wife, friends and all people who encounter each other have mutual responsibility and the proper kind of
affection and expectations between them in their positions. Relationship implicates friendship and an affectionate responsibility on which the rationale of *wu-lun* (the five relationships) is built. Through the *wu-lun*, everyone knows what to do and how to perform their ‘expected’ roles in the position in order to be a successful or ‘virtuous’ person, the *junzi* (Tsai, 2001, 2005).

Tsai (2001, 2005) offers an alternative way to that of Liang’s (1987) for presenting the *wu-lun* through the *junzi* (virtuous person). In his reference to the *wu-lun* while addressing specifically bioethics in dementia care, Tsai (2001) also discusses the notion of responsibility and affection. However, he focuses on the cultivation of the ‘virtuous’ person or *junzi* living by Confucian principles. This ‘virtuous’ person embodies two dimensions: The moral dimension in the vertical axis with a focus on hierarchy, autonomy and independence, and the relational dimension on the horizontal axis with a focus on human relatedness and love. On one dimension, the *junzi* strives for virtue and independence, and on the other, for relational connectedness and affection. The *junzi* takes responsibility for as well as seeks and shares relational connectedness and affection with those around him. The *junzi* does so in a gradational way (Tsai, 2001), starting first with members in the immediate family, and then outwards from the family core to the extended family, community and society. In his approach to presenting the *wu-lun* (the five relationships), Tsai (2001, 2006) juxtaposes the two axes of morality and relational connection in a way that fuses the rational and emotional dimensions of filial piety. In doing so, not only does he resonate Liang’s (1987) notion of mutuality and duality in moral responsibility and affection, Tsai also highlights the mutuality and duality of the individual and the relationship of which the individual is always a part.
Finally, according to Liang (1987), the transmission of *xia* (filial piety), *li* (propriety and etiquette) or other Confucian values that promote the sense of emotional responsibility, transpires, like Bourdieu’s (1977, 1990) practical logic, through the practices and habits of people as they go about their everyday lives in relationships with each other. Here again, feelings facilitate the acquisition of these values through everyday practices. According to Liang (1987), whereas the mind can rationalize the good and bad of things, or think through a problem, it is the heart and feelings that enable the person to know whether or not the answer is right or correct. Consonant with Ikels’ (1998) description of the one heart-mind and Sun’s (1991) “emotive reasoning” (p. 3) of the Chinese people, Liang (1987) calls this learning and rationality of Chinese people *li-xing 理性* or emotional rationality.

To sum, I have presented notions from three scholars that can address different levels and aspects of the dynamics of families: Buber’s (1947) ‘meeting’ in I-Thou relationships, Bourdieu’s (1977) duality of dispositions where objective and subjective structures meet, and Liang’s (1987) presentation of the responsibility and affection inherent in the position of a Chinese relationship. Remarkably, the emphases of these scholars converge on the importance of relationships, emotions, and practice, and importantly, on the duality and co-constitution of different aspects and levels of persons and phenomenon through everyday practice.

Together, they form an integrated conceptual frame that can address the interpersonal, social relational and cultural aspects of families. At the interpersonal level, this framework draws attention to the partners in care and the relationship. At the social relational level, the framework situates the interactions of the partners within their relations with the larger society and structures. Finally, the cultural aspects can be brought to light using a cultural
frame of families and relationships within Confucian traditions. This framework is useful in that it highlights the actual practice of Chinese family caring which to-date has received inadequate attention. In particular, these highlights can begin to tease out the complexities related to the multifaceted and multilayered nature of families and caring. These include the qualities and textures of the persons in the relationship and the nature of the relationship itself, the pathways and relationships between the partners and the larger family and society, as well as the relationship between their values and beliefs and their actual practices.
This study responds to three major gaps in the literature on dementia caring in Chinese families. The first major gap points to the restricted way in which the notion of family or filial norm is applied in current family care literature. Specifically, the key element of love and affectionate is missing from the way the notion is examined or explored. Second, the pathways and relationships between different pieces of information are missing in the care literature. For instance, while there is information on the values of caring, beliefs about the illness, or the structural barriers such as the lack of knowledge, language gaps and culturally insensitive services, how these values, beliefs or barriers actually shape or affect caring is often not clear. These missing pathways, links and relationships between objective structures and barriers, thoughts, values and beliefs, and actual caring practices of families are important for understanding the dynamics and complexities of family caring. The third major gap is that little is known about the persons in the caring relationship, particularly the partner with dementia in Chinese families. In particular, how the partners interact with each other and what their relationship looks like within the larger caring structures and contexts are also not well understood.

Recognizing these major gaps, the purpose of this study was to explore, through the everyday practices and experiences of caring in families, a holistic and contextualized understanding of caring in Chinese families. Along with exploring their values and beliefs as well as the missing links and pathways, the study aimed to understand who the partners in care might be and what their actual caring practices suggest about their relationship with each other and with others in the larger contexts. An integrated framework with a focus on relationships,
emotions, and practice was developed based on the works of three scholars (Bourdieu, 1977; Buber, 1947; Liang, 1987). This conceptual frame provided a lens for exploring the textures and complexities in the everyday dementia care practices of the Chinese families. The framework helped provide a focus that started at the interpersonal level of the partners in care, and then situated their relationships within the larger social relational and cultural contexts.

One main research question guided the study, with sub-questions to help expand, elaborate and develop details:

- What is it like for a Chinese immigrant family in Greater Vancouver, BC, to provide care to an elderly family member with dementia?
  - Who are these partners in care in the family?
  - What do they do in everyday caring?
  - Why do they do what they do?
  - How do they feel about the caring?
  - What do their caring practices and experiences tell us about their relationships with each other in the family and with others in the community and society?
  - Does culture play a role in caring? How?

My study is part of a larger study funded by the Canadian Institute for Health Research (CIHR). The larger study looks at how culture influences the experiences of carers in the provision of care to an elderly relative, with or without dementia, in Chinese, South Asian and Latin American Canadian groups living in Vancouver and Calgary. Using constructivist grounded theory approach (Charmaz, 2006), the larger study aims to develop an initial conceptual framework to begin understanding some of the cultural interpretations and
meanings of family care, and how these cultural meanings influence the ways family members provide care to an older family member.

The purpose of my study was to develop a more in-depth understanding of the Chinese family experience in providing care for an elderly relative with dementia. From among the 10 Chinese participants of the Vancouver sample of the larger study, four families agreed to assist me in developing more in-depth case studies. The aim was to understand the participation of different members of the family in caring, including the person with dementia, and the nature and texture of their relationships within the family and with the larger community. My study dovetails the larger study and offers a rich, in-depth and contextualized understanding of several cases of Chinese families providing care for a person with dementia. The information could help fine-tune the questions, areas and themes to be further investigated by the larger study in order for the latter to build an initial conceptual framework for understanding cultural influences on Chinese care provision.

**Research Design: Case Study**

Given the goal to develop a rich, in-depth and contextualized understanding of experiences of Chinese family care, this study drew on the literature related to case study research. The case study approach works well with various paradigms and methodologies (Stake, 2005, Yin, 2003). This approach has the ability to develop a rich, detailed, dense and contextualized account of the phenomenon (Stake, 1995, 2005) of dementia care, and equally important, emphasizes the real-life contextual conditions of the phenomenon, particularly where there may be difficulty separating the context from the phenomenon itself (Yin, 2003).

The objective of understanding the experiences and meanings of everyday practices within the frame of the research question of my study calls for a qualitative research approach.
The flexibility of a qualitative design can manage the unexpected turns and evolving nature of complex phenomenon (Locke, Silverman, & Spirduso, 2004) such as the dynamics of family care provision. As well, the inherent openness of qualitative research and its “thick descriptions” (Geertz, 1973) are particularly suited where little information is available.

Specifically, an interpretive approach lends itself well to understanding the experiences and meanings of everyday practices of people. Within the interpretive approaches, the epistemological lens of hermeneutical interpretation of phenomenology (Van Manen, 1990), in particular those notions from existential hermeneutics (Alvesson & Skoldberg, 2000), were especially suited to guide the framing and decision-making in the various steps and procedures of the research design and process for this study.

Above all, those aspects of existential hermeneutics related to some of Heidegger’s (1927/1962) ideas of Dasein were relevant. Dasein, or Being-in-the-world, is Heidegger’s notion of “care” (p. 227) or “concern” (p. 237), or things that “matter” (p. 158) in people’s existence. The world is already all there, or ‘present-at-hand’, and Dasein enables a person to engage in things that matter to her or him, turning the world into one that is meaningful, or ‘ready-to-hand’. According to Heidegger (1927/1962), care and concern is the primordial capacity in every being to Interpret [upper case: author’s original] and know what matters for her or his existence.

This primordial capacity to care or interpret occurs in all aspects and levels of a person’s existence, for example at the interpersonal level of Buber’s (1947) ‘meeting’ between persons, or in the person’s interaction with the broader environment. According to Heidegger (1927/1962), the interpretation always occurs in context, in the world of “average everydayness” (p. 69), always a part of “within the worldness” (p. 131), and ‘being-with’ and
involved in relationship with others and a familiar world that matter to the person. In other words, experiences and meanings need to be understood within the historicity and contexts, including cultural context, of the person (Alvesson & Skoldberg, 2000).

*Dasein*, or Being-in-the-world, is not retrospective or recollective, but in a hermeneutic circle somewhere between understanding and pre-understanding, and inhabits a circular time zone (Alvesson & Skoldberg, 2000), where “Dasein ‘is’ its past” (Heidegger, 1927/1962, p. 41), where past, present and future embrace each other. The philosophical underpinnings of this hermeneutic circle provided a theoretical base and platform from which the case study could develop in an interactive way: through dialogue, interpretation, questioning and counter-questioning in the production of knowledge. In the process, the case researcher moves back and forth between the parts and the whole, between the world of participants and her or his own, and between participants and texts (Van Manen, 1990).

Moving in a circle between the different parts and the whole helps keep an open and ongoing conversation in the intersubjective construction of knowledge. In doing so, the case researcher remains cognizant of her or his own history and background, and how this may contribute to the interactive process. This is particularly important during activities related to analysis and interpretation. The in-depth reflexive conversations require constantly thinking, questioning, clarifying, and dialoguing with participants, texts, literature, as well as mentors and peers (Van Manen, 1990). While moving in a hermeneutic circle between the parts and the whole of the research process with the objective of understanding the case, I nevertheless tried to keep the participant as well as her or his experience and understanding, and her or his world in focus.
For case study research, an important first question to ask is: What is this a case of? Case studies can be intrinsic (of inherent value), instrumental (of ultimate value), evaluative or for theory building (Stake, 1995; Thomas, 2011). Each case in this study was an intrinsically interesting, unique, specific and complex functioning unit (Stake, 2005) through which the phenomenon of dementia caring could be refracted and some of its aspects understood (Thomas, 2011). For this study, those aspects related to their practices, experiences and relationships of caring were specifically relevant.

The objective of case research is to start with the particular in order to get specific details for a thorough understanding of each case (Reinharz, 1992). The objective of this study was to understand thoroughly each case, as every family is a unique, specific and complex functioning unit. Case study research generally focuses on the activities of the case and emphasizes the contexts and particular situations in which the activity takes place (Berg, 1998). This focus on “concrete, context-dependent knowledge” of “virtuoso experts” (Flyvbjerg, 2011, p. 302) aligns with both the conceptual frame and the theoretical underpinnings of this study. Case researchers look for and observe the “ordinary” activities (Stake, 1995, p. 44) in the natural habitat of participants with the least intervention from the researchers themselves. Efforts are made to bring the activities, functions, relationships, history and setting or contexts of the case together for in-depth understanding of the case itself. Its forte is not in its ability to represent other cases in general, but neither should that be its priority (Flyvbjerg, 2006). As Thomas (2010) explains, the representativeness for generalizability to population can actually hinder the kind of spirit of inquisitiveness and serendipitous noticing and insight necessary for case study research. Instead of generalizing, the power of the case study approach lies in its ability to attend to particularities of a local nature and handle complexities of contexts, for
example the social locations of gender, race and class, for in-depth and contextualized understanding (O’Connor, Phinney & Hulko, 2010).

Qualitative case study research employs different data generation measures, including in-depth interviews, observations, documents and archival history that can enhance understanding of particularities and complexities of context. The triangulation of data sources aims less at objectivity but rather at allowing different aspects of the case to illuminate each other. Triangulation ensures that multiple aspects and complexities of each case are captured (Stake, 2005).

The kind of in-depth and intensive analysis in case study research allows teasing apart the details and particularities, and uncovering the complexities and intricacies on different dimensions and at different levels of the phenomenon. Such details are particularly useful for areas of research for which there is not much information, such as in our understanding of dementia care in Chinese families. The details of activities and contexts of a case in turn can serve to illustrate “the change in the phenomenon over time, the significance of the phenomenon for future events, and the relation among parts of the phenomenon” (Reinharz, 1992, p. 164).

Whereas in-depth study of each case reveals the uniqueness, particularities and complexities of the individual case, cross-case analysis facilitates the discernment of emergent themes at the individual level that go beyond the single case. Examining themes across cases can shed light on some aspect or structure of the phenomenon at a broader level. There are no exact rules for producing cross-case analyses (Helstone, Van Zuuren & Houtkpper, 1999). The general guideline is first to establish each case in its uniqueness, separate from any other, in its own right and with its unique insight (Stake, 1995). Once each case has been established, the
researcher moves back and forth between cases, like in a hermeneutic circle, in search of overriding themes that illustrate convergences and divergences across the cases. The objective is to understand the processes and mechanisms that could illuminate the commonalities and differences in order to develop a richer and multifaceted understanding of the phenomenon (Helstone et al., 1999).

The Research Process

Ethics approval

I received ethics approval separately from the larger study from the Behavioural Research Ethics Board at the University of British Columbia for all research protocols and procedures pertaining to this study. Approval was received for the following forms:

- Interview guide for primary carer and family members (Appendix A)
- Interview guide for service provider (Appendix B)
- Demographic information for primary care-partners (Appendix C)
- Demographic information for third family member (Appendix D)
- Consent form for primary carer (Appendix E)
- Consent form for person with dementia (Appendix F)
- Consent form for person with dementia (by proxy) (Appendix G)
- Consent form for third family member (Appendix H)
- Consent form for service provider (Appendix I).

Recruitment

The joint nature of this study with the larger study at the initial phases of project implementation limited the possibility to select cases using paradigmatic or exemplary (a
strong and vivid instance of phenomenon) (Benner, 1985), purposive (or strategic), or maximum variation criteria (Stake, 1995). Rather, recruitment of participants for my study came from the initial criterion sample of primary carers of the larger study. The following criteria applied to participants of the larger study:

- Participant carers must define themselves as Chinese and be aged 19 and older.
- Participant carers are performing unpaid assistance to an elderly family member (including a significant other who could be a relative, friend or neighbour).
- Participant carers must play a primary or have a major role in coordinating or performing activities of daily living or instrumental activities of daily living tasks for the elderly person.
- Participant carers may include those residing with or not residing with the person being cared for.

For this study, the aim was to move beyond the carer’s perspective to develop a rich, detailed and in-depth understanding of the phenomenon in its complexity. Given how research has shown that caring often involves other kin besides the primary carer (e.g. Purves, 2010), this study included other participants in the family as well as service providers, with a view of capturing the complexities of caring. For this study, family was broadly and inclusively considered to include those recognized by law as in parent-child relationships, marriage or common-law relationships, as well as “persons or groups with familial feelings or a family-like situation” (White, Larson, Goltz, & Munro, 2005, p. 5). Additional conditions to the criteria of the larger study in order to participate in my study, therefore, were:

- Participant carer must be caring for a person diagnosed with dementia.
• The person with dementia and, where possible, one other or more family member/s and/or service provider (e.g. home support worker, nurse, social worker, or family physician), was/were willing and able to participate in my study.

Intensive recruitment activities for the larger project took place from August to December 2008. I contacted service providers, community leaders, acquaintances and friends in or working with the Chinese community, explained to and discussed with them details of my study, and emailed and/or delivered the advertisement and invitation letters to them. Community contacts referred the names and contact information of potential participants who had given permission for me to contact them. I followed up with an initial telephone call during which I introduced the larger project and myself, as well as chatted with the potential participant to build some rapport and ascertain fulfillment of the criteria and suitability of the primary carer to participate. I let potential participants know that they could choose to meet me in their home, or if they preferred, at a location of their choice such as in a community centre they were familiar with, but that their home, their natural habitat, was my preference.

From a total of 27 community contacts (see Table 1), five potential participants who met the criteria for the larger project agreed to meet with me from this first round of recruitment, and only one in this group, however, a wife-carer, met the criterion of caring for a person with dementia. A second round of recruitment took place from January to March 2009. This second round brought five more carers for a relative with dementia. In all, a family physician introduced this study to 2 participants, an assisted-living facility referred one, and an adult day program referred the remaining three, making a total of six potential participants for this study.
Table 1. Recruitment

<table>
<thead>
<tr>
<th>Type of contact</th>
<th># of entities contacted</th>
<th># of carers recruited Aug to Dec 2008</th>
<th># of carers recruited Jan to Mar 2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community agencies/assisted-living facility</td>
<td>7</td>
<td>1</td>
<td>4*</td>
</tr>
<tr>
<td>Neighbourhood Houses/community centres</td>
<td>6</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Seniors’ associations/intercultural societies</td>
<td>5</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Family doctor/dentist</td>
<td>4</td>
<td>1*</td>
<td>1*</td>
</tr>
<tr>
<td>Vancouver Coastal Health (Mental Health Team)</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low-income housing managers</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public health forum</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteer setting</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

* caring for person with dementia

After the first interview, the 6 primary carers from the larger study who also fulfilled the additional criteria of my study were asked to consider participation in my study, and if they were agreeable, to contact their family members and/or service provider on my behalf. Out of these 6 participants with a relative with dementia, 4 were agreeable to follow-up interviews as well as contact the care-partner with dementia, other family members and/or service providers on behalf of my study. For the remaining 2 participants who had explicitly requested our meeting to take place outside of their home, seeming tensions in their family relationships did not allow participation of the family as a whole. Both immediately declined the involvement of the person with dementia, or contacting other family members. Consistent with guidelines provided by Stake (1995; 2005) for comparative case studies, a sample size of between 3 and 5 was deemed reasonable given the emphasis on developing rich, in-depth contextualizations.
Characteristics of the Cases

In order to increase theoretical generalizability, variability or diversity is considered important for case study research so as to capture more aspects of the phenomenon for contextual richness and depth (Stake, 2005). Consequently, although all participants with pseudonyms (see Table 2) were of Chinese ancestry and spoke a common dialect of Cantonese fluently, there was variation in terms of gender, role relationship, family structure, age of carers, point on the trajectory of caring for the illness, and background in terms of country of residence prior to arriving in Canada.

Members of the family who participated in the study are listed in the order of primary carer, followed by the family member with dementia, and other family members. Service providers who participated in the study are listed below the details of the family. Unlike the other families, there was no interview with a third family member or service provider for the last family, given that Josephine and Stephen had no children, were very independent, and apart from the adult day program, did not receive help from public services at the time.
<table>
<thead>
<tr>
<th>Cases</th>
<th>Countries of residence (# years)</th>
<th>Years of caring at 1st interview</th>
<th>Age</th>
<th>Family structure</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Case 1</strong></td>
<td>Hong Kong (59), Canada (14)</td>
<td>3</td>
<td>73</td>
<td>2 sons here; 1 son 1 daughter in HK</td>
</tr>
<tr>
<td>Jeannie Lee (wife-carer)</td>
<td>Same as wife</td>
<td>77</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chung Chin Po (husband)</td>
<td>Hong Kong (32) Canada (14)</td>
<td>46</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nick (son)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jackie (daughter-in-law)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dr. X (family physician)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Case 2</strong></td>
<td>China (30), Hong Kong (10), Malaysia (10), Canada (39)</td>
<td>9</td>
<td>89</td>
<td>1 son here</td>
</tr>
<tr>
<td>Derek Ma (husband-carer)</td>
<td>Same as husband</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vera (wife)</td>
<td>HK (11), Malaysia (10), Canada (39)</td>
<td>60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peter (son)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Case 3</strong></td>
<td>Hong Kong (16), Canada (44)</td>
<td>8 months</td>
<td>60</td>
<td>3 brothers far away</td>
</tr>
<tr>
<td>Alice Chiu (daughter-carer)</td>
<td>China/HK (68) Canada (12)</td>
<td>80</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mrs. Liu (mother)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meiling (home support worker)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Case 4</strong></td>
<td>Burma (6), China (5), Hong Kong (50), England (2), Canada (12)</td>
<td>3</td>
<td>75</td>
<td>no children, occasional visits with her 2 sisters here</td>
</tr>
<tr>
<td>Josephine Cheyne-Law (wife-carer)</td>
<td>China/HK (57) Taiwan (6), Canada (12)</td>
<td>75</td>
<td>3 siblings in different cities; see each other very infrequently</td>
<td></td>
</tr>
<tr>
<td>Stephen Law (husband)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Consent

The consent procedures in place for all participants were reviewed and approved by the UBC Research Ethics Board. Specific to persons with dementia, this involved obtaining consent from her or him directly. Where the person with dementia had difficulty following through with the whole consent procedure and/or signing the consent form, consent by proxy was obtained from an authorized third party. In the latter case, continuous assent was obtained from the person with dementia through assessing her or his feelings of agreement and comfort to be engaged in the research process (Slaughter, Cole, Jennings, & Reimer, 2007).

Data Generation

Data generation methods are the means to answering research questions (Maxwell, 2005). The various methods envisaged in case study research allows the generation of multiple points of view that facilitate the development of detailed and information-rich cases (Stake, 1995). The primary data generation methods I employed were interviews and observations. I adopted a triangulation of data sources, including the carer, the person with dementia, different family members and/or a service provider.

Table 3 provides a summary of the data generation process. There were a total of 13 participants, eighteen interview sessions amounting to 29 hours 5 minutes of interviews, and six observation sessions amounting to 14 hours 40 minutes, exclusive of shorter telephone conversations for maintaining contact and rapport or brief follow-up questions or clarifications. All interviews, except for two in English, were conducted in Cantonese. All interviews took place in the home of participants except for one at the family physician’s office. Observation sessions took place mainly in the home, with two exceptions: One in the
dining hall of the assisted-living facility where the couple resided, and one at the food court across the street where the couple regularly had their lunch.

### Table 3. Summary of data generation

<table>
<thead>
<tr>
<th>Family/case</th>
<th>Date of interview</th>
<th>Duration</th>
<th>Date of observation session</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Case 1:</strong></td>
<td>Nov 7 08 (JL-CCP)</td>
<td>1h50m</td>
<td>Mar 12 09 (JL-CCP)</td>
<td>3h10m</td>
</tr>
<tr>
<td>JL carer</td>
<td>Nov 27 08 (JL)</td>
<td>1h</td>
<td>Apr 14 09 (JL-CCP)</td>
<td>2h</td>
</tr>
<tr>
<td>CCP caree</td>
<td>Jan 16 09 (JL-CCP)</td>
<td>2h</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NC son</td>
<td>Feb 7 09 (JL-CCP-NC-JC)</td>
<td>1h20m</td>
<td></td>
<td></td>
</tr>
<tr>
<td>JC daughter-in-law</td>
<td>Mar 27 09 (FP*)</td>
<td>1h30m</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FP family physician</td>
<td>May 23, 09 (NC-JC)</td>
<td>1h</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sub-total:</strong></td>
<td>6 interviews</td>
<td>8h40m</td>
<td>2 observ sessions</td>
<td>5h10m</td>
</tr>
<tr>
<td><strong>Case 2:</strong></td>
<td>Apr 20 09 (DM-VM)</td>
<td>2h</td>
<td>Oct 26 09 (DM-VM)</td>
<td>2h</td>
</tr>
<tr>
<td>DM carer</td>
<td>Jul 3 09 (DM-VM)</td>
<td>2h</td>
<td>Dec 21 09 (DM-VM)</td>
<td>1h30m</td>
</tr>
<tr>
<td>VM caree</td>
<td>Aug 20 09 (PM*)</td>
<td>1h30m</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PM son</td>
<td>Oct 26 09 (DM-VM)</td>
<td>1h</td>
<td>Dec 21 09 (DM-VM)</td>
<td>1h30m</td>
</tr>
<tr>
<td><strong>Sub-total:</strong></td>
<td>5 interviews</td>
<td>7h</td>
<td>2 observ sessions</td>
<td>3h30m</td>
</tr>
<tr>
<td><strong>Case 3:</strong></td>
<td>Apr 17 09 (AC)</td>
<td>1h30m</td>
<td>Oct 26 09 (AC-ML)</td>
<td>3h</td>
</tr>
<tr>
<td>AC carer</td>
<td>Jul 27 09 (AC)</td>
<td>1h15m</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ML caree</td>
<td>Aug 28 09 (HSW)</td>
<td>1h30m</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HSW home support worker</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sub-total:</strong></td>
<td>3 interviews</td>
<td>4h15m</td>
<td>1 observ session</td>
<td>3h</td>
</tr>
<tr>
<td><strong>Case 4:</strong></td>
<td>Jun 15 09 (JCL-SL)</td>
<td>2h10m</td>
<td>Oct 27 09 (JCL-SL)</td>
<td>3h</td>
</tr>
<tr>
<td>JCL carer</td>
<td>Sep 4 09 (JCL)</td>
<td>3h</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SL caree</td>
<td>Mar 29 10 (JCL)</td>
<td>3h</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mar 29 10 (JCL-SL)</td>
<td>1h</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sub-total:</strong></td>
<td>4 interviews</td>
<td>9h10m</td>
<td>1 observ sessions</td>
<td>3h</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>18 interviews</td>
<td>29h05m</td>
<td>6 observ sessions</td>
<td>14h40m</td>
</tr>
</tbody>
</table>

*interviewed in English
Much as this text may give the impression that the whole research process flowed smoothly, the length of this text does not allow me to go into details of matters that took time and intuition to work out before both the participants and myself were able to settle into our ‘research relationship’. For example, whereas Derek and Josephine clearly had experience in contributing to academic and community research, Jeannie seemed unsure about how she could be of help to the study, and her somewhat restricted and short answers at the first interview suggested some unease and uncertainty. As well, I had to make precious use of Alice’s availability when it became evident to me that she was giving me what little time and energy she had left after or alongside her caring. Among more minor things, twice participants had forgotten our confirmed and reconfirmed appointments, when I luckily caught them at the door.

**Interviews**

Data gathering began with interviews that took place between November 2008 and March 2010. With a view of developing rapport, I try to make participants feel comfortable and relaxed by setting the stage for the interview in the following ways: I let my participants know that I was thankful to them for allowing me into their home and sharing with me something invaluable. I did my best to use methodical and active listening (Maxwell, 2005; Yin, 2003) in order to sensitize myself to the kind of language, views, feelings and thoughts of the participants. I used plain language myself that gave a sense of social ease and invitation for participants to be open about sharing with me their knowledge and experiences. I did my best to ask them “real” questions (Maxwell, 2005, p. 92), the answers to which I was genuinely interested in, as well as tried to hear how my questions might have sounded to the participant’s ears. Finally, I let our conversations flow as naturally as could be using the ordinary rules of
conversations—using simple acknowledgement of reception, or showing interest with an affirmation or a question to follow up an important thread of the participant’s thinking—ordinary rules that usually engage interlocutors to participate in conversations (Bourdieu et al., 1999).

As well, I reminded myself that although the case researcher is knowledgeable in the area of expertise of the research, s/he is at the same time open to the novel and the as-yet-unknown (Thomas, 2010; Yin, 2003), to the extent where, as Bourdieu et al. (1999) describe, s/he can help “create the conditions for an extra-ordinary discourse, which might never have been spoken, but which was already there, merely awaiting the conditions for its actualization” (p. 614). I tried my best to emulate such skill by continuing the participant’s arguments in an open-ended way, and by remaining sensitive and responsive to the conversation and the speaker. As well, I stayed alert to anomalies, remaining aware of where and how a case began to differ from what was expected, and questioned how and why this might be so (Thomas, 2010).

The inclusionary approach of this study to enable the participation of the person with dementia demanded creativity and flexibility in the data generation process that would facilitate the sharing of their experiences. The approach suggested that there be no fixed rule as to who should or should not be present particularly at the first interview with the primary carer. I let the primary carers lead as to how they felt most comfortable sharing information with me, whether speaking together with or in the presence or absence of the care-partner or another family member. On occasions where there were two or more family members present, I asked them to always try to speak one at a time in line with polyphonic
interviewing (Fontana & Prokos, 2007), which would facilitate deciphering the speaker and contents during the transcribing process.

I did purposely arrange two interviews, both with wife-carers, at a time when the care-partner would be at an adult day program. One carer in particular had broken down into tears very briefly at the first interview when the care-partner left the room momentarily. I had interpreted her behaviour as a “proxemic communication” (Fontana & Prokos, 2007, p. 71) for the need of some privacy and opportunity to speak with me one-on-one, without her husband present. However, at the subsequent interview on their own with me, neither of the carers had anything particularly private and personal about their caring or relationships to share with me. Upon probing, the carer who had broken down previously explained that she was experiencing a particularly stressful period during the time of the previous interview when her best friend and brother-in-law were both hospitalized at the same time, and she was running between hospitals to visit them while coping with her own care responsibilities.

The consent process preceded each first interview, at which time I went through with the participants the purpose and details of my study and the ethics and confidentiality procedures provided in the consent form. I also reminded participants of the consent procedure in place at subsequent meetings. In particular, emphasis was placed on the confidentiality of the data as well as assurance that the data would not be shared with service agencies and that their participation would not affect or jeopardize in any way any services or programs they were attending or would attend. I described how their input could benefit other families who might go through the same journey of caring, perhaps not immediately, but in the future. I also explained that policy makers and service providers could benefit from the information through workshops, forums, presentations and publications. I invited participants or their delegated
representative to read the consent form and ask any questions they might have. After they had read and signed the consent forms and given me permission for audio recording, I turned on the recorder.

Participants chose the language of the interview in English, Cantonese or Mandarin. In a loose semi-structured format within the framework of the interview guide (see Appendix A), I invited participants to talk about their daily practices of caring, including how they were providing care, what providing the care meant to them, what might be the sources of the meanings and understandings, what the relationship was like, whether and how others in the family and friends contributed to caring, and what were their needs and use of services and support. If not already covered spontaneously during the interview, at the end of the interview, I asked them if and how they saw culture influencing their care, as well as followed up on any question or points of interest that emerged during the interview.

Besides inviting other family members, two families arranged for one of their service providers to participate in the study. The interview with service providers followed the same loose semi-structured format, with a focus on their knowledge and experiences of their professional relationships with the client with dementia, the caring in their family, and their thoughts about cultural influences on caring (see Appendix B). All participants gave their consent for audiotaping the interviews. Audiotaping serves the purpose of providing “data more faithful to the interview event” and strengthens the audit trail for increased credibility of the research process (Sandelowski, 1994, p. 311). As well, this back-up record partially freed me from having to make notes and allowed me to focus on engaging the participant in the interview (Mason 2002). Interviews usually ended when participants indicated they had said all that they needed to share with me for the day.
Following usually the lead of initial data, the next steps of who to go to and what questions to ask were determined for subsequent interviews. For example, whereas the first interview with the primary carer usually focused on the general scope of the larger study and the concrete, context-dependent information of everyday activities and practices, the second interview moved the experiences of care to the more nuanced and textured level of intricacies and dynamics of the care relationships and culture not captured in the first interview. This kind of “progressive focusing” (Stake, 1995; Wolcott, 1994) allowed me to fill in the gaps, probe further and check out with participants the ambiguities and contradictions (van Manen, 1990) around my understandings of their care practices and experiences from previous interviews. Simultaneously, this exercise performed the kind of member checking that adds to the rigour and dependability of the research process (Lincoln & Guba, 1985). Given the asymmetry of power inherent in a relationship between the researcher and the participant (Kvale, 2006), data not owned by the researcher but shared with the informant in a subsequent interview can help erase some of the distance between the researcher and people s/he writes about (Denzin & Lincoln, 2005). As well, at the end of the interviews, participants were asked if they wished to receive a copy of the transcript in English. All participants in this study declined and preferred a verbal summary. Stake (1995) reported this preference as a common choice among participants according to his experience.

**Observations**

Given the importance of the participation in and contribution of persons with dementia to this study, where an interview with the person with dementia was not feasible or practicable, observational data supplemented the oral data. As well, recognizing the limitations of interview data in regards to the sole reliance upon use of language, prolonged
engagement in observation of actual interactions could instead help develop a more holistic and comprehensive context of understanding. In this regard, two care-partners with dementia participated in loosely structured interviews in the presence of the spouses as well as observations, while two other participants with dementia provided data mainly through observation sessions. A suitable everyday activity during which the person with dementia could be observed in interaction with the carer was negotiated in consultation with the family. Among the possibilities were mealtime, a stroll or another leisure activity.

Observation of the care-partners in interaction was an important supplementary source of information, particularly where communication challenges posed difficulties for the partner with dementia to engage in other data generation methods. In ordinary activities and interaction with the primary carer and/or others around them, the ‘voice’ of the person with dementia could speak through her or his actions, in “non-discursive” ways (Kontos, 2004, p. 845). For all cases, I conducted at least one observation session of the care-partners at mealtime with the consent of the person with dementia, and where this was not possible, the consent of the primary carer with the assent of the care-partner (Slaughter et al., 2007).

When I explained the rationale and requested the observation session with a selection of possible activities, all carers gladly invited me to join them for lunch or dinner. At first, I courteously declined and thanked them for the invitation because I did not want to disturb them. When I explained that I had simply wanted to observe them while they had their meal, they dismissed that I was being too “hack hei” [courteous]. They would not accept that I would work while they ate. Knowing the importance of food within Chinese culture, and the emphasis upon being socially respectful in the acceptance of an offer or invitation to food (Wong, 2010), I quickly realized that being a researcher-fly-on-the-wall would not have
worked well with these Chinese elderly and less elderly persons. Recalling how one participant anthropologist in Jackson’s (1990) study puts it so aptly, that fieldwork is not about “taking notes in the field but is the interaction between the researcher and the so-called research subjects” (p. 23), I accepted their invitation with thanks.

Observations serve the dual purpose of showcasing the interactions, actions and behaviours that are an important part of the social reality of care, as well as provide an additional data source to cover aspects of the social reality (Mason, 2002). For this study, observation provided a direct and powerful complement or discussant to interview data, especially when participants may be reluctant, or have difficulty, sharing their thoughts directly in interviews, or where people’s facial and bodily cues as well as gestures, expressions and interactions could not be captured on audiotape (Maxwell, 2005). For example, it happened twice with different colleagues who, upon reading a transcript, remarked how the carer was acting in a way that was ‘personhood-suppressing’ or contrary to person-centred principles. Having been there personally to see a fuller picture, including observing the interactions, I realized how misleading the sole reliance upon words in a transcript could be. For example, the importance of this context was vital to understanding how Alice’s spoken words differed dramatically from her actions. As well, I noticed how Jeannie in particular was more relaxed without the ‘formal’ format of the interview, despite my efforts to make our meeting as informal as possible. Without the digital recorder on the table, she walked around her home, attending to her knick-knacks, and chatted away instead of waiting, as she usually did, for my question and then carefully considering her response. In this way, observation of actual interactions gave an alternative mode of data generation as
well as an extra perspective to help confirm and check understandings and inferences (Maxwell, 2005).

The importance of selectivity and perspective in observations is crucial, so I paid particular attention where to direct my ‘gaze’ (Gordon, Holland, Lahelma & Tolonen, 2005; Mason, 2002). I knew that while staying open to stimuli in the observation setting was important, I went into each observation session with a broad frame that focused my attention in a strategic way as to what I could be observing, be it appearance, artifacts, talk, behaviours, interactions, bodily gestures and other communications that would generate data, like the interview questions, to illuminate the phenomenon of dementia care in the family.

**Demographic information and other textual material or documents**

At the end of the first interview, I asked participants for basic personal information such as age, gender, education, language history, income ranges and health situation according to demographic data sheets (see Appendices C and D). Other textual material and documents related to care provision that were shared or suggested by the carers became part of the data. For example, 1 participant with dementia chose a few of his journal entries over the years for me to read. He also read out a couple of them. Not only did the readings give a sense of the thoughts of this participant, but also the changes in his writings over time, from entries filling an entire page before the illness, to a single or half line. Another participant lent me his binder in which he meticulously documented his initial readings of the illness and caring, with highlights of aspects of knowledge of and caring for the illness he found important for his caring role. Another carer took me on a tour of their apartment, explaining the set-up of their home spaces that facilitated their caring activities, for example, where they administered injections. She also gave me permission to take photographs of these spaces.
Field notes

I made it a routine to write field notes the same day of any interview or observation session, or I audio recorded my “headnotes” (Jackson, 1990, p. 5) in the car immediately after the visit and transcribed them later. Field notes allowed me to document the details of the contexts as well as preserve certain experiences of the interview or observation closer to the moment of occurrence (Emerson, Fretz, & Shaw, 1995). I could easily have forgotten these experiences had I not written the notes soon after the visit. Following Jackson’s (1990) suggestions, I used field notes to document entire observation sessions or to supplement interview data. In the documentation, I included the settings or context, the persons, their actions, interactions and non-actions, verbal or non-verbal communications, and the silences that trespassed between them. As well, I used field notes to record any special hunches or questions I had (Gordon et al., 2005). Similarly, after interviews, I recorded my impressions of the interview and the participants, feelings they emitted, nuances, and ‘disquiet’ or ‘disjuncture’ in participants’ accounts that could not have been captured on tape (Mason, 2002). Every hour of observation took approximately 2 hours of field-note writing, coinciding with the average time of field-note writing in the general literature (Emerson et al., 1995).

I read these field notes as I did a preliminary analysis of the data before going into subsequent interviews with further questions and areas for clarifications or expansion. As well, I reread the field notes as an aid to refresh and clarify my understandings of the research process before I started coding and analyzing the transcripts. In a way, field notes elicited my recall of the observations, and like observations before they are turned into text, allowed me to go continuously between the experiential and the textual (Emerson et al, 1995), between the forest and the trees, in order to get a better feel of the quality and textures of caring (Maxwell,
The second purpose of the field notes was to add to the audit trail (Sandelowski, 1986) or chain of systematic evidence (Yin, 2003) that enhances rigour and credibility to the research process (Anfara, Brown & Mangione, 2002).

Transcribing

According to Tilley (2003), transcribing adds a layer of interpretation; hence the procedure denotes the “impossibility of interview transcripts to replicate the lived experience” (p. 763). Transcribing into another language further increases this distance between the text and the raw data (Tsai et al., 2004; Twinn, 1977; Nikander, 2008) when translators act as cultural-brokers between the audio record and text production (Tsai et al., 2004). For my study, direct analysis of the Chinese transcript would have kept closest to the original words of the participant. The downside was that I would not have been able to check or share my understandings with my supervisor and peers. So transcribing into English was my only choice. I always listened to the audio files at least a couple of times before I started transcribing them. Given how consistency of translation maximizes the reliability of the translation for subsequent analysis (Twinn, 1997), I transcribed all the interviews myself. I transcribed verbatim for interviews in English, and kept as close to verbatim as I could for those transcribed directly from Cantonese into English, ensuring minimal loss of meanings of the sentence or compromise on the flow of the communication. In the process, it was inevitable that some of the more colloquial characteristics of the original language could not be replicated in their exact form (Twinn, 1997), and that the transcript will always remain a “good enough” (Nikander, 2008, p. 229) representation of the raw data (Sandelowski, 1994; Tsai et al., 2004).
In translating, I did one of two things: I used direct or literal translation of the Chinese word or phrase into the English equivalent or meaning, or I used phonetic translation of the word or phrase in Cantonese or Mandarin. My choices followed these basic rules:

(1) I translated the words directly into English with the literal translation in square brackets, for example “conscience [kind heart in Chinese]”, or a phonetic translation in Mandarin with the translation in English in square brackets, for example “ganqing [affectionate feelings and relationship]” where the concept or term already exists in that language or form in the literature (e.g., Dilworth-Anderson & Gibson, 2002; Kipnis, 1997).

(2) I used a literal or phonetic translation with the equivalent or meaning in square brackets where keeping the original words literally or phonetically is useful to give the reader a sense of the language use of the speaker, e.g. a literal translation “my heart is [I am],” or phonetic translation, “tok lai [blessed].”

(3) Where phonetic translation was appropriate, I used Mandarin, the official Chinese dialect, as my first choice. Where there was no equivalent or appropriate concept or term in Mandarin, the Cantonese word was retained in phonetic translation, e.g. “tok lai [blessed]”, “tum [persuade gently].”

(4) Where participants used English words during an interview in Cantonese, the English words were kept in single quotation marks within the translated quotations in double quotation marks.

Two participants in particular used English words frequently while talking in Cantonese. As well, the transcribing process confirmed Twinn’s (1997) reporting on the lack of use of tenses and pronouns in the Chinese language. Whereas both the timing of an action and the indexing of the person speaking, spoken about or being referred to, were evident
from the flow of the conversation, the distinction between the first person singular or plural could at times be tricky. While I automatically incorporated tenses into the translation according to the structure of the English language, I added the missing pronouns within square brackets, for example, [I/we], after having discussed the issue with my supervisor.

**Coding and Analyzing Data**

First and foremost, the purpose of the study was to develop holistic and contextualized case studies with rich and in-depth details. To do so, I took the following steps: I read and checked every transcript against the audio file, and prepared for preliminary coding after the initial transcripts were ready. I listened to the audio files again and reread the field notes several times to get a feel of the ‘story’ (Kvale, 1996) of the participants, remembering the contexts and my impressions of the care-partners and our conversations. In particular, I paid attention to what the participant had most wanted me to know and tell others on her or his behalf. I moved back and forth between the tapes and texts, immersing myself into and conversing with the participants in the text. I listened carefully to the tapes in order to ‘see’ their world (Van Manen, 1990). At the same time, I moved out of the participants’ world in text so as to ‘hear’ the experiences of the phenomenon from alternative perspectives.

I repeated this process with all additional transcripts for better connection with the case, noting for example the different ways of providing care and how choices were made in the family to do and act in some ways instead of others. I read the transcripts again and again, marking segments of data and noting their themes and the relationships between them. I employed a form of connecting strategy (Maxwell, 2005) until a pattern emerged and a focus ‘spoke’ to me about who the participants were and what held the entire case together. I wrote
down all these global impressions and ideas in notes and memos, which included ideas and themes about patterns and changes, the attention given to or avoidance of topics or spaces by the participants, flows and ruptures, the contradictions, avoidances and silences. Based on these notes and memos, I wrote a summary or preliminary ‘story’ of caring in each family.

Once I had established this ‘story’ of caring for a case, I embarked on a categorizing strategy of coding and dissected the data into parts (Maxwell, 2005). Using ATLAS.ti, I did a line-by-line coding to extract descriptive codes, substantive categories and thematic aspects from phrases, sentences and larger chunks or segments of data (Maxwell, 2005). The codes, categories and themes often take the participants’ own words and concepts, staying close to the data and telling the ‘emic’ or participant’s understandings of her or his own care experiences (Maxwell, 2005). Together with the entire team of the larger study, I developed these codes, substantive categories and thematic aspects following abductive principles. Abduction (Charmaz, 2005; Thomas, 2010) recognizes practical limits, specifically that decisions made are the most plausible explanations among many possible explanations. It differs from induction in its absence of the kind of inference of representation or replication of reality assumed in inductive procedures. Working together, the team developed a codebook and held several coding sessions together to try out the codes and discuss them.

Thereafter, my attention moved towards embracing the more phenomenological experiences of caring, for example using line-by-line reading (Alvesson & Skoldberg, 2000) to see how their practices and experiences might be related to one or more of the following structures of experience: Their lived space (spatiality), lived body (corporeality) including feelings, mood, and emotions, lived time (temporality), and lived human relation (relationality or communality) (Van Manen, 1990). I began looking for relations between
these elements and the established emic or substantive codes, categories and themes. I drew up networks as to how all the new elements and established codes, categories and themes might be related to one another (Maxwell, 2005) as well as to the preliminary ‘story’ of the participant. My supervisor helped me with feedback on a couple of coded transcripts.

Sometimes I created new codes from thinking through and analyzing the codes, categories, themes and relations. For example, I noticed how much the Chinese language actually uses parts of the body to denote feelings and emotions (e.g. serene = calm heart; my heart is = I am). This led me to rethink the initial categories of ‘practical’ versus ‘emotional care’. I no longer saw ‘practical care’ in its original connotation comprising activities of daily living and instrumental activities of daily living including physical care. Instead physical care implicated both ‘caring for the body’ as well as ‘caring about feelings’, and as one participant prompted, physical and emotional caring are intricately linked. This rendered caring in a new light and took me back to looking for data in the case, and then in other cases, around the newly developed code around feelings.

Alongside abductive coding and analysis, I also sought to understand my interpretation of the codes, themes and relations, as well as ask questions of them using my prior knowledge of the phenomenon, a process of theoretical analysis (Maxwell, 2005). An example was how feelings in caring might play a role in the caring relationship or the promotion of personhood, and what might have been the conditions of possibility for the expression of certain emotions and not others in their caring practices. Every time there was a new code, relation or question, I cut into the data again to look for supporting or refuting data, thinking through and analyzing them, and came up with a ‘story’ of dementia caring from my ‘etic’ perspective (Maxwell, 2005).
Once a holistic picture had been established for each case, thematic areas were compared and contrasted across cases to see how they cut across the data sets (Creswell, 2007). This comparison and thematic analysis across cases allowed the cases to ‘talk with’ each other, providing a more comprehensive and richer level of understanding of each case as well as the relationships between different aspects and levels (Benner, 1985) of caring. I wrote notes and memos throughout the coding, interpretation and analysis process to converse with the data as well as document how the new codes, categories, themes, relations and networks had come about. ATLAS.ti facilitated the writing and retrieval of these notes, memos and the corresponding data. This was an important documentation and trail (Sandelowski, 1986) of the continuous movements in a hermeneutic circle between the parts and the whole, namely between various components and levels of analyses, as well as between textual materials and myself, with input from supervisors and peers.

The different rounds of coding, analysis and interpretation yielded composite cases with a holistic picture filled with particularities. There were fine details of description and explanation initiating from the participants themselves about how and why they provided care the way they did. This information was further developed by moving between abductive and theoretical analysis to produce an understanding of the spatial, emotional, temporal and relational contexts among the different aspects and levels of caring of each case. These findings are presented in the next five chapters, one for each of the four families within the social, cultural and time contexts of each family. A fifth chapter presents major themes of caring and caring practices from analyzing across the cases.
Trustworthiness

The hermeneutic circle facilitated my striving for trustworthiness and credibility of the study. In particular, issues of power and representation characterize some of the major threats to the credibility of every research study. To address these issues, allowing the participants’ voices to be heard (Roulston, 2001), the researcher’s immersion in the field (Stake, 1995), and provision of detailed descriptions of the process and practical expertise involved (Thomas, 2010), may provide a well-intentioned response.

To begin, I paid special attention to ethical issues, exploitative potentials and power asymmetries of the interview (Kvale, 2006) and of the research relationship itself (Mauthner & Doucet, 2003). Allowing the ‘voices’ of participants to be heard is one step that aims to shift the power dynamic from the researcher to the participant as expert (Kvale, 2006). This was particularly important for this research involving persons with dementia. The different ways they could participate in the study was always negotiated flexibly with their input wherever possible, together with that of their family. The purpose was to ensure that the ‘voice’ of the person with dementia could be heard in discursive as well as non-discursive ways.

Nevertheless, the ‘voices’ and experiences of participants are co-constructed with and interpreted by researchers who are themselves subject to frameworks of meaning and relations that help structure their experience of research (O'Connor, 2001). My own experiences would colour my perception and appreciation of caring in my research work. To compensate for these biases, I frequently checked my understandings with my supervisors and peers. Insightful feedback from mentors and colleagues is important in providing alternative perspectives and fodder for thought (van Manen, 1990). The sharing of learning among researchers works towards deeper and richer understanding, and the consideration of alternative perspectives.
increases the credibility of the analysis (Lincoln & Guba, 1985), the ultimate objective of which is to “produce an analysis in the interest of those about whom knowledge is being constructed” (Campbell & Gregor, 2002, p. 68).

As well, given that the research relationship remains a social relationship that could implicate power, I attempted to reduce to the extent possible any distance between my participants and myself. I did so by spending extended time on site in order to be in contact with the participants. In addition, I reminded myself to always be respectful and sensitive to the participants as persons and experts with their own experiences. I tried to be mindful of this need for respect and sensitivity whether in their physical presence, or when interacting with the text.

Spending time on site with participants and research activities facilitated the securing of rich descriptive data. The time spent in the field provided the possibility not only for collecting rich data and description, but also for opportunities to reflect on and draw meanings from the data. I maintained this kind of continuous dialogue between data generation, meaning production, and knowledge and background in available literature (Flyvbjerg, 2006; Yin, 2003), always cognizant of the need to balance staying close to the data while engaging theoretical and academic expertise (Hoskins & Stoltz, 2005). One of my objectives in securing sufficient descriptive narrative for the reader is to enable the reader to discern this balancing between data and knowledge. In sharing research experiences vicariously (Stake, 2005), readers can then draw their own conclusions about how the work of both construction and understanding produced the text (Bourdieu et al., 1999).

This understanding is important as every case researcher recognizes that neutrality is impossible in any research process (Lincoln & Guba, 1985), myself included. Nevertheless, the
process of my interpretation and understanding of the cases, as well as the construction of this
text, are aimed towards Bourdieu et al.’s (1999) “realist construction” (p. 618), whereby I have
aimed to provide sufficient details and context to enable the reader to make her or his own
decisions around the trustworthiness of my interpretations. Sufficient details and context will
help readers discern how I came to my understandings, make sense of the cases, and decide
whether and where to agree or disagree with me, knowing that my views remain always a
‘partial’ view (Thomas, 2010).
CHAPTER 4.
“"I HAVE TO DO EVERYTHING”"

Jeannie Lee, in her early seventies, lives with and has been providing care for her husband Chung Chin Po, four years her senior, since he was diagnosed with Alzheimer’s disease three years ago. Mr. Chung does not take medications for Alzheimer’s disease due to intolerance of the drugs prescribed for it, but takes those for diabetes and high blood pressure. Although still calm and easy to care for, Mr. Chung is deteriorating quickly according to Jeannie, and beginning to require more reminders and assistance from her. Jeannie is in good health.

Mr. and Mrs. Chung immigrated to Canada from Hong Kong in 1996. She identifies herself as the primary carer and manages on her own with the support of their two sons and their families. The three families live close to one another. The couple’s youngest son Nick and his wife Jackie, both in their mid-forties, live two floors below the parents. They agreed to participate in this study. Their eldest son, his wife and their young teenage son, reside a few blocks away. The two brothers and their wives support Jeannie in various ways in the care of their father. This includes, for example, providing instrumental assistance such as help with shopping, some cleaning, transporting the couple to appointments with doctors or specialists, and taking them out for dim sum and strolls to spend time together. Two other children, a son and daughter, continue to reside in Hong Kong but call frequently to talk with the parents as their way of showing support, care and concern.

Jeannie and Mr. Chung present themselves as an elderly couple with good family relationships and financial means. They live in an apartment they own in Richmond, British Columbia, where there are many Chinese shops and restaurants. Many people from Hong Kong choose to settle there because of the high concentration of Chinese population. The
apartment is situated in a well-kept building located on a quiet street in a central location, close to shopping, transit, and amenities. For the first few years, Jeannie and Mr. Chung went back and forth between Canada and Hong Kong every year to visit their children and relatives.

Jeannie and the children speak some English but not well. In Richmond, one can get by with limited English. For example, Jeannie and Mr. Chung found a Cantonese-speaking doctor in Richmond upon arrival, who they still see. In addition to their physician and a brain specialist, Jeannie has been to support groups a couple of times together with Nick and Jackie, and Mr. Chung goes to an adult day program in Richmond once a week using a transport service provided by the health care system.

The family physician has offered Jeannie more days for Mr. Chung at the adult day program as well as home support services but Jeannie keeps declining the doctor’s offer. This is intriguing given the way Jeannie summed up the progress of the illness and consequent care repeatedly with the phrase: “I have to do everything.” The repeated phrase would suggest that she might be feeling overwhelmed, frustrated, tired and/or fatigued, so why would she not accept more services? Understanding who these participants are, paying particular attention to who Jeannie and Mr. Chung are, where they come from, their history and experiences as well as their relationship with each other and others around them may give insight as to why Jeannie cares for Mr. Chung the way she does, and help shed light on the seeming contradiction.

Who They Are

Whenever seen, Jeannie was casually and smartly dressed in slacks and a fleece or knit top. She looked fit and serene in her 5’2” stature, with beautiful smooth white skin, and
shoulder-length white hair pulled back by a hairband. She always extended a courteous
greeting, in a soft and gentle voice accompanied by a lovely warm smile, and offered a hot
cup of Chinese tea. Mr. Chung is of medium build and height at approximately 5’7”, and like
his wife, was always well groomed, friendly and dressed smart and neat, in a cardigan and
sweat pants.

The elderly couple gave a sense of relaxed comfort and warmth. Their home reflects
their Chinese heritage. Except for the Western style leather sofa, the neat and tidy apartment
is covered from wall to wall and in every nook and cranny with Chinese furniture and
ornaments, big and small statues of Chinese mythical figures, vases and paintings inside and
outside of two big Chinese display cupboards.

The objects hold special meanings for the couple. For example, with a smile, Jeannie
drew attention to a couple of the statues noting how they stood taller than their grandson
when he used to walk up to them in toddlerhood. She explained how Mr. Chung “liked those
things and he’d buy buy buy every trip he went on.” These collectibles or spoils of Mr.
Chung’s brought back pleasant memories to Jeannie of an earlier time as she reminisced,
“We went everywhere. We also went on cruises. We went to the three gorges of the Yangtze.
We used to go everywhere.”

**Belonging to “The more traditional mentality”**

Talking about themselves and their relationship, Jeannie described that both she and
Mr. Chung belong to “the more traditional mentality” as they grew up in traditional Chinese
families. By traditional, Jeannie meant that Mr. Chung’s mother was very “strict…. He
followed rules...be home at appointed times, that you don't go out all the time, get up at
regular hours, eat at regular hours, [and] know the hierarchies.” Rules and regularities did not
pose any problems for them: “It’s easy for us to obey.” This was because she came from a “kind of ‘well-read’ family environment,” in the sense that family members “learnt rules of hierarchy and etiquette.” Their similar family backgrounds had a positive effect on their relationship: “I'm used to the same traditions. That's why I get along with him.” Jeannie grew up in an environment that was not only strict, but kind as well:

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I \text{ mean in my family, when there is a need to help someone, everyone in my family would do their best to help. Everyone helps others from the kindness of the heart. You get used to it, influenced by the group, something to do with growing up.}
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She has learnt to live by her motto of using her heart and the “promise of sincerity”:

\[
I \text{ always use my heart with people…. Basically, if you use your heart to treat others well, and others feel that you are sincere, they will also be good to you in return…. Being sincere is the best way. Don’t hurt others. Don’t harm others for your own benefit.}
\]

Jeannie grew up seeing everyone practice kindness and sincerity in her family. She described how family extended to ‘relatives’ and close friends who would simply “pull out a folded bed from nowhere, from behind a door or cupboard, and the house filled up at night.”

Jeannie and Mr. Chung continued with a traditional set-up in their own family. Until moving here, Mr. Chung “was only concerned about his work, going out to make money,” and Jeannie took care of the family. Earlier on when the four children were young, she had help from Mr. Chung’s mother: “His mother helped me look after the family and I hired [two] Philippino maids.” At that time, Jeannie supervised meal preparation on a daily basis as “every night there were seven or eight people for dinner, lots of people.” When at 90, old Mrs. Chung was diagnosed with Alzheimer’s disease, Jeannie looked after her in the family for five years with hired help until they left for Canada. For the year after immigration,
Jeannie and Mr. Chung returned occasionally to visit his mother until she passed away at 96 years old.

Outside the family, Jeannie helped her husband with his business. After graduating from a technical college, Mr. Chung had worked at a major TV broadcasting corporation as a wireless technician before he “started a repair shop for appliances, air conditioners and refrigerators…washing machines…all home appliances stuff, did that for many decades.” The business was quite successful and apparently allowed Mr. Chung not only to provide well for his family, but enabled him to lead a fruitful and enjoyable life. According to the family physician, Mr. Chung came across as “a healthy man…very active, enjoyed life, energetic…drove everywhere,” and who “used to ride a motorbike in Hong Kong when he was younger,” activities which attested to his former vitality in life.

With the success of the business, Jeannie shared that Mr. Chung was somewhat reluctant to leave Hong Kong and close the business. Nevertheless, the move to Canada was made to accommodate their sons’ futures. Specifically, all the sons had worked at Mr. Chung’s appliance repair shop without having had formal training like their father, and Mr. Chung had applied to come to Canada because the two younger sons were worried about the future of Hong Kong but did not possess the qualifications to apply on their own. The second youngest son decided to stay in Hong Kong in the end, and Nick came over with the parents. Unlike many immigrant families where it is usually the young adults who sponsor elderly parents, in this family it was the elderly parents who made some sacrifice in order to bring Nick over.

Care arrangements of Mr. Chung reflected the dominant influence of the parental role in this family. Nick spoke about the children’s involvement in the care of Mr. Chung mainly
in support of Jeannie, adding an acknowledgement: “Mother is still the major force.” In fact, after Mr. Chung had an accident, Nick said it was “actually she [Jeannie who] couldn’t let him drive anymore.” The family doctor also confirmed the primacy of the parental role when he remarked that he had never met either of the sons three years into the disease, even though he knew how supportive the children and how good the relationships were in this closely knit family.

Relationships: “The family is very close and dear”

Positive relationships in this family were prominent in the interviews. With satisfaction and content, Jeannie had the following to say about their children:

...very harmonious, very good. I feel very ‘tok lai’ [blessed]. Whether it's about their father, their mommy, things in general, towards their family, both sons are very responsible and caring in a loving and appreciative way.... I have good daughters-in-law. They help me as much as they can.

Mr. Chung too showered Jeannie and the children with praises throughout the interviews. For example, about Jeannie he said, “My wife can really cook well. The daughters-in-law love her cooking,” and about Nick, “He’s so remarkable he did everything...everyone likes him.” Mr. Chung communicated slowly but clearly the sense that the sons are their pride and joy when he repeated time and again, “especially the boys...both sons are good.... Everyone is good,” and Jeannie would be nodding in agreement on the side, content showing on her face.

The good relationships extended from a history of past good relationships. Nick described his relationship with his father as “quite close because we have always lived together from when we were small. As well, the family is very close and dear.” The closeness of this family consolidated into solid lasting relationships among family members as the couple raised their children together, working independently and capably in
crisscrossing spheres and responsibilities between shop and home to provide for and take care of the old, young and each other.

**Settling into Canada: “We adapted very well”**

The positive relationships continued along the same vein, albeit with modification of contents and pace, as the couple moved into retirement mode in a foreign land. Mr. Chung replaced ‘money-making’ with gardening. Jackie recounted how Mr. Chung “planted many pots and pots of indoor plants, like orchids and those he cared for himself…those took a lot of time, at least half a day.” Jeannie continued with her domestic expertise, taking care of their daily necessities. She described: “I only had to take care of the home. Two three meals a day, make some soup,” which left her enough time and personal space to “go out on my own, see my friends, or go shopping sometimes.”

The family considered their transition into Canada as smooth, except perhaps for Mr. Chung. Mr. Chung first compared his experience here to that of Hong Kong: “Where I’m concerned, everyone is quite ‘friend’ with me in Hong Kong. [They] feel that I’ve worked for so long, they’re all good friends. There wouldn’t be any defects [friction], shuns.” He continued, in his somewhat disjointed statements, insinuated difficulties of integrating into Canada:

*It’s very very hypocritical here, the people here. I find that in Canada, I give to others before others to me…. Those I’m in contact with are mostly Chinese…. Actually they look down on you in a way…. Wherever we go, others will see you: “Oh Hong Kong people,” like that…they can feel that you’re not a local…. It was very difficult. Whatever we did, others in their mind already felt that it’s not easy to accept [us].*
Jeannie thought what Mr. Chung had said was “all confusing [laughs].” She later described that here “people were quite nice.” Nick felt the same way: “There were no problems with everyday life and routines. We adapted very well.”

The financial resources with which they came could have facilitated their settling into Canada. The two sons transitioned into stable jobs and both are now drivers. In addition, they all speak some English. Interestingly, even though Jeannie grew up in a traditional family, she had studied in an English secondary school. This helps account for her good English pronunciation. However, she maintained that, “If it’s a few things for socializing, that I know. But if it’s medical, all kinds of symptoms of illnesses, and terms of the sort, we certainly are not familiar.” Like their mother, Nick related how the children could speak simple English but had problems when they “had to communicate with certain departments.”

Overall they were leading stable lives. Their stable lives, however, started changing when Mr. Chung’s increasing forgetfulness culminated in an accident three years ago and he ended up in the hospital emergency. He was finally brought to the attention of doctors and a brain specialist who diagnosed him as having Alzheimer’s disease.

Like the positive family relationships that she attributed to “tok lai” or blessings from a higher order, Jeannie considered Mr. Chung’s “unfortunate” illness as an arrangement from heaven above:

\[
\text{This is heaven's way for nature and creation.... Sometimes you have more, sometimes less, good or bad, heaven has arranged it for you. You can't complain about it. You can only take the negative positively as it comes, and you do your best so that your conscience feels okay, that's about it.}
\]

This philosophy guides Jeannie’s actions. How she does her best, and how her way of doing her best in caring is related to her conscience are articulated in subsequent sections.
Doing Everyday Care

Over three years, the couple’s daily lives have evolved into what Jeannie called a “typical day.” A weekday is when “everyone’s busy,” and when the children are at work, Jeannie prepares breakfast for Mr. Chung and herself, after which he goes for a nap while she:

\[
\text{Start[s] preparing lunch, something nutritious for him to eat. After the meal, we watch some TV, listen to the news, read newspaper, just like that, we'll pass another day [laughs]. If it's raining, we can't go anywhere. If it's not raining, we can go outside for a stroll, just stand outside the entrance [of the building] and walk back in. Even if it rains, we sometimes still go downstairs [the lobby] and walk around to let him move a bit.}
\]

In contrast, weekends and festivities are family days: “During holidays, the children, the sons, the daughters-in-law, will drive him everywhere to walk around, get some food, to please daddy a bit…. We would do it altogether.”

This is a stable scenario of today. Three years ago when Mr. Chung got the diagnosis, the scenario was quite different. Jeannie has experience caring for someone with Alzheimer’s disease having provided care to her mother-in-law for five years. However, compared to her mother-in-law who was diagnosed with the disease at 90, Jeannie found Mr. Chung’s diagnosis at 73 years old to be “sudden…very unexpected.” Her initial reaction was, “I felt very shocked…. I was very worried.” Ever since the diagnosis, Jeannie has had to take on more and more of the activities and responsibilities of daily living that gradually Mr. Chung could not do by himself. Jeannie summed up her care of Mr. Chung repeatedly with the phrase: “I have to do everything.”

By “everything,” Jeannie meant that besides her usual daily activities of meal preparation and taking care of the home, she has to make extra efforts to help him maintain his health and bodily functions by ensuring that he gets nutritious food and some exercise,
turning herself into some kind of expert carer and his “personal nurse” in so doing. Basic daily care extends to helping Mr. Chung with his personal hygiene. Beyond the activities of daily living, she interprets and speaks on his behalf as well as mediates between him, the children and professionals regarding his care and use of services.

Food has taken on more time and a different importance since the diagnosis. Instead of preparing “three meals a day, breakfast, lunch and dinner,” food preparation entails more thinking and planning after the illness. Unlike “earlier times, [when] our thinking did not care about eating, you'd eat whatever was there,” Jeannie related how she prepares food now: “I think about what to cook that is suitable for him, something nutritious…. I pay special attention to what they teach about what elderly people should eat and when I have time, I'll experiment with what to eat.”

To better assist him regulate his bodily functions, she tries to ensure that he gets some exercise, “I would go out with him and do our shopping together, just to go out for a stroll.” Limited by his “incontinence problems” and because “he does not have the energy to walk far,” they now restrict their strolls to the immediate neighbourhood.

Over time, she has developed her daily cooking into a form of dietary expertise, for example, in helping Mr. Chung regulate his bowel movement through his intake of food and liquids:

*I make him oatmeal every day. If he has his bowel movement that day, he'll eat [oatmeal] just once. If he doesn't, I'll give him oatmeal twice, morning and afternoon.... I would divvy up the six or seven glasses of water during the day, giving them to him gradually. He would drink them so his intestines won't get too dry and it would help his bowel movement.*
She exuded pleasure and pride when recounting her newly acquired care skills, and compared her care work to that of a professional: “I mark it all down like a private nurse taking care of him in everything [laughs].”

Daily basic care extends to helping Mr. Chung with his personal hygiene, including dressing. This includes constant “reminding” and “instructing”:

> Things he can do independently without my care are practically none…. He can still for example take a shower. I’d hold the tap and adjust the water temperature, and he would rub his body himself and clean everywhere. This he can still do. I still have to care for him with brushing his teeth and cleaning his face… I have to tell him each thing to do.

She has to tell him “each thing individually” because, similar to how she understood the disease had affected her mother-in-law when “her brain regressed to a third,” it is affecting Mr. Chung’s “memory…his brain all confused…his thinking declined significantly.” As a consequence, a simple task such as brushing one’s teeth “can become quite a confusing situation” for him.

According to Jeannie, the confusion is a result of the deterioration of his cognitive abilities in the brain whereby: “He doesn't know directions. He doesn't recognize places….he doesn’t know what he is doing and he wouldn’t know what to do. He is confused in everything.” She is convinced that Mr. Chung inherited the disease from his mother even though Nick, feeling somewhat uncomfortable about Jeannie’s statement, softly contested, “I don’t know if it’s hereditary.”

Nevertheless, Jeannie, Nick and Jackie all agreed that it *is* a disease, one that is, according to Jeannie’s observation, deteriorating “every six months” as well as imposing a time limit on Mr. Chung’s abilities. Jeannie noticed this time limitation from his shower, “Six months later, he couldn’t control the water. That means everything [every ability] has
about six months’ time and it worsens slightly.” After several of these landmark changes over the years, Jeannie concluded that “[b]asically after he's had the illness, he's not aware, he doesn't know anything,” and that his cognitive ability is at a point where he cannot even learn how to use a walker because “his brain cannot think how to walk.”

Yet, it was interesting to note that time and again Jeannie would contradict herself in stating that Mr. Chung actually knows everything. He simply cannot express himself or remember things, “Now he does know things. He knows everything. It's just in expressing, he's not that able to express himself…. He doesn’t remember.” As well, she often attributed the illness to the aging process instead of the disease: “In life, these things happen. It's only a matter of time.” Nick thought it was “normal, I mean when [a person] ages,” and Jackie agreed, “I felt that it was an elderly person’s condition…he was advancing in age.”

Jeannie summed up the practical result of their circumstances: “He doesn't remember and he doesn't know how to say it, so I have to take care of everything for him.” The fact that he cannot “express himself” makes her feel that she has to do everything, including taking up the role of interpreter and spokesperson of Mr. Chung. During the interviews I often found that Jeannie would be excusing and explaining, sometimes seriously, and other times with a good-natured or amused tone, that, “He doesn’t know how to express it...he doesn’t know what he’s saying [laughs]…he can’t express so he wouldn’t speak.” Frequently, she would interpret and speak on Mr. Chung’s behalf when she intercepted him: “He said that...[or] he’s saying...[or] that’s what he means.”

One specific example of Jeannie speaking on Mr. Chung’s behalf was recorded in my field notes: “Then I asked [Mr. Chung] if he liked to take pictures and Jeannie answered from the kitchen that he did, but that he does not and cannot anymore.”
Hand in hand with the felt necessity to interpret and speak for Mr. Chung, Jeannie constantly mediates and balances on his behalf. She acts as a go-between for Mr. Chung, family members and professionals in regards to the type and amount of services the family can or should use. For example, going to the doctor or specialist is a constant balancing act. On one hand, Jeannie does not feel the visits are all that helpful because Mr. Chung “doesn’t take medications, you can’t control it [disease]. And even if he took medication, the medication can’t cure him.” On the other hand, the sons want their father to be checked by the brain specialist whenever they notice changes. A visit to the specialist requires Jeannie to first go through the family doctor and Jeannie expressed somewhat helplessly that if the family physician thinks, “It’s nothing, we would just come back to wait and see how he is [laughs]. I feel that it’s not that helpful.” Despite how she feels about the visits being “not of much use,” Jeannie would still call the family doctor at the sons’ insistence, and see whether or not Mr. Chung could get a referral.

Jeannie also mediates and balances their use of other services. She had been to support groups with Nick and Jackie. While the children found the information useful, Jeannie thought the service not useful, “…it’s all talk. In reality, I haven’t been able to do anything.” She decided not to go after a couple of times but that the family would keep the support group as a contact point for the future. Finally, with the encouragement of the children, she continues to send Mr. Chung to an English-speaking adult day program with Chinese volunteers once a week despite Mr. Chung being “aversive to it at the beginning. He didn't like to go at all. He said he wasn't interested…. And after only a few times, he didn't complain much anymore. And when we asked him to go, he would.” She continues sending him as that is the only day when she can organize and get some balance for herself: “When
there is more time for me to do things, when I have this one day, I'm much better…I let myself relax a bit more.” Yet she consistently refuses the family physician’s offer to send him for an extra day because she knows that Mr. Chung does not like going there.

The doctor offered Jeannie and Mr. Chung more services because of his understanding of the care situation of the couple, “It’s a one-way demanding relationship…it’s a lot of stress on her…we definitely need to do more to help Mrs. Chung before she crashes.” ‘Do more’ meant offering them more services that “would allow [Mrs. Chung] to have a little bit more free time and less burden.”

Unfortunately, Jeannie did not feel the services would be that helpful and declined them. She used the word “troublesome” to describe home support service: “After the bath, they would leave…I can still help him now, bath, take care of him, go in and out, I can still do these things. It’s really not that helpful, I feel.”

In addition to community supports, the physician has also encouraged her to consider admission into a care facility. Jeannie declined the doctor’s offer to place Mr. Chung in long-term care for quite different reasons than turning down home support, namely timing and consideration of her husband’s feelings. She recounted her conversation with the doctor, “But I said, ‘It's not the time’,” and explained how she sees Mr. Chung would feel:

...because he knows things. Although he cannot express himself very well, he still knows that this is his home. He needs to be close to me. If he’s not close to me, he doesn’t feel safe and happy. Even when I go out briefly, he’d be concerned. So how can you leave him at the old-age home for the whole day?

Knowing that they did not want to be separated from each other, the doctor also offered “placement for both of them,” with charges applicable to Jeannie. According to the doctor, placement of couples is a service to facilitate couples to stay together “even [when] one doesn’t have the illness or disease, they [health care system] accept that. They
understand that they need to be together, if it’s available. It’s a long waiting list.” Jeannie declined this offer as well. The doctor thought that Jeannie would not have liked “the language, the diet, and also the social environment” of a long-term care facility, and that “almost 90% [of facilities] are English-speaking.” The doctor added that in general, such an environment is foreign to and hence can “scare” Chinese seniors, but unfortunately according to the doctor, the resources are simply not there to build ethnic-specific homes: “It’s just the resources is not there. The health system doesn’t have enough money to build enough nursing homes for general population, let alone for some certain ethnic groups.”

Nick agreed with his mother that his father should be cared for at home, “I feel that it is more appropriate to provide care ourselves.” The children, therefore, do what they can to support their mother. From Jackie’s accounts, this includes for example “driv[ing] them to Vancouver for [doctor’s] visits…buy[ing] their daily necessiti…talk[ing] more with her about things regarding my father-in-law.” Jeannie expanded upon this list, noting for example that, “Our daughter-in-law always comes up to do the cleaning for me.” However, family members are not always ready to share everything about their relationships and care arrangements. For example, when probed in a separate interview as to whether the other daughter-in-law or Nick’s brother shared the cleaning, Jackie digressed after an ambivalent reply, “Yes, [they take them to] see the doctor and sometimes do some shopping for her [Jeannie].”

Besides the family, friends and relatives are “very nice” too, reminding Jeannie to “take it easy. If you need to, if you need any help…. They tell me to speak up, let them know that they would do their best to help me.” So far, Jeannie has not needed extra help from
beyond her immediate family and although “we're still in touch occasionally but mostly we talk on the phone,” she rarely has time to ever see these friends.

Perhaps one of the main ways that the couple’s children help support their parents is by facilitating opportunities for social activities. For example, going for dim sum continues to play an important role in this family’s routine. Nick related: “What is not different from before is he still wants to go with the family for dim sum.” So the two brothers and their families always take turns or the whole family goes together with the parents. Going for dim sum is the family’s favourite pastime. As well, dim sum is a venue for talking. Jackie explained, “It’s mostly during meals, at dim sum, that we talk,” including talking about organizing and planning Mr. Chung’s care as a family, and Mr. Chung is always there with them at dim sum.

Jeannie emitted joy as she smilingly confirmed how Mr. Chung becomes ecstatic when:

*He hears his son is coming to take him for dim sum, he’s very happy and would be waiting for the time to come. When are they getting here? When are they getting here? Like a kid. He’s happiest when the sons call him to go for a walk and a meal.*

**Caring About Feelings and Feelings About Care**

How this family attends to and cares for Mr. Chung’s feelings and emotional wellness is exemplified in the way Jeannie cares for Mr. Chung bodily and emotionally. In addition, her accounts illustrated how her own feelings are intricately intertwined with his, and how the partners adjust to each other over time for the sake and comfort of both in living their lives together.
“My body is very tied down, my heart is always concerned”

Jeannie consistently adjusts her daily care in ways suited to Mr. Chung’s condition which gets “slightly worse every half year.” I recorded in my field notes how Jeannie pays attention to Mr. Chung in a quiet way that is attuned to his pace and comfort level during their mealtime:

Jeannie gave Mr. Chung an extra piece of food each time that he finished the one in his bowl. Mr. Chung ate all the dumplings and the noodles. She asked him to try to finish the vegetables, explaining to him that they’re good for him and that he needed to eat more fruit and vegetables, according to the doctor’s advice…. As he slowed down, she tried to encourage him again to finish the vegetables. She was constant in the pace, tone and volume of her voice with him.

In regards to her own feelings, Jeannie conveyed a sense of loss in how she misses the independent man full of ideas and abilities who would “touch this and do that…. Even the radios, he’d hook them up here and there and putt around.” As well, she misses the small pleasures from simple things and routines like food shopping that she used to but can no longer have or enjoy:

I like to go myself and see what's there...I like to go to the market and see what there is to buy [laughs]. I like to look at things myself. So I'm used to going out myself. My daughter-in-law would say: tell me and I'll buy them for you.... But if I see what I like to buy, I can buy what I want [laughs].

Taking care of Mr. Chung places his needs in some tension with hers, and inevitably interferes in some way with her own independence. All she permits herself is one day a week free time when Mr. Chung goes to the adult day program. Her social network has narrowed and Mr. Chung’s brother and family with whom they were very close had meantime repatriated to Hong Kong.
She commented on the challenge of caring when she likened her care of Mr. Chung to that of caring for “a little kid, from day to night, as long as he's not sleeping, you still have to care for him,” and expressed that she felt “stressed” by it:

_Now that I have to take over all his responsibilities, all on me, of course there is more stress. I have to do everything myself, I have to personally and physically do everything...watching over him 24 hours a day, looking after him, my body is [I’m] very tied down.... The physical and emotional stress is the largest. I have to pay attention to him in everything._

When asked to clarify whether the stress was from the physical care of everyday living or the emotional clinging because she felt “tied down,” she replied: “Everyday living is a problem and clinging is also a problem. Basically, you can’t separate them [laughs]. I have to follow him all day.” She has to follow him because she wants to avoid accidents: “Sometimes if I don't pay attention to him, when he does it wrong, there will be accidents.”

And accidents do occur. While she described some days are “not too bad,” others are more physically and emotionally demanding. Jeannie recounted a particularly trying episode after Mr. Chung got up from bed to urinate in the middle of the night and his legs gave way:

_After he fell, perhaps he really had to urinate, the urine leaked out and wet all his clothes. So [he] had to slowly catch his breath, and sat on the floor and finished urinating [giggly voice]. When he was done, [I] told him to crawl onto the bed and slowly, helped him sit up. I couldn’t help him up, couldn’t haul him up, and he didn’t have the strength to push himself up. I wasn’t strong enough. [We were] quite flustered then. Slowly after [we] caught our breath, [I] told him to slowly crawl back onto the bed, [I] helped support him to get up before he could get onto the bed. And [we] resolved it._

Despite great difficulty that night, they did not disturb Nick and Jackie living downstairs. The elderly couple worked together and managed to resolve everything on their own, somehow.

Like that day when she noticed Mr. Chung could not control the water temperature in the shower, this night signaled changes for Jeannie.

_After the incident, Jeannie waited three days before going to the family doctor. This_
wait was not surprising given how Jeannie feels about the futility of doctors and specialist
visits when there is no cure for the illness and Mr. Chung cannot tolerate medications.
Nevertheless, at the children’s insistence, she went for consultations, “I said that he’s
deteriorated in his walk this month. It seems as though he would fall anytime.” Nick too
noticed that his walk “has worsened” and Jackie described it “got worse and worse.” Such
moments of change have consequences on Jeannie’s body and being as well:

I’m more nervous about him. I mean my heart is [I am] always thinking about
him, I can’t sleep soundly…I mean [I] don’t sleep enough, my heart is [I am]
always concerned, I don’t sleep well, I sleep much fewer hours…I weighed
myself and this month, I lost two pounds.

Knowing the situation and what their mother is like, the children tried to remind Jeannie to
take care of herself. However, caring for Mr. Chung is something Jeannie does without
consciously thinking and weighing the pros and cons all the time:

...they always say that. My sons and daughters-in-law all say: you have to
take care of yourself. If you keep working to take care of him...and I'd say: I
can't help it. As long as I am able, I have to do it.

“As long as I’m around, his heart is at ease”

She continues to take his feelings to heart and keeps them at the forefront of her care.

For example, besides agreeing with the children that Mr. Chung should not be left alone lest
“he would fall,” Jeannie mentioned another reason. She ‘reasons’ about his heart and feelings
with her own heart and feelings:

He would be very disoriented. He wouldn’t know what to do, like he’s very
lost… I need to be by his side all the time. If I’m not there, he seems very
empty, lacking a sense of security.... Essentially, as long as I'm around, his
heart is at ease.

Most importantly, she connects Mr. Chung’s ‘knowing’ and ‘thinking’ to how he feels at the
time:
If I'm not there, it's like his heart is scattered, he doesn't know anymore, he doesn't know what to do…. All in all, when I am by his side, there are no problems, he is serene and happy. He would think in a stable way.

There was something particularly striking about Jeannie’s feelings about caring.

Apart from the rare moments when Jeannie expressed some kind of frustration about the situation, and only one occasion when she may have missed an opportunity to attend to Mr. Chung in her usual caring way, throughout the interviews Jeannie was always attentive and never spoke of Mr. Chung with anger or blame. Rather, she always spoke affectionately of him, whether in his presence or not, and often with a hearty laugh.

I recorded the one exceptional occasion in my field notes. I was asking Mr. Chung if he liked taking photos, and Jeannie, who was doing dishes at the sink, answered from the kitchen that he did. However:

[seconds later]...I was brought back to Mr. Chung’s voice calling for his wife’s attention: “Mom.” His voice noticeably lacked volume today, probably also drowned by the TV and the running water of the sink. She couldn’t hear him, so I called out louder for him, “Mrs. Chung, Mr. Chung wants to say something to you.” He spoke about showing me something but his wife couldn’t hear it. So I repeated that there might be something, pictures perhaps, that he wanted to show me? She didn’t answer. He then added that she didn’t like to show things to people. He repeated it in a stealthy way as if he didn’t want her to hear what he was saying.

Despite the exceptionally noisy background, this inattention was quite unusual for someone like Jeannie who always seemed attentive towards Mr. Chung. In fact, once she was done the dishes and had put Mr. Chung to bed for a nap that afternoon, Jeannie told me about the accident and fall a few nights ago. Her fatigue from lack of sleep since might help explain this unusual episode. Generally, they would talk playfully with each other, giving the sense of deep understanding and affection between them, and she always conveyed that his safety,
comfort and happiness are her priority: “In order that his heart is at ease…even if there's nothing to do, you just sit there in front of him, then he is much happier [laughs happily].”

Why Jeannie Cares the Way She Does

When asked why she cares for Mr. Chung the way she does, taking on the bulk of the care herself and utilizing few community services, Jeannie ascribed two reasons. First it is because of her Chinese values and beliefs, and second, the affection in her relationship with Mr. Chung.

“We should do our duty”

Jeannie immediately attributed the reason for care to Chinese values and beliefs, saying that it was her duty and responsibility to take care of him:

“All in all no matter what, we are Chinese. No matter what problems he has, whatever conditions, we should do our duty to take care of him…. Our custom, our culture, is to do that. This has been passed down to us.”

As well, she considered care of a family member more an individual than a public responsibility. She said:

“If I have the ability, I should do it…if the government has to help every single one, it will be a big problem for the government to help with everything. That's why whatever I can do, I try my best to do them.

Interestingly, Jackie thought that immigrants, compared to locally born Canadians, have fewer entitlements to services: “Perhaps being local, their benefits are better than those for the Chinese. We are still immigrants. I believe our benefits could be less than theirs?”

Nick and Jackie support Jeannie in caring by keeping up family routines with the parents, such as going for dim sum because routines give them positive feelings:

Nick: [routine of dim sum]…is passed on to us, I mean how it used to be done, now—I mean without knowing or thinking, you would do those
kinds of behaviours, I mean that's how it's done.

SM: What does it give you? Because if a person does something, there would be some motivation there...

Jackie: ...I mean [we] can see that he's happy.

SM: Happy.

Nick: Yes.

Jackie: Yeah, [we] can see that he’s happy...

From Jeannie’s articulation, this way of taking responsibility of Mr. Chung is a natural extension of their character, and who they are as persons. Her account of Mr. Chung very much mirrored her own personal stance on responsibility and duty:

As a person, he bases himself on his conscience...being responsible...genuine in his heart and mind to his family, parents, brothers and sisters. That's how he is as a person...a good person.... Whatever he does, he follows his conscience [kind heart]...he would do his duty to the best of his ability.

Conscience is the yardstick by which she has always lived. This is part of her Chinese culture, “Our Chinese mentality will say: In everything, we need to take our responsibility, do what we can until we can tell ourselves that our conscience should feel no guilt or blame.”

Ganqing

Interestingly, Jeannie related doing one’s duty and responsibility with affection. She cares for Mr. Chung the way she does because of “ganqing” 感情, a kind of mutual affection or affective feeling for another person that is usually found in important or long-term relationships. She described ganqing as:

What two people, all along, from beginning to end, it's the same, he treats me—that is he cares in every way. He's responsible towards the family, takes care of everything well, so I feel very content. That's why we continue into our old age...you take care of me and I take care of you. When there are problems, we solve them together. When there are good days, he shares them with me.

Jeannie confirmed that her statement infers a strong interchange between doing and feeling, and that responsibility is an action itself. By doing responsible work for her and their
children consistently over decades, Mr. Chung’s work generated good feelings between them and deepened their ganqing. Jeannie said: “In his life, he's fulfilled his responsibility as a daddy, doing his part to look after different aspects of the family. He has been a good father, a good husband. That's why our ganqing is quite good.”

That is why she too would continue to do her duty and responsibility to the best of her ability to care for Mr. Chung so that they could “continue supporting each other.” For her, it is a matter of fact as well as a fact of life: “When you get old, you support me and I support you, each other. It's simple.”

In supporting Mr. Chung, Jeannie is fulfilling her “promise of sincerity,” another yardstick by which she has always lived. When asked with whom this promise is made, Jeannie responded: “the promise is not necessarily made with one’s partner. Everyone should have a promise. Everyone should have her/his promise.” Instead of a promise with the partner as one would usually expect in marriage, for Jeannie this promise of sincerity returns to the “conscience,” seemingly with a connection to some higher order:

\[It’s the promise of sincerity [laughs]…. Most important in life is, no matter what people say, no matter what people do, most important is one’s own conscience feels no blame. You didn’t let down the sky and the earth [deities]. Then your heart can be at peace.\]

**Moving Forward: “Much Better Than Those That Are Worse”**

Jeannie’s case is characterized by stability alternating with tension and contradiction. She vacillates between contradictory understandings of Mr. Chung’s condition as a disease and as part of the normal aging process. As well, a sense of calm accompanies intermittent stress as she tries to balance care of Mr. Chung and her own needs. For example, even though she finds caring for Mr. Chung “a bit clinging” and that she has lost her “freedom” as a
result, overall she seems quite pleased at how well she has adapted to the new situation that heaven has sent her way:

Actually, it’s routine for me now to take care of just him, one person.... My body is very tied down, right. But in these three years or so, I've got used to it...my whole heart now is on looking after him, I have no other worries.

By drawing strength from her Chinese cultural beliefs and values within a supportive network of family relationships, Jeannie is able to derive positive aspects from caring. Specifically, she draws on duty and conscience on one hand, and her “ganqing” and affection with her husband and children on the other.

Her desire is to be able to continue to care: “I pass day by day with him. I don’t have many expectations.” By that, Jeannie meant passing the days with him the way they have always lived, independently, with very limited use of public resources: “I feel that my condition allows me to be independent. I can do it by myself, I don’t have to bother others…I still don’t need help from others yet.”

All she hopes for now is that “his health is good, my health is good too…so I can look after him for longer.” Indeed the question of how much longer she can continue in her role crosses her mind occasionally:

Because I'm not young anymore, right? With my age, and his weight, if I need to assist him, support him, to go to the bathroom, or how to care for him, it will be quite demanding. Now that he can still walk and move, I'm still okay.

In other words, she recognizes the uncertainty of their situation. The safety valve, should he no longer walk or move, is potentially governmental support: “But I hope that the government, when I do need and ask, that they can help. Of course that would be best, right?... If there are for example equipment and facility in the home.”

In the meantime, she is managing their situation which she considers “not as good as
those that are better, but it's much better than those that are worse” and puts her future into the hands of heaven:

I don’t think about taking care of myself or my situation... I can't think that far, what to do with myself... I dare not think about it... take it one day at a time.... Whatever happens later on, we'll worry about it then... I just hope that I'll be fine, with some luck. Life is simple. We—basically our Chinese mentality is like that [laughs heartily].

Jeannie’s Chinese mentality seems to give her not only strength, but also comfort.
CHAPTER 5.
“ROT IN THE BASEMENT”

Derek Ma is 89 years old and has been providing care for Vera, one year his junior, all by himself since she was diagnosed with Alzheimer’s disease 9 years ago. Vera has been taking medications since. She has practically no more memory and, other than her hearing problem of 60 years, no significant health issues or problematic or challenging behaviours that could exacerbate care demands. Derek is in good health.

They came from China originally and immigrated to Canada in 1970. They were living with their son Peter, his wife and two small children in a suburb of the Lower Mainland at the time of diagnosis. A couple of years later, Derek decided to move out with Vera despite Peter’s plea with them to stay. They have a good relationship with their son and sufficient financial means to live independently.

The couple first moved to an apartment in South Vancouver. During this period, Derek took complete care of Vera. Three years ago, they moved into the current assisted-living facility for seniors in Chinatown. Besides lunch and dinner services, the couple does not require any of the other services such as personal hygiene or administration of medications that are provided to residents of the facility. Derek takes complete care of Vera and requires little or no help from Peter except for translation at specialist visits where language becomes a problem. Derek minimizes calling Peter for help to these instances as he knows his son has his own family to take care of. Derek takes care of Vera’s every detail and brings her with him everywhere, including driving her to weekly church service and back to Peter’s place to spend a few days every week with the grandchildren.
The couple just celebrated their 60th anniversary with family and relatives. Derek is happy about their living arrangement and particularly proud of how well and independently he has been taking care of Vera. In this regard, however, he expressed time and again how he does not share what he perceives as the traditional Chinese idea of living in a large family where the youngsters have to go to work, leaving the elderly to “rot in the basement.” In order to better understand what Derek means by this repeated statement, it is useful to take a look at who the couple are as persons, their history and the relationships around them, which may shed light on why he does not want to live with his son and prefers to provide care for Vera in his own way.

**Who They Are**

Although he walked with a slight stoop as he came to open the door at the main entrance, Derek had a tall and lean body, neatly cropped grey hair, wore glasses and dressed simply and tidily in a sweater over a shirt and grey or dark pants. Vera was also tall when she stood up from the sofa, a slim and smart-looking woman, much like Derek, dressed in a sweater over black slacks, and wearing fashionable black, thick-rimmed glasses. When he introduced Vera, Derek mentioned briefly that Vera has had hearing problems for decades and could not hear much. She could lip-read sometimes. During the first interview, she was very quiet.

They live in a small but bright one-bedroom apartment. Windows spanned the length of one side of the apartment with an open kitchen at one corner. At the entrance of the apartment was a computer and above it, binders neatly stacked on bookshelves on the wall. Recognitions and awards of community participation and service lined the walls of the living room. In fact, in his slight Fujian accent, he intimated at the first interview that he has always
helped the research community by participating in various studies about knowledge and experiences of caring and living in Canada. As well, he participates in interviews with TV stations and other media in the hope that the information could benefit others in the community.

Derek always sat in his rocking chair facing Vera and guests on the sofa. The television in front seemed huge for the size of the small sitting area. There was a washing machine and dryer in a small storage space behind a cupboard door on one side of the room, and shelves for photo albums under the windows on the other side. Decorations on the shelves encircled a digital photo frame next to a small fortune-bamboo plant standing in some water. Derek explained that the digital photo frame was a gift from their teenage granddaughter and grandson who wanted to share with the grannies photos of their recent vacation with mom and dad in Hawaii. Derek seemed particularly pleased to draw attention to another frame in which the granddaughter was receiving an award of achievement for earning first position in her grade the previous year.

Achievement tended to play an important role in Derek’s accounts of his life. The arrival of Derek and Vera in Canada was quite an achievement in itself. To better understand this achievement, it is important to situate the life voyage of the couple within some of the history that predated their travels together.

“When I think it’s not good here, I’d try somewhere else”

Derek had always been on the move from a young age. In particular, his moves from when he was a teenager enabled him to learn how to survive with friends and take care of each other:

*My family was from the countryside…my father [from Fujian, China] went to*
Canada and I was with my mother in our village. I went [to the city] at eleven and when I was 15 or 16, the war started. When the war started, I fled with the school on my own. I was separated from my family...shelter was always provisional. [We’d] flee to one place, the group of us schoolmates, we would look for a place to rent. It was like a group of sisters living together...[I] depended on my father’s remittances.... We lived together. It was never like I had money and I ate, and you didn’t, that’s your business. Whatever came, we spent it together. And then we waited to see whose money came next.... We cared for one another.”

Derek had always gone back and forth between China and Hong Kong for his schooling before the war and university education after, as well as for the birth of Peter later.

An accountant by university training in Hong Kong and by profession, Derek continued his travels for many decades. He kept moving with Vera and the children from 1949, from their land of origin, Mainland China, every 10 years because of circumstances until they reached and settled in Canada in 1970:

[from] China it was because of war that [we] moved to Hong Kong. In Hong Kong, it was because of a living, I had to look for something to do. But when the conditions in Hong Kong [for his car business] were not good, when there didn’t seem to be a future for me or room for expansion, of course I wanted to look for a better place. At that time, I heard about Borneo [Malaysia]. As a person, I have the ambition to better myself. When I think that it’s not good here, I’d try somewhere else. If young people do not try this way, you wouldn’t know. Why not give it a try? And I got to Borneo. I had a stable job myself [accountant] and she was teaching. Of course our circumstances with the children going to school, it was OK. The moment they finished, the circumstances changed again [no university in Malaysia]. What to do after they finished? So [we] looked for answers and moved here [Canada].

Like Derek, Vera must have come from a family with good resources. I could see while we were looking at old photos together that as a young lady from a family also from Fujian, she was energetic and even drove a car. Derek commented on the photos: “She was very active when she was young...the best at swimming.... Yes back then, for that time. She even had a driver’s license.”
In another photo, Vera was posing next to a motorcycle. She explained, slowly and with some delay: “That’s me again…I learnt how to ride on it sideways…learnt how to sit on it.”

Her father was just as impressive. Pausing at one photo, Derek recounted how her father “invented this car—he himself invented not to use petrol, it used coal…it ran on coal…burnt coal.” He added that the car was not for business but for personal use, to which Vera confirmed, “It was our own…our own private car”.

Vera must have been quite sociable too. Her fingers lingered slightly on the photos of a group of young women. Vera expressed “…my schoolmates…” to which Derek added details, “Colleagues, [she] helped them put on makeup…one after another…at their wedding.” She extended this sociability later to fellow churchgoers of a Protestant church they have been frequenting in Vancouver, “She was always driving church sisters and brothers to meetings.”

Immediately after they arrived in Vancouver, Derek found a job as accountant in a fruit and vegetable wholesale business despite earlier concerns about starting all over again. Friends had reminded him of his age, 50 years old then, and what he felt was “very poor” English because he had studied at a Chinese university. Derek recounted that after several years at the wholesale company, “I had the chance to get into business again,” when he and his coworkers bought the enterprise from the owner who was retiring and ran it successfully “and made money” until Derek himself retired in 1987, selling his shares.
“I accept local ways—that’s why I’m different”

Thereafter, the elderly couple moved to a suburban neighbourhood in the Lower Mainland with Peter and his wife, mainly to help look after their first grandchild, a baby girl, while the young couple went to work. A baby brother soon followed.

Derek emphasized his preference for separate living quarters because of his belief in the age-old Chinese saying, “[I]t’s good to see each other but difficult to live together.” His living arrangement reflected his belief:

That’s why I built a house with the different floors separated. I didn’t live in the same house each with his/her room, like in a big family. I’d rather you be in yours and I in mine for cooking. We two cooked whatever we wanted to eat, that’s our business. You take care of your own.

Derek speaks about the traditional Chinese norm of large families with multiple generations with distaste, calling the idea “old fashioned,” and that his “way of thinking belongs to us modern people.” He explained that what makes him modern is because he “accept[s] local ways. That’s why I’m different”:

I came to this place Canada and saw it was multicultural and the environment is different. All the Westerners are independent…once they’re grown up, they go on their own…. Only we Chinese want everything—[voice changes to express ridicule] “Son, you live together with me, eating together is good.” Westerners don’t do that.

In fact, Derek has a unique way of describing his cultural background on the demographic survey. His answer was, “gen chiu lau [follow the trends]”.

Interestingly, Derek had no problem with Vera’s parents coming to live with them in Borneo. He explained that the times are different now:

I do it for the younger ones, each generation to his own. The young ones should live together among themselves…. It wasn’t like that before. But now our generations, we divide things very clearly…. The generations are different…. Let them be free, we be free. The main point is to have a meal together and see each other.
He drew the dividing line first because “[f]or me, I like to have clear boundaries and hierarchies,” and second and more important, he was doing it for the younger generation’s sake. His intention was to minimize material and other encumbrances on the younger generation so that they could have more room and freedom to develop in their own direction:

*He’s [parent is] retired. How can he take care of you? If the son doesn’t have it, I don’t have it either. How will I have money to take care of you when I’m retired?... You go expand on your own, go do your own things.... So you [I] have to draw the line [boundaries] clearly.*

Thus the grandparents took care of the grandchildren and each family did their own cooking and other things in their own quarters. According to Peter, Derek still “likes to, he likes gardening. He likes to putter around the house,” when he comes with Vera on their weekly visits. That was how the two families used to go about their lives, together and separately, under one roof.

However, in 2000, Vera started becoming forgetful and began losing things, at times accusing someone in the house of taking them. At that point, Derek knew something was amiss. He took her to see the doctor who referred her to a specialist and Vera was diagnosed with Alzheimer’s disease. Derek recounted that against Peter’s entreating them to stay, “There’s a floor, there’s space, you don’t have to move out. There’s everything downstairs, kitchen and all,” he decided to move out with Vera in 2003, to an apartment in Vancouver. Peter, nevertheless, understood his father’s good intention, “I guess in his mind he doesn’t want to burden us.”

Although living apart, close connections between the two families have continued. Derek recounted that he and Vera still went on pleasure trips with his son, daughter-in-law and grandchildren after they moved out. However, their travelling together with the family
had stopped because of Vera’s condition: “She used to like it before but now with age, [we] do without as much as we can, too troublesome.” Giving up travelling was not a big sacrifice for Derek as he had seen the world, “Everywhere. I came from Malaysia, I’ve been all over the world. Everywhere.” Rather, he seemed quite pleased the way they are “always in touch” with the family. At least weekly, he drives Vera “home,” the one in the suburbs with Peter and his family. Incidentally, even though Derek lives in Chinatown with Vera now, he still considers “home” where his son and family are, where he and Vera would “go home to party” on holidays and festivities such as for the birthdays of the seven or eight grandchildren among their closest relatives, “sometimes at my house, sometimes at theirs.” Family and relatives include “we two are the eldest and her younger brother,” who has children, Peter’s cousins, as well as grandchildren.

**Doing Everyday Care**

The elderly couple goes about their everyday lives quite happily and serenely. With two meals served to them at the dining hall, their other activities on an average day are:

*We would watch TV. Because all the actors/actresses of the 60s, she still has some idea about them…she watches those. When she gets tired from watching TV, she would get into bed and sleep a bit…. And I would do my own things. I’ll go on the computer and what not. When [she] comes out, I would stop doing what I’m doing, and keep her company, sit down together…after her nap in the afternoon at 2 or 3 o’clock. [we] might go for a walk to [the supermarket]…to [the wholesale store].*

Amidst their everyday routines, they are in close touch with their son Peter, his wife, and the two grandchildren:

*Every week, we call them to come out for dim sum. And every week, I go home to see them…connect with them. I take the grandchildren out for meals, dim sum…. Wednesday, I would drive to go home…spend the night there. Thursday, [we] come back here.***
And “on the day of the Lord,” he takes Vera to church service, a short drive from their apartment. Occasionally, he goes out with friends and acquaintances from church or “for dim sum with ex-colleagues from work,” and he brings Vera with him.

Having to care for Vera on his own did not set off any particular alarm for Derek. What follows are mainly Derek’s accounts of caring for Vera as if it were any ordinary day. Worthy of note is first his emphasis on how he is no different from any ordinary person living an independent life, and second, the practical approach he takes when mediating and planning for Vera’s care, building relationships around her in the process.

Caring independently: “I completely manage by myself”

When asked how he felt at the moment he received her diagnosis, he said: “When [I heard] the news, nothing.” He took it as quite an ordinary matter: When a person is ill, s/he takes medications the doctor prescribes: “She took medications and everyday passes like another.” He felt nothing extraordinary about caring either, “She didn’t have any particular conditions…there’s nothing particularly difficult in taking care of her.”

He related how he took complete care of Vera when they first moved to an apartment in South Vancouver along the Fraser River:

*I was retired then. So I cooked, I cooked everything. I didn’t need her to do anything...I did everything myself. I took care of everything. The purpose why I moved out was to care for her...we’d drive to do our shopping because at that place, you have to drive everywhere.*

For exercise and leisure, “We would go for a walk by the sea. We went downstairs and it’s the seashore. We would walk by the sea and come home after.”

While living there, the case manager for Vera enrolled her at a Chinese-speaking adult day program in Chinatown. Derek also joined support groups where carers “all talk a
bit about their elderly person, their things and what’s happening…. It’s only information…. It’s the same every month…. Nothing special.” At the various programs, he learnt about the illness and services through “presentation and discussion groups, I would participate and listen. So I’m very familiar with medical material. I understand very well.” As well, he met service providers and heard about an assisted-living project for Chinese seniors under development. Derek recalled, “I got it the moment I applied,” and the couple became one of the first residents to move into the building when it was completed in 2006.

After moving into the assisted-living facility, some aspects of caring remained the same and others changed. Examples of continuity are giving Vera her medication, doing the laundry, driving her to church service every Sunday and bringing her “home” to see the grandchildren every week, shop at the local Chinese supermarket, or stroll or have dim sum with friends in the neighbourhood.

Caring changed in terms of domestic chores such as vacuuming and cooking which became optional as the services are provided by the facility: “They help us vacuum…[we] eat downstairs, I don’t need to take care of that. They cook, when it’s time, [they] call her to go downstairs to eat. [We] make our own breakfast here.”

With the voice of an expert like Jeannie, Derek described how, besides breakfast, he would prepare extra meals and snacks for Vera because he believes that “for seniors, [they] should eat less but have more meals.” In fact, he was able to help Vera regain the weight she lost after an illness. Like Jeannie, he feels proud about the expertise he has developed as a capable and independent carer as defined by his ability to attend to Vera’s nutritional and other needs: “That’s why the nurse said that she gained weight…the nurses downstairs say that I completely manage by myself. You don’t need us to help you [laughs]. I say ‘yes’.”
Derek likes these compliments, and similar to Jeannie, he particularly cherishes his independence. Throughout the interviews he emphasized how he takes care of Vera all by himself:

*The nurses are actually here to care for the others who are physically challenged…. We don’t need [help], no need at all. I look after her… I don’t bother them at all, not for medications, not for shower, not for anything.*

That he can take care of his wife all by himself is what distinguishes him from all “the others” in the building. Time and again, he stressed this difference and how the assisted-living facility for him, if not for the meals served, is simply an apartment like any other:

“Here is an apartment…I am totally free to go in and out…I mean for me, it’s like living in an apartment here, it’s the same. The others are not. They [nurses] have to take care of them.” His sense of independence is so strong that it seems like he does not even let his own son get too involved in care: “Where my son is concerned, when you ask him, you’ll find out that he doesn’t need to provide any care specifically.”

Other aspects of Derek’s caring for Vera resemble very much those of Jeannie caring for Mr. Chung. For example, Derek recounted that care involves “watching over her all the time…in the shower…when she puts on her clothes…how she eats…” Similar to the observation session of Jeannie and Mr. Chung at lunchtime, Derek had to keep reminding Vera to eat some more, and Vera would take another bite with the reminder. With an amused laugh like Jeannie’s, Derek summed up taking care of Vera the same way Jeannie depicted care for her spouse:

*You need to remind her, need to instruct her…in everything. Because she’s like a kid, a newborn child, she doesn’t know anything…you need to tell her. If you don’t tell her, she’d put the underwear on top [laughs]…makes a mess. She has no memory…. That’s why I have to care for her in everything.*
Even though Derek speaks of Vera as having Alzheimer’s disease for which he takes care of administering her medication, his accounts often reflected an understanding of the disease as merely a problem with memory. He repeatedly described the disease as “the illness of no memory because this illness is all about not having memory, that she forgets immediately,” which he then translated for the grandchildren into “grandma had become clumsy.” Furthermore, he echoed Jeannie and her children that the illness is part of the aging process, “Like she has no memory now, OK, whatever. That’s what life’s about…. Everyone will get all kinds of things when they grow old.” Nevertheless, according to what Derek has heard, the disease could become much worse, even if that is not yet their case:

*People say she would lose control of her bowels and bladders in the future, and this and that. With this illness, sometimes they would hit people, run out into the street and not return…. I said, ‘No, there’s nothing, I don’t find anything of the sort.’*

**Mediating and planning**

Most remarkable about this participant is the extent to which he mediates and balances for services in a practical, assertive and proactive way. An illustration of his practical and assertive approach is how he kept two family physicians available, one in their downtown neighbourhood while keeping the other one in the suburbs. Derek explained simply that the arrangement is for “convenience.” When the doctor made some remark to him regarding the subsidized medication Vera had been taking, he assertively offered the following suggestion: “The doctor said that she’s taken so much medication, s/he’s not sure if the government would still be willing to…. I said, ‘You just tell them that there are no changes,’ meaning that the medication is effective, right?”

His assertive style manifested itself in other ways. I saw in various instances how, always in a correct and friendly manner, he negotiated with staff for services, and
investigated with staff for expected services not rendered. The day lunch was not delivered as usual after Vera’s fall, my field notes read:

> He called downstairs later to complain about the tardiness, that there was no vegetables, and that they had to consider that he could not move from the apartment because he had to watch her. He accepted that there was substitute staff today.

To people who remarked about driving at his age, he responded practically: “They say you’re 90 and you’re still driving? I say I can’t help it. If the government says I can drive, I’ll drive.” After 40 years in Canada, Derek sense of entitlement is solidly grounded: “When you’re retired, the government provides for you.” He expressed how there should be more public resources going into building assisted-living facilities: “The government should establish more of these places.” Nevertheless, like Jeannie, he also appreciates the need to be cooperative, considerate and respectful of limited government resources that are available, using his dining hall experience as an example:

> You just look at this big [dining] hall, it’s for public use. It has to provide food for so many people. If you can, each person says you won’t eat this, you won’t eat that, how can the kitchen manage.... When they give you something, eat it if you like it. If you don’t, eat less.... Don’t have to make so much noise about it. You make it hard for the others to manage. That’s how one should be in life.

His practical stance extends much further and is most evident in his proactive participation in the community, “I join every activity [and] opportunities to participate,” and in the assisted-living arrangement they are now in, Derek recounted that after reading his morning newspapers downstairs, “[I] help out at the front desk…until 9 o’clock when the receptionist arrived and took over.”
Peter described how Derek “helps with everybody, getting pictures printed from the electronic files [on his computer]…send it to [wholesale store], and then walk over to [store] pick up the pictures and bring it back to the staff.”

In his give and take, Derek sees himself as a contributor and partner in care: “I always help them…I’m what is known as volunteer. They downstairs call me a volunteer who helps them do things.”

Peter recalled how Derek’s active contribution to community life was awarded with “a personal commendation from the Queen…[for] the 60th anniversary or something like that. They got a certificate [laughs].”

Derek supplements his proactive work with nice gestures to help maintain the good relationships he has built around Vera and himself. For example, he always offers food to the nurses and staff when they come to visit: “There’s everything in my fridge. Cakes, everything’s there to eat. For fruit, there’s all kinds,” and this gesture brings positive interactions, “everyone is very easygoing with me.”

From how he considered himself at the beginning as a carer without “much clue, I just looked after her,” Derek became the mover and pivot of care for Vera, planning and organizing to the last detail, to the point where Vera would be taken care of with the best available options within existing health care resources, and without having to bother Peter, should Derek himself not be there or able to take care of her:

When I can’t do it, I’ve told downstairs…to the village head [manager] …and to those from the social service department…. They say they’ve input it all into the computer. In the future, people can turn on the computer and know her condition, what her situation is….In the future, the government would take care of her. I moved here in the hope that there is a record here…even if I’m not around anymore, she would have a chance and I wouldn’t have to, our son, to apply all over again…you get transferred next door to long-term care for seniors…transferred automatically. I’ve thought about all that….I’ve made
the best choice. I’ve planned for things for the future.

Caring About Feelings and Feelings About Care

Besides the practical aspects, similar to Jeannie’s case, much of Derek’s caring involves attending to Vera’s physical well-being and feelings. With his own understanding of Vera and the illness as background reference, Derek lets Vera guide his way of caring. In so doing, he keeps her feeling settled, involved and secure, and in turn, he feels good himself and she thrives.

Attending to physical well-being and feelings: “She can wait here with a calm heart”

Derek’s very first response to Vera’s hearing problem is to listen: “I know this, when she talks I listen.” In addition, he finds various ways to communicate with her: “Because she can’t hear, [I] can only use gestures. I gesticulate for everything…. At times, she lip-reads. Sometimes it’s not clear from reading the lips. When she doesn’t understand, I would write it on a piece of paper.” As well, he labels everything for her:


Writing notes and labeling are particularly indicative of Derek’s belief that Vera can understand as well as organize herself. He writes her notes too when he has to go out in the morning before she rises, “Everyday when I go out, I write her a note: I’m going downstairs now, downstairs to pedal and walk. You stay here and wait for me. I’ll be back in half an hour.” He would let her know in the notes should he have to run errands at “the bank” or “get medication,” which would take him longer.
According to Derek, written communication is particularly important for persons with dementia like Vera who cannot hear. With the notes:

*She waits for my return. She can wait here with a calm heart [serenely]. If you don’t tell her where you’re going, she’ll—if she doesn’t see you, she’ll worry and look for you. You write the note for her, ah she knows where you are.*

Derek added that understanding the importance of space in relation to Vera’s physical well-being and feelings, and organizing physical spaces accordingly, further enhances her feeling of serenity:

*That’s why I’d rather not live at home with plenty of space…in a small place, she can see me sitting here, working on the computer and she wouldn’t care…where she can see you all the time, she is very serene.*

He pays close attention to her feelings and wishes but gears his response according to what her body is capable of, using persuasion when he has to say no to her, such as happens on very cold wintry mornings: “She wants to come walk with me. I tell her not to come for the walk with me because it’s cold in the morning and you can’t walk to far away places. I appease [tum in colloquial Cantonese] her.” Where persuasion does not work well, he uses other innocuous but effective tactics:

*Whenever it comes to this type of patient, they have a strong personality. If she says it’s like this, it’s like this…. Even if she is wrong, you just say OK. If she says, “Today I have to go to the US,” you just say OK. She’ll forget the next moment. You need to handle this way.*

He finds it quite amusing that at his day and age, he has to start doing things against his religious beliefs, “With my belief in God, I can’t help telling lies [laughs].”

**Letting her guide his care: “She knows how to use her strength”**

Derek found this way of following Vera’s bodily rhythm and cues beneficial both to Vera and himself: “You can only go along with them, not let them get irritable, not excite
them, and that also means no stress for myself.” Accordingly, he lets her lead at mealtimes:

“She’d eat it if she likes it. If she doesn’t, she wouldn’t. Sometimes she’d say she’s full. I’d say, ‘Don’t eat if you’re full’.” Other times when he could see she has not eaten much, he would remind her to eat some more.

Derek trusts Vera’s ability to know the capability and limitation of her own body. One observation session took place barely four weeks after Vera had a serious fall, injuring her knee that kept her in hospital for three weeks and sent her home with an apparatus that held her knee together. Unlike Jeannie who thought Mr. Chung’s brain could not learn anything, Derek was proud to detail that once home, he taught Vera by showing and helping her in a practical way how to use a walker in “just one day and she learnt it”:

> At first when I told her to hold the ‘walker’, she would pinch it with her fingers. She couldn’t lift it. She couldn’t push it. Nothing. So I held her hand and said: “Now push like this. Push like this. Push like this,” like that. And now she knows. She holds it and pushes it herself. She can turn herself. I taught her myself. They taught her at the hospital. They did teach her but she didn’t learn. She has no [cognitive] memory.

Very soon after, Vera began to walk again without the walker. She moved incessantly from a chair to the sofa and back again for almost the two full hours I was there. At one point when she was lowering her body, she said, “Ah it’s very tiring!” Derek was watching her closely, then pointed to a chair and said softly to her, “Come, sit here,” advising her, “sit here, don’t sit there. It’s too low [there].” When Vera sat down on the low sofa, he laughed and explained:

> Now she is so steady, I’m less scared. I can sleep through at night…. She keeps getting up and down. It’s like that all day…it’s fortunate that she does it slowly and steadily…. She knows how to use her strength to hold on…to support herself…. As long as she can walk, just let her walk, exercise a bit.

He added that his maxim of letting her and her bodily cues lead him works well, “Basically,
[I] let her do whatever she wants… You just watch her and let her do what she likes.”

In summary, his job as her carer comprises mainly two things. The first is to keep her healthy. Besides a good diet, he helps her stay active and occupied to maintain good functioning and independent bodily capacities that distinguish them from the ‘others’ in the building:

What’s most important is to find activities. I take her for a stroll, just so [she’s] not doing nothing…. Basically more walks and movements. That’s why she doesn’t need a cane or wheelchair, there’s no need. She doesn’t need anything. She continues to walk. We both walk. Here, everyone uses a wheelchair.

He cannot do the first job well without the second, which is to care for her in a way that keeps her feeling settled, involved and secure.

**Keeping her feeling settled, involved and secure: “Be close to her”**

What Derek can share about good care is that, “if you settle her, she’d be fine.” Nested within his descriptions of how he attends to her body and feelings in order for her to feel settled and serene was an invaluable piece of information. This information suggested how much the two of them are intricately connected, and that if she is fine, so is he:

Most important is to watch over her, care for her, be close to her. She wouldn’t want to be alone…I had to bring her with me. Why? Because I worry, I’m afraid she might go out on her own. As well, she feels a sense of security.

That his feelings are so closely intertwined with hers comes as no surprise given the very tender and loving way they interact with each other, in particular, how unaffected he was every time she did not recognize him as her husband. Yet she ‘knew’ who he was and called him “ba-ba [dad]” instinctively all the time. Rather than being offended, disappointed...
or upset, he found it all quite funny and amusing. For example, they were conversing below
over a photo of the two of them when they were young:

Vera: That is my—that boy—I don’t know what he’s doing. He’s
accompanying me, next to me.
Derek: [getting her attention, softly, pointing to himself] Eh, it’s me, this is
me.
Vera: Not you.
Derek: Not you [looking at her ever so lovingly and laughs].
Vera: That face, it’s not you.
Derek: That face, it’s not me [laughs]...

Where she recognized herself and her bridesmaid in another photo taken at their wedding,
again she did not recognize Derek. She would not believe him that he is the man she married
in the picture. She would repeat this again at lunchtime in the dining hall. She asked me
suddenly at the table, “Who is this man?” pointing to Derek, “Who’s he?” When I asked her
“Who’s he according to you?”, she just looked at Derek but did not answer. Derek likes to
poke fun, saying: “She thinks I’m her dad. Then she asks me when I am going to get married.
If only she knew about my 60th anniversary!”, with Vera, obviously.

Helping her thrive: “I have such a good husband”

How Derek accepts Vera just the way she is and cares for her so that she feels settled,
involved and secure seems to allow her to thrive, and to continue being the enthusiastic,
warm, affectionate and spontaneous person she must have been always, before and after the
illness. For example, when a neighbour dropped by to visit her after she came home from
hospital, she waved her arms at the gentleman and said “Ayah!”, clapping her hands with
enthusiasm, before saying, “How are you?” In particular, she seems to like the touch and
warmth of another person:

Lunch was over, we went slowly slowly, all the residents had started leaving
the room. We also left. I could see she was also interacting with other
residents. They were acknowledging her. They were smiling at each other and Vera would touch the other person, such as touching their arm or holding onto their arm.

When Derek took pictures, she put her hand on my shoulder.

Besides being warm and enthusiastic, Vera can be quite spontaneous and witty as well. We were holding open the apartment door for Derek to pass through and she remarked “So dead heavy!” There is a playful side to her that engages others to interact with her.

For example at lunch, she asked the dining hall manager to feed her, “I want you to spoon-feed me,” then immediately added “I’m just joking.” When the manager actually fed her a spoonful and said, “Now you can eat yourself,” Vera responded with a smirk, “No I can’t.” After some brief exchange between them, the manager gave Vera a gentle squeeze on her arm before walking to another table.

From what she says or does and how she interacts with people, Vera really gives the impression that she knows what is happening around her. This was evident in other instances. Shortly after being seated at the table in the dining room before food was served, she asked: “Why is there nothing on the table?” When Derek carefully moved a pair of chopsticks and put them on top of a bowl in front of her, she remarked, “I’ve got them already,” indicating the chopsticks placed on the table before her. At Derek’s repeated urging for her to eat some more, she responded, “I’m tired of the food.”

She never forgets her good manners either. After she excused herself to go lie down and was walking towards the bedroom, she stopped midway, turned around, and asked me, “Would you like tea?” When Derek gave her a cup of ice cream, she asked him if he had offered me one, and as the gentleman who visited was leaving, she asked him, “When will I see you [again]?”
Vera has been impressive since the first interview. She was very present despite her silence that day, sitting quietly almost throughout the whole interview. Derek had done all the talking about his care for her and their daily lives when she intercepted, “I really thank this husband who helps me the way he does.” Later again, she said: “And he’s done his best. And after I’ve listened, I have to thank God. I have such a good husband.” It must have been nice for Derek to hear how much Vera appreciates him and all that he does for her. Small wonder he continues caring for her the way he does.

Peter, however, expressed concern about the situation, in particular about his father’s physical condition: “But, uhm, what we could see [is] that he’s being run down. He’s doing a lot. He spends practically all his time looking after her. And at times you can feel there’s a sort of tiredness in him.” Peter thought that his father’s fatigue was the result of having to watch over her all the time, getting no “reprieve…I guess he didn’t have the heart to go somewhere else or sleep alone.”

In fact, some months into the interviews at one observation session, I also noticed some change in Derek when he was getting Vera ready to go downstairs for lunch. I wrote in my notes:

*I could see he was having difficulty reaching for the other side of the vest from behind her back. With some effort, he got her second arm through the sleeve opening and zipped her up. I noticed he was stooping more and more. He also seemed more tired. Today, he was visibly much shorter than Vera even though I didn’t seem to notice such a big difference earlier.*

Regardless, Derek continues to forge ahead, caring for Vera every day just like any other ordinary day in life. He knows that he is providing the best care possible for her, this person whom he would look at with fondness in his eyes and calls “this missy of mine.” Small wonder too that Derek recounted what staff had to say about them: “Staff would say,
‘You two oldies look like you’re love birds, always touching and holding hands when you go out’.”

**Why Derek Cares the Way He Does**

When asked why he cares for Vera the way he does, Derek offered two main reasons. One is their affectionate and long-term relationship and the implicit responsibility that comes with marriage, and the other is a practical reason in that what he does befits his and their circumstances.

**Long-term relationship and marital obligation: “It should be that we take care of each other”**

Derek had actually met Vera in secondary school, “Now when I first went to Hong Kong when I was 12, with her we were schoolmates then, at CY Secondary School.” He emphasized how they were simply schoolmates and friends at the time. During the Japanese invasion, “We each went our way, fled the war.” He met this “old friend” again “accidentally” on the street” after the war:

*At that time, we weren’t that young anymore. We needed some courtship to get to know each other. Only then did we seriously—we courted for about a year, my dad in Canada came back to the country to retire. [He said:] ‘You’re so big now you should get married.’ OK, I’ll get married, and I did.*

Derek described how their long passage in life together cemented the bonds of their relationship in 60 years of marriage: “But our daily living, our daily lives after marriage—we were together. Whatever sufferings I had, she would forgive me. Whatever she had, I would help her.” Their life passage together moving from place to place had more than its fair share of trials and tribulations in terms of experiences of parenthood: “I had other sons and
daughters [he was speaking very quickly, almost stuttering, then back to normal speed] but they had innate defects. Some afterwards, some like that. There’s only a son remaining now.”

Specific to his reason for caring, Derek did not explicitly name the cultural values of duty and responsibility like Jeannie did. Rather, he wove the reason of their long-term relationship into the responsibility and obligation of marriage whereby the person who is well ought to do his or her best to take care of the other who needs care:

_What I mean is: We’re two old people now. I’m [we’re] married 60 years now. Now that she’s not well physically and I’m fine, it should be that we take care of each other, of her, right? I will only do to the best of my ability to take care of her. Take care one day more._

**Be practical: “Do according to circumstances”**

In addition to his sentiments, taking care the way he does has its practical aspects. First, Derek sees caring as a natural process in life’s trajectory: “Everyone will get all kinds of things when they grow old. When something like this happens…[we] can only live each day as it comes, right?... Just flow with it naturally…. You can only do according to circumstances.” In fact, he took the news of the illness as a matter-of-fact kind of event and focuses on the practical consequences, “The doctor said [she] had to take medications, I said OK. If [she] has to take medication, she’d take them.”

Second, caring this way fits well with his circumstances at this point and time. He feels he has done and seen as well as had enough in his life:

_Now, since I retired at old age, I’m very serene [calm heart]. Clothes, etc., I’ve bought everything from before already and don’t need anymore. Food, it’s all included here, food and accommodation. Whatever you like to eat, you can add and cook it yourself. There’s lodging, a car to go around. Or when it comes to worries, there aren’t any._

He has the energy and ability to take care of Vera, probably better than anyone else because like Jeannie with Mr. Chung, he knows Vera best and has time at his disposal. That he is tied
all day to caring for her does not seem to tax him physically or create huge inconveniences for him. In an amused tone, he commented:

*I’m not tired. I thank God that I have the energy [laughs]. I have nothing to do all day; I’m bored. What would I do in my retirement? There’s not much to do… I would look after her and not bother with anything else. The most I’d do is some exercise to maintain my health.”*

Third, caring without requiring help from anyone makes Derek feel satisfied and competent. Specifically, he feels capable and independent, not like the “others” in the facility who are all dependent on others. As well, by getting everything organized for Vera’s future, Derek is doing something important for their son. He knows that Peter does not and will not have the time to take care of his mother now or in the future.

Interestingly, his independent living arrangement with Vera is testimony of a good and practical alternative to the Chinese tradition of the elderly living with children, a notion Derek seems to detest: “An elderly living at home stays in the basement. Everyone’s at work and school. You rot alone. It’s so quiet. No window-shopping. How annoying.” He explained that he would not bother the children and would rather set them free. He prefers separate living arrangements, and highly recommends more assisted-living facilities be built for seniors as he disagrees with “old ideas” of “old-fashioned people” around living with children:

*They say an elderly person should live at home. Why would they go into old people’s places? They should be with family. I say: You don’t understand… here [assisted-living], it’s very good… not have to bother the children…. There’re all kinds of activities. Everyone is in contact.*

Fourth and finally, caring the way he does is part and parcel of Derek’s general comportment in life. Derek holds to the principle that one should, “Know what adequate is. Know oneself and think about others.” The way Derek treats people resonates how Jeannie
treats people with her heart. Derek always “treat others [right] and others will treat you right, takes both to make it right. Care about others.” Incidentally, this way of caring for and about others fits comfortably in a practical way with the religious teachings that he follows. Derek explained:

*What religion says is how to be a good person in life, not other things…. I find out myself that I should be like this and that. This is from religious beliefs. It teaches you how to be a good person.*

**Looking Towards the Future: “I Need to Rest, Too”**

With thanks to God, Derek continues to immerse himself fully in the care community, and utilizes government services very assertively and comfortably as and when he needs the service or support in order to care independently for Vera. He trusts his own ability and Vera’s bodily cues and capacities to guide him in caring, like Jeannie, “One day at a time.” He draws from a complex mix of sources of strength to continue caring independently. In particular, his inclination to follow local Canadian trends of independent living of the elderly is relevant. Time and again, he expressed strong disagreement with the traditional Chinese norm of living with children, a situation where the elderly “rot in the basement”, and advises his peers to be proactive about taking care of themselves:

*I think at our age, elderly and retired, we should have some arrangements. We won’t be healthy forever. There will be a day when we will decline. That’s why when we are still fine, we should prepare early...so that I won’t have to depend on my children. Someone helps you here with everything. I would urge people to connect more with the outside.*

Importantly as well, Derek draws strength from his sense of affectionate obligation after 60 years of marriage with Vera. Incidentally, fulfilling this care obligation also befits his current condition of elderly retiree-carer, and is compatible with his principles to be content with
what is adequate, as well as his religious teachings of how to be a good person in life. He summed up his satisfaction and contentment about their situation:

*I have no worry and no daily concerns [laughs].... Just eat and enjoy. Don’t bother about children, lottery or politics...I don’t bother about anything. During my spare time, I watch over her, hoping that she would [laughs] be well, just watching her /looking at Vera and smiling, then laughs.*

However, physical conditions do change and there is a limit to everything. Derek would have liked to continue caring for Vera for some time to come. Unfortunately, seven months into my fieldwork with the couple, the mishap happened: “She had this fall, it’s really! Otherwise she would still have a long time to walk, to stay with me for another two years. Now there’s no way. [She] can only go next door [long-term care]. I need to rest, too.”

Derek’s care of Vera does not, of course, stop outside the door of their apartment. He would continue caring for her to the best of his ability and according to circumstances. He already has intentions for the new circumstances: “So I’ll let her go over next door. I’m close by. I can go visit her…train her…until she gets used to them.”

Indeed he kept to his words. Derek eventually moved back with Peter and his family after Vera went into long-term care, visiting Vera daily to help her get used to her new living arrangement. Interestingly and surprisingly, contradictory to all he had said against the Chinese tradition of the elderly living with their children, Derek seemed quite happy resuming his previous residential pattern of living in an extended family.
CHAPTER 6.
"I CAN’T DO WHAT I WANT TO DO”

Alice Chiu is 60 years old, a retiree and cancer survivor. She is taking care of her mother, 80 year-old Mrs. Liu who was diagnosed with Alzheimer’s disease almost three years ago. Eight months prior to our first interview, Alice brought her mother to come live with her and Richard, her 70-year-old husband who is also retired. They live in a large white house on a quaint and tidy street in an affluent neighbourhood in Vancouver west side. Alice initially came to Canada for her studies when she was 16 years old. She has two sons, one lives in Toronto and the other in Los Angeles (LA). Alice recently became a happy grandmother for the first time. Richard is of Chinese ancestry and was born in Canada. For both, this is their second marriage.

Mrs. Liu has been taking medications after her diagnosis. She has memory problems and apart from some arthritis, is in good health. She immigrated to Canada in 1997 and was living independently on her own in Richmond, BC, when the illness started. She has three sons besides Alice. The sons live in Hong Kong, Toronto and Los Angeles respectively. After the diagnosis, Mrs. Liu decided to move in with her own sister and the sister’s husband who also lived in Richmond. However, the arrangement did not work out well and Alice decided to bring her mother home to live with her and Richard.

According to Alice, Mrs. Liu is a very pleasant elderly person and quite easy to care for. Mrs. Liu attends a Chinese-speaking adult day program and gets home support service. Besides the home support worker, Alice hires a worker-companion privately as well.

Mrs. Liu’s arrival introduced many changes and challenges to the life of the retired couple who were just getting ready to do some travelling and enjoy a life of leisure. Alice
summed up her situation succinctly, “I can’t do what I want to do personally.” In order to appreciate the meaning and impact of her statement, it is necessary to understand who Alice and Mrs. Liu are as persons, their history and relationships, and how caring for her mother has set Alice on an unknown path, the caring trajectory, that would modify her life, and ultimately, change her as a person.

**Who They Are**

Alice presents as a small, slim and pretty lady, who looks much younger than her stated age. At our first meeting, she was well dressed and trendy. She was wearing a T-shirt and zippered top over trendy jeans and a wide belt with a huge and sparkling gem-studded buckle. She had light make-up and straight short black dyed hair tucked behind her ears.

Alice considers herself Chinese as well as westernized given the time she has been in Canada: “I’m very ‘adapted to Western culture’.” Alice shares some characteristics of the Chinese and others of the westernized world. For example, one characteristic for Alice of westernization is frankness, “I’m very frank. Whatever people ask me, I would answer.” Her attribution of frankness to westernization was made against the yardstick of a Chinese characteristic, being “phony”: “I’m actually very westernized in everything. I mean I’m not phony like the Chinese. I have none of that. When I don’t like something, I won’t have it. I mean I’m like that, so that’s westernized.”

Her westernization, however, did not extend to her views on certain aspects of family relationships, “I was not influenced by ‘Western culture’; I mean they didn’t change me.” Specifically, Alice was referring to how she does not always share in some notions of independent living of local families: “Sometimes I also feel that if some people feel very happy living together, there is happiness in big families.”
She contrasted herself with her husband who “is local born. He was born here. He’s basically a ‘ghost’, ” a term Cantonese-speaking people commonly use to indicate westerners. By that, Alice meant that Richard is more like a Canadian than a Chinese person from her perspective. According to Meiling, the home support worker, Richard “could speak a bit of Chinese [Cantonese].”

Alice further described Richard as an energetic individual who is into golfing and fishing. She added that because Richard has a hearing problem, “he tends to speak loudly,” and sometimes his loud voice could frighten her mother.

Mrs. Liu was very gentle in demeanor, with a pretty face, a beautiful smile, smooth transparent skin with a tinge of healthy red glowing from underneath. She was wearing short, neatly-combed and dyed hair, dark pants and a beige and brown sweater with a short turtleneck, a gold watch on her wrist and precious gems on her fingers.

According to Alice, her mother is an elderly who is easy to care for because of Mrs. Liu’s good family background and education:

...a rich family. She’s always had maids...a family of importance, I mean a family with good education and background... That’s why she is very well-mannered and she has no temper...a very easy-going person...doesn’t have a lot of ‘demands’...quite happy about everything.

Apart from Alzheimer’s disease, “she doesn’t have cholesterol, no high blood pressure, nothing. She sleeps well, 12 and more hours a day. So she’s very healthy.”

As well, Alice described her mother as a “very brainy woman” who “graduated high school,” which was no small feat in Mrs. Liu’s times. Mrs. Liu herself recounted running her own “stocks-trading business” while bringing up four children. Alice cited further examples of her mother’s intelligence such as after she came to live in Canada at 68 years old and had
to study for her driver’s license test, available only in English at that time. Her mother’s English was very limited, yet she managed to get 100% when she finally took it.

Meiling confirmed some of Alice’s description of Mrs. Liu: “Well-mannered…very intelligent…so good…very friendly…very clean…among all the K-see [cases], according to me [laughs] one of the easiest to work with. Really.”

Alice was proud when she recounted how Mrs. Liu was able to drive herself around to the doctor’s and shopping and started an independent life in a new country at her not so tender age. This started changing, however, when Mrs. Liu began having memory problems three years ago: “She used to live by herself before. She lived in Richmond. She was OK, no problem. But two, three years ago, three years ago, she began—I found that she was beginning to have these problems.” Mrs. Liu was diagnosed with Alzheimer’s disease.

**Doing Everyday Care**

For the past three years, Mrs. Liu has required assistance with everyday living. In recounting the everyday caring, Alice noted two particular aspects of caring. First, she noted that her own understanding of her mother’s condition is quite different from how her mother sees herself, and this differential understanding complicates the provision of care. Second, Alice described how an initially isolated process where she was responsible for overseeing all aspects of care gradually and continuously transforms as she mobilizes and organizes services, family and other resources to support her mother and herself.

**Taking on caring**

Throughout the first interview, Alice kept her voice very deep and extremely low as if she did not want to awaken her mother sleeping upstairs or have her overhear what she was
saying. She described caring for someone with Alzheimer’s disease as extra-ordinary, something that could entail significant inconveniences:

*My mother has ‘Alzheimer’. This has been for the past two to three years but it’s only the last year that she’s living with me. When you’re taking care of an ordinary elderly person, it would be a lot easier than taking care of one with ‘Alzheimer’ because even if the senior is old from age, if his/her brain functioning still works clearly, you’re just taking care of an extra person. There wouldn’t be huge inconveniences for you.*

According to Alice’s accounts, her mother was living an active and independent life in Richmond, British Columbia, before showing signs of dementia. Richmond is an area that has a large percentage of Chinese people. According to Alice, when “[s]he was already diagnosed. But it wasn’t as severe,” at the beginning, Mrs. Liu had chosen to move in with her own sister, Alice’s aunt, and the latter’s husband, who also lived in Richmond. From Alice’s account, her mother had made that decision because, “my mother never wanted to bother the children. She felt that we have our own lives, she won’t be a burden on her children.” Aside from Alice, this aunt is the only other family who lived close by. Mrs. Liu does have “three sons too but the three sons are, one in Toronto, one in Hong Kong and one in LA.” So their input and ability to provide support is more limited. According to Alice, had Mrs. Liu not minded about being a bother or burden to her children, she would have preferred to follow her Chiu Chow tradition and live with a son: “My mother would like to be with my younger brother…because a daughter is married out, you [we] are Chiu Chow. This belief is even stronger with the Chiu Chow.”

The living arrangement with her sister did not work out for Mrs. Liu. Alice indicated that there were “family” and monetary problems with the aunt and after two years:

*I feel that perhaps her experience of living with her ‘sister’ was not happy, so she would just lie in bed and refuse to get up. She was very ‘depressed’. So I brought her here and I feel that she’s a lot happier.*
When Alice first brought her mother to live with her, she provided care all by herself.

It was not an easy eight months to get to where her mother is now, “a lot happier.” She described the initial shock:

*Because at the beginning…for many years I’ve never needed to take care of anyone, right? So for me, when I suddenly brought my mother home to live with me…it suddenly became like you have this extra something you have to take care of. It’s not like you don’t have to take care of her, [she’s] like a baby that needs your care.*

To begin, this “extra something” created discomfort when persons and spaces collided:

*You’re not used to it at first. So at the beginning, you would feel that everything—this is in my way, that is in my way, this too is blocking me, so you would feel that many things are not right…. He [husband] doesn’t object to my bringing my mother to live here but it is in his way. He would feel that way.*

Alice says her mother feels the same way: “[B]ecause she’s afraid she’s in my way. My mother is very afraid she’s in my way [with husband].” Consequently, Alice has to organize their time and spaces accordingly, “That’s why I chase my husband away on some evenings,” so she can watch TV with her mother.

Besides organizing time and space, Alice helps her mother with personal hygiene, “‘basic care’…. She can ‘manage’ everything herself. I ‘help’ her with washing her hair.” However, like Mr. Chung and Vera, Mrs. Liu needs help with dressing, “She wouldn’t know to change clothes, wouldn’t recognize the clothes. You need to tell her to put this on, put this on, that’s the situation.” Like Jeannie and Derek, Alice pays attention to her mother’s diet, “I watch her diet. I mean I feed her more nutritious foods, ‘make sure’ she eats fruit, ‘more so than’ for myself [laughs].”

Most challenging, however, for Alice is to have to deal with her mother’s memory loss and the constant supervision that this often requires: “Her memory is now really totally
gone...Because in ‘Alzheimer’, she’s ‘totally’ forgetful, [she’s] ‘lost’,” and its consequences, “she has to ask you for everything. After she asks you, she would ask the same question again five minutes later.”

Yet, like Jeannie, Alice also contradicted herself about her mother being “a ‘total loss’,,” when she added that her mother actually understands: “When she hears it, she understands. She understands but she cannot connect the whole story.” Meiling, the home support worker, also noted how Mrs. Liu retains certain abilities despite brain deterioration. Using landmarks nearby the house, she was able to teach Mrs. Liu how to find her way home: “There used to be a big box outside their house, those for moving house, right there. She recognized that: Over there.”

Complicating the provision of care for Alice, however, is her mother’s different understanding of her own condition. Specifically, Mrs. Liu does not seem to have good insight into her deterioration and this has forced Alice to be careful about not naming the ‘un-name-able’:

You say ‘Alzheimer’ is— the ‘term, proper term’ is [there was no sound issuing from Alice’s mouth but just lip movements in Chinese and her mother could not see her] ‘disease of idiotic and dazed old people’. She considers she just has no memory; she isn’t [again no sound] ‘disease of idiotic and dazed old people’ yet.... She says it’s ‘dementia’ but ‘not’ [Alzheimer]... ‘her mind is still alert’, [she] says that.... She feels that her health is very good, there’s nothing wrong except for her memory, she has no memory, she can’t remember.

Incidentally, the translation of ‘dementia’ in Chinese is commonly ‘illness of brain decline or deterioration’ and the term seems more acceptable to Mrs. Liu.

Mrs. Liu’s unwillingness to accept that she has a serious problem like Alzheimer’s disease hampered her daughter’s attempts to get help: “At first I wanted to hire a helper at home but my mother would not allow it. ‘No, no I don’t want it, I don’t want anyone’.” As a
result, Alice initially declined services when her mother’s case manager who, aware of Alice’s own health history, offered services. Like Jeannie, Alice did not feel comfortable herself about having a stranger in the house: “There’s an extra person taking up space here. My mother goes to sleep always and s/he’d just sit here, looking at me…I’m not used to it.” As well, she thought she would manage somehow: “I felt I was ‘OK’ myself. She knew how to walk and run and move. She didn’t need to follow me around. It was ‘OK’ so I didn’t need the ‘help’.” Instead she found this “extra something” around her night and day, and that caring was far more challenging to deal with than she had expected. One problem was that she did not know how to talk with her mother:

_You don’t know her reactions. Sometimes you use the wrong methods, she would immediately get ‘depressed’. Her whole person would immediately—she would cry…. So you would know that what you said was wrong._

Furthermore, she did not anticipate the degree to which caring could upset her usual routines and activities:

_I couldn’t even go exercise because I had to rush back. You’re scared not knowing what she was doing. If she was ‘desperate’ enough, she could ‘injure’ herself. She could turn on the stove to cook. She could go outside, etc. Although she said she wouldn’t, she could do it and you wouldn’t know._

After a while, Alice knew that she could not cope on her own and called the social worker. Alice recounted, “After three months, I couldn’t anymore [let out a sigh],” and Mrs. Liu started participating one day per week in “‘adult day care’.” This was helpful but still watching her mother by herself “for the other six days from morning to night” remained very challenging for her.

It was challenging because Alice was keeping herself occupied with Mrs. Liu in one activity after another in order to keep her mother’s brain active. She described, “I said [to mom], ‘If you sleep, your brain dies’,“ and added, “she really sleeps a lot, almost 12 hours at
night and 3 hours in the day...and I won’t let her sleep.” She tried to keep her mother awake:

You do this, you exercise, you go ride the bicycle, you sit down and watch TV with me. It’s like you have to constantly…. Her only pastime is to play mahjong. I would drag my husband. Now perhaps ‘three times a week’, oh yes—in the evening, the pastime before dinner…I hate mahjong.

Alice also found a way to cope with having to play mahjong: “What’s the only way I can ‘relieve myself’? I would turn on the TV and listen to the news. I would listen to the news while I play [mahjong] with her, let her play a bit.”

Meiling remarked about the family’s preoccupation with keeping the brain and body of Mrs. Liu constantly active: “Once we came back early and her son-in-law said, ‘[She’s] always thinking up tricks to not have to walk.’ But in fact, there can be times when she really is tired, right?”

In fact, Alice was exhausted every evening and had to ask the social worker for more help. The social worker increased services to “two days ‘home care’. And ‘adult day care’ gave me an extra day,” and was able to send the same workers following Alice’s request: “I said to not keep changing them [workers] for me. They [people with dementia] can’t, they get scared. They get scared.”

Mrs. Liu initially resisted going to adult day care: “When I first sent her, she cried there. She was really unwilling.” Once her mother started getting used to it after “a few days, a few times, two or three times…she [mom] really ‘looks forward’ to going there.” Alice particularly appreciated adult day care as the service kept Mrs. Liu and her brain active:

She really ‘enjoys’ it and it ‘stimulates’ her brain and she wouldn’t sleep so much…‘I’d rather send her five days a week’. It would be like going to school for her everyday…there are lots of people to play with you, to exercise with you, tell you the news, it’s actually like going to kindergarten…she would be even happier, really.
Similar to how Jeannie considers caring her personal responsibility before that of the government, Alice is considerate towards the government: “I also feel - the government is helping you a lot already. So I feel that I—I feel like—perhaps it’s my responsibility and I should do it myself. You can’t push it all to others.”

Alice prefers adult day care to home support, her preference being based on the costs and benefits of the service for someone like her mother. In particular, the primary benefit for her is that adult day care keeps her mother stimulated and active, and Alice expects that this will slow down the progress of her illness:

*For people like her, if you give her ‘home care’, it’s useless. They would just sit with you to watch TV…. They’re tired already, the ‘home care’ people…they pay them a lot of money, do you understand?... It wouldn’t need that much to send her to a resource centre.*

Moreover, in comparison to private home-help, Alice commented on the benefit of increased public accountability and scrutiny. For example, she described her sense that home-support workers may take advantage of the system, to her mother’s disadvantage. Commenting on one home-support worker she notes that: “[She’s] ‘supposed’ to leave today at 1.45 p.m. But I came back at 1:15 p.m. today and she was already nowhere in sight, really! [laughs]. Sneak and idle away.”

Unfortunately, “‘Chinese-speaking adult day care’ is insufficient,” according to Alice. She would like to send her mother for more days but she said, “There are many people waiting on the ‘waiting list’ …. You have to be more ‘considerate’ [of others].” She would not send her mother to English-speaking centres where she was told there are plenty of spaces because “she [mom] wouldn’t know anything about what people are saying, it wouldn’t ‘make sense’.” So Alice is happy with what she gets for her mother at the moment:

*I mean where Chinese people speak Chinese, there’s only one of them in*
Chinatown. They can give me two days. And that’s already good…. That’s why I’m very happy she’s going for two days. That can help me and she’s happy she has something to do.”

Her acceptance with what her mother is given does not obviate the fact that support is clearly inadequate.

For herself, Alice recounted joining support groups, “I don’t go there to grumble, I just go there to ask questions, listen to others talk about their opinion and experiences. It’s useful.”

**Re-defining care: Mobilizing and organizing**

The increase in use of services marked an important turning point for Alice. She was able to get back into her own routines and activities:

*I go exercise in the morning now. For example, I’ve always exercised in the morning. I swim. I’ll do a bit of exercise, like Tai Chi. I have Tai Chi class on Saturday and Sunday. Now I can ‘keep’ my morning ‘activities’. So it’s better…I’m doing really well now with four days, four ‘half mornings’...the resources really ‘helped’ me.*

Basically, caring has changed from being physically present for her mother night and day to mobilizing and organizing resources around her mother so that both mother and daughter can spend a part of their time fruitfully in their own space. This shortening of direct care time seems to provide relief for Alice and helps make the challenges of doing care manageable:

*When I come back in the afternoon, she would be sleeping. She sleeps until past 3 o’clock…. After dinner, she would go to sleep at 9 o’clock for sure. So I don’t really have that many ‘hours’ [to care for her]...6 hours—[tell] myself to be more patient. It’s 6 hours, I keep having to tell myself that, it’s 6 hours only.*

Perhaps taking some of the pressure off of doing care has allowed Alice to explore her role more creatively and skillfully. For example, Alice slowly learnt how to communicate
with her mother, “You speak more with her like playfully, that kind of tone. And you praise her more. Encourage her more…. You need to gently persuade her.” As well, she found additional ways of communicating and caring that work with her mother such as using notes: “I would leave her a note: ‘Today you’re going to the centre. You have breakfast quickly.’ I would have prepared breakfast for her, and she would have breakfast and wait for you.” She also learnt about the kinds of stimuli her mother, in her condition, could appreciate. She talked about TV programs:

*She can’t ‘link’ it to what follows…she enjoys watching like news because it’s not continuous…. Then she would watch singing performances…‘concerts’, she would ‘enjoy’ the dances and movements…. And it’s really interesting when she watches nature and landscapes, she would ‘relate’ them to her past: ‘Oh—looks like we’ve been here.’ But it’s not true. She’s making it up.*

Finally, Alice learnt how to mobilize help from her husband and home care workers so that they could support her in caring for her mother. She related how Richard helps her: “I have to run some errand, I would say to him: ‘Oh, you stay home, she’s here. You—if I’m not back yet, could you prepare her a fruit?’ Like that, it’s OK.” However, Alice recognizes that there are boundaries related to what she can request from Richard. For example, she does not feel that she can leave her mother with Richard for longer periods. When she went by herself to Toronto to visit her newborn grandson for a week, she hired “a ‘part-time’ to come cook for them” so that Richard was only responsible for watching her mother after dinner. Unfortunately, this departure from routine did not work. Alice concluded: “It wasn’t good for all of us…my mom was afraid, scared to death. I didn’t go away serenely and he felt a ‘burden’.”

Alice also mobilized Meiling, the home care worker, to support her and her mother. In fact, Meiling confirmed that because Alice’s mother requires very little care, her four
hours of work per week with Mrs. Liu revolves mainly around supporting the family in their care goals for the senior: “Most important is to be able to help grandma go for walks, cook something for grandma to eat, when I come, I keep her from going to sleep, talk with her.”

At times, she also acts as mediator between Mrs. Liu and her daughter or son-in-law over certain matters the children may find hard to say:

*Maybe sometimes the family can’t tell it right in their face.... One is the ‘face’ [dignity] of the elderly person, another is they don’t want too much conflict between them. So [they] change another angle and get someone on the side to say it.... It does, it would pacify things a bit I feel.*

Meiling spoke most appreciatively of her job with Mrs. Liu. With “the Health Department keeps cutting the time,” she called this one “a ‘very good K-see [case]’” when compared to the workload with other clients where she is usually given “‘one hour’, some even half an hour...[where] the volume of work is not great.... Just going in and out.” What gets challenging is trying to get to the next “order” which may be at another end of town within the ten minutes for transportation and five minutes for coffee they are allowed. While the problem of transportation is endemic across all of home support care, according to Meiling it is particularly an issue with Chinese clients since her company tries to keep the consistency of workers assigned to clients, and so “our Chinese team has to cover more distances” because the Chinese clients do not necessarily live close by. She described the consequence:

*We’re running on the roads. I drive the speed of an ambulance. Can I get there in 10 minutes?[laughs] Terribly tight...it is time for lunch [for another client] and we run back to the second case. So we’re running back and forth, it’s rather hectic.*

Unsurprisingly, given the stress associated with trying to accommodate more clients, Meiling feels particularly appreciative when she is able to spend a full four hours with
a client, as she does with Mrs. Liu: “That’s why we say these four hours, these hours
with grandma, are for me, for us are really [a very good case]!”

Nevertheless, Meiling emphasized that regardless of the number of hours, distance or
the difficulty of the job with extremely difficult clients or family at times, “I’d still do it
well…. They need our help and we can only do it,” and she does it with her “heart,” echoing
Jeannie’s approach and work ethic in caring for Mr. Chung.

Towards the end of the interview with Meiling, Alice returned and Mrs. Liu went to
help her daughter with the groceries. Meiling added her last comments, almost like a proffer
to Alice, as she knew she was within earshot of the latter: “That’s why I like to come here to
work, the hours are good and I’m greedy [laughs]. I’m really very happy to come work here
at grandma’s. The hours are good. Usually it’s one [hour] at a time.”

With the help of Richard and Meiling, Alice moves caring along and decided after a
period of time to hire someone privately for an addition two mornings per week. She happily
exclaimed, “I’ve ‘arranged’ six mornings for myself to be ‘off’. That’s enough for me.”
Ultimately, by the time of our last visit she organized yet another half morning from the
social worker. With seven mornings of the week free, Alice indicated that things looked a lot
happier not only for Mrs. Liu, but also for herself.

**Caring About Feelings and Feelings About Care**

As mentioned, the “happier” situation did not come about immediately, or easily.
Alice related how difficult the process was in terms of the impact on her physically and
emotionally. She was straightforward about the experience being incredibly negative,
especially at the beginning. Nevertheless, she plodded on, attending to the feelings and needs
of her mother, balancing them with her own, often struggling in between.
Alice listed a very practical impact and it is the lack of time: “This last year, I’ve ‘accumulated’ 500, 600, now 700 and more [emails] that I still haven’t ‘read’. Things people send me, ‘interesting’ stuff.” Such impact could seem minor compared to her description about how she felt before taking up services:

_Earlier on, it really could—stress could—I actually couldn’t breathe. When I finally called the social worker, I said that I actually couldn’t breathe. My ‘chest’ hurts a lot. I felt that from the morning when I woke up, it was like a big stone pressing on you. You’re only—gasp for air, gasping, gasping, gasping. I kept telling people that I couldn’t breathe. People couldn’t understand why [I] couldn’t breathe. I really felt that I couldn’t breathe. I was totally ‘stressed’. Now that I can ‘arrange’ my ‘morning off’, I am a bit better, much much better. Here [indicating her chest] I won’t feel so pressed. My heart is not so tense._

In the end, the stress and fatigue was destroying her health to the point where she had to get help from services: “I was so tired. I lost all personal joy and interest.”

This was at the beginning when Alice did not know how to communicate or interact with her mother, and wrong words and misunderstandings piled on top of each other to wear her out. In particular, it was the repeating and repeating: “It’s from morning to night like that. So if you’re repeating and repeating—even if you are a healthy person, you will ‘wear out’. That, that’s the situation.” Alice was in constant aggravation over her sense of culpability when, for example, she would slip at times and remind Mrs. Liu that the latter had asked the same thing five times, after which Alice would feel awful about her own ‘forgetting’ because her mother “would immediately ‘shut up’. Then you would feel bad. She speaks and you tell her to shut up, right?” That is why “you really struggle yourself over these things,” over which she felt “helpless”: “‘Mentally’ you need to be very ‘strong’. Otherwise, you’ll be crying all ‘the time’. ‘Even’ now if I don’t think, I won’t cry. If I think, I’ll cry,” because these things make her feel incapable, at fault and sorry for her mother and herself.
Alice made no qualms about the experience being negative, “this is basically a very ‘depressing experience’,” and did not go in roundabout ways to say so, “You shouldn’t feel she is a burden because actually she is but you can’t say it” because it would hurt her mother’s feelings if she heard it. She admitted to feeling “annoyed” and “frustrated like any person,” and activities such as playing mahjong with her mother were a “sacrifice” for her. In fact, Alice’s experience with her mother tells her not to bother her sons in the future:

‘I would never burden my kid like that.’ If I have ‘Alzheimer’ in the future, I would make it clear to my ‘kid’: If I have ‘Alzheimer’, you must send me to a seniors’ home, I will go for sure, I will go for sure…. It’s so difficult for me now. Why would you want your children to ‘look after you’, right?

She was in such a bad state that the family doctor “made us an ‘appointment’ to go see a ‘psychiatrist’ [laughs], Dr. X. We saw her/him.” The psychiatrist “would ask her [mom] to see how was her condition. I ‘translated’.” Alice also talked about herself and their situation: “S/he asked us, asked me what the situation was. I told her/him everything. S/he said: ‘If you have any ‘problem’, come back to see me.’ I never made another appointment.” From her tone, Alice gave the impression that she did not find the service helpful and so never returned.

At the back of her mind, Alice is worried. According to her, caring for a person with dementia can wear out even a healthy person and she is not a healthy person to begin with:

My friends are all worried that I would get ‘caretaker burnout’ because I’ve many illnesses myself. I’ve had cancer. Now I’m well, but I can’t be stressed. I don’t have relapse now but that doesn’t mean I won’t, right? That’s why sometimes I would think: Oh my, don’t stress, don’t stress, what would happen if I die? It’ll be worse. But no matter how much you say to not stress, it is there.

Friendship has also taken on new meanings since she started caring. Alice had felt misunderstood and “hurt” by one group of her “close friends” and recounted how she dealt
with and overcame the hurt:

[They] ‘judge’ me behind my back: “Well you always want to go have fun yourself! You don’t keep your mother company.” And I feel - I mean it’s not ‘fair’ when people say that about you...over the past year, I have ‘gone through’ many things. So I feel: Ay [sigh] I mean between friends, you you are very broken-hearted, sometimes you feel, I don’t want that many friends. I’d rather be alone at home. If I have time, I’ll read books and watch TV, etc. I mean people’s tattering can be so harsh...I’ve ‘dropped the group’...It’s better to have no friends than friends like these, I’ll save some time. I’m busy too...I helped myself understand and I started—that’s why I’m ‘better’.

Alice has another group of “health-care professional” friends who offered to come play mahjong with her mother but she sounded somewhat ambivalent and did not want to oblige them, “I mean they treat her [mom] really nice when they come. But I don’t dare bother people. They ‘offer’ but I shouldn’t bother people.”

According to Alice, not even her own family understands her. She elaborated how they would see the situation:

What’s so hard about it? They don’t feel that it’s hard. If they don’t experience it directly, they wouldn’t know. As well, they would only hire a servant to take care of her, so what’s so hard? She knows how to walk, move around and eat herself. So what’s so difficult? And when I think about it, it’s true. So I’d better not complain so much, it’s not really that hard.

She is very much alone in caring and this creates tension at times in her relationships with her brothers. While she never spoke badly about her brothers during the interviews, in particular she seems to have a good relationship with the youngest brother, my field notes did record some small grudge when she remarked and questioned, “why the sons don’t call” their mother and “calling her brothers ‘heartless’” for not making the connection.

Basically Alice is not happy, “[N]ow I feel, I myself don’t feel happy,” about the situation where caring is hard on her, yet she can only talk to “support groups”, “health care professionals” or acquaintances and friends in those professions. Alice explained the reason
for this restriction of interlocutors: “They understand you because they themselves did it ‘physically’. They know that it is very difficult.”

Last but not least, Alice equated caring with intrusion into her marriage. She said, “Because I have to take care of an elderly person with ‘Alzheimer’, I can’t do what I want to do personally.” In particular, she described how she can no longer have “‘free time’” to enjoy life with her husband:

_Originally I would have ‘free time’ but now no more…. I was hoping to live the life of a retiree, hoping to do some travelling and enjoying life in retirement, doing more activities… I’m beginning to get old. I have to wait 10 years before I can have my freedom [choking laughter]? Then I can go and have fun!?… I mean my husband is retired now. He looks forward to travelling with me. Of course, my husband is almost 70 years old, he would like to—for the last 10 years [when he still can]—if you don’t go [travelling] now, you won’t go anymore. He doesn’t have the time to wait anymore._

She could leave her mother at respite care for short periods or with her “very rich” younger brother in Los Angeles who “could get a maid to take care of her from morning till night ” so that she can rest or go travelling with Richard. She explained, however, that she would not because she had heard from support groups not “to take these patients to different places. I mean they’ll be worse when they get back…I have to ‘train’ her all over again.”

In fact, the impact of care on her relationship with her husband is not insignificant:

_He’s very accommodating towards me. He lets me decide, so he doesn’t say anything. But he doesn’t care now. He just goes out on his own…. You don’t play [do things] with me, I’ll go play on my own…I mean he has his own programs everyday. So the affection between me and my husband has worsened._

Despite all the hurt and challenges, Alice plods on, attending to her mother and learning how to better read her bodily cues in order to better care for her: “You could see her whole ‘face’, you could see it immediately ‘withdrawn’, immediately ‘went into an upset mood’.” Alice could see when her mother does not want to go for walks with the home
support worker: “If she won’t go, her legs will falter, her legs would immediately fail to walk [laughs]…[or] she would come down and walk around the house in her pajamas.” Coming downstairs in pajamas is something her mother would never do. In fact, when Mrs. Liu heard it, she looked shocked and asked Alice: “That didn’t happen, did it?” Alice assured her mother it did. Interestingly, rather than attribute these physical signs to dementia, Alice interprets them as willful demonstration and communication of her mother’s desire to stay indoors.

Being sensitive to Mrs. Liu’s bodily cues allows Alice to understand her mother’s situation and find ways to resolve matters at hand that “‘minimize upsetting’ her [mom].” Alice’s empathetic approach helps her to understand and recognize something precious and unique in their relationship: “Their mind is totally gone, so she’s very scared. She is not very willing to go out now, except with me, she trusts me.” This understanding helps contain any sense of blame or frustration she might have. As well, it helps Alice see how her mother trusts her both emotionally as well as physically, a trust that permits only Alice to attend intimately to the bodily care of her mother. So Alice respects her mother’s wishes:

So you can’t—because ‘physically’ she wouldn’t let anyone wash her hair. She wants me. She’s ‘embarrassed’, she wouldn’t, she’s not used to it. She’s ‘mentally’, she still knows somewhat, she’s not used to a stranger watching her take a bath…. That’s why I don’t let ‘home care’ [workers] do these things.

Where provision of personal care is one among a list of items under community care services, the same provision of care holds very different meanings of caring and concern within the private space of an intimate relationship. Meiling sees this special something in the mother-daughter relationship when she remarked, “[H]er daughter loves her very much, loves her very much.”
In fact, my field notes attested to some instances when this loving care and concern was at play. To an extent suited to Mrs. Liu’s ability, Alice included and involved her mother in preparing and serving dinner. For example, she let Mrs. Liu help her wash and cut up the salad as well as set the table. She offered reminders to help her mother accomplish her tasks and did not forget her compliments when the mission was accomplished:

*Mrs. Liu would ask from the kitchen what she needed to do and Alice repeated “fork, knife and napkin.” Mrs. Liu came back with the cutlery to lay the table.... She was done and Alice saw that there were no knives, so she asked her to get knives too, which Mrs. Liu did. When she was all done, Alice remarked: “You see, how nice and neat she can do it.” In fact, Alice was right, it was a nice and neat-looking table.*

She also let Mrs. Liu clear and wash the dishes afterwards because there were “very few,” five actually. At the sink, Alice inferred that there was more than doing dishes there:

*She’s doing this only because she wants to help me. She’s not used to doing this kind of work. She’s always had maids.... She’s full of arthritis but she wants to do it because she knows my health is not that good. She doesn’t want me to work that much. She wants to help me.*

Doing dishes was mother’s way of caring about her daughter, and letting mother do the dishes was Alice’s acknowledgement and appreciation of mother’s loving intention. As well, the kind of understanding and intention between the two women allows them to share a joke or two. I wrote in my notes that at a certain point during dinner, Mrs. Liu asked Alice why the latter had a red spot in her left eye.

*Alice: But I’ve told you so many times already. It’s from an old wound. Don’t you remember? You keep asking me that.  
Mom: What’s the wound from?  
Alice: [with a playful expression and in a playful voice] Well, what else? He beats me up. That’s why.*

Mrs. Liu, Alice and Richard all started laughing. Mrs. Liu was feeling comfortable and relaxed that evening. Alice remarked that her mother was “more talkative than usual.” After
dinner, Mrs. Liu was eating chocolates and touching some tin cans on the kitchen counter when she commented about life in general, sounding somewhat like Jeannie: “I’m not afraid. When things are meant to be, they’ll be;” then about life and death, “I’m not afraid. When it’s time, it’s time,” adding finally, “I don’t have to care because I have a good daughter.”

When Alice asked her mother, “Oh, since when are you good at ‘shining shoes’ [buying people with nice words]?”, Mrs. Liu laughed.

**Why Alice Cares the Way She Does**

With a tender relationship of the sort, it would not be easy for Alice to find comparable alternative caring solutions to the current one, which is to provide care herself at home. Alice described three aspects that exert their push and pull on keeping her mother with her: their relationship, culture, and no adequate alternative. She summed this up in one paragraph:

*This situation is—is because she’s my mother and she’s very afraid of going into a seniors’ home, and I can’t—my heart myself—basically I’m Chinese, so ‘until’ she really cannot ‘manage’ one day, I mean when I cannot ‘handle’ her ‘at home’, I cannot bear to send her away to a seniors’ home.*

Like Jeannie, Alice related assuming care responsibility to the culture of “Chinese people.” She expressed, “Our ‘culture’ I mean is to ‘look after the elderly’…I mean you feel this is my responsibility…I myself wanted to ‘assume the responsibility’.” Again similar to Jeannie, these cultural values are consistent with her familial history and experiences. For example, she noted that she grew up in a household where the old and younger generations lived and cared together, “My surroundings from when I was small, people all lived in a big family, three generations living together…from a young age when we were ‘brought up’, you feel [know], [you] have to take care of him/her.”
Unfortunately, Alice finds herself in quite some predicament considering the enormity of this responsibility. She expressed, “I feel that this ‘responsibility’ is huge and lasts very long, don’t know how long.” Further, she considered caring to be so difficult that, “If you ask someone if s/he really wants to do it, nine out of ten would say no…it makes you want to shun it.” She added about her own case:

_I don’t want to do it [caring]. [starts whispering in a crying-like voice] No matter how filial you are, if you ask me if I really want to do it, I don’t. I want to be free [sighing-like laugh], right? No matter how loving [actual words used: loving heart] you are, you don’t want to do it…. But—I have a loving heart so what to do? You are forced by your loving heart to, force you to endure this._

Even given a viable alternative though, Alice is not able to ‘shun’ her caring responsibilities. For example, she notes that her younger brother “is most willing” and would easily take over her mother’s care using hired help but somehow a move of the sort would contravene some ‘standard’ she feels she needs to uphold: “But now that I’ve brought her here, I wouldn’t want to ‘shuffle’ her ‘away’. That would be very bad of me. I can’t do it. Although I feel it’s very hard, I would still keep doing it.” Even talking about her reluctance raises some sense of culpability for her. Again, she gave the impression of not having lived up to some ‘standard’ for voicing negative things about caring for her mother when she asked, “Is there anyone who complains like I do [nervous laugh]?”

Finally, what fortifies her cultural beliefs and her loving heart to keep her mother home is the lack of an adequate alternative care solution. Alice knows that compared to seniors’ homes, on one hand, her mother gets better care with her, “I can give her a bit more. I mean, it’s good, ‘much better care I’m sure’.” On the other hand, she recounted several “horror stories” she had heard which keep her from considering institutionalization. This is an example of a less scary one:
I mean basically I don’t feel that nursing home is a ‘bad thing’... But with my mom’s situation, they would not put her in a normal ‘wing’, they’ll put her in the ‘locked up wing’... there are some who are already mad, they would be screaming in a high pitch all the time. I mean it’s like locking you up with a group of crazy people... even if you weren’t crazy, you would become crazy quite quickly.... It would frighten her so much she would go back to her room to sleep.

So Alice is quite thankful her mother is in fine condition at home: “But she’s not deteriorated to the point of being ‘aggressive’, there’s none of that. So I feel very lucky. I mean I have to ‘look after’ her. Among the sick, she’s not the ‘aggressive type’.”

The lack of an alternative pushes against Alice’s Chinese family values and her feelings for her mother as well as their relationship. Together they bear upon Alice’s efforts, some aiding and others hampering her, at one time or another, in her struggles against the demands and challenges of caring. They keep Alice constantly in what she called a “dilemma” and tension about whether to keep her mother with her or send her to a nursing home.

Moving On: “You Have to Adapt to This”

Even though Alice often feels in a dilemma, “I sometimes feel that I have unnecessarily grabbed this responsibility,” she still prefers to keep caring for her mother. She would rather take this unpleasant responsibility now than regret later for not having done it, “If you don’t do it, you could regret it.” Despite the constant tension and dilemma, Alice continues to meet the challenges and adapt to the changes by drawing strength from her cultural belief of responsibility and her affection for her mother. Her story, in particular, shows how the use of community health services and support provided that crucial turning point to help set Alice on a more manageable path of caring. Instead of representing a potential loss of independence as in the case of the older spousal-carers, the use of services
and support helped to restore to this daughter-carer some of her lost independence, freedom and space.

Nevertheless, in lack of a viable alternative, she can only put off her own plans. “For the moment, we’re [Alice and Richard] ‘holding off our plans’”, and continue caring for her mother herself: “So for the future years, of course I hope she will have good health and she will stay more resolute and remain in this stage for a longer period.” Alice sounded resolute herself, “I mean you feel this is my responsibility, I have to care for her, and I have no more of my own fun. You have to adapt to this.” Given the excellent health of her mother apart from this illness, Alice’s only preoccupation is if “she [mom] outlives me.” Her care experience has made her more confident about asking for more or trying new service and support, and resonates somewhat with Derek’s approach to life and caring. Alice remarked, “I mean I feel that I have given myself [learnt] one thing: ‘If you haven’t tried, you can never know’.”

She will continue to do what she feels has been working well for her mother so far:

[I] don’t want her to deteriorate so much, so I would always ‘encourage’ her, hoping that by watching TV she could understand more, going out for walks would do good to her legs, I mean strengthen her body.

She will continue with what works for herself as well: “I ‘find out ways to handle her better’…I ‘try to’ arrange as much as possible so that I wouldn’t be so ‘stressed out’…to have more of a ‘life’ for myself.”

Overall, Alice feels that she is managing well their routines, dedicating the whole Sunday to her mother:

Actually, I have lots of ‘spare time’ now. I mean the time I’m with her…is not much, not long, except Sunday when I play mahjong with her once a week. That day, I’m with her the whole day on Sunday.
She added that both daughter and mother are more pleased with their current situation:

*So ‘to me’, I’m much more ‘relieved’ because I have my own space. So I’m more patient with her and I wouldn’t, because I spend too much time with her I get irritable, like that. And she feels: ‘My daughter is taking very good care of me, I’m very happy’.*

Alice has plans for the future, for when she really cannot care for her mother herself:

*I originally—if she deteriorates further, I want to hire long-term help...who can ‘handle’ live-in or some other arrangement. Then she can stay at home until the final ‘stage’. At the final ‘stage’, when you have to ‘lift’ her, ‘lift’ her to the ‘bathtub’, and things of the sort, then [I’ll] send her to a seniors’ home. That’s my plan.*

Alice’s plans differ from those of Jeannie, who hopes to be able to continue providing care at home even at those later stages with government support in terms of equipment and personnel to facilitate the process.

Through caring, Alice has arrived at new understandings and meanings of life, friendship, and relationships that help her move forward with caring and life in general:

“Then sometimes I would feel, aye, I’m already this age, I don’t really need that much that much freedom. So let it be.” Even her way of dressing seemed to indicate a change of pace and direction in her life. From the trendy jeans and wide belt with a huge sparkling buckle, my notes of the last visit recorded: “She wore a set of casual black gym jacket and pants, and no make-up.”
CHAPTER 7.
“MEANWHILE, I HAVE COMPLETED MY UNIVERSITY DEGREE”

Josephine has been caring for her husband Stephen, both close to their mid-seventies, for over three years since he was diagnosed with Alzheimer’s disease. Stephen takes medications for Alzheimer’s disease and other health conditions. Besides an operation on the parathyroid three years ago, he has a history of problems with the stomach, heart, diabetes and poor dental health, while Josephine recovered from angina many years ago and currently has diabetes and arthritis.

Soon after their retirement, Josephine and Stephen emigrated from Hong Kong to Canada in 1995 and 1994 respectively. She was a nurse-educator and he was a dentist there. Josephine did her ‘landing’ procedure in Canada a few months after Stephen as she had to wrap up some work at the hospital before she retired. She continued to go back and forth between Canada and Hong Kong mostly by herself for consultancies at the hospital before finally settling down in Canada in 1997. Josephine speaks fluent English while Stephen’s English is limited. The couple does not have children.

Immediately after landing, they moved into an apartment they bought in Metrotown, Burnaby. The apartment is located in the same building where Josephine’s mother lived until she passed away a year ago. Josephine’s younger sister who cared for their mother still lives there. Josephine has another younger sister in Vancouver who is married with grown-up children. Stephen has three siblings in British Columbia. Only one lives in the Lower Mainland but they do not see each other often.

Besides Josephine’s family, initially they met occasionally with other immigrant friends and acquaintances from their school or professional circles from Hong Kong at
annual dinners and less formal gatherings, but the contacts have narrowed in particular after
Stephen’s diagnosis of Alzheimer’s disease. As well, many of the old acquaintances have
returned to Hong Kong in the meantime.

Several years after their arrival, the couple bought an additional apartment in
Chinatown as an investment as well as for closer accessibility to Chinese cultural and
community activities. Josephine also joined an art cooperative in this neighbourhood and
after Stephen’s diagnosis, they moved to this apartment permanently for proximity to the art
gallery and community care services.

Apart from deteriorating memory, Stephen does not have any behaviour issues. He is
able to do many things himself including his personal hygiene, but sometimes he forgets how
to dress properly or adjust the water in the shower. Because the couple has various health
issues, they use medical care services frequently. Stephen had an operation and was
hospitalized three years ago. Ongoing health care services include visits to their physician, a
geriatrician, other specialists, and lately, an ophthalmologist. In regards to community care
service, Stephen attends an adult day program twice a week. Otherwise, the couple lives
independently with Josephine providing instrumental assistance to Stephen and hiring help
for regular house cleaning and sometimes a companion for Stephen when needed.

They seem settled and well adjusted to the new society as well as to Stephen’s health
conditions. Interestingly, Josephine’s communications about caring inevitably led to a
plethora of her achievements in life. For example, in response to Stephen’s remark that there
are no problems in their daily lives after the illness, she added: “‘Meanwhile’, I have
completed my ‘U’ degree.” How achievement is important to Josephine even after she
became a carer can be appreciated once the statement is understood within the context of who Josephine and Stephen are as persons, their history and relationships.

**Who They Are**

At the first interview, Josephine came down to open the door at the main entrance. She extended her greetings in a soft gentle voice. She has a small round build, shoulder-length black dyed hair held back by a hair-band, and was very neatly dressed in black pants, patterned shirt and a sweater top.

Josephine swiped her security card in the lift and pressed the button for the 26th floor where their two-bedroom and two-bathroom apartment was located. There was an open kitchen to one side of the entrance, and a corridor leading into a carpeted living room painted in creamy tones. Stephen was in the living room. He is of medium height and slender build, wore glasses, and with graying hair against his darkish-looking skin. He was neatly dressed in grey slacks and pullover.

Adjacent to the kitchen was a good-sized study, all in white, with a computer and shelves of books and binders. Large windows lined the entire wall of the study and across the whole living room. The windows gave a 180-degree view over False Creek. The living room was spacious with a wooden set of Chinese sofa and matching armchairs. There was a small rectangular wooden dining table and four chairs at the far end of the room against the windows. Chinese paintings of landscapes, a pair of peacocks, a horse, and Chinese calligraphy hung on the walls. On the coffee table, there was a wooden music box with Stephen’s photo on the lid. The younger-looking man in the photo was in the middle of doing something with a Chinese paintbrush in his hand. Next to the music box was a pile of writing pads and a notebook with a weathered-looking blue cover to which was clipped a gold-plated
ball pen. In addition to these mementos, a TV guide, a Reader’s Digest, and some other papers were on the coffee table.

Immediately after she seated me in the living room with Stephen, Josephine went to prepare tea in the kitchen. Shortly after, she reappeared with the tea and a plate of chocolate-covered biscuits. As she sat down, she gently reminded Stephen to drink the tea only. The interview began with an invitation for the participants to share their experiences of living and caring for each other in Canada. Josephine immediately asked if she should first talk about their backgrounds, and she was invited to do so.

“**He was a dentist [who] didn’t charge**”

Throughout the interviews on caring, Josephine placed great emphasis on their professional and social status and achievements, hers in particular. She began with Stephen’s background, explaining how the little boy from a village in China grew up and went to:

*Taiwan National Military Medicine School…he graduated as a dentist…four years in the school and two years in the hospital. After six years when he came back [to Hong Kong], he had to take an exam in English…. So finally in 1969 he started his ‘private’ practice…He did that until 1993, he retired.*

Stephen was a hard worker and his work habits caused health problems at times. Josephine recounted that in Hong Kong:

*Maybe life was stressful, he had stomach problems…. That day he had bleeding. He knew it himself but he went to work. Luckily he didn’t get on the bus yet. After he fainted, he was brought to QE [Queen Elizabeth Hospital]…. Luckily he was alright…. That was around ’81.*

More than hardworking, Stephen was a generous and kind professional. In a neutral and matter-of-fact tone, Josephine recounted how his “business” was “‘half like a charity’”:

“Even though he was a ‘dentist’, at that time, he was [doing it] for ‘patients’. I mean he ‘charged’ very ‘low’. Sometimes, he didn’t even charge, like that.” Furthermore, he seems to
have been good at taking care of others but not himself. Josephine noted, “Even though he’s ‘dentist’ himself, his own ‘dental care’ is very poor. Now his teeth are already, ‘most of’ his ‘upper’ teeth have ‘dropped’ [fallen off].”

Stephen’s way of doing business for patients naturally did not make him a wealthy man: “That’s why ‘financially’, I mean when he’s ‘off’, he ‘finished’ [retired], he didn’t have much [money].” The little he had after retirement, he took to his village in China “for his older brother’s youngest son” because his older brother had “married someone else, ‘abandoned his first wife’. That’s why he helped them I mean he built a house there for them.”

As well, Josephine explained the fact that Stephen had no money was because, basically, “‘financially’ he never cared…. He always knew what money was but he didn’t count.” She was implying that Stephen places his values elsewhere.

**Being a “secondary citizen”**

In regards to herself, Josephine was born in Burma to Chinese parents, who were migrant workers from Chiu Chow, “‘Daddy’ sold embroidery at the ‘different suburbs’.” Like other people from Chiu Chow in their vicinity, the parents were churchgoers, “‘Christian’, I mean we have ‘Sunday school’. After ‘Sunday school’, we would all go to the house of the big boss [also from Chiu Chow], all the workers and children, because there is a big garden…like a big family.”

She started English kindergarten in Burma at three years old and considers herself westernized like Alice, but Josephine was also racialized: “I think I’m ‘westernized’. Because I ‘started off’ with English. I mean the teacher could be considered good even though he was quite—I mean ‘racism’ was quite ‘strong’ because I was ‘second class citizen’
at that time.” Even though Josephine spoke Chiu Chow at home and in her larger Chiu Chow ‘family’, she developed more strength in her English language mastery. She speculated the reason, “I think English people were ‘superior’”. By that she meant even at that young age, she already understood what she now defines as social strata: “Because your ‘social strata’, they’re one class higher than you. I mean in that ‘situation’. You get that ‘impression’ when you were little.”

When the Japanese invaded Burma, her parents took the children back to China. Josephine was about five to six years old at the time. The family stayed in Chongqing for the next four years. The children were often left in the care of a teenager “servant” who took care of the younger siblings with Josephine’s help when the parents had to travel for work. Back in China, Josephine had difficulty initially learning Mandarin: “It was very hard at the beginning…I only knew two [Chinese] words: One and person.”

Josephine had to learn other things in Chongqing, the most important of which was probably how to move between separating and conflicting worlds that could be hard for a child her age to understand. To begin, she recognized how her knowledge of the English language held very different meanings for everyday living in different contexts. For example, Josephine recounted that during wartime on the streets of Chongqing, she and her siblings always hid their ability to understand or speak English: “[W]e didn’t dare speak English. We didn’t dare say we knew English because people could become very repulsed by it, that we weren’t Chinese.” It was not that the children were in any kind of danger:

No, just ‘animosity’. There would be some ‘animosity’, so we absolutely didn’t dare. The people could be considered decent, ‘provided’ we didn’t let them know we knew English or foreigners. We ‘pretended’ to be ‘as Chinese as possible’, so there was no problem.
The young Josephine and her siblings carried this fuzzy ‘knowledge’ about some connection between language, national identities and their everyday existence into their school life as well:

*There were ‘missionaries’ there, foreigners living there. Their children didn’t study with us, we were not together. But we did play together...I wouldn’t know. Perhaps there was some ‘racism’ then. Like they wouldn’t talk to us, they would talk to their own...we didn’t say anything [in English]. We didn’t show it. So they didn’t know we could hear [understand] them.*

In another context, however, her English mastery brought her advantages and privileges. She recounted her experiences helping out in her parents’ shop next to the Chinese Foreign Affairs Department building:

*Their staff would come to our shop. When the staff came and found out that my mother or father knew English, they felt surprised...the people found that I could speak English, they were surprised.... They were very ‘friendly so much so’ that we could go to the property of the Foreign Affairs Department and play there...[a]nd when we needed a bathroom [laughs]...if the Japanese came to drop some bombs, we would go to the bomb shelter of the Foreign Affairs Department close by, and didn’t need to run to the public one. It’s very scary, the public one [laughs]. It was full of ‘centipedes’.*

At this young age, Josephine learnt that there are different worlds, confusing worlds for her as to her own identity, for example whether she is Chinese or not: “The people there [in Chongqing] didn’t feel that we were ‘foreigners’ [Chinese born in Burma who can speak English] because there were ‘foreigners’ [westerners] there.” She saw personally how the worlds were separated into worlds of privileges or disadvantages according to fuzzy connections to the appearance and language of the person and the time and context in which she found herself.

She learnt how to move between these worlds. This expertise became invaluable when her family fled again from Chongqing to Hong Kong where Josephine was offered new separated worlds to navigate. In Josephine’s case, she navigated towards that world of
privilege, which she felt was superior. Josephine concluded that over time, “There is ‘racism’ in me too, I would say. I ‘adopted’ their things.”

**Being part of “hospital authority”**

Evident throughout her accounts of her development, there was strong emphasis on her successes and achievements despite consistent experiences of being a “‘secondary citizen’” most of her life, with over half a decade spent in the ex-British crown colony of Hong Kong:

*We were a secondary cultural group before, that was in Burma too...Burma and lots others. Even England, ‘right after the war’, when I went in the ’60s, it was there too, just not as overt, not as overt. And in Hong Kong, in the ’50s, the foreigners ‘treated’ us as ‘secondary citizens’, right?*

She gave an example of how discrimination marked her work life in Hong Kong: “You can be ‘nurse, more than nurse’ no. Promotion will be for those they bring from England. It was like that then. You Chinese need not dream about being promoted to ‘sister’.”

Nevertheless, Josephine had a long and remarkable history of incremental successes and achievements. In 1953 in Hong Kong, “after graduating secondary school, I went to become a nurse...in a government hospital”. In 1963, the government sent her “to UK to study nurse educator.” She returned in 1965 and started teaching. She was one of “only two teachers...at [major hospital in Hong Kong], just opened, so I trained a big class [laughs - proudly] of people, almost 60 nurses in one class.” In 1983, she “became principal,” first of “‘general’” nursing, then “‘post-basic’” nursing. She was proud to specify that with the latter, she was “‘developing university program’...‘transition to university’...with the ‘professors’ of ‘[name] U[iversity]’” and “working in a government hospital and ‘hospital authority’.”

She retired after 30 years of teaching nursing in 1995 when she came to Canada.
Their transition to Canada was smooth. Here, Josephine did not feel the kind of “apartheid, apartheid-treatment” that made her feel like a secondary citizen: “Most westerners [wai guo ren] you meet are friendly…. Not here [secondary citizen treatment]. I mean less, a bit less. Here it’s comparatively much more friendly.”

For an older person like Stephen with limited English, whom Josephine described as “‘very Chinese’. He likes Chinese culture stuff,” Stephen described the comfort of a familiar world like Chinatown that facilitated his transition:

*It’s like this. There are many Chinese here, like a Chinese place [huffs a laugh]. So we don’t need to socialize with the westerners. You walk out and there’re Chinese everywhere. So we can get used to it. If when you walk outside and they’re all westerners, then how we feel would be very different. What you eat would be different [laughs], the people you see would be different. Now when you go out, the streets are full of Chinese.*

Even in retirement here, Josephine held positions of importance, first in a school for elderly people, “I was teaching their computer class…I was the school’s ‘director’”, then as “‘Gallery Chair’” at an arts council in one of the Lower Mainland cities. Together with Stephen, she took arts and painting classes as well as courses for herself that ultimately culminated in a Bachelor of Arts degree at a provincially recognized university, with a diploma in the studies of elderly people. She complemented her studies in the arts by partnering with local artists in an art cooperative, joining them in the sharing and running of an art gallery in Chinatown.

On the side, she held volunteer positions of significance, “[M]yself, I have my own group of nurses. My nurse students—I was the chairperson for [their association here]…with 400 members [initially].” She named some of the heads of community agencies here in Vancouver as her former students, one of whom invited her to lead support groups for families caring for a relative with Alzheimer’s disease, which she did.
Josephine was the successful achiever who always took care of everyone close to her, especially financially. Before she got married, “I ‘looked after’ the whole ‘family’…for 19 years.” Her three younger siblings are all doing well in life, “one ‘brother’s in big business’” and two sisters, also retired, one a ‘nurse’ and other a ‘teacher’.” She shifted taking responsibility from her family of origin to taking care of Stephen after they got married in 1972, “he moved into my home,” when they were both in between their mid- and high-thirties at the time. She described their social standing and status, “We could consider ourselves living in the upper-middle class.” Given that Stephen “‘financially’ never cared”, she has always taken care of the finances for both of them: “The ‘management’ of this ‘home’, or the ‘finance’ aspects, I foot them all. I mean they’re all mine…how to ‘invest’ that money, or how to ‘make it viable’, I did some homework on that.”

The two ex-professionals have been married almost four decades. She described their relationship as “emotionally close…[you] can say ‘we are a very loving couple’.” In addition to Stephen, Josephine had her mother close by until the latter passed away a year ago, and is in touch with her two sisters here. Stephen’s family consists of three siblings, “one is in ‘Saltspring’, one in ‘Surrey’, one in ‘Victoria’,” whom they do not get to see often.

They described a small social network consisting more of acquaintances than family or close friends. They each used to periodically see some friends from their professional associations, Stephen from “his clan association [where] he was even director,” and Josephine from her nurse association and some new “artist friends” she had met.

Despite a small social network, the loving couple was enjoying their retirement, “I mean—up to what, ‘up to’ 2004, [he was] ‘very alright’, nothing much, [we] still ‘travelled’, went everywhere for fun.” They ate out frequently until Stephen’s dental problems and the
diabetes they both had necessitated cooking more at home. The couple enhanced their fun and leisure by using hired help they paid “‘privately’…to do cleaning work” so they could have more free time for their social life.

Unfortunately, around 2004 they started noticing unusual things happening to Stephen:

_His memory was declining a bit…. He would tell me when he woke up, it was ‘blank’, the ‘mind’ was ‘blank’. He didn’t know where he was. He tried to ‘orientate himself’. He would ‘go to the window’ and look out and then he would remember where he was._”

Josephine provided a detailed medical explanation of what happened subsequently: A visit to the specialist and blood tests showed that “his ‘calcium’ was ‘extra high’…the ‘parathyroid gland’ was enlarged.” Even though Stephen had an operation immediately and “the level of ‘calcium came down to normal’…‘the damage to the nerve cell’ had already been done.” His condition of the beginnings of Alzheimer’s disease could not be reversed and it is “three years he’s been taking medication.”

**Doing Everyday Care**

Prior to Stephen’s diagnosis, the couple shared responsibilities and took care of each other on a daily basis. With the addition of Alzheimer’s disease onto Stephen’s list of chronic ailments, more responsibilities for everyday activities shifted gradually from Stephen to Josephine as he became increasingly unable to look after his share of responsibilities and his own care needs. In the process of this shift, Josephine began integrating care and Stephen into her everyday life of activities towards achievement, because achieving seems very important in her life.
Shifting

At first, the diagnosis itself did not lead to a change in the couple’s interactions. Initially after the diagnosis, Josephine thought that Stephen was doing quite well, “He was ‘all right’ … He was ‘fairly independent’. He ‘prepared’ breakfast…he even washed all the dishes.” It was only later that “he deteriorated” and she had to take over the cooking and cleaning of dishes. They continue to attend church services, something they have been doing since they were living in Hong Kong even though Stephen never converted. Sometimes they participate in community leisure activities but not lately because “we looked again and again and couldn’t find anything that fit our schedule.”

Although Stephen is able to do many things even today, the changes in his capabilities have necessitated slowly shifting many responsibilities to Josephine. Her descriptions of caring resemble those of other care-partners. Besides cooking, Josephine needs to supervise Stephen in areas where he used to be able to do things independently. Like Vera and Mrs. Liu, Stephen can dress himself but in the wrong sequence whereas before “he would get dressed ‘in correct sequence’.” Similar to Mr. Chung, he continues to take his own shower but “he can’t remember how to adjust the hot water.” Moreover, even though he can physically manage it, taking a shower has become a “‘problem’” in that “the ‘problem is not’ when he’s [actually] doing it. It’s in ‘‘persuading’ him to do it.” Shaving has become a problem like showering, “He wouldn’t shave, almost refusing,” or he would shave “[halfway] and leave the other half.” Josephine finds ways to cope: “When I have to get a haircut, I would drag him to get a haircut and get that [shave] done too…. Sometimes he lets you do it, sometimes not.” She learnt that familiarity helps, “[I] would quickly get the ‘girl’ with whom he’s familiar…to quickly shave him.” As well, she learnt that sometimes, it is
simply better to let some things go in life, “I would pretend I didn’t see anything [referring to Stephen’s half shaven beard].”

Stephen is still capable of taking his own medications, but with Josephine’s supervision for certain things: “Those for ‘anti-hypertensive’, ‘heart diseases’ and ‘diabetic’, all those. And his stomach, stomach medications, yes…he takes them himself…no problem.”

However, with blood tests which Stephen described as “you just poke your finger” and insulin injections, Josephine now has to “run after him…he pokes it himself. He does his own injection, like that. But I have to ‘supervise’.”

**Integrating**

Interestingly, beyond the minutiae of caring and the shifts in activities and responsibilities of everyday life, much of Josephine’s accounts about care seems to revolve around how to integrate Stephen and the demands of his new condition into her own life. In fact, her very first thought upon hearing the diagnosis was:

*At that time, I mean the very first thing is that I have to quickly ‘finish my degree’. Yes, ‘that was the dream of my life, that’s it. ‘It’s to finish my degree’ and at that time, [I] was also very ‘earnest, earnest about becoming an artist’.*

She was in her last year of studies for her BA, so she did what at that moment was most important and practical for someone with her medical and university background and resources to do: She went immediately to research on the illness, “I would quickly quickly kept on ‘searching’, I mean to know ‘more about what what it entails’.”

After ‘losing’ Stephen a couple of times in malls after he went to the bathroom, Josephine began to keep him close to her at all times. Again, familiarity becomes a useful resort, “When we go anywhere, we go to ‘familiar’ places.” She was able to bring Stephen with her to class as he was familiar with the university grounds, “Earlier on, I ‘dragged’ him
with me to school…sometimes when the professor is willing, [I’d] let him sit inside.”

However, with his development of “‘gut motility’” problems which sent Stephen to the bathroom frequently especially in the mornings, taking him to class became impossible.

Since then, if Josephine needs time to do things on her own, she does them on the two days that Stephen goes to the adult day program. She highly recommends the program:

> Carers need to get rest themselves, sometimes they’re really ‘exhausted’. For example, the first time after I took him there, I came back to sleep and did nothing [laughs]. I just slept until it was time to pick him up.

On other days when she needs time for herself, she arranges for either her sister “or hire a ‘care’ uh hire a ‘care’ a ‘companion’, hire someone to come” and keep Stephen company.

This younger sister who was the primary carer for their mother has been able to help Josephine with Stephen’s care since their mother passed away over a year ago. The relationship between the sisters has become closer from the increased contact, “my ‘sister’ is alone, ‘one person only’, so we go see her. ‘I mean at least’ we can ‘social’ a bit.” In regards to the hired help they found recently, Josephine seems very pleased because Stephen is particularly happy with this couple:

> We knew some people who worked as ‘home help’…Chinese people, our own people, I mean introduced by friends. And we found a couple who’s very good. He [Stephen] likes it that the husband is handy, he can do small renovations, ‘repair’ things. So [we] feel they’re particularly good.

In the end, Josephine brought the dream of her life to fruition. She was elated to “‘brag a bit’” about her BA certificate hanging on the wall during the last interview and share details and photos of her convocation two weeks earlier. She continues to keep her artistic aspirations alive in the art cooperative for which partners take turns to keep shop. On those days, Stephen always accompanies her. Echoing Alice, Josephine exclaimed, “[We] need to ‘keep’ the ‘brain stimulated’ [laughs]…‘keep active’.”
Feelings About Caring and Caring About Feelings

Similar to the accounts of other carers, for Josephine caring is very much about coping with her own feelings while caring for Stephen’s needs and feelings at the same time. Like Jeannie, Josephine has come a long way from how she had felt at the beginning when she found out about the illness.

“Feeling very lonely…painful…‘worry’…scared”

Josephine’s initial reactions after the diagnosis were not positive. She felt “‘rather, rather upset’” at the beginning. It was actually a sense of loneliness she was feeling because the illness seemed to have erased what they had shared for a long time:

\[\text{At that time, [I] started feeling very, you can say very ‘lonely’ because I found, as well—‘shall we say; ‘it’s like everything about the two of us, totally became a blank for him. He can’t even remember the house we lived in for over a decade. ‘All he could remember’ is the time when he was a kid.}\]

She feels lonely too because she cannot talk about how she feels with others, for two reasons. First, because “there is a bit of ‘denial’” on the part of Stephen about the illness, Josephine feels that “it wouldn’t be ‘loyal’ of me to speak about him…I feel ‘guilty’ that I say this and that about him.” As well, there is a risk about talking, “because if you tell others, you’re afraid that they would ‘cycle’ it back to him. It might ‘hurt’ him.”

Second, she feels that talking to people who do not have “‘medical knowledge’” does more harm than good. Even though she is close to her younger sister who is “an especially nice person”, Josephine has other considerations: “I don’t want to ‘burden’ her…she doesn’t have ‘medical knowledge’, she was a teacher, she taught. That’s why she might be more scared about this type of thing. I mean we ‘nurses’ are less afraid.” She did not talk to her other sister either even though this sister was a nurse. This was because the sister “had her
‘hands full’” at that time with matters in her own family. So Josephine has been talking only to her one good friend who had looked after her “‘quadriplegic’” husband. Like Alice, Josephine feels that only fellow-carers can understand each other.

During this lonely period, accepting the changes in Stephen was one of the most difficult challenges for Josephine. Her sense of loss and pain resonates how Jeannie misses the person Mr. Chung used to be. Josephine reminisced about Stephen:

He was ‘perfectly intelligent’...his ‘literary sense’ and all was very high. Now it’s ‘hardly’...I mean after you got through ‘the stage of’ I mean ‘still thinking of him as he was before’, you ‘accept’ him, right? ‘That was the most painful stage’.

There is more to the basket of her feelings in that she is beginning to feel some regret. She asks herself whether her devotion to her achievements, which she always pursued without questioning, had compromised her care of and relationship with Stephen: “Before, it could be that when I was studying, I had to ‘concentrate’. So at times I ‘left him alone’. I didn’t realize it so much then. I thought that he could watch TV, that it was ‘alright’.” As well, she sometimes feels “stress over him” and “there’s a bit of ‘worry’,,” mainly about the future. She is afraid of the future, frightened by what she has learnt about it: “I ‘found out’ to ‘what stage the progress’ would go. I got very scared then, like that. Wow, when at that ‘stage’, how to handle it, what to do?” And she is wary for herself: “I’m thinking: ‘Wow, ‘when my time comes’, would I also have this illness?… I fear that I could ‘become like that’, afraid of that.”

“He can feel his ‘self-respect’”

All carers constantly balance their own feelings or needs with those of the care-partner. In this regard, Josephine tries to help Stephen maintain his self-respect in several
ways: by not talking about the illness which he seems to know something about, yet does not want to acknowledge, by helping him be the best he can be, preserving his positive aspects and respecting his boundaries.

Similar to Alice’s situation, Josephine tries to not talk about the illness. She avoids naming the un-nameable because, except for the acknowledgement of memory problems like Mrs. Liu, Stephen “would ‘insist’ he hasn’t changed,” saying, “I don’t have any big problems. We’ve got used to it [illness].” Josephine explained that her reason for not discussing the diagnosis with Stephen is to help him keep his self-respect, “I mean he can feel his ‘self-respect’, if I can maintain it, [I] would keep it, for the ‘time being’.” The avoidance does not make caring easier for Josephine: “He knows he’s ‘lost’ [memory], he knows. But if you say he has ‘Alzheimer’s’, he would get very angry. He doesn’t like that.” One reason why Stephen gets angry is because he knows he is not “crazy” like some other regulars of the adult day program: “He says they’re crazy, they’re nuts, like that. He says that about others, like that. I mean he says: ‘I’m not’ [like them].” In fact during one interview, Stephen referred to the other seniors at the program as “[t]hose with Alzheimer’s disease.” Then Josephine gently tried to sway him from his perspective: “[T]hey’re in the beginning stage. They just can’t remember things.”

According to my field notes, Josephine does other things to help Stephen maintain his sense of self-respect. For example, she helps him be the best he can be by following a general motto: “As long as he feels he can ‘handle’ it, I’ll let him ‘handle’.” First, the notes indicated that Josephine entrusts Stephen with different responsibilities: “[w]ith shoes on now, she put her handbag into Stephen’s bag,” which he carries. In addition, she creates opportunities for Stephen to be ‘in charge’, such as when she attaches gadgets of different colours and shapes
to keys and fobs, supplementing them with hints when “Stephen locked the door with keys
from his bag.” As well, she speaks with Stephen and answers his repeated questions calmly:

Stephen asked where we were going. Josephine said, “T mall.”...We were
getting close to the red lights and Stephen asked where we were going for
lunch. Josephine said, “Over here, let’s cross here,” indicating T mall. They
have their lunch here almost daily. The light was red for us and Josephine
said, “It’s a red hand. We have to wait for the white guy.” It was a very calm
and matter-of-fact voice, unaccompanied by any use of hand gesture to stop
Stephen.

In addition, she quietly lets Stephen lead and respects his choices:

There were very few people at the food court. Josephine seemed about to take
a table near the foodstall P where we were going to buy our lunch. It wasn’t
right next to another table with clients but there were people not far away.
Stephen moved further towards an area where there were lots of free tables.
Josephine followed him. I did the same. He looked at a table, hesitated and
moved on to another. There were at least three free tables from this one in all
directions. Stephen sat down.

Finally, she fosters his efforts to do things by himself as much as he is able to:

When we were done with our food, Stephen looked around, saw that there was
no tray and went to fetch one on top of the disposal stand. We all helped place
everything onto the tray and Stephen disposed it. This looked like it could be
his usual chore when the two of them ate there as he did it very competently
and naturally all by himself.

Whether in front or in the absence of Stephen, Josephine always draws attention to
how Stephen helps her and others. For example, she related how Stephen is always helpful
when he accompanies her to the art gallery on her day of “duty” and on special occasions:
“Yes, at the time of the art exhibition, he helped out. Even now he helps at the ‘art gallery’.”
For example, he would help “if there happened to be a Chinese customer wandering in, he
would chat the person up gladly”.

At the adult day centre where he goes willingly and regularly, Josephine reinforces
Stephen’s understanding that, besides attendance, he is there to give a hand, “[He’d] play
some mahjong and check the cards—those name cards people wear.”

Nevertheless, there are always challenges in caring. Like Alice, Josephine admitted that Stephen’s repetitive questioning is difficult to handle: “‘Although sometimes’ I also ‘got impatient’ [laughs]. Because if he asks you ‘about the key 10 times a day’ or ‘more than 10 times in a row’, it’s really quite hard for you to take [laughs].” But Josephine has her own way of managing her frustration: “Sometimes I’m naughty. When he asks too many times, I ask him to write it down. When he asks me [again], I’ll tell him to go look at what you’ve written [laughs].” Josephine means that Stephen should write it down in his diary, a journal where she encourages Stephen to keep writing his thoughts and activities everyday, an exercise to help his memory, “[h]e writes about events to recall.” He is willing to do this, even if over the years, journal entries have changed from poetry and prose writing, to writing about everyday activities, to Josephine dictating it to him lately.

In addition, Josephine fosters Stephen’s self-respect by helping him preserve his positive aspects. She does so by appreciating who he is, for example how he uses what Josephine considers “good humour” to help himself and her as well: “He’s quite good-humoured. I mean he often ‘uses humour to ease the situation’, I mean ‘ease his own stress’.” And his good humour often helps her in caring for him: “He’s ‘good-humoured’. He doesn’t let out his temper on me. If he finds me too ‘pushy’, he would say, ‘Why are you so concerned about it?’ [laughs] He means I don’t have to be so concerned.”

In fact, Stephen has a clever, friendly and witty way of making his point, and is even humourous at times. For example, when Josephine asked him to talk about the times he woke up and did not know where he was, something he probably could not remember, he replied, “I don’t remember them [laughs],” adding in a joking voice in Mandarin, “wang diao le [I’ve
forgotten them] [laughs].” When he heard Josephine say he could not find his way back to his room on a cruise ship, he sounded surprised and asked, “[I] couldn’t get back to the room. [I] didn’t know how to get back to the room [laughs]? Was I so lousy [laughs]? [za in Cantonese].” When Josephine mentioned that he needs to go to the toilet “all the time”, Stephen corrected her in a joking tone, “It’s actually less [frequent].” When Josephine said he was forgetful, Stephen protested, “What forgetful [laughs]? I know how to eat and cook [laughs].” When Josephine insisted that he should write calligraphy so that she could print cards of his work, citing someone else who did it, Stephen responded, “She’s brave,” and they both laughed. A point of interest: According to Josephine, he was not humourous before the illness.

Finally, Josephine fosters Stephen’s self-respect by respecting his boundaries, by not “nagging too much, not give him a bad impression…and got [him] stuck with that ‘idea’ against me.” She seems to respect his boundaries by knowing where to draw the line. If he is unwilling to do something, she would “let someone else ‘persuade’ him,” or simply wait it out. She does not force him to do things because she considers him “an adult [person]” first and foremost.

She makes every effort to respect Stephen for who he is, “[H]e’s like this. He’s very ‘good natured’,” so that he is the best he can be and continues to be the generous person he is:

At the centre, they do riddles, Chinese riddles. He would say: I actually know the answer. I don’t say anything until nobody says anything, then I’d open my mouth. And I’d say: Good, that’s how it should be. He would say: If I guess them all, others will have no chance.

Josephine respects and treasures this very cultured, intelligent and above all extremely giving person, the man whom she chose almost 40 years ago as her life-long
partner: “He’s not like those ‘grabbing’ dentist…he’s not ‘potentially well-off’…I liked him particularly for that [laughs].”

**Why Josephine Cares the Way She Does:**

“*Well, He’s My Husband!*”

Josephine respects Stephen for the person he is and treasures his unique qualities. Her respect for him and valuing of him influences her caring, and enables her to put the illness into context. In addition, she cited two other reasons for caring the way she does, namely their relationship and Chinese tradition.

She cares for Stephen first and foremost because he is a very special person, and this very special person happens to have an illness. Josephine almost repeated Jeannie’s exact words when the former said: “These types of things, he didn’t want them either, right? It’s from the disease itself.” Josephine still gets “‘irritated’,” but unlike Jeannie, Josephine rationalizes using a medicalized explanation to account for symptoms: “But I ‘try to remind myself’ that he is missing some ‘nerve cells’.” This understanding enables her to care in a way to “keep him happy” because “you understand he’s like this, so there’s no reason to not keep your temper.”

A second reason for caring is plain and simple. Stephen is the person with whom she has a very long and important relationship, namely their marriage: “Well, he’s my “husband [laughs]!”, with whom “we did ‘share’ and ‘enjoy’,,” from the time they were working hard during their young professional days, doing some travelling together and having fun, to painting and reading “‘Shakespeare’” and “Chinese poets”. The most recent years of retirement that preceded the diagnosis seemed particularly important as a source of enjoyment in each other’s company.
Further, her Chinese tradition tells her that as a couple, caring this way is how husband and wife should be. Speaking about how they were living their lives after the illness, Josephine conveyed, “We rely on each other in our lives.” She spontaneously added that the source of such an idea or thought should come from her Chinese tradition: “When [we] are husband and wife, that’s how it is [laughs and looking sideways towards Stephen for confirmation]. That should be our Chinese ‘tradition’.”

The couple’s own families and upbringing seem to have informed their idea of a husband-wife relationship, based largely on what they saw in the relationship of their own parents. Stephen recounted how his father and uncle worked together to run the shop. The two brothers and their families lived under one roof and everyone in the larger family helped to keep the shop running and the family together: “When we look at our older generation, there wasn’t, there wasn’t much relationship. We all depended on the shop for a living. We all had to cooperate with each other.” Although Josephine described her relationship with Stephen as that of “a very loving couple,” she also referred to an image of her parents fleeing the war with her and her younger siblings and the kind of obligations that characterize the husband-wife relationship: “With those circumstances, you’ve seen everything…how they look out for each other.”

**The Future: “Status Quo”**

Skillfully, Josephine has managed to integrate the caring of Stephen into her everyday life of achieving. She makes quiet and consistent efforts to be respectful and inclusive of Stephen, this very special person whom she values and holds dear and with whom she has a precious marital obligation. The couple seems to be doing well together. However, at the back of her mind, Josephine is cognizant that she can no longer take “‘just simple things’”
for granted, simple things like “you walked out the door, and he would close the door.” Now, they can no longer “‘share’ and ‘enjoy’” like they used to because “his ‘attention span’ is ‘short’ even for [things in] Chinese.” Nevertheless, she feels “‘happy that it wasn’t that bad’…. Because [I] can see others who are really miserable, really bad ‘going downhill’.”

What Josephine hopes for is to maintain their current situation: “I just hope he wouldn’t deteriorate further. I mean he ‘remains independent enough’ or ‘status quo’, that’d be good because I do know ‘the progress of other patients’.” That ‘progress’ she saw when she spent time at a ‘special care’ unit of a facility was not a promising picture:

*There I could see those with ‘Alzheimer’s’, those at ‘late stage’, I mean those quite ‘ill’, quite something, I saw that...I felt it was quite hard to ‘handle’. I mean when the time comes, I mean under his circumstances, because he is very ‘Chinese-cultured’, very ‘Chinese’, I mean ‘anything’ like what I just saw how miserable the Chinese were, I mean there was only one or two people who were Chinese and everyone was speaking English, so that person was very miserable. So when s/he saw me, s/he asked me to take her/him home [laughs]. It’s so difficult to handle.*

Josephine is thus consoled of Stephen’s current condition: “He [Stephen] himself is relatively, I mean he didn’t go totally crazy. He’s been quite good really until now, I mean quite ‘sensible’, like he wouldn’t just run away by himself or something of the sort.” Her preference resonated that of other carers who want to keep the status quo for as long as possible. Josephine conveyed: “The best would be that we could ‘continue live-in’, I mean ‘continue’ the way it is and have some ‘home help’ to come.” Again, similar to Jeannie and Alice, Josephine is considerate towards the government and limited resources in regards to eventual home support service: “I mean the government also has its difficulties. Because there are so many homes to serve. They can’t send—I mean they may not have enough staff, or what not.”

With an emphasis on the importance of a familiar world and routines in caring,
Josephine and Stephen will keep to their routines of everyday caring for each other, “We are very routinized. The doctor says we need to do four blood tests every day.” They intend to stay healthy and keep active together as best they can, creatively transforming their local mall into their social, clinical and community care grounds:

Josephine: Yes. The ‘good thing about it [art gallery] ’ is that there is a food court there...

Stephen: We eat there.

Josephine: There’s bathroom.

Stephen: Our lunch.

Josephine: Have lunch, there’s bathroom there too.

Stephen: [I] mean it’s very convenient.

Josephine: So we even do our ‘blood tests’ there [both JCL and SL laugh], blood tests and injections [laugh].
CHAPTER 8.
ROUTINES, RELATIONAL SELF AND CULTURAL UNDERSTANDINGS

To this point, I have provided a detailed description of the experiences of four families caring for a family member with dementia, drawing attention to their actual caring practices, their thoughts and feelings, and social and cultural background. In the caring process, they are often balancing the push and pull of forces between their values and beliefs, their affection for and needs of the relative as well as their own, and the level of suitability and adequacy of available services. Although their stories are very different and unique, the minutiae of care are very similar across the cases in this study as summarized in Table 4 below.

Table 4. Everyday caring

<table>
<thead>
<tr>
<th>Providing care</th>
<th>Jeannie</th>
<th>Derek</th>
<th>Alice</th>
<th>Josephine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cook</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Clean</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Assist with personal hygiene</td>
<td>x</td>
<td>x</td>
<td>Washes mom's hair</td>
<td>x</td>
</tr>
<tr>
<td>Administer medications</td>
<td></td>
<td>x</td>
<td>x</td>
<td>monitors</td>
</tr>
<tr>
<td>Arrange for/mediate with services</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Accompany to doctor's/day care</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Exercise/stroll/shopping</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Watch over</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Remind/instruct</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Talk with</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Stay close</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Interpret/speak on behalf</td>
<td>x</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
The main objective of this chapter is to highlight and develop three thematic areas\(^1\) that emerged from across all the participants’ stories of their everyday caring practices. These are: the importance of routines, the Chinese cultural value of a relational self, and the complexity and fluidity of cultural understandings and expressions. The three areas are interrelated in terms of how practice, culture and emotions are implicated in all of the areas, feeding into each other in everyday caring.

The following sections will first describe how routine practice is an adaptive strategy that embodies the personal, cultural and relationship history of the care-partners, and is conducive to positive emotions and relationships of family members. It then explores how these family care routines are often routines that help to meet cultural expectations on the family, in particular the obligation of responsibility and affection in the notion of a Chinese relational self. This obligation of responsibility and affection promotes caring practice that fosters the physical and emotional well-being of the person with dementia as well as the sense of meaningful existence of the carer. Carers derive feelings of competence and satisfaction from the caring that ultimately benefit both care-partners in the relationship. The final section illustrates how the participants, while drawing from Chinese cultural values, also draw from other sources from their various backgrounds and life history. They do so in non-thinking ways in routine practices, introducing contradictions and tension between what they say or think and what they feel and do in the caring process.

\(^1\) In the process, it is inevitable to repeat some quotes from the individual cases. All efforts are made to shorten and minimize repeated quotes wherever possible.
The Importance of Routines

Everyday practice is a highly adaptive mechanism (Bourdieu, 1990). Participants’ stories suggest that caring is very much a matter of maintaining everyday routine practices once they have adjusted to the presence and effects of the illness. While conscious efforts are required particularly at the beginning to adapt familiar everyday practices to changed circumstances, subsequent adaptation is usually done in gradual and practical ways. After every adjustment or adaptation, they routinely cook and clean, spend time and celebrate with family, go out for meals and dim sum, for strolls or shopping, and watch TV together or, more occasionally, meet with relatives or friends. This emphasis on routines recalls the importance Bourdieu (1990) places on rhythms and routines as a culturally adaptive device in an Algerian village, and how the regularity provides meaningful structure for the inhabitants. For participants in this study, routine practices serve several purposes: Routine practice facilitates the preservation of structure, continuity and equilibrium for these participants. It does so by helping them bridge change as well as provide a familiar and comfortable environment during periods of transition. As well, adapting familiar routines requires little thinking and energy, and thus provides the most practical and logical, or ‘economical’ means of bridging change. Besides being ‘economical’, routines create a sense of normalcy as well as generate positive feelings and rewards. Routines may even be a cultural way of transmitting values and practices from generation to generation in a family. Last but not least, routine and regular everyday activities have the ability to hold the family members and their relationships together.

The notion and importance of everyday routine practices in caring emerged specifically from the accounts of participants. To begin, routines allow carers in this study to
maintain continuity and stability. Jeannie used the notion of routines to describe how caring is a gradual process of adaptation, every six months with changes in Mr. Chung’s conditions, until caring becomes a matter of “routine” for her after three years. Derek described everyday caring in terms of routines comprising “everyday concerns…daily walks” and general activities in the couple’s “daily lives.” Josephine described her everyday life with Stephen as “we are very routinized” between lunch at the mall, injections, strolls and cooking dinner. Peter described the routines of his parents in their “everyday things.” while Nick talked of supporting his parents in “routines and habits” like going for dim sum, which the family has always been doing together.

The importance of the continuity of routines is most noticed when routines that usually run smoothly become interrupted. Alice gave an example of this interruption, elaborating on how difficult it was for her when her routines were upset at the beginning after she brought her mother home: “Because at the beginning…that changes your daily routines. You can’t go out whenever you want to, and you cannot not take her with you.” Alice’s case suggests that the importance of routines is twofold: It allows her to regain some level of equilibrium but also it helps her mother manage. Alice posited the importance of routines in relation to change: “I feel that they—with ‘Alzheimer’—need ‘routine’. They like ‘routine’. They don’t like it when you change things.” Mother likes routines, and so does daughter. Routines allowed Alice to adapt and regain equilibrium: “it’s OK now that things are on track…. So the most difficult thing at the beginning was to adapt to this…. I’m better because she—I ‘get into’ this ‘schedule’.” Breaking the rhythm of routines can threaten the continuity. The threat to continuity is why Alice would not take advantage of the respite she could get by sharing the caring responsibilities with her brother in LA. Once the continuity is
broken, she risks having to help her mother settle again into her routines of adult day programs and with new home support workers: “When she gets back, I have to ‘train’ her all over again. It’s even harder, right? I’d rather not.”

As well, the participants’ stories suggest that routines are important for bridging change for both themselves and their family member with dementia. It is the maintenance of routines that helps them personally adapt and assist their family member to adapt to new conditions. This translated into practice by continuing as much as possible those routines and relationships with people they are “used to,” or acquire familiarity with new ones they are trying to “get used to,” and trying to organize support so that it too facilitates the continuation of old routines, and where continuation of old routines is not possible, the development of new ones. For example, Alice identified how important it was to her that she had a consistent home support worker with whom Mrs. Liu could become familiar and feel comfortable in order to do everyday routines together. Alice herself would personally accompany and stay with her mother at the adult day program in order to help provide a bridge for her mother’s transition into the new surroundings and routines there. Similarly, Josephine selects the lady at the barber’s shop with whom Stephen is most “familiar” to shave him, knowing this will be a sensitive issue for him. While these two participants use routines and relationships with others to facilitate routine, Derek described how he would strategically use routine visits and do routines with Vera to “train” her at the long-term care facility to help her “get used to” or familiarize herself with the staff there.

Feelings of familiarity and comfort are important to adaptation (Bourdieu, 1990). Helping the partner with dementia by doing familiar routines with familiar people seems to bring this comfort. A first signal around the significance of familiarity and comfort from
across the accounts of all participants is the importance of proximity to the Chinese community, something that was important even before the illness. Proximity to the Chinese community provides participants easy access to a familiar environment with their favourite and comfort foods as well as familiar sights, smells and sounds. This proximity is important especially for elderly couples where either care-partner or both could not speak English, which is the case with all the spousal care-partners in this study. Not surprisingly, they all live in areas with a high density of Chinese population such as Chinatown and Richmond. In these neighbourhoods, participants can conduct their routines of everyday living independently with or without English proficiency.

It is no surprise that the importance of Chinese-speaking amenities continues to be relevant and convenient after the onset of the illness, particularly in regards to connections and relations with medical, professional, community and other services. For example, Jackie explained that Jeannie and Mr. Chung go on their own to “the specialist that they see and the family doctor [who] are both Chinese.” Alice cannot praise the Chinese adult day program enough and would “send her [mom] five days a week” if possible. As well, familiar environments afford the possibility of continuing a familiar way of life for these families, such as routines that are familiar to both care-partners. For example, Vera enjoys going on strolls to “the Chinese supermarket” with Derek, and Stephen and Josephine moved to Chinatown immediately after the diagnosis in order to be “close to ‘China—near [two Chinese community service agencies]’” where Stephen feels comfortable attending their programs, and “at home” whether strolling in the neighbourhood or helping Josephine out at the art gallery.
Behind these routines is an important element: The history of the care-partners and their relationship. Participants’ stories draw attention to how they take into account the history, preferences, hobbies and condition of the partner with dementia when adapting their routines in order to maximize the feelings of comfort and safety of the care-partner. This was seen in Josephine arranging with the girl at the barber’s shop for Stephen’s shave and the hired companions whom Stephen likes. As well, their move to Chinatown to be closer to the arts centre and gallery related as much to Stephen as Josephine, both having a long history and love for the arts. Likewise, Alice bridges Mrs. Liu’s transition into the adult day centre where the activities such as mahjong suit not only Alice’s preference for exercises of the brain for her mother, but also her mother’s leisurely interests and background. In other words, routines are adaptive devices that respond well to the dispositions such as history and preferences, as well as changing needs for feelings of comfort, familiarity and safety of both care-partners.

A further advantage of routine practice is that adapting routines to changing conditions in gradual ways require little energy and effort. All carers blend caring into their everyday routine activities and social life. For example, Nick discussed how adapting routines gradually to incorporate caring could be done simply by allotting more time: “We need more time to go in and out with him as his mobility has decreased.” As well, routines demand little thinking: “Without knowing or thinking, you would do those kinds of behaviour.” This low investment in terms of energy, effort and time makes routines the most practical and logical, or ‘economical’, choice in Nick’s circumstances:

...that is what we can do, I feel. I mean what else is there [we] can do? We might not be able to do it. For example, like what mom does everyday to care for him, you can’t do it. [You] have to go to work. So we can only spend more time.
While the importance of using routines to facilitate easier adjustment and adaptation for the person with dementia emerged in the stories of all participants, there is something precious beyond the adaptability and ‘economy’ of routines. It is the positive feelings derived from routines. For Nick, the ‘economy’ of routines is not only in terms of time and energy required, but also in relation to his emotional investment and rewards: “To be together when we’re off, it’s happiest for him to do this. What else can make him happy? I can’t think of it.”

All participants noted positive emotional returns. All recounted their routine activities with enthusiasm, and practice the activities with diligence and joy. Mr. Chung and his family happily go for dim sum together. Josephine and Stephen carry on with their everyday outings and strolls with pleasure. Alice adds in a game of mahjong to her routines with her mother on “Sunday when I play mahjong with her,” that day of the week she has dedicated to doing things her mother likes. Seemingly ordinary activities can in fact also be the highlights of these families, as Jeannie and her family illustrated in this conversation:

Jeannie:  Every day’s the same.
Nick:  Like the average, the average family, family’s routines of daily living.
SM:  When you say the average family, do you mean the routines of an average Chinese family?
Nick:  Yes.
Jackie:  Yes.
SM:  What do you mean by average?
Nick:  Mainly it’s the holidays, dim sum and eating together. These are the major things [laughs].
Jeannie:  It’s like that.
Jackie:  That means sometimes...
Nick:  [interjects] We’d get together.
Jackie:  ...we would get together and come here for dinner together.
Nick:  Yes, yes.
Although these ordinary routines pertain to the present, the practice of spending time together as a family is usually a continuation of and pattern from the past. For example, Derek reminisced about immediate and extended family members and the time they spent together as he was going through the photos with Vera. Nick talked about the history of spending time together in his family thus:

\[ After \ immigration, \ the \ pattern \ is \ more \ or \ less \ the \ same. \ Maybe \ it’s \ less \ busy \ here, \ work \ is \ usually \ from \ Monday \ to \ Friday \ only. \ So \ we \ have \ one \ extra \ day \ off \ Saturday \ to \ be \ together. \ We \ usually \ go \ for \ dim \ sum, \ that’s \ it. \]  

In addition to creating a sense of equilibrium and continuity, maintaining routine practices over time could be a cultural way family members convey their tradition, value and practice of doing things together in the family from one generation to the next.

As ordinary as holidays, dim sum, mahjong, strolls and eating together may seem, there may be something special about them if families maintain these routine practices over time. Perhaps this something special about routine practice is the adhesive quality of regular activities that hold family members and their relationships together. For instance, when asked for the reason for caring and doing all the routine caring practices the way they do, all participants talked about the importance of their relationship. Derek best illustrates how his routine visits and meals with the family are his way of maintaining the connection and relationship with those whom he holds dear:

\[ I \ go \ home \ once \ a \ week, \ stay \ the \ night. \ Because \ my \ children \ are \ there, \ so \ I \ go \ back \ to \ see \ them, \ connect \ with \ them.... \ That’s \ why \ every \ week, \ we \ call \ them \ to \ come \ out \ for \ dim \ sum. \ And \ every \ week, \ I \ go \ home \ to \ see \ them. \ I \ take \ the \ grandchildren \ out \ for \ meals, \ dim \ sum, \ so \ we’re \ always \ in \ touch. \]  

To summarize, routine practice is a highly adaptive mechanism (Bourdieu, 1990) that can provide satisfaction and effective ways that assure these carers of continuity and the ability to maintain important relationships. In particular, routines help satisfy their desire for
“status quo,” with Jeannie, Derek and Josephine expressly emphasizing the importance of continuing to live independently as they always have, with their care-partner at home, doing their routines together. Alice also wants to keep her mother home for as long as possible although mother and daughter may have less common and more separate routines than the spousal care-partners. In fact, carers’ accounts, those of spouses in particular, show that carers would rather complement the care-partner, making up for what the other person cedes to be able to do and adjusting to the new care conditions, in order to continue in their relationship, in what they have always been doing together between them as well as with other family members. Beyond being a highly adaptive mechanism, the possibility that routine practice may also be a culturally adaptive device to convey cultural tradition, values and practices in the family deserves further attention.

**Chinese Values and the Relationship**

This section explores how Chinese cultural routines for a family may also be routines informed by Chinese cultural expectations on the family. Participants’ stories suggest that, in understanding and making sense of their own caring, they often draw on Chinese cultural values. Values and practices can come from many different sources, first and foremost from the family in early socialization (Bourdieu, 1990). A common understanding of caring across all cases relates to the Chinese family value contained in the *wu-lun* (the five relationships) (Liang, 1987), in particular the relational self. This Chinese relational self emphasizes the obligation of responsibility and affection of a position in a relationship. This notion of the relational self urges a person to do her or his best to fulfill the obligation of duties and affection inherent in one’s positions. The participants’ accounts highlight how commitment and conviction to this obligation provide them with comfort and strength in effecting the
routines of care. In particular, relating responsibly and affectionately with the partner with
dementia fosters both partners in the relationship.

**Chinese cultural practices and values: The relational self**

While all participants draw strength from their Chinese family values when
undertaking caring routines for their partner with dementia, their accounts illustrate how first
and foremost they draw their values and learn ways of doing things from the family in their
early socialization. For example, Jeannie explained that she is caring for Mr. Chung the way
she had seen her family “help others from the kindness of the heart” while she was growing
up. Alice echoed that she feels she should take care of her mother “from what we saw from
when we were small.” Josephine takes care of Stephen the way she saw her own father and
mother “look out for each other.” Derek’s way of caring for Vera is, according to Peter, how
members are supposed to take care of each other in Chinese families: “We’re Chinese
family…what we perceive as values are basically gained from what we see in our
past…passed down from generation to generation.”

Specifically, the participants’ stories point to values inherent in the Chinese relational
self of Liang’s (1987) treatise of *wu-lun* (the five relationships). Within *wu-lun* is the notion
of *xiao*, commonly translated as ‘filial piety’ in caring research. Most of the time, ‘filial
piety’ is considered a responsibility, duty and obligation in the caring literature. Alternatively
and quite rarely, filial piety is considered an affectionate tie or bond. The participants’
stories, however, suggest a Chinese relational self with more specific characteristics. In
particular, participants place a high value on the position in the relationship, the attendant
obligation of both responsibility *and* affection for each position, and the expectation to work
hard to fulfill the obligations of the position (Liang, 1987).
To begin, it is important to note that only one of the participants used the term *xiao* to describe her own caring practices, and even this exception used it only once throughout all the interviews. However, all made clear reference to the position in the relationship (Liang, 1987) with the care-partner and that they are doing what they are supposed to do in that position. Jeannie and Alice called it “responsibility” of wife and daughter respectively. Derek referred to his marriage, “I’m [we’re] married 60 years now…it should be that we take care of each other.” Josephine echoed this spousal obligation, “Well, he’s my husband!”

While such assertions are common to all cultures in caring research, carers in the general literature do not usually attribute this responsibility or obligation to their culture. Most often, it is assumed that culture is the source of the finding because the researchers are examining or comparing specific ethno-cultural groups. Instead, the participants in this study linked it specifically to their Chinese heritage themselves. Both Jeannie and Alice referred this sense of responsibility as part of “our culture…[or] our Chinese mentality.” Peter explained his father’s sense of obligation for his spousal position from the Chinese tradition: “We’re Chinese family…it’s that obligation to look after the spouse no matter what…something we just got passed down from generation to generation.” Josephine added, “When [we] are husband and wife, that’s how it is…our Chinese ‘tradition’,,” which Nick echoed: “I mean from our family, our tradition is like this, perhaps. I mean before dad and mom took care of grandma. Now we hope, if we have the ability, if we can care for them, we would.”

This Chinese traditional value of the position in a relationship urges a person to do her or his best to fulfill the responsibilities of the position with care and affection (Liang, 1987). One way of looking at these participants’ stories is that holding on to this value of
their position in a relationship gives them the comfort and strength to work diligently and methodically in caring ways to fulfill the obligation or responsibility of the position. All participants mentioned that they are doing so “to the best of my ability” and/or show by example their practice of this commitment. Doing one’s best is a way of being which they have been used to since they were small.

Their conviction and commitment to the position in the relationship seems to help them concentrate on the bright side of things and do their best in the routines of caring. Not surprisingly, despite the demands of the work involved in caring, these participants do not tend to complain, except for Alice during the first few months after taking up caring responsibilities for her mother. Furthermore, these participants even seem to take the work with good spirit as if it was part of everyday life. For example, even though Jeannie talked about challenges of “stress” and feeling “tied down”, or Alice of “huge inconveniences” initially, on the whole they do not make a big issue about the amount or intensity of work and energy involved. Again, their cultural belief and commitment to do their best seems to help them adapt to the changes, adjusting and blending any difficulty into normality, as for instance, Derek asserted, “There’s nothing particularly difficult in taking care of her.” Doing their best to fulfill their obligation also implies shifting focus to the constructive side of work and making good of the positive aspects of things. For example, Josephine and Stephen see “‘The good thing about it [art gallery]’ is that there is a food court there…[and] bathroom there too.” Jeannie takes work for granted and even on respite day, “I refurbish the stuff in the fridge…[and] make soup.” She finds the work “routine for me now to take care of just him, one person…I have no other worries.” Alice’s success is remarkable considering how
she moved from “crying all the time” at the beginning to her present perception that, “She [my mother] feels: ‘My daughter is taking very good care of me, I’m very happy’.”

This way of looking at participants’ stories from a cultural lens of a Chinese relational self helps explain how the commitment to take care of a family member with dementia provides carers with a meaningful way of living. This cultural belief seems to give carers the strength to focus on caring and the positive side of caring work while minimizing any self-sacrifice. In the process, these participants are able to overcome challenges and feel pleasure and pride about their abilities to stay independent. For example, Derek emphasizes how he is “independent…not like the others.” Jeannie shares proudly, “I feel that my condition allows me to be independent. I can do it by myself.” Alice aims to take care of her mother independently for as long as possible as well, with the support of services and some hired help. While Josephine and Stephen live very independently too, Josephine does not talk as much about challenges or accomplishments like the other carers. This could be related to Stephen’s ability to still do most things on his own. Important to note is that this independence of the participants is independence with the care-partner in preserving their “status quo” together in an interdependent relationship.

Again, a useful way of understanding the participants’ emphasis of independence with the partner is to see them as a relational self (Liang, 1987). The notion of relational self places emphasis on the relationship and not the ‘self’. The notion demands proper conduct for each position in the wu-lun (the five relationships). The proper conduct for a father is to show kindness, a son to show xiao (filial piety), and husband and wife have mutual responsibility of duty and affection. Behind every position and relationship is an important cultural expectation: By working hard and taking responsibility for her or his position in a
relationship, the relational self ensures independence for himself or herself as well as for the partner in their interdependent relationship. An important motive for staying independent as a couple is that the work inherent in one’s position is done and will not fall onto someone else’s shoulders (Liang, 1987).

Participants’ accounts show a consistency in their caring routines and practice to meet this cultural expectation. For example, parents in this study try not to let their responsibility fall onto someone else’s shoulders. They try to stay independent for themselves as well as out of a caring concern for their children. Specifically, all these carers had cared or are caring for a parent, yet those with children do not want or expect their own child or children to do the same for them. Jeannie took care of Mr. Chung’s mother for five years, but avoids bothering her own children as much as possible, even in an emergency situation like a fall. Jeannie emphasizes, “I don’t have to bother others…I still don’t need help from others yet.” Alice is caring for her mother but would not want to burden her sons in the future: “I would make it clear to my ‘kid’: If I have ‘Alzheimer’, you must send me to a seniors’ home.” Vera’s parents came to live with Derek and herself in the younger couple’s home in Malaysia until they immigrated to Canada, yet Derek purposefully separated himself and Vera from Peter and his family, seemingly for the younger generation’s sake: “My son doesn’t need to provide any care…let them be free…they have their world and they have their lives…he can’t take care of it. I also don’t want to bother the young people.”

In a similar vein, spousal participants focus on their obligation of duty and affection towards their partner with dementia. Remarkably, in meeting this cultural expectation in caring, this independent yet relational way of caring is usually done without too much thinking for oneself. For instance, when asked how they care for themselves while caring for
their partner, spousal participants were not able to think about themselves but answered only in relation to their care-partner. For example, Jeannie could only think of being careful so nothing happens to her that would jeopardize Mr. Chung’s care:

I'm not thinking of anything [laughs] ...not much really. Basically, I try to be more careful in everything and there is no problem. The most important thing is to be careful...I don't think about taking care of myself or my situation. Essentially, as long as I have the ability, I will be with him and do my best. That's all I want. I can't think that far, what to do with myself.

Josephine worries like Jeannie about the same problem if she should not be there to care for Stephen: “What I fear is my own ‘health’. I won’t be able to ‘look after’ him. That is what I fear.” Derek echoed: “Hobbies, I don’t have any hobby. I would look after her and not bother with anything else. The most I’d do is some exercise to maintain my health.”

It seems as though they have been caring for each other and doing things for each other the same way with the same cultural expectations for so long that there is no need to think about the why or wherefore of their caring and practices. Caring responsibly and affectionately for each other as a Chinese relational spouse should is so entrenched in the way of being of these elderly couples that such cultural expectation has become taken-for-granted, something forgotten as history yet always present in the background, as the declarations of the three spousal participants attested. They do not generally think of their ‘self’ on its own, but rather as a relational self with the partner. Alice, the only daughter in the study, is the exception who is clearer about the spaces she shares with her mother, those she does not nor want to, and those she willingly gives up for her mother’s well-being when ultimately she and her husband put their “plans on hold” for Mrs. Liu’s care. One way of understanding the differing emphasis placed upon one’s own needs in this situation is that the element of a Chinese relational self could be more common among the older spousal
participants who have a different role, a longer history of relationship with their partner as well as more time and depth of exposure to and immersion in Chinese values and practices. That the participants’ accounts suggest a relational self may be more common among the spousal participants draws attention to how relational dynamics could be particularly pertinent to older care-partners. This was seen in how Alice’s family physician appealed to Mrs. Liu to let Alice hire help not for her own sake but for the sake of Alice: “Don’t do that, not let your daughter hire [someone]. You have to help her. Her health is not good. She has lots of illnesses.” In like manner, Jackie did not appeal directly to Jeannie to take care of herself but had to implicate Mr. Chung’s well-being in entreaty her mother-in-law if her swaying were to have any effect: “Be careful with yourself. If there is any problem, not only will you suffer, but daddy will have no one to take care of him.”

The cultural expectation of responsibility of position and not burdening another person is an important part of the Chinese relational self (Liang, 1987). Participants’ accounts illustrate how relations based on the cultural understanding and expectation of responsibility and affection extends beyond the family into the community in a gradational way (Tsai, 2001). Carers for example try as much as possible to not let what they consider as responsibility of their position fall onto their friends. In other words, the participants’ accounts suggest that in their social networking, there may be a tendency of their Chinese relational self to think of the other person first, for the sake of the other person. This is seen in how Jeannie appreciates her friends’ phone calls and expression of support, “If you need any help…. They tell me to speak up, let them know,” yet she would not take up their offer to help her with Mr. Chung. Neither would Alice oblige or inconvenience her friends when they offered to play mahjong with her mother, “[T]hey ‘offer’ but I shouldn’t bother people.”
Derek consistently claims he never needs help from family or friends. He is actually able to give to others, “I always help them,” while caring all by himself, by being a friend and equal to those around him, “I’m what is known as volunteer.” While this way of thinking of others allows participants to care responsibly and independently for their partner as well as feel good about their successes, it is also possible that the emphasis on always taking one’s responsibility of position and not burdening others can have the unexpected effect of impeding carers from taking up available support in his or her social and community networks.

In regards to relations with government and services, the participants’ stories support Liang’s (1987) assertion of the weight the Chinese relational self places on personal responsibilities rather than individual rights. While all participants use community and health care services and programs to some extent, their accounts suggest a generally conservative attitude towards use of public services. Despite the fact that they do encounter challenges in caring and their experience of inadequacy of services to support them as depicted in the individual cases, all participants are very considerate of the limits of government resources. Jeannie considers caring her personal responsibility before that of the government: “If I have the ability, I should do it…if the government has to help every single one, it will be a big problem for the government.” She even compared her Canadian situation to Hong Kong where there were far fewer services available. Alice considers “the government is helping you a lot already.” Even though she would like to send her mother to the adult day program for more days, she is considerate of limited resources: “They can give me two days. And that’s already good…I’m very happy.” Despite Derek’s assertiveness in accessing public resources, he too is considerate and respectful of others sharing resources: “You just look at
Obligation of responsibility and affection

The previous section describes how participants care responsibly for their partner. However, caring responsibly is only part of the obligation of one’s position in a relationship. The other part is to care affectionately for the partner (Liang, 1987). According to Liang (1987), every person is naturally endowed with feelings and compassion (qing). It is emotions that allow a person to learn important values such as humaneness (ren) and tell right from wrong (zi). It is feelings that enable people to form relationships and appreciate and value the sense of obligation and affection inherent in a position of a relationship. Feelings from the ‘heart’ (xin) play a very important role in Chinese culture (Liang, 1987; Sun, 1991) and participants’ stories draw attention to this ‘heart’ and its obligation of affection as well as rewards from caring.

Continuing positive and constructive caring is not only about providing practical care. These four cases draw attention to how, in fulfilling their obligation of position to continue care in positive and constructive ways, carers also attend to the partner with dementia with caring concern and affection. Specifically, the feelings of care-partners are intricately tied to all actions of caring. For example, all four described the importance of keeping their family members close or bringing the care-partner with them everywhere they go. This was particularly evident with the three spouses. While this could be happening because of concern for leaving the person alone or for other reasons, the stories of all four suggest that they include the care-partner because the feelings and well-being of the care-partner are a priority for them. For example, Jeannie’s “heart is always thinking” about Mr. Chung who...
“would be very disoriented…[his] heart is scattered” without her. So Jeannie would organize routines with Mr. Chung or even “just sit there in front of him, then he is much happier [laughs happily].” Derek organizes routines and physical spaces in a way where Vera “can see you all the time, she is very serene.” By the same token, he writes her notes so that when she does not see him, she would not “worry and look for you.” Like Derek, Alice organizes routines and physical space in order that her mother can feel comfortable spending time with her alone because “my mother is very afraid she’s in my way [with my husband].” During their routines alone, they watch “news…performances…‘concerts’…‘dances’” together, programs her mother “enjoys watching.” Josephine shows the same consideration for Stephen by organizing their routine activities where he could either accompany her or have hired help stay with him. In the latter case, her choice of hired help is based mainly on his feelings as to how much “he likes [the couple].”

Alongside the feelings of security, ease and pleasure, the importance of attending to the physical comfort of the care-partner emerged across all four cases. For example, they filter services and accept only those that are attuned to the liking and comfort level of the care-partner. This was Alice’s case when, appreciating her mother’s sense of and preference for privacy, she “help[s] her [mom] with washing her hair” rather than leave the task to the home support worker. According to the home support worker who has been working consistently with the family for many months, the way Alice cares for her mother is that of a daughter who “loves her mother very, very much.” Other carers like Jeannie and Derek attend to the bodily comfort of the care-partner by choosing suitable clothing for the partner’s bodily warmth, “Mrs. Chung must have spent some time in dressing Mr. Chung comfortably and warm enough to come and see me,” the family physician attested. They also prepare
foods that are not only nutritious but which the care-partner likes. All carers put energy and time into preparing food. In the case of Derek who no longer needs to provide meals since moving into the assisted-living facility, he nevertheless prepares food on the side for Vera that is not only nutritional for her, but food that he knows she likes and would enjoy.

Participants’ stories point to the importance of the ‘heart’ and feelings in caring. Their accounts suggest how the rational planning and execution of practical care and chores implicate to a high degree their ‘heart’ or feelings that facilitate an inclusive kind of caring. For example, in order that Mr. Chung’s “heart is at ease,” Jeannie refers constantly to her feelings from the “heart.” In caring, Alice relies on her feelings as well: “Your heart also wants to take care of her.” Josephine keeps Stephen’s feelings of self-respect close to heart while Derek feels and intuitively lets Vera’s physical and bodily cues guide his care.

Together with their heart and feelings, carers’ stories draw attention to how they also rely on their knowledge of the care-partner, such as the partner’s history, preferences, hobbies, tastes, abilities and needs. The importance of this knowledge is notable across the cases. As earlier noted, caring routines are often based on participants’ familiarity with this knowledge and how they use this knowledge to guide their caring practices, such as how Josephine arranged a shave for Stephen with someone he is familiar with, or the companion who could do handiwork around the house, an aspect that particularly pleased Stephen. Their accounts suggest that when carers are sensitive and attentive to this kind of intuitive knowledge, this caring approach can even allow the partner with dementia to retain some abilities or learn new things and develop alternative capacities and strengths. For example, Vera learnt how to use a walker and turn around corners with it with Derek’s help. Mrs. Liu learnt how to find her way with the help of landmarks like a construction bin outside her
home. Both Vera and Mrs. Liu can still organize themselves to a good degree when Derek and Alice respectively leave them notes, and this is despite their cognitive decline, of nine years in Vera’s case!

While this affectionate and attentive way of caring is not uncommon in other cultural groups, carers in the general literature do not usually attribute their way of caring to culture. These participants, however, attribute their affectionate way of caring specifically to their Chinese tradition and mentality. For example, besides the frequent references to the Chinese notion of ‘heart’ or xin, Jeannie ascribed her way of caring and concern for Mr. Chung to “ganqing,” a notion of affection in long-term relationship that strongly implicates affectionate feelings with the sense of responsibility:

...what two people, all along, from beginning to end, it's the same, he treats me—that is he cares in every way. He's responsible towards the family, takes care of everything well, so I feel very content. That's why we continue into our old age...you take care of me and I take care of you.

Alongside the affection in their long-term relationship, Derek and Josephine both called up their spousal obligation and responsibility, with Josephine referring specifically to how she saw her parents cared and “look[ed] out” for each other. Alice referred to her “responsibility” from her “Chinese mentality” alongside her feelings from the “heart.” Worthy of note is that their attribution of their way of caring to Chinese culture and mentality was not immediate. All participants had to pause or seemed at a loss for an answer when asked the reason for their caring practices. It seems as though such cultural expectations in their relationship and practices are so entrenched and taken for granted that they do not usually have to think about them. Their stories suggest that relying on their ‘heart’ or feelings rather than their thinking somehow allows them to adhere to their obligation of responsibility and affection, without
having to think about the notion or value itself. They simply put it into action when they practice the value in the way they affectionately care for and look after each other in their routines of everyday life.

**Caring inclusively**

The inclusive and caring environment of these families resonates the kind of ‘meeting’ and ‘encountering’ of Buber’s (1947, 1970) I-Thou relationships. In such an environment, the Chinese persons with dementia in this study are able to actively participate in and contribute to the relationship when the carer includes and supports their involvement in everyday activities. Participants with dementia have their own ways of being and expressing themselves, ways that the carers, family and others around them, can clearly appreciate. For example, Mr. Chung showered compliments on the family with his observations, “everyone is good…the daughters-in-law love [Jeannie’s] cooking,” which his wife and children acknowledged with smiles or nods as he spoke. Their accounts also pointed to appreciation of Mr. Chung’s contribution to the family with his presence, joy and enthusiasm whenever he sees the family or goes out with them. Likewise, Mrs. Liu showed her awareness and acknowledgement of her daughter’s care, saying: “I don’t have to care because I have a good daughter,” to which Alice responded with a beam of appreciation on her face seeing this happy and relaxed mother around her. Stephen generously gives to others at the adult day program by letting others answer the riddles: “I don’t say anything until nobody says anything,” and sends Josephine into bursts of laughter with his humour. His generosity and humour are qualities which Josephine fully appreciates as they often help to “ease the situation” for her. Even Vera at an advanced stage of Alzheimer’s disease performs all the manners of a warm and welcoming hostess, and knows where boundaries are
with staff when, in her bantering with the manager, she specified, “I’m joking.” She is full of life, someone whom Derek cannot help but admire when, despite her illness, she expressed her appreciation and acknowledgement of Derek’s tender loving care: “And he’s done his best. And after I’ve listened, I have to thank God. I have such a good husband.”

The participants’ accounts and the observations of their interactions demonstrate how the participants with dementia in this study are all still there! They actually actively contribute to everyday caring and the relationship. Caring inclusively and attentively by being in touch with the feelings and being of the partner with dementia, including their history and preferences, seems to be the key to preserving the partner. However, this attention to feelings is not limited to those of the partner with dementia. Participants’ stories suggest that although the Chinese relational self thinks of the other person in the relationship first, the carer is also aware and mindful of her own feelings. For example, Jeannie and Josephine both expressed their feelings of loss of the person they used to know, with Josephine acknowledging her acceptance of the loss, “He was ‘perfectly intelligent’…his ‘literary sense’ and all was very high…you ‘accept’ him, right?” The acknowledgement of loss facilitated Josephine’s acceptance of Stephen’s new condition in order to continue their relationship on which “we rely on each other in our lives.” Similarly, Jeannie described how she feels about her relationship with Mr. Chung after accepting the loss: “…very content. That's why we continue into our old age.” After Alice acknowledged her conflicted feelings, “I have a loving heart so what to do? You are forced by your loving heart to, force you to endure this,” she can focus on her goal to continue the relationship and face the challenges, rather than later regret not having done her best to fulfill her responsibility: “If you don’t do it, you could regret it.” Interestingly, Derek, the only male in the study who also happens to
be the oldest participant, hardly drew attention to any personal and emotional conflict or trauma as a result of the illness. His resort to feelings while caring was limited to staying receptive to Vera and intuitively letting her bodily cues guide his care. Whether and how gender and age or developmental stage may play a role in caring requires, however, a larger sample for assessment.

Participants’ stories suggest that caring practices based on this relational way of being and caring fosters both care-partners. Their accounts illustrate how preserving the partner with dementia and their relationship gives the carers joy and satisfaction, particularly in regards to their own sense of competence. Specifically, their accounts of caring in their everyday lives were filled with liveliness, pride and satisfaction as demonstrated by Alice who noted with pride, “I mean the way I’ve organized her now, it’s quite good.” The importance of this was not just conveyed through carers themselves, but family also picked up on it. For example, despite recognizing his father’s physical condition as somewhat rundown, Peter shared his joy and satisfaction from caring for his mother when he commented upon Derek’s sense of capability and feelings of satisfaction with the care that the latter arranges and manages all by himself, “[He] feels very great…he likes it, it keeps him occupied, give him something, I’ll say satisfaction. Everyday you have something to look forward to do that he likes to do.” Carers’ accounts also suggest that despite the hard work, caring gives participants a sense of purpose and meaning to life, as Derek remarked, “I’m not tired. I thank God that I have the energy [laughs]. I have nothing to do all day; I’m bored. What would I do in my retirement?” Jeannie arrives at an understanding of her situation that is “not as good as those that are better, but it's much better than those that are worse.” In Alice’s case, caring has brought her new understandings and meanings of
friendship, relationships and life in general: “Then sometimes I would feel, aye, I’m already this age, I don’t really need that much that much freedom. So let it be.” The participants’ stories suggest that in caring, fostering the partner with dementia benefits not only their immediate relationship but other close and important relationships in the family as well. Last but not least, caring also contributes to the carers’ own emotional growth and well-being in this study.

To summarize, everyday routine practices can be a culturally adaptive device (Bourdieu, 1990) that provides structure and meaning to these families, at the same time enabling them to meet cultural expectations on the family, often without conscious effort but through practices in everyday life. Specifically, the participants’ stories suggest how their everyday care routines are aligned with Liang’s (1987) Chinese relational self. In other words, unlike most studies on Chinese family caring that usually focus on family or filial norms as responsibility or, more rarely, as affection, the caring routines facilitate the fulfillment of the obligation of responsibility and affection of position in a relationship for these carers. In a mutually constitutive way, this relational way of caring fosters both care-partners and their relationships on one hand, and give meaning and motivation to maintaining the routines of caring on the other. However, this general congruence between their Chinese value and routine care practice is far from perfect. The next section describes the contradictions and tension of participants when their Chinese and other values conflict with actual caring practices.

**Cultures and Complexity**

Alongside the congruence of Chinese values that give them comfort and strength to continue with caring and maintain their relationship, participants’ stories show that in their
practices of caring, they also experience conflict from these cultural expectations. Further exploration of their accounts suggest how, when engaging in practices, participants draw from a complex mix of cultural understandings and expressions. Other sources of cultural understandings include their social, religious, and life history experiences and backgrounds. Furthermore, participants indicate that they often draw from these sources in fuzzy and non-thinking ways, similar to how they do not think about their ‘self’ when caring, or the reasons for caring in their everyday care practices. In these fuzzy spaces in between the cultural, social, religious and life histories, the various cultural understandings of participants straddle each other as participants simply do what they are used to and feel good about in everyday practice.

Feeling good about doing familiar things points to the importance of affectivity embedded in everyday practices throughout the history of an individual’s life (Bourdieu, 1990). Participants’ stories suggest that alongside conscious thoughts and actions, they often go by familiar feelings without too much thinking, introducing contradictions and tension between their beliefs and caring practices at varying moments and circumstances.

**Chinese cultural understandings and expressions: Contradictions and tension**

Participants’ stories suggest that while Chinese values and beliefs learnt from early socialization in the family are important sources of understanding in their everyday caring, the references participants make to Chinese culture and their cultural expressions are not always uniform. Their accounts show general complexity and diversity in the different references they make for understanding and expressing Chinese culture in thoughts or action. For example, Alice referred to traits or typical characteristics of populations as culture, saying that she identifies more with “Western culture” because westerners are “frank.”
whereas Chinese people are “phony,” as according to her, the Chinese do not say what they think. Derek on the other hand equated Chinese culture to residential patterns and practices of “living with children.” Josephine, who made the least references to Chinese culture and tradition, almost always related culture to historical and structural issues of “discrimination” and “second-class citizenship.” Furthermore, different participants can hold different ideas about the same cultural concept; even the same person has a different idea of the concept at different times. For example, Derek likes “boundaries and hierarchies,” which, according to Jeannie, pertain to Chinese family tradition and mentality. Yet Derek dismisses Chinese family tradition and ideas as “old fashioned.” Specifically, Derek consistently associated Chinese culture and tradition to the norm of the elderly living with children and “rotting in the basement,” a notion he speaks against strongly. Unlike Derek on this issue, Alice distanced herself from local models of living arrangements, “They [‘Western culture’] didn’t change me…there is happiness in big families.” Quite surprisingly, Derek eventually moves back with Peter and his family after Vera enters long-term care, and is quite happy resuming the previous residential pattern of an extended family.

Their references suggest that rather than some absolute understanding or meaning of the essence of culture (Tylor, 1958), these carers take a fluid access to the understanding and meaning of culture when referring to persons, relationships or situations. In particular, their approach to interpreting culture, whether carers are alluding to cultural values and beliefs, referring to character traits, denoting behavioural or ideological patterns, or connecting to historical and structural issues such as experiences of racism and discrimination, resorts to a broad spectrum of cultural understandings. From this broad spectrum, individuals draw unique meanings in a complex and fluid way, depending on their personal experience, the
specific issue, circumstance and time context in which the cultural interpretation and expression is made.

This fluid reference to culture can introduce contradictions and tension at times, for example, those seen around the cultural values and beliefs on the obligation of the position in the relationship of participants. On one hand, the obligation provides strength and on the other, it introduces tensions. This was seen in Jeannie’s attempts to reconcile the call of “duty” and her personal needs. Likewise, Peter juggles on one hand, “this conflict with traditional family value…we’re supposed to look after our own aged parents…. On the other hand, with the balance, the demands of work and the children.” Alice is constantly torn between feelings of frustration over losing her personal freedom and feelings of “responsibility” for caring for her mother. In a similar manner, Josephine conveyed feelings of regret over an obligation she felt she might not have fulfilled because of circumstantial demands and personal priorities at the time: “Before, it could be that when I was studying, I had to ‘concentrate’. So at times I ‘left him alone’. I didn’t realize it so much then. I thought that he could watch TV, that it was ‘alright’.”

The level of complexity increases with the internal contradictions and tension of two participants. In Alice’s case, she admitted that caring is a job which no one, “no matter how filial,” would want to undertake, yet she would not relinquish it despite her own health issues and having the option of her brother in Los Angeles as alternative carer. Derek’s strong views against Chinese tradition are equally perplexing, considering on one hand the vehemence with which he associates the traditional family residential pattern with “rotting in the basement,” and on the other hand, first how he had lived quite pleasantly with and taken care of his in-laws, and second, how he eventually moved “home” after Vera’s placement.
Adding to the complexity is that the participants do not draw only from Chinese cultural values and practices; for example, two participants talked about the role of religion in their lives. Josephine and Derek recounted how they have been Christians and churchgoers since childhood and young adulthood respectively, and interestingly their accounts focus more on the social than religious or spiritual aspects of religion. Specifically, religious practice provides a social network as well as a model of caring. Derek talked about his “church sisters and brothers,” and how the church teaches him “not to be obsessive, not other things… [but how] to be a good person.” Similarly, Josephine learnt about values in her ‘social family’ of the church: “After ‘Sunday school’, we would all go to the house of the big boss, all the workers and children, because there is a big garden…like a big family.” There, she also learnt about caring for and helping each other: [After arriving in Hong Kong] “‘Sunday school’ took us to visit it [school]. We saw it ‘Wow, it’s great’ [laughs]!”

Furthermore, the participants’ accounts illustrate that in caring, they draw from all the different sources, often without thinking about the source or the why and how of their practices and actions. Peter gave a description of the fuzzy way that informs his father’s cultural understandings and actions:

*It’s basically his background, what [how] he’s brought up, and what he as a person understood to be his duty, his natural duty…it’s all a combination of his personality, the situation, everything, it seem to work out for him. It’s not something you can put a formula to then [laughs], it just so happens.*

By “natural,” Peter could be inferring that the duty is compatible with many aspects of Derek’s being: His sense of marital obligation in “Chinese families,” his religious teachings on “how to be a good person,” his circumstances of a “retired” husband and his identity of a capable and “independent” person and “volunteer.” The compatibility makes the duty easy, simple and hence ‘natural’ for him to perform.
The participants’ stories suggest one more source alongside their familial, social and religious backgrounds that possibly informs their cultural understandings and expressions: Life history. The life histories of the participants are diverse and complex, both geographically and professionally. For example, whereas Jeannie remained largely within the “family” and the family’s “shop” most of her life in Hong Kong, Alice considers herself very “westernized” after having lived on a different continent for a long time. Derek was on a continuous journey with Vera every “ten years” across three countries with successes as a “professional accountant,” as well as in “business” where he “made money.” Josephine climbed the social ladder onto an endless list of achievements despite the “discrimination” and “second-class citizenship” that accompanied her across the first few countries and decades of her life. Although carers did not specifically link their life history over the long term to any caring experience in particular, their actual practices of caring do recall certain aspects of their life history. For instance, Jeannie focuses on caring for Mr. Chung in the home. Alice, who considers herself very ‘westernized’, seems more torn than the other carers between her need for “personal freedom” and her Chinese “responsibility,” although her age (being the youngest participant), gender and role in the relationship (being the only daughter), need to be considered. Derek is extremely assertive with his expectations from people he deals with from “government” and “services.” And in her accounts of caring, Josephine places enormous emphasis on her experiences of discrimination, and on the wealth of “medical knowledge” she acquired during her nursing career.

**Straddling and emotional knowing**

Culture is thus very complex and comes from many sources: Values and practices of one’s ethnic culture and family, and the social, religious and other experiences in the life
history of a person. Participants’ stories suggest that it is difficult for them to separate out whether the understanding of their own caring comes from one particular source and not another. In fact, the participants’ accounts illustrate how this straddling of cultural understandings is common. For example, Jeannie and Alice specifically expressed how they cannot separate out their cultural sense of responsibility from their personal feelings. Alice goes back and forth between her sense of “responsibility” and her “loving heart” in relation to caring for her mother. In the end, she concluded, “It’s both. There’s both,” embedded in her caring. When Jeannie was asked whether a certain attitude of hers around caring and being was related to her “culture,” she unambiguously asserted that it was “personal,” and then moved to familial, as it was “cultivated from within the family.” However, after some thought, she could not exclude that Chinese culture also played a part: “In regards to culture, I think there is some of it.” Josephine’s sources of understanding straddle each other as well. She related her way of understanding relationship to “Chinese tradition” as well as to the familial, the latter in how she saw her parents “look out for each other.” It would likewise be difficult to separate the social from the religious for Derek and Josephine.

What is important here for understanding dementia caring practices in the stories of these participants is not the ability to separate the sources of understanding or different aspects of care, but to explore what might be behind the impossibility of the separation. In this regard, the participants’ stories draw attention to how routine caring practices are often performed in non-thinking ways, involving different understandings and aspects of culture and caring all in concert. On one hand, the simultaneity from different understandings and aspects of the person and caring can generate conflict and contradictions at times, giving the impression that the participant’s actions contradict other or previous actions, or her or his
reasoning or beliefs. On the other hand, the straddling or impossibility to separate individual aspects in practice points to possible alternative ways of knowing and being beyond the cognitive and rational mode of separating and categorizing in everyday practice. Given the strong emphasis of participants on their ‘heart’ and feelings in caring, one such possibility could be emotive reasoning (Sun, 1991) or emotional rationality (Liang, 1987).

This alternative way of knowing and being through emotional rationality may shed light on better understanding some of the contradictions and tension of these participants. Using the example of separating the affective or emotional from other aspects of caring, the accounts of participants illustrate difficulty in teasing things apart. For instance, Jeannie cannot separate the emotional “clinging” and the more practical “constant care” tasks as they are intricately tied: “Basically, you can’t separate them [laughs].” As well, all carers except Josephine, the nurse-educator who has more professional medical knowledge than the others, swayed back and forth between their knowledge of the disease and what they know and feel from their personal and emotional experiences with their care-partner. For instance, on one hand, Jeannie, Derek and Alice ascribed the disease to a problem of “the brain” which renders the person “like a kid,” and not like “normal” people. Alice further described her mother as “a total loss.” Jeannie thought, “he [Mr. Chung] knows nothing.” And Derek was convinced that, “she [Vera] can’t give me now. She can’t talk, she can’t do anything.” On the other hand, Alice affirmed that her mother “understands.” Jeannie contradicted herself by saying that Mr. Chung “knows everything.” And Derek enjoys a vibrant relationship with Vera. These contradictions suggest that what carers understand and express through rationalization and verbal articulations on one hand, perhaps based on their rational knowledge of the disease process, and their personal feelings and experiences on the other
hand, based probably on their daily verbal and non-verbal interactions with the partner with
dementia, do not always agree with each other.

Basing their understanding on their feelings and experiences seems to be a possible
alternative way of knowing for these participants in their everyday lives. Moreover, their
stories seem to suggest that, even when in disagreement, the rational and emotive aspects of
their caring somehow work together in everyday practice. This could be because many things
they do in caring are oftentimes a matter of routine practice, what they have been used to,
things they have learnt along life’s journey from early childhood, and by now, do without too
much thinking. Nick used the example of dim sum: “how things used to be done…without
knowing or thinking, you would do those kinds of behaviour.” Derek too confirmed that he
often does things by following the way things are often done around him, without too much
thinking:

_Without shape or form, wherever I go, I adapt to the environment of that
place. That’s how I am. I wouldn’t particularly think much about things.
When [I] went to Hong Kong, I adapted to the environment in Hong Kong and
coped with living there. When [I] got to Borneo, [it was about] how to live
and make a living to upkeep the family in Borneo. It was like that.... Like after
I got to Canada, the environment is like this and the people need these
conditions. So I learn the conditions. Their culture is like this, so it is. I follow
it._

This is not to say that there is no rational and conscious thinking involved in Derek’s
adaptation to new contexts and conditions. He is merely inferring that alongside rational
thinking for doing things in cognitive ways, there are also plenty of moments, circumstances
and aspects in life and caring where he learns and does things without too much thinking,
without specific “shape or form.” Jeannie also does things she learnt without too much
thinking. In caring for Mr. Chung, she is doing what she had been used to seeing done around
her while growing up in a family where, “everyone helps others from the kindness of the
heart. You get used to it.” Alice echoed that one knows and does what one has seen and been used to, “You feel [you] have to take care of him/her [parent]…. I think it’s from what we saw from when we were small.” Josephine commented on her “Chinese tradition” as coming from “family teaching [jia jiao].” But when asked if her parents or elderly relatives talked to her about such teaching, she could not answer. Stephen clarified for her: “You don’t need to say it. You see that it’s done in that way in your environment. No need to [say or think about it].”

Seeing or doing something over and over again seems to have trained a long-lasting memory into the ‘heart’ or xin of participants, a memory that could be of the emotively rational kind. In fact, one becomes so used to doing things in certain ways that one does many things without having to think about why or how to do them. As the participants’ stories suggest, one simply knows in the ‘heart’. Jeannie illustrated the force of this kind of taken-for-granted practices with an example: When her children cautioned her to look after herself while caring for Mr. Chung so that she would not get hurt, Jeannie understood, acknowledged and shared their concern in the firmest cognitive manner, “I say that I know.” Yet Jeannie could never stop to think about how or when she might be exceeding her limits and get hurt when it comes to caring for Mr. Chung. Caring is simply something she does and continues to do her way, “I can't help it!”, suggesting something that does not always follow rational and conscious thoughts.

The participants’ accounts suggest that they often take a non-thinking approach in many everyday practices. Carers often resort to ways of doing and being that they have been used to, are familiar with, and which feel safe and good; hence, these are ways and strategies that facilitate these participants to adapt to their environment. As Derek described, he often
does things “because everyone around us was [doing it]…so we followed the group.” His actions and attitudes are all consonant with his general idea about life and learning being a matter of sensibilities and knowing that lie beyond a purely cognitive realm: “You don’t learn these things about life. You experience different things, you see things in the world. It’s very simple.”

Participants’ stories suggest that there could be alternative ways of knowing and being, and one of them could lie right there in the personal feelings and emotions in the daily routine interactions of the care-partners. In fact, emotions are crucial throughout the caring process, in everyday routines, cultural and other expectations around caring, as well as the non-thinking moments of caring. For example, all participants use their heart and feelings in providing routine care. Routines provide feelings of comfort and safety, while cultural expectations provide carers with the strength to accomplish the routines, and feeling competent and satisfied about their caring. Feeling and doing are intricately intertwined, with Jeannie finding it difficult to separate her feelings from her caring practices, and Alice unable to separate the feelings of her heart from her responsibility and cultural obligations as a daughter. As well, despite participants’ conviction that their partner with dementia is totally lost, knows nothing, or cannot give anything, participants also asserted, based on their personal feelings and experiences, that their partner understands, knows everything, and that together they can enjoy an active and meaningful, at times even vibrant, relationship. Relating emotionally and rationally, rather than solely rationally, with their partner with dementia seems to let the ‘heart’ or \textit{xin} of these carers ‘know’ that their partner and their relationship are still there.

To summarize, participants’ stories draw attention to how routine care practices,
besides being an adaptive strategy to maintain caring and continuity of the relationship, also help carers to meet cultural expectations and norms of responsibility and affection on the family. Their accounts highlight how effective caring practices embrace the personal, cultural and relationship history of the care-partners. As well, the accounts suggest how the cultural obligation of responsibility and affection is conducive to an inclusive way of caring, making participants aware of the feelings and emotions of the partner with dementia as well as her or his own. This inclusive way of caring brings not only positive feelings and fosters the well-being of both care-partners and their relationships, but also brings conflict and tension at times. Conflict and tension occurs when complex cultural understandings and expressions straddle and contradict each other in routine practices. The straddling suggests the relevance of notions of historicity, affectivity and familiarity and the intertwining nature of these elements in everyday practices. In addition, this fuzziness of boundaries in the caring practices of these Chinese families suggest possible alternative ways of knowing and being, such as when people engage and relate with each other in emotionally rational ways (Liang, 1987). The next chapter initiates a dialogue of these thematic findings with relevant studies on the topic available in the literature.
CHAPTER 9.
THE RELATIONAL AND EMOTIONAL

The purpose of this study was to understand and describe in detail and depth the actual caring practices in four Chinese families caring for a family member with dementia. Specifically, the study aimed to see, through their actual everyday practices, how participants understood and made meaning of their caring, as well as how their practices and understandings were related to contexts, including their Chinese and other cultural contexts, in which the caring takes place. In order to do so, this study looked both at carers’ verbal articulation of attitudes, beliefs and actions in interviews, as well as the behaviours and practices of care-partners observed in their actual everyday interactions with each other. The minutiae of care of the Chinese families in this study recall in many ways the portrayal of mainstream family dementia carers pushing a big rock uphill, day in and day out (McCurry, 2006). However, the participants’ stories also show that these Chinese carers do manage the everyday demands of caring, much like the mainstream carers ‘manage’ in the study of Le Navenec and Vonhof (1996), and pass ‘one day at a time’. Specifically, carers in this study generally make efforts in their own ways to do many of the steps of McCurry’s (2006) dementia ‘dance’, by not arguing, accepting the disease, creatively solving problems and enjoying the moment with the loved one. The carers in this study manage caring by using the different material and non-material resources they have personally, or have access to at the personal and community level, optimizing the balance between their beliefs, emotions, needs and available services within the conditions of possibility in their circumstances. Their different histories, contexts and backgrounds contribute to the particularities and uniqueness of each story.

Importantly, this study also reveals new and important findings across the cases. The
findings described in the three thematic areas in the last chapter have not been elaborated upon previously in family care studies; these findings are useful for initiating a meaningful dialogue with available knowledge in the literature. This chapter discusses these findings and the implication of this information for research, practice and policy. The discussion will centre on the relational and emotional emphasis and the importance of duality that have emerged throughout the findings of the study. There are three main points: First, this study shows how routine caring practice is a culturally adaptive device as it takes into consideration the history and preferences of both care-partners. In particular, the usefulness of this adaptive device in terms of how routine practice facilitates positive feelings and maintenance of well-being and relationships has not been given adequate attention in the caring literature for the elderly.

Second, unlike most studies on Chinese family caring that usually focus on family or filial norms as responsibility or affection, this study draws attention to the duality of the obligation. Specifically, participants’ stories suggest how family or filial norms comprise both responsibility and affection, and that the two aspects should not be looked at separately. Importantly, it is the obligation of both responsibility and affection together that fosters a relational approach of these families towards mindful, inclusive and effective caring.

Third, duality is also found in the complex and fluid nature of straddling cultures within the practices of these families. The duality and fuzzy boundaries in the non-thinking moments in between thinking and action in everyday practice point to alternative ways of knowing and being beyond the conscious and rational, such as emotionally rational ways of relating. Alternative ways of knowing and being are areas that deserve more attention in future research and practice towards better understanding and supporting dementia care.
Routines: A Culturally Adaptive Device

This study draws attention to the importance of routines as an important adaptive device for participants to work with the changing conditions and contexts in their caring for the partner with dementia. Like the Algerian peasants (Bourdieu, 2000a) who had to find strategies to adapt to their new role of ‘worker’ within a market economy, these carers also strategized and adapted routines to fit with their added role of ‘carer’ in new environments and structures of care within which they find themselves. Besides facilitating the participants through the chores of everyday living, routines also served to help them maintain meaningful relationships. Despite the hard work, caring also gives the participants the sense of spirit, purpose and fulfillment in life described by Liang when a person fulfills her or his obligation (1987). In fact, carers derive satisfaction and an appreciation of life like the Chinese-American participants in Vickrey et al.’s (2007) study. Note, however, that carers are not talking about heroic feats or grand rewards. Similar to Mok et al.’s (2007) participants, carers here just want to adapt, minimize the impact of the illness and continue with life. They appreciate the ordinary and simply want to pass another day.

These carers do not take simple and ordinary things for granted. Once they have accepted the illness, the carers in this study strategize, like the African American man with dementia in Harris’ (2008) study. This man emphasizes how he deals with “what is” (p. 49), and “make it [life] enjoyable” (p. 50). As well, like carers in this study, this man highlights the importance of acceptance: “one of the fundamentals in terms of living a good life, is accepting that you cannot control what happens to you because fate is fickle” (Harris, 2008, p. 50). All carers in this study accept the illness and try to make the best of every single day. It seems that by rooting themselves in everyday things, everyday care “can transform the
ordinary into something sacred or extraordinary” (Phillips & Reed, 2009, p. 212). Without romanticizing the stresses and challenges in caring, carers in this study, nevertheless, seem to “hold on to ‘care’ as something that makes life worthwhile” (Taylor, 2008, p. 333), and routines facilitated this small group of participants in the process. Whether and how this finding holds with larger samples requires further research.

Intriguingly, despite the literature’s stress on the importance of routines as an adaptive device in the care of children in families, there is limited attention paid to routines in elderly care. In the general childcare and family literature, routines are described as “observable, patterned, predictable interactions that are repeated over time” (Koulouglioti, Cole & Moskow, 2011, p. 144), such as spending time together eating meals, doing chores, leisurely activities, and bedtimes (Sheely, 2010). The literature overall suggests that family routines are important for the well-being and positive outcome of children (Sheely, 2010), and can be particularly important for the family during transitions. For example, routines or disruption of routines were related to parental stress in families whose children entered kindergarten (DeCaro & Worthman, 2011). In another study (Buchbinder, Longhofer & McCue, 2009) looking at the role of routines in families where a parent has recently been diagnosed with cancer, the researchers found that adapting routines created a space in which all members of the family, including young children, could participate in the care of the parent diagnosed with cancer. The authors concluded that routines have a resiliency that not only provided the families with a sense of stability and normalcy, but also actually brought the family together at a difficult time.

Other researchers investigated how routines are important for adaptation of families in different circumstances or with particular challenges. For example, the ability to maintain
routines was an essential part of the parental role and indication of successful parenting for a
group of single mothers (Koulouglioti et al., 2011). African American parents used routines
adapted to their living conditions in the inner city to manage their young child’s asthma
(Yinusa-Nyahkoon, Cohn, Cortes, & Bokhour, 2010), while other researchers showed how
the level of routines moderated the level of school disengagement for African American
adolescents (Lanza & Taylor, 2010), as well as child hyperactivity/impulsivity and
oppositional defiant disorder in children from low-income, urban and ethnic-minority
families (Munkvold, Lundervole & Manger, 2011).

Routines are family constructions of ‘ecocultural niches’ (Maul & Singer, 2009)
adapted to the particular needs and preferences within the contexts and time frame in which
family members find themselves. Surprisingly, there is very little or only peripheral
information in the literature on routines on elderly care. For instance, Carpentier et al. (2008)
noted that research literature sometimes mentions that carers use routines to occupy the day,
suggesting that routines take carers away from having to think about genuine problems and
the future. This could be particularly relevant for the Chinese as according to the study of
Kuo, Hsu and Lai (2011) on indigenous counseling with grieving clients in Taiwan, “Chinese
are accustomed to keep ‘doing’ and not staying with the emotions [of grief]. It is through
continuous ‘doing’ that one comes to remit oneself from the feelings of guilt and anxiety” (p.
13). Perhaps this could be one reason why, without forsaking caring for Stephen, Josephine
locked herself into her achievements so as not to have to think about Stephen’s future and her
own. In another study on frailty of elderly women, Grenier (2006) also described how her
carers kept busy managing routines of self-care. She coined this “strategy for achieving
continuity” (p. 309) as a protective mechanism, a defense against feelings of frailty and
mortality, without elaboration of the details or implications of routines per se. In the same fleeting manner, Harris (2008) also hinted, without focusing on the routines themselves, that the drive to continue with routines is the functioning of a mechanism in the human adaptive system.

Regardless of its ability to detract the person from problems or the present and future, or as an adaptive mechanism, the importance of continuity that routines bring to participants in this study suggests an appreciation of life itself. This finding may be understood within the context of time appreciation and awareness. Several studies have drawn attention to this. For example, research suggests that older adults are keenly aware of time (Phillips & Reed, 2011). Harris’ (2008) participant knows that he is in his twilight years, so does the elderly lady in Grenier’s (2005) study when one by one, her good friends bid their farewell. Another elderly person described this awareness of time by older people, and how this awareness shines a particular light on her perception of her relationship (Neysmith & Reitsma-Street, 2009):

> We've accepted our life situation and yet this is because we know it's temporary and know we're both old, life is temporary. Our physical disabilities are going to increase. We don't know how long we've got, so there's a bitter sweet aspect to this that intensifies the beauty of our relationship because there are no hidden agendas here. (p. 242)

In another study (Sanders & Power, 2009), the husband-carer recognizes the finality of his relationship when routines of caring for his wife are severed, “I realize that this is all I have left with her, and then I sob…” (p. 49).

In the study of Neysmith and Reitsma-Street (2009), awareness of time places constraints on the options mainstream participants have and the choices they make. Phillips and Reed (2011) further postulate that ordinary everyday care can create a legacy that
transcends even the constraint of mortality. While this study suggests that Chinese elderly persons may hold onto everyday care routines for continuity, the participants’ stories do not seem to indicate any strive towards immortality. Instead, the priority of carers in this study around routines is to maintain their relationships in the here and now. They seem satisfied to ‘pass another day’, ‘one day at a time’. This may have a particular meaning related to Chinese culture. Specifically, the focus on the here and now is part of the general pattern of Confucian thinking that a person actualizes his goals in life, namely his ‘virtues’, in his actions and be a junzi (cultivated person) (Tsai, 2001) in this world, in the here and now of this life (Liang, 1987). Fei (1947) also described the Chinese as a people of the land, who come from the ground and go back into the ground, in a cycle within which the purpose of their passage in this world is to sustain the land of their existence for the next generations.

This study suggests how the objective of working hard at everyday routine caring and doing one’s duty can have the result of keeping important relationships together. In the context of participants in this study, routines could be the answer that enables them to stay in the here and now, do things “the way they have always done things” (Grenier, 2005, p. 142), and in so doing, upkeep their ganqing and relationships. The stories of these participants suggest that these everyday routines and relations just might be the kind of “ordinary magic” (Harris, 2008, p. 59) that is highly adaptive for human life.

Given the adaptiveness and implications of routines, it is indeed surprising that there is so little attention given to routines in elderly care research. While there are many studies of routines in organizational or institutional settings (see Essen, 2008), the study of routines in elderly care in the family are much fewer. These include for example Essen’s (2008) study of routines in the Swedish home health delivery service. Although the study’s objective was to
understand routines from an organizational perspective, the routines crossed into the home domain of elderly care. The author showed how, when care routines are actually performed, concrete established rules of the organization and artifacts that make up the routines become malleable when the emotional-ethical principles of care workers are elicited. Taking on roles not prescribed by rules could include, for example, the mediating role of the home support worker in this study. The potential mediating role of home support workers is an area that has received little attention but holds promise of contributing to understanding of quality of care for the elderly. Another study crossing the institution-home domains is Johnson’s (1988) research on bedtime routines, and how bedtime routines disturbed the sleep patterns of seniors residing in nursing homes and those residing in their own homes. A team of researchers (Riche & MacKay, 2007) focused exclusively on routines of the elderly in the community. The study looked at communication routines and identification of communication devices and technology that could aid the elderly’s aging in place. The researchers suggested that the awareness of each other’s rhythms and routines among an elderly group of friends in their study was important to help the seniors stay in touch with each other. This last study provides useful information about the role of routines for community living of elderly persons. More research of the sort is needed to gather information on actual daily activities, and especially the structures and settings that sustain elderly people in their routines of everyday life in the community. Information on the structures of their routines could be particularly useful for developing a framework of support and/or intervention (Bernheimer & Weisner, 2007) that is effective as well as conducive to healthy aging in the community.
The importance of routines has a cultural aspect to it. Alongside continuity, routines allow families to fulfill their obligation and maintain their relationship. According to Liang (1987) and Tsai (2001), these are important features of the Chinese relational self of the *wu-lun* (the five relationships), and the family based on the *wu-lun* is the adhesive that has kept Chinese society together for over two millennia. What is important to note is that this sense of obligation comprises two aspects, namely the moral aspect of responsibility and the relational aspect of affection. Unlike previous studies in the caring literature that focus predominantly on the aspect of responsibility, commonly under the notion of ‘filial piety’ (e.g., Holroyd, 2003; Li & Lemke, 2004; Li et al., 2010; Schwarz et al., 2010), this study highlights how the two aspects of responsibility and affection co-exist and co-constitute each other. The two need to be considered together, in unison and duality.

Intermingling among cultural understandings is this emphasis on the obligation of affection for the person with whom one is in an important and meaningful relationship. This relational emphasis that crosses both the beliefs and practices of participants suggests how an emotional orientation can provide an additional and complementary entry point to that of responsibility for understanding different aspects of caring in Chinese families. For example, this alternative or additional lens of affectionate responsibility could further dialogue and understanding of the notion of reciprocity in the current caring literature.

Rather than approaching reciprocity from the perspective of exchange of material and nonmaterial support (Schwarz et al., 2010), this study suggests incorporating a relational and emotional lens could broaden the alternatives of understanding reciprocity. For example, in this study participants did not couch their caring on material terms. Leaving participants quite
freely to talk about their care experiences from their perspective, none of the children mentioned paying back the parent in exchange terms. Instead, the children pointed to what they have seen and ‘know’. They put themselves into the parent’s shoes and made reference to what they thought the parent would like and how the parent might feel. They wanted to do something for the other person, their relationship, and themselves, and not out of any calculation or need to balance an account. This study would add support to the findings of Merz, Schuengel and Schulze (2009) whose Dutch adult-carer participants associated their own well-being with relationship quality with parents, rather than exchange of support.

In addition, the finding of a relational and emotional orientation in this study stimulates dialogue with the discussion around the notion of autonomy and independence in the caring literature. Many researchers (Fine & Glendinning, 2005; Perry & O’Connor, 2002; O’Connor et al., 2007) argue that when people are caring for each other in relationships, the relationship takes the foreground, and concepts of ‘dependence’ and ‘independence’ become contestable in the giving and taking between care-partners. Specifically, O’Connor et al. (2007) urge that a view of the person, whether the person with dementia or the carer, be grounded in her or his interactions with others. In doing so, these researchers promote a shift of focus from the individual to the relationship, or relational care. The relational orientation of carers in this study shows how the emphasis on the interdependence of care-partners supports both care-partners to thrive in their relationship. Their emphasis on the relationship actually helps them to keep the person in the other position of the relationship, the care-partner with dementia in this case, always present and in perspective. In the process, the person with dementia is fostered and the carers realize meaningful existence in ways similar to those of mainstream care-partners (Hellstrom et al., 2005, 2005a; Kirsi et al., 2004; Nolan
et al., 2003; Phinney, 2006).

Nevertheless, the Chinese carers in this study differ from mainstream carers in subtle ways. Despite more emphasis on the relationship in recent research on mainstream carers, the individual and the ‘self’ remains centre-stage. The overriding focus or objective continues to revolve around the identity and independence of the individual (Funk, 2009), or how to counter the losses in dementia by preserving the personhood and sustaining the identity and autonomy of the individual person with dementia (Phinney, 2006). Instead, for Chinese carers the ‘self’ is less prominent in the relationship and the boundaries of the individual or ‘self’ more permeable and fuzzy. This is particularly the case for the older spousal carers for whom independence and autonomy of the couple, rather than the individual self, is dominant. They generally see themselves as a self-in-relation with others around her or him. This was seen in how the three spousal carers found it difficult to talk about themselves and their own ‘self-care’ without relating to their being there for the sake of the care-partner. Note, however, that their inability to speak about themselves or their self-care does not mean absolute self-sacrifice, or that carers do not take care of themselves. Without downplaying the efforts required in caring, these carers seem able to incorporate caring for the partner into their everyday life together without excessive impairment to themselves or the relationship. The way carers in this study steer the caring course recalls Fei’s (1947) Chinese self who is the centre that moves her or his relationship network. Nevertheless, the stresses and challenges of caring reported by the participants at the centre of the caring network should not be overlooked.

As well, the inability to speak of themselves or their self-care might give the impression that these carers are not independent. In regards to the question of independence,
Ho et al. (2003) alluded from their study of Chinese carers that independence is a Western value. Instead, this study suggests that there may be alternative ways of interpreting independence. Chinese participants in this study are extremely independent. At the same time, they strive to stay independent without losing sight of those with whom they are in an interdependent relationship. The distinction here is that their independence is not in the ‘self’ only. The centre of the ‘self’ does not seem to lie within the Chinese carers in this study, but in what Liang (1987) describes as the fulcrum of her or his relationships with others. In fact, deferring to others (Liang, 1987) is in accord with how a person is supposed to behave in a relationship. It is considered usual for one person to think of the person in the other position in a relationship. Albeit an oxymoron, this study suggests the duality of an independent and autonomous relational self in these Chinese carers who are used to thinking and taking care of their care-partners out of a sense of affectionate responsibility towards them and others, something they learnt, ‘know’ and is deeply ingrained in these participants throughout the history of their relationships.

The emergence of the notion of a Chinese relational self in this study stimulates thinking around the ongoing dialogue in a person-centred (Kitwood, 1997) as opposed to a relationship-centred approach (Keady & Nolan, 2003; Davies & Nolan, 2003) to dementia care. Hellstrom et al. (2005a) in particular reported how some couples do not consider caring as work but a way of continuing their established ways of life together. Such an attitude allowed some of the couples to find meaning and quality of life. The present study suggests a similar tendency about the lightening of the care workload when carers can find meaningful existence in the work that they do. Notwithstanding, the stresses and challenges of caring for these participants are many. Hellstrom et al. (2005a) particularly caution that the lack of
acknowledgement of the illness could weigh more on as well as isolate the carer.

Further scrutiny of this dialogue shows an important point. Whether these scholars and researchers are advocating for the person-centred or relationship-centred focus of caring, their positions on one side of the argument never exclude the other side. For example, Nolan et al.’s (2003) relationship-centred approach draws attention to the importance of respecting personhood. Greenwood et al.’s (2001) accounts of how the institution and staff value and work on relationships in the long-term care facility revolve around the story of preserving the personhood of the resident, Maurice. As well, O’Connor et al. (2007) promote the personhood of the person with dementia but draw attention to the importance of the person’s relationships with immediate as well as the broader sociocultural contexts. It seems like there could often be more points of agreement and overlap than separation and distance between the two sides of the dialogue around person-centred and relationship-centred care.

Albeit a small sample, this study provides support to how, in a Chinese family setting of dementia caring, carers can practice the personhood and relational aspects of Kitwood’s (1997) concept of dementia caring in unison. Specific to duty and affection of a Chinese relational self, the findings resonate with what Kitwood (1988) describes as the inseparability of feelings and emotions on one hand, and moral life on the other, that motivate human beings to action. These carers with a relational self provide care for the partner with dementia without separating moral duty from affection, or the person from the relationship. They ‘work’ for themselves as well as for the partner with dementia in a way that when “caregivers preserve the personhood of their partners, they also preserve their own” (Perry & O’Connor, 2002, p. 60), benefitting both care-partners and fostering the relationship at the same time. The reciprocity (Hughes et al., 2002) and complementarity within such practices are not only
adaptive, but also culturally appropriate in terms of satisfying both the moral and affectionate responsibility of caring. This study would, therefore, support Smith’s (2003) assertion that morality is at the base of people’s actions and interactions and should, therefore, be given more consideration and inclusion in social science research. However, this study distinguishes from Smith’s (2003) ‘moral, believing animals’ in that morality in this study shows up as an affectionate obligation of moral feeling beings.

As well, this way of practicing affectionate responsibility and its outcomes seen in the positive well-being of persons with dementia as well as carers, lend support and give body to the notion of moral and ‘relational personhood’ (Kitwood, 1988, 1997) for understanding dementia care. However, for a Chinese relational self, the notion of ‘relational personhood’ embraces both the moral and affectionate aspects of the obligation, making the separate mention of morality redundant. Specifically, findings in this study show, as paradoxical as it may seem, how the emphasis on the relationship actually focuses attention on the person in the other position of the relationship. The seeming paradox disappears once the duality of the person and the relationship is seen within the notion of the ‘heart’. Although lodged in the body of one individual, the heart is there to unite two persons “by the exchange of ‘hearts’ (xin) between two ‘bodies’” (Sun, 1991, p. 2). The duality of the person-in-relationship necessitates that these Chinese carers attend to both personhood and the relationship simultaneously. Depending upon the circumstances and time context, there may be overall complementarity and occasionally conflict. This approach of relational personhood could be a cultural way of seeing and understanding the world as well as a relevant notion for approaching family care research, policies and programs for Chinese families and other groups with an emphasis on family and relationships. In other words, persons need to be seen
in interaction and relationship with others within their immediate and broader contexts (O’Connor et al., 2007). This study adds support to researchers calling for a more relationship-based conceptualization as well as relationship-oriented social policies and programs of care (Henderson & Forbat, 2002; Molyneaux et al., 2011; O’Connor et al., 2007).

**Complexities: Moving Understanding and Knowing Beyond the Rational**

Despite the consistency of a Chinese relational self across the cases, cultural understandings are complex, coming from many different sources such as familial, cultural, social, religious, and other life history experiences. Bourdieu (1990) considers the latter a particularly significant contributor to everyday practices. Rather than a culture like Tylor’s (1958) complex whole made up of essential ingredients, or an explicit, compartmentalized and coherent type of culture that comprises a limited number of observable values, attitudes and beliefs, so called “cultural stuff” (DiMaggio, 1997, p. 264), culture in this study shows itself to be fluid and shifting. Cultural understandings from different sources from participants’ earliest socialization and throughout the decades of their life straddle each other in non-thinking ways, introducing conflict, contradictions and tension to everyday caring. The complex and shifting nature of culture is not uncommon in persons with the kind of diasporic history (Hall, 1992) of the participants. Their understandings and ways of being are born in the encounter of two or more geographies and cultures and will always remain in a dual or hybrid (Rutherford, 1990) and hyphenated (Cheng, 2004) space. Their entry into conditions of a new country, and then into the new territory of dementia care-partners, demand them to forge new ways of being and doing as well as reconcile with new meanings.
of existence in complex ways.

Particularly worthy of note is that, in these non-thinking moments and spaces of caring where cultures meet, categories and dualisms of ‘objective’ and ‘subjective’ (Bourdieu, 1990) straddle each other. This was seen for example when participants could not separate out the cognitive from the emotional, duty and obligation from affection, the cultural from the personal, or the disease discourse from their personal experiences of the illness and the care-partner. Moral duty and affection, in particular, are important elements that motivate human beings to action (Kitwood, 1988). This motivation happens in the non-thinking moments of routine practice in an in-between space between the cognitive or objective on one hand, such as from cultural values, and subjective experience on the other, such as when they simply do what they have seen done that works and feels good to them.

Interestingly, the accounts of the families in this study around such straddling of dualisms resonate with what Peng and Nisbett (1999) describe as the tendency of Chinese people to accommodate opposites. Rather than dialectical reasoning based on formal logic and differentiation strategies, the authors (Peng & Nisbett, 1999) conclude from their empirical findings how contradiction is a more accepted way of thinking and being for Chinese participants compared to their American counterparts, supporting their premise that opposites “coexist in everything” (p. 743) in accordance with Chinese folk wisdom and worldview of constant flux and change.

According to Liang (1987) and Bourdieu (1977, 1990), these non-thinking spaces where polar opposites or categories straddle each other in ordinary everyday practice can be an important font of knowledge. In fact, many researchers and scholars point out how privileging ‘knowing’ from a single category of cognition or rationality impedes
understanding of dementia care, in particular understanding the partner with dementia (Hughes, 2001; Kitwood, 1997; Kontos, 2004; Post, 2000). The emphasis on autonomy, rationality and memory disenfranchises the person with dementia and runs counter to the notion of self as a shifting, unfolding and life-long process of meaning-making (Bastings, 2003; Beard, 2004; Hughes, 2001). In addition, a focus on cognitive abilities ignores the alternative capacities such as expressive, bodily (Kontos, 2004, 2005) and relational (Herskovits, 1995) capacities of the person with dementia as well as the reciprocal qualities (Hughes et al., 2002; Perry & O’Connor, 2002) of the caring relationship.

The in-between spaces and alternative ways of ‘knowing’ beyond the cognitive and rational is an area of research to which investigators have begun to pay more attention. An example is the suggestion of Strauss and Quinn (1997) for better understanding of the cognitive-emotional and motivational structures in between “the extrapersonal and intrapersonal realms” (p. 8). The authors propose the use of connectionist models to understand how schemas work, specifically which and how certain schemas and not others, get activated, and how they provide the kind of durability and motivation in people’s practice. Elder-Vass (2007) proposes exploring the meaningful mental states somewhere between the conscious and non-conscious realms stored in neural networks, and the relations of these neural bases to relevant social factors. Specific to clinical dementia care, Kontos (2004, 2005) shows how persons with dementia, even in the advanced stages, are not only ‘knowledgeable’ about their body and self. They are also capable of engaging with the world and others by using this primordial bodily intelligence. To convey the importance of this bodily intelligence, Kontos and Naglie (2009) use dramatic performances to train care staff about this way of understanding and working with residents with dementia, sensitizing the
care providers to the capacities of the body and embodied dispositions of residents. Their work shows how this awareness and receptivity to bodily intelligence can improve person-centred care.

Care-partners in this study engage in everyday caring practices in non-thinking spaces and emotive ways. These spaces made room for better understanding their contradictions and tensions at different times and contexts of caring. These in-between spaces and ‘borderlands’ of contexts and time (Hinton, Flores, Franz, Hernandez, & Mitteness, 2006) hold the promise for uniting polarities and traversing dualisms, dualisms which, according to Neysmith and Reitsma-Street (2009), impede understanding of complex social phenomena. In particular, findings in this study point to the importance of dualities and that emotions and feelings are at work alongside carers’ cognitive understandings in their routine caring practices. These findings suggest the potential for considering emotional and relational ways of thinking and knowing, described by Liang (1987) as emotional rationality. According to Liang (1987), it is emotions that help people to learn and know things. To many Chinese, it is the heart rather than the mind that thinks (Sun, 1991). In fact, the participants in this study consistently use the word ‘heart’ or ‘feel’ in lieu of ‘think’ or ‘know’. Emotional rationality and intelligence (Liang, 1987) may be a cultural way of understanding and living life and caring that could be particularly useful for understanding the Chinese person who is described as having one heart-mind (Ikels, 1998; Sun, 1991).

**Implications**

The inclusion of multiple perspectives in this exploratory study with different members within and outside the family provided a more in-depth and contextual understanding of the individual cases as well as a broader view of possible alternative
experiences of dementia caring in these families. In particular, the inclusion of the Chinese person with dementia and observation of her or his interaction with the carer and other family members provided special insights into the actual caring and dynamics of the relationship itself, which no interview with solely carers would have been able to provide.

This emphasis on richness and depth of understanding of the four Chinese families precludes any intention of the study to represent Chinese families, Chinese culture or the larger dementia care community. Rather, the aim of the study is to understand and describe the phenomenon of dementia caring and cultures within a small group with sufficient depth and details that could either strike a chord with other researchers in some of their own research (Thomas, 2010), or theoretically generalize the findings to available literature and initiate a dialogue as well as raise further and meaningful questions (Flyvberg, 2011).

Having recruited participants from the larger study, a limitation of this study is the lack of a purposive sample for expanding into more conceptually guided or data-driven areas and issues. As well, more diversity in terms of socioeconomic background or quality of family relationships could have provided more complex contextual understanding of the phenomenon. Regrettably, those with more complex family relationships were not available to participate in the case study as a family, and even the couple living in a government-subsidized assisted-living facility had adequate financial and non-material resources. As well, there is the inevitable loss in translation that increases the distance of the text from the raw data (Tsai et al., 2004). What the coding and analysis as well as the final text might have looked like had the original Chinese interviews been used is, at this point, unknown. This question is particularly important given that people often do not simply speak or use different languages but enter into the world and worldviews of the language in which they are
speaking or which they are using (Cross & Gore, 2003). The question promises to be an interesting area of research and application that warrants further exploration.

Despite the limitations, this study offers new information on routines, culture and emotions as well as how they co-constitute each other in practice. Also, this section highlights new ways of integrating available information on routines, culture and emotions that could be useful for practice or policy, theory and research in several areas.

First, the importance of routines and familiarity is not given adequate attention in the elderly care literature. For example, it is mentioned on one page of a 300-page volume on dementia and care (Mace & Rabins, 1999). Alternatively, the information is only peripheral in the literature. Instead, the importance of routines and familiarity in this study suggests the usefulness of building flexible models and approaches around these notions and applying them in fluid ways to practice and policy of caring in the community. Specifically, routines point to how, between care-partners, there is knowledge of each other’s history, cultures and preferences that facilitate their everyday caring and life together. Within their routines are cultural and emotional components that have a long history in the elderly persons’ lives. Keeping in mind the relevance of the immigrant’s historicity (Ducharme et al., 2008), affectivity and familiarity and the intertwining nature of these elements in everyday practices when designing structures for services and programs for immigrant groups is important. It is important to learn about the daily activities and relationships of the care-partners, as well as the emotions they attach to these activities and relationships in order to know how to provide the appropriate structures and contexts that would sustain them in their everyday life in the community (Bernheimer & Weisner, 2007). Programs and services built on such ongoing knowledge and information could be more relevant to potential service users, and hence
increase the likelihood of uptake of services.

This information is particularly important for understanding a huge diasporic population such as the Chinese, recently estimated at around 45 million (Liu, 2011). Knowing where, when and how to build services and programs into the routines already existent in their local structures and modes of social life could be more cost-effective than reinventing the wheels. Importing programs and services that are not grounded in the history, place and life of peoples may not work as efficaciously as ‘tweaking’ what they are used to and familiar with, in other words what is more likely to work for the potential service users. Incorporating programs and services in small steps in creative and innovative ways into the elderly’s existing routines and infrastructures and ways of being and doing, might just benefit seniors and their families in enormous ways.

Second, routine practices revealed the very complex nature and components of cultures in between people’s thoughts, feelings and actions. It is important for service providers to consider that embedded within this complexity of cultures are the conditions of possibility of the existence of agents (Bourdieu, 1990). Similar to how participants in the study of Hicks and Lam (1999) drew fluidly on their cultural understandings, agents in this study work in complex and fuzzy ways within their cultures and conditions of personal resources as well as available and accessible services. Particularly important to note is that the pathways between their beliefs and practices are fluid when the push and pull of forces between beliefs, personal resources and available services in the context and time of an agent are enacted in practice.

The fluidity of practice suggests something else important. Rather than focusing on the social positions of agents, that is their ethnicity, gender, or class, as fixed entities, this
study suggests the relevance of embracing dualities and looking at the fluid relations of agents with each other, in the family as well as with community and services (Bourdieu, 1990; Keenan, 2004). Instead of fixed social identities or locations, the relational emphasis highlights “meanings and actions of specific persons in a specific context” (Keenan, 2004, p. 542). In doing so, the emphasis shifts to how meanings can alter the culture-power relations amidst the fluid combinations of privileges and constraints of social positions. It becomes unwise to fix any position, value, belief or action into a category or label, into an absolute benefit or constraint, or a positive or a negative. Instead, the action or relation needs to be flexibly situated within the person-circumstance-time context for better understanding (Yan, 2008a). For family care researchers and practitioners who find categorical models too static or restricted, the relational notion emerging from this study could provide an additional or alternative lens with more flexibility for understanding and practicing with Chinese immigrant families.

Equally important, the complexity of culture serves to remind professionals working with immigrant groups how culture-power relations are complex. Professionals are usually in positions of power. Professionals relying solely on expert or ‘recipe’ knowledge about people from specific groups in fixed and uniform ways (Este, 2007) can commit the ‘category fallacy’ (Iliffe & Manthorpe, 2004) of forcing persons into groups to which they do not belong. Instead, professionals need to be flexible with an open awareness and respect for the diversity and uniqueness of each individual (Yan, 2005). Keenan (2004) further recommends professionals to hold an “informed not-knowing” approach towards clients (p. 543) that recognizes the cultures and culture-power relations which professionals themselves bring to their interactions with clients and the client-professional relationship (Yan, 2008).
Third, this study extends the literature and adds to the discussion on theoretical and practice implications surrounding person-centred and relationship-centred care beyond mainstream groups. Despite its different philosophical origin, the inclusive caring of these Chinese families suggests the compatibility of practicing person-centred and relationship-centred care in unison, as well as the potential usefulness of extending the notion of relational personhood to other groups outside of the mainstream, particularly groups that place emphasis on the family and relationships.

An inclusive approach is also a relational approach (Buber, 1947; Liang, 1987), and the relational emphasis has practical implications beyond theoretical extension. For example, a relational approach is useful for practitioners working with clients in areas of decision-making where decision-making is not always an individual but a relational process in Chinese (e.g. Hicks & Lam, 1999) as well as mainstream families (e.g. O’Connor & Kelson, 2009). Likewise, rather than focusing only on the execution of health care tasks of home support workers, the potential of relational or mediating roles of the workers for the senior with their family and other relationships (Essen, 2008) perhaps deserve more attention. As well, the emphasis on relationships draws attention to the importance of social inclusion of different groups who emphasize relationships and may have been used to different social settings where relationships are maintained simply when “[y]ou can open your front door and there is somebody to talk to” (Grenier & Guberman, 2009, p. 18). Designing innovative structures or settings where different groups are able to maintain relationships and/or connect with new ones could be key to healthy aging and family caring in the community.

In addition, the relational emphasis, specifically the notion of relational personhood, raises the conceptual question of the relationship between the relational and the individual,
for example the question of individual rights of persons with dementia in the legal arena. Specifically, Behuniak (2010) questions how, if from a legal standpoint, the person with dementia is tied to the biomedical definition of the person having mental capacity or not. Using the mental capacity of a person with dementia to determine her legal status that allows her to assert her rights is obviously problematic given her or his progressive cognitive decline. Behuniak (2010) advocates to reframe the political model of rights into one based on compassionate power for vulnerable persons that is in line with the ethics of care, a feminist notion of how women’s focus on relationships shapes their understandings of justice and model of care (Neysmith & Reitsma-Street, 2009). According to Behuniak (2010), the ethics of care model that promotes values of compassion, nurturance and empowerment better protects persons with dementia who may not be able to defend themselves against measures of cognitive and mental capacity in order to be accorded legal status as persons or non-persons. The notion of Chinese relational personhood emergent in this study would support Behuniak’s (2010) call for more dialogue on relational rights, as well as family and professional advocacy and action together with persons with dementia. However, what this notion of compassionate power for vulnerable persons (Behuniak, 2010) or relational rights could look like or entail is not clear, in particular whether and how it could actually work on the ground in legal and everyday practices without compromising the rights or best interest of the person with dementia. It is a dialogue and debate that is in a fledgling state and warrants full and urgent attention.

Fourth and finally, this study illuminates the importance of emotions and affection in people’s practices. Specifically, it advocates for more research on alternative ways of knowing such as emotional knowing and being that would foster understanding and
supporting persons with dementia and their families. Specific to professionals working with persons with dementia, knowing who the elderly person with dementia is, what she or he is familiar with, what works for the person (Kontos, 2004, 2005; Phinney, 2006) and in particular, what she or he likes or dislikes, will increase the chances of finding ways to support persons with dementia to continue being who they are, and to do what they are able and like to do, ultimately increasing the quality of dementia care. This understanding suggests the usefulness of an intuitive and inclusive approach to dementia caring. The approach would be flexible and open to accommodating dualities and alternative ways of knowing and being. Alternative ways of knowing and being could include primordial bodily intelligence (Kontos, 2004, 2005) or emotional rationality in the in-between spaces and moments of relating between persons using the heart-mind (Liang, 1987). Such information could help design programs and services that target educating carers and the general public about ways to interact with alternative capacities and strengths of persons with dementia in order to support and foster them through optimized caring practices.
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APPENDICES

Appendix A.
Interview Guide for Primary Carer and Family Members

Interview Guide for Qualitative Face to Face Interview

Thank you for agreeing to participate in this research. We appreciate your willingness to share your time with us. During this interview, we would like to ask you some questions about your experiences. Our purpose is to try to better understand your experiences of support or helping a senior (65 years or older) who may be your family member, friend, neighbour, relative or other person. We are particularly interested in better understanding how culture has helped shape your experience of providing care and accessing support.

1. Please tell me about your relationship with this person whom you help/assist/support?
   a) Please tell me about the senior who you help/assist/support.
   b) How do you make sense of what is going on or happening to your relative/this person?
   c) What other roles/duties do you perform/have in your relationship with this person?
   d) How has your relationship with this person changed since you began providing help?

2. Please explain what it means to you to “help, assist, care for” an older or elderly family member, relative, friend, neighbor, or other person.
   Possible probes:
   a) What influenced or motivated you to become involved in this role of assisting/supporting the older person that you mentioned?
   b) What does this experience mean to you?

3. How do you support/help this person you mentioned/your relative?
   Possible probes:
   a) Tell me about the types and nature of “help/care/assistance/support” you provide for the person you mentioned (i.e. What do you do for, to and with the person you care for? How do you do them?)
   b) Would you please describe a typical day (or… Would you please describe yesterday - probe for what they did, didn’t do and then ask how ‘typical’ this day was.

4. Are there others involved?
   (Probe for: sources of informal support, formal support and services)

5. Who does what to provide you help or support?

6. How did this arrangement come about?

7. How do you feel about this arrangement?
8. Based on your experience,
a) What insights in relation to this person’s needs could you share with us about your experiences of helping/caring/assisting the elderly person you mentioned?

b) What insight in relation to your own needs when helping/caring/assisting the elderly person that you could share with me?

9. What are the things that are useful to you in providing care or help to this person? Possible probes:
a) What are the sources of help that are useful to you in providing care or help?
b) What are the other places that you receive support (e.g. spiritual, cultural etc)?

10. When you think of your experiences of assisting/helping/supporting the person you mentioned, how might your cultural background have influenced your experience? Possible probes:
a) How are the needs of this person influenced or not influenced by his/her cultural background and/or values?
b) How do you honor or try to fulfill these needs in relation to the person’s cultural beliefs and/or values?
c) How do you think your cultural background, knowledge, and/or values influence the ways in which you seek support for assisting this elderly?

11. Based on your experiences, what would you like to tell health professionals and/or policy makers so that they can better understand your situation/experiences/needs? Possible probes:
a) What words of wisdom do you have to offer to others in a position similar to your own?
b) Do you have anything else that you might like to add that we have not talked about or addressed that you would like to expand on?

Thank you again for your time and willingness to share your thoughts and experiences.
Appendix B.
Interview Guide for Service Provider

Interview Guide for Qualitative Face-to-Face Interview
(for worker providing support/assistance to a Chinese senior with dementia)

Thank you for agreeing to participate in this research. We appreciate your willingness to share your time with us. During this interview, we would like to ask you some questions about your experiences. Our purpose is to try to better understand your experiences and practices of providing support or service to a Chinese senior client with dementia.

1. Please tell me about your relationship with this client.
   a) How long have you been providing services/support to this person?
   b) Please tell me about the senior client.

2. Please explain what it means to you to “help, assist, care for” an elderly client with dementia.
   Possible probes:
   a) What does this experience mean to you?
   b) How do you feel about the experience?

3. How do you support/help this client?
   Possible probes:
   a) Tell me about the types and nature of “help/care/assistance/support” you provide for the client (i.e. What do you do for, to and with the person? How do you do them?)
   b) Would you please describe a typical day when you come to assist him/her (or… Would you please describe yesterday - probe for what they did, didn’t do and then ask how ‘typical’ this day was).

4. Are there others involved in assisting this person?
   (Probe for: assistance from family members, other sources of informal support, formal support and services)
   a) Who does what to provide help or support?

5. Based on your experience,
   a) What insights in relation to this client’s needs could you share with us from your experiences of helping/caring for/assisting elderly persons with dementia?
   b) What insight could you share with us in relation to your own needs when helping/caring for/assisting elderly persons with dementia?
6. What are the things that are useful to you in providing care or help to this person?
   Possible probes:
   a) What are the sources of help that are useful to you in providing care or help?
   b) Are there other places where you receive support (e.g. spiritual, cultural etc)?

7. When you think of your experiences of assisting/helping/supporting the elderly client with dementia, how might your cultural background have influenced your experience?
   Possible probes:
   a) How are the needs of this person influenced or not influenced by his/her cultural background and/or values?
   b) How do you try to accommodate the client’s needs in relation to his/her cultural beliefs and/or values?
   c) How do you think your cultural background, knowledge, and/or values influence the ways in which you provide support to this elderly client?

8. Based on your experiences, what would you like to tell health professionals and/or policy makers so that they can better understand your situation/experiences/needs?
   Possible probes:
   a) What words of wisdom do you have to offer to others in a position similar to your own?
   b) Do you have anything else that you might like to add that we have not talked about or addressed that you would like to expand on?

   Thank you again for your time and willingness to share your thoughts and experiences.
Appendix C.
Demographic Information for Primary Care-Partners

Demographic Data Sheet -- *(To be administered only after the interview)*

Name of participant: _____________________

Date of Interview: ______________________  Time: ______ to ______ a.m./p.m.

Name of interviewer: ____________________  Language of Interview: ______________________

A. Person requiring care *(Age 65 and over)*

A1. Gender of the person who requires care: ___ a. male ___ b. female

A2. What is this person’s current marital status?
   ___1. Married or living common-law  
   ___2. Separated  
   ___3. Divorced  
   ___4. Single (never married)  
   ___5. Widowed

A3. How old is he/she?
   ___1. 65-69  ___2. 70-74  ___3. 75-79  ___4. 80-84
   ___5. 85-89  ___6. 90-94  ___7. 95 and above

A4a. What is/are his/her religions or spiritual beliefs? ______________________

A4b. Does he/she practice these religions or spiritual beliefs? ____________

A4c. How does he or she practice these religions or spiritual beliefs? ________________
   ______________________________________________________________

A5a. What is the highest level of education that this person you provide help or support has achieved?
   ___ 1. No formal education  
   ___ 2. Elementary school  
   ___ 3. Some high school/ junior high  
   ___ 4. Complete high school  
   ___ 5. Some post-secondary education (please specify)  
   ___ 6. College diploma  
   ___ 7. University degree  
   ___ 8. Other (specify): ______________________
A5b. Where did he or she obtain this education? ______________________________

A6. What was the previous occupation of this person who you provided help or support?

_____________________________________________

A7. What language does the person you provide care for mostly speak at home?

________________________

A8. How would you rate his/her fluency in English?

___1. Very Poor
___2. Poor
___3. Fair
___4. Good
___5. Very Good

A9. What is his/or citizenship or immigration status?

___1. Canadian citizen by birth (Go to A12)
___2. Immigrant/Refugee (go to A10)
___3. Other (specify) ______________________ (go to A10)

A10. In what year did this person you provide care for immigrate to Canada? ______

A11. How long has he/she been living in Canada? ______

A12. How long has he/she been living in this city? ______

A13. What is his/her before tax personal annual income?

___1. No income
___2. $1 - $9999
___3. $10,000 - $19,999
___4. $20,000 - $29,999
___5. $30,000 - $39,999
___6. $40,000 - $49,999
___7. $50,000 - $59,999
___8. $60,000 - $69,999
___9. $70,000 - $79,999
___10. $80,000 - $89,000
___11. $90,000 - $99,000
___12. $100,000 and above

A14. What is his/her before tax family annual income?

___1. No income
___2. $1 - $9999
___3. $10,000 - $19,999
___4. $20,000 - $29,999
___5. $30,000 - $39,999
___6. $40,000 - $49,999
___7. $50,000 - $59,999
___8. $60,000 - $69,999
___9. $70,000 - $79,999
___10. $80,000 - $89,000
___11. $90,000 - $99,000
___12. $100,000 and above
A15a. In your opinion, how well does his/her current financial status satisfy his/her needs?
___ 1. Very well
___ 2. Adequately
___ 3. Not very well
___ 4. Very inadequate

A15b. Please explain: _____________________________________________________

B. Carer (The interviewee)

B1. What is your gender: ___ a) male ___ b) female

B2. What is your current marital status?
___ 1. Married or living common-law
___ 2. Separated
___ 3. Divorced
___ 4. Single (never married)
___ 5. Widowed

B3. What age category do you belong to?
___ 1. 18-24 ___ 2. 25-34 ___ 3. 35-44 ___ 4. 45-54
___ 5. 55-64 ___ 6. 65-74 ___ 7. 75 and above

B4a. What is/are your religions or spiritual beliefs? _______________________

B4b. Do you practice these religions or spiritual beliefs? ____________

B4c. How do you practice these religions or spiritual beliefs? ________________

________________________________________________________________________

B5. What language do you mostly speak at home? _______________________

B6. How would you rate your fluency in English?
___ 1. Very Poor
___ 2. Poor
___ 3. Fair
___ 4. Good
___ 5. Very Good

B7. How do you describe your cultural background? ___________________________

B8a. What is your highest level of education?
___ 1. No formal education
___ 2. Elementary school
___ 3. Some high school/ junior high
___ 4. Complete high school
___ 5. Some post-secondary education (please specify)
___ 6. College diploma
___ 7. University degree
___ 8. Other (specify): ______________________

B8b. Where did you obtain this education? _______________________________________

B9. What is your original credential/training/professional background?
____________________

B10. What is your current employment status?
________________________________________

B11. What is your current occupation?
________________________________________

B12. What is your citizenship or immigration status?
___1. Canadian citizen by birth (go to B15)
___2. Immigrant/Refugee (go to B13)
___3. Other (specify) _____________________ (go to B13)

B13. In what year did you immigrate to Canada? ________________ year(s)
B14. How long have you been living in Canada? ________________ year(s)
B15. How long have you been living in this city? ________________ year(s)

B16. What is your relation to the person you are providing care for? You are his/her _______

B17. Are you currently living with this person?
___ No (go to B19)
___ Yes (go to B18)

B18. What is the living arrangement of this person you provide care for (i.e. living alone, living with spouse/partner, living with children, living in institution, group living with family/friends)?
____________________________________________________________

B19. Among the family members living in your household, how many of them are:

a) younger than 6 years old: _____
b) 6 to 11 years old: _______
c) 12 to 14 years old: _______
d) 15 to 17 years old _______
B20. Among the family members living in your household, how many of them are age 65 and over? ____________

B21. Among these older adults who are 65 years and older in your household, how many of them require your care (not including the person who you have referred to earlier)? ____________

B22. Would you identify yourself as the primary family member responsible for providing care:
   ___ 1. yes  ___ 2. no  ___ 3. don’t know

B23. How would you rate your health? (please circle one number)

1 2 3 4 5 6 7
Poor Excellent

B24. What is your before tax personal annual income?

___ 1. No income  ___ 8. $60,000 - $69,999
___ 2. $1 - $9,999  ___ 9. $70,000 - $79,999
___ 3. $10,000 - $19,999  ___ 10. $80,000 - $89,000
___ 4. $20,000 - $29,999  ___ 11. $90,000 - $99,000
___ 5. $30,000 - $39,999  ___ 12. $100,000 and above
___ 6. $40,000 - $49,999
___ 7. $50,000 - $59,999

B25. What is your before tax family annual income?

___ 1. No income  ___ 8. $60,000 - $69,999
___ 2. $1 - $9,999  ___ 9. $70,000 - $79,999
___ 3. $10,000 - $19,999  ___ 10. $80,000 - $89,000
___ 4. $20,000 - $29,999  ___ 11. $90,000 - $99,000
___ 5. $30,000 - $39,999  ___ 12. $100,000 and above
___ 6. $40,000 - $49,999
___ 7. $50,000 - $59,999

B26. How would you describe your thoughts about your current financial situation? (please circle one number)

1 2 3 4 5 6 7
Very worried 3 4 5 6 7 No concern Whatever

Thanks again for your time and participation in this study.
Appendix D.
Demographic Information for Third Family Member

Identifying code: __________

1. What is your age? __________________________ (years old)

2. What is your gender?
   a) male
   b) female

3. What is your relationship to the senior?
   a) spouse
   b) child
d) other – please specify ________________________________

4. How long have you been providing care to the senior? __________

5. What was the last schooling you completed? (check one)
   a) no formal schooling
   b) elementary school
   c) some high school
d) complete high school
e) some post-secondary school training (please specify)
f) college diploma
g) university degree
g) other – please specify ________________________________

6. How many years have you lived in Canada? __________________________

7. How would you describe your cultural identity? __________________________

8. How would you rate your health?
   poor  __________  good  ________  excellent  ________
   1  2  3  4  5  6  7

9. How would you describe your thoughts about the current financial situation of the senior?
   Very worried ________________________________ No concerns
   1  2  3  4  5  6  7

Thank you so much for helping with this study!
Appendix E.
Consent Form for Primary Carer

THE UNIVERSITY OF BRITISH COLUMBIA

Individual Interview Consent Form
Project Title: Dementia Care in Chinese Families

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Co-investigator and Student:
Sing Mei Chan, Ph.D (candidate), School of Social Work and Family Studies, UBC

The purpose of this study is to understand the experiences of Chinese families caring for a relative with dementia in the Lower Mainland. The study aims to understand the experiences of multiple members within the same family as well as those of a front line service provider working with the family. This research is important because little attention has been given to the experience of family care in culturally diverse communities in Canada. We hope that the findings will help service providers and policy makers develop and offer more appropriate and effective support to Chinese family carers. As well, this study will provide data for Sing Mei Chan’s dissertation for completion of her PhD degree.

If you decide to participate in this study, you will meet with Sing Mei to discuss your experiences providing care to your relative with dementia. This meeting will likely last about 90 minutes. If you are willing, there will be a second follow-up interview of approximately the same length. All meetings will take place at a time and location of your choice – this could include your home.
With your permission, these meetings will be audio-taped in the language of your choice and transcribed into English. Upon request, you will be given a copy of the original tape or English transcript for your records.

Your participation in this study is voluntary, and you will be free to withdraw from the project at any time. You have the right to refuse to answer any questions, to request that recording be stopped at any time, and to withdraw any information you do not wish to be included in this study. You also have the right to withdraw from the study at any point. Should you withdraw, the information you have provided up to the point of your withdrawal will be used in the data analysis, unless you state that you wish to have it destroyed. Your decision to withdraw or refuse to participate in this study will in no way jeopardize your involvement with any programs or services that you are or will be using.

Unless you specify otherwise in writing, your input will remain confidential. Confidentiality will be maintained by removing all identifying information from your transcripts and tapes, and using a pseudonym to reference you. Identifying information will be accessed only by Sing Mei and myself. Files will be stored in a secured location separate from any information which might personally identify you and computer files will be password protected.

We recognize that talking about this experience may be distressing to some people. We will be prepared to stop the interview immediately upon request and are prepared to help you locate appropriate support if participation in this study is unsettling to you.

We will analyze the information that you give us, looking at it in relation to what others have said as well. Sing Mei will write up her dissertation to fulfill her PhD degree requirements based on this study. As well, we will report our findings in academic research reports, journals, presentations, and community workshops. Every attempt will be made to insure no information is included in any publications that could readily identify you.

All identifying data, including recordings and interview consent forms will be destroyed five years after the final completion of this research unless you agree in writing to an alternative plan for your data to be kept for a longer period. Non-identifying data may be kept and used for future data analysis for academic research and publications on the same topic by the researchers on this team.
If you have any questions regarding any aspect of this study, you are invited to contact Dr. Deborah O'Connor at (xxx)xxx-xxxx. Furthermore, if you have any concerns regarding your treatment or rights as a participant in this project, you may contact the Director of the UBC Office of Research Services and Administration at (xxx)xxx-xxxx.

Thank-you for considering involvement in this project. If you agree to participate, your signature will be required below.

Sincerely,

Deborah O'Connor, PhD, RSW
School of Social Work, UBC

I hereby consent to participate in the study described above. I have received a copy of this consent form.

(Name - please print) (Signature)

(relationship to person with dementia: self/spouse/daughter/son/service provider e.g. home support worker) (date)

I agree/do not agree (please circle): The information I am providing may be used in future studies being conducted by a member of this research team related to this topic, assuming that the study is reviewed and approved through the university Ethics Review Committee.

(Signature) (date)
Appendix F.
Consent Form for Person With Dementia

THE UNIVERSITY OF BRITISH COLUMBIA

School of Social Work
2080 West Mall
Vancouver, B.C. Canada V6T 1Z2
Tel: (604) 822-2255 Fax: (604) 822-8656
www.swfs.ubc.ca

Individual Interview Consent Form (for senior)
Project Title: Dementia Care in Chinese Families

Principal Investigator and Supervisor:
Deborah O’Connor PhD., RSW, School of Social Work, UBC
Telephone: (xxx)xxx-xxxx
Email: xxxxx@xxxxx

Co-investigator and Student:
Sing Mei Chan, Ph.D (candidate), School of Social Work and Family Studies, UBC

The purpose of this study is to understand the experiences of Chinese families caring for a relative with dementia in Vancouver and the Lower Mainland. The study aims to understand the experiences of multiple members within the same family and, where feasible, those of a front line service provider working with the family. This research is important because little attention has been given to the experience of family care in culturally diverse communities in Canada. We hope that the findings will help service providers and policy makers develop and offer more appropriate and effective support to Chinese family carers. As well, this study will provide data for Sing Mei Chan’s dissertation for completion of her PhD degree.

If you decide to participate in this study, you will meet with Sing Mei to discuss your experiences of caring and being cared for. This meeting will likely last about 90 minutes. If you are willing, there will be a second follow-up interview of approximately the same length. As well, there will be an observational session with your carer on some daily activity chosen by you both that also lasts
about 90 minutes. All meetings and observations will take place at a time and location of your choice – this could include your home. With your permission, the observational session will be video-taped while interview meetings will be audio-taped in the language of your choice and transcribed into English. Upon request, you will be given a copy of the original tapes and/or English transcript for your records.

Your participation in this study is voluntary, and you will be free to withdraw from the project at any time. You have the right to refuse to answer any questions, to request that recording be stopped at any time, and to withdraw any information you do not wish to be included in this study. You also have the right to withdraw from the study at any point. Should you withdraw, the information you have provided up to the point of your withdrawal will be used in the data analysis, unless you state that you wish to have it destroyed. Your decision to withdraw or refuse to participate in this study will in no way jeopardize your involvement with any programs or services that you are or will be using.

Unless you specify otherwise in writing, your input will remain confidential. Confidentiality will be maintained by removing all identifying information from your transcripts and tapes, and using a pseudonym to reference you. Identifying information will be accessed only by Sing Mei and myself. Files will be stored in a secured location separate from any information which might personally identify you and computer files will be password protected.

We recognize that talking about this experience may be distressing to some people. We will be prepared to stop the interview immediately upon request and are prepared to help you locate appropriate support if participation in this study is unsettling to you.

We will analyze the information that you give us, looking at it in relation to what others have said as well. Sing Mei will write up her dissertation to fulfill her PhD degree requirements based on this study. As well, we will report our findings in academic research reports, journals, presentations, and community workshops. Every attempt will be made to insure no information is included in any publications that could readily identify you.

All identifying data, including recordings and interview consent forms will be destroyed five years after the final completion of this research unless you agree in writing to an alternative plan for your data to be kept for a longer period.
Non-identifying data may be kept and used for future data analysis for academic research and publications on the same topic by the researchers on this team.

If you have any questions regarding any aspect of this study, you are invited to contact Dr. Deborah O'Connor at (xxx)xxx-xxxx. Furthermore, if you have any concerns regarding your treatment or rights as a participant in this project, you may contact the Director of the UBC Office of Research Services and Administration at (xxx)xxx-xxxx.

Thank-you for considering involvement in this project. If you agree to participate, your signature will be required below.

Sincerely,

Deborah O'Connor, PhD, RSW
School of Social Work, UBC

I hereby consent to participate in the study described above. I have received a copy of this consent form.

(Name - please print)     (Signature)

(date)

I agree/do not agree (please circle): The information I am providing may be used in future studies being conducted by a member of this research team related to this topic, assuming that the study is reviewed and approved through the university Ethics Review Committee.

(Signature)     (date)
Individual Interview Consent Form (Proxy)

Project Title: Dementia Care in Chinese Families

Principal Investigator and Supervisor:
Deborah O’Connor PhD., RSW, School of Social Work, UBC
   Telephone: (xxx)xxx-xxxx
   Email: xxxxxx@xxxxx

Co-investigator and Student:
Sing Mei Chan, Ph.D (candidate), School of Social Work and Family Studies, UBC

The purpose of this study is to understand the experiences of Chinese families where one member has a dementia. By talking to different members within the family circle, we hope to gain an in-depth understanding of how Chinese families take care of their elderly relative and why they do what they do. This research is important because little attention has been given to the experience of family care in culturally diverse communities in Canada. We hope that the findings will help service providers and policy makers develop and offer more appropriate and effective support to Chinese family carers. As well, this study will provide data for Sing Mei Chan’s dissertation for completion of her PhD degree.

If you decide to participate in this study, you will meet with Sing Mei to discuss your experiences providing care to your relative with dementia. This meeting will likely last about 90 minutes. If you are willing, there will be a second follow-up interview of approximately the same length. As well, there will be an observational session of the primary carer and the relative with dementia around
some daily activity of their choice lasting approximately the same time. All meetings and observations will take place at a time and location of your choice – this could include your home. With your permission, the observational session will be video-taped while interview meetings will be audio-taped in the language of your choice and transcribed into English. Upon request, you will be given a copy of the original tapes and/or English transcript for your records.

Your participation in this study is voluntary, and you will be free to withdraw from the project at any time. You have the right to refuse to answer any questions, to request that recording be stopped at any time, and to withdraw any information you do not wish to be included in this study. You also have the right to withdraw from the study at any point. Should you withdraw, the information you have provided up to the point of your withdrawal will be used in the data analysis, unless you state that you wish to have it destroyed. Your decision to withdraw or refuse to participate in this study will in no way jeopardize your involvement with any programs or services that you are or will be using.

Unless you specify otherwise in writing, your input will remain confidential. Confidentiality will be maintained by removing all identifying information from your transcripts and tapes, and using a pseudonym to reference you. Identifying information will be accessed only by Sing Mei and myself. Files will be stored in a secured location separate from any information which might personally identify you and computer files will be password protected.

We recognize that talking about this experience may be distressing to some people. We will be prepared to stop the interview immediately upon request and are prepared to help you locate appropriate support if participation in this study is unsettling to you.

We will analyze the information that you give us, looking at it in relation to what others have said as well. Sing Mei will write up her dissertation to fulfill her PhD degree requirements based on this study. As well, we will report our findings in academic research reports, journals, presentations, and community workshops. Every attempt will be made to insure no information is included in any publications that could readily identify the participant.

All identifying data, including recordings and interview consent forms will be destroyed five years after the final completion of this research unless you agree in writing to an alternative plan for your data to be kept for a longer period.
Non-identifying data may be kept and used for future data analysis for academic research and publications on the same topic by the researchers on this team.

If you have any questions regarding any aspect of this study, you are invited to contact Dr. Deborah O'Connor at (xxx)xxx-xxxx. Furthermore, if you have any concerns regarding your treatment or rights as a participant in this project, you may contact the Director of the UBC Office of Research Services and Administration at (xxx)xxx-xxxx.

Thank-you for considering involvement in this project. If you agree to participate, your signature will be required below.

Sincerely,

Deborah O'Connor, PhD, RSW
School of Social Work, UBC

I hereby give consent for _________________________________ to participate in the study described above. I have received a copy of this consent form.

______________________________  ______________________________
(Name - please print)  (Signature)

______________________________  ______________________________
(relationship to person with dementia: self/spouse/daughter/son/other – please specify)  (date)

I agree/do not agree  (please circle): The information I am providing may be used in future studies being conducted by a member of this research team related to this topic, assuming that the study is reviewed and approved through the university Ethics Review Committee.

______________________________  ______________________________
(Signature)  (date)
Appendix H.
Consent Form for Third Family Member

THE UNIVERSITY OF BRITISH COLUMBIA

Individual Interview Consent Form (for family members)
Project Title: Dementia Care in Chinese Families

Principal Investigator and Supervisor:
Deborah O’Connor PhD., RSW, School of Social Work, UBC
Telephone: (xxx)xxx-xxxx
Email: xxxx@xxxx

Co-investigator and Student:
Sing Mei Chan, Ph.D (candidate), School of Social Work and Family Studies, UBC

The purpose of this study is to understand the experiences of Chinese families where one member has a dementia. By talking to different members within the family circle, we hope to gain an in-depth understanding of how Chinese families take care of their elderly relative and why they do what they do. This research is important because little attention has been given to the experience of family care in culturally diverse communities in Canada. We hope that the findings will help service providers and policy makers develop and offer more appropriate and effective support to Chinese family carers. As well, this study will provide data for Sing Mei Chan’s dissertation for completion of her PhD degree.

If you decide to participate in this study, you will meet with Sing Mei to discuss your experiences providing care to a senior with dementia. This meeting will likely last about 90 minutes. If you are willing, there will be a second follow-up interview of approximately the same length. All meetings and observations will take place at a time and location of your choice – this could include your home.
With your permission, the interview meetings will be audio-taped in the language of your choice (English, Cantonese or Mandarin) and transcribed into English. Upon request, you will be given a copy of the original tapes and/or English transcript for your records.

Your participation in this study is voluntary, and you will be free to withdraw from the project at any time. You have the right to refuse to answer any questions, to request that recording be stopped at any time, and to withdraw any information you do not wish to be included in this study. You also have the right to withdraw from the study at any point. Should you withdraw, the information you have provided up to the point of your withdrawal will be used in the data analysis, unless you state that you wish to have it destroyed. Your decision to withdraw or refuse to participate in this study will in no way jeopardize your involvement with any programs or services that you are or will be using.

Unless you specify otherwise in writing, your input will remain confidential. Confidentiality will be maintained by removing all identifying information from your transcripts and tapes, and using a pseudonym to reference you. Identifying information will be accessed only by Sing Mei and myself. Files will be stored in a secured location separate from any information which might personally identify you and computer files will be password protected.

We recognize that talking about this experience may be distressing to some people. We will be prepared to stop the interview immediately upon request and are prepared to help you locate appropriate support if participation in this study is unsettling to you.

We will analyze the information that you give us, looking at it in relation to what others have said as well. Sing Mei will write up her dissertation to fulfill her PhD degree requirements based on this study. As well, we will report our findings in academic research reports, journals, presentations, and community workshops. Every attempt will be made to insure no information is included in any publications that could readily identify you.

All identifying data, including recordings and interview consent forms will be destroyed five years after the final completion of this research unless you agree in writing to an alternative plan for your data to be kept for a longer period. Non-identifying data may be kept and used for future data analysis for
academic research and publications on the same topic by the researchers on this team.

If you have any questions regarding any aspect of this study, you are invited to contact Dr. Deborah O'Connor at (xxx)xxx-xxxx. Furthermore, if you have any concerns regarding your treatment or rights as a participant in this project, you may contact the Director of the UBC Office of Research Services and Administration at (xxx)xxx-xxxx.

Thank-you for considering involvement in this project. If you agree to participate, your signature will be required below.

Sincerely,

Deborah O'Connor, PhD, RSW
School of Social Work, UBC

________________________________________________________________________

I hereby consent to participate in the study described above. I have received a copy of this consent form.

_________________________________________  ______________________________
(Name - please print)                        (Signature)

(relationship to person with dementia: self/spouse/daughter/son/other – please specify)

________________________________________________________________________

I agree/do not agree (please circle): The information I am providing may be used in future studies being conducted by a member of this research team related to this topic, assuming that the study is reviewed and approved through the university Ethics Review Committee.

_________________________________________  ______________________________
(Signature)                                (date)

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Appendix I.
Consent Form for Service Provider

THE UNIVERSITY OF BRITISH COLUMBIA

School of Social Work
2080 West Mall
Vancouver, B.C. Canada V6T 1Z2
Tel: (604) 822-2255 Fax: (604) 822-8656
www.swfs.ubc.ca

Individual Interview Consent Form (for service provider)
Project Title: Dementia Care in Chinese Families

Principal Investigator and Supervisor:
Deborah O’Connor PhD., RSW, School of Social Work, UBC
Telephone: (xxx)xxx-xxxx
Email: xxxxxx@xxxxx

Co-investigator and Student:
Sing Mei Chan, Ph.D (candidate), School of Social Work and Family Studies, UBC

The purpose of this study is to understand the experiences of Chinese families caring for a relative with dementia in Vancouver and the Lower Mainland. The study aims to understand the experiences of multiple members within the same family and, where feasible, those of a front line service provider working with the family. This research is important because little attention has been given to the experience of family care in culturally diverse communities in Canada. We hope that the findings will help service providers and policy makers develop and offer more appropriate and effective support to Chinese family carers. As well, this study will provide data for Sing Mei Chan’s dissertation for completion of her PhD degree.

If you decide to participate in this study, you will meet with Sing Mei to discuss your experiences providing care to a senior with dementia. This meeting will likely last about 90 minutes. If you are willing, there will be a second follow-up interview of approximately the same length. All meetings and observations will take place at a time and location of your choice – this could include your home.
With your permission, the interview meetings will be audio-taped in the language of your choice (English, Cantonese or Mandarin) and transcribed into English. Upon request, you will be given a copy of the original tapes and/or English transcript for your records.

Your participation in this study is voluntary, and you will be free to withdraw from the project at any time. You have the right to refuse to answer any questions, to request that recording be stopped at any time, and to withdraw any information you do not wish to be included in this study. You also have the right to withdraw from the study at any point. Should you withdraw, the information you have provided up to the point of your withdrawal will be used in the data analysis, unless you state that you wish to have it destroyed. Your decision to withdraw or refuse to participate in this study will in no way jeopardize your work with any programs or services that you are providing.

Unless you specify otherwise in writing, your input will remain confidential. Confidentiality will be maintained by removing all identifying information from your transcripts and tapes, and using a pseudonym to reference you. Identifying information will be accessed only by Sing Mei and myself. Files will be stored in a secured location separate from any information which might personally identify you and computer files will be password protected.

We recognize that talking about this experience may be distressing to some people. We will be prepared to stop the interview immediately upon request and are prepared to help you locate appropriate support if participation in this study is unsettling to you.

We will analyze the information that you give us, looking at it in relation to what others have said as well. Sing Mei will write up her dissertation to fulfill her PhD degree requirements based on this study. As well, we will report our findings in academic research reports, journals, presentations, and community workshops. Every attempt will be made to insure no information is included in any publications that could readily identify you.

All identifying data, including recordings and interview consent forms will be destroyed five years after the final completion of this research unless you agree in writing to an alternative plan for your data to be kept for a longer period. Non-identifying data may be kept and used for future data analysis for academic research and publications on the same topic by the researchers on this team.
If you have any questions regarding any aspect of this study, you are invited to contact Dr. Deborah O'Connor at (xxx)xxx-xxxx. Furthermore, if you have any concerns regarding your treatment or rights as a participant in this project, you may contact the Director of the UBC Office of Research Services and Administration at (xxx)xxx-xxxx.

Thank-you for considering involvement in this project. If you agree to participate, your signature will be required below.

Sincerely,

Deborah O'Connor, PhD, RSW
School of Social Work, UBC

I hereby consent to participate in the study described above. I have received a copy of this consent form.

(Name - please print) (Signature)

(occupation) (date)

I agree/do not agree (please circle): The information I am providing may be used in future studies being conducted by a member of this research team related to this topic, assuming that the study is reviewed and approved through the university Ethics Review Committee.

(Signature) (date)