

## EAST ASIAN RESIDENTS AND MAINSTREAM LONG TERM CARE FACILITIES

EAST ASIAN RESIDENTS AND MAINSTREAM LONG TERM CARE FACILITIES

BY

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### *Abstract*

As Canada becomes increasingly ethnically diverse, health care professionals must extend their knowledge base of a range of cultural groups. Of interest in this thesis is how these cultural values and traditions intersect with those of the dominant culture. The principle guiding question was to explore the intersection between race and age and how these facets of identity impact the welfare, care, and cultural needs of the ethnic elderly living in mainstream long term care facilities (LTCFs).

The purpose of this research study is to examine the experiences of elderly East Asian immigrants who currently reside in mainstream LTCFs in Southern Ontario, through the perceptions of their informal primary caregivers. In particular, the research has focused on the participants' family member's challenges in living in a residence where the resident is cared for with Western ideology and methods, and primarily in English.

Three primary caregivers were interviewed using an in-depth, qualitative methodology. Findings of this study suggest that despite assumptions of a monolithic family culture that exists for minority families where each family member abides by the rules of filial piety and is willing to give or receive care from one another, with appropriate cultural supports available, Asian families may be more prepared to consider placement for their elderly family members in LTCFs.

“Around here, however, we don’t look backwards for very long.  
We keep moving forward, opening up new doors and doing new things...  
And curiosity keeps leading us down new paths.” [Walt Disney]

I am in gratitude to a supportive supervisor, Dr. Mirna Carranza, who walked me through this lengthy process and never once fretted about the constant obstacles we faced.

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I sincerely appreciate my father, for giving me everything that I’ve ever needed, and to my sisters, Maxie and Gladys, for sacrificing parts of their lives so that I could have more freedom in mine.

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In dedication to three Asian immigrants in particular:

to my loving mother, Hee Sook Bai,  
my kind uncle, Jei Young Bai,  
& my sweet grandmother, Kan Ran Kim.

I hope I have made you proud.  
Peace be in heaven.

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## ***Chapter 1: Introduction***

As Canada becomes increasingly ethnically diverse, health care professionals in all arenas must extend their knowledge base of a range of cultural groups. Of interest in this thesis is how these cultural values and traditions intersect with those of the dominant culture. According to a report by Statistics Canada, as the Canadian population ages, the need to place elderly family members in long-term care systems will also increase (Trottier, Martel, Houle, Berthelot, & Legare, 2000). Furthermore, the need for long-term care beds could impact Canada's health care system at an unexpected pace (Trottier et al., 2000). This growing area of interest represents a demographic reality, whereas the bulk of Asian immigrants who came to Canada in the 1960s to 1980s are coming of retirement age. The interaction between minority elderly people and health care systems has proven to be stressful and challenging for both parties (MacLean & Sakadakis, 1989).

The purpose of this research study is to examine the experiences of elderly East Asian immigrants who currently reside in mainstream long term care facilities (LTCFs) in Southern Ontario, through the perceptions of their informal primary caregivers. For use in this research, I have defined 'primary caregiver' to be the person who was most involved in the care of the elderly person before entering into the long term care system and/or the person who is the primary contact for the LTCF, and who is a member of the residents' familial system (including family-of-choice). 'East Asian' has been defined to include the Korean, Japanese, and Chinese populations. In particular, the research has focused on the participants' family member's challenges in living in a residence where the resident is cared for with Western ideology and methods, and primarily in English.

The research investigates if such challenges affect the residents' feelings of loneliness, isolation, and/or sadness. Thus, this research will observe whether or not LTCFs will require more culturally competent practice methods and supportive policies or if there are sufficient cultural supports available already.

Much health care policy assumes that within ethnic minority families there exists a monolithic family culture in which all members prefer and are willing to give or receive care from one another. MacLean and Bonar's (1986) pioneering article noted that there is a common belief that because of cultural tradition, most ethnic groups will care for their elderly relatives in the home. However, there is a tendency for each succeeding generation to assimilate into the Western culture more than the previous generation. This, coupled with the fact that their families may not have the social and economic resources to care for them at home (MacLean & Sakadakis, 1989), is forcing more ethnic elderly people into LTCF placement. Therefore, the principle guiding question to this research is to explore the intersection between race and age and how these facets of identity impact the welfare, care, and cultural needs of the ethnic elderly living in mainstream LTCFs.

This paper will begin by briefly defining the terms 'race', 'ethnicity', and 'culture' as it has been understood for this paper. This should clarify any misinterpretation, as these terms have been generally over-employed in society and in literature and have been articulated with a range of connotations. Next, I will review relevant literature to provide the context for this research. The fragmented nature of current available knowledge with regards to this specific population will exemplify the need for further research for both policy and practice implications. Following, the findings of the research will be

discussed to provide some insight into the experiences of East Asian immigrant residents in mainstream LTCFs. And finally, some recommendations for future research, practice, and policy will be suggested.

### *Terminology*

With the general growth of racial diversity in North America, it is not surprising that the issues of race, culture, and ethnicity have attracted increasingly considerable attention in empirical literature. Although each of the terms, ‘race’, ‘culture’, and ‘ethnicity’, is a fluid and dynamic concept, they are also over-employed terms and have been articulated and conceptualized in a range of ways. A brief definition for each will be provided here to afford some consistency in this paper.

While the terms ‘race’ and ‘ethnicity’ are often used interchangeably, they refer to different demographic attributes. **Ethnicity** is a term that represents different social groups with a shared history, sense of identity, geography, and cultural roots, which may occur despite racial difference (Pan, Glynn, Mogun, Choodnovskiy, & Avorn, 1999). Most generally, ethnicity refers to a shared and mutually understood cultural identity. Conversely, **race** is the categorization of the human population, which are considered distinct based on physical characteristics, and implies inheritable biological and genotypic traits (Pan et al., 1999). For example, these characteristics may be the colour of one’s skin, the shape of one’s nose, or the texture of one’s hair. **Culture** is a much broader and variable term than ethnicity or race. It is a system of shared beliefs, values, customs, behaviours, and perspectives on life that the members of society use to navigate through

the greater world and to relate with one another, and that are transmitted from generation to generation through learning (Pan et al., 1999). It is important to note that one's culture may or may not be the same as their ethnicity. Furthermore, as many scholars have noted, most societies are fundamentally constituted by divisions of class, race, and ethnicity. Nonetheless, culture remains significant to the way in which people identify themselves.

## ***Chapter 2: Review of Relevant Literature***

In this chapter, some literature that is relevant to the main themes of this research will be discussed to afford some context to this paper. Firstly, the current state of research concerning the population sample will be examined. This will be followed by some current research on themes such as assumptions and stereotypes, acculturation and adaptation, mainstream long term care facilities, language barriers, and ambiguous loss.

Although we can be sure that the numbers of Asian and other ethnic minority immigrants to Canada are increasing, there are substantial knowledge gaps regarding the circumstances of these populations. The investigation of ethnic dimensions in the health field is still being relatively neglected (Jones & Van Amelsvoort Jones, 1986; Mui & Burnette, 1994; Robinson, 1998; Smaje, 1996). Even more scarce is research and information about the elderly of these immigrant groups. When research is available, it is generally focused on the ethnic group's deficits or it is conducted as a comparative piece between the minority and dominant population (Zhan, Clutterbuck, Keshian, & Lombardi, 1998). Otherwise, research cites Asian populations within the arbitrary 'black and minority ethnic' category (Seymour, Payne, Chapman, & Holloway, 2007), or as the 'Asian-Pacific Islander' (API) group which fails to account for pan-Asian variation (Pang, Jordan-Marsh, Silverstein, & Cody, 2003). Literature has been additionally exclusionary towards certain minority groups, among which Asians are located (Ahmad & Bradby, 2007). Overall, research on the general geriatric population and on ethnic minority groups and culture has been inclined to proceed separately (Bowes, 2006).

More recently, there has been a notable debate around whether race and culture should continue to play a prominent role in health care research. This argument is premised on the fact that ‘race’ and ‘culture’ are both socially constructed terms and that they are both fluid across time and space (Bahr, 2007). However, from a social work perspective, race and culture remain to be significant indicators of equal access to resources. Since race and culture are socially constructed and not a biological fact, observed patterns in the intersection of race, culture, and access to health services are consequences of social forces and thus, is undoubtedly an issue that is worthy of further research. Current research consistently demonstrates that there are racial gaps in the health care field, regardless of the efforts made to adjust for other demographics, such as socioeconomic inequality (Bahr, 2007).

What this lack of knowledge perpetuates is the model minority myth that suggests Asian immigrants are likely to be educated, are more financially secure than other minority groups, and that the family life of Asians is supportive, tight knit, and ideal (Braun & Browne, 1998). This, however, also insinuates that Asian minority groups have little need for services for their elderly outside of the family (Bowes, 2006; Phillips, Mayer, & Aday, 2000). Mui and Dietz Domanski (1999) define ‘need’ to be a demand for service for which a certain population is willing to trade something, usually money, but this trade also is required to be profitable or of value to the agency. Therefore, if both the demand and the value of the service do not exist, the services will not be available. This exemplifies the constant cycle of how the economy and labour market justifies colour blindness. Currently, there are not enough East Asian residents in LTCFs to

support a cost-benefit analysis or needs assessment for Asian residents but without specialized cultural supports, there are few East Asian elderly immigrants and their families who will be willing to consider placement in a LTCF. Fields (1990) further contends that in the changing face of Canada's elderly today, there is a lack of fit between the demands of the society and the needs of the older individual. LTCFs and other agencies need to become more aware of the capacity of the informal support system of Asian elderly people so that the caregiving can be supported by services, instead of superseding the family's role.

Informal social support for the ethnic elderly is stronger when caregivers are from their own ethnicity and if they are in an environment which is familiar with their culture, language, and tradition (Fields, 1990). McLaughlin and Braun (1998) note that groups which are highly dependent solely on their own community for their well-being may postpone their use of formal services, such as LTCFs, and/or Western medicine. This path of care becomes problematic because it often results in a tendency to utilize formal health care services at a later stage of the disorder (Pang et al., 2003). Overall, research continues to conclude that unease of the Western medical system, compiled with a system that does not provide culturally sensitive care creates barriers to equal access to services (Newbold, 2005).

### *Assumptions and Stereotypes*

Barriers are found not only between the Asian and Western cultures, but also within Asian culture itself. The notion of filial piety originated from ancient Chinese



philosophy, but has been adopted by most East Asian nations at various points in history (Zhan et al., 1998) and is now deeply ingrained in current Asian cultural value systems (Pang et al., 2003). Filial piety includes a heavy accent on collectivism and respect for the elderly, and may lead immigrant families to be more likely to endure adversity. Asian families are also more likely to keep their true wishes silent if they believe that their feelings will inconvenience someone else in the family (McLaughlin & Braun, 1998). Furthermore, care is seen as a cyclical part of life; the parents care for a child, and when the parents become elderly, the care is returned willingly and with gratitude and happiness by the children (Lawton, Ahmad, Peel, & Hallowell, 2007). It is a culturally mandated sense of family responsibility. Due to this sense of familial obligation, talking to an outsider about family issues or reassigning the task of caring for elderly family members to an outsider would likely cause shame to the family and thus, creates a major barrier to receiving services if required (McLaughlin & Braun, 1998). In actuality, because of the implicit nature of filial piety, it becomes nearly impossible to broach the topic of potential disruption to the solidarity of the family and the impracticality of caring for the elderly family member in the home with an Asian family (Hu, 1995). Seymour et al., (2007) illustrate that voluntary placement of a family member to a LTCF would indicate to the elderly person that they have become an unmanageable burden to the family, leading to feelings of shame, loneliness, and depression. In collectivist societies, such as those in East Asia, any major decisions are not typically made individually but by the families as a whole or otherwise assigned to the eldest son (McLaughlin & Braun, 1998). However, in Canada, where there is the highest rate of institutionalization of the

elderly in the world (Fields, 1990), health care decisions such as LTCF placement may be relegated by the physician due to biomedical reasons. In this case, the shift of power in these crucial decisions may come as either a blessing or an additional source of stress to the Asian family.

Although previous research has demonstrated that there are certain, perhaps stereotypical, arrangements and expectations in Asian culture in regards to caring for one's elderly family member, using these known beliefs to guide practice in the health care field can be ineffective. In the age of political correctness, we tend to lump people into broad groups, such as "Asian" or "Latino", which are unhelpful in the clinical setting (Robinson, 1998). Such tendencies to amalgamate people in general ways may lead to a one-size-fits-all model to cultural supports and care (Bowes, 2006; Molassiotis, 2004). In an effort to combat this, however, many agencies and service providers are responding to this need by utilizing what is known as the 'fact-file' approach. This method entails the practice of having resources on hand for staff to use when associating with a minority client (Richardson, Thomas, & Richardson, 2006). These resources are oftentimes filled with superficial and benign details of an ethnic group's practices, beliefs, and traditions and fail to account for intra-group variation. Numerous scholars, for example, Firth (2005), Gunarantnam (1997), and Brotman (2003), have researched and documented the highly ineffective fact-file approach in health care systems in North America, as well as in the United Kingdom. Not all Asian people have the same cultural, linguistic, or social backgrounds to presume them a homogenous group (Robinson, 1998) and it can also lead to an unmerited overemphasis on cultural factors (Bowes, 2006).

Mui and Burnette's (1994) research found that ethnic minority groups reported far more use of informal caregivers and also that families are central to caregiving for family members in late life. Notably, several studies affirmed the stereotypical notion that Asian elderly people and their families preferred traditional methods of care practices with little or no discussion of the rationale for these patterns aside from "filial piety" or "cultural custom" (Braun & Browne, 1998; Haley, Han, & Henderson, 1998; Lawton et al., 2007). However, as Sudha and Mutran (1999) demonstrate, filial piety and related beliefs informing a family's choice against LTCF placement is assumed, rather than actually documented or studied. Furthermore, a high prevalence rate does not necessarily equate to ideal practice, as concluded in research by Hu (1995). It is likely that other reasons exist for such high numbers, but a lack of sufficient research leaves this issue under-examined and under-challenged. For instance, lack of specialized cultural supports in mainstream LTCFs or structural and financial constraints may shape a family's decision for placement (Sudha & Mutran, 1999). There is also some question about equal access to information about LTCF opportunities and availability and the family's ability to comprehend this information. When scholars provide the world with research based on assumptions and stereotypes, health care providers may use this skewed information to effectively restrict the quality of services this population may receive (Bowes, 2006).

### *Acculturation and Adaptation*

Berry (1997) defines the concept of acculturation to refer to cultural changes resulting from the encounters of two groups in a cultural context. Although there has been

some evolution within literature for this term to become synonymous with ‘assimilation’, ‘acculturation’ fundamentally conveys the subsequent changes to the cultural patterns of one or both groups. Adaptation similarly refers to the changes that occur in individuals or groups in response to an environmental demand (Berry, 1997); for example, when a person immigrates to a new country with a different cultural setting. While these two concepts may go hand-in-hand at times, with adaptation as a more short-term phenomenon and acculturation occurring over a longer period, there are other times when they clash. When the acculturating individual and the new cultural context does not “fit”, the two groups may settle into a pattern of conflict and stress (Berry, 1997). This fit is determined largely by levels of cultural maintenance (the extent the individual considers their cultural identity to be important) and cultural participation (the extent the individual interacts with the other culture) (Berry, 1997). The problem with this theory is that it is highly based on the assumption that minority individuals and groups have the freedom to choose how and how much they want to acculturate, which obviously is not the case. Berry (1997) believes that this can only be true if there is a sense of mutual accommodation. This would mean that the dominant group is open and inclusive to cultural diversity and is prepared to adapt its societal systems and institutions “to better meet the needs of all groups now living together in the plural society” (Berry, 1997, p.11). In the instance of East Asian immigrants residing in LTCFs, ethno-specific LTCFs are not readily available in comparison to mainstream facilities and thus, does not allow for freedom of choice to acculturate to the dominant culture. Furthermore, mainstream

LTCFs are not generally able or willing to provide adapted care practices to better meet the needs of all of their residents equally.

It is generally assumed that the ethnic elderly are less likely to acculturate and more likely to retain their cultural beliefs and practices to a larger extent than their younger counterparts, yet it would be naive and ignorant to regard elderly Asian immigrants as homogenous (Congress & Lyons, 1992). On the other hand, many younger immigrants have been found to be more easily acculturated through their interaction with employment, education, and other societal systems and thus, also be more likely to stray away from traditional values (Zhan et al., 1998). And so, there is some evidence that the familial supports regulated by the notion of filial piety may not be as readily available to Asian elderly people as it was previously or as expected (Congress & Lyons, 1992). A second pattern noted from research is that immigrant families are amongst the poorest of the poor, which then is likely to force young women immigrants into the labour market (MacLean & Bonar, 1986). The new economic pressure allows for significantly less time available to devote to caregiving for elderly family members. These emerging trends suggest that the issue of how ethnic elderly people experience aging in a country different than that of their birth may be more complex than initially indicated.

### *Mainstream Long Term Care Facilities*

Like the rest of the population in Canada, ethnic elderly people are living longer and are thus, this forces an increasing amount of people into LTCFs that are organized by

and *for* the dominant population. MacLean and Bonar (1986) conducted an early study of the ethnic elderly in LTCFs and found that placement for this population has a greater potential to produce negative institutional effects. This is due to the inability to cope with the new environment that is different than their culture, difficulties in communication, and a loss of familial support systems. For the ethnic elderly who do have family connections, the loss of daily and consistent interaction with family members has more pronounced emotional consequences than their dominant population counterparts because they are less able to rely on the staff for relations (MacLean & Bonar, 1986). When an Asian elderly person is placed in a Western LTCF, their daily existence is bonded to and organized by a different culture and a different set of expectations and values more than any other point in their lives. Many scholars, such as MacLean and Bonar (1986), Mold, Fitzpatrick, and Roberts (2005), amongst others, suggest that placement into a Western LTCF for the ethnic elderly creates a major cultural loss at a time when they are least able to cope with such stress, mentally and physically. Jones and Van Amelsvoort Jones (1986) discuss the cultural aspects that are most commonly disregarded in LTCFs for the ethnic elderly; these include food, language, customs and traditions, socialization opportunities, religious practices, and holidays or special occasions. Correspondingly, Phillips et al., (2000) found in their work that some efforts were made at being culturally supportive and although a number of participants were satisfied with the attempts, a substantial percentage also described feeling unequal to their White counterparts. Therefore, in other words, satisfactory care does not necessarily equate to a barrier-free existence and good culturally sensitive services.

### *Language Barriers*

When language barriers exist, communication and information delivery problems can become critical as patients and their caregivers are required to have certain information to make decisions about diagnoses, treatment options, and even long term prognosis (Richardson, Thomas, & Richardson, 2006). A further consequence of language barriers is a lack of awareness about available services and resources; it has also been noted in the literature that those who are less likely to understand their diagnosis will be less likely to understand treatment, which is then linked to overall health and recovery (Richardson, Thomas, & Richardson, 2006; Zhan et al., 1998). Additionally, for those minority families who are able to speak the dominant language adequately may comprehend the actual information but may miss important subtle implications of what they have been told, such as the complexities of care that lies ahead of them (Richardson, Thomas, & Richardson, 2006).

### *Ambiguous Loss*

Ambiguous loss has been defined to include “a state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system” (Dupuis, 2002, p. 95). However, the concept of ambiguous loss encompasses much more than just this one piece; although the entirety of this concept will not be discussed at length here, there are two other parts that are significant to note in regards to this topic. Frank (2007) discusses a manifestation of ambiguous loss called disenfranchised grief. This is noted to occur when the loss and

grief experienced by someone is not acknowledged by others, such as LTCF staff members. When one's loss and grief is not accounted for, feelings of isolation, stress, and guilt are common (Frank, 2007) and perhaps also feelings of frustration at the lack of understanding for their situation. Secondly, the first of three phases of ambiguous loss is the anticipatory grief stage. The term "anticipatory" grief is misleading as this type of grief does not solely attend to losses anticipated in the future, but also incorporating losses previous and presently (Frank, 2007). In the long term care setting, it is possible and realistic for a resident's family member to experience anticipatory grief due to their relative's biomedical condition. However, specifically in regards to the Asian culture where there is an expectation for children to provide care for their elderly parents, there is also a likelihood of feeling anticipatory grief over the loss of power and control of their parent's care after LTCF placement.

In sum, this review of relevant literature demonstrates that the current literature available is fragmented and fails to provide a clear picture of how East Asian culture and mainstream health care services intersect in the Canadian landscape. This literature review also indicates that there are major knowledge gaps in this area and illustrates how research has been unable to consistently articulate the complexities of this growing population.



### ***Chapter 3: Methodology***

In this chapter, the process of the research will be discussed. This provides some insight into the decisions made at each step of the research to justify the methodology of this project. Lastly, my role as an outsider-insider researcher will be explored in this section.

For the purpose of conducting research about a very specific and hidden population, it seemed imperative to utilize a qualitative methodology. This study was small in size and employed an in-depth, interview-based approach. The population of interest for this project is East Asian immigrant residents of mainstream LTCFs. Although in many studies the sample is selected directly from the population of interest (Engel & Schutt, 2005), there have been many limitations in accessing the population of interest, as will be discussed in a later chapter. And so, to learn more about this population's experiences, the research instead focused on the perceptions of this population's informal primary caregivers/ relatives. For the purposes of this research, a purposive sampling technique was utilized. Qualitative sample designs, such as purposive sampling, may not be relevant to the greater public but will provide a better understanding of a specific social process (Faugier & Sargeant, 1997). Prior to the initiation of this research project, approval was granted by the McMaster University Research Ethics Board (Appendix A).

### *Recruitment Process*

The sample was recruited through the community. More specifically, posters were distributed in-person to ethno-specific (East Asian) churches in Southern Ontario. A total of 14 churches were contacted and all agreed to aid in the recruitment for this study. Two of the 14 churches had affiliations with mainstream LTCFs and, without the researcher's prior knowledge, requested the facilities to forward the posters to families who may be eligible to participate. Two of the participants were recruited through this manner; the third was obtained through a subsequent snowballing technique. The snowball sampling technique is a method for recruitment of participants whereas the initial sample of participants refers one or more potential participants from their network to the researcher (Neuman, 2003). Faugier and Sargeant (1997) stated that this technique first ensued as an attempt to study hidden populations, which is fitting for this sample.

Due to the very narrow focus of the population of interest, a small sample size was sufficient. However, the sample actually acquired was much smaller than anticipated and proved more difficult to access than originally believed. Given that, this research involved only three participants. However, on a more positive note, each of these three participants was from a different ethnicity that is encompassed in East Asia (Korea, Japan, and China).

### *Interview Process*

Interviews were conducted on a one-to-one basis at the location of the participant's choice. The interviews lasted for an average of 45 minutes. In this study,

the participants were ensured of their rights to confidentiality and privacy, especially from the LTCF that their family member was residing in. Although some facilities were involved in the recruitment process unknowingly to the researcher, the LTCFs and I never had direct contact. Therefore, the facilities would be highly unlikely to identify which residents' family members contacted the researcher. Once the participants had agreed to participate, they were offered the decision of where the interview was to take place. Two participants invited me to their homes, while the third preferred to meet at the LTCF. The participant was cautioned about the risks involved with this meeting place, and as an added precaution, the participant was waiting at the front entrance so I would not have to identify myself as a researcher to the receptionist. Although the meeting place was on the LTCF property, it was in a public area and thus, did not require the LTCF staff to assist us. Lastly, with regards to the one participant who required a professional translator, the translator was also required to sign a confidentiality form (Appendix B) that explicitly stated that the information was to be kept private specifically from the LTCF. It was possible that the participants would feel cautious of the LTCF knowing that they are speaking out about their possibly negative experiences and how this information could affect their family member's care at the LTCF. As part of the confidentiality standard, the researcher made all realistic and possible attempts to maintain the participants' privacy specifically from their respective LTCFs. As reported above, it was unlikely that the LTCFs would be able to identify which residents' family members were involved in this study. However, the researcher erased all of the tape recordings once the transcription was completed. Furthermore, although I was aware of the LTCF affiliated

with each participant, this was not recorded anywhere and the participants were not asked to name the facility while being tape recorded. The participants were given pseudonyms after the interview, and subsequently only referred to as their pseudonyms. All data was held either under lock and key or via encryption on the computer for the duration of this study. The participants reviewed the Letter of Information (Appendix C) and signed the consent form (Appendix D) prior to the commencement of the interview, which outlined the risks involved with participating and allowed for the participants to have their questions answered. It was required that the participant was to provide written, informed consent. Engel and Schutt (2005) describe informed consent as consent that is given free of explicit and implicit coercion and thus ensured that the respondent's choice to participate was free of persuasion.

The interview included a series of semi-structured, open ended questions to obtain data regarding the primary caregiver's perception of the challenges the resident may face in the LTCF which stem specifically from being an immigrant. The semi-structured format of interview allowed the participant to talk about the aspects of the research issue that are relevant to their experience but only within the framework set out by the researcher, ensuring that certain points were discussed. An interview guide (Appendix E) was developed for this research study which contains an initial set of questions that sets the focus of the area of interest (Padgett, 2001). The interview was tape-recorded with the participant's consent. The interviews were conducted primarily in English. All participants were offered the use of a professional translator, and yet only one participant accepted use of this service. In the case of the participant who utilized a linguistic

translator, the quotations used in this paper will be presented in the text as the participant's own words. An informal interpreter, the participant's grandchild, was utilized during the pre-interview phase; for instance, the informal interpreter contacted the researcher on the participant's behalf. The informal interpreter proved to be effective and helpful in ensuring that the participant was comfortable with having the professional translator attend the interview as well.

### *Sample Characteristics*

Of the three participants, two were female and one was male and of the elderly residents, two were women and one was a man as well. The participants' relationship to the elderly resident of the LTCF included one spouse, one sibling, and one uncle. The age of the resident in care ranged from 72 to 87 years old. The birth countries of the immigrant residents were Japan, China, and Korea, and the residents were from these ethnicities respectively. Each elderly resident had been an immigrant to Canada; however, their length of immigration spanned over 60 years (a range of 24 to 86 years in Canada) and so, none of the elderly residents were recent immigrants to Canada. The residents were also differed in their length of residence at the LTCF; one resident had lived there for 2 years, another for 4 years, and the third for 8 years. All of the participants believed that the placement of their family member was involuntary.

*Background information.* Some background information is needed to fully understand the barriers that the respondents' family members faced in their mainstream LTCFs, and thus, will be briefly provided first. As previously stated, none of the

participants felt that their relative's placement in a LTCF was voluntary. Two participants, Mr. C and Ms. K, were adamant that there was absolutely no choice because of their family member's biomedical status. One of them emphasized further that the ideal situation for her family would have been to have her relative at home but that the around-the-clock care that he required was unmanageable. In one specific case it was reported that the partner simply required too much care to attempt to keep her in the home. Additionally, two participants described their relative to be free of any mental impairments or illnesses and declared them to be lucid and aware of their placement. The other participant's family member was unable to communicate and speak, and was unaware of her surroundings. The third participant felt that there were some elements of choice in her sibling's placement. Her husband and child died in [another city], so she reported that she had nobody. Although the resident could have been cared for in the home, Ms. J felt that because there was no other family, the responsibility of the care would fall onto her solely and that she was, herself, physically unable to keep up with the schedule.

### *Data Analysis*

Data analysis is always an on-going process, and in qualitative research, the data collection and data analysis are often occurring at the same time. Qualitative data collected from the interviews was rendered into text format by way of transcription verbatim by the researcher. The data was first analyzed in a line-by-line method with an open coding system, and subsequently with an axial coding system (Neuman, 2003). Lee

and Fielding (2004) define codes as words or short phrases that label certain occurrences in the text. These occurrences are that of which the researcher determines to be tentatively important to the research question (Pidgeon & Henwood, 2004). Extracting similar occurrences given the same code in various participants' transcripts allowed me to compare and contrast between the data. Pidgeon and Henwood (2004) advise researchers to begin open coding as soon as practical after the first round of data collection, and thus, I began this process immediately after the first interview was transcribed. These initial themes are relatively general, and the researcher should be open to creating new codes or themes and to revising the codes or themes as new data emerges (Neuman, 2003). Although there was initially far more data than needed in the beginning stages of coding, it was difficult to know what was significant or insignificant until all of the data was collected and analysed.

As the analysis moves forward, the initial coding developed into a more progressive level of analysis, which required the researcher to choose an appropriate level of deduction from all of the initial codes. This is known as axial coding (Neuman, 2003). For the purposes of beneficial analysis of data, it was not critical to acknowledge each concept located in the data but to record the concepts that were significant to the issue being researched (Pidgeon & Henwood, 2004). Therefore, in axial coding, I focused more on the initial codes from the open coding stage than the data itself. The goal of axial coding is to organize the themes and identify the relationship between key concepts in the data (Neuman, 2003). Neuman (2003) suggests that axial coding helps the researcher to make connections between codes, but also guides the upcoming data

collection by focusing the research on the expansion of certain themes while decreasing the importance of others. One of the most commonly used methods of coding is constant comparative analysis. Constant comparative analysis is an on-going method to data analysis where an occurrence is noted in the data (Neuman, 2003). It is then identified with similar instances from the data, which are compared against the other, and then labelled with a code as a concept. This method of data analysis is intrinsically a part of qualitative research by way of its continually re-evaluative nature.

Each transcript was reviewed for open coding approximately three times each. After moving into the axial coding phase and whilst utilizing the constant comparative analysis method, the transcripts were read through several more times to compare and contrast the themes and codes noted between the individual transcripts. Themes were organized firstly by the amount of data that each theme provided (i.e., most significant relationships). Once the general themes were established, sub-categories were arranged to make best efforts for continuity of ideas and smoothness between topics. The emergence of themes and sub-categories is best described as concepts that were noted repeatedly within and between transcripts, and also because of instinct. Often, a researcher's self-identity speaks to which pieces of the data are seemingly important to the research. In my personal case, the fact that I am an insider researcher supplemented the overall organization of concepts.



*The Outsider-Insider Researcher*

It is important to note here that as a member of a community (i.e., East Asian) conducting research on that same community, many scholars would consider me to be an insider researcher. Many anti-discriminatory researchers believe that having an insider identity is essential to exploring a group's oppression (Boushel, 2000). Because some issues lie beyond an outsider researcher's commonsense knowledge, many questions or themes are not even considered, although they may be crucial to their research or the participant's experience. Insider researchers have a unique ability to more easily understand the issues the participants are facing due to personal familiarity (LaSala, 2003). In data collection of a qualitative study, establishing a rapport between researcher and participant is necessary in obtaining useful and honest information. This is especially important when working with Asian clients or participants. For example, many Asian people do not prefer to allow strangers into their lives when dealing with personal issues because the culture tends to emphasize confidentiality within families. It may be suggested that as I am a member of the same community, the participants would more open to discussing their experiences with an insider researcher. Yet, these implications are simply speculations and this situation could also go in the opposite direction. Perhaps the participant would have felt more comfortable in speaking with a non-member of the community for fear of the researcher breaking confidentiality (LaSala, 2003). From my own experience, there was no evidence that the participants in this research project were uncomfortable with my insider researcher status. However, there were some inferences to me being Asian, whereas the participants would assume that I was familiar with Asian

culture or traditions and then they would not elaborate in full. There are also major limitations with being an insider researcher, such as when the insider researcher assumes that they know the experiences of the participant too well, and fails to notice any distinct pieces of the story.

Additionally, another criticism is that there is too much emphasis placed on the benefits of being an insider because in reality, people inhabit several identities at once and thus, will never be a 'full' insider of any population (Boushel, 2000). LaSala (2003) refers to this phenomenon as an 'Outsider Insider', in that many researchers are rarely entirely outsiders or insiders to the group they are researching. This is where I locate myself in my own project. For example, I am East Asian, the same as my participants. However, I am not elderly nor do I have a family member who resides in a LTCF. Furthermore, though my life experiences have been within the Asian culture, I was born and raised in Canada. Thus, to many Asian immigrants, I may be seen more as a Canadian than otherwise despite my physical appearance. I live with a dual identity, both inside and outside of two cultures. There too is the complexity of the 'Asian' culture; practices, beliefs, and culture itself is varied across the vast span of 'Asia'. More specifically, in most Asian cultures, it is the elderly who are seen as wise and knowledgeable. Being an insider yet also fairly young may be a hindrance if the participants found my approach to be offensive to their traditional status as elder than I. Similarly to above, there was little evidence that my own personal identity affected the participants in the ways described above.

### ***Chapter 4: Findings***

This section will present the findings of this qualitative research study that are related to the initial research question. Despite diversity in the residents' characteristics, these interviews provided insight into how the participants perceived their family member's care at the LTCF in regards to the availability of cultural support and culturally sensitive services. Participants' descriptions of their relative's experiences in long term care were varied but similar themes were noted, suggesting that culturally-informed meanings, experiences, and interpretations were at least partly at play. The three primary themes identified are institutional barriers to equitable care, cultural supports, and acculturation and adaptation in later life.

#### *Experiences of Long Term Care for East Asian Elderly Immigrants*

Several findings were observed from the data that suggested that the ethnic elderly who reside in mainstream LTCFs are not receiving care that is equitable to their dominant population counterparts. The language and communication barrier is the most significant obstacle and the consequences of this barrier include effects on nutritional intake, residents' physical well being, and lack of pain management. There are emotional effects on both the residents and their extended family as well, such as internalized shame, grief, and burn out. All of these issues will be discussed in the following section.

### *Language Barriers: Impact*

The most prominent cultural challenge that these elderly East Asian immigrant residents face while residing in LTCFs, as described by their family members, is the language barrier. One of the residents was unable to speak English at all, while another could communicate in basic English but had difficulties with comprehension when it became too complex or if it was too quickly spoken. The third resident was fluent in both English and her native language, Japanese. Those participants whose relatives did not have full command of the English language also made the strongest statements with inferences that their family member's basic needs were not being met. For example, although Ms. K reported that her uncle was able to understand some English, the staff approached this resident as if he was able to understand everything and communicate fully. This caused the resident to nod 'yes' to things he did not understand because of confusion and, conversely, also hindered him from requesting basic necessities, like water if he was thirsty. Regardless of their relative's level of comprehension, every participant discussed the facilities' utilization of informal translators as the primary method to managing the language barrier between Asian immigrant residents and staff members. Ms. J and Mr. C both discussed other residents who were able to speak the Asian language as well as the English language and would take on the role of translating for staff. The participants also felt that they were held responsible if the LTCF staff members were unable to communicate with their family member, demonstrated by facilities' dependency on the family to attend the LTCF and translate. The following quote is an example: "Because she does not understand English, and I don't feel comfortable to just

leave her there, so I suppose I have to go and look after her and attend to her needs” (Mr. C). Therefore, these participants felt obligated to attend the LTCF as much as they could for interpretation purposes. It was clear in all three interviews that the LTCFs were dependent on the availability of a non-English speaking resident’s family or other residents to transfer information and carry out services. The language barrier was found to have a significant impact on several facets of life at the LTCF, which included nutritional intake, physical harm, pain management, and on the family members.

*Nutritional intake.* One particular discussion of potential for physical consequences was in association to the Western meals served in the LTCFs. Although Mr. C’s spouse used a feeding tube and meals were thus not an issue for this family, he presented the lack of communication as a factor to blame for difficulties with Western food. Aside from the general dislike of Western food by Asian elderly immigrants, there are ways of modifying the meals to be more appealing to the Asian palate. For instance, many Asian people describe Western food to be very bland and serving these residents with salt or soy sauce on the side could easily amend this problem. Again, the issue of the food being liked or disliked is not the matter at hand here; food is directly related to physical health, illness, and one’s ability to heal properly. This participant describes his observances of other Chinese, non-English speaking residents in his spouse’s LTCF. “Sometimes they feed them, give them food, and they are not able to express, for example, sometimes it’s too hot and sometimes they don’t like to eat it and then they give up eating” (Mr. C). Like in the example, many concerns raised by the participants were issues that could be easily remedied and yet, the residents’ inability to effectively

communicate their needs subsequently results in potentially serious physical problems. A lack of essential nutrients is the smaller part of the greater concern regarding food intake. In particular, a low level of dietary intake or starvation could have harmful effects on an elderly resident dependent of the residents', for instance, illness or medication. This is highlighted by another participant's account of her family member's experience.

He doesn't like the food and sometimes he'll just eat enough so that he's not hungry and then maybe the staff will sometimes say he wasn't feeling well because he didn't finish the food. And I guess they use cues like that but it's not that he wasn't feeling well, he just didn't like it. (Ms. K)

If the LTCF relies on non-verbal cues to assess well being with residents that they are not able to verbally communicate with, there is high potential for risk of physical harm. If such cues are utilized to interpret the status of a resident and should they influence any part of the care, like medication dosage, possible detrimental effects are created.

Furthermore, two of the three participants reported that their family members had diabetes, which is partially regulated by dietary intake as well as injected insulin and other medications. Diabetic shock is associated with diabetes and generally occurs when the management of the illness is compromised, either by an incorrect dosage of insulin or other diabetes medication or by changes in diet, such as skipping a meal or vomiting up at meal (Lawton et al., 2007). Diabetic shock, if not detected in its early stages, can result in diabetic coma and in extreme yet recurrent cases, death. Therefore, there are potentially serious consequences to language and cultural barriers that may hinder a facility's ability to provide good and equitable care to the ethnic elderly.

*Physical harm.* The potential for physical harm to a resident due to language and/or communication barriers is not simply an imagined possibility. The participants have observed and reported that their own family members have been victims of actual physical harm in their respective facilities. Prior to providing any of the respondents' statements or describing specific circumstances, it is important to note here that what will be expressed below are not instances of deliberate physical abuse per se; rather, they are the unintended (but nonetheless serious) effects of miscommunication between staff members and non-English speaking residents. One respondent reflected on a particular incident that occurred and where he felt that the staff at the LTCF had managed this incident improperly. When this resident first entered the LTCF, she was quite lucid and cognizant at the time, although she did not speak the dominant language. One of her first interactions with the medical team was during her intake assessment and she was fearful of the staff. During this intake assessment, she was taken away from the rest of the family in order to provide her with some privacy. "Accordingly, they wanted to hold her for some reason, and by holding her, the part of her body had bruises" (Mr. C). There are two significant pieces to this statement. Firstly, despite the fact that the family members who attended the placement of this resident were able to speak English, she was taken to the medical assessment alone and separated for "privacy". Good intentions may have made this decision, but it is quite obvious that the LTCF failed to account for the language barrier. There was no one available to explain to the resident of what they were going to do to her and as we can see from the participant's quote, there was no one to explain to the resident and the family why she needed to be held. The second significant

point should be clear: the resident had bruises, actual physical harm that stemmed directly from an inability to communicate effectively. This participant added to this statement that after this incident, he now attempts to be with his family member whenever there is a medical procedure scheduled to aid in the translation and comfort. Thus, with this precaution in place, she is cooperative with the staff. “If I were there, I would explain to her, I would tell her, well they are going to do something for you, for example, going to have an injection. After realizing that, she would cooperate and maybe even raise up her arm” (Mr. C).

*Pain management.* Another regrettable physical consequence to language and communication barriers between mainstream LTCFs and the ethnic elderly was in regards to pain medication. Similar to the discussion around other basic needs, these respondents believed that their family members are not able to have the same access to pain medication as the mainstream population in the LTCF. While there is some ability, albeit limited, for staff to utilize non-verbal communication methods to interpret a resident’s needs, pain management in particular requires vocalization because there may not necessarily be any physical symptoms of pain. The absence of physical symptoms (i.e. wincing or tears) cannot be conclusive in determining whether or not a resident requires medication. Mr. C expressed his concerns about his spouse being unable to communicate whether or not she required more pain medication. “When she has discomfort or pain, she is not able to express it properly. Then she needs family members to go to the [LTCF] to assist her, to look after her” (Mr. C). Pain management contributes to the overall well being of the resident and is a part of the care routine that is normally



extended to Canadian-born residents without complication. One participant acknowledged that her family member would only receive pain medication when she or another relative of the resident would attend the facility; it became the family's responsibility to ensure that this resident was receiving medication because the LTCF staff would not administer the medication without declaration of actual pain. Ms. K stated, "I don't know if you can imagine... If you're going for six hours and you're not vocalizing that and you're sitting in pain. I don't know how I would handle it". Ms. K's family member, like others, was left unnecessarily in extreme pain for significant lengths of time because of the gaps in the LTCF's care toward the ethnic elderly.

*Family members.* If the staff were unable to communicate effectively to the resident, there was cause for great concern for the family members. Having one's basic needs met, such as water for thirst, pain medication, or requesting aid in toileting, is dependent on communication. For instance, one participant explained that he notices the language barrier hindering physical care at the LTCF, not only for his spouse but also for the other Chinese residents. "If there is another person who is able to speak the language or so on and explain, [the staff members] realize their needs" (Mr. C). As another respondent stated, "[because of the language barrier], if I'm not available, my brother's not available, we're in trouble". Furthermore, Ms. K described feeling frustrated and upset at the lack of proper care that her family member receives when she or another English-speaking family member was not at the LTCF to translate needs. This lack of care did not necessarily refer to cultural services, but to physical care. Regardless if a mainstream LTCF is providing culturally appropriate services, the ethnic elderly should

have access to the same level of physical care that is equitable to their Canadian-born counterparts. The very nature of long term care demands the nursing staff to be accountable for a resident's physical well being. A frightening finding from the interviews was that without effective negotiation of cultural or language barriers, physical harm as well as emotional distress can occur. The respondents felt that the ethnic elderly were often cared *for* by the nursing staff, instead of being cared *about*, which indicates a sense of disregard for the person. The feeling of indifference was central to the respondents' accounts and developed into discussions around the physical consequences to the ethnic elderly residents.

### *Supports*

*Positive accounts of cultural supports.* Despite the fact that each of the participants' relatives resided in mainstream LTCFs, two facilities described in this study had a significant concentration of one particular ethnicity in their overall resident population. In two of the cases, there were a considerable number of Asian (Chinese and Japanese respectively) residents aside from the larger mainstream population. Additional to the positive effects of a sense of camaraderie and community, it was these facilities that were noted to be more willing to provide culturally appropriate services to the Asian population. In the LTCF that accommodated a significant number of Chinese residents, there was an event once a month that included a Chinese performance and an authentic Chinese meal afterwards for the Chinese residents. This facility also made efforts to celebrate the Chinese New Year, the Moon Festival, and the May Festival, which are

prominent traditions in the Chinese culture, with decorations and special meals. Correspondingly, Japanese residents of another LTCF attended an ethno-specific religious service, once per every two weeks. Afterwards, the Japanese volunteers would make and serve a Japanese meal. These volunteers also run an exercise program once a week for the Japanese residents called Tae-So, which stems from the Japanese culture. This serves not only as an exercise program but also a social outlet where residents were able to speak and congregate with other Japanese residents. “There are other Japanese here and they get together when they do their weekly exercises and they all get together and then they can talk to each other in Japanese” (Ms. J). Lastly, this facility further offered a special Japanese affair once a year.

What we do is once a year, [the volunteers] put up a program here for all the residents... and we have it during the summer for just one hour. There is Japanese dance and sing along and harmonica band, and then in-between the one hour [the volunteers] serve refreshments to them. (Ms. J)

Neither respondent reported any formal services that are provided, although there are some bi-lingual, Japanese residents who are able to fulfill some of this need for other residents. The Korean representative was unable to report any culturally specific services or supports provided by the LTCF. This resident was able to meet with a Korean-speaking minister regularly but the family arranged this independently. Although in two of the circumstances it appears that there are many services provided by the mainstream LTCF, it can be observed that these programs that are offered to the residents are mostly recreational, only occur a handful of times per year, and generally fail to absorb the impact that Western ideology and practices has on the daily life of the ethnic elderly.

*Connections.* It is apparent from the interviews that, quite simply, higher numbers of people requiring a service equates to a demand for services. Using these three facilities as an example, we can see that with increased numbers of a certain ethnic group, there is also an influx of cultural events, supports, and some services. Two of the respondents' LTCFs had above average numbers of their respective cultural populations, despite the fact that both of these LTCFs are mainstream facilities that are administrated by the dominant group and through Western ideology and practice standards. It can also be observed from the data that once some cultural supports are established, more people from a specific ethnic community become more willing to place themselves or their family member in that specific LTCF. "She knew that there were other Japanese in here so that's why she preferred to come here" (Ms. J). Ms. J's family member felt more comfortable leaving her familial home to move into an institution because she was able to have some continuity, familiarity, and solidarity with the other Japanese residents.

Conversely, in the third case, there was virtually nothing offered to the family or the resident and there is some connection to the fact that there were also no other Asian residents in this facility. This can be further exemplified by an account from another participant. This participant described a time when another minority, but not Asian, resident at his spouse's facility questioned why they only celebrated Chinese holidays, outside of the Canadian norm. Although the Chinese celebrations were funded by donations to the LTCF as a whole (and not by, for instance, a Chinese organization) only the one ethnic group was provided with specific supports and this was apparent to other residents. "The other patients raised a question. How come only the Chinese have this

type of thing, but we don't have it, we're not Chinese. How come [the] Chinese have this type of support and we don't have [it]?" (Mr. C). Therefore, this other minority resident's observation highlights the significant relationship between the number of people requiring a service and the willingness of the facility to provide such services. However, this relationship is problematic when a minority population, such as East Asian elderly immigrants, are residing in a mainstream facility. Hence, by nature, this population will never be the dominant group. It is my argument that this method of evaluating which services to implement into a facility will continue to ignore the needs of all minority groups and can never allow for equitable provision of care for all residents.

#### *Adaptation and Acculturation in Later Life*

In this section, the findings exemplify that the participants and the residents of this study require continued negotiation of their two cultures. Due to this, the participants are unable to hold the LTCF and its staff members accountable for the gaps in equitable service. This phenomenon will be illustrated below.

#### *Continuation of Asian Filial Piety in the Western World*

Current long term care policies and practices are built upon the premise that the family is, or should be, the primary caregiver for impaired older persons. This notion, which has its roots in Western ideology, emphasizes the *impaired* piece of role delegations (Berry, 1997). It is also assumed that when a resident of a LTCF is not cognitively impaired, the primary responsibility is shifted to the individual. The belief of

a familial responsibility to care for their elderly family members was central in all of the participants' accounts of their relative's experience in a mainstream LTCF. This concept is deeply rooted in East Asian culture, history, and in filial piety. However, what is most interesting about this issue is that one would expect that once a resident is admitted to a LTCF, the paid, professional caregivers would supersede the informal, familial caregivers in a more principal role. What we can see from the interviews is that due to language and communication barriers, the caregiving role was shifted back to the family but the LTCF retained the power and control over the situation.

For some participants, the issue extends beyond linguistic challenges and the cultural barrier is considered to play a role in this as well. "I don't think you can separate the language barrier and the cultural barrier because he just basically doesn't get what he needs" (Ms. K). This phenomenon is complex and difficult to understand without having a full realization of the entirety of Asian philosophy. With regards to this participant, it appears that the resident is unable to move beyond the cultural barrier to request aid; "I know it's hard for people to grasp that... he's been in pain for five hours or something and he won't say that he has been. And they don't understand why". Therefore, ideally, culturally sensitive services for the ethnic elderly in LTCFs would include not only language interpreters but cultural brokers as well.

*Internalized shame.* The converse side of this exploration was the resident's internalization of these role shifts as well. Because of the notion of filial piety, if an elderly person is placed in an institution or cared for by a paid outsider, the elderly person often internalizes and truly believes that they have become the ultimate burden on the

family. In some cases this will cause negative effects on the family's relationship; in other situations, the relationship between the elderly person and the family remains unaffected but the elderly person will begin to withdraw to avoid becoming an inconvenience to anyone. "Family that come in and basically anyone that takes time out of their schedule to be with him, even though they want to be and they don't complain and they come freely and make sure everything's ok, he thinks he's being a bother" (Ms. K). In turn, it can be interpreted that the family may feel as if they have handed over the entirety of their responsibility onto the LTCF and have become powerless as well.

*Grief.* The participants' discussion of their family members' LTCF placement resonated with notions of being powerless and grief. Ambiguous grief centres on the losses experienced by the caregiver and the family members as whole. In this sense, although the participants in this study still played a major role in the daily care process of their relatives in the LTCF, they nonetheless experience loss when they relinquish the ability to direct the care to the LTCF staff. The interview process clearly substantiated the general perception that due to this instinctive obligation to be the caregiver of one's elderly relative out of respect and filial piety, the participants were compelled to continue playing a primary caregiving role even after the LTCF placement gaining power and control over the care process. In the discussion of his experience with the admission of his spouse to the LTCF, Mr. C stated, "It is my responsibility to look after her, support her... Now I have to look after her". The description of Mr. C's perception of his spouse's life at the LTCF shows that he places himself as the primary caregiver in her life, although he does not have any power or control over the care.

Two participants also expressed feelings of loss, grief, and powerlessness in regards to the effects on their personal lives. Responses generally focused on loss of time or loss of freedom. In response to a question about daily challenges, a respondent replied, “[there were] a lot of difficulties on my part as well and how to adjust to it”. Another participant presented a similar view when the doctor reported that their family member would require around-the-clock care and need to reside in a LTCF, the first thought reported was “I’d better be a responsible person and look after her”. Although numerous statements were noted in the interviews which echo these findings, it was best summarized, and perhaps one of the most powerful statements that came out of the discussion of new challenges since the placement, by Mr. C: “Actually, my life patterns have been changed, has been forced to change because I have to look after her and I naturally need to pay a lot of attention [to] her, energy wise”. Such statements reflect the burden experienced by family members of immigrant residents in LTCFs, which is a part of loss and grief. Therefore, reports about sacrificing time and freedom to continue caring for a relative after LTCF placement illustrate anticipatory grief. A significant piece of these understandings of who is the primary caregiver is that if the participants continue to accept these roles and undertake the related responsibilities, the LTCFs will also continue to relegate their responsibility to the families without any real comprehension of the difficulties in caring for Asian elderly immigrants. Subsequently then, without this comprehension, changes to service delivery are not likely.

*Family members’ burn out.* Two of the participants described a sense of emotional exhaustion towards the placement of their family member in a LTCF. It could be



expected that with such high levels of care required for each of the respondents' relatives, a sense of relief from caregiving duties would occur after placement but there was nothing in their reports that would portray this. On the contrary, having their family member cared for in a mainstream LTCF created an anxiety for most of the participants because they were unable to be with their family member all of the time. Ms. K recounted being at work all day and only being able to attend the LTCF after work hours or on the weekends. The participant reflected on her emotions during the times when she was at work and unable to check in on her family member; "It makes me worry even more when I'm not there". And again, at a later point in the interview, "It is [stressful]. I mean, it's a lot easier than me having to skip work and stay home but at the same time, it doesn't leave your mind. There's no peace". In this way, the Asian family members have not been able to relinquish their caregiving responsibilities to the LTCF, as other families would have the option to. Due to the gaps in the care delivery to the ethnic elderly, who have either language or cultural barriers to equitable service, the LTCF becomes reliant on the family to facilitate the care. The ultimate responsibility for the care of a resident in a facility shifts from the paid, professional caregivers back onto the family, which is an extremely stressful and emotionally exhausting experience.

### *Feeling Powerless*

Each of the three participants asserted that they could not make the LTCF staff work too hard or demand too many things from the LTCF because the LTCF ultimately, in the participants' eyes, had control over their family member's well-being. Although

Ms. J did not feel that her sister had any outstanding cultural needs to address with the LTCF, the other two participants interviewed did not report similar thoughts. However, these participants were apprehensive in formally addressing these concerns with LTCF staff or administrators. Mr. C discussed his wife's needs with the social worker at the LTCF only once and he requested more rehabilitation exercises for his family member. The physiotherapist placed pictures of the stretches that the nursing staff should do with the resident several times per day. The participant stated that not every nurse was following the instructions and in some cases, they would simply place a pillow under his spouse's leg but this would actually make her knee and leg more stiff and painful. While no changes were ever made to his wife's care, Mr. C felt that he could not bring the issue up again. When I asked the participant why he had not raised this issue with the staff, his reply was, "Well, if I have an issue, I just mentioned to you, once is good enough. We are not willing to express or make so much noise". Ms. K, on the other hand, continues to address her concerns with the staff on a daily basis but stated that it is only in passing and never officially. "Well, it's generally every day when I run into them. It's just an everyday conversation" (Ms. K). Furthermore, there were no changes seen in this case either; "No [changes]. Everything's still status quo". Both of these participants' decisions appeared to stem from fear that there would be negative consequences on their family members if they were labelled as 'pushy' or 'demanding'.

*No Complaints: Fear of Negative Consequences*

A significant subject that was gleaned from the interviews was the underlying yet unmistakably clear fear of negative repercussions on the elderly resident due to the participant's actions. An example of this occurred when I asked Mr. C about the cultural support that is lacking in the LTCF. Although Mr. C addressed his concerns with the facility's social work team initially, he was unwilling to continue to request that changes be made to his wife's care. The reason for this was very strongly and quite clearly stated:

It's no good to keep talking, repeating the same issue, you see, because our family member is in their hands. We do not want to upset anybody from the [LTCF]. We do not want to, we cannot afford to upset any member of [the LTCF] because our family member is in their care... I don't want her to suffer in any way. (Mr. C.)

As exemplified in this statement, there is an apparent insinuation of the participant's submissiveness to the LTCF's power and control. Similar sentiments were echoed in the other interviews as well. When asked about whether or not Ms. K has tried to discuss her family member's cultural needs with the staff, Ms. K stated that she is hesitant and cautious. Although she has brought it up "in passing", she is too afraid of "bothering" the LTCF or its staff about these issues specifically. These statements suggest that there is a very clear and, yet, intricate relationship between the demand for services or support and the nature of services and support received. Without the family challenging the LTCF to make changes, the likelihood of the LTCF introducing such services is poor.

Participants seemed concerned that the confidentiality clause could be breeched unknowingly and hence, the fear and apprehension of the LTCFs retaliating against one's

family member was also perceptible in the use of the word “complain”. This word was used consistently through each of the interviews and undoubtedly demonstrates that these feelings exist. All three of the participants were observed to ensure that the researcher knew that they were not complaining. Ms. J punctuated her discussion of the Japanese culture within the facility with, “but I am happy [with] the way they are treating her so I have no complaints about the place here”. Ms. J’s account contains the insinuation that any critique or complaint, even a small one, has the potential to jeopardize their family member’s care and to these participants, it simply cannot be risked. In an almost identical context, Ms. K quickly noted after she spoke about the lack of understanding of the Korean culture with her family member, “I’m not complaining or anything, it’s just challenging, that’s all”. The same participant affirmed at a different point in her interview, “I’m not complaining about the staff”, when discussing her uncle’s communication difficulties with the staff. It can be inferred from this statement that although there are difficulties in obtaining cultural support, this participant is reluctant to vocalize these concerns because of the care that her relative requires.

#### *Failing to Hold LTCF’s Staff Accountable Due to Fear*

The pattern of the minimization of the lack of cultural support in the LTCF is seemingly contradictory to the feeling of fear for the participants’ family member but it could also be inferred that it is actually intrinsically related to it. The fear that there could be potentially negative consequences onto the participants’ relatives’ care, such as ignoring the resident or being slow to respond to needs, appears to alter the thought

process of the respondents. Even though confidentiality was ensured, especially in regards to the LTCF in which their family member was a resident of, participants were fearful that the LTCF would discover their reports about the lack of cultural support to this researcher. It was evident that each participant continually minimized the problems in the LTCF. One comment during an interview in particular demonstrated this. In Ms. J's discussion of informal linguistic translators, she asserted that there was no real need for formal translators because "most of [the Japanese residents] do understand the English language. They just can't answer back to [the staff]". This participant has minimized the problem of the language and communication barrier by claiming that the residents can understand the staff members, and thus, the language barrier is only one way. However, the concern then is that while the residents may be able to understand direction from staff members, their needs continue to go unmet because they cannot voice them.

#### *Unstated Insufficiency*

In analysis of the participants' interviews, it was commonly reported that the participants were satisfied with the level of cultural support provided to the residents and their families. In comparison to the residents' mainstream counterparts, the services, supports, and level of care provided appeared to be far from sufficient or satisfactory. More specifically, the participants' interviews revealed variability in attitude towards the provisions of – or attempts of – cultural support at their family members' facilities and yet, they still reported similar accounts of sufficiency. Unfortunately, sufficient and acceptable do not equate to fair and just. Additionally, deeper analysis of the words and

terms (e.g. “fine”, “not bad”, “not really”, “for the most part”, “I guess”) the participants used in these discussions suggests that despite reports of sufficiency, there is an underlying tone of reluctant acceptance. During the conversation about cultural support, the participants were each asked whether or not they felt that the current practices were adequate. The answers to this question are as follows:

I suppose it’s really acceptable. It’s fine. (Mr. C)

They try... but it’s not the same. (Ms. K)

More or less. (Ms. J)

None of the participants were able to concretely say that they felt that the staff members and the LTCF offered adequate services their family members. In fact, Ms. K honestly stated, “he doesn’t have any support”, when asked about cultural support in the LTCF. The statements above are indicative of a consistent pattern of participants from various LTCFs accepting low standards of practice. One participant continued and admitted, “I don’t think there’s great cultural support, but I’d like to think there is some”. Therefore, even the assumption or belief without evidence of actual services or accommodation is sufficient enough to appease the need for culturally appropriate services.

Overall, the general theme from the interviews was simply tolerance. Culture and ethnicity are, for most people, directly related to their identity and it is difficult to believe that the few pieces of the culture offered in facilities are enough to sustain cultural identity for the client. Because of a history of serving a diverse range of clients from a dominant, mainstream, and Western ideology, many people, such as the participants in

this study, believe that anything offered should be good enough. One statement from Ms. K summarized this belief eloquently.

For now, I accept it because there's not much you can do. There's actually nothing I can do to change it. I mean, we're one person and one minority and that's the nature of business, you cater to the majority. So, I understand that. (Ms. K)

### *Thankfulness*

It was also often noted that the participants actually justified the issues on the behalf of the LTCF. It was quite evident by the expressions of the participants. For instance, after articulating her feelings about the barriers her family member faced in obtaining culturally sensitive care, one participant quickly added, "But, for the most part, I know money is an issue [and] staff is an issue, so ... I understand that. They would have a hard time regulating if everyone [brought in food], they would be all over the place". In this participant's understanding of the lack of cultural support, it appears that she has shifted the responsibility to provide culturally sensitive care off of the LTCF and thus, justifying the difficulties her relative encounters. A second participant reiterated this justification as well as he stated, "The patients are getting more than before, and accordingly, people, [the] staff in the hospital, their workload becomes heavier". The same participant went on to offer the statement that "[cultural support] is not easy to accommodate". Because the participants are knowledgeable about caseload burdens and the increasing numbers of elderly people residing in LTCFs, they are more concerned with the physical care provided to their family members. Less tangible services, such as cultural care or emotional support, become a lesser priority to the family members. Mr. C

acknowledged this, and further exemplified the justification of unsatisfactory levels of cultural care, by stating, “You have to know that this is not the place to cure your illness. It’s a place for long term care and the person stays there”. In this statement, it is easily observable that due to the highly ill and vulnerable nature of LTCF residents, the physical side of care provided needs to take precedence and anything else, such as culturally relevant services, is just an added bonus.

Lastly, the fear of potential repercussions was evident in the participants’ speech patterns during their interviews. On several occasions throughout the interviews with each of the participants, as they began to say negative things about the services or care provided, it was then recanted. Many of these statements were completed with “but...” and either a minimization or justification of what had been stated previous. Examples of such patterns include, “but you can’t blame someone for not understanding someone else’s culture” (Ms. K) and “but it’s fine [because] the point is that it’s hard to please everybody” (Mr. C). The respondents were keen to stress that despite the lapse in cultural services and cultural support, the LTCF was not at fault. However, by presenting the LTCF as not being responsible, there is little incentive for the LTCF to bring about change in the way in which they care for the ethnic elderly. In fact, I would argue that any change would require a LTCF to be obligated to account for their gaps in service to their residents and their families. Debating whether or not negative repercussions on the elderly resident will actually occur because of a family member’s words or actions is futile and irrelevant; the evidence from the participants demonstrates that the inherent belief of this relationship between LTCF, family member, and resident, where the LTCF



has ultimate control and power, is effective in shaping the interactions between the family member of the resident and the facility. In this sense, then, this belief of power and control surrenders any power that the resident and their families may have to the LTCF and allows the LTCF to continue to operate without providing essential cultural supports and services.

## ***Chapter 5: Discussion***

This chapter will highlight the key findings from this research, as well as discuss the extent to which this study aligns with the current available literature on the subject.

The results of this research project are indicative of two discoveries. Firstly, there are noteworthy gaps in long term care between the same services provided to the ethnic elderly and the Canadian-born residents. This is demonstrated by the accounts of the LTCFs relying on the Asian residents' family members to aid in the facilitation of the care process. There is also concern for this inequitable care provision as exemplified by the potential for physical consequences or actual physical harm against non-English speaking, immigrant residents due to language and cultural barriers. Secondly, the ethnic elderly who reside in mainstream LTCFs in Southern Ontario are not receiving an adequate level of cultural support or culturally specific services. Although the participants each relayed similar versions of acceptance of the low standards of practice, as a researcher and as a social worker, the general theme of tolerance is insufficient evidence to support LTCFs' lack of culturally appropriate supports and services. In relation to this point, a major outcome of this research noted that there was an observable essence of fear of discussing negative characteristics of the LTCF where their family member lived, or even to critique the facility in any way. Hence, this finding that the participants perceived the cultural supports to be adequate may be located more accurately within this other theme of fear.

The findings further suggest that there is a connection between the number of residents in one LTCF of the same ethnic and/or cultural background and the number of

cultural supports and services offered by the LTCF. In two of the mainstream LTCFs, there were significant numbers, albeit still in minority to the dominant population, of Asian elderly immigrant residents. With a noticeable group of residents from one specific ethnicity (Chinese and Japanese in these cases), there is a visible rise in the number of cultural events observed and celebrated and culturally appropriate services provided. Conversely then, in the one facility where the participant's family member was the sole Asian resident, there was virtually nothing offered to the resident by the LTCF in specific relation to their culture. This is similar to Pang et al.,'s (2003) research that highlighted that where medical facilities made efforts to have bi-lingual staff and/or translators, it is generally in areas that have a high concentration of a certain population.

The findings from this study are important as Canada is becoming increasingly diverse (Trottier et al., 2000). Health care professionals in all sectors must be able to extend their knowledge to increase and better support for these clients, as well as their families. The ethnic immigrant elderly represent a demographic reality because the bulk of Asian immigrants who came to Canada in the 1960s to 1980s are coming of retirement age, as noted in much literature. The interaction between minority elderly people and health care systems has proven to be stressful and challenging for both parties and this study provides an admittedly small glimpse into this collision of worlds. Due to seemingly indirect issues, such as the current economy where more families are becoming reliant on a woman's second income and the pace of acculturation by younger generations of immigrants, the need to place the ethnic elderly in LTCFs is increasing. Additionally,

the need for long-term care beds has an absolute impact Canada's larger health care system.

This research supported much of the findings from previous and larger studies. Firstly, many studies raise the issue of the model minority myth, where it is assumed that Asian families are tight-knit, able, and willing to provide care for their elderly family members. It is clear that many Western systems buy into and perpetuate this myth by relying on clients' relatives to facilitate their care. In many instances, this myth is even justified by the notion of filial piety. However, in practice, the two most problematic aspects of this assumption are the family's *ability* and/or *willingness* to provide this care. It is unrealistic to presuppose that a resident's relatives are in a position to be at the facility at all times to fill in the gaps of care. Pang et al.'s (2003) study suggests that there are few middle-aged children in immigrant families who are able to practice the classical form of filial piety, where daily and constant devotion to the elderly parents is expected, mainly because of their need to work. Furthermore, just as in any other culture or ethnicity, there are some Asian families who have dysfunctional familial relationships and there simply may not be a willingness from the family members to aid the LTCF in caregiving responsibilities. What's more, this assumption and any practice which rests upon this assumption fails to account for those Asian residents who do not have an extended family. Most significantly, the practice of this assumption forces the ethnic elderly to become and stay dependent on their extended family members. Placement to a LTCF does not necessarily require the resident to be cognitively impaired or unable to make sound decisions. The LTCFs' reliance on informal caregivers and the lack of

motivation to offer formal cultural supports to residents eradicates any power and control that an ethnic elderly may have over their own care and diminishes their ability to stay independent.

The findings of this research are limited but nonetheless consistent with the copious amounts of literature available on the ethnic elderly in health care systems. In particular, the articles by Jones and Van Amelsvoort Jones (1986), MacLean and Bonar (1986), Mold, Fitzpatrick, and Roberts (2005), and Phillips et al., (2000) are uniform in describing the many obstacles that the ethnic elderly face while residing in mainstream LTCFs. When an Asian elderly person is placed in a Western-based LTCF, their daily existence is bonded to and organized by a different culture and a different set of expectations and values more than any other point in their lives. This is also the time when research shows that they are least able to cope with such vast changes. The study by Phillips et al., (2000) specifically echoed the themes resounding in this research; although a number of participants were satisfied with the attempts to provide cultural supports, a substantial percentage also described feeling unequal to their majority counterparts. Therefore, in other words, sufficiency does not necessarily equate to a barrier-free existence and good culturally sensitive services.

It can be speculated that the responses of the participants in this study may reflect some of the issues that can be relevant to a larger scope of ethnicities and cultures. Although some issues are inherent to the Asian culture, such as the model minority myth and the concept of filial piety stemming from Confucianism, there are other concerns that may translate into other populations. For instance, the difficulties that the participants'

family members faced due to ineffective management of language and cultural barriers are likely to be applicable to many different groups. Regardless of the actual language, if that language is not coherent with the dominant language, there will be barriers to equitable care and service provision.

Finally, it must be noted that the elders in this study were not recent immigrants and their time in Canada spanned over a range of 60 years with the most current immigrant having moved here nearly 25 years ago. The significance of this observation is because some scholars have hypothesized that with greater acculturation we can anticipate a shift from filial piety to filial autonomy, even among the older immigrant populations (Pang et al., 2003). However, the results of the interviews in this study exemplifies that the residents have had time to acculturate to the dominant culture in which they reside and yet, a minimum of 24 years was not long enough to lose their unique cultural identity or language. As discussed, the interaction between the participants and their respective LTCFs demonstrates that even in later life, navigation between two cultures continues to be difficult. Therefore, the findings of this study did not support this reported trend of elderly immigrants shifting away from their minority culture and requiring less culturally specific supports and services in the health care system.

## ***Chapter 6: Limitations***

This chapter will provide a discussion of two distinct areas of limitations. First of all, the limitations placed upon the project by means of obtaining Ethics approval will be noted. Then, an examination of the subsequent limitations of this study concerning the validity of the results will follow.

### *Ethics' Board*

Initially, during the proposal stage of this study, the study was to be conducted with the actual East Asian immigrant residents of mainstream LTCFs. However, this proposal was denied due to several reasons. Firstly, there was some concern about the ability of the researcher to distinguish between the potential participants who were cognitive and able to speak soundly to their experiences in the LTCF and those who have dementia, Alzheimer's disease, or other mental disorders that would affect their lucidity. Should a participant be included in the study with cognitive impairment that was overlooked by the researcher, the participant's data would have skewed the research results. Since privacy laws and ethical standards would limit me as a researcher, I would be unable to access residents' medical records. Therefore, I would have needed to be reliant on the LTCFs' administrators to advise whether or not these residents would be eligible to participate. Consequently, more concerns arose regarding the involvement of the LTCF administrative team. There were possibilities of the LTCFs interrupting the ethical process of research with their own agenda, perhaps pressuring the resident to either agree or disagree to participating. Whether this notion is realistic or not is futile;

there was more apprehension from the idea that the participant may interpret this pressure regardless of its actual existence. In turn, the potential participant may report untruthful information if they believed the LTCF knew that they are speaking out about possibly negative experiences and how this information could (negatively) affect their care at the LTCF. All things considered, there were major opportunities for bias with this sample.

Although the sample was shifted to the primary caregiver of the elderly resident to speak about their perceptions of their family member's experience, there were additional limitations placed upon this proposed project. The McMaster University Research Ethics' Board noted similar concerns when recruiting through local LTCFs was proposed. It was concluded that having the LTCF aid in contacting family members of residents to be potential participants would equate to a parallel likelihood of bias as discussed above. Even without active involvement of the LTCF, for instance, having the posters hung in the facility may insinuate to the prospective participant that the LTCF is aware of the study and is in some way associated with it. Furthermore, as there are very small numbers of East Asian residents in the majority of facilities, the probability of the LTCF discovering who the actual participant is was high and thus, also worthy of consideration. The fear of negative consequences of a family member being cared for by the LTCF being discussed in a research study was no less troublesome than if it were the participants themselves. In fact, this fear may even be exacerbated. Hence, any recruitment that had affiliations to a LTCF was not approved, which severely diminished the opportunities available for recruitment.



### *Limitations of this Study*

While some limitations specific to the initial stages of this study are noted above, there are several limitations to this study in relation to its conclusiveness that are worthwhile to mention. The sample of three participants used for this study was far too small to draw conclusions that would be generalizable to a larger population. Additionally, the size of the sample still cannot be fully relevant to the East Asian population of Southern Ontario. The amalgamation of ethnicities in this study was required to satisfy the concern of too few people interested in being a participant in this research and thus, ‘East Asian’ cultures had to be examined instead of a more detailed research project conducted on one ethnicity or culture. And so, upon closer inspection, it can be observed that in actuality each ethnicity studied only had one representative. This further limits the validity of results drawn from the qualitative interviews.

Unintentionally, this research project failed to account for pan-Asian differences, which, under examination, could vindicate certain themes, patterns, or simply discrepancies in the understanding of “mutual” concepts (e.g., filial piety). Thus, my position should be clear – to do full justice to the richness and complexities of cross-cultural variations, a more extensive approach is required and this could be conducted in one of two ways. As stated above, an intensive and larger study completed on one ethnic or cultural group would suffice. Otherwise, a comparative and multifaceted research project would have been beneficial to further explicate the positions salient to interpretation, such as when some themes (like fear of repercussions) were not explicitly articulated by the respondents. Comparative data is advantageous because those who

conduct studies “at home” (i.e., with people from the same ethnic group as they belong, such as myself) are more inclined to regard certain cultural aspects noted by participants as normal and self-evident (Lawton et al., 2007).

As mentioned earlier due to difficulties in acquiring approval from the McMaster University Research Ethics’ Board, the initial research project that sought information from the ethnic elderly themselves was shifted to the perceptions of the experiences of the ethnic elderly in LTCFs by their primary informal caregivers. Unfortunately, although there were some interesting revelations found with this shifted study, the opportunity to gain knowledge from the people who had actually lived the experience would have provided a much clearer picture of barriers they face. There is a common belief that to be placed in a LTCF, one must be cognitively impaired with a form of dementia or Alzheimer’s disease. Out of the three participants’ family members, only one was cognitively impaired and this was due to a stroke. While each participant reported that there were bio-medical reasons for their relative’s placement, two of these residents would have been capable of participating in an interview-based study. Cognitive impairment does not necessarily inhibit one’s ability to consent or to tell their story; the very fact that we limit such populations’ interactions with researchers neglects large masses of people and forces them to be/stay invisible. The ability for others to speak on the behalf of another is essentially hearsay and insufficient in knowledge seeking and qualitative research methods.

## ***Chapter 7: Recommendations***

In this chapter, I will be looking towards the future and will briefly provide some implications for future research and implications for practice. Also, my own dissemination plans will be afforded in this section to outline how I hope that this research study will affect positive change.

### *Implications for Future Research*

Regardless of the limitations of this research project, the patterns that have arisen from this investigation warrant further consideration and examination. Some recommendations for further research include a much larger scaled study and ideally, the involvement of ethnic elderly immigrant residents of mainstream LTCFs themselves as participants. As noted in the previous chapter, while the perception of this population's experiences by their family members can provide some insight into the challenges they face, this knowledge is very limited. Also, the information sought about the lives of East Asian elderly residents in this study was fairly general due to the nature and scope of the project. However, future study needs to address the needs of this group more specifically. For example, various service access determinants such as cultural acceptability and knowledge of service availability. As well, more research on the barriers to equitable provision of care (why they are perpetuated and how can they be reduced) is required.

Furthermore, it should be noted that some of the very values that have been outlined in this research study may also complicate research conducted with this population; for instance, if the Asian culture demands harmony and looks down upon

discussing private family matters with outsiders, participants may tell the researcher what they believe wants to be heard and will be reluctant to speak negatively about their family situation. For this reason, all future researchers of this area are recommended to seek out the potential for such values to affect their research and to mitigate these possible effects to the furthest, realistic extent.

### *Implications for Practice*

It is apparent from the literature and this small research project that cultural sensitivity and cultural support services are lacking in the current health care landscape. Because the uprooting process involves changes in social and cultural climates, immigrants in particular may be frustrated by the fact that their social skills and coping mechanisms are not functioning typically or appropriately in their new setting. Thus, when immigrant families collide with health care systems that are organized and administered through Western ideology and primarily in English, it should be expected that specialized practice methods are needed.

Aside from the more conventional, yet nevertheless necessary, recommendations, like bi-lingual staff members and professional interpreters, I will note here some suggestions that may be helpful in interacting with the ethnic elderly that has stemmed from discussions with the participants. Firstly, LTCFs should have less reliance on assessment tools when working with this population because these are generally scripted with the dominant population in mind. The results of such assessment tools may incorrectly identify the client, and dependent on which assessment tool was being

utilized, could be detrimental to the care of the elderly resident. Secondly, the participants suggested that simply increased sensitivity towards their family members by the LTCF staff members would be appreciated. Therefore, affording all people the same courtesy, consideration, and respect, regardless of whether the same language is spoken, is recommended. In addition, it can be advised that in practice it would be beneficial to learn about the group one works with, although it would also be further recommended to move away from using the fact-file method. This method has not proven to be effective and is often understood as condescending towards minority people. Lastly, improving upon non-verbal communication skills can be useful when all other options for translation, informal or formal, are absent. This can include paying closer attention to the client's body language and/or a lack of response that may signify conflict, fear, or tension.

### *Dissemination Plans for Research*

The dissemination plans for this research project will be directed to three separate audiences. A more detailed report in a printed booklet form will be mailed out to each mainstream LTCF in Southern Ontario. In an attempt to provide these LTCFs with valuable information, the report targeted to the professional audience will be easily readable yet intellectually stimulating as well. This report will contain more concrete suggestions for their in-house policies and practices. The aim will be to bring awareness to LTCFs of the challenges that many East Asian immigrant residents and their families

are facing with their agency, and will attempt to provide some recommendations for service provision as expressed by the participants.

The participants were invited to provide their mailing address for a report on the findings of the project at the time of signing the consent form. The participants also had the opportunity to request that the report to be translated into their preferred language for optimal sharing of the final conclusions. This report will likely be in form of a pamphlet and will be more concise than the report for professionals. The objective of this report is not focused on recommendations and solutions, but to provide the participants some support in knowing that they are not alone in their challenges. This pamphlet will utilize ‘voice’ more than the other report to exemplify others who are facing similar battles.

A final dissemination strategy will be to submit a brief outline of the research project and its findings to the Ontario Association of Community Care Access Centres’ monthly newsletter. The Community Care Access Centre (CCAC) in each region is the agency responsible for the integrated health care system including long term care (“OACCAC”, n.d.). In particular, the CCAC is the governing agency for admissions into LTCFs. This newsletter can be located on the organization’s website as well as it is distributed to all of the stakeholders and employees in Ontario. Also, the Hamilton CCAC has recently has begun to publish their own local newsletter twice annually, entitled ‘The Navigator’ (“OACCAC”, n.d.). Both newsletters welcome small press releases of interest to be submitted for publishing.

### ***Chapter 8: Conclusion***

This exploratory study has added to the current knowledge base and understanding of a small but growing population at the intersection of race and age. East Asian elderly immigrant residents of mainstream LTCFs face numerous barriers to equitable, fair, and just services and care in comparison to their dominant population counterparts. Furthermore, the families of these residents are also being burdened with filling in the gaps where the LTCFs are not satisfying the residents' needs. Most simply, this becomes a matter of systemic racial disadvantage.

Despite the fact that all of the participants' family members were required to be in LTCFs due to biomedical reasons, a stronger preference for LTCF placement was expressed by participants than originally anticipated by the researcher. Hence, it could be speculated that with a better system of culturally appropriate services and cultural supports, a greater number of Asian immigrant families would be more willing and/or more comfortable with the placement of their elderly family members. This also indicates that any preferences for care expressed by an Asian elderly person are mediated by a range of intricate social and interpersonal considerations and, quite plainly, cannot be regarded as culturally determined or scripted. Therefore, the continued practice of determining service provision and policies based on the assumption of filial piety is no longer acceptable. The conclusion from this research study as well as much of the current literature persistently concludes that immigrants in Canada are under-served and in turn, under-utilize health care systems, regardless of need.

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*Appendix A – Ethics Certificate*

<b>McMaster University Research Ethics Board (MREB)</b> <small>c/o Office of Research Services, MREB Secretariat, GH-305/H, e-mail: <a href="mailto:ethicsoffice@mcmaster.ca">ethicsoffice@mcmaster.ca</a></small> <b>CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH</b>			
<b>Application Status:</b> New <input checked="" type="checkbox"/> Addendum <input type="checkbox"/> Renewal <input type="checkbox"/> Project Number 2008 062			
<b>TITLE OF RESEARCH PROJECT:</b> East Asian Immigrant Residents and Mainstream Long Term Care Facilities			
<b>Faculty Investigator (s)/ Supervisor(s)</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
M. Carranza	Social Work	23789	carranz@mcmaster.ca
<b>Student Investigator(s)</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
J. Bai	Social Work	905-902-9915	baija@mcmaster.ca
The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB: <input type="checkbox"/> The application protocol is approved as presented without questions or requests for modification. <input checked="" type="checkbox"/> The application protocol is approved as revised without questions or requests for modification. <input type="checkbox"/> The application protocol is approved subject to clarification and/or modification as appended or identified below:			
<b>COMMENTS AND CONDITIONS:</b> Ongoing approval is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and approved before any alterations are made to the research.			
Reporting Frequency: Annual: <input checked="" type="checkbox"/> Other: <input type="checkbox"/>			
Date: May 23, 2008 Dr. D. Maurer, Chair/ Dr. D. Pawluch, Vice-chair:			

***Appendix B – Confidentiality Agreement***

**A Study of East Asian Immigrant Residents and Mainstream Long Term Care Facilities**

**Principle Investigator:**

Jennifer Bai  
Department of Social Work  
McMaster University  
Hamilton, Ontario, Canada  
905-902-9915

**Supervisor:**

Dr. Mirna Carranza  
Department of Social Work  
McMaster University  
Hamilton, Ontario, Canada  
905-525-9140, extension 23789

**CONFIDENTIALITY AGREEMENT**

I, \_\_\_\_\_, have been retained as a professional translator between the researcher and the participant in a study being conducted by Jennifer Bai of McMaster University.

I understand that any information I am privy to as a professional translator hired for this study is to be held under strict confidentiality laws and the participant's privacy is to be respected. I also understand that my involvement with this study will be specifically kept confidential from the long-term care facility that the participant or participant's family member resides in.

I have been given a copy of this form if I have requested one.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

### *Appendix C – Letter of Information*

#### A Study of East Asian Immigrant Residents and Mainstream Long Term Care Facilities

**Principle Investigator:** Jennifer Bai, B.A., B.S.W.  
Department of Social Work  
McMaster University  
Hamilton, Ontario, Canada  
Phone: 905-902-9915  
Email: baija@mcmaster.ca

**Supervisor:** Dr. Mirna Carranza  
Department of Social Work  
McMaster University  
Hamilton, Ontario, Canada  
Phone: 905-525-9140, extension 23789  
Email: carranz@mcmaster.ca

#### **Why are we doing this study?**

In this study, I want to hear about the experiences of family members or primary caregivers of elderly immigrants from East Asia (i.e. Korea, China, or Japan) who are now living in Canada and are residing in a long-term care facility. I am hoping to find out about the challenges of living in a Canadian care facility for those people who come from a very different culture. I am specifically looking for what family members or primary caregivers perceive to be difficult for the elderly immigrant residents in residing in a facility that relates to their homeland culture and/or their cultural needs. For example, language or communication barriers, differences in food or meals, neglected holidays or special occasions. My goal is to be able to provide long term care facilities with information on such challenges to help the facilities to better support East Asian immigrant residents.

#### **What will happen during the study?**

I will meet with you at your home or another location of your choice to talk about your experiences of having a family member living at a long-term care facility. If English is not your primary language, with your permission, I will also bring someone to translate. I will be asking you questions about why your family member is living there, what is hard about living there, what pieces of your culture would make it easier to live there for your family member, and what is the facility doing well to support your family member's cultural needs. I will also ask you some demographic information like your age and place of birth. The interview should take about 1 hour. If you get tired or need a break, we can stop the interview at any time. I will be tape recording the interview, with



your permission, so that I don't miss anything you have to say. If you would prefer to not have your interview tape-recorded, please let me know.

### **Will anything bad happen during the study?**

It is not likely that anything harmful will happen to you during the study. Some of the questions may cause you to think about situations or experiences that you find difficult. Also, you may feel worried about other people knowing that you are participating or knowing what you have said. If you should feel uncomfortable with any question or would simply prefer not to answer simply let me know. I will take all precautions to help keep your involvement in this study as private as possible. I explain more about this below. You can ask me to stop anytime. If we stop, I will stop tape recording immediately. You will have the choice whether to restart the interview, reschedule the interview, or withdraw completely with no consequences. If you want, I can help you to contact some local agencies to deal with any issues or emotions that may have surfaced during the interview.

### **What good things could happen if I participate?**

The research will not benefit you directly. I hope to learn more about the difficulties that are specific to East Asian immigrants living in long-term care facilities. By understanding these challenges, I hope to be able to provide this information to facilities in the future to better support East Asian immigrant residents' cultural needs.

### **Reimbursement**

By participating, you will receive \$25 as a token of my appreciation.

### **Confidentiality**

Your privacy will be respected. No one but me will know who did or did not participate in this study. I will not use your name or the name of your relative in my final report. Also, I will not include in my report any information that would allow you or your relative to be identified, including the name of the long term care facility where your relative lives. If an interpreter is needed, the interpreter will also sign a contract stating that they will keep your information private.

Any information I collect from you will be kept in a locked cabinet in a locked office at McMaster University and will only be available to myself. The information will be destroyed within one year of the interview. Information obtained will be kept confidential to the full extent of the law and I will treat all information provided to me as subject to researcher-participant privilege. However, under some circumstances, I may be

compelled by law to break confidentiality. For instance, if you disclose that you will harm yourself or someone else.

### **What if I change my mind about participating?**

Your decision to participate in this study is voluntary and absolutely your choice. If you decide to participate, you can decide to stop at any time, even after signing the consent form or part-way through the study or interview. If you decide to stop, there will be no consequences and you will still receive your compensation for your efforts. In a case of withdrawal, any data that you have provided to that point will be destroyed immediately unless you indicate otherwise. If you do not want to answer some questions but still want to be in the study that is also acceptable. Your decision to participate or not will not affect your family member's care or services received at the long-term care facility.

### **Information about study results**

You may obtain information about the results of the study by notifying me at the time of the interview and providing me with an address to mail the report. The report can be translated into your language if requested. The anticipated date for the final report is late September, 2008.

If you have any further questions or require more information about the study itself, please feel free to contact me, **Jennifer Bai**, or my supervisor, **Dr. Mirna Carranza**. Our contact information can be found at the top of the first page.

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a research participant or about the way the study is being conducted, you may contact:

McMaster Research Ethics Board Secretariat  
Telephone: 905-525-9140, extension 23142  
Email: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)

Thank you for taking the time to read more about this research project. If you are interested in participating, please contact me to discuss this matter further and to schedule a date and time for the interview.

Sincerely,

Jennifer Bai

***Appendix D – Consent Form***

**A Study of East Asian Immigrant Residents and Mainstream Long Term Care Facilities**

**Principle Investigator:**

Jennifer Bai  
Department of Social Work  
McMaster University  
Hamilton, Ontario, Canada  
Phone: 905-902-9915  
Email: baija@mcmaster.ca

**Supervisor:**

Dr. Mirna Carranza  
Department of Social Work  
McMaster University  
Hamilton, Ontario, Canada  
Phone: 905-525-9140, extension 23789  
Email: carranz@mcmaster.ca

**CONSENT**

I, \_\_\_\_\_, have read the information presented in the Information Letter about a study being conducted by Jennifer Bai of McMaster University. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about this study.

I understand that I may withdraw from this study at any time, my involvement is voluntary, and I agree to participate. I also understand that my involvement in this study will be tape recorded.

I understand that professional translation services may be utilized and I further understand that any hired translator will sign a confidentiality form. I also understand that my involvement with this study will be kept confidential from the long-term care facility that my family member resides in.

I understand that I will have access to the research findings, and if I would like a copy of the final report I will provide a mailing address below.

I have been given a copy of this form.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Mailing Address (Optional) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Translator Required? Yes \_\_\_\_\_ No \_\_\_\_\_

### *Appendix E – Interview Guide*

1. Describe research study and interview process.
2. Explain how confidentiality will be protected and obtain signed consent form.
3. Ask participant demographic questions, including: relation to elderly resident, age, gender, birth country, length of immigration to Canada (i.e. year immigrated) of family member, ethnicity, and length of LTCF residence of family member.
4. Ask participant about his/her family member's LTCF placement.
  - a. Did you agree to the placement? If not, why?
  - b. Were there medical reasons for your family member's LTCF placement, mental or physical?
  - c. Can you tell me about the experience of moving your family member in?
    - Prompt – How did you feel about the move?
    - Prompt – What made it difficult; easier?
5. Ask participant about his/her perspectives of their family member's daily experience at the LTCF.
  - a. What are your family member's biggest challenges on a daily basis?
    - Prompt – Ask for examples.
  - b. Does the language barrier affect your family member's life at the LTCF?
    - Prompt – Does your (lack of a) language barrier make things easier/more difficult?
    - Prompt – Describe an example of when this was a problem.
    - Prompt – How do you and/or the LTCF manage this barrier?  
(What did you do?)
  - c. Do these challenges affect you emotionally? Your family member?
    - Prompt – What kinds of feelings?
    - Prompt – Ask for examples.
6. Ask participant about cultural support in the LTCF.
  - a. What does your family member miss about their culture?
    - Prompt – How about the differences in food?
    - Prompt – How about any special occasions or holidays?
  - b. What pieces of their culture would make it easier for them to live here?

- c. Can you tell me what the LTCF is doing well to help you and/or your family member with their cultural needs?
  - d. Have you discussed your cultural needs with the LTCF staff?
    - Prompt – If yes, was the staff receptive? Did anything change? Ask for examples.
  - e. What would be the best change the LTCF could make to help you and your family member?
7. Ask participant if there are any comments s/he wishes to make further about this topic that have not yet been addressed.