

**Squeezed In:  
The Intersecting Paradoxes of Care for Immigrant Informal Caregivers**

**by**

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## **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Jenny Flagler-George

## **Abstract**

While the feasibility of maintaining informal care for older adults is a growing concern for many Canadians, support is not the same for everyone. The situation for immigrants is even more precarious because of their unique social locations. They find themselves squeezed into a system that neither reflects their realities nor addresses their needs. This thesis argues that, due to their multiple marginalities as gendered and racialized newcomers, immigrant informal caregivers lack needed resources in caring for aging family, friends, and neighbours. It also argues that mainstream home care and long-term care providers face challenges in caring for older immigrants because health care provision for older adults was not developed to advance immigrant interests. To develop this argument in an empirically grounded way, I use a theoretical framework combining feminist theories of care work and intersectionality theories in order to analyze a series of semi-structured interviews with informal immigrant and Canadian-born caregivers, as well as management and staff in home care and four long-term care facilities in Southern Ontario.

The results show that immigrant informal caregivers in Southern Ontario face challenges in accessing supports, services, and resources because of the gendered nature of care work and their immigrant social locations. My research indicates that many immigrant informal caregivers experience a burden as a result of taking on the caregiver role, often squeezed between the expectations of care from their home countries and the demands of caregiving in a Canadian context. Moreover, when informal care can no longer be provided by immigrant informal caregivers in the home, a host of systemic barriers restrict access to, and accommodation in, long-term care facilities. The dissertation concludes by demonstrating how proposed improvements in the delivery of long term care facilities are contingent on formal service providers being respectful, reflective, and responsive to the diversities among immigrants (‘inclusion’), rather than fitting them into existing mainstream programs (‘integration’). In doing so, this dissertation adds to the sociology of care by reinforcing a multidimensional approach for accommodating complex diversities in ways that are workable, necessary and inclusive.

## Acknowledgements

I have many people that I would like to thank for their ongoing support and contributions throughout my PhD program. I begin by thanking each of the people who participated in my research. This dissertation could not have been possible without their openness and willingness to share their experiences and perspectives.

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## **Dedication**

This dissertation is dedicated to my mother, Lynda Flagler, who has given me the unwavering support and positivity that I need to face any challenge in my life. She has inspired me in so many ways to achieve my dreams.

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## **Chapter 1: Introduction**

### **1.1 Overview**

Canada's aging population is growing rapidly. This growth has resulted in many fearing that the Canadian health care system will be unable to keep pace with evolving needs (Public Health Agency of Canada, 2009). Statistics Canada (2005) data reveal that the number of persons aged 65 and older living in Canada increased dramatically between 1956 and 2006. By 2016 there will be 5,799,000 Canadians over 65 years of age, compared to just 1,244,000 in 1956 (Statistics Canada, 2005). In preparation of the increased costs associated with caring for aging Canadians, there were a number of health care reforms that occurred in Canada during the 1990s focused on promoting fiscal conservatism. These changes centred largely on the deinstitutionalization of services, including reducing the number of available hospital beds in order to keep pace with increased usage on the part of older adults (Romanow, 2002).<sup>1</sup> Armstrong and Armstrong (2004) argue that this shift coincided with the continued and progressive reduction in social welfare programs across Canada, including more restrictive criteria for those programs that remained. In order to compensate for the reduction in formal health care provision, the Canadian government began to heavily promote the idea of care in the community. Specifically, there was a move to transfer a portion of health care from the public sector to the private sphere of the home. In a discussion paper prepared for the Canadian Policy Research Network, Fast and Keating (2000: 20) concluded that the steps taken towards community-based care have not been met with the resources to sustain it. The care of aging family members, friends and neighbours

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<sup>1</sup> The same trend has been noted in other developed countries, such as the United States (Swanberg, 2006).

(FFN) has been placed in the hands of unpaid caregivers, also referred to as informal caregivers (Rathge and Clemenson, 2002).<sup>2</sup> In this research care is used in a broad sense to include all mental, emotional and physical efforts involved in responding to the needs of an aging FFN that they cannot meet themselves, due to frailty, illness or other impairments.

The challenges associated with providing unpaid care for an FFN has been well documented in North America (Kim, et al., 2012; Carretero, Garce's, and Ro' denas, 2007; Fast et al., 2005; Gallagher-Thompson et al., 2000; Zarit, 2002). For example, in a longitudinal study on breast cancer patients and their primary caregivers, Grunfeld et al. (2004) found that there are significant psychological, occupational and economic burdens associated with caregiving, which dramatically increase closer to time of death and as functional health declines. However, not all Canadians have been equally affected by the increased reliance on informal caregivers. With a median age of 47.4, Canada's immigrant population is 10.1 years older than the Canadian-born population (Ferrao, 2011).<sup>3</sup> This is an important consideration, given that the 2011 National Household Survey results indicate that Canada now has 6,775,800 foreign-born residents, representing 20.6% of the Canadian population. Ontario is home to the largest percentage of immigrants with 53.3% (Statistics Canada, 2011). There is also an increasing proportion of racialized immigrants, due to shifts

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<sup>2</sup> See Appendix H for a list of acronyms frequently used in this dissertation, including FFN (family, friends and neighbours).

<sup>3</sup> Immigrant refers to a person who has immigrated to Canada either a long time ago or recently. Included in this definition are people who have, or have ever had, landed immigrant or permanent resident status in Canada (Region of Waterloo Immigration Partnership's Community Action Plan, 2014). This definition is consistent with Health Canada reports, which classify immigrants as persons born outside of Canada, but who have been granted the right to live permanently in Canada (Kinnon, 1999). Immigrants who entered Canada between 1975 and 2011 were the group researched in this thesis.

in immigration patterns to Canada from Western Europe to East and South Asia.<sup>4</sup> With an older population compared to those who are Canadian-born, services designed to support informal caregivers and their aging FFN must include immigrants. This claim is consistent with a policy commitment made by the Canadian federal government through the official Multiculturalism Act adopted in 1971 and passed into law in 1988.<sup>5</sup> The policy dictates that the federal government must make policy decisions that are in line with enhancing multiculturalism in a way that preserves and promotes cultural diversity and equality at the institutional level and reduces discrimination (Library of Parliament, 2010). Separate from official Multiculturalism policy at the federal level is Multiculturalism policy at the provincial level. Most provincial governments, including Ontario, have some Multiculturalism policies or legislation. Included in Ontario's Multicultural policy commitments is the recognition of a pluralistic society that stresses full and equal participation of all Ontarians (Library of Parliament, 2010). These policies commit the Canadian federal government and Ontario provincial government to develop and implement programs that address the needs of immigrant informal caregivers. Sociologists have noted that Canada's commitment to Multiculturalism policy has become a significant part of Canadian identity itself (Satzewich, 2006).

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<sup>4</sup> Lai (2010) notes that Canada's proportion of racialized minorities increased from 8.8% in 1991 to 13.4% in 2001. According to Statistics Canada (2003) visible minorities, which is used in place of racialized minorities, is a term used to describe "persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour."

<sup>5</sup> Since its creation, Official Multiculturalism in Canada has passed through a number of phases. While the fundamental principles of the policy have remained relatively stable there have been a number of different policy priorities (Satzewich, 2007).

And yet, despite these well intentioned initiatives, immigrants in Ontario continue to face unequal access to a range of needed supports and resources. There is a stark contrast between good intentions and the harsh realities faced by immigrants, including immigrant informal caregivers. I was drawn to understand the needs of immigrant informal caregivers through my own personal experiences. In 2008, I was part of the project *Communities Working together against Hate Crimes* with Dr. Alicja Muszynski at the University of Waterloo, which was designed to address hate crimes against the African community in the Region of Waterloo. Through my involvement in this project, I saw that African immigrant women and their families face a number of difficulties in accessing required settlement resources, including access to adequate housing, suitable employment and health care. This realization formed the basis of my Master's thesis, which explored the settlement support needs of African immigrant women in the Region of Waterloo. Although informal caregiving was not my primary focus, I found that many of the women I interviewed were providing informal care for an aging FFN. Associated health care costs had a considerable impact on the ability of these women to become economically self sufficient. For example, several of the women had a difficult time balancing paid work with caring for an aging FFN because they could not find suitable home care support, as a result of the care receiver's language barrier.<sup>6</sup>

Upon completing my Master's thesis in 2009, I continued working with immigrant women through my involvement with several local non-profit organizations, including World

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<sup>6</sup> Home care in Canada includes a range of services provided in the home, including health promotion, curative interventions, rehabilitation, general support and health maintenance and support for informal caregivers (Canadian Home Care Association, 2011). Hogenbirk, Pong, and Lemieux (2005) identify four main types of home care in Ontario, including acute care, chronic care, preventative care, and palliative care.

Wide Opportunities for Women, the Canadian Council of Muslim Women, African Women's Alliance of Waterloo Region, and the Kitchener-Waterloo Social Planning Council. I saw a larger pattern around caregiving emerge and I began to collect anecdotal evidence indicating that many of the existing supports for those caring for aging FFN in Ontario, such as home care, day programming and long-term care facilities, do not match the conflicting cultural expectations of care held by many immigrant women.<sup>7</sup> All of my experiences began to draw my attention to the fact that multiple categories of difference, including immigration status, ethnicity<sup>8</sup>, class<sup>9</sup>, culture<sup>10</sup> and gender impact the suitability of caregiver support resources, including direct care support and financial supports, which will be discussed at more length in chapter four.

## **1.2 Thesis Statement and Research Questions**

This dissertation develops the thesis that, due to their multiple marginalities as gendered and racialized newcomers, immigrant informal caregivers lack needed resources in caring for aging FFN. Feminist theories related to caregiving alongside intersectionality

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<sup>7</sup> Long-term residential care facilities are designed to provide needed medical or nursing care for patients who are unable to remain at home, but who do not require hospital care. These facilities are intended to provide a viable alternative to informal caregivers who feel that they are unable to provide the required care to their sick or aging FFN, or for those who have no informal caregivers to turn to for needed care.

<sup>8</sup> According to Pinquart and Sorensen (2005: 91) ethnicity is a multifaceted concept. "Ethnic or ethnocultural groups are distinguished on the basis of a common history, a unique language or communication system, group-held values and beliefs as well as normative expectations and attendant customs and practices, the intergenerational transmission of these shared values, and a common locale or country of origin." Fleras also (2012: 117) argues that ethnic identity is rooted in a sense of belonging within a particular ethnic group.

<sup>9</sup> Although I acknowledge that class is a multifaceted concept, for the purpose of this research household income is used as a rough determinant of class status because it is tied closely to the ability to pay for costs associated with caring for an aging FFN.

<sup>10</sup> Culture is a set of shared values, meanings, rituals and overall world view (Krakauer, Crenner and Fox, 2002: 184).

theories are applied to highlight differences (like race, class, ethnicity and gender) that remain invisible. In order to support this argument interviews were conducted with formal and informal caregivers of aging immigrants in Southern Ontario. The theoretical framework was operationalized by the use of three research questions.

1. What challenges in managing care are faced by informal caregivers in Southern Ontario?
2. What challenges in managing care are unique to immigrant informal caregivers in Southern Ontario?
3. What challenges do home care and long-term care facility staff in Southern Ontario face in addressing the needs of aging immigrants and their caregivers?

The first two research questions help to establish the challenges that are shared by all informal caregivers in Southern Ontario, in order to then outline what challenges are unique to immigrant informal caregivers. Interviews were conducted with 25 caregivers living in Southern Ontario, including five Canadian-born caregivers and 20 immigrant caregivers. I interviewed immigrant caregivers from a wide variety of class, ethnic, race and cultural backgrounds.<sup>11</sup> For the purpose of this research, only high intensity informal immigrant and Canadian-born caregivers were interviewed. A high intensity caregiver is one who provides four hours or more of care per week (Pyper, 2006). This ensures that only those informal caregivers directly involved in the care are included, rather than including people who simply provide minimal direct care, or only financial assistance. The third research question investigates the challenges faced by paid health care providers in accommodating the needs of aging immigrants and their informal caregivers. Interviews were conducted with 17 management and support staff involved in formal health care for older adults, including four

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<sup>11</sup> In this study the term race is not used to describe a static physical category. I use it to refer to a socially constructed racialization. Tang and Browne (2008: 113) define racialization as a process where certain behavioural patterns become associated with physical characteristics, such as skin colour, in a specific historical and social context.

management and six support staff at three mainstream long-term care facilities, and one management and two support staff at a designated multicultural facility in Southern Ontario.<sup>12</sup> In addition, interviews were conducted with one manager from a Muslim senior's centre, one manager at a Community Care Access Centre (CCAC), and two support staff contracted through a CCAC in Southern Ontario.

This dissertation makes an important empirical contribution to the sociology of care by taking a two pronged approach that explores both the private (informal care in the home) and public spheres (formal funded home care and long-term care facilities) involved in the care for older adults in Southern Ontario. It provides needed information about the impact of downloading care previously provided by formal health care services in Ontario to unpaid informal caregivers, in the context of a rapidly aging and increasingly diverse society. It offers a fuller understanding of the barriers and challenges faced by informal caregivers in Southern Ontario and unique to immigrant informal caregivers through the analysis of qualitative data. Luh (2003) argues that there is a pressing need for more qualitative research that helps to better understand the needs of ethnic older adults and their caregivers by applying appropriate theoretical frameworks. The Canadian National Advisory Council on Aging (2005) claims that filling in the gap in knowledge about immigrant informal caregivers is the next logical step for research on informal care because acknowledging the experiences of immigrants will help to facilitate a well-rounded health care platform. Much of the research on immigrant caregivers in Canada has focused on immigrants as a uniform category or it has focused on one group of immigrants in particular. For example, Neufeld et

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<sup>12</sup> I use the word mainstream to refer to conventional long-term care facilities created to meet the needs of the dominant Canadian culture.



al. (2002) conducted an ethnographic study that explored the barriers faced by Chinese and South Asian informal caregivers in accessing community supports in Alberta, Canada.

Pillemer, Suitor, and Wethington (2003) argue there is a critical need for more theoretically based sociological research on health care support and delivery for older adults. This is particularly the case for research involving informal caregiving for immigrants. After conducting a review of research completed from 1980-2000 on informal caregiving among diverse groups, with specific attention given to race, ethnicity and culture, Dilworth-Anderson, Williams and Gibson (2002) concluded that the wide use of non-theoretical approaches in previous studies limits the understanding of caregiving and caregiver experiences among diverse groups. Previous studies that have made use of a conceptual or theoretical framework have often omitted a discussion of diversity. Dilworth et al. (2002) list several approaches, including the structural model of caregiving dynamics, choice and social exchange theory and the hierarchical compensatory model as examples. Because research indicates that there are differences in the experiences of immigrant caregivers based on variables like culture, Dilworth et al. (2002) argue that in order to be useful a theoretical approach should take the unique social locations of diverse caregivers into account. The cultural competency approach has been used repeatedly in health research on aging immigrants, but this approach is limited because it originated as a clinical assessment tool rather than as a broader conceptual framework (Purnell, 2002). While it may be useful for understanding the provision of formal health care in the public sphere, it is not as applicable to informal care in the home. In addition, Jiwani (2001) argues that research focused on developing culturally competent health care tends to focus on culture to the exclusion of a larger structural analysis. A context driven analysis is important because the provision of

health care is built on a foundation that privileges white middle class men. I use a theoretical framework that combines feminist theorizing related to caregiving and intersectionality theory in order to provide a solid framework that acknowledges the impact of factors like race, class, gender and ethnicity on informal and formal care for older immigrants. The two theoretical strands work in tandem and offer strengths that address each other's weaknesses.

Feminist theorizing on care is a necessary theoretical starting point for understanding the structure of care for older adults. It can be used to explain how and why caregiving is gendered in Canada. Specifically, both formal and informal care for older adults continues to be disproportionately shouldered by women. Moreover, when taking on the role of informal caregiver, women face a greater burden. For example, research conducted by Waliser-Navaie, Spriggs, and Feldman (2002 ) found that in addition to being more likely to act as primary caregivers, women are more likely to care for aging FFN in poorer health, to complete more complex health care tasks, to experience greater difficulty in completing required care tasks, and to access less formal support resources. Several factors can explain these differences, including the implicit assumption that underlies policies adopted by the federal and provincial governments that women are more able to provide informal care without requiring substantial formal care support. For the purpose of this research, intersectionality theories complement feminist theorizing on care by taking on a multidimensional approach to identify the caregiver support needs unique to immigrant informal caregivers, as well as the responses of formal supports like mainstream long-term care facilities in Southern Ontario. Intersectionality theories are grounded in the assumption that various categories of difference, such as race, class, gender, culture and ethnicity intersect and interact to create unique experiences of marginalization or

empowerment.<sup>13</sup> As one of the pioneering scholars in intersectionality theories, Kimberlé Crenshaw (1991) argues that a multidimensional approach is necessary to understand the lives of racialized women in particular because multiple systems of oppression, such as racism and sexism, work together to create realities that cannot be understood by looking at each experience separately. In addition, intersectionality theories are more responsive to complex realities because they acknowledge that groups typically thought of as marginalized, such as racialized women, are capable of exercising autonomy and power, depending upon context and other intersecting variables. They problematize the tendency to simplify multidimensional realities. A multidimensional analysis of care for aging immigrants connects lived experiences to larger social patterns.

### **1.3 Relevant Research of Health Care Provision for Older and Immigrant Adults**

The following is an overview of the relevant data and empirical studies related to formal and informal care for older adults to provide a contextual background for this thesis. Figure one outlines how health care is funded and organized in Ontario. The Canadian constitution provides provinces and territories with the authority to regulate health care.<sup>14</sup> However, there is some consistency in health care between the provinces and territories in Canada, largely due to the Canada Health Transfer provided by the Canadian Federal Government. In order to receive these transfers, each provincial government must adhere to certain regulations and requirements outlined in the Canada Health Act (Ministry of Health

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<sup>13</sup> Marginalization refers to groups/persons who are excluded from access to resources, privilege and power (Van Herk, Smith, and Andrew, 2011).

<sup>14</sup> In Ontario, health care falls under the jurisdiction of the Ontario Ministry of Health and Long-term Care.

and Long-term Care, 2008).<sup>15</sup> In Ontario, health care is largely planned and administered by 14 local health integration networks (LHINs).<sup>16</sup> LHINs allocate funding to community support services, long-term care facilities and the 14 Community Care Access Centres (CCAC).<sup>17</sup> CCACs are responsible for the provision of home care services in Ontario.<sup>18</sup> The primary duty of CCACs is to assess client eligibility for professional and non-professional services.<sup>19</sup> In addition, CCACs authorize the entry of clients into long-term care facilities, which are regulated through the Ontario Long-term Care Act (Ontario Ministry of Health and Long-term Care, 2013).<sup>20</sup> Specific regulations listed under the Long-term Care Act will be discussed at greater length in chapter five. Informal caregivers and care receivers can access funded home care and day programming or enter a long-term care facility if they are deemed to be eligible through a CCAC assessment. Long-term care facilities are paid for jointly by the ministry and the resident.

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<sup>15</sup> This includes the prohibiting of extra billing and user charges for insured services, and adherence to five main health care principles (public administration, comprehensiveness, universality, portability and accessibility). Health care programs and supports continue to differ between provinces as these principles are open to interpretation. For example, accessibility ensures “reasonable access to health care facilities”, which may not be defined in a uniform way.

<sup>16</sup> LHINs were created in March, 2006 based on a community care model that presumes health care administration should be rooted in the needs of the community.

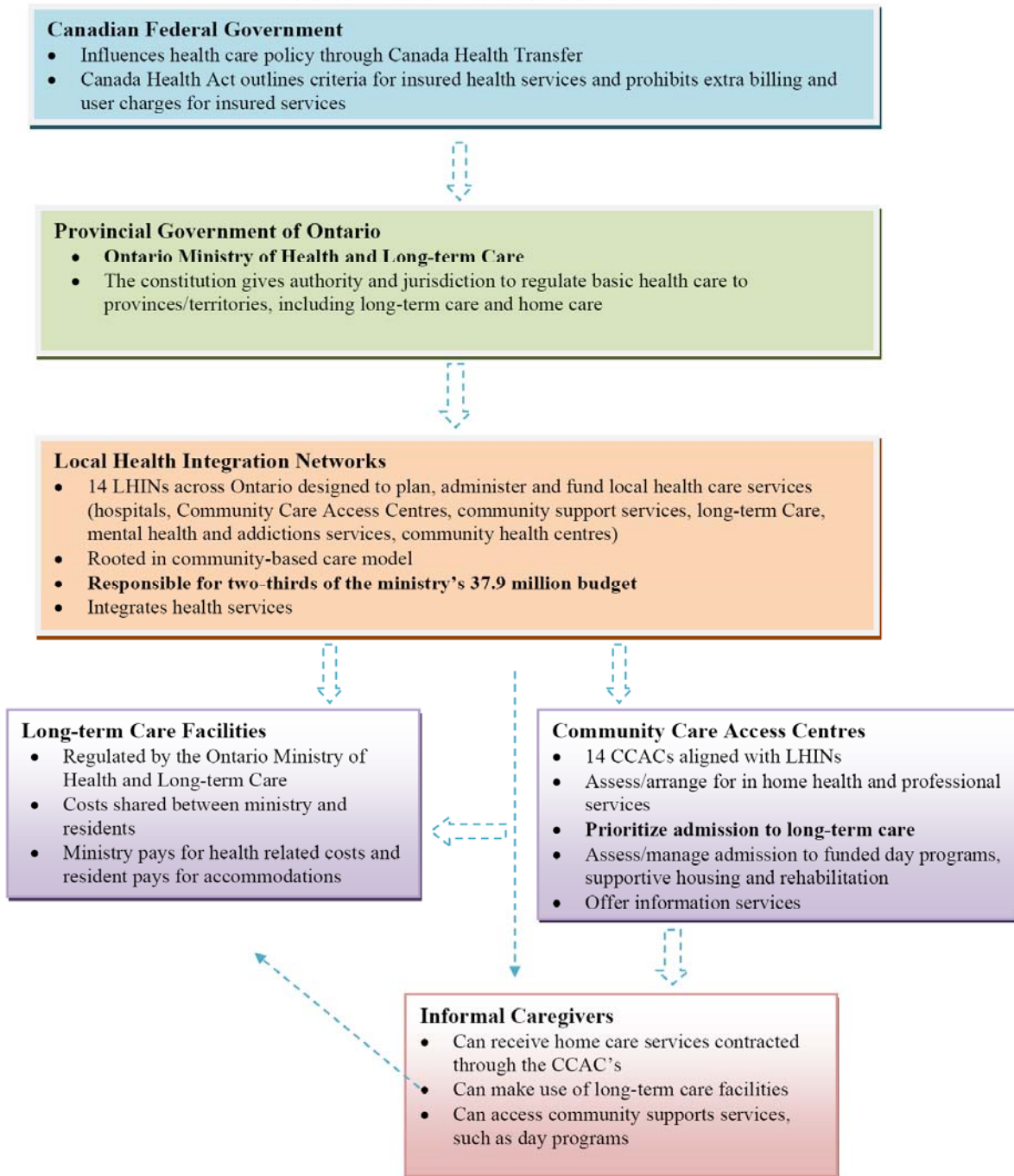
<sup>17</sup> Each CCAC is aligned geographically to one of the LHINs.

<sup>18</sup> The CCAC subcontracts with private home care companies, such as the Red Cross, rather than providing direct home care services.

<sup>19</sup> Professional services include nursing, occupational therapy, physiotherapy, speech language pathology, dietetics and social work. Non-professional services include the assistance of PSWs, who assist with activities of daily living such as bathing and meal preparation.

<sup>20</sup> Services provided through the CCAC are designed to reduce the use of long-term care facilities and limit the amount of time spent in hospital (Ministry of Health and Long-term Care, 2010).

**Figure 1: Health Care Administration in Ontario**



Source: Ontario Ministry of Health and Long-Term Care, 2008

There are over 327,670 Canadians who live in long-term care facilities, with 110,000 Canadians living in facilities that provide 24 hour care and constant medical supervision (Canadian Institute for Health Information, 2005). In Ontario alone there are 634 long-term care facilities, which can hold 77,783 residents (Alzheimer's Society of Ontario, 2013). Long-term care has traditionally been, and continues to be, used predominantly by older adults. Facilities designed specifically for older adults account for 77% of long-term residential care beds across Canada (Canadian Institute for Health Information, 2005). However, the number of Canadians who are in long-term care settings has begun to decrease. The percentage of older Canadians living in long-term care facilities fell to 14% in 2001, which was a 3% decrease from 17% in 1981. Part of the decrease in rates of use for long-term care facilities can be attributed to rising costs, which is in-line with the overall push on the part of the Ontario provincial government to privatize certain aspects of health care and encourage more informal care in the home. In 2004, only 73% of spending on long-term care came from a public source in Canada, leaving the other 27% to private sources. A majority of the remaining 27% came from out-of-pocket spending by the individual receiving care, or their caregiver. The typical cost of long-term care accommodations in Ontario is \$49 per day in a publicly funded facility (Canadian Institute for Health Information, 2005).

Researchers have also found that for-profit facilities fare worse on almost all quality indicators used compared to non-profit long-term care facilities. For example, Hillmer et al. (2005) conducted a critical review of literature published between 1990-2002 comparing the quality of care received in for-profit versus non-profit long-term care facilities in Canada and the United States and found that for-profit facilities are associated with deficiencies in resident care. The quality indicators used included the inappropriate use of restraints, rate of

mortality, infections, and dehydration of residents. Given these findings, non-profit facilities appear to be a better option. However, where space is scarce there are few options available for choosing a facility that best serves the client's needs. In Ontario 57% of long-term care homes are run by for-profit operators (Alzheimer's Society of Ontario, 2013). A discussion of non-profit and for-profit facilities will be picked up again in chapter five.

Despite the fact that there is a large number of Canadians on waiting lists, living in long-term care facilities is not in line with the wishes of most older Canadians. For example, research shows that 58% of older adults who require care prefer to be cared for at home (Eckert, Morgan and Swamy, 2004) and 86% of Canadians prefer to die at home (Canadian Hospice Palliative Care Association, 2008). Many older Canadians living in long-term care suffer mental illnesses, including depression. According to the Canadian Institute for Health Research (2012), the estimated prevalence rate of major depression among long-term care residents is approximately 44%. In a study conducted with approximately 50,000 long-term care facility residents across Canada, Hall (2010) reported similar findings. Hall concluded that the high rates of depression are attributable to a number of factors, including general unhappiness with personal surroundings and living conditions. The dissatisfaction with long-term care facilities may be even greater for immigrants. Luh (2003) found that staff in mainstream long-term care facilities in Ontario were unable to meet the needs of diverse older adults, including an inability to offer linguistically and culturally appropriate services. Due to the fact that there are fewer immigrants living in long-term care facilities in Canada, particularly among racialized immigrants, a related barrier is the loss of community and ethnic identity. This calls attention to the importance of maintaining ties to ethnic communities even after entry into long-term care. The National Advisory Council on Aging

in Canada (2005) also found that certain immigrant groups experience a sense of rejection and shame after entering long-term care when it conflicts with cultural expectations of care. Contradictory cultural expectations may make adjusting to long-term care more difficult for certain ethnic older adults compared to those who are Canadian-born. In the face of these difficulties, Koehn (2009) argues that long-term care facilities in Canada may not be doing enough to address the needs of immigrants. Older immigrants are often neglected in research and policy on long-term care because of the assumption that they do not use long-term care facilities, which has led to a gap in long-term care planning.

Long-term care facilities catering to the needs of immigrants from select ethnic minority groups (designated multicultural facilities) have begun to emerge slowly in Canada in response to the growing need for equitable access to quality care.<sup>21</sup> Unlike the mainstream long-term care facilities in Canada geared towards white Canadian-born residents, these facilities are designed to meet the needs of a specific ethnic community. For example, Yee Hong Centre for Geriatric Care in Mississauga, Ontario, has recreational activities, religious services and food intended to meet the needs of Chinese and Filipino residents (Yee Hong Centre for Geriatric Care, 2012).<sup>22</sup> Designated multicultural facilities like Yee Hong appear to be successful in providing superior care to ethnic older adults. Internal reports completed by Yee Hong indicate that the rates of depression and weight loss

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<sup>21</sup> Currently, these designated multicultural facilities mainly serve Chinese and South Asian communities (Gorham, 2012).

<sup>22</sup> The Yee Hong Centre for Geriatric Care has four long-term care facilities in the Greater Toronto Area, including two facilities in Scarborough, one in Mississauga, and one located in Markham. The centre originally opened in October, 1994 under the direction of Dr. Wong and 30 other Chinese Canadian community members living in the GTA. The centre continues to offer suitable and accessible care to Chinese Canadians, in addition to other identified groups such as Filipino Canadians.



among those living at the facility are well below the national average (Gorham, 2012).<sup>23</sup>

Designated long-term care facilities may be an important way to meet the evolving needs of aging immigrants in Southern Ontario.

In lieu of the use of formal long-term care facilities, many older adults and their caregivers rely on formal home care support. According to the Law Commission of Canada (2009), in 2006 659,000 people received home care in Ontario. Of this number 58% were over the age of 65. The demand for home care is growing rapidly as the population ages. From 1997 to 2007 the number of recipients of home care grew by 51% (Canadian Home Care Association, 2011). The use of formal home care support is often promoted by health policy makers in Ontario as a viable alternative to long-term care or hospitalization. According to health researcher John Hirdes (2012), the shift to encouraging home care confirms that the government of Ontario recognizes the desire of most aging Canadians to be cared for at home. However, it may actually represent a progressive drive to push more care into the hands of informal caregivers. Home care costs are 40% to 75% the costs of long-term care (Hollander and Chappell, 2002). Research conducted by the Canadian Home Care Association (2011) found that those who do opt for formal home care for their aging FFN receive less assistance when the situation deteriorates. For example, hospitals are less likely to admit older adults who receive formal home care support. Consequently, many caregivers who access formal home care for their aging FFN are less likely to be able to access long-term care and hospitalization when home care becomes unsustainable.

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<sup>23</sup> 25% of residents show symptoms of clinical depression compared to approximately 44% at other long-term care facilities across Canada.

Caregivers in Canada report that the home care services available are insufficient. For example, the amount of personal support care is not enough and wait times to access formal home care are excessive (Maytree, 2010).<sup>24</sup> According to an audit of CCACs by the Auditor General of Ontario, 11 of the 14 CCACs have wait lists for home care services, which amount to 10,000 people waiting for home care services (Ontario Ministry of Health and Long-Term Care, 2013).<sup>25</sup> Assessment wait times alone can be up to 15 months. When home care services are approved, the Long-Term Care Act caps regular home care support at a maximum of 15 hours per week. A majority of informal caregivers report receiving much less formal home care for their FFN through the CCAC than they feel is necessary, and that care is generally rushed. Standards for home care vary between CCACs in Ontario. For example, one CCAC allotted 30-45 minutes per bath for clients, while another had established guidelines of 5-15 minutes per bath (Ontario Ministry of Health and Long-term Care, 2013).<sup>26</sup> Without sufficient levels of home care, many informal caregivers either provide care themselves or hire additional home care support privately. Hogenbirk, Pong and Lemieux (2005) estimate that 80% to 90% of care provided in the home for those who are frail, chronically ill or disabled in Ontario is not publicly funded. Even where home care itself is covered, there are many necessary assistive devices and services that are not. As Table 1 shows, the extra costs related to home care in Canada can quickly add up. For example, a registered nurse generally charges \$37 per hour. Based on a study from over two

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<sup>24</sup> Access to home care through CCACs is not guaranteed and may vary depending upon which CCACs jurisdiction a client falls under in Ontario. CCACs reject between 12% to 39% of requests for service provision (Ontario Ministry of Health and Long-term Care, 2013).

<sup>25</sup> Wait times range from an average of eight to 262 days depending on the service needed.

<sup>26</sup> Martin-Matthews (2007) argues that the vast majority of home care workers across Canada face unrealistic expectations for providing care in an unreasonably small allotted amount of time.

thousand Canadians, Coyte (2000) reports that 25% of home care clients and their caregivers spend \$407 per month on home care costs. While formal home care may represent a cost savings for the federal and provincial governments, it does not necessarily provide comprehensive support to informal caregivers and their aging FFN.

**Table 1: Average cost of assistive devices and supports for home care in Canada**

<b>Assistive device/support</b>	<b>Average cost</b>
Homecare beds	\$2,223
Physiotherapy assessment	\$48 per assessment
Physiotherapy session	\$39 per hour
Registered nurse	\$37 per hour
Registered nurse-special tasks	\$40 per hour
Registered nursing assistant	\$27 per hour
Orderly	\$17 per hour

Source: Canadian Institute for Health Information, 2005

An additional challenge to accessing suitable formal home care exists for immigrants who do not speak fluent English or French. According to Luhtanen (2009), CCACs do not offer the kind of help required for those with a language barrier. Even where informal caregivers who can speak English or French are available to help facilitate formal home care, the Canadian Research Network for Care in the Community (2011) argues that professional translators are preferable. Translation provided by an informal caregiver puts the quality of care at risk for a number of reasons. Informal translation represents a breach in patient confidentiality, which may discourage clients from discussing all medical program or symptoms. Misleading translations can occur between home care providers and informal translators, which may compromise care. And requiring informal caregivers to translate may place additional stress that should otherwise be avoided during an already difficult time.

In consideration of the above challenges, the experiences of Canadian-born and immigrant informal caregivers are a growing concern in Canada. Approximately three

million people in Canada provide unpaid informal care for those who are frail, disabled, dying, or chronically ill, which amounts to one in ten Canadians (Ashpole and Cole, 2000). Beyond completing simple tasks, such as assistance with activities of daily living, informal caregivers often provide advanced medical care for FFN for a prolonged period of time (Earle and Heymann, 2011). Informal caregivers also make an important financial contribution to Canada's health care system. Stajduhar (2004) estimates that informal caregivers provide upwards of 85% of care in Canada, a total of \$25-26 billion dollars annually (Canadian Hospice Palliative Care Association, 2012). These numbers confirm the reliance of the Canadian government on private sources of care. While informal caregivers provide care to all age groups, older adults require a majority of the informal care in Canada. Overall, 66% of female caregivers and 64% of male caregivers provide care for someone who is over 65 years old, and the average care recipient is 66 years old (Waliser-Navaie, Spriggs and Feldman, 2002). According to the Canadian Institute for Health Information (2005), approximately one million older adults in Canada report receiving informal care from a FFN because of a long-term health problem. Moreover, caregivers of aging FFN in Canada report higher rates of physical and mental health problems compared to those caring for people of younger age groups (Earle and Heymann, 2011).<sup>27</sup>

While approximately 70% of caregivers in Canada work in the paid labour force (Pyper, 2006), only 22% are employed full time, which reduces access to financial support programs available to informal caregivers. For example, the Compassionate Care Benefits

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<sup>27</sup>Canadian studies show that between 40-70% of people caring for aging FFN exhibited symptoms of clinical depression with at least 25% having major depression (Earle and Heymann, 2011).

program, which will be discussed at more length in chapter four, is part of Canada's Employment Insurance Program. As a result, one of the eligibility requirements is 600 insured hours of work in the last 52 weeks (Service Canada, 2013). Many informal caregivers report that caregiving negatively impacts their paid work. Fast et al. (2013) found that 313,000 employed caregivers in Canada reduce their work hours because of caregiving duties, for a total of 2.2 million work hours lost each week. Many caregivers have a modest household income. In Ontario 37% of informal caregivers have an annual household income of \$20,000- \$49,000 (Hogenbirk, Pong and Lemieux, 2005). As a result of taking on informal caregiving roles for aging FFN, many Canadians are part of what researchers have come to refer to as the "sandwich generation" (Williams, 2005). The term "sandwich generation" is generally used to describe those in the middle-aged adult group who are caught between the conflicting demands of multiple caregiving roles and other demands, such as paid work. Most informal caregivers in Canada fall in the middle-age range, with 71% between the ages of 45 and 64 (Pyper, 2006). In Canada informal caregiving continues to be gendered with women taking on the majority of care, and performing more hands-on tasks inside the home. For example, 67% of the informal care that women provide takes the form of inside activities such as housekeeping, while men only spend 40% of their time on inside activities (Canadian Institute for Health Information, 2005). Women are also more likely to provide more complex medical care, including dressing changes and assistance with medical equipment, such as catheters (Waliser-Navaie, Spriggs and Feldman, 2002).

Immigrant informal caregivers from certain backgrounds are likely to feel a greater sense of obligation to care for aging FFN than those who are Canadian-born. This sense of obligation also appears to be gendered in many cases. For example, according to Korean

cultural standards, the oldest son (and his wife) is expected to provide his parents with a comfortable living environment during their old age. As a result, there is a higher percentage of daughter-in-law caregivers among those who are Korean-born compared to North American-born caregivers (Yoo, Jang and Choi).<sup>28</sup> After completing a content analysis of online support groups, Yoo et al. (2010) found that many Korean daughters-in-law suffer negative emotions because of caring for a mother-in-law. This is partly because of the fact that in Korea relationships between mother-in-laws and daughter-in-laws are expected to be a source of stress. Cultural conventions result in a lack of communication and appreciation between mother-in-laws and daughter-in-laws, which creates room for friction. Many Korean women experience self-focused anger and sadness because of caring for someone who is not emotionally close to them. The authors conclude that additional research is needed to understand the experiences of racialized immigrants caring for aging FFN.

There has been some research in Canada that addresses the experiences of immigrant caregivers. Stewart et al. (2006) did a study to determine the impact of Canadian immigration settlement services on immigrant women who were caregivers. Using qualitative interviews with women immigrant informal caregivers and service providers, they found that immigrant women informal caregivers face additional challenges in managing care as a result of insufficient support.<sup>29</sup> As part of the economic restructuring in the 1980's and 1990's, Canada's settlement services for immigrants were cut back. This has meant less

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<sup>28</sup> Yoo et al. (2010) note that 55% of unpaid caregivers in Korea caring for older adults with dementia are daughters-in-law compared to 8.6% in the United States.

<sup>29</sup> In total, 29 individual qualitative interviews were conducted with immigrant women informal caregivers. Two group interviews with seven of these women were then conducted, along with two group interviews with 15 service providers.

support from settlement services like skills and language training, coupled with the reduction in assistance provided by formal health care services as part of the progressive dismantling of the social safety net.

It is commonly believed that immigrant communities are bound more tightly to their aging FFN. However, according to the Canadian National Advisory Council on Aging (2005), it is misleading to presume that all immigrant families will be prepared to provide the needed care to older adults. “Idealizing ethnic families as being highly supportive is a mistake and creates the risk of neglecting the need of ethnic seniors for formal supports and community programs. To successfully reach this population group, community programs need to be designed to meet a diversity of interests and needs.” (Canadian National Advisory Council on Aging, 2005: 15) This assumption has resulted in a gap in public programming and support. Based on an ethnographic study of Chinese and South Asian immigrant women caring for ill or disabled family member, Neufeld et al (2002), found that, even for cultures that do share the belief that family members are natural caregivers, there are different levels of adherence to this expectation. Intervening factors can reduce the likelihood that a family member will assume the expected role of informal caregiver, including paid work. In addition, research conducted in the United States indicates that cultural expectations of providing informal care are negatively correlated with adapting to American culture. Upon completing a systematic review of literature on caregiving among ethnic communities in the United States, Knight et al. (2002) conclude that immigrants experience a decrease in dedication to caring for aging FFN after acculturation in the US because American culture is embedded in individualism. Those coming from cultures that emphasize collective good are more likely to view informal caregiving as an expected familial duty, whereas those from an

individualistic culture view caring for an aging FFN as an unwanted interference. Knight et al. (2002) found that commitment to community good decreases markedly for second generation immigrants, compared to first generation immigrants.<sup>30</sup> Similarly, Wong, Yoo and Stewart (2006) studied Chinese and Korean-born immigrants in the United States and found that these groups are increasingly bicultural after settlement. Bicultural identity was associated with a number of factors, including a shift in the economic environment, increased independence and separation from extended family members<sup>31</sup>. All of these factors may reduce the likelihood of taking on the role of primary informal caregiver for an aging FFN.

Moreover, the idea that immigrants routinely take on primary care for an aging FFN, even in their home countries, is misguided. For example, Gupta (1999) notes that care for aging FFN in South Asian countries is frequently divided among several family members, and that hired help is more affordable and available. It is only outside of their homeland that a majority of South Asian nuclear families provide primary care for aging FFN. Gupta (1999) identifies one of the main factors in immigrant caregiver burden as a perceived lack of alternative resources to provide care for an aging FFN. While this particular burden may also exist for those who are Canadian-born, it is exaggerated for those who do not have access to culturally appropriate resources. Lai argues that formal health service providers should not see adherence to cultural expectations of care as a total solution, particularly as the population continues to age. “Without adequate support and tangible resources, the good

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<sup>30</sup> The research of Knight et al. (2002) focused on Latino informal caregivers.

<sup>31</sup> Most research regarding the impact of acculturation on caregiving has been conducted in the United States. As Canada has a unique culture and pattern of immigration, additional research specific to Canada is needed to draw a full comparison.



will of family caregivers will eventually burn out.” (Lai, 2010: 217) Support is urgently needed to address the needs of immigrant caregivers.

#### **1.4 Conclusion**

The research reviewed above demonstrates the following problems. First there is a gender gap in caregiving among those who are Canadian-born and immigrant groups. Specifically, research confirms that women continue to provide a majority of the needed unpaid care to aging FFN (Yoo, Jang and Choi, 2010; Canadian Institute for Health Information, 2005; and Waliser-Navaie, Spriggs and Feldman, 2002). Second, according to Lai (2010), the Canadian National Advisory Council on Aging (2005), Pillemer, Suitor and Wethington (2003), and Neufeld et al. (2002) existing research has not adequately addressed the experiences of immigrant informal caregivers. In addition, there is a lack of theoretical analysis in the research on immigrant informal caregivers (Anderson, 2000; and Dilworth-Anderson, Williams and Gibson, 2002). For this reason, chapter two explores feminist theories of caregiving and combines these with intersectionality theories in order to offer a theoretical framework that facilitates an understanding of the marginalities of differences. Chapter three contains an explanation of how qualitative methods were used in the data collection. Chapters four and five then provide a detailed analysis of the research data alongside an application of the theoretical framework developed in chapter two. Chapter six contains a general summary of the research findings and offers suggestions for future research.

## **Chapter 2: Theoretical Framework**

### **2.1 Feminist Theorizing of Caregiving as Women's Work**

In this chapter I demonstrate the theoretical framework that will be used to develop the thesis statement presented in chapter one, which is that, due to their multiple marginalities, immigrant informal caregivers lack needed resources in caring for aging FFN. I will focus on relevant feminist theorizing on formal and informal care, and intersectionality theories. I argue that feminist theorizing on formal and informal care helps to establish an understanding of the how and the why behind the structure of care for aging Canadians. In mainstream research and health policy planning, as noted in chapter one, caregiving is often discussed without addressing the gendered assumptions that underpin who is assigned the role, and how the role is supported. In addition, I argue that intersectionality theories offer the necessary tools for a multidimensional analysis to develop an understanding of the challenges faced by formal and informal caregivers in addressing the needs of aging immigrants.

Giving and receiving care is necessary for maintaining human existence. As Kittay, Jennings and Wasunna (2005: 443) state “people do not spring from the soil like mushrooms”. While few people would argue with this, it was not until the early 1970's that theorizing around caregiving in North America began to develop (Fisher and Tronto, 1990). Much of the initial research on caregiving was produced by feminist scholars (Andersson, 2012). Some of the first discussions related to caregiving grew around the domestic labour debate, which centred on the question of whether or not women's unpaid labour inside the

home could be considered productive, in a Marxist sense.<sup>32</sup> Through this debate, feminist scholars began to draw attention to the contribution of women's unpaid work in the home, and the value of that work to the economy. Feminist theorists argue that the contributions of women's unpaid labour became obscured with the emergence of the separation of the public sphere of the labour market from the private sphere of the home, a product of industrialization and the capitalist mode of production (Baines, Evans and Neysmith, 1991).

<sup>33</sup> This economic division is buttressed by an ideology of the (nuclear) family as the centre of loving support and care, which holds that the mother's primary responsibility is to provide total emotional and physical care to her family, with any paid work outside of the home being secondary.<sup>34</sup> According to the nuclear family model, women are biologically designed to be caregivers. Clow and Kemp (2012) maintain that policies that refer to "the family" as the main source of care for aging FFN are misleading because women continue to do the bulk of the caregiving in the family setting. A number of important questions

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<sup>32</sup> Marxist feminists argued that women's unpaid household labour was productive because it provided use value. The unpaid domestic labour done by middle class women was necessary for maintaining the capitalist mode of production. Women produced the next generation through reproduction and reproduced the working capacity of men in the paid labour force by taking care of their physical and emotional wellbeing (Curtis, 1980). In contrast, Marxist theorists argued that women's domestic labour was not productive because it did not produce exchange value. Labour has to be exchanged for a wage in order to produce surplus value. Women's unpaid domestic labour lacked exchange value because it was not sold for a wage like the labour power of men (Stelling, 1994).

<sup>33</sup> While a gendered division of labour was present in pre-industrial societies, men, women, and children all contributed to maintaining the family household. Wage labour obscured the role of middle class women in maintaining the capitalist mode of production because they continued to work in the home, while men's work shifted to the public sphere outside of the home. Middle class families began purchasing products that had formerly been produced in the home by women, while the man of the house brought home a wage that the whole family depended upon (Wilson, 1991).

<sup>34</sup> Under capitalism, the nuclear family model reduces the family to the smallest possible unit. The purpose of the (middle class) family in a capitalist system is to provide emotional support for the father, and guidance and training for children. This necessitates the participation of the father as an instrumental leader, while the mother acts as an expressive leader (Parsons and Bales, 1956).

emerged from the domestic labour debate, including whether or not women's unpaid domestic labour, including care for dependents, should be paid. And, if so, by whom (Vogel, 2000)? Several feminist theorists responded by arguing that the government should play a key role. For example, Blumenfeld and Mann (1980) argue that women's domestic labour should be remunerated by the state as a public responsibility funded through increased taxation.<sup>35</sup> The Government of Canada has taken several small steps in moving towards these recommendations, including offering a Caregiver Tax Credit for those caring for aging FFN, which will be discussed at greater length in chapter four.

By highlighting the historical development and importance of women's unpaid domestic labour, the domestic labour debate opens the door for politicizing the role of women as informal caregivers of aging FFN. Specifically, it offers a way of beginning to understand the political and economic structures in Canada as inseparably linked. According to Armstrong, Armstrong and Scott-Dixon (2008), political and economic structures determine the position of women in society, and consequently how resources are allocated between the private and public spheres. During the last four decades there has been a substantial increase in women's paid labour outside of the home because many families now require a double income.<sup>36</sup> Muszynski (1999) argues that this trend has not been accompanied by men increasing their amount of time spent on unpaid domestic labour in equal proportions. Consequently, in order to compensate for the disparity, previously unpaid

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<sup>35</sup> The idea of the government providing a wage to women as domestic labourers was also proposed by Evans (1991), who claimed that a homemaker's pension would allow women to dedicate themselves to care for young children and aging adults.

<sup>36</sup> According to Ferrao (2011), from 1976 to 2009, the employment rate of women with children under the age of 16 living at home increased by over 33% (from 39.1% in 1976 to 72.9% in 2009).

care work has been shifted into the public sphere. Mahon (2006) refers to this trend as “defamilialization”. While Mahon’s research explores the new demands placed on the state in terms of child care, this is also the case for the care of older Canadians, which has been partially taken over by the health care industry.

According to Armstrong, Armstrong and Scott-Dixon (2008) nearly 10% of Canadians are employed in the health service industry, and more than 80% of those working in caregiving industries (health and social care) are women.<sup>37</sup> While this change shows a willingness to pay women for the care they provide, women’s status as paid caregivers is *also* tenuous. Baines, Evans and Neysmith (1991) argue that women’s care work is undervalued, no matter what sphere it occurs in. For example, nursing is subject to frequent changes, such as layoffs and changing regulations around the provision of care, because it is seen as an extension of women’s unpaid caregiving, and thus lacking advanced skill. As a result of the extensive government cutbacks in the 1990’s, Canadian nurses face precarious working conditions such as increased workloads, part time and contract work, and extensive layoffs (Hornosty and Wicks, 2012). By and large, the continued downsizing of nursing as a profession has met with little resistance from the majority of Canadians. This is arguably due to the fact that “the family” model remains strongly intact. Caregiving is seen as a natural role for women in “the family”. If women are naturally inclined to be caregivers, it makes little difference whether or not they perform these duties in a paid or an unpaid setting. Reliance on “the family” model ensures that the government can depend upon women to

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<sup>37</sup> The gendered division of labour holds strong within the health service industry with women taking on the majority of low paying jobs considered to be less skilled , such as personal support workers (PSWs) and registered practical nurses (RPNs) , while men are overrepresented as specialist physicians. For example, over 90% of the PSWs employed in long-term care facilities in Canada are women (Seeley, 2012).

provide care for aging FFN with little remuneration, even if women are not prepared to take on the responsibility.

Developing alongside the domestic labour debate was feminist scholarship that theorized caregiving as an extension of motherhood. Though not directly related to care for aging FFN, this body of literature makes an important contribution to understanding the socialization of women as caregivers. For example, Shulamith Firestone and Ann Oakley claim that motherhood is limiting to a woman's development because women are socialized into becoming self-sacrificing mothers. Firestone (1970) argues that the only way to escape the subordination that results from motherhood is through the development of advanced reproductive technologies that free women from the biological constraints of child bearing.<sup>38</sup>

While agreeing that the ideology of motherhood is limiting for women, Adrienne Rich argues that biological motherhood in itself is not the problem. Caring does not necessarily create dependency, but rather the institutionalization of motherhood creates dependency (Rich, 1977).<sup>39</sup> By this Rich means that the ideology of motherhood, which extends to caregiving in all its forms, including care for aging FFN, assumes that women are nurturing and caring because of their biological makeup. Because caregiving is associated with nurturing as a biological fact, it follows that women need not receive compensation for tasks that are biologically given. According to Rich, this assumption is the crux of a mother's subordinate status.

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<sup>38</sup> She argues that the liberation of women will never be achieved as long as natural reproduction is the norm.

<sup>39</sup> In order for women to be empowered, they must retain control over their own bodies, including having a say in the care of their children (Rich, 1979).

Rather than focusing on how women should overcome the limitations associated with motherhood, feminist scholars relying on psychoanalytic research sought to understand why motherhood, and caregiving more generally, took on its current form. Dinnerstein (1977) approaches this question with the belief that gender is achieved through psycho-sexual development, not through biological endowment. She argues that motherhood is shaped by how women conceive of themselves.<sup>40</sup> Unlike Dinnerstein, Chodorow (1978) used a psychoanalytic approach to explain *why* women choose to become mothers even though they know that this role will result in subordination.<sup>41</sup> Stemming from this line of inquiry, feminist theorizing began to frame care more in terms of its ethical implications. Feminists working from an ethic of care focus theoretical critiques on the devalued position that caregiving has in Western societies. For example, Carol Gilligan and Nel Nodding draw attention to an ethic of care that is specific to women (Gilligan, 1982; Nodding, 1984). Carol Gilligan's (1982) seminal book *In a Different Voice* challenges the misconception that women are less moral than men by asserting that women simply have a *different* moral orientation.<sup>42</sup> According to Gilligan, a man's moral orientation is directed towards

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<sup>40</sup> As the primary caregiver, the mother is the centre of an infant's universe and represents the source of all pain and pleasure. Men seek to control women in order to avoid experiencing the same sense of powerlessness in later intimate relationships, while women seek to give up control to men to avoid inflicting the same pain on others that their mothers inflicted upon them. Women willingly relinquish their power to men, which further perpetuate the negative psychological representations of women as mothers.

<sup>41</sup> According to Chodorow (1978: 107), the infant boy is aware that his body is not the same as his mother's, which causes him to distance himself from her. On the other hand, the infant girl is aware that she and her mother share the same basic physical makeup, which results in "prolonged symbiosis". A girl's close relationship with her mother restricts her from seeking her own independence as an adult woman. Becoming a mother is an extension of a woman's need to weave her life with that of another as an adult.

<sup>42</sup> Gilligan was a student of developmental psychologist Lawrence Kohlberg, who greatly influenced her ideas of moral reasoning. At the time that Gilligan published *In a Different Voice*, Kohlberg's (1971) scale of moral development was considered one of the most influential in moral development theory. Kohlberg's (1971) theory of moral development consisted of six stages. The highest level of moral development was based on internalizing universal principles of justice. Using Kohlberg's scale of moral development, women were

restricting behaviour that would impinge on other individuals' basic rights; an "ethic of justice". A woman's moral orientation is directed towards a responsibility to care for others and the self; an "ethic of care".<sup>43</sup> Gilligan concludes that women are better equipped to provide care than men because of a better developed "ethic of care" (Gilligan, 1982). She does not see women's caregiving roles as problematic. Rather she questions the focus on objective, dispassionate and rational thinking as the only path to morality. Gilligan argues that by refusing to recognize an ethic of care, parents and educators devalue women's moral development.

Unlike Gilligan, Nodding argues that women are as adept as men at applying an ethic of justice. But, unlike men, women are not socialized to develop an ethic of justice. Women are socialized to develop a moral orientation based in caring for others and being cared for (Nodding, 1984).<sup>44</sup> Her analysis contributes to a more complete explanation of why women, in general, appear to be more inclined than men to provide care to others. Like Gilligan, Nodding argues that children should be taught how to develop an ethic of care. Using the work of Gilligan and Nodding, Lisa Bass (2009) argues that an ethic of care is a powerful

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routinely rated as being less ethical than men. Women and girls rarely achieve the highest level of moral development based on Kohlberg's scale.

<sup>43</sup> Gilligan (1982) traces three levels of moral reasoning based on an ethic of care. First, individuals show great concern for themselves (overemphasizing personal interest); second, individuals begin to show great concern for others (overemphasizing the interests of others); and third, individuals are able to find a balance between concern for self and concern for others.

<sup>44</sup> People want to care for others because they innately see the caring relationship as a good in and of itself. Both young boys and girls are oriented towards a morality that seeks to maintain the caring relationship through reciprocal caring (Nodding, 1984). For example, a child may help a parent with household chores because he or she wants to be connected to the parent. In later life, the natural inclination towards caring may fade, but young men and women still remember the experience of caring and receiving care. Remembering the feelings of caring and being cared for translate the natural inclination of caring to an ethic of caring. "As a feeling---as an I must." (Nodding, 1984: 79) An ethic of caring is developed when wanting to provide care for another is replaced by feelings that one should provide care for another.



tool for pursuing social change because those who have an ethic of care will not be easily dissuaded from their cause. Care in and of itself would become a social good. If care was framed as a social good for the basis for health care policy development, funds could be redirected from other spending sources to ensure that those in need of care receive it. For those who provide informal care to FFN, additional programs could be created to support the care dynamic.

The above theoretical strands lay the groundwork for a specifically care-focused feminism. Care-focused feminists recognize care as both an attitude and a form of labour, and insist that caregiving should be performed in the private and public spheres. According to Tong (2009), Eva Feder Kittay is one of the most influential care-focused feminists. Kittay argues that caregivers do not necessarily have to be women, but within a male-dominated family structure the role is assigned predominantly by gender. For example, Andersson (2012) demonstrates that, even among paid care providers, gender is prioritized over relevant education or training. In *Love's Labour*, Kittay contextualizes care by situating it within the political debate between the left and right during the 1990's in North America. Kittay argues that the right intends to push for citizens with 'good' values to address poverty, while the left calls for the creation of jobs.<sup>45</sup> She takes issue with both sides, claiming that each base their argument on the individual male breadwinner model. Her main contention is that neither side

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<sup>45</sup> Kittay notes that the two policies typically advocated in North America to address poverty are residualism and behaviourism. Left wing residualists believe that there must be a line that no one is allowed to fall below. But residualism still assumes that there is something wrong with the beneficiary. Behaviourism argues explicitly that poverty is the fault of the individual and focuses on behavioural changes, such as work for welfare. Kittay (1999: 193) argues that both residualists and behaviourists are in agreement that not everyone can work (the ill) or is expected to work (the elderly). Single mothers were originally among those not expected to work, but this changed when women began to enter the work force. Kittay (1999) argues that those women who could not enter the work force were viewed as undeserving of assistance. Any persistent unemployment appeared to be unrelated to gender inequalities, or caregiving responsibilities.

acknowledges that the system relies on women's unpaid caregiving.<sup>46</sup> Mahon (2002) argues that the focus on creating equality of opportunity for paid labour over the life course overlooks the fact that women, particularly racialized and immigrant women, continue to take on the majority of non-standard work, such as part time work, in order to manage unpaid care work. Upper-middle class, white women also contribute to the devalued position of women as caregivers by decontextualizing their caregiving and focusing on promoting proper morality. Through this process, welfare programs become linked with notions of morality, which is translated into policies like home visits to monitor household cleanliness and caregiving practices. These types of policies demonstrate an absence of public recognition of care as a “good” in and of itself by framing some caregivers as unworthy of support. These policies often go unchallenged by the majority of women because they are consistent with an ethic of care, in that they promote the development of care as an important moral orientation. Kittay warns that for this reason it is very important to be cautious about how such an ethic of care is implemented. She suggests an alternative by focusing on creating policies that respect and support people caring for dependents, thereby appreciating care as an intrinsic “good”.

In contrast to other care-focused feminist theorists, for example Sara Ruddick (1995), who refer to the dynamic between the caregiver and the care receiver as “maternal relations”, Kittay develops the concept of “dependency relations” to avoid essentializing the caregiving role of women. A dependency worker can be either male or female so long as they provide the care needed for another’s survival. In *Love’s Labor* Kittay uses a personal narrative about caring for her disabled child to explore the experiences of caregivers. She argues that the

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<sup>46</sup> There is a connection here to care as a form of unpaid labour.

dependency of caregivers is structural, not inevitable, because proper supports implemented by the government would allow a caregiver to support him or herself while caregiving (Kittay, 1999).<sup>47</sup> Although she speaks from the perspective of an upper-middle class white woman, Kittay acknowledges that not all caregivers have the same access to resources and support. She argues that privileged white women are often exempt from the caregiver role because they are able to hire low income women of colour to take on these responsibilities. Within the past decade researchers have begun looking at how paid care work is structured for immigrant women in particular. For example, Browne and Braun (2008) study the policy implications of contracting long-term care workers from developing countries and conclude that the “feminization and colourization” of long-term care workers in North America is perpetuated through long-term care facilities that frequently hire new immigrants with low levels of education and limited English language proficiency in return for wages that amount to economic exploitation.

Kittay argues that appropriate support and compensation for caregivers of all backgrounds is needed in order for this work to be recognized and valued.<sup>48</sup> In the private sphere, a caregiver should receive the same support that other workers receive, including financial compensation and protective benefits. In the public sphere, paid caregivers should

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<sup>47</sup> The subordination of the dependency worker results from three characteristics that separate it from any other job. First, the dependent is helpless, which gives the dependency worker a moral obligation that extends beyond any other job. Second, being a dependency worker involves responsiveness and anticipation of the needs of the dependent, which requires an emotional attachment. Third, the dependency worker has to do whatever is required, rather than a set number of tasks, which often takes precedence over the needs of the dependency worker herself (Kittay, 1999).

<sup>48</sup> Kittay (1999) claims that the principle of care requires that three main assumptions be satisfied. First, dependents will receive the needed care. Second, dependency workers will get the support that they require to provide care to a dependent. Third, those who are dependent on dependency workers will still be cared for if the dependency worker becomes dependent him/herself.

receive more pay and better benefits. Kittay suggests that, rather than an act of charity, support for unpaid informal caregivers should be considered a form of mutual reciprocity.<sup>49</sup> The work of care-focused feminists helps to establish who is more likely to take on the caregiver role in Western societies and how working conditions associated with the caregiver role can be improved.

From the 1970's onward, feminist theorizing related to formal and informal care effectively drew attention to women's caregiving by exploring the economic, ideological, psychological and social underpinnings of care. However, alongside the debates and concepts outlined above, feminist theorists began to question whether or not existing research on caregiving applied to the lives of all women (Tong, 2009). Much of the theoretical research referred to the caregiving experiences of white, middle class women living in North America. For example, while Kittay acknowledged the disproportionate impact of caregiving on low income women of colour, her work assumes a shared experience for women from various backgrounds based on caregiving (Calixte, Johnson and Motapanyane, 2005). In other words, caregiving experiences are not uniform for all women, but rather mask inequalities based on structural factors like race and ethnicity.

## **2.2 Intersectionality Theories**

Intersectionality theories can be broadly defined as theories that explore how multiple systems of oppression, such as racism, classism and sexism, intersect and interact to create unique experiences of marginalization or empowerment. These theories emphasize the fact

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<sup>49</sup> Kittay (1999: 204) uses the concept of *doulia* to explain the need for reciprocity. *Doulia* means "just as we have required care to survive and thrive, so we need to provide conditions that allow others—including those who do the work of caring—to receive the care they need to survive and thrive." Kittay's concept of *doulia* allows caregivers to recognize and legitimate their own needs.

that categories of difference, such as ethnicity, race, class, and gender, are mutually reinforcing. In practice this means that the experiences of those with multiple marginalities cannot be understood by looking at each category of difference in isolation because categories of difference intersect, and operate within a specific social and historical context. For example, low income racialized women may experience caring for an aging FFN in a dramatically different way from middle class white women who have access to greater resources. While the incorporation of feminist theorizing related to care is a relevant starting point for this research, I extend it to include intersectionality theories in order to facilitate a more complete understanding of the invisible work of informal caregivers, particularly those caring for older immigrants, and the related lack of resources offered by formal health care services.

I use the plural form of intersectionality theory in order to acknowledge that intersectionality theories developed in the late 1980's as a response to a number of debates within feminist theory. Specifically, there were critiques offered by critical race theorists and socialist feminist theorists. Mann (2012) anchors these debates in the inadequacies found in social movements like the socialist movement and the civil rights movement that emerged from the cycle of protest of the 1960's and 1970's. While class and race were addressed, gender was noticeably absent from many discussions. At the same time, the feminist movement itself had not adequately addressed the experiences of women who fell outside of the white middle class norm. Mainstream liberal feminists claimed that women's issues could be dealt with through a policy agenda that focused on changes like creating more equitable access to managerial positions, affordable daycare and protection from sexual harassment (Levine-Rasky, 2011). But the problems facing racialized and low income

women were much different. For example, Aylward (2010) contends that racialized and low income women were fighting for issues like underemployment, inadequate housing, lack of social services and racism. Critical race feminists and socialist feminists argued against the notion that all women share similar experiences because of a “sisterhood”, and further claimed that a single-axis framework is unable to capture the complexity of lived experience for many women.

Since the early 1990’s intersectionality theories have quickly gained academic support. For example, scholars like Patricia Hill Collins (2000a) and bell hooks (2000) have applied an intersectional analysis to inform theoretically based academic research. Collins (2000a) argues that the traditional nuclear family in the United States helps to maintain a social system that is gendered and racist. She concludes that the family can serve as a site of resistance to the social structure by using intersectionality as a guide to challenge different forms of power that maintain the current hierarchy. Collins identifies four types of power that shape what she refers to as a “matrix of domination”, including a structural dimension that works through social institutions; a disciplinary dimension supported through government regulation and surveillance; a hegemonic dimension fostered through ideological control; and an interpersonal dimension operating through everyday social interactions (Collins, 2000b). Collins suggests that a critical incorporation of the perspectives of marginalized women can reveal how the matrix of domination operates to create diverse social realities that privilege some and disadvantage others.

The work of bell hooks is consistent with Collins in that she also argues that it is necessary to begin a theoretical analysis from the vantage point of marginalized women. In *From Margin to Centre* hooks argues that racialized women have been kept at the margins of

feminist analysis, which gives them a unique viewpoint. She uses her own experience living in a racially segregated town in Kentucky to explain this point. hooks contends that in such a social world, the survival of a Black woman depends upon being aware of informal and formal rules that perpetuate racism. Although Blacks must constantly negotiate the resulting social boundaries, whites remain naïve to life on the margins of society. Since mainstream feminist research is rooted in the perspectives of white middle class women, an analysis of the differences between life in the margins and the centre of society is absent. To correct this problem, hooks concludes that more research from the perspective of racialized women is needed. hooks studies the interactions of race, class, and gender, albeit with a focus on race as the main source of analysis. However, intersectionality theorists acknowledge that, depending upon the research focus, certain differences will have more salience than others. There may be certain circumstances where race will impact a person's life circumstances more than class status because it is more visible.

While intersectionality theories problematize marginalization they also call into question the dominant binaries. For example, they question the dichotomization of gender (man or woman) and race (racialized or white) by looking at the differences that exist within these categories (Prins, 2006). By addressing the differences within categories, intersectionality research serves to directly challenge normalized standards. Exploring the interaction between both dominant and subordinate statuses is important because people can benefit from a dominant status in one circumstance, while also being marginalized because of another.

The term intersectionality was coined by legal scholar Kimberlé Crenshaw (1989) to emphasize the fact that the experiences of those who are marginalized are multidimensional.

Crenshaw uses a number of previous legal cases to demonstrate this point. For example, in 1976 five Black women began a law suit against General Motors on the grounds that they did not hire Black women prior to 1964 and that all Black women hired in the early 1970's wrongfully lost their jobs in a series of layoffs supposedly based on seniority. The courts dismissed the case because General Motors had previously hired both women and Blacks, though none of them were Black women. Crenshaw argues that in this case, antidiscrimination laws were inadequate because they did not acknowledge the intersection of multiple marginalities for Black women (Mann, 2012). According to Verloo (2006), Crenshaw originally distinguished between two types of intersectionality; structural intersectionality and political intersectionality. Structural intersectionality refers to analyses that explore the ways in which inequalities and their intersections are directly relevant to the experiences of people in society. Crucial questions in this type of theoretical inquiry are: How and when does racism amplify sexism? How and when does class exploitation reinforce racism? In contrast, political intersectionality specifically addresses intersections as they relate to political differences.<sup>50</sup>

Intersectionality theorists argue that the marginalization that results from being a poor Black woman cannot be understood by looking at the marginalizations that result from each category of difference separately. It is not that being a poor Black woman compounds three categories of oppression (additive approach), but rather categories of difference work in tandem to create a singular experience of oppression (Hulko, 2009). Intersectionality

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<sup>50</sup> Verloo (2006: 214) points out that very few researchers after Kimberle Crenshaw have worked to develop political intersectionality. An exception to this is research conducted by Rooney that applies an intersectionality approach to the conflict in Northern Ireland. Rooney (2006: 370) argues that an intersectionality analysis is needed because it includes a specific focus on women, who are typically ignored in research on the Northern Ireland conflict.



theorists contend that there is a need to go beyond a simplistic additive model because it reduces women's complex lived experiences to a sum of the categories of oppression, rather than analyzing their unique social positions. Purdie-Vaughns and Eibach (2008: 378) argue that exploring marginalization through adding categories of difference together means risking treating these categories as homogenous. "Because people with multiple subordinate identities (e.g., African-American woman) do not usually fit the prototypes of their respective subordinate groups (e.g., African-Americans, women), they will experience what we have termed "intersectionality invisibility."<sup>51</sup> The claim that the additive model invisibilizes the experiences of those with multiple marginalities is supported by Crenshaw's reference to the General Motors' lawsuit.<sup>52</sup> Intersectionality theory goes beyond an additive approach by emphasizing the fact that differences shape the experiences of an individual or group simultaneously.

Despite the above criticism, Yuval-Davis warns that although categories of difference are inseparable from one another, they are also not reducible to one another. For example, not all racialized minorities or women have a marginalized class status.

While all social divisions share some features and are concretely constructed by/intermeshed with each other, it is important also to note that they are not reducible to each other. We are not talking here only about a unidimensional differentiation between the powerful and the powerless, nor are some differentiations just a reflection of more profound others. To be Black or a woman is not another way of being working class, or even a particular type of working-class person. (Yuval-Davis, 2006: 200).

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<sup>51</sup> The concept of invisibilized was developed by intersectionality theorists who use it to describe the impact of research that overlooks the experiences of those with multiple marginalities by referring to subordinate groups as though they were homogenous.

<sup>52</sup> Ward (2004) argues that despite the fact that intersectionality theorists typically reject an additive model, its use can serve a strategic purpose in social organizations. For example, prioritizing gendered oppression may be necessary for women who work in organizations that focus on racism because women's experiences of racism are often subsumed under the experiences of men.

Intersectionality theorists acknowledge that different systems of oppression, such as racism, classism and sexism, have unique ontologies that must be incorporated in order to conduct a more complete analysis. For example, Verloo (2006) argues classism is based in the organization of labour, while racism is rooted in how citizenship and belonging are structured. The unique origin of each category of difference means that addressing related inequalities requires a complex analysis, rather than a quick fix that could be achieved through a surface level description. Zambrana and Dill (2009b), insist that an historical and contextual analysis is the cornerstone of intersectionality theories because power is socially defined and fluid. Depending upon the subject matter, intersectionality theories can be applied at an individual, relational or structural level of analysis. The individual level of analysis studies lived experiences. The relational level studies social interactions. The larger structural level explores social structural factors, like the economic and political system, that shape various forms of marginalization (Nash, 2008). With multidimensionality in mind, intersectionality theorists have argued that the use of intersectionality theories often addresses more than one level of analysis at once because they are often interdependent (Mens-Verhulst and Radtke, 2006). For example, much of the health research that uses an intersectionality approach addresses the individual level and relational level of analysis. Mens-Verhulst and Radtke (2006) argue that this two pronged approach is necessary to connect biological health to environment in a meaningful way. Birke (2000) uses this method to critique the gendering of bodies, such as the gendering of hormones, while also exploring how one's environment can impact that body.

Intersectionality theories provide a more complex explanation of the interplay of differences like race, class, and gender by acknowledging that these categories are not static

(Shields, 2008). That is not to say that there are not generally agreed upon definitions.<sup>53</sup> But, what it means is that to be a woman, for example, is socially contingent and not the same in all situations. No one category of difference can explain all facets of experience without attention to other categories. This claim underlies Sefa Dei's statement that oppressions are best understood with an "and/with" approach, rather than through an "either/or approach" (Sefa Dei, 2010: 4). Gender cannot be explained without attending to class or ethnic background. In addition, because categories of difference are not static, it cannot be assumed that all individuals will experience race, class, or gender in the same way even if they do live in the same society in the same period of time. For example, Buitelaar (2006: 260) shows that it is not an easy task to explain what it means to be Muslim because it can vary considerably. "In practice, what Islam or 'being Muslim' means varies for different individuals, categories and groups of actors." This statement raises the problem of extreme relativism found in some intersectionality research, which is that if everyone is different and there are no categories that can hold for all cases, then no theory is adequate to explain social phenomena (Judd, 2006). The current research avoids this dilemma by relying on existing categories of difference as a way of understanding the experiences of informal caregivers. This (intracategorical) approach will be discussed at greater length further in the chapter.

Although social researchers generally assume that people with multiple marginalities have subordinate statuses that perpetuate social exclusion, having a marginalized status may offer a source of power in certain circumstances. For example, based on an in-depth case

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<sup>53</sup> For example, "Class has traditionally been marked by income, education, and occupation although gradually it is being acknowledged that education is the best indicator for women" (Mens-Verhulst and Radtke, 2006: 6).

study of five Black women working as school administrators and teachers at various levels, Bass (2009) concludes that for Black women in these positions ethnicity actually facilitates the role of social leader and activist. Bass argues that the history of caring within the African community encouraged the women in her study to advocate on behalf of their students. Their status as Black women also made them more sensitive to the needs of marginalized children. Bass attributes this to the fact that Black women are more personally aware of injustices faced by marginalized youth, as a result of race, class and gender, because they themselves have faced injustice. By becoming successful educators, the women in this study felt compelled to encourage marginalized youth to pursue social justice as well.

Intersectionality theories have a role to play in promoting changes in policies. Stasiulis (1999) argues that such an approach is more likely to provide tangible results than an attempt to create a totalizing political agenda. Much of her research is focused on identifying Canadian policies that overlook those with multiple marginalities. For example, in research conducted on West Indian and Filipino women as foreign-domestic workers, Stasiulis and Bakan (1997) contend that foreign domestic workers in Canada face continued abuse because of how the program is regulated. Specifically, foreign domestic workers are admitted under federally regulated policy, while labour legislation falls within provincial jurisdiction. Consequently, there are no common labour laws for these workers in Canada, which leads to varying standards and a general lack of protection. In Ontario, there is a complaint driven process that foreign domestic workers may use to seek amelioration for poor working conditions. However, Stasiulis and Bakan argue that there is an institutionalized power imbalance between the non-citizen woman of colour and the usually white upper middle class man or woman employer who controls the workers right to stay in

Canada, which perpetuates the abuse of foreign domestic workers. Like Stasiulis and Bakan, Henderson and Tickamyer (2009) claim that an intersectionality analysis can unravel the embedded relations of power weaved into contemporary policies. They argue that in order to do this, policies need to be context specific to address existing structural barriers. A one-size fits all approach cannot uncover the experiences of those who have been invisibilized. Goswami, O'Donovan and Yount (2014) argue that the project of revealing obscured oppressions is one of the main tasks of intersectionality theories.

Using an intersectionality approach that specifically addresses power dynamics is useful for understanding the structure of formal and informal care for aging immigrants because it can explicitly address equity issues involved in health care administration. For example, Mens-Verhulst and Radtke (2006) found that racialized immigrants who access health care resources on behalf of their sick family members are frequently confronted by power relations that work against them. Regulations do exist to streamline delivery, but the question of who is best served by regulatory practices rarely comes under scrutiny. For example, while establishing visiting hours may appear to be a fair way to limit the time all visitors can spend with aging FFN in a long-term care setting, visitors who speak the same language as the health care staff are able to negotiate these guidelines. In contrast, immigrant informal caregivers with a language barrier are excluded from challenging formal rules around visiting hours. Mens-Verhulst and Radtke argue that health care staff support the power structure by helping to maintain this process of exclusion.

Based on a combination of a review of existing literature and previously conducted empirical research, Anderson (2000) argues that nurses should receive training that specifically incorporates an intersectionality perspective because it provides an avenue for

acknowledging complex lived realities. Following from this research, Van Herk, Smith and Andrew (2011) explore how the use of an intersectionality approach might offer practical tools to help nurses to improve quality of care for patients with multiple marginalizations. Based on an analysis of five case studies involving the interaction of Canadian Aboriginal women with the health care system, the researchers conclude that intersectionality could support changes in nursing care practice through improving education and research. Specifically, nursing educators themselves should be encouraged to reflect on the complexities of educating nursing students with multiple marginalities in order to adequately educate future nurses about caring for people from diverse backgrounds. In addition, including intersectionality theories into nursing research would force practicing nurses to examine whose experiences are being represented in nursing research and what perspective the researcher is taking. This would support a more critical examination of privilege among formal care providers.<sup>54</sup> Rogers and Kelly (2011) claim that most research is based on the experiences of white men because they continue to fund most health care research. This has begun to change slowly in recent years, which is seen as a positive step because framing white men as the norm and ‘othering’ those who do not fit this category can further exaggerate existing marginalization.<sup>55</sup>

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<sup>54</sup> Serving as an additional example, Banks and Kohn-Wood (2002), contend that the treatment of mental illnesses should incorporate an intersectionality analysis. They review relevant literature regarding depression among Black women to support this claim, concluding that gender, poverty and discrimination all contribute to mental illness. Multiple systems of oppression, including sexism, classism and racism isolate low income Black women from mainstream society and limit their ability to access help when it is needed, which creates a feeling of hopelessness. Banks and Kohn-Wood argue that a treatment strategy should incorporate an understanding of the coping mechanisms that Black women use to deal with marginalization, as well as the development of more complex strategies for addressing these issues at a structural level.

<sup>55</sup> To this end, Rogers and Kelly (2011: 400) provide the example of research on ‘crack babies’ in the 1980’s. Initial research greatly exaggerated the physical and emotional impact of intrauterine exposure to cocaine by

Intersectionality theories provide a promising ground for research. Yet, there are important concerns that have been raised about the viability of intersectionality theories. As a fairly recent theoretical approach, some researchers have argued that intersectionality theories are frequently used in erratic or unclear ways (Phoenix and Pattynama, 2006). However, the primary criticism of intersectionality theories is that they are difficult to measure. McCall (2005: 1771) agrees that the methodology of intersectionality theories requires further development. “Despite the emergence of intersectionality as a major paradigm of research in women’s studies and elsewhere, there has been little discussion of how to study intersectionality, that is, of its methodology.” To fill this gap, McCall identifies three major methodological approaches found in intersectionality research; anticategorical complexity, intercategorical complexity and intracategorical complexity. Although the three approaches may appear to be similar in some respects, they are nevertheless distinct.

Anticategorical complexity deconstructs the categories of difference that are commonly used in intersectionality research. Anticategorical methodology originates from the poststructural feminist critique that calls into question the categories and concepts that have been used to organize modern society (McCall, 2005; Davis, 2008). According to anticategorical complexity, existing categories are too simplistic to capture the complexity of social life. In other words, those who use anticategorical methodology see using categories of difference like race and gender in research as limiting. The use of categories gives rise to

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ignoring the role that “poverty, violence, and prejudice in prenatal care” have for the babies of those who commonly use cocaine during pregnancy. The resulting implication was that the ‘crack baby’ myth became entrenched in the minds of the public and policy makers. Those who use cocaine during pregnancy are blamed for all of the physical and mental problems of their children, without recognition given to the social context. For example, the poverty that many of the mothers experienced translated to children living in unsafe housing conditions, such as overcrowded housing with lead paint and mold, and being malnourished.

essentializing. For example, the category of sexism led to biological essentializing (male/female). Anticategorical researchers argue that making use of these categories stabilizes and homogenizes fluid and heterogeneous social experiences (McCall, 2005). Deconstructing these categories is part of a larger project to address persistent inequalities. Practical applications of an anticategorical approach have been used in a number of disciplines across the humanities and social sciences. For example, sociologists have argued against the use of sex as a distinguishing category in research by questioning how sex is categorized. For example, is sex determined by biological sex, and if so are chromosomes or sex organs the deciding factor? As a result of this kind of research, some researchers argue that there are five sexes, rather than the relied upon binary of male or female (Fausto-Sterling, 2000).

A major critique of the anticategorical approach is its extreme relativism. Because this approach dismantles all categories that have been used to organize society, it is not suitable for research that seeks to explain structural barriers by engaging with established policies. In contrast, intercategory complexity accepts and makes use of the commonly identified categories of difference in order to explain marginalization and group inequality. The logic behind this approach is that to address persistent inequality it is necessary to analyze the impact of categories like race and class, at least provisionally, because these categories continue to be used in the allocation of power and privilege. Glenn (2002: 14) argues that the commonly identified categories of difference can act as “anchor points—though these points are not static.” Maintaining these anchors allows for a more complex analysis. McCall (2005) argues that the categorical approach allows for a solid basis of comparison and a more context specific analysis in application. She uses an intercategory



approach to analyze the impact of declining gender inequality in the labour force during the 1970's on both men and women. It was commonly held that men were the victims and women benefited from what was referred to as the new economy. However, McCall questions the assumption that all women benefited. She includes an analysis of class and racial inequality among women to compare women of different class backgrounds and different ethnic backgrounds. She concludes that low income and racialized women do not benefit from the new economy, but rather they appear to be marginalized.

Lewis (2009) argues that the provisional use of established categories of difference is necessary for intersectionality researchers who wish to make changes to existing policies. Inequality can only be addressed by understanding how political agendas shape current conceptions of race, class, and gender. For example, Stasiulis (2013) claims that Quebec's neo-liberal communitarian approach to a recent value code for immigrants marginalizes Muslims. In this context, the neo-liberal approach focuses on citizen responsibility and morality, while the communitarian approach encourages newcomers to conform to established moral standards in order to belong. On the surface this code is designed to promote the values of Quebec among recent immigrants, but in reality Stasiulis argues that it prioritizes the values of the majority group, who are anxious about the threat of immigration, framing Muslim men as barbaric and Muslim women as oppressed. For example, newcomers are cautioned against using violence to safeguard honour, which speaks to the media sensationalization of honour killings among Muslim immigrants in Canada.

Intracategorical complexity lies in the middle of the continuum between anticategorical and intercategorical complexity. Like anticategorical complexity, intracategorical complexity looks at how categories of difference have been socially

constructed and reified. It is important to recognize that categories of difference are not natural. It is “social structures that generate these social groups and determine social position” (Rushton and Perrons, 2007: 6). Yet, like intercategorical complexity, intracategorical complexity avoids extreme relativism by making use of existing categories of differences that have a relatively enduring status in society. Nash (2008) argues that categorization in research in and of itself is not the problem. Using established categories on a provisional basis can be useful if they are used in appropriate ways, particularly in health research. For example, Grace (2010) argues that an intersectionality analysis that makes use of established categories of difference on a provisional basis is helpful for explaining how race, class, and gender impact health. Grace cites research that shows that a person’s experience of racism, and position as an ethnic minority, has a negative health consequence on psychological wellbeing in particular. While race is a socially constructed category, the experience of racism has a very real health consequence, in terms of increasing a feeling of isolation and depression among those who experience it on an ongoing basis. The use of categories of difference in research continues to offer an important way of understanding the lived experiences of those who are marginalized.

This research evolves from an intracategorical approach within intersectionality. Making use of an intracategorical approach provides me with a solid analytical base for understanding the experiences of immigrant informal caregivers whose experiences are often left out of the sociology of care literature, as well as policy discussions around the care for older adults in Ontario. McCall (2005) maintains that an analysis that attends to intracategorical complexity is useful where a social group does not fit neatly into existing categories. In other words, it is useful for “people who cross the boundaries of traditionally

constructed groups” (Dill, 2002). For example, immigrant informal caregivers can easily be excluded from policies designed to reduce caregiver burden *and* policies designed to help immigrants integrate into Canadian society. Existing research indicates that immigrant informal caregivers with a language barrier are unable to use financial support programs because they cannot access needed information about these programs, or even fill out the required forms when they are aware of them (Flagler and Dong, 2010). In addition, many immigrant informal caregivers are unable to take advantage of employment or educational upgrading programs for new immigrants in Canada because they do not have anyone else to take care of the care receiver during the class times. Intracategorical complexity tries to capture the experiences of those who lie at the intersections of categories of difference.

An example of a study that uses an intracategorical approach is Hondagneu-Sotelo’s (1994) research conducted in the United States on Mexican domestic workers. Using qualitative interviews and observation, Hondagneu-Sotelo compares their experiences to that of earlier Mexican immigrants. In the 1980’s there was a large shift in the population immigrating to the United States due to an economic crisis in Mexico, which resulted in the downsizing of many workers. The immigrating population shifted from mainly rural men to a more heterogeneous group including greater numbers of urban women and children. Hondagneu-Sotelo concludes that Mexican domestic workers, a majority of which are women, face greater levels of marginalization than previous Mexican immigrants because standard work arrangements are largely based on the experiences of men. For example, mothers face additional barriers to managing demanding domestic work with caring for their children. Yet, maintaining this employment is a necessity in order to remain in the United States. The existing policies do not account for the fact that for many foreign domestic

workers from Mexico, gender operates simultaneously with race and class to create a unique experience of marginalization.

Intersectionality researchers who use the concept of intracategorical complexity readily acknowledge that most people do not fit easily into established categories of difference, but argue that starting with these categories is necessary in order to connect lived experiences to larger social patterns. McCall (2005) argues that intracategorical complexity provides the potential for research that can create positive social change because of its attention to the unique expression of categories of difference. In a well-known critique made against intersectionality theories, Judith Butler (1990) claims that intersectionality theories do not offer a sound basis for theoretical arguments because they cannot possibly address all categories of difference. As a result, many intersectionality theorists close with an insufficient “etc.” at the end of the list of categories of difference. However, the use of intracategorical complexity as a methodological tool responds to this criticism by acknowledging that while the use of existing categories of difference cannot fully explain the complexity of all power dimensions that is not its intention. Intracategorical complexity uses established categories of difference, by no means an exhaustive list, in order to explore who is left out. Chapter three will provide additional concrete examples of research that has made use of an intracategorical approach.

### **2.3 Complex Diversity**

Extending from an intracategorical approach within intersectionality, I also incorporate the concept of complex diversity. Complex diversity is a term used to describe the differences that exist within immigrant groups and ethnic communities (Phillimore,

2011). While diversity is a term typically used to describe differences between those who are Canadian-born and immigrants, complex diversity acknowledges that, with increased immigration from non-traditional source countries, such as India, China and Somalia, there are also important differences among groups of immigrants. For example, immigrants have a range of ethnic, cultural, and religious backgrounds that impact their experiences. It can strengthen an intracategorical analysis by providing an avenue for investigating the unexplored challenges in caring for aging immigrants in Southern Ontario. Kraus (2012) argues that the concept of complex diversity allows for a multidimensional analysis, which is consistent with intersectionality theory.

The concept of complex diversity emerged in the early 2000's in response to the increased immigration in Western Europe and North America. Specifically, it was developed to account for the fact that existing Multiculturalism policies were developed prior to changing immigration patterns (Vertovec, 2007).<sup>56</sup> For example, Canada adopted an official Multiculturalism policy in 1971 at a time when guaranteeing immigrants the opportunity to enhance and share their cultural heritage meant responding to a much more limited range of diversity. Given the shift of immigration to Canada from countries in Western Europe to countries in East and South Asia, and Africa, researchers have begun to study the adequacy of settlement supports and existing programs for addressing the diverse needs of ethnic minorities.

Jiwani (2001) argues that within the existing structure, systems of interlocking oppression restrict the access of immigrants to support programs and leave them unprotected.

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<sup>56</sup> When referring to official Multiculturalism policies a capital M is used, while a small m is used when referring to multiculturalism to describe a number of cultural groups living in the same nation.

Based on a series of interviews and focus groups with racialized immigrant women who have experienced intimate violence and service care providers who address the resulting health implications, Jiwani concludes that racialized immigrant women are especially vulnerable to intimate violence because of their structural locations. Specifically, racialized immigrant women are at an increased risk of intimate violence because of their level of isolation, resulting from a combination of racism, sexism, lack of language skills, and difficulties in moving into the labour market. Many racialized immigrant women also enter North America as dependents of their spouses, which creates a power imbalance that may encourage abuse. In addition, the response of health care providers is not adequate to address intimate violence when it does occur. For example, in many cases immigrant women with language barriers are forced to rely on their spouses or other family members for translation. As a result, victims of intimate violence are discouraged from reporting their experiences. In order to encourage women in these situations to seek health care when needed, diversity within immigrant communities must be considered. Specifically, Jiwani argues that interpreters must be made available to ensure that women who are victims of intimate violence do not have to rely on their abusers for translation. A one-size fits all approach will not address the needs of immigrant women from all ethnic backgrounds, as each will have differing language needs.

Mainstream health and social programming in Canada was originally designed for the dominant white population, leading to the exclusion of immigrants. Complex diversity is useful for formulating necessary structural changes for the support of immigrant informal caregivers by contextualizing their experiences within existing power relations. Based on a commitment to official Multiculturalism, the federal and Ontario provincial governments

have a responsibility to ensure that the health care system accommodates the needs of all aging Canadians and their informal caregivers. In order to accomplish this, the health care system must operate based on a model of inclusivity. According to Fleras (2012), an integration model addresses the resource needs of diverse communities or persons by fitting them into an existing system. Diversity is incorporated by treating everyone the same (formal equality), despite any differences that exist. Within this model different cultural groups become essentialized and the mainstream norms remain unchanged and unquestioned. Diversity is viewed as a problem to be solved, and as a consequence complex diversity is overlooked. For example, Rottmann and Ferree (2008) note that the right of Muslim women to wear hijabs remains a highly contested issue among feminists and politicians in the European Union because hijabs signify women's subordination in Western nations. They argue that the discrimination of Muslim women at the hands of the state becomes invisible because the problem of discrimination on the basis of race is treated as separate from gender discrimination in public discourse. Rottmann and Ferree conclude that in order to address this invisibility, Muslim women must be invited to assert themselves in the public sphere and challenge the perception that the state is a protector of subordinated Muslim women.

Tang and Browne (2008) note that discourses around egalitarianism in the health care system have led to similar experiences of exclusion for Aboriginal people in Canada.

Pervasive and interlocking systems of oppression result in two competing versions of reality, "namely the health care rhetoric of treating everyone the same and the perception among many Aboriginal patients that they were being treated differently by health care providers because of their identity as Aboriginal people, and because of their low-socio-economic status." (Tang and Browne, 2008: 109) The authors question the effectiveness of health care

programming that treats all people as equal in a context rooted in systemic inequality. Under a model of integration, the allocation of health care in long-term care settings, and by extension programs designed to support informal caregivers, continues to be highly problematic for immigrants.

In contrast, Fleras (2012) argues that an inclusivity model directly challenges the status quo. Being responsive to complex diversity encourages inclusivity by challenging caregiver supports that seek to integrate immigrants into existing programs through assimilation. Under an inclusivity model diversity is viewed as an asset and differences are taken seriously in order to produce equality of results (equity). Fleras insists that an inclusivity model must hold diversity as a foundational principle. If the interaction and intersection of categories of difference were taken seriously at the base level, then the health care system could develop effective treatment interventions that meet the needs of all Canadians, rather than simply those who fit the norm of the white, heterosexual middle class man.

#### **4.5 Conclusion**

This chapter outlined the theoretical framework applied to the data presented in chapters four and five. I explored feminist theories around the domestic labour debate. Although it is often considered outdated, the domestic labour debate provides a solid basis for understanding the care for aging Canadians as an important form of unpaid labour. It allows for a necessary discussion about how formal and informal care has become gendered and devalued. I included a discussion of “the family” in order to establish how the devaluation of women’s care work has continued to be relatively unquestioned. I then



provided an overview of feminist theorizing around care that took up psychoanalytic explanations for why women provide care, which led to a discussion of an ethic of care. The economic, political and psychological roots of women's care work form the basis of care-focused feminist theory, which attends to the gendering of care work within Canada. Following this, I introduced intersectionality theories as an essential component of a theoretical framework addressing the care of aging immigrants in particular. Intersectionality theories allow for a multidimensional analysis of the ways in which categories of difference interact and intersect to create unique challenges in caring for aging immigrants. I described different methodological approaches within intersectionality theories and identified intracategorical complexity as the approach used for this research. The concept of complex diversity was extended from an intracategorical approach in order to offer a tool for investigating the degree to which existing health care supports accommodate the needs of diverse immigrant groups. In order to be truly inclusive, I argued that health care supports for aging immigrants must strive for equity of results through inclusion, rather than integrating aging immigrants into existing programming based on the white Canadian standard. In chapter three I explain how the theoretical framework guided the data collection strategy for the two phases of research, and I provide details of the data collection.

## Chapter 3: Methodology

### 3.1 Overview of Methodology

In this chapter, I demonstrate how an intracategorical approach within intersectionality guided the methodology. I link this approach to a discussion of the qualitative research strategy used for the data collection. The data collection occurred in two phases. Phase one involved 25 interviews with Canadian-born and immigrant caregivers caring for aging FFN. The informal caregivers were asked a series of 19 questions (see Appendix A for a list of the questions and Appendix B for the brief demographic questionnaire filled out by each caregiver). Phase two consisted of 17 interviews with those providing paid formal care to aging immigrants. In phase two of the research long-term care facility staff and home care staff were asked 10 main questions (See Appendix C for a list of the questions).<sup>57</sup> In both phases of research, additional sub-questions and probes were used on an as needed basis.<sup>58</sup> Taken together, the two phases of research provide a basis for

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<sup>57</sup> Before beginning the interviews for phases one and two, I conducted a pre-test for each of my two interview guides. Varkevisser, Pathmanathan and Brownlee (2003: 264) argue that pretests help to identify potential problems before the research begins. The pre-test participants were able to offer valuable advice. For example, for phase one I had initially planned to give a blank schedule to each informal caregiver, so that they could fill in the caregiving activities that they had planned for the month. However, it quickly became obvious that this was not appropriate. For many of the participants caregiving consumes almost all of their time. To write down each activity may be an overwhelming task, which could detract from the flow of the interview and the comfort level of the participant. In addition, my pre-test participant suggested that writing down so much information may be very difficult because many of the people I intended to interview spoke English as a second language. As a result, I decided that it would be more suitable to ask for the information verbally. The pre-test participant for phase two was helpful for two main reasons. First, he gave me needed background information about long-term care facilities that helped me draft my questions. Second, he helped me to word my questions in a more appropriate manner. Specifically, he told me that it was important not to ask for too much client information or details because health care personnel are required to maintain patient confidentiality.

<sup>58</sup> For example, informal caregivers were asked more specific questions on their duties if too little information was originally offered. Formal care staff were asked to be more specific about programming available at the facility when the information given initially was too general. The number of probes used was based on my discretion as interviewer. While the probes may have been slightly different for each interview, the semi-

understanding the structure of both formal and informal care of aging immigrants in Southern Ontario.

Interviews in phases one and two lasted approximately an hour to an hour and a half. The interviews took place in a quiet location that was conveniently located for the participant. In phase one of the research, the location was either in the home of the participant or at a local coffee shop. In phase two, all interviews with formal care staff took place at the facility where the participant worked. The interviews were recorded using a digital recording device with the written consent of each participant. After reading an information letter provided, all participants were required to sign a letter of informed consent and were asked to retain a copy of the consent form for their records.<sup>59</sup> (See appendix D for the information letter provided to informal caregivers, appendix E for the information letter provided to long-term care and home care staff, and appendix F for the consent form)

### **3.2 Phase 1: Semi-Structured Interviews with Canadian-born and Immigrant Caregivers**

Phase one of the research consisted of semi-structured interviews with informal Canadian-born and immigrant caregivers conducted from October, 4, 2012 to March, 18, 2013. Only participants who spoke English were interviewed to avoid difficulties with translation. All of the participants interviewed in the first phase are high intensity caregivers who are currently caring for an aging FFN. The interviews were conducted using an intracategorical approach. According to Black and Veenstra (2012), research that uses an

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structured guide ensured that the information collected covered the same topics to allow for a comparison among the participants (Fetterman, 1998).

<sup>59</sup> The consent form clearly indicated that the interview, and all research resulting from the interview, would be kept confidential and that their participation was voluntary. Each participant was provided with a \$15 Tim Horton's gift card for his or her participation. Participants were informed that if they chose to withdraw from the research at any time, they could keep the voucher.

intracategorical approach produces multidimensional data through an analysis of how a single social location, in this case informal caregiving for an aging FFN, intersects with multiple categories of difference (such as race, class, ethnicity and gender). Offering an in-depth account of a particular social location can contribute to a deeper understanding of how the larger structures can shape lived experiences. For example, Hulko (2012) used an intracategorical approach to analyze the experiences of older adults diagnosed with dementia. Based on qualitative interviews with older adults with dementia and their family members, Hulko (2012) found that those with multiple marginalities (based on race, class, gender, and age) are less likely to view a dementia diagnosis as negative to the family or the individual. This is because people with multiple marginalities have more experience with resisting negative labels, and are thus able to frame themselves as people with dementia without it being an all consuming identity. Conversely, otherwise healthy white middle class men are less able to deal with the diagnosis of dementia in a positive way because they have never had to manage a negative label.

In phase one I interviewed informal caregivers with multiple categories of difference to allow for a complex analysis. McCall (2005) argues that addressing differences within groups is consistent with an intracategorical approach because it seeks to identify those who remain invisible. Although a large number of women were included (n=23), I also interviewed two men. The disproportionately high number of women in the research reflects the gender imbalance among informal caregivers in Southern Ontario. Interviews were conducted with participants who identified themselves as Muslim, Hindu, Protestant Christian, Catholic, Buddhist, spiritual but not religious, and Atheist. The religious diversity among the participants allowed me to analyze the responsiveness of formal supports to the

faith-based needs of aging immigrants and their informal caregivers. I interviewed caregivers with household incomes ranging from under \$10,000 per year to over \$60,000 per year in order to determine to what extent, if at all, income helps to reduce the burden of caregiving or to open up access to support programs. All of the informal caregivers currently live in Southern Ontario, including the GTA (n=8), the Region of Waterloo (n=14), the City of Kawartha Lakes (n=3) and Oxford County (n=1). The caregivers are originally from Canada (n=6), Guyana (n=1), Somalia (n=1), Ghana (n=1), Jamaica (n=1), Trinidad (n=1), Hungary (n=1), Germany (n=1), India (n=5), Pakistan (n=1), Scotland (n=1), England (n=2), China (n=2), and Vietnam (n=1). A number of participants were interviewed from the same country if they had other significant differences. For example, there were five caregivers interviewed from India because they varied in age, household income, gender and religious background. Two participants from England were interviewed because one identified as English and the other identified as a Black woman of Jamaican heritage. This allows for a more complex analysis of how categories of difference (such as race and ethnicity) shape caregiving experiences for immigrants, even when they come from the same country of origin.

Because the perspective of immigrant caregivers has been relatively underexplored in social science research (Lai, 2010, Pillemer, Suito and Wethington, 2003), the comparison group of Canadian-born informal caregivers offers a way to uncover which challenges and experiences are unique to immigrant caregivers and which are shared by caregivers of all backgrounds. Youn et al. (1999) note that one of the limitations of existing research on immigrant caregivers is that it fails to include adequate comparison groups. They compared 44 Korean caregivers, 32 Korean-American caregivers and 54 white American caregivers on

different measures related to caregiver burden. On the basis of this comparison, they conclude that Korean and Korean-American caregivers show higher rate of depression and anxiety due to caregiving. They explain this finding by arguing that Korean caregivers feel more pressure to provide extensive care because of cultural expectations of familism, which encourages children to care for their aging parents.

McCall (2005) argues that establishing a point of comparison is particularly useful for intracategorical research that focuses on “new” groups because it helps to distinguish them. While aging immigrants are by no means a new group, their rapidly growing numbers make their experiences as informal caregivers a growing concern. In order to effectively use an intersectionality approach, Jusova (2014) argues that multidimensional realities must be highlighted by establishing relational differences with a comparison group. Hankivsky et al. (2012) contend that making reference to a relatively homogenized comparison group, in the case of this research Canadian-born white informal caregivers, facilitates a more complex analysis of the social group under study. Through this approach it becomes possible to challenge the tendency of past research to erase the differences between and among informal Canadian-born and immigrant caregivers. This approach can be seen elsewhere in intersectionality research. For example, Clark and Hunt (2012) compare the access to health care resources of young rural and urban women. They conclude that applying an intersectionality analysis confirms that race, class and gender intersect to create unique barriers to health care for young rural women. For example, Aboriginal young women living on reserves are far more likely to live in rural areas with fewer options for health care. In addition, this group tends to have fewer economic resources to facilitate access to services that are further away from available resources, demonstrating that both Aboriginality and

income background impact access to health care in Canada.

Neufeld et al. (2001) argue that existing qualitative data lack sufficient depth related to the experiences and perspectives of immigrant women because immigrant women are a difficult population to recruit. My own experience with recruiting African immigrant and refugee women for my master's thesis research corroborates this statement. I found it difficult to find women who were willing to participate in an in-depth interview with an unknown researcher. The lack of diversity among participants in qualitative studies is troubling given that producing data that reflect diverse viewpoints is a cornerstone of solid feminist research. The exclusion of immigrant women from research further exacerbates their marginalization. Neufeld et al. (2001) sought to address this problem by conducting qualitative research in order to better understand how Chinese and South Asian women informal caregivers accessed health resources. To enlist research participants, they contacted a gatekeeper who could help establish a network of connections with individuals in the South Asian and Chinese communities. The use of key informants for snowball sampling helped to identify these hidden populations and produced richer qualitative data on informal caregivers in Canada.

Based on this research, and my own past experience, I chose to include a non-probability snowball sample of informal caregivers. During my volunteer work with the African Women's Alliance of Waterloo Region (AWA) and World Wide Opportunities for Women (WWOW), I established connections with a number of immigrants from various backgrounds. Through these sources, I identified two main gatekeepers who have ties to various immigrant communities in Southern Ontario and who were willing to help me recruit phase one research participants. The gatekeepers are respected leaders in their communities,

and are involved in a number of local non-profit organizations that work with immigrants. According to Berg (2007), it is most useful to find a gatekeeper who holds an important position in the group or organization under study because it helps the researcher to establish their own credibility and a needed level of trust. Both gatekeepers agreed to provide me with the names of possible interview participants, after asking them for permission to provide me with their contact information. In addition, I made presentations at the organizations where I volunteer, including AWA and WWOW, in order to secure more participants from various backgrounds. I distributed an information letter on October 2, 2012 and November 4, 2012 to prospective participants in order to ensure that they had detailed information regarding ethics clearance and my supervisor's contact information. (see appendix D for information letter) Each participant interviewed was also asked if he or she could recommend any other informal caregivers who might be interested in participating in the research. Snowball sampling was effective in helping me to recruit the desired number of participants, and in establishing a needed level of rapport.

Throughout the data collection process, I reflected on my own role as the researcher. McCall (2005) argues that it is essential for intersectionality theorists who use an intracategorical approach to situate themselves in the research. This claim follows from the critique that many social scientists have used broad generalizations based on their own experiences to explain social groups or individuals with multiple marginalities. Situating oneself in the research requires an understanding that the relationship between the researcher and the research participant is both complex and interactive. While the researcher is not prohibited from making use of existing categories of difference as a way of explaining or understanding the social group or phenomenon under study, he or she is asked to use these



categories in a more critical way. During my interviews with immigrant informal caregivers, I found that being a white Canadian-born woman impacted interviewee responses in a number of surprising ways. For example, one of the questions that I asked immigrant caregivers is: Do you think that the experiences of immigrants taking care of FFN differ from those who are Canadian-born? On a number of occasions I found respondents insisted that their experiences were the same, despite describing instances where their needs for support had gone unmet because of language barriers or culturally inappropriate services. Upon further discussion they revealed specific ideas of how their aging FFNs needs could be better met. For example, a participant from India explained that she could better care for her husband if she had increased financial support. Through my own reflection, I concluded that some of the immigrant respondents felt compelled to praise the Canadian health care system. A number of factors could have been at play, including the fact that I am a woman, I am white and I am a Canadian-born researcher. I developed additional probes after becoming aware of this early in the research process. For example, I asked specific questions about how accommodating formal supports were to specific language needs, culturally based food and recreational preferences, and religious or faith needs. By asking more specific questions, I was able to gather additional useful data. In addition, the semi-structured guide provided me with the flexibility that I needed to adjust the language used in the questions. For example, there were times that it was necessary for me to reword questions in order to meet various levels of English language proficiency. Although all of the participants that I interviewed spoke English, some of them did not understand some of the more abstract concepts.

Reflexivity was important for this research because it allowed me to acknowledge the

fact that additional or different information may have been gathered from the immigrant interview participants if I myself was not a white Canadian-born woman. At the same time, being a white Canadian-born woman was helpful for gathering information in other areas. For example, immigrant informal caregivers were asked: who should provide care for an aging FFN in need of support? This question led to many of the immigrant caregivers explaining how care was structured and organized in their countries of origin. Participants discussed care expectations in their countries of origin in great detail because I was seen as an outsider. If I was from a similar background the participants may not have discussed care expectations in as much detail because they would assume that I already have a certain level of knowledge. Moreover, I felt that the white Canadian-born caregivers were more forthcoming to me about their opinions because I was white. One of the questions asked during the interviews was: what would you look for in a long-term care facility to make sure that it would meet the needs for your FFN? In response, a white Canadian-born caregiver said that one thing that she would look for, if she were to put her father into a long-term care facility, was a facility with few racialized immigrant residents. Specifically, she said that her father would not like a facility that had people from Pakistan as residents. Although I cannot be certain that she would not have disclosed this information to me if I had been from a Pakistani background, it seems that she was more willing to offer this opinion because I was white. When talking about issues relating to caring for aging FFN, it was easy for interview participants to begin discussing issues unrelated to the research. For example, several participants began discussing unrelated family dynamics. For this reason, as Lecompte and Schensual (2010) argue, it was necessary for me to enter the interviews with a strong focus on the research topic, while also ensuring that the participant felt heard. When interviews

veered off course, I would gently guide them back by referring to a related comment that they had made earlier in the interview.

This research was undertaken with the understanding that immigrants constitute a vulnerable population. Some of the immigrant informal caregivers were experiencing a significant amount of stress at the time of the interview, as a result of having to navigate a difficult and unfamiliar health care system in order to access resources for an aging FFN. In addition, a number of participants were caring for a very close FFN who was dying. Discussing these issues in depth caused several participants a certain amount of distress. In order to reduce the impact of any emotional distress, I was cautious as to what topics of conversation I chose to pursue. In several of the interviews participants appeared visibly upset and began to cry. In these cases I quickly moved to a less sensitive topic that focused on opinions around caregiving rather than personal experiences. In the event that a participant showed a significant level of emotional distress, I was prepared to offer him or her suggestions for a range of *suitable* counselling services in the area. For example, some Muslim immigrants may prefer to speak with an imam rather than a mainstream counselling agency.<sup>60</sup> After her interview one participant withdrew from phase one of the research because she was concerned that her interview contained information that was too personal. The interview was immediately deleted from all paper records and electronic storage. Contact information for counselling was offered to this participant, but this information was unnecessary as the participant has already sought counselling. For all other participants any emotional distress appeared to be temporary.

The research questions for phase one focused on the participant's experiences with

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<sup>60</sup> I also held the interviews during business hours so that I could contact my supervisor if I felt that a participant was having an emotional response that I could not respond to appropriately.

caring for an aging FFN. LaForest (2009) argues that maintaining a focus on the perspectives and insights of those who are interviewed is one of the main goals of semi-structured interviews. For the first segment of questions I gathered general background information, including finding out where the participant was from and why he or she first came to Canada. I then asked questions that explored the caregiver role; for example, why did you start to provide care? And, what caring activities do you do in an average week? Following this, I asked if the caregiving was shared, if at all, with other FFN or if support services were used. I then asked about how caregiving impacted other aspects of the person's life, including employment, health and personal relationships. Next, I asked questions about the participant's opinions on caregiving, such as who should provide care and how they should be supported in an ideal situation. Finally, I asked questions related to the participant's opinions on the quality of long-term care and related programming issues.

### **3.3 Phase 2: Semi-Structured Interviews with Long-term Care Facility Management and Support Staff**

Phase two of the research involved semi-structured interviews conducted between December 6, 2012 and February, 26, 2013 with management and support staff working in home care and in long-term care facilities. (See appendix C for questions) Based on a systematic review of Canadian research studies related to the health care of older immigrants, Koehn et al. (2012) argue that there is a pressing need for research that examines how formal health care providers approach the care of aging immigrants. They conclude that there is a substantial body of literature that claims to take multiple marginalities into account, but that this is largely in name only as any real analysis appears to be absent. For example, most research on the care of aging immigrants tends to focus on ethnicity without analyzing the ways in which other categories of difference, such gender and class, interact with ethnicity.

The interviews conducted in phase two seek to address this concern in order to complement interviews with the informal caregivers conducted in phase one. The facilities where interviews took place were located in the Region of Waterloo (n=3), the GTA (n=2) and the Hamilton-Niagara Region (n=1). Management staff included executive directors (n=4) from four different long-term care facilities and a client service manager (n=1) from a Community Care Access Centre (CCAC). Interviews were conducted with two PSWs (n=6) and RPNs (n=4) from four long-term care facilities and the CCA.

The interviews with the management staff help to uncover what efforts local long-term care facilities have made to make their facilities, programs and marketing inclusive to an increasingly diverse client base in Southern Ontario. The interview with the client service manager reveals what efforts the CCAC has made to ensure that home care is culturally appropriate and accessible to immigrant informal caregivers. The interviews with PSWs and RPNs help to determine if those working directly with clients have knowledge of the policies that have been established, and how they experience the regulations imposed by those in positions of power. Jusova (2014) argues that applying an intersectionality analysis requires an exploration of power relationships and the ways in which hierarchies shape lived realities. In some cases the PSWs and RPNs expressed the fact that they did not feel they were able to implement all policies set out by the long-term care facility or the Ontario Ministry of Health and Long-term Care. In other cases the RPNs and PSWs felt that the resources available were not sufficient to meet the needs of a diverse client base. In addition to the main interviews, an interview was also conducted with a Chaplain working in a long-term care facility and an Executive Director working at a Muslim Seniors Centre. These interviews help to identify the unique spiritual and religious needs of older immigrants. The interviews

with long-term care facilities include representation from both non-profit and for-profit facilities in Southern Ontario, which will be discussed at more length in chapter five. This offers a point of comparison in order to determine if the programs/marketing offered are relatively similar or different at each type of facility.

In order to connect with interview participants for phase two of the research, I contacted a selected list of long-term care facility executive directors in Southern Ontario by e-mail and requested to interview a management staff member and at least two RPNs or PSWs. The long-term care facilities contacted were chosen through purposive sampling. I chose to interview more people at a smaller number of facilities in order to ensure that the data collected would allow for thick descriptive analysis. If only one interview was conducted at each facility the data produced would not be nearly as rich, nor would it produce results that could be considered as accurate without drawing on available comparisons.

As in phase one of the research, reflecting on my role as a researcher was an important part of my interviews with management and support staff. Although it was not an original part of the research design, I was able to interview a fairly substantial number of long-term care staff who were not Canadian-born, including participants from Croatia (n=1), Pakistan (n=1), China (n=3), Ghana (n=3), Poland (n=1), and Zimbabwe (n=1). One of the questions asked during these interviews was: are the concerns of immigrant FFN different than Canadian-born FFN? If yes, how? Some staff members who were not Canadian-born appeared to be reluctant to answer this question. For example, one nurse from Ghana felt that Canadian-born residents and their family members were far more demanding, and received more attention as a result. However, initially she was hesitant to disclose this

information. She stated there are groups who are more demanding than others. When I probed about which groups were more demanding, I was asked by the participant to pause the tape. Once the tape was paused she explained that white Canadians are generally far more demanding than residents born outside of Canada. After I explained to her that it was perfectly acceptable to express this opinion, I turned on the tape and she repeated her statement. In a number of other cases immigrant long-term care facility staff expressed the same view. Sometimes this view was stated with a joking tone or a small laugh because participants appeared to be worried about offending me as a white Canadian-born person. Others briefly hinted towards the same view, but did not directly state it. For example, a nurse from Zimbabwe said that Canadian-born people were not necessarily more demanding, but it changes on a case by case basis. She argued that while not all Canadian-born residents are more demanding with how baths are done, for example, Canadian-born residents seem to be more particular overall.

Both the management staff and the support staff were asked the same questions. The first set of questions focused on the facility itself; for example, how the demographics of the facility changed over time, how the facility is funded; and to what degree, if at all, the facility's client base is diverse. Second, there was a series of questions that further explored whether or not the facility staff felt as though clients born outside Canada had distinct needs and if the facilities had programs available to meet these needs. Third, participants were asked about their roles at the facility, including position title and training and what their duties were in an average week. Fourth, participants were asked to describe their roles in interacting with clients and their families.

### 3.4 Data Analysis

I personally transcribed each of the interviews for phases one and two of the research. I felt that transcribing the interviews personally would facilitate a more complete understanding of the data. During the transcription process I immediately began to see patterns in the data emerge. In order to ensure validity, I provided each of the participants with an opportunity to review their interview transcript and omit anything that he or she felt misrepresented what was originally intended.<sup>61</sup> Each of the interviews was coded using NVIVO 10 software. I started my analysis by using open coding to identify the main themes in the data, which allows for a more complete analysis (Berg, 2007). After the initial open coding I refined the code categories in order to develop a more nuanced analysis. NVIVO 10 was an effective tool that helped me gain a comprehensive picture of the caregiving experience. During the axial coding phase I used NVIVO 10 to create more sophisticated linkages between the codes that I had developed. These linkages helped me to distinguish more clearly between the major and minor codes that the data produced.

As soon as the interviews were transcribed any identifying information was separated from the transcripts. All names included in the transcripts for phases one and two of the research are pseudonyms. Creswell (2003) argues that the use of pseudonyms is an essential part of maintaining the privacy of research participants. The pseudonyms were chosen based on a list of the most popular names for the country of origin of each participant. Pseudonyms are especially important when dealing with immigrants who are members of small communities. For the immigrant informal caregivers, it may pose a threat to

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<sup>61</sup> Participants were also asked to provide an e-mail address, or a mailing address, if they would like to receive an executive summary of the research findings.



anonymity to give specific details about caregiving experiences combined with country of origin. In order to reduce the threat to participant anonymity each participant was informed of this risk and asked to choose whether to reveal certain information in the interview. (See appendix G for the feedback letter provided to each participant)

### **3.4 Conclusion**

The qualitative research design outlined above explains the methodology used to collect the data for phases one and two of the research. I used an intracategorical approach within intersectionality to explore how multiple marginalities shape the formal and informal care of aging immigrants. In phase one, Canadian-born caregivers served as a comparison group for immigrant informal caregivers. Drawing on this comparison offers a solid reference point for determining the degree to which the social location of immigrant informal caregivers and their aging FFN impacts the accessibility and suitability of various health care resources, including home care and long-term care facilities. In phase two I interviewed health care management and support staff involved in the provision of care for aging immigrants. This facilitates an analysis of the challenges faced by formal care providers in caring for aging immigrants. The qualitative interviews provide the needed data for an analysis of the private and public spheres involved in the care of older immigrants in Southern Ontario. Chapter four provides an analysis of the data collected in phase one while chapter five provides an analysis of the data collected in phase two. Chapter six explains the usefulness of applying care-focused feminist theory to the experiences of all caregivers.

## Chapter 4: Data Analysis of Informal Caregiver Interviews

Informal caregivers in Canada face substantial challenges in managing care for aging FFN, and have difficulty obtaining suitable resources. In this chapter, I rely on the qualitative data collected through interviews with Canadian-born and immigrant informal caregivers. The findings reinforce the usefulness of the theoretical framework that incorporates feminist theories related to care and intersectionality theories. The move on the part of the Government of Ontario to progressively download care of older adults to the community has resulted in an overreliance on informal caregivers, particularly women. In addition, immigrant informal caregivers face a unique set of challenges as a result of their multiple marginalities, including race, class, gender, and ethnicity. Existing resources are proving exclusionary to immigrant informal caregivers and their aging FFN, due to an inadequate response to language barriers, religious differences, culturally based food preferences, and recreational needs. Programs designed to meet the needs of specific ethnic groups are more responsive to the needs of immigrant communities in Southern Ontario. Participant information is provided in Table 2, including participant name (pseudonym used); age range; education; country of origin; number of children; marital status; care receiver; household income range; first language; ethnic background; and employment status.<sup>62</sup>

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<sup>62</sup>The participants were given the opportunity to self-report their ethnicity on a brief written survey. As a result, a number of participants reported Black as their ethnicity. It was used for the purpose of this dissertation because it reflects the self-identification of the interviewee.

**Table 2: Informal Caregiver Information**

Name	Age Range	Education	Country of Origin	# of Children	Marital Status	Care Receiver	Household Income Range	First Language	Ethnicity	Employment Status
Amina	46-55	Post-Graduate School	Somalia	4	Divorced	Mother	\$26,000-\$35,000	Somali	African/Black	Part-time/Student
Brianna	46-55	High School	Canada (Kawartha Lakes)	3	Married	Mother	\$26,000-\$35,000	English	Canadian	Unemployed (Disability)
Cara	18-30	University	Vietnam	1	Married	Grandfather Grandmother	\$36,000-\$60,000	Vietnamese	Vietnamese	Full-time
Chanda	46-55	Post-Graduate School	India	2	Married	Mother-in-law Father-in-law	Under \$10,000	Punjabi	Indian	Part-time
Dafiya	31-45	University	India	4	Married	Mother-in-law	\$36,000-\$60,000	Punjabi	East Indian	Part-time
Dorothy	56+	Less Than High School	England	3	Married	Husband	\$10,000-\$25,000	English	English	Retired
Ellie	46-55	High School	Scotland	2	Common-law	Father	\$10,000-\$25,000	English	British	Student
Eman	56+	University	India	1	Married	Mother	\$36,000-\$60,000	Urdu	Indian	Part-time
Frieda	46-55	College	Germany	2	Divorced	Mother	Under \$10,000	German	German	Unemployed
Heather	56+	High School	Canada (Waterloo Region)	1	Divorced	Father Mother	\$10,000-\$25,000	English	Black	Unemployed (Disability)
Imran	56+	University	India	3	Married	Wife	\$36,000-\$60,000	Urdu	Indian	Retired
Jaw-Long	31-45	Post-Graduate	China	2	Married	Mother	\$61,000 +	Cantonese	Chinese	Full-time
Kelly	31-45	College	Canada (Oxford Country)	3	Married	Grandmother Grandfather	\$61,000+	English	Canadian	Full-time
Li Na	31-45	University	China	2	Married	Mother-in-law Father-in-law	\$36,000-\$60,000	Mandarin	Chinese	Full-time
Lila	46-55	University	Hungary	2	Married	Volunteer companion	Under \$10,000	Hungarian	Hungarian	Unemployed (Disability)

Name	Age Range	Education	Country of Origin	# of Children	Marital Status	Care Receiver	Household Income Range	First Language	Ethnicity	Employment Status
Martina	31-45	High School	Jamaica	3	Single	Father	\$26,000-\$35,000	English	Black	Student
Murium	31-45	University	Pakistan	3	Married	Mother-in-law	\$61,000+	Urdu	South Asian Pakistani	Part-time
Nazma	56+	College	India	3	Married	Husband	\$36,000-\$60,000	Urdu	South Asian	Retired
Odessa	18-30	University	Guyana	0	Single	Father	\$36,000-\$60,000	English	Guyanese	Full-time
Olivia	46-55	High School	England (Jamaican)	3	Divorced	Mother	\$26,000-\$35,000	English	Black Jamaican	Full-time
Paula	56+	University	Canada (Kawartha Lakes)	0	Married	Mother Husband	\$36,000-\$60,000	English	Canadian	Retired (Health Reasons)
Rita	31-45	College	Ghana	3	Married	Mother-in-law	\$61,000+	Twi	Black	Full-time
Samantha	56+	High School	Canada (Kawartha Lakes)	0	Divorced	Father	\$26,000-\$35,000	English	Canadian	Full-time
Shannon	31-45	College	Trinidad	3	Married	Mother-in-law	\$61,000+	English	Trinidadian	Full-time
Tammy	46-55	College	Canada (Region of Waterloo)	3	Married	Father	\$36,000-\$60,000	English	Canadian	Full-time

#### 4.1 Challenges in Managing Care Faced by Informal Caregivers

In this section I discuss the challenges in managing care for aging FFN faced by both Canadian-born and immigrant informal caregivers. The data in phase one show that while there are important barriers unique to immigrant informal caregivers, caregivers share some similar experiences regardless of immigrant status nevertheless.

Caring for my mother-in-law is very difficult. It's hard to get enough resources and hard to manage caring for her with everything else I have to do. I know I have a harder time getting supports that suit my mother-in-law because she is from Trinidad, but I know other women caring for their family members who were born in Canada and they have difficulties too. We all feel that we need more help. There are just not enough resources for caregivers no matter where you are from. (Shannon)

Shannon claimed that both Canadian-born and immigrant informal caregivers have difficulties in managing caregiving duties for their aging FFN. In addition, Shannon drew out another similarity among informal caregivers, which is that they are predominantly women. Specifically, she argued that she knows of other *women* facing the same difficulties as she does. In doing so she acknowledged the gendered structure of care work for aging FFN in Southern Ontario. Her observation is reasonable given the fact that this research includes 23 women and only two men. Both men were providing care with the assistance of women FFN. Research conducted by Carstairs (2010) confirms that the disproportionately high percentage of women caring for aging FFN holds across Canada. Specifically, 77% of informal caregivers in Canada are women. As they remain the primary source of informal care, women share barriers related to the systemic gender discrimination built into the Canadian health care system, whereby women are encouraged to take-up care for aging FFN where formal health care provision leaves off. For example, Samantha claimed that she was persuaded by representatives from the hospital and the CCAC to care for her father at home.

Well, the doctor's at the hospital and the people from the CCAC all told me I should take my dad home. They said that you can look into long-term care, but here it takes five years to get into one, so there's no point in me even doing it now. My dad's 91 and I don't think he's going to live to be 96. I'll just have to look after him. I just feel like they expect the daughters and the wives to look after everybody when they get old. There isn't enough help out there for the family.

Samantha argued that there are no real alternatives to caring for her father at home because of the long wait lists for the local long-term care facilities in her area. Like Shannon, Samantha noted that it is women, specifically daughters and mothers, who are most often tasked with providing the needed care to older adults that Ontario's hospitals no longer provide. A review of Canadian home care services conducted by Coyte (2000) confirms that there has been a progressive shift from hospital care to care in the community across Canada. This has led to CCACs adding to the pressure placed upon women to care for aging FFN at home. According to the CCAC Client Service Manager, the expectations placed upon home care staff and informal caregivers have increased dramatically since the health care reforms in the 1990's.<sup>63</sup> "It's a challenge for us to deal with patients who shouldn't have been released from the hospital. We're doing stuff in the home care sector now that 10 and 15 years ago we weren't doing. It's plain and simple." Mark argued that the CCAC is now providing more extensive home care support to informal caregivers than ever before. The apparent willingness of the provincial government to download the care for older adults to women without sufficient compensation, support, or alternatives shows that the value of women's care work continues to be overlooked in Ontario. This finding confirms Armstrong, Armstrong and Scott-Dixon's (2008) argument that the contributions of women's

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<sup>63</sup> Hepburn (2014) argues that Ontario Health Minister Deb Matthews has failed to respond to ongoing warnings indicating that the home care sector cannot meet increasing demands. "The home care sector can't cope with the government's overall objective of controlling hospital costs by discharging patients with false promises of home and community care services that can't be delivered."

unpaid care work to the economy remains obscured and invisible in a capitalist system that only values the contributions of paid labour. Moreover, the invisibility of women's care work is fostered by policies that claim that "the family" in the home is best suited to provide care. For example, the Client Services Manager explained that the CCAC now operates on the principle that home care is the preferred method of care.

We think that the best place for people is in the home with their families. Even if they need long-term care placement they should be going home first. That's what one of our programs is called; Home First. We get them home so that their families can research the nursing homes, and then decide if that's the right choice for them.

Mark claimed that the Home First program is one example of how CCACs are encouraging care of aging FFN in the family home. The Home First program is a strategy wherein informal caregivers are given access to funded home care above the normal limit allotted by the CCAC, to a maximum of 24 hours per day for a period of up to 90 days in order to ensure that acute care patients can be treated safely at home after being discharged from the hospital. According to the Central Local Health Integration Network (2014), more than half of the people who participate in the program remain at home even after finishing the program. While support resources like the Home First program can help caregivers to avoid making snap decisions, it can also push some caregivers into a role that they are not prepared for. Although the Client Services Manager spoke of caregiving as a task best suited for "the family" this again ignores the fact that the bulk of caregiving is performed by women in "the family", rather than jointly by all family members. This finding supports Exley and Allen's (2007) claim that reliance on "the family" model reinforces the idea that "the family" is a natural source of love and protection, and that women are natural caregivers. Because care continues to be framed as a labour of love in "the family" rather than work, the financial

costs associated with it are all but excluded from policy discussions. Moreover, because care is framed as a moral commitment to an FFN, there are a number of programs and policies in Ontario that have been directed at promoting proper caregiving. However, the notion of proper caregiving tends to decontextualize the experiences of informal caregivers by erasing the difficulties they have in managing care without sufficient external support. For example, Olivia argued that the involvement of the CCAC in her mother's care has made the situation more difficult to manage because they were focused on telling her *how* to care for her mother, rather than offering her the needed support to do so.

Her doctor is the one—when he realized my mom had dementia he called the CCAC. He called them before us. What happens is that all of a sudden you have to do this, this, and this. You don't have time to think or analyze the situation. You don't have time to sit down with the family and decide what to do. You don't have time because they're demanding. That's why mom's situation was pure confusion. To me, what happened with my mom is that we were pushed and cornered to do something. To tell you the truth they haven't given us any support we can use, they've just told us how to do everything to their standards.

Olivia claimed that she was pressured by the CCAC to establish a care plan for her mother right away. Although she did not feel that the CCAC has given her needed resources, she argued that they have set up very specific guidelines. They have clearly established ideas of who is and who is not a good caregiver. This finding supports Kittay's (1999) warning that there is a need to be cautious about how an ethic of care is woven into policies because it can be used to tie women to specific expectations of care; for example, the dutiful caregiver who is dedicated to the welfare of the care receiver with no external commitments, paid work or otherwise. Policies and programs that demand immediate action do not take into account different levels of ability or support among informal caregivers. In addition, any informal caregiver who does not choose to provide ongoing care is viewed as an exception by Ontario



health care policy makers, as evidenced by programs like Home First, which are built on the assertion that the best place for aging FFN is in the family home. This argument is reinforced by Coyte's contention that the Canadian government's reliance on home care is nested in a number of unwritten assumptions that impact the provision of support for informal caregivers.

It is believed that Canadians want to assume substantially greater responsibility for health care delivery at home; that they want to be discharged from acute care early; that they want to remain in the community rather than be residents of long-term care facilities; and that their family and friends want to provide informal care. (Coyte, 2000: 12)

Coyte concludes that the Canadian government believes that most people want to exit formal health care institutions, including hospitals and long-term care facilities, as soon as possible and that their FFN want to provide ongoing care once they do. An explicit reliance on the family reflects implicit support for the role of women as natural caregivers for aging FFN. The belief that women have a natural ability to provide care for aging FFN was internalized by many of the participants. For a number of the immigrant informal caregivers, the expectation that women can provide the best care to aging FFN is linked to culture. For example, as a Somali woman, Amina argued that it is her duty to take care of her aging mother.

Culturally, there are different factors that people believe in. I think that in my culture we believe that if you are the oldest daughter then you have to take care of your mom and dad. Some cultures don't believe that. Some cultures believe that everything should be equally shared between siblings.

Amina claimed that in Somalia the oldest daughter is expected to care for her parents, which shows that gender intersects with cultural expectations for some informal immigrant caregivers. The fact that the gendered nature of informal care work is tied to cultural

expectations of care for aging FFN among certain immigrant groups has been noted in previous research (Yoo, Jang and Choi, 2010). But, the standards are not the same for all immigrant groups. For example, in South Asian cultures it is the responsibility of the oldest son to provide care for aging parents. However, Dafiya noted that in reality, the day-to-day caregiving tasks usually fall to the daughter-in-law. This was her experience in caring for her mother-in-law.

Culturally it's not really acceptable for her to live with her daughters. It's the son's responsibility, so basically a lot of the times the parents usually go off to live with the oldest son. However, in reality it is the responsibility of the daughter-in-law to provide the care on a daily basis. In our families the girls are told that you are going to be living with all of your in-laws, like a joint family.

Dafiya argued that despite the expectation that South Asian men will care for their aging parents, women are socialized from a young age that providing care for their in-laws is their responsibility. This is consistent with Gilligan's (1982) theory that while men are taught to develop an ethic of justice that focuses on fairness, women are taught to develop an ethic of care that encourages them to look after the needs of others. This helps to explain why women continue to take up a disproportionate amount of informal care for aging FFN, despite the fact that many know that it will be a difficult role to fill. For example, as noted in chapter one, Yoo, Jang and Choi (2010) found that Korean women care for their in-laws despite the fact that it is viewed as an unpleasant responsibility. The Canadian-born caregivers interviewed also share an internalized belief that women are natural caregivers. For example, Brianna argued that men are unsuitable to care for aging FFN because they are not as caring as women by nature.

I believe men are less likely to care for older family members than women. They're fine when it comes to financial help and stuff like that, but they don't have the personality to deal with people like my mother sensitively. Some do, but for the most part women are just naturally better at it. I think that if I got sicker and I needed more help that I would want my daughter to care for me. I mean, how many men do you actually know who want to look after a woman? I mean, some do and it's no problem. But, not every man would be comfortable with that and I think that's the problem. I mean, it's the truth and there's nothing wrong with that. They're not as personalized in that. They'll do other things, but they're not into that.

Brianna noted that while men tend to help out with providing financial support, they are not suited for direct care. She accepts some help from her brothers in the form of financial compensation for caring for her mother on an ongoing basis, but provides all physical care herself. Brianna's statement supports the fact that there remains a division between the place of women in the home and men in the public sphere. According to Baines, Evans and Neysmith (1991), this artificial division between the public and private spheres created by industrialization ensures that men are seen as primarily responsible for providing economic support. Like Brianna, many of the women who were interviewed discussed getting financial support from secondary male caregivers. For example, Martina said that her brother provides financial support for her father. In addition, he takes care of him on weekends. However, she noted that the direct care support came as a result of a social worker's intervention on her behalf.

Well you see, my dad's social worker kind of demanded my brother take my dad for the weekends because I need a break. I used to have him 24/7 with no break in between there. He kind of fought it because his excuse was that he works two jobs, but that's not my problem. He just didn't think he should have to do it because I'm the daughter. It's kind of hard. What little money he gives me is not enough to pay for all of the stuff my dad needs.

Martina's brother was resistant to providing direct care for their father, and conceded only after the insistence of a social worker. Moreover, he claimed that he should not have to

provide direct care because he works two jobs, which reinforces the division between women and men as discussed above. Martina's experience confirms that, like women, men have internalized the expectation that a woman's primary responsibility is to her home and family, which exempts men from the responsibility of caring for aging FFN to the same degree. Jaw-Long is one of only two men included in the research giving primary care to an aging FFN. He stated that the majority of his role as a caregiver is providing his parents with transportation, financial support and translation at doctor's appointments. He admitted that, as his parents age and their health care needs increase, his wife will most likely begin providing more of the care.

I just feel like it's the way it's supposed to be. The kids are supposed to take care of the parents. Right now my parents are in pretty good health. My wife does quite a bit to help my parents too. I think that later she will take over when their health gets worse. She is a very detail oriented person. She will find out what we need to do to take care of my parents. My wife is very good.

Rather than seeing caregiving as an unworthy role for himself, Jaw-Long argued that his wife has skills beyond his that would make her more suited to the role. His statement shows that he valorizes his wife's ability to care, rather than subjugating it as an unimportant household task. This example supports an ethic of care, which Nodding (1984) argues can contribute to a greater social good by ensuring that those in need are cared for and those who provide care are respected. However, while this ethic of care has been internalized by some it has not served as a basis for health policy development in Ontario, as current policies that encourage the responsibility of informal caregivers remain couched in assumptions about "the family" that do not recognize the care work of women as essential.

Despite a fairly widespread internalized ethic of care, many of the participants claimed that they will not be able to maintain the role indefinitely because of increasing

pressure to contribute financially to the household. The difficulties in balancing paid work with informal care are likely to be experienced more by women than men in Canada.

Research shows that 44% of employed women are considered high-intensity informal caregivers, compared to only 27% of men (Pyper, 2006). Managing informal care and paid work proves impossible for some women. For example, Odessa, who was born in Guyana, has stopped work completely to care for her father after his kidney transplant surgery.

I worked in accounting and finance, but it was a contract position. They were going to hire me, but when my dad got sick I had to step back. I had said to them, is there any way that I can take a leave of absence because my dad's really sick, and I know that when he comes out of the hospital I'm going to have to take care of him? They said, unfortunately no. There is very little protection when you go through agencies or you're on a contract. You have no security. I made the decision to take time off work. I thought there is no way that I can work and take care of my dad. I had just graduated from university at the time too. I know it's a tough times and it's hard to get a job right now but, the thing is, I just have to take care of my father.

Caring for her father means that Odessa must exit the work force after finding a job in her chosen career path related to her recently obtained university degree. With little work experience it may be more difficult for her to reenter the work force at a later time. This finding supports existing research conducted by Fast et al. (2013), which indicates that many informal caregivers leave the work force at a crucial point in their careers. In addition, many people who leave their job to care for an FFN are unable to make up the loss in wages over the life course, an estimated \$566,443. Fast et al. (2013) conclude that this contributes to the long-term financial instability of many informal caregivers.

During the interviews, many of the participants argued that programs in Canada designed to support informal caregivers are not sufficient for addressing the challenges faced by people caring for aging FFN in Southern Ontario. One of the main programs designed to

financially support informal caregivers is the Compassionate Care Benefits (CCB) Program. CCB is a federally regulated program implemented in 2004 as part of Canada's Employment Insurance program. Canadians who qualify for CCB are able to receive short-term financial support and secured leave from full-time work to care for a dying family member. Care is defined broadly by the CCB as providing direct care, emotional support, and/or arranging for care from a third party (Service Canada, 2011). Table 3 provides a brief summary of the eligibility criteria and features of the CCB program.

Table 3: Eligibility Criteria and Features of the CCB

CCB Eligibility Criteria
<ul style="list-style-type: none"> <li>• Claimant's regular weekly earnings have decreased by more than 40%</li> <li>• He or she has accumulated 600 insured hours in the last 52 weeks, or since the start of the last EI claim</li> <li>• Claimant can receive CCB to care for a family member, or a spouses family member (excludes cousins and other extended family members)</li> <li>• To care for an extended family member, friend or neighbor, a separate attestation has to be submitted for review</li> <li>• A doctor's note must be submitted with the application to prove that the loved one has a significant risk of death within the next 26 weeks</li> </ul>
CCB Features
<ul style="list-style-type: none"> <li>• The basic benefit rate is 55% of the average insured earnings, up to a maximum payment of \$485/week</li> <li>• There is a two-week unpaid waiting period after CCB approval</li> <li>• Benefits will be paid for a maximum of 6 weeks</li> <li>• If a claim is rejected, there is a board of appeal in place and a standard appeal procedure to be followed</li> <li>• 8 weeks of job security to care for a family member (definition family member varies by province/territory)</li> </ul>

Source: Service Canada, 2011

Only Tammy mentioned accessing CCB to care for her dying father.

Last November my dad started to get really sick, so I applied for Compassionate Care Benefits. You only get six weeks paid through unemployment, which I didn't think that was very feasible. You get some money, but not as much as you would have from working. So far I have taken about six months off unpaid.

Tammy's father has lived beyond the six week paid benefit duration, resulting in her taking an unpaid leave from work for the past six months to be his primary caregiver. The fact that the CCB has such limited benefit duration indicates only a minor commitment on the part of the Canadian government to reduce the financial burden associated with caring for a dying FFN. The CCB program is consistent with what Mahon (2006) refers to as a model of "new familialism". Governments adhering to this model focus on the development of programs designed to enable the (woman) caregiver to return to the labour market without undue barriers. Rather than challenging the structure of care work for women, programs like CCB maintain the status quo by allowing women to take time off from paid work to provide care, albeit very temporarily. In doing so, the Government of Canada is attempting to prevent the devaluation of informal caregivers in the labour market, while failing to acknowledge the value of informal care itself to the Canadian economy. Mahon concludes that in reality, these programs do little to address inequality between caregivers and non-caregivers because they provide an insufficient level of support, particularly for those who need to provide informal care for a prolonged period of time.

Tammy initially found information about the CCB program through her family physician, although she later explained that it was a complicated and time consuming process. In fact, research indicates that the CCB program is not well known or promoted to informal caregivers across Canada, leading to an under-utilization of the program itself (Williams et al., 2011). Gaining access to the CCB program can be even more difficult for

immigrants because they are unfamiliar with the Canadian health care system, or even where to begin looking for information.

Immigrants don't know who to ask when they need help with caring for their aging parents. If you're born in Canada you may not know either, but you know that you can ask your doctor and he or she will probably be able to point you in the right direction." (Mark)

Mark added that although Canadian-born caregivers may be equally unfamiliar with what is available to them, they know that physicians often serve as the first point of contact for information and referrals. Olivia, a Jamaican woman born in England, was unaware that the CCB program exists even after caring for her mother for four years. "I would like support for people who have a minimum income. I would like the government to give some compensation for the time you have to take off work. I think the government should have a more active role in giving support for the family. A program like that is definitely necessary." Olivia argued that a program that compensates workers for time off is needed, despite the fact that this is the goal of CCB. Olivia's lack of awareness about programs like CCB increases her financial burden because she is not able to take advantage of existing supports. Gupta (1999) also found that immigrant women informal caregivers are particularly vulnerable to financial difficulties associated with caring for aging FFN because they are unaware of how to access formal supports and no longer have the assistance of established social networks in their home countries. Beyond identifying this barrier, Olivia's claim that the government should play an active role in financially supporting informal caregivers also shows that she is resisting the belief that women's caregiving is not real work. Olivia's statement supports Blumenfeld and Mann's (1980) argument that women's care work should be paid for by the state rather than given freely because it is essential for



maintaining the capitalist economy. Specifically, it ensures the health of workers in the paid labour force and reduces the burden of care placed on formal health care services.

In addition to the CCB program, there is a Caregiver Tax Credit. The Caregiver Tax Credit is a non-refundable credit introduced by the Canadian federal government in 1998 (Service Canada, 2012). It is designed to compensate eligible informal caregivers for the costs associated with caring for eligible dependents. It allows caregivers to deduct a portion of the expenses associated with caregiving from the amount of taxes that are owed for the year (Keefe and Fancey, 1999). Table 4 provides an overview of the main features and eligibility criteria of the tax credit.

Table 4: Eligibility Criteria and Features of the Canadian Caregiver Tax Credit

<b>Caregiver Tax Credit Eligibility Criteria</b>
<ul style="list-style-type: none"> <li>• Claimant maintains a household where the dependent also lives</li> <li>• Dependent is one of the following:               <ul style="list-style-type: none"> <li>▪ a claimant or claimant’s spouse or common-law partner's child or grandchild</li> <li>▪ a claimant or claimants spouse's or common-law partner's brother, sister, nephew, niece, uncle, aunt, parent, or grandparent who was resident in Canada</li> </ul> </li> <li>• The dependent is not just a visitor in the claimant’s home</li> <li>• The dependent has to meet all of the following conditions:               <ul style="list-style-type: none"> <li>▪ 18 years of age or older</li> <li>▪ has a net income of less than \$18,906; and</li> <li>▪ is dependent due to an impairment in physical or mental functions or, over the age of 65</li> </ul> </li> <li>• The claimant is not eligible if he or she has to make child support payments for the dependent</li> </ul>
<b>Caregiver Tax Credit Features</b>
<ul style="list-style-type: none"> <li>• The maximum amount for the Caregiver Amount Tax Credit is \$4,223 per year</li> <li>• Caregivers are eligible to receive income tax savings worth 15% of the tax credit</li> <li>• The maximum deduction of federal income taxes will not exceed \$633 per year</li> <li>• The credit is reduced when the care receivers income is more than \$13,141</li> </ul>

Source: Service Canada, 2012

When asked about financial support available from the federal or provincial governments for informal caregivers, Amina discussed the tax credit. She argued that the tax credit is a step in the right direction because it shows that the Government of Canada has begun to recognize the costs associated with caregiving. However, she has not received it because she does not have enough taxable income.

I think that now there are caregiver taxes and that's good. I've never gotten a Caregiver Tax Credit because I don't have enough taxable income myself. If you look it's also only maybe \$200-\$300 per year. That's not big money. The government has to give people a real choice between an institution and people who want to stay with their families. I don't have a lot of money, so I need more support than that.

Amina felt that the tax credit does not provide enough support to low-income caregivers. Because it is a non-refundable tax credit, those with little or no taxable income receive no benefit from claiming it. As such, the tax credit does not offer real financial help for the caregivers who arguably need it most. Existing research shows that women informal caregivers in Canada have lower levels of taxable income than men, and that many work part time (Stajduhar, 2004). Moreover, the most frequently cited reasons for working part time among Canadian women is caring for children and aging FFN. As a result of their unpaid caregiving duties, low income women such as Amina are less likely to benefit from the Caregiver Tax Credit than higher income caregivers. This demonstrates that gender and income intersect to create a structural barrier to accessing the Caregiver Tax Credit for low income women in Canada. Financial support for informal caregiving continues to be framed as something that must be earned, rather than as a social good in and of itself.

Another drawback of the Caregiver Tax Credit is that it only acknowledges the care of aging FFN living in Canada, which exempts informal caregivers who send remittances

back to their home countries to contribute financially for the care of aging FFN. A number of the immigrant informal caregivers interviewed routinely send a substantial amount of money to aging FFN for this purpose. For example, Rita has to care for her mother-in-law in Canada, as well as having to send money to care for other aging FFN in Ghana.

Even though we are here in Canada we are still taking care of our family members back home. We have large families. It's not just you and your husband; it's not just your immediate family here. We have parents that need help. If they need help then you have to support them because we don't just worry about ourselves as individuals. We send maybe about \$500-\$1000 every three months depending on what we can give. It's a lot of money. In Ghana that is what children are expected to do. They also think that because we are in Canada we have a lot of money. They don't understand how many bills Canadians have.

For Rita, caring for aging FFN in Ghana is tied to cultural expectations. Even though she does not live in Ghana with her parents, she is expected to contribute on an ongoing basis. Rita also noted that “we”, referring to people from Ghana, do not just consider the needs of immediate family when an extended family member requires support. This corroborates Knight et al.'s (2002) research finding that those from cultures that emphasize the collective good of the community are more likely to provide needed care to aging FFN, even when it represents a substantial burden. In Rita's case, the burden associated with sending large sums of money result from cultural expectations of care and status as an immigrant in a country perceived to be a land of opportunity. She noted that her family members in Ghana assume that she has a high income simply because she lives in Canada. Rita's experience demonstrates how culture can intersect with immigrant status to increase the financial burden for immigrant informal caregivers. Rita's experience also provides support for Satzewich's (2006) claim that women are more strongly tied to their home countries, particularly when leaving behind aging parents. Satzewich (2006) concludes that

because of having a closer connection, women are more likely to send remittances to aging parents compared to men. While it is not necessarily possible to direct health care spending in Ontario to those who send remittances to care for aging FFN outside of Canada, this is a factor that policy makers may wish to consider as Ontario's immigrant population continues to grow.

In addition to using financial support programs like CCB and the Caregiver Tax Credit, many caregivers discussed receiving home care support through the Community Care Access Centre (CCAC) to assist with caregiving duties. Dafiya explained that she receives a range of services through the CCAC for her mother-in-law.

We have a Red Cross worker that comes in the mornings, and her job is to help with my mother-in-law's personal grooming. She always gets a sponge bath. The CCAC is taking care of that, so PSWs from Red Cross come. They have also arranged for a nurse who comes and changed her bandages twice a week, and also a physiotherapist was here. That was covered. An occupational therapist also came. Those supports have been a big help.

Dafiya has access to funded personal support care, nursing care, physiotherapy and occupational therapy for her mother-in-law, which she feels have been very helpful for her. While most caregivers valued the support they received through the CCAC, many did not feel that they got enough. CCAC Client Service Manager Mark explained that there are strict limits on the amount of assistance offered through the CCAC. For example, Mark discussed the maximum cap placed on personal support care. "The normal for PSW care in the home is 90 hours a month maximum." As discussed above, an exception to this is when more care is provided for those in the Home First Program. Although Mark stated that 90 hours is the maximum amount of personal support care provided, it is important to note that, depending on the CCAC assessment, the allotted home care support can actually be much lower than the

maximum allowed. This claim is supported by a review conducted by the Ontario Ministry of Health and Long-term Care (2013), which found that standards for care provided through the CCAC are discretionary and that guidelines can vary widely. As a result, while an informal caregiver in one area of Ontario may receive personal support care for their aging FFN, an informal caregiver in another area may not. Typically, informal caregivers do not receive the maximum amount of personal support offered through the CCAC. For example, Paula receives 16 hours of PSW support per month to help care for her father.

They give me a three or four hour respite at a time. That is all I could get. Even that is hard because I live in the country. It's nothing for me to take four hours by the time I go to do my shopping and come back. That's where you feel trapped because you have no life. You are working all the time and you only get out to do grocery shopping. You need a break!

Paula's experiences support research conducted by Chang, Brecht and Carter (2001) that found that many caregivers feel socially isolated and overwhelmed due to providing high intensity informal care. In addition, social support and assistance with caregiving activities were found to reduce feelings of social isolation among informal caregivers. Paula argued that the limited amount of support she receives through the CCAC does not give her the time she needs to take a break from caregiving. Similarly to Paula, Eman stated that she does not receive enough support.

I have to go to work, I have to take care of my grandchildren and I have to take care of my house. All of that is hard to manage with taking care of my mom. Right now we get a little bit of support from home care. I feel like I would like more, but I don't feel like I should be asking.

Eman's experiences with managing paid work, care for younger dependents, and care for her aging mother indicate that she is part of what researchers refer to as the sandwich

generation (Pyper, 2006). However, Eman noted that she has not asked the CCAC for more support than she was originally offered. Hazel, a PSW from Zimbabwe, argued that in her experience new immigrants like Eman are less likely than those who are Canadian-born to access caregiver support services, such as home care through the CCAC. According to Hazel there are a number of reasons for this. First, as previously noted there is a lack of information on available resources. Second, many immigrants have a fear of overusing the system. Third, many immigrants face cultural expectations that encourage them to provide care to an aging FFN without formal health care support.

Some of it is a lack of knowledge that they can access these services and some of it is fear that they will make people mad by asking for too much. I think that is one major reason that not as many African immigrants seem to use home care. Another reason is that I think some cultures prefer to take care of their own people. For example, where I come from we would rather take care of our own people. I would rather have my grandma at home, take her to the hospital and take her home, rather than take her to a nursing home. Because I'm in Canada and there is only me, I would need somebody to help relieve me. In that case, I would try to access home care. However, if there was myself, my sister and my cousin then I know we would take turns to take care of that person. I know those are the issues.

After describing the reasons why immigrant informal caregivers are reluctant to use formal home care support through the CCAC, Hazel discussed her own feelings about caring for an aging FFN in Canada. She argued that, while it would not be consistent with cultural expectations in Zimbabwe, a lack of family support would make using home care necessary for her if she were to care for her grandmother in Canada. Hazel's response provides support for Knight et al.'s (2002) research conducted on immigrant informal caregivers in the United States, which found that after immigrating caregivers begin to conform to American standards of care for aging FFN. Specifically, they become more open to using formal care supports. The current research indicates that immigrant informal caregivers in Canada are

experiencing the same shifting expectations of care. The fact that the context of care can alter cultural expectations underscores the importance of understanding the complexity of caregiving relationships based on social location. Intersectionality theories become an important part of a theoretical framework used to explain the experiences of immigrant informal caregivers because, according to Zambrana and Dill (2009b), they acknowledge the impact of historical and social context, which leads to a deeper analysis of multiple marginalities. Like Hazel, Mark argued that immigrants often have a harder time accessing home care through the CCAC. According to Mark, as with financial support programs like CCB, these services are more difficult to access because immigrants are often unaware that they exist.

I know that a lot of the immigrants are told about our services from somebody else. The one case I just referred for the person from the Indian background actually got the referral information from a friend of their community. They said you get the CCAC in there because they'll do this for you. Yeah, there is a difference between how they find out about us. The community link is stronger for immigrants who use our services. If you've lived in Ontario then you know about home care. You might not understand what CCAC is but if you say home care then you know.

In Mark's experience new immigrants are more likely to find out about home care through informal social networks compared to Canadian-born caregivers, who likely already know that home care is an option. This clearly poses a challenge for those without established social networks, particularly recent immigrants in Southern Ontario. It is important for the provincial and federal governments to proactively respond to the needs of new immigrants because social networks that traditionally provide support no longer exist. The findings indicate that it may be unreasonable to assume that immigrant informal caregivers will request the help that they need. Overall, the Canadian-born caregivers

interviewed were more willing to ask for supports from formal health care providers. For example, Kelly noted that she is constantly seeking more services for her grandmother.

We pretty much used everything that I know of. I wish I knew more. I think I have a pretty good idea of what support there is, just from what I see. I've always tried to throw that in when I'm talking to the doctors. I think you have to ask the right questions. You don't just go in and say; what do we qualify for? You've got to be specific, which is hard if you've never had to deal with that. It would be hard for people who aren't familiar with the system here. You might just assume that if you qualify for something then they would tell you what you can have. I'm going to try anything I can get if it means that I get extra care.

Kelly frequently advocates for herself and her grandmother by asking her physician what services are available. While she may not have a complete knowledge of all of the programs that are available, she knows that her physician is a gatekeeper for this information. She argued that this persistence plays an important role in helping her to get extra care for her grandmother. Unlike the racialized immigrant informal caregivers, the Western European-born caregivers interviewed also appeared to be more prepared to search out formal care supports. For example, Ellie said that she has had to be tough in demanding support for her father.

You have to be investigative. You really have to go out and find all the information you need. Nobody is going to come knocking at your door and say this is what we can give you. You've got to go right to the source. You have to do your own research. I think the government is honestly unprepared because it is an aging population.

Ellie has done a lot of research in order to find out about the services that are available to support those caring for aging FFN. While she did not necessarily feel that the government is intentionally hiding this information from informal caregivers, she claimed



that they are not prepared to support those caring for aging FFN because the population of aging Canadians is growing so rapidly. The responses of the Western European-born caregivers like Ellie indicate that not all immigrants take the same restrained approach to asking for caregiver resources. Informal caregivers from Western Europe may also be more familiar with the Canadian health care system, and programs available for informal caregivers, because some similarities do exist. For example, there is the Carer's Allowance program in Britain, which bears some resemblance to Canada's CCB (Directgov, 2009). Through the Carer's Allowance, those caring for an aging FFN for 35 hours a week or more are given an allotted weekly allowance. The above findings indicate that not all immigrant informal caregivers share the same experiences simply because they are immigrants. There are important differences within immigrant groups that shape access to and utilization of formal care support, such as how similar the health care system in the country of origin is to Ontario's. This indicates that the concept of complex diversity is useful for analyzing the experiences of immigrant informal caregivers because it acknowledges that immigrants do not represent a single homogeneous community.

In this section I have outlined three main challenges shared by Canadian-born and immigrant informal caregivers: barriers related to the gendered structure of caregiving embedded in federal and provincial health care policies; financial difficulties associated with managing care; and a lack of home care support. The data indicate that while these barriers are experienced by all caregivers regardless of background; immigrants often face the same barriers to an exaggerated degree because of factors like a lack of information about available informal caregiver supports.

## **4.2 Challenges in Managing Care Unique to Immigrant Informal Caregivers**

In this section I discuss the challenges in managing care that are unique to immigrant informal caregivers. The analysis is rooted in the responses given by the immigrant informal caregivers who were interviewed. According to hooks (2000), it is important for feminist research to incorporate the viewpoints of women with multiple marginalities because they have a unique perspective as a result of their marginalization. Specifically, immigrant informal caregivers are more aware of the lack of support that exists for caregivers with multiple marginalities than white Canadian-born caregivers. Resources designed to support informal caregivers in Ontario have been created with the needs of white Canadian-born caregivers in mind. The data from phase one of the research revealed four main barriers that are experienced by immigrant informal caregivers: language barriers; ability to access programs that accommodate the religious background of aging immigrants; supports that address culturally based food preferences; and programs that have suitable recreational activities for aging immigrants.

### **4.3.1 Language Barriers**

The primary barrier discussed by many of the immigrant informal caregivers was difficulties in caring for an aging FFN with a language barrier. While immigrant and Canadian-born caregivers shared similar experiences with the types of tasks required in providing care, those caring for someone with a language barrier were also often called upon to act as a translator. For example, Amina has to translate for her mother who only speaks Somali.

The other difficulty that my mom has is that, since she doesn't speak the language, I have to translate for her. I have to be her translator, her driver, her assistant, her cook, her nurse—her everything. Sometimes I feel that I have several roles as her caregiver. I have to do all of those things. I do a combo of work for her.

Amina argued that having to translate for her mother is another task on her long list of caregiver duties, including assisting her with activities of daily living. Amina's statement confirms research conducted by the Canadian Research Network for Care in the Community (2011), which indicates that the need to provide translation for an aging FFN with a language barrier further intensifies the caregiver burden experienced by immigrant informal caregivers. Unlike Amina, Cara argued that providing assistance with translation for her grandparents is actually one of her main duties because they are still in good physical health. For example, Cara translates for her grandparents when they have a physician's appointment.

I usually just have to help them with the stuff for physical health concerns. I have to take them to their doctor's appointments. I have to go for anything where I need to translate for them. Like, for a specialist appointment I would go with them. If there is any paper work for them to fill out I help them with that. Sometimes it's hard to use the right terminology, like the right word to explain something. It takes me a bit. Sometimes I have to call my dad and ask him how you say certain things in Vietnamese. I don't want to steer them wrong.

Cara recalled times when she was unsure of how to translate medical terminology for her grandparents. The fact that she does not know how to translate some medical terminology may lead to compromised medical care for her grandparents because research shows that untrained interpreters frequently provide inaccurate translation of medical information (Canadian Research Network for Care in the Community, 2011). This results in things such as taking medications in a way other than that prescribed by a physician. Cara said that in the past she has had to reach out to her father who is more fluent in Vietnamese than she is. In these circumstances, the personal medical information of Cara's grandparents is being passed through three people before it is conveyed to them directly. Cara's status as a 1.5 generation immigrant impacts her ability to translate for her grandparents because

growing up in Canada since the age of five has meant that she has lost some of her fluency in Vietnamese.<sup>64</sup> Cara's experiences provide support for McCall's (2005) argument that the experiences of those who do not fit neatly into established categories of difference become invisible. Cara exists at the margins as a 1.5 generation immigrant caregiver because her experiences do not match either Canadian-born caregivers or first generation immigrant caregivers who came to Canada as adults. Policies that implicitly rely on immigrant informal caregivers to translate needed information for aging FFN with a language barrier do not accommodate the needs of 1.5 generation immigrants.

Imran argued that it is impossible for the Ontario government to attend to the needs of all immigrants with language barriers. "It is very difficult for them to provide support to people of all the languages because there are so many people from different countries, you know? I don't think that they can provide every language. They can't provide for every linguistic group, you know?" Imran noted that Ontario is so diverse that it would be impossible for the government alone to provide language specific programming to all immigrant informal caregivers and their aging FFN. Imran's statement demonstrates the fact that language is one of the main factors that contribute to complex diversity among immigrants, which has also been noted by Kraus (2012). Although offering programming in the languages of all aging immigrants may not be possible in Ontario, there is clearly a pressing need to work towards a solution. A number of informal caregivers who were interviewed argued that ethnic communities should play a role in assisting immigrant

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<sup>64</sup> The term 1.5 generation immigrant is used to describe immigrants who came to Canada as young children, and grew up in Canada.

caregivers with translation. For example, Cara suggested that the Vietnamese community in her area should organize services for its aging members.

I think the Vietnamese community could really be a bit more organized because there are a lot of elderly people. I think a lot of people are going through the same sort of ordeal. I think that people who are willing and able to should get together. I think there should be a volunteer driving program, like what the hospital has. That would be really nice. I think that would help out a lot because then language wouldn't be a problem. Language is definitely a problem.

According to Cara, the Vietnamese community where she lives is not currently organized well enough to provide needed support to aging Vietnamese immigrants. However, she argued that if it were to organize, it would be more effective in providing culturally tailored support to aging Vietnamese immigrants than formal health services in Ontario. For example, Cara is aware of transportation programs that exist for older adults, but does not feel that these programs are accessible for older Vietnamese immigrants with language barriers. Where the ethnic community could not provide needed supports informally, a number of caregivers looked for formal care providers from the ethnic community. For example, Freida found a solution for her mother's language barrier by acquiring a German-speaking physician.

Our family doctor is German, but getting in to see him is very difficult because there are only a few German-speaking doctors. They're always quite booked because the community here is huge. I don't know how many people it is, but it's like a lot. My whole family is with the same doctor. They intentionally looked for a German doctor.

Freida's family physician is able to clearly communicate with her mother because they share the same language. However, the high demand in the community makes booking an appointment with the physician very difficult. Where health care providers do not speak

the same language as aging immigrants, Jaw-Long argued that professional translation is very important, particularly in cases where immigrants do not have a dedicated full-time caregiver.

Translation is very important. Not all elderly parents have their children with them. Not everyone's children can speak English fluently either. To do translation could be hard for the children. It would be much better to have professional translators. Even I don't know all of the medical terms. If a professional translator was available that would be great, great, great.

Jaw-Long explained that it is often difficult to translate specific medical terms, even for those who are fluent in both English and the care receiver's first language. Like Cara, he also noted that not all immigrant informal caregivers speak the same language as aging FFN. Chanda argued that language barriers present such a problem for her in-laws that she must go with them everywhere.

It's very hard for them to understand other people's languages. That's why we have to go with my in-laws everywhere. Sometimes my in-laws can't communicate what they are saying in your language. The main thing is really the language. If they speak the same language it doesn't matter if it's a different culture as long as they understand the language.

Chanda has been unable to access programming that is suitable for her in-laws' language requirements, or a reliable translator. When professional translation services are available in Southern Ontario, they do not appear to be easily accessible or widely publicized. For example, Cara was aware of a telephone hotline that provides translation services for medical appointments, but claimed that it is not very useful because of the long wait time between point of contact and service provision.

They have this line that you can call, but it kind of sucks. You have to wait a bit. They put you on hold or the person calls you back and sets up a time to come see you at that appointment. If they can't make that appointment you just have to reschedule it or do it yourself. Maybe the other programs they have aren't being publicized as much as they could be, but maybe that's because they don't have the resources to publicize it as well.

According to Cara, in order to access interpretation over the telephone an appointment must be booked in advance. This type of lag is troubling when it involves health care that could be related to a medical emergency. What is more troubling is the fact that telephone interpretation is not uniformly available in all parts of Southern Ontario. For example, a report by Nicholas Keung of the *Toronto Star* on October 1, 2012 announced the first 24/7 GTA-wide medical interpretation service of approximately 170 languages funded through the Toronto Central Local Health Integration Network. Prior to this, hospitals and clinics in the area offered telephone interpretation services at their discretion by paying interpreters rates of \$1.70 to \$8 per minute, depending on the language. According to Keung the move to implement a GTA wide program was spurred by studies indicating that patients with a language barrier experience negative health outcomes, including a longer hospital stay, more emergency visits, avoidable health complications, and more frequent readmissions. While the program represents a positive change, it has not been implemented everywhere across Ontario. As a result, geographic location impacts access to formal health care for aging immigrants and their informal caregivers. Without the assistance of an interpreter for medical appointments available in her area, Rita admitted that she does not necessarily give her mother-in-law all of the details about the medications that she is prescribed.

Let's say, you just tell her what the medication is for. You just say the medication is for blood pressure because she knows what blood pressure is. I don't get into the details with her. We say blood pressure in our language, so she knows what that is. The side effects—we just tell her the most important side effects in our language.

Rita claimed that she does not give her mother-in-law information about all of the possible side effects of her prescribed medications, which could result in deadly complications. In addition to translating for aging FFN at medical appointments, a number of caregivers argued that accessing home care through the CCAC was more difficult because Canadian-born PSWs cannot communicate well with clients who have language barriers. For example, Rita's mother-in-law from Ghana speaks only Twi. As a result, Rita said that she cannot seek home care support from the CCAC. "I can't ask the government to help me. The CCAC cannot find someone who speaks my mother-in-law's language. That's very hard too. It sucks. I'm just scared about how I will manage without help." Rita argued that without the help of formal home care support, she will find it very difficult to continue to manage her role as an informal caregiver. Unlike Rita, Eman has accessed home care support through the CCAC despite her mother's language barrier. Because she was unable to find a PSW who speaks her mother's language, she must translate for her mother.

None of the nurses speak my mom's language. I did ask for that, but they said there's nothing they could do. It's hard for my mom to communicate with the nurses that they send. My mom can say a few words, like hot water or use the white towel. I feel like I have to be with her when they are there, so that I can translate what they are saying for my mom.

While the home care provided through the CCAC has been helpful for Eman, she does not feel that it has reduced her burden to the same degree as someone who is Canadian-born because she must always be on hand when a PSW is present. The CCAC offers the



same services to all aging Canadians and their caregivers with staff who speak either English or French. However, for those who do not speak either official language, there is an implicit assumption that they will squeeze themselves into the existing system. The findings indicate that the CCAC runs based on what Fleras (2012) refers to as a model of integration, which focuses on equality of treatment, rather than equality of result. Although the CCAC is not overtly discriminatory to immigrant informal caregivers or their aging FFN, there are systemic barriers that prevent immigrant informal caregivers from benefiting from the full range of supports. In order to manage her mother-in-law's language barrier, Dafiya's family made the decision to privately hire PSWs of the same language background.

My sister-in-law actually knew somebody from her church group who does home care. She had put it out there she was looking for somebody to help take care of my mother-in-law. She was looking for somebody who could speak the language, as well and somebody that she would be comfortable with. We knew we were not going to get that much from the CCAC. These PSWs have been a huge help. I couldn't do it without them.

Dafiya argued that the support provided by PSWs who speak her mother-in-law's language has been essential for her to manage her role as an informal caregiver. The privately hired PSWs are paid by Dafiya's husband and his siblings. The family's collective income affords them the resources to hire PSWs with specific language skills. Many of the other immigrant informal caregivers interviewed simply could not afford to hire private home care staff. This finding is consistent with research conducted by Williams et al. (2013), which found that the ability of those with higher incomes to hire private home care support results in an unequal playing field for low income caregivers. Ethnicity intersects with income to create a barrier for low-income immigrant informal caregivers in accessing a sufficient level of suitable support. Moreover, progressive moves on the part of the

Government of Ontario to privatize certain aspects of health care disproportionately impact those who are not able to supplement services with private care. The above findings support Yuval-Davis' (2006) argument that categories of difference are not reducible to one another, meaning that not all immigrant caregivers will share the same experiences or have the same needs simply because they have the same ethnic background or race. If the Government of Ontario creates programming with the needs of middle income immigrant informal caregivers in mind, they will not address the unique needs of low income immigrant informal caregivers.

In several cases, a care receiver's language barrier restricted caregivers from considering alternatives to informal care in the family home. For example, when asked what she would look for in a long-term care facility for her mother-in-law, Rita discussed the need for a facility where the staff spoke her mother-in-law's language.

I would want to get somebody who could speak her language if I put her in a long-term care home. She hasn't learned any English while she has been here. It's really hard for someone her age to learn a new language. She has never been to school so it would be difficult for her. It would be good if nursing homes maybe advertised for nurses who speak those languages, right? If they advertise for somebody who speaks Chinese, who speaks this, or who speaks that I think it would be good. It would help the people who don't speak the same language. I think that nursing homes should advertise something like that because then they would get people to come in. That way people would be much more likely to put their family member in a nursing home, because then they would be able to meet their needs. If somebody, I mean, maybe somebody wants something simple but because you don't know their language you can't help them. It's something that they have to look into.

According to Rita, having staff at long-term care facilities who could communicate with her mother-in-law is a primary consideration. Rita argued that beyond having staff who can speak different language, long-term care facilities need to advertise this fact in order to

attract older immigrants with language barriers. Murium noted that in addition to staff, she would look for a long-term care facility where other residents speak her mother-in-law's language.

I think that one of the biggest things is that the caregiver in the nursing home needs to be able to speak the same language. It's better if she can communicate with the person openly. She should be taken care of by someone from our community. I would definitely need someone who was a woman who also spoke her language, so that she could communicate with them. The language is the most important. She loves to talk; chit-chatting is her favorite thing. I would want there to be people around that she could talk to, like other patients there too. If this situation comes up then I would definitely look to see there were other patients who spoke my mother-in-law's language.

While Murium maintained that language was the most important barrier to accessing long-term care, she also indicated the need for companionship. Murium argued that her mother-in-law would not be happy if she could not speak with other residents in her language. In addition, Lila argued that service provision in the care receiver's mother tongue is important because as people age they often lose their second language. "Older people who forget the language need somebody from their country who can speak with them. People sometimes forget their second language when they have dementia and things like that." Lila pointed out that many people with dementia lose their ability to communicate in English as the disease progresses.

#### **4.2.2 Religious Differences**

A number of immigrant informal caregivers discussed difficulties in accessing caregiver supports that accommodate the religious differences of their aging FFN. Religion or faith was mentioned by both Canadian-born and immigrant caregivers as a source of

strength for themselves and their care receivers. For example, Nazma explained that prayer has gotten her through many of the difficulties she has faced caring for her husband.

I pray a lot; I do. I pray and I talk to God. I never share my difficulties or my problems with my kids because I don't want them to think, you know, that caring for their father was a burden. I have a friend who is having problems caring for her mother and I told her to get out and do something for herself. We are Muslims so I said go to the Mosque. The Mosque is the best place to listen to some spiritual words and meet with people. There are so many kinds of gatherings there.

Nazma argued that she relies on her faith as an outlet for the stress she experiences as a caregiver. Experiences like Nazma's confirm that religion/faith is important to many caregivers. Moreover, for Nazma, sharing religion with others is more important than sharing perceived cultural similarities. For example, Nazma noted that there is a government funded South Asian senior's centre in her area, but that she has not made use of it. Nazma would prefer a Muslim's senior's centre because she and her husband like to discuss their faith with others.

We like to talk about religion and spiritual things, but over there it is all different communities together. It would be Hindus, Muslims, Punjabs and everyone, so it's hard to do things like that. It would be easier if there were more people of the same religious background together, so that they could get together.

Nazma noted that she does not share a common faith background with South Asians who are Hindu or Punjab, despite the fact that they share a similar cultural background. Her experiences show that programs in Ontario designed to meet the needs of immigrant groups may not be responsive to important differences that exist within groups, including religious orientation. Because the Ontario government has overlooked the complex diversity among South Asian immigrants, informal immigrant caregivers like Nazma remain excluded from recreational programming for older adults. Specifically, Nazma's race intersects with her

religion in a way that limits her from making use of programs purportedly designed to address her needs. This finding supports research conducted by Vertovec (2007), which indicates that policy planners often discuss ethnicity when creating programs for multicultural communities, rather than discussing factors such as religious differences. Vertovec reviewed policies directed at immigrant communities in Britain, and concluded that policy makers tend to create programs that link cultures to specific religious affiliations. For example, there are programs that assume that British people are mostly Christian and Bangladeshis are mostly Muslim. Vertovec argues that this has the unintended consequence of ignoring variations within immigrant groups, such as the fact that those born in South Asia may be Hindu, Sikh or Muslim, and that even among these religions there is considerable variation in sects.

Like Nazma, Dafiya has not found existing programming in Southern Ontario responsive to her aging FFN's religious needs. Specially, Dafiya argued that she has been unable to find a PSW through the CCAC that meets her mother-in-law's religious needs. She claimed that her mother-in-law would feel more comfortable knowing that the person caring for her was of the same faith background.

Being from the same church group is important because you have the same sort of morals, you know? She wants to be around people with the same sort of beliefs. She trusts them more, you know? Those types of things, just trust and being able to communicate with her, are important to her.

Dafiya argued that her mother-in-law trusts those with the same religious background. In addition to her mother-in-law's language barrier, the need for religious accommodation prompted Dafiya to hire additional PSW support privately. As previously noted, there are many immigrant informal caregivers who cannot afford this alternative. Without suitable

programming and resources many low-income immigrant caregivers are left to pick up the slack or have their aging FFN integrate into the existing system and make do. A number of other participants indicated religious accommodation as a barrier to accessing suitable long-term care for their aging FFN. For example, Odessa argued that if she were to consider long-term care for her father, she would need a facility that accommodates his Hindu faith.

For my dad religion would be important because my dad's a priest. We're Hindu and he's a Hindu priest, and that's everything to him. If he had to go into a home and they were forcing him to eat beef or they were saying you can't do your prayers in the morning because there's no accessibility, it would be horrible for him. I think he would be miserable. He would be absolutely miserable. I think that's really important, being able to cater to more religious diversity. If there was a nursing home where there was a shared religious or cultural background then I think that would be really good. I don't know of anything like that around here though.

As a Hindu priest, religion is a central concern for Odessa's father. She stated that he would be very unhappy if he were unable to actively practice his faith, and that she was not aware of any long-term care facility in her area that would suit his needs. As a result, Odessa faces structural barriers to accessing suitable long-term care based on religious grounds. This finding supports Clow and Kemp's (2012) argument that many women often "choose" to provide ongoing care to dependents because there really are no viable options that meet the needs of their aging FFN. Odessa has chosen to provide ongoing care for her father at home because she does not have any suitable long-term care options. Because women like Odessa appear to provide this care willingly, there is very little motivation for the Ontario government to design programming that is responsive to the needs of older immigrants with multiple marginalities.

### 4.2.3 Food Preferences

In addition to accessing resources that accommodate specific religious backgrounds, many of the immigrant caregivers interviewed argued that accessing supports that accommodate the culturally-based food preferences of their aging FFN is an important concern. As a volunteer who met her care receiver through an on-line volunteer advertisement, Lila spends a lot of her time helping her aging FFN to prepare Hungarian food.

The last time I went to visit her we were cooking a lot too. We cook all Hungarian foods. She always teaches me how to do new recipes. It makes her feel useful that she can help me learn to cook. Cooking Hungarian food makes her feel closer to home and that makes her feel less lonely.

Lila explained that food offers a desired connection to Hungary for her aging FFN. Lila was chosen as a volunteer caregiver largely because she was able to bridge the gap between Hungary and Canada for her care receiver. In addition, being able to share her cooking skills with Lila makes Lila's care receiver feel that she has a purpose. Dafiya noted that the ability to prepare culturally appropriate food was a consideration for her when she hired private PSWs.

The PSWs we hired privately would ask what she wanted to eat, so they made the same sort of foods culturally that she was used to. That was a big help. The PSWs from CCAC would just make them whatever they could make, and it wasn't what my mother-in-law wanted. That's really just it, so for her having somebody from the same culture was big.

Dafiya claimed that the privately hired PSWs were able to respond to the culturally-based food preferences of her mother-in-law in a way that the PSWs sent from the CCAC could not. Despite their best intentions, the Canadian-born PSWs that Dafiya works with do

not know how to cook South Asian foods. The interviews with home care staff, which will be discussed at greater length in chapter five, indicate that those working for companies contracted through the CCAC are open to providing suitable care to older adults of all backgrounds. However, the CCAC does not appear to have taken significant steps towards offering supports that respond to the needs of those with multiple marginalities, at least in terms of accommodating culturally-based food preferences. This is despite the fact that one of the main goals of the CCAC is respect for differences and diversity. The above finding is consistent with Davis' (2008) argument that without substantive changes to policies, any attention given to promoting diversity will be in name only. Specifically, the CCAC does not appear to have taken any serious steps towards accommodating the food preferences of older immigrants.

As with language barriers and religious accommodation, the lack of culturally appropriate food choices means that most immigrant informal caregivers do not have access to suitable long-term care facilities for their aging FFN. Eman, whose mother is completely physically dependent on her, stated that she has considered long-term care but there is no facility close by that meets her mother's food preferences.

We were thinking about it, but the problem is she has an issue with the food. She only eats East Indian food and she won't change at this age. She always says don't put me in a nursing home; let me die in the house if you can't take care of me. She says just leave me in the bed but don't put me in a nursing home. She refuses.

For Eman's mother, the lack of culturally appropriate food in mainstream long-term care facilities is quite literally a matter of life and death. Her mother argued that she would rather die than go to a long-term care facility that does not provide her with the food that she is used to. The importance of food was also discussed by Olivia. She stated that without



culturally appropriate food, the health of immigrants living in long-term care facilities declines. “For people who are a different culture to go into a nursing home—the food changes. They will go down quicker than somebody else. They are not in their environment. They will do much better if the food is what they are used to.” Olivia’s claim that food is linked to overall health is in line with research conducted in Canada and the United States. Widespread nutritional deficiencies among long-term care residents is linked to a host of health issues, including higher rates of mortality (Alibhai, Greenwood and Payette, 2005; MacIntosh, Morley and Chapman, 2000). In addition, Olivia’s contention that culturally appropriate food can reduce these types of nutritional deficiencies among older immigrants in long-term care facilities is supported by reports prepared by Yee Hong’s Centre for Geriatric care, which found that the average weight loss of immigrant residents in the designated multicultural facility is lower than immigrants living in mainstream long-term care facilities (Gorham, 2012).<sup>65</sup> While the importance of food was repeatedly brought up by immigrant informal caregivers, Odessa stated that long-term care facilities continue to ignore the significance of culturally-based food preferences. She argued that for this reason her father would not like to live in a mainstream long-term care facility.

With my dad being a Hindu, his vegetarian diet is very important. I would need a facility that can cater to a vegetarian diet. In a lot of retirement homes it’s kind of like, this is what we make and this is what you’ll eat. As an anthropology major I also know a lot about how different cultures view the elderly. Elderly people kind of lose their identity when you put them in a nursing home. It doesn’t matter what your culture is about there. It doesn’t matter what your identity is. It’s just like be grateful that there is food on your plate. I think that’s one of the reasons why people of colour would try to never put their parents in a home unless they absolutely *had* to. Their lifestyle is just so different from a typical Canadian lifestyle.

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<sup>65</sup> Additional details of this report are presented in chapter one.

Odessa's statement reflects Rushton and Perron's (2007) contention that policies or programs that focus on a single aspect of a person's identity without attending to how other categories of difference interact and intersect with it are unlikely to meet the needs of those with multiple marginalities. Specifically, being a vegetarian is linked to faith for Odessa's father, which she argued is a fundamental part of who he is. She also felt that her father's cultural background would be invisible in a mainstream long-term care facility. Specifically, his identity as a Guyanese man and a Hindu priest would be overshadowed by his status as a long-term care resident. Shannon suggested that designated multicultural facilities offer a viable alternative to mainstream long-term care facilities because they are designed to take into account unique cultural differences, such as culturally-based food preferences.

If there was a nursing home that was geared towards Trinidadians I would probably be leaning on that a little bit. I think that would be better, because I know they have the Chinese ones that cater to the elderly Chinese. She (mother-in-law) would get the foods that she likes to eat. It's hard in other nursing homes, you know? I mean if somebody is cooking the foods that you want and you're able to communicate with people of the same background then you're more comfortable.

Shannon argued that a designated multicultural facility designed for Trinidadians would be more suited to her mother-in-law because it would provide culturally appropriate food, in addition to having staff who are able to convey information in a culturally appropriate way. Shannon also noted that an older Chinese adult would likely be better served by a facility designed for Chinese residents. She concluded that, when it comes to offering long-term care to aging immigrants, the differences within immigrant groups matter. There is not a single multicultural long-term care facility that will meet the needs of all immigrant groups. Moreover, the interviews with Canadian-born informal caregivers indicate that mainstream long-term care facilities will not be able to augment existing

programming for diverse immigrant residents in a way that will be agreeable to older Canadian-born residents, or their informal caregivers. For example, Brianna, who recently placed her mother in a retirement facility, said that she does not want her mother to eat Caribbean foods.

She's not used to fancy sauces, and she's not used to a lot of pasta or rice. They're putting far too much spice in their food and it makes them ill. I mean, really and truthfully they need to relook the food situation over there. I mean, one day they gave them jerk chicken. It's Jamaican! She's never tasted jerk chicken in her life. Never! It's not food you give them. Some of these foods they give them—she doesn't even know the word for it. One day it was ababa chicken. I didn't even know what it was so I went home and Googled it. It's a Caribbean food! I mean, she don't (sic) know that! I mean, give her normal food. I even wrote this down when they had a questionnaire.

Brianna was reluctant to have her mother eat food that was too spicy, and referred to traditionally Caribbean food in particular. Brianna's statement shows resistance to making accommodations for racialized minority immigrants. Similarly, when asked what she would look for in a long-term care facility for her father, Tammy argued that she would look for a facility that had predominantly white Canadian-born residents.

I would look for a place where there were probably not too many ethnics. That would maybe be something to look at with an older person. They have a little more prejudice. You have to watch everybody's needs, right? I don't think my dad would have appreciated it if I had put him in with a whole pile of Pakistanis—do you know what I mean? So, you have to watch your ethnic things.

Tammy stated that older Canadian-born adults like her father are more likely to have prejudiced attitudes towards racialized immigrants. The reluctance of some Canadian-born older adults and their caregivers to accept the inclusion of older immigrants and their needs

presents an additional barrier to developing culturally specific programming in mainstream long-term care facilities.

#### **4.2.4 Recreational Activities**

In addition to providing direct care support, one of the main duties of informal caregivers is providing aging FFN with suitable recreational activities. While all caregivers shared the need to find recreation for their aging FFN, this was a more difficult challenge for the immigrant informal caregivers. For example, Lila argued that her care receiver's children sought out a Hungarian volunteer to provide their mother with culturally suitable companionship, which she has been unable to receive from Canadian-born volunteer caregivers. "They needed to find somebody who was coming from the same country. It's good if you can find caregivers with the same culture, not just language but also hobbies, heritage and everything. That way they could keep her more entertained." Lila argued that her ability to speak Hungarian allows her to entertain her aging FFN. Although many immigrant caregivers initially identified language barriers as the biggest challenge, deeper discussion revealed that offering suitable recreation was also very important. During her interview Amina said that there are a number of activities that she uses to keep her mother occupied. However, she claimed that there are not enough activities in the community that suit her mother's needs as a Somali Muslim woman. As a result her options for recreation are limited.

Every day I walk with her for 10 minutes. I also watch TV with her, just to distract her. We watch Italian soap operas because she understands Italian, but not English. The other thing that I do with her is that I try to play card games with her twice a week. I was thinking that if it was an ideal situation I would like to take my mom to more recreational activities, instead of just staying home. I wanted to take her to swim, that way she could increase her mobility and meet more people. There are no

swim classes for seniors that meet her needs though. A lot of Muslim women cannot swim with men. Even if recreation is available they cannot use it. If we had an alternative that was culturally appropriate I would look into that too.

Amina noted that there are no swim classes designed for older Muslim women in her area because Muslim women require women's only swim classes. Amina's mother's status as a Muslim intersects with the fact that she is an older woman to create a structural barrier to participating in swim programs. While Amina later noted that there are separate swim classes in her area for older adults and for women, there are no classes that combine these two needs. Like Amina's mother, Rita's mother-in-law is mainly confined to the house because she is unable to access existing recreational activities. Rita argued that having a language barrier limits her mother-in-law's participation in many outside recreational activities.

I would like to help more with her entertainment. Sometimes we don't have time to take her to places, and because of the language barrier she can't go anywhere alone. She could not take a bus to go anywhere or anything. Who is going to interpret whatever is going on there for her, right? I would like more cultural stuff. I would like to use more entertainment for her—like African stuff.

Rita argued that providing her mother-in-law with recreational activities that meet her cultural and linguistic needs is an important part of caring. Currently, Rita's mother-in-law is not able to go anywhere by herself because she cannot communicate with people in English. In order to overcome the inaccessibility of mainstream recreational activities, a number of the immigrant informal caregivers interviewed have consulted their respective ethnic communities. For example, Li Na found a senior's club for her father-in-law and mother-in-law.

Here it's very hard to make friends, but there's a Chinese Senior's Club. Every Sunday there's a whole group that will gather together. If you are interested in Chinese dancing then you can join the dancing group. They also have a chess club, so that they can play chess. The senior's club is just for them. I think they are really organized. On Chinese New Year's Eve we have a New Year's Gala. Last year over 500 people came. In the summer time we also organize a BBQ party. The seniors really love those kinds of activities.

Li Na argued that the Chinese community in her city is very organized and provides older adult Chinese immigrants with an opportunity to participate in holiday celebrations and events that are tailored to their cultural backgrounds. Li Na claimed that the older Chinese immigrants she knows are very fond of participating in these events. Nazma suggested that it is the duty of ethnic communities to assist informal caregivers and their aging FFN in this way.

The community should also chip in. The East Indian community should be there for older people. It's kind of like there should be humanity and sympathy with other people. God knows what will happen to us if we don't have the support of the community. No, we don't have enough community support. We don't have nearly enough. We need more. One of my friends, her husband died and she doesn't have any kids, so she is alone. She has been very, very, very sick for a long time because she has fibromyalgia and all kinds of things. She has lots of troubles, trust me. I talk to her for hours. I do as much as I can.

Nazma argued that it is her responsibility as part of the local East Indian community to support older adults in need of companionship. She noted that she makes frequent contact over the telephone with an older friend who has lost her husband. Nazma concluded that more support of this kind is needed from those in her ethnic community. The experiences of Nazma and Li Na illustrate that although the barriers to accessing culturally appropriate recreation are similar, no one program can meet the needs of all immigrant groups because of the complex diversity among immigrants. Ethnic communities fill an important recreational

function that mainstream recreational programming cannot match. This finding echoes Vertovec's (2007) claim that the contributions of ethnic community associations help to offer a sense of belonging for older immigrants by incorporating them into the public sphere. During her interview, Li Na argued that joining the local Chinese club has helped to give her in-laws a greater sense of belonging in Canada. This opinion was also shared by Dafiya, who has enrolled her mother-in-law in an adult daycare program for Muslims.

There is this government funded daycare centre for the elderly that she goes to. She absolutely loves it. It is specifically for Muslim people. When she tells me what she has eaten there it was always East Indian food. The support workers working there were also East Indian as well. That is a great thing that they have. Getting her out is a bit of an issue. She is cooped up here alone all day.

Dafiya explained that the Muslim day program offers her mother-in-law culturally appropriate recreation by giving her an opportunity to interact with other older Muslim adults. Dafiya noted that the Muslim centre for older adults that her mother-in-law attends is funded through the Government of Ontario. This is an important point as many ethnic communities do not have the resources required to sustain organized recreation without core funding. Nadia is the Executive Director of a Muslim-based organization that offers support to older Muslim adults. For example, the centre runs a phone buddy program to ensure that older adults in the community have company outside of their immediate family.

When seniors are at the stage where they can't go out of the house we try to set them up with programs. We have this phone buddy system. We can't go all the time and visit, but if I am sitting at home all the time alone then I would like to talk to someone. We connect people with each other so that at least once a week you call. We get people who can speak their language. They have a good time and they can relate to you. It's hard to keep these programs going because we never have enough money. We need more help from the government because these programs are important. In our parent's time the culture was such that the older you get the more

respect you get. Now it's different. People in Canada just don't have the same amount of time for that.

Nadia argued that her organization fills an important role for homebound older Muslim adults. She claimed that the demands of life in Canada mean that aging FFN may not get all the care they need from their informal caregivers. It is important that organizations like Nadia's exist to fill these gaps. However, Nadia noted that organizations like hers continue to face funding barriers that limit the amount of help they can provide.

The need for long-term care facilities with culturally appropriate recreation was also mentioned by a number of the immigrant informal caregivers interviewed. Although many admitted that long-term care is not their first choice, the pressures of a Canadian lifestyle were repeatedly mentioned as a variable in the decision to provide ongoing informal care. Cara noted that there is a long-term care facility that would meet the needs of her grandparents because it is designed specifically for older Vietnamese people. She explained that one of the main differences in this facility, compared to mainstream facilities, is that the recreational programming is designed to be accessible for people from a Vietnamese background. However, Cara stated that her family has not considered this option because the wait list is too long.

There's a place that I know of that has Chinese satellite on TV, and they have people who speak the language that you need. They have people who speak Chinese and Vietnamese. They have newspapers that are in their languages that they can read. I would want to put my grandparents there, just because culturally that's what they're used to. Entertainment would be very important. I couldn't imagine putting them in a place that they didn't like. They would curse me for the rest of my life (laughs). I think facilities need to be more culturally specific. A lot of them are based on North American culture or Europeanish (sic) culture right now. In some cases I could see that there's more burden placed on the family because they don't have that option to choose a nursing home. I know the waiting lists are so long for nursing homes that



are geared towards different cultures. I do know some families that have someone on the wait list for the place I was talking about, but while they're waiting it's a big burden on them. They are quite burnt out. It would be helpful if there was more than one nursing home they could choose from.

Cara argued that although some culturally specific long-term care facilities exist, there are not enough spaces available to meet the growing demand in her community. She recounted specific incidents involving other Vietnamese families who have had to struggle to manage care for an aging FFN without timely access to the culturally tailored long-term care facility she spoke of. Cara's claim that long-term care facilities do not have enough spaces to fill the need is consistent with research conducted by the Canadian Institute for Health Information (2005), which found that the occupancy rate of long-term care facilities across Canada has been between 80-97% for the past decade. As a result, informal caregivers who need the support of long-term care are left to manage the burden by themselves.

Murium argued that she would not consider a mainstream long-term care facility for her mother-in-law because she would not have access to Bollywood movies. While this may seem like a small thing, for her mother-in-law it is a primary source of entertainment. A possible solution to this problem would be for Murium to put a television in her mother-in-law's room, but Murium was adamant that her mother-in-law would not be satisfied watching movies alone in her room.

My mother-in-law watches all Indian movies, so I would want a place where she could watch them on TV because she enjoys that. She watches all the Indian news channels and all the Bollywood channels. She enjoys that. I would prefer if a facility had that, and if there were people there who could talk to her in our language. She wouldn't want to watch movies alone all day. She likes being around people. Most old South Asian people are like that.

Murium argued that her mother-in-law is a very social person and concluded that her mother would not be content to be socially isolated from others. Recreation represents a unique challenge because it goes beyond simply meeting basic language requirements. It requires ongoing interaction with others. Unlike the above participants who cared for an aging FFN with a language barrier, Olivia argued that there is a need for culturally appropriate recreation even for older immigrants without a language barrier. Despite the fact that her mother's first language is English, Olivia said that the typical activities found in mainstream long-term care facilities are not consistent with Jamaican culture.

I think the entertainment would need to be different, you know what I mean? They could bring in music that was from Africa and the Caribbean. They can do arts and crafts and things that different cultural groups are used to doing. For example, in the Caribbean a lot of them were carvers or they learned to weave baskets and stuff. They could even do crocheting. A lot of crocheting was popular when I was growing up. The men liked to play dominos, you know? It's the little things like that most people don't do in Canada. Dominos is huge in the Caribbean. Most people would know how to play dominos. They could do things like go to events for Black History month. They could do little things like that to help them feel more at home. For example, my mom was in her apartment building and that was geared to income for seniors. My mom never participated in any of the events because they weren't what they liked. It isolated her more.

Olivia provided several examples of recreational activities that would be suited to her mother's Jamaican background, including listening to Jamaican music, wood carving, basket weaving, crocheting, celebrating Black history month and dominos. She emphasized dominos in particular as a common Jamaican game that would most likely be unavailable in a mainstream long-term care facility in Southern Ontario. In addition, she explained that her mother has been unable to participate in mainstream social activities at her apartment building because they do not offer options like those listed above. Olivia concluded that the

lack of culturally appropriate recreation has served to isolate her mother from other older adults. The experiences of Olivia's mother underscore the fact that culturally appropriate recreational activities are needed even for those who do not have to overcome a language barrier. This finding is consistent with research conducted by Phillips et al. (1996), which found that addressing language barriers is not the only needed step for providing accessible care. In fact, it is only a first step in determining how to meet the unique needs of older adults with multiple marginalities. Phillips et al. (1996) argue that the need to move beyond language is particularly important given that many countries have adopted the English language, despite maintaining considerable cultural variation from Western cultures.<sup>66</sup> In order to be inclusive of all older adults, long-term care facilities in Southern Ontario must offer suitable recreational programs. Amina argued that she knows of long-term care facilities that have moved towards a more culturally appropriate model for older Muslim adults in particular.

Some of the long-term care facilities in the U.S. are very good. I saw that there they have some that are culturally appropriate. Even in Toronto there is one or two like that. That is very good. At least there they speak their language, and they have culturally appropriate programs. The program was so good. They had English classes, crafts, wellness activities, and all of that, that were made to meet the needs of Muslims. Every week they had an outing for the older people. It was beautiful. What they did was hire someone who could speak the language of everyone who came. All of the caregivers spoke the same language as the participants. Activities in nursing homes need to be culturally appropriate.

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<sup>66</sup> This conclusion was drawn based on qualitative interviews comparing the experiences of white-Anglo American and English-speaking Mexican American informal caregivers. Phillips et al. (1996) found that despite having a common language, English-speaking Mexican Americans have a distinct cultural background that impacts their roles as informal caregivers.

The facilities that Amina described have recreational options suitable for older Muslims like her mother. These programs illustrate an alternative approach to fitting aging immigrants with multiple marginalities into mainstream programs that do not address their needs. Furthermore, these long-term care facilities are readily acknowledging the experiences of older Muslim men and women by taking their needs seriously.

#### **4.3 Balancing Cultural Expectations of Care**

The desire to provide informal care to an aging FFN does not necessarily preclude the use of formal health care resources, including the use of long-term care in the future.

Research indicates that immigrant informal caregivers are increasingly receptive to the use of these types of resources for their aging FFN. For example, based on qualitative interviews with 113 Chinese informal caregivers of aging FFN in the United States, Tang (2011) concludes that many immigrant informal caregivers view the use of formal supports as a way of strengthening the caregiving relationship and reducing the negative effects of caregiver burden. However, Tang also notes that many resources are not culturally appropriate for aging immigrants because of factors such as language barriers. Each participant was asked in what circumstances he or she would consider the use of long-term care for his or her aging FFN. Although the immigrant informal caregivers expressed reluctance to consider long-term care as an option, each described concrete situations where long-term care would be necessary. On the part of formal long-term care staff, Esi, a nurse from Ghana who works at facility four, stated that she has come to appreciate the purpose of long-term care facilities in Canada.

When I first moved to this country I didn't understand the notion of a nursing home. I said why don't they keep them at home? We take care of our family members at home. Why can't they do that here? I think back home it is different than life here. For life here you pay a lot of bills. To raise your children you have to work to pay

those bills. If taking care of your mom keeps you at home that means you can't work. You can't work because they have to stay with you. Some people want to care for their aging parents, but they can't do that. If they have to go to work and they leave their family members alone at all they could end up falling. If you leave your mom at home to go to work by the time you get home she will be lying on the floor. Anything can happen when you are gone. The nursing homes are the best places to keep those kinds of people, or maybe the retirement homes. I understand the need for nursing homes. It's a very good thing.

Esi argued that because using long-term care facilities is not a standard practice in Ghana, when she first arrived she did not understand why Canadians would use them. However, once she began to integrate into Canadian culture, Esi realized that the pressures of a Canadian lifestyle, including balancing paid work, make the use of long-term care facilities necessary in certain situations. This corroborates research conducted by Yoo, Jang and Choi (2010), which found that immigrants progressively conform to expectations of care for aging FFN in the United States as a result of a need to accommodate a shift in the economic environment. The above findings offer support from a Canadian perspective. As in the United States, many Canadian families must have a dual income to make ends meet, which makes managing informal care for an aging FFN at home challenging. Many of the informal immigrant caregivers who were interviewed expressed willingness to consider long-term care. For example, Dafiya argued that long-term care would be necessary if her mother-in-law were completely physically dependent. "She can feed herself and go to the bathroom by herself. Someone with limited mobility, who can't care for themselves to any degree, would have to go to a nursing home. If you can't meet that standard then, yes, you need to be in a nursing home." Dafiya concluded that long-term care would be the only option for someone caring for an aging FFN who could not go to the bathroom by him/herself. Likewise, Odessa said that long-term care may be a necessity in certain circumstances, such as if her father

could not go to the bathroom by himself, but she argued that it would be a difficult decision because it goes against her culture's expectations of care.

That's such a difficult question because in our culture we don't do that. I think that if your family member is beyond care that you can give, like if they require injections three times a day, then it is okay. I think that if you know that your family member is at a point of no return and they're only going to get worse, then I think that it's acceptable. You can't stop your whole entire life. It's impossible, especially at this point in my life, to put my whole entire life on hold to take care of my dad forever. In a situation like that if they had said your dad is just going to get progressively worse, then I think he would have to be in a long-term care facility.

Odessa claimed that relying on long-term care for an aging FFN is not the norm for someone coming from a Guyanese background. However, as a young adult she would not be able to dedicate her entire life to caring for her father. Similarly, Martina acknowledged that the use of long-term care facilities is also not typical in Jamaica. However, given her struggles with caring for her father, she argued that she would recommend long-term care to anyone caring for an aging FFN in Canada for a prolonged period of time. This is an important finding, given that the National Family Caregivers Association (2004) argues that the average length of informal caregiving for an aging FFN is 4.3 years.

In Jamaica we don't usually put our people in nursing homes, but honestly I would recommend any family who has parents in this situation to either have somebody come in 24/7 to take care of them or put them in a nursing home. Putting a parent in a nursing home doesn't mean that you don't love them or anything like that; it's just that you have to survive just as much as they need to survive. For instance, if I was working I couldn't do this. I definitely couldn't do this. It's hard to manage this type of care with the Canadian lifestyle. I saw a lady on the TV the other day and they were talking about taking care of her dad. She's at home with her dad and she thought it was draining and whatever. She got somebody to come in every so often so that they could sit with him and she could go to the gym. I said hmm, because it's just recently that this has happened with her dad. I thought to myself try doing it for 4 years!

Martina said that after four years she finds it very difficult to continue caring for her father. She added that she would not be able to maintain her role as a caregiver if she were working in the paid labour force as well. Experiences like Martina's reinforce the fact that it is necessary for the government to make long-term care facilities available to meet the needs of aging immigrants with multiple marginalities. Health policy makers in Ontario do not have the luxury of assuming that immigrant informal caregivers will not consider long-term care facilities for their FFN, particularly given the fact that research indicates that even in countries where people are expected to care for aging FFN they receive extensive family support (Gupta, 1999). For immigrants who are separated from their extended family the needed support is often unavailable. The lived realities of immigrant informal caregivers must be incorporated into health programming in order to respond to the needs of those who feel pressured to manage a Canadian lifestyle and conflicting cultural expectations of care. For example, Chanda argued that she has felt increasing pressure to adapt to a Canadian lifestyle.

I am in a similar situation because I am in between my in-laws and the new generation that has grown up here, right? We are like the sandwich. We are sandwiched between both. The seniors are pushing us because they want to know why we are not taking care of them, and our kids are pushing us too. I have to change according to the new generation, and I have to change according to the older generation. I am in between both and that's very hard for us. I have to change myself for my children and for my in-laws. I'm the only one adjusting myself here.

Chanda stated that it is difficult for her to meet the expectations of her in-laws who were born in India, and her children who were born in Canada. In addition to being sandwiched between care for aging dependents and children, which is typically referred to as being part of the sandwiched generation (Williams, 2005), Chanda is also being sandwiched

between South Asian standards of care for aging FFN and the Canadian lifestyle demanded by her children. A number of immigrant informal caregivers claimed that being a part of this new kind of sandwiched generation will change care patterns for aging immigrants in the future. For example, Dafiya stated that immigrants will be less likely to care for aging FFN at home in the future.

As people begin to age, how people are cared for will change. People are more career focused in Canada. People of our generation who have lived in Canada some time are not that type to take care of their elderly parents at home. With my mother, who lived in India all her life, it would have been expected of her that you're taking care of them when they're old. Nowadays it's like this generation needs a choice. Now it's like I don't know if I can do that. I think it's a generational difference as well as a cultural difference, you know? We may be more open to using nursing homes.

Dafiya concluded that there is a generational difference with respect to conforming to cultural expectations of care. While her mother-in-law feels that Dafiya should maintain traditional expectations, Dafiya claimed that immigrants of her generation who have lived in Canada for a number of years need to have the choice between informal care at home and long-term care. In addition, Eman argued that her experiences in Canada have shaped her own expectations for future care. This indicates that the length of time in Canada impacts the care expectations for immigrants.

The people who come from India expect their kids to be doing things in a certain way. But, after living in Canada for so long I am changing. Suppose if my daughter is working and I cannot be dependent on her. I'm not going to be depending on my kids. I'm not expecting that from them. I have different expectations because I understand. My mom gets upset sometimes. She doesn't understand that part because back home the system is different. No matter where people live they have a joint family system. Families live on the same street, cousins and everything. Here it is different, you can't expect that. She's grown up in a different way, you know? If something happens to me then I know I have to go in a senior's home.



Eman concluded that, unlike her mother, she no longer expects to be cared for by at home when she ages because she is aware that her daughter may not be able to balance paid work with informal caregiving. According to Jones, Lee and Zhang (2011) immigrant informal caregivers who identify more with the Western culture than their traditional culture are less likely to feel responsible for caring for aging FFN, and in turn expect that they will also be cared for by Western standards as they age. Eman's experiences indicate that acculturating to Canada means shifting expectations of care for aging FFN. Policy makers in Ontario will need to consider the implications of this as they develop caregiver support programs in the future.

Throughout the interviews, both Canadian-born and immigrant informal caregivers agreed that additional support is needed in order for informal caregivers to continue caring for aging FFN. Tammy claimed that increasing the level of caregiver support is particularly important because of the unprecedented number of older adults in Ontario. "You have all these baby boomers coming. What the heck are they going to do with them all? Most families aren't going to be able to look after the people with the level of support out there right now." Tammy argued that there are not currently enough resources offered to help informal caregivers manage ongoing care at home in Southern Ontario. Policy makers must provide sufficient resources to informal caregivers as the aging population continues to grow. These resources must include additional financial support for caregivers taking time off from work, support in providing care at home, and the option for a suitable long-term care facility if needed and/or wanted. It is imperative that these opportunities be inclusive of all Canadians, rather than integrating those with multiple marginalities into programs that overlook structural exclusion as a result of variables like race, class, gender, and ethnicity.

While such a claim is inconsistent with health care policies focused on the privatization of health care and fiscal conservatism, it is supported by Kittay's (1999) idea that care must be framed as a social good. If care is conceived of as a good in and of itself, providing informal caregivers with the resources needed to maintain the caring relationship becomes essential, rather than optional. Government support is an integral part of a sustainable network of care, alongside community support and informal care from FFN. Jaw-Long summed up this sentiment well.

I think that it should be everybody's job to help. The kids should take care of their parents, but I know that they have other obligations. It is hard to balance caregiving, but with other help it would be easier. Without additional help there is no alternative to taking care of your parents. If there is no alternative then we have to do it. It won't be manageable for everyone though. Something has to be done. The government needs to help, and the community should have a role too.

Jaw-Long argued that caring for aging FFN should be everyone's responsibility, and that providing high intensity care will not be manageable for informal caregivers alone. He concluded that something has to be done to change the current system to make it more supportive of informal caregivers. Jaw-Long's statement demonstrates that many caregivers already conceive of care for aging FFN as a social good.

#### **4.4 Conclusion**

The theoretical framework developed in chapter 2 was used in this chapter to analyze the interviews with immigrant and Canadian-born informal caregivers. The findings demonstrate the usefulness of feminist theories related to care work. They draw attention to the gendered nature of care work for informal caregivers in Southern Ontario. The interviews confirm that informal care for aging FFN is disproportionately shouldered by women without sufficient government support for the financial burden of care. Health policy

makers in Ontario continue to ignore women's care work as real work by relying on implicit assumptions of "the family", which frames women as natural caregivers. While informal caregivers themselves tend to view care as a social good, this sentiment is not reflected in the level of support offered to informal caregivers by the government. Specifically, informal caregivers face a lack of assistance in managing the financial burden of caregiving with limited access to resources including the CCB and the Caregiver Tax Credit. These resources have exclusive eligibility criteria that reduce their usefulness. There is also a lack of direct care support, including limited funded home care services provided through the CCAC. The data also support the relevance of intersectionality theories in explaining how categories of difference like race, class, gender, ethnicity and immigrant status create structural barriers to managing informal care for immigrants. The immigrant informal caregivers interviewed experienced greater challenges in caring for aging FFN due to language barriers, and programming that does not accommodate religious differences, culturally-based food preferences, or culturally-based recreation needs. For example, while there may be programs designed for older adults and programs designed for immigrants, there is a lack of programming designed for older immigrants. Therefore, the experiences of older immigrant groups remain largely invisible. The data support the need for programs that attend to the needs of specific immigrant groups, rather than broad programs designed for all immigrants. For example, a number of immigrant informal caregivers found ethnic communities, culturally specific day programming and multicultural long-term care facilities to be the most useful in meeting the needs of their aging FFNs. In the following chapter I demonstrate how the theoretical framework is useful for understanding the care of aging immigrants from the perspectives of formal care providers.

## **Chapter 5: Data Analysis of Long-term Care Facility Staff Interviews**

Formal health care providers face a number of challenges in addressing the needs of aging immigrants and their informal caregivers. In this chapter, I rely on the qualitative data collected through interviews with management and support staff working in home care and long-term care facilities to identify what these challenges are in Southern Ontario. In doing so, I show how the theoretical framework developed in chapter two supports the analysis. I begin by demonstrating that the structure of formal health care work is gendered in Southern Ontario. Specifically, low-paid support positions continue to be predominantly filled by women, as well as racialized minorities. Higher status positions in management are more likely to be filled by whites, who are less aware of the unique needs of older adults with multiple marginalities. An intersectionality analysis reveals that older immigrants are not well served by mainstream long-term care facilities because accommodation of diverse residents is not well promoted, and resident diversity is often overlooked for immigrants who do use long-term care.

As was the case with informal caregivers in the previous chapter, the paid care staff identified four main barriers to accommodating the needs of older immigrants, including an inadequate response to language barriers, religious differences, culturally-based food preferences, and recreational needs. All of the home care and long-term care staff identified underfunding and an insufficient staff to resident/client ratio as the largest obstacles in addressing these challenges. Interviews conducted with staff members at a designated multicultural long-term care facility in Southern Ontario show that culturally tailored programs are more equipped to address the needs of older immigrants. Table 5 summarizes the background information collected during the interviews, including the occupation of each

participant, facility number, country of origin, and gender. Participants are clustered by facility number in order to provide a clear reference point for comparison.

**Table 5: Formal Care Provider Background Information**

<b>Participant Name</b>	<b>Occupation</b>	<b>Facility Number*</b>	<b>Country of Origin</b>	<b>Gender</b>
Claire	Registered Practical Nurse	1	Canada	Female
Oliwia	Registered Practical Nurse	1	Poland	Female
Lisa	Executive Director	1	Canada	Female
ZhenZhen	Personal Support Worker	2	China	Female
Ying	Personal Support Worker	2	China (Hong Kong)	Female
Qiao	Executive Director	2	China	Female
Hazel	Personal Support Worker/Unregulated Care Provider	3	Zimbabwe	Female
Jane	Personal Support Worker	3	Canada	Female
Mark	Client Service Manager	3	Canada	Male
Esi	Registered Practical Nurse	4	Ghana	Female
Kakra	Personal Support Worker	4	Ghana	Female
Joanne	Executive Director	4	Canada	Female
Janet	Personal Support Worker	5	Canada	Female
Irena	Registered Practical Nurse	5	Croatia	Female
Nancy	Chaplain	5	Canada	Female
Deanna	Care Coordinator	5	Canada	Female
Nadia	Executive Director	6	Pakistan	Female

\* See table 8 for a description of each long-term care facility

### **5.1 Long-term Care Facility Overview**

This research includes representation from private non-profit and private for-profit facilities. Before continuing with the analysis I will differentiate between the various forms of long-term care facilities because research indicates that there is often confusion among those outside the health care industry about the differences (McGregor and Ronald, 2011). Public facilities are owned and operated by the government, and includes municipally operated homes in Ontario. Private facilities can include both non-profit and for-profit

facilities. Non-profit facilities are owned by nongovernmental organizations that reinvest any revenue generated by the facility to benefit resident care. These non-profit facilities are frequently run by religious groups, which is the case for two of the non-profit facilities included in this study. Private for-profit facilities are run like businesses, wherein any profit that is generated goes to owners or shareholders (McGregor and Ronald, 2011). Basic funding for both for-profit and non-profit long-term care facilities is provided through the Ontario Ministry of Health and Long-Term Care.<sup>67</sup> All long-term care facilities are held to the same standards and must adhere to the Long-Term Care Homes Act, 2007.

All Long-Term Care Homes in Ontario (including those formerly known as Nursing Homes, Municipal Homes for the Aged, and Charitable Homes) are governed by the Long-Term Care Homes Act, 2007 (LTCHA). The requirements in the LTCHA ensure that residents of these homes receive safe, consistent, and high-quality resident-centred care in settings where residents feel at home, are treated with respect, and have the supports and services they need for their health and well-being (Ontario Ministry of Health and Long-term Care, 2013).

The purpose of the Ontario Long-term Care Homes Act is to ensure the safety of residents and consistency of care across all long-term care facilities in Ontario. The act is oriented towards encouraging resident-centred care (Service Ontario, 2010). In practice, this means that residents living in long-term care facilities have the right to challenge recommended changes to long-term care policies or programs through an open Residents' Council. Family caregivers are given the same opportunity through involvement in Family Councils. Both councils must be established at all long-term care facilities in Ontario. The Long-term Care Act sets out an extensive set of regulations for resident rights, care, and services (Service Ontario, 2010). Table 6 summarizes the regulation categories and provides

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<sup>67</sup> In Ontario the number of for-profit facilities has increased over the last two decades. McGregor and Ronald (2011: 4) estimate that two-thirds of all new long-term care beds are in for-profit facilities.

an example of each. Long-term care facilities are regularly inspected to ensure that they meet established guidelines. However, McGregor and Ronald (2011) demonstrate that non-profit facilities consistently obtain higher scores on quality indicator measures compared to for-profit facilities.

**Table 6: Ontario Long-term Care Act Regulation Categories and Examples**

<b>Regulation Category</b>	<b>Example</b>
What constitutes a safe and secure home	All doors leading to stairways and the outside of the facility must be kept locked
How to develop care plans	Every licensee at a long-term care facility must hold a care conference within the first six weeks of a resident's admission, and annually thereafter, to discuss a plan of care with the resident or their decision-maker, where applicable
General requirements for programs	Staff will use equipment, supplies, devices, assistive aids or positioning aids that are appropriate for the resident's condition
Nursing and personal support services	Every licensee must ensure all residents receive individualized personal care on daily basis
Required programs	All licensees must ensure that the facility has a pain management program to identify and manage the pain of residents
Responsive behaviours	Written strategies and techniques to prevent, minimize and respond to a resident's responsive behaviour
Altercations	All licensees must ensure steps are taken to minimize altercations between residents
Restorative care	Restorative care approaches must be incorporated into the care plan for all residents
Recreational and social activities	Recreational and social activities at the facility must include a range of indoor and outdoor activities that benefit all residents and reflect their interests
Nutrition care and hydration programs	All licensees must ensure meal plans that include alternative choices of entrees for lunch and dinner
Medical services	Licensees shall ensure all residents have 24 hour a day access to medical services in the facility
Attending physicians and registered nurses	All licensees ensure that either a physician or registered nurse attends the facility on a regular basis to provide services, including assessments
Religious and spiritual practices	Residents must be given reasonable opportunity to practice their religious and spiritual beliefs
Accommodation services	Every licensee must ensure that housekeeping

	services are provided seven days a week
Pets	Every facility must have a policy regarding pets
Volunteers	Every licensee ensures that a staff member is available to guide or direct volunteers whenever it is necessary for resident safety
Prevention of abuse and neglect	Every facility must promote a zero tolerance policy to abuse and neglect
Reporting and complaints	Every complaint made to a staff member of a facility should be investigated and resolved within ten business days, where possible
Misuse of funding	Using allocated funding for a purpose other than what is specified
Minimizing of restraints	When a resident is being restrained he or she must be monitored on an ongoing basis and released when necessary, based on circumstances
Drugs	Every licensee must ensure that every resident receives recent and relevant information regarding the drugs he or she is given
Pharmacy service provider	Every licensee must retain a pharmacy service provider for the facility
Obtaining and keeping drugs	Every licensee of a long-term care facility must ensure that all drugs are obtained based on a residents usage, except for any emergency supplies kept on hand
Absences	A licensee may arrange for a resident to receive a different bedroom where the resident's needs have changed
Discharge	No licensee may discharge a resident unless permitted to do so under stipulated regulations

Source: Service Ontario (2010).

Regardless of how each long-term care facility operates, all residents are expected to pay an accommodation fee. The fees are set by the Ontario Ministry of Health and Long-term Care through the Long-term Care Act, and vary depending on type of accommodation (see Table 7). An amendment to the Long-term Care Act implemented in 2013 raised the maximum rates for accommodation fees in long-term care facilities. For example, the fee for a basic accommodation room increased from \$55.04 per day to \$56.14 (Service Ontario, 2012). Basic accommodation rooms may be subsidized. For those residents with subsidized basic accommodation, the fee will be covered through Old Age Security Benefits. After the fee is paid each resident will be left with a small living allowance for any additional living



expenses. Each facility is required to have a percentage of basic accommodation beds available. In Ontario 60 per cent of long-term care beds are designated as preferred accommodation. According to the Alzheimer’s Society of Ontario, preferred accommodations are private or semi-private rooms that people can access if they are willing to pay higher fees.

**Table 7: Costs of Long-term Care by Accommodation Type**

<b>Maximum allowable co-payment charges</b>	<b>Type Of Accommodation</b>	<b>Co-Payment Daily Amount</b>	<b>Co-Payment Monthly Amount</b>
Basic or standard accommodation	Various styles	\$56.14	\$1,707.59
Preferred accommodation	Semi-private room	\$66.14 (Basic plus a maximum of \$10.00)	\$2,011.76
Preferred accommodation	Private room	\$77.64 (Basic plus a maximum of \$21.50)	\$2,361.55

Source: Ontario Ministry of Health and Long-term Care, 2013.

The research also includes a non-profit designated multicultural facility. A designated multicultural facility is a facility where a certain number of beds are guaranteed to those of a specific ethnic background. While people outside of the designated population may be granted access, first priority will be given to those of the targeted population. The targeted population is carefully chosen through demographic studies in order to determine what the greatest need is. There are an increasing number of multicultural facilities across Ontario, which indicates a growing realization among policy makers that ethnic background impacts the suitability of long-term care for older immigrants. Additional interviews were conducted with a Client Service Manager from the CCAC and two home care PSWs that work for companies contracted through the CCAC.

When discussing the experiences of staff working in long-term care facilities, I refer to the care receivers as residents. For those who work in home care, I refer to the care

receivers as clients. This terminology reflects how the management and support staff themselves refer to the care receivers in each setting. The long-term care facilities where interviews were conducted vary in size. Facility five was the smallest accommodating 96 residents at capacity. Facility two was the largest with 200 residents at capacity. The CCAC that Mark manages oversees care for approximately 34,000 clients per day. While the CCAC’s largest client group is older adults, this number includes adults of all ages, and children. Table 8 provides an explanation of each facility, including facility type and religious affiliation.

**Table 8: Long-term Care Facility Type and Description**

<b>Facility Number</b>	<b>Facility Type</b>	<b>Religious Affiliation</b>	<b>Facility Location</b>
1	Non-profit	Catholic	Mid-sized city, Southern Ontario
2	Non-profit Designated multicultural facility	Not directly affiliated (Offers Catholic and Buddhist support)	Large city, Southern Ontario
3	Community Care Access Centre/ Home Care Agency Contracted Through CCAC	Not Applicable	Mid-sized city, Southern Ontario
4	For Profit	Lutheran	Mid-sized city, Southern Ontario
5	Non-profit	Mennonite	Mid-sized city, Southern Ontario
6	Senior’s Centre	Islamic	Large city, Southern Ontario

Interviews with long-term care staff offer needed insight into the accessibility of long-term care facilities for aging immigrants. Despite the fact that many of the immigrant informal caregivers interviewed in phase one argued that it was against their cultural beliefs to use long-term care, each agreed that there was at least one situation where they would have to rely on long-term care. This was most often related to caring for an FFN who had

severe dementia, or an FFN who was completely physically dependent. A number of caregivers also admitted that they would consider long-term care as an option now, if there was a suitable facility, because of economic pressures. For many keeping up with a Canadian lifestyle means maintaining a hectic paid work schedule alongside care responsibilities. This argument sets the backdrop for arguing for long-term care facilities that are inclusive of aging immigrants.

The demographic characteristics of participants in phase two reveal that, like informal care, paid care work continues to be gendered in Southern Ontario. Specifically, all but one of the long-term care staff who were interviewed were women. This supports Armstrong, Armstrong and Scott-Dixon's (2008) claim that women take on paid care for aging FFN when that care is not provided by unpaid women in the home. The fact that, even when in the paid labour force, care work is viewed as a natural role for women is reflected in the consistently low pay of those working in support roles in Ontario's health care industry. For example, Payscale (2014) reports that the average PSW in Canada earns C\$14.99 per hour. In addition, the average pay does not significantly increase with experience. PSWs with 20 years of seniority make only marginally more than those who are newly hired. The same is true for RPNs, who have an average salary of C\$23.38 per hour in Canada (Payscale, 2014). Nursing across Canada continues to be female-dominated with only 6.2% of men working as Registered Nurses, despite the fact that men are entering the profession in larger numbers (Canadian Nurses Association of Canada, 2012). Zeytinoglu and Muteshi (1999) show that when men do enter the nursing industry, they are more likely to take on management level jobs and receive higher pay than women. They explain this finding by arguing that gender structures which jobs are seen as suited to men and women. Men are viewed as natural

leaders and women are viewed as natural caregivers. This results in women's disadvantaged positions in the nursing field because direct care roles continue to receive less pay than management jobs. The current research supports this finding. The only man interviewed was the Client Service Manager at the Community Care Access Centre.

The results from phase two confirm Zeytinoglu and Muteshi's (1999) research, which also found that white men are more likely to get management level positions in the health care field than white women. In addition, white women are more likely than immigrant women to hold management level positions. While seven of the ten support staff were born outside of Canada, the executive director at the designated multicultural facility was the only manager who was not Canadian-born. The fact that immigrants are not equally represented among management level positions and over represented in support positions demonstrates that gender intersects with ethnicity to marginalize immigrant women in the health care industry. The exclusion of women, immigrants and racialized minorities from top levels of management in home care and long-term care in Southern Ontario may limit the likelihood that those in positions of power will be aware of the systemic discrimination experienced by aging immigrants and their informal caregivers.

## **5.2 Promotion of the Facility**

This dissertation develops the thesis that immigrant informal caregivers lack needed resources in caring for aging FFN due to the caregivers' multiple marginalities, which includes access to suitable long-term care as an alternative to informal care in the home. In order to fully develop this argument, I begin by exploring what steps long-term care facilities have taken to accommodate older immigrants. Two of the ways that facilities can accommodate older immigrants is through promoting the facility as being open to racial and

ethnic diversity, and providing specifically tailored programs for residents with multiple marginalities. Each participant was asked to describe the facility where he or she works, including whether or not the facility makes any special efforts to attract clients from diverse ethnic backgrounds through marketing or special programs. Asking about how each facility advertised was an important part of the research because even if programs for immigrant residents are offered, they will be of little help if people do not *know* that they are offered.

The findings indicate that the way in which admission into long-term care facilities is structured discourages the promotion of services, let alone the promotion of programming that is accessible for immigrants with multiple marginalities. Specifically, all long-term care facilities must accept residents based on a list assessed and maintained by the CCAC (Ontario Ministry of Health and Long-term Care, 2013). The CCAC list determines who is next eligible to receive a bed in long-term care. However, people who have urgent needs are placed at the top of the list. Esi, a registered practical nurse at facility four, explains that new residents for the facility are found through the CCAC. “They work with the CCAC, right? There could be somebody in the community and if there is a bed available they contact CCAC and they will bring the person. The CCAC people working in the hospital will also connect with our home and then bring them.” The CCAC is responsible for bringing in new residents to the facility, and residents are often admitted directly from the hospital. Deanna, a care coordinator at facility five, went into further detail about how the CCAC long-term care lists are structured and how crisis placements are determined.

Part of my job is looking after the CCAC wait list. There’s over 300 people on it. What happens is we’ve had people on our wait list for 1,500 days but somebody out in the community all of a sudden has a crisis so they get bumped. They would move to the top of the list or they might not even be on the wait list. When they are assessed then they bump people who are more stable. Probably, in the last year, maybe four or five have been on the wait list for a really long time and the rest have

been more crisis admissions. I find it interesting because twice a week they do tours of the facility. I'll hear people talking about their three choices but I'm thinking you're never going to get in here unless you have a major crisis.

As a care coordinator, Deanna's primary role is in managing the CCAC wait list. However, she claimed that, for the most part, people do not enter the facility until they are considered for crisis admission. For example, only four or five people have been admitted from an extensive 300 person wait list in the last year. This leaves many informal caregivers and their aging FFN who have planned for long-term care in advance waiting as long as 1,500 days to enter the facility where Deanna works. Deanna concluded that as a result of how admissions are structured through the CCAC, efforts made by the facility to provide informal caregivers and their aging FFN with informational tours are not useful. Most of the participants working in the long-term care facilities agreed that they did not see a great need to promote long-term care because the admission list is maintained by the CCAC. This reflects the general lack of effort and resources put towards advertisement. The findings suggest that mainstream long-term care facilities in Southern Ontario will remain out of reach for aging immigrants who are unaware of if/how efforts have been made to make facilities culturally appropriate for diverse residents. The lack of attention given to promoting culturally appropriate programs in long-term care facilities supports Shields (2008) contention that most formal institutions have not yet reached the point of actively problematizing the marginalization that results from indirect exclusion. Shields concludes that additional intersectionality research is urgently needed to inform effective policy change in this regard. According to Lisa, the Executive Director of facility one, there generally are no available vacancies *to* advertise.

We don't advertise (laughs). I mean, you know, truthfully—it's interesting. From time to time we may do something in the paper but we don't advertise. We just can't accommodate that. We might send an article in about a particular event that went on to the media, so that we get some media coverage. But, we don't typically advertise other than to say these are the services and programs we have because we don't have any available spaces.

Lisa explained that her facility does not directly advertise, aside from promoting successful events held at the facility in the local newspaper. While efforts have been made to garner positive media attention, no media attention was directed at encouraging the inclusion of diverse residents. In Kakra's experience as a personal support worker, without widespread advertisement most people only consider long-term care on the advice of a physician. "Most of the time I think the nursing home thing is suggested by the doctors. The condition of the person would tell you whether or not you should take the person to a nursing home or a retirement home." Kakra's assertion that most residents enter long-term care on the recommendation of a physician is consistent with Deanna's claim that most people enter long-term care after being assessed as eligible for a crisis admission. All of the long-term care staff interviewed noted that the facility they work for has a wait list. In many cases the wait times were more than a year long. Lisa mentioned that wait times at her facility could be up to six years.

It's interesting because I was just looking at some figures. We're going to do some strategic planning but the average wait time, or the median, is about 63 days. Remember that is everything rolled into one, so if you're waiting for basic accommodation we've been told here it's probably a five or six year wait list to get in here. If you're prepared to pay for a private or semi-private room it can still be a number of months to years. It just depends because you can be on that list for a couple of years but if the wrong gender is the one that is dying—there's all these sorts of things that you have to do to match. Just because a bed becomes available—if it's a female bed and you're a male then you're not getting in even if you're at the top of the list.

Lisa noted that on average there is a wait of approximately 63 days at her facility. According to the Alzheimer's Society of Ontario (2013), this is substantially lower than the average of 170 days in some regions in Ontario. Lisa stated that wait times can increase for a variety of reasons. For example, Lisa noted that because the rooms are separated by gender, a room with someone of the same gender must become available for the person at the top of the waiting list to receive it. In addition, those who want basic accommodation that come at the lowest cost may have to wait up to five or six years. As a result, those who can afford to pay extra for preferred accommodations will experience a shorter wait time. Likewise, according to the staff at the designated multicultural facility, those wishing to enter designated multicultural facilities will also experience a shorter wait if they can pay for preferred rooms. Even though all long-term care facilities are provided base level funding through the Ontario Ministry of Health and Long-term care, it is clear that there is an unlevel playing field with people of lower income backgrounds continuing to face longer waits. As of 2013, there were over 19,000 people in Ontario on waiting lists for placement in a long-term care facility, which is nearly four times more than in 2005 (Alzheimer's Society of Ontario). These numbers are expected to grow substantially as the population in Ontario ages over the next several decades. Born, Dhalla and Laupacia (2011) note that most people waiting for long-term care placement are being cared for in the community by informal caregivers. The researchers note that approximately half of older adults waiting for long-term care have what are classified as very high medical needs. Coupled with a lack of funded home care support, providing informal care for this population may be particularly difficult for informal caregivers. Moreover, in 2011 there were approximately 4,700 patients in Ontario hospitals waiting for placement in a long-term care facility, who are often referred



to informally by hospital staff as “bed blockers” (Born, Dhalla, and Laupacis, 2011). The negative connotations associated with this label underscore the fact that the Government of Ontario continues to push for a reduced usage of hospital care by older adults.

While most of the participants did not feel that widespread advertisement of long-term care was needed, many mentioned their facility’s website as a source of information. According to Lisa, the website for her facility states that it is open to diversity. “On the website there is a mission statement where we’re clear that we’re a religiously based facility—there’s a little bit about our history. We say that we’re open to people that are of all race, creeds, ethnicities and the whole bit. It’s just a quick little statement.” Lisa insisted that the facility’s website specifically states that despite the fact that it is associated with the Catholic religion, the facility is open to those of all religions. However, this was clearly not something that was strongly emphasized because Oliwia, who works at the same facility, did not know of any such statement on the website.

I don’t think that’s something that this facility has. I’ve looked at the website once and I don’t think that they do that. It’s not widely displayed. We don’t promote that we speak this and that language, or the other. They don’t say other backgrounds are welcome. I don’t think they advertise that.

Oliwia said having looked at the website herself, she did not see any mention of openness to diverse residents. Evidently the efforts made to include residents who have historically been marginalized due to race, class, ethnicity, and religion are not well publicized, even to the staff working at the facility. This indicates a disconnection between messages promoted by management and information that is reaching staff who work most directly with residents, and their informal caregivers. In contrast, openness to diversity was very explicitly stated on the website of the designated multicultural facility. For Joanne, the

Executive Director of facility four, the main goal of marketing on the website was attracting a wealthier clientele.

We haven't purposely diversified and we haven't purposely not. I guess that would be my honest answer. We're not marketing specifically to a Christian population, but we're also not specifically trying to diversify. We're marketing to a wealthier population. We want to continue in that way. It's about service and it's about high quality of care too. That's intertwined and we want that to be a little bit in the background. We don't want it to feel like you're coming into a care facility when you walk through the front door. We're attracting people who want that kind of a lifestyle, regardless of background or ethnicity.

Joanne argued that, as a for-profit facility, her organization has not actively sought to attract more diverse residents because their efforts are dedicated to attracting high income residents, regardless of their backgrounds. Those with the ability to pay more money for preferred accommodations tend to be the target market for advertising and promotion when it does occur; showing again that having a high income is a key variable in accessing the best service in Ontario's long-term care. This may be especially true at for-profit facilities where the organization is run on a business model. According to Janet, for-profit facilities tend to be less focused on patient care.

I used to work somewhere else before but it was for-profit, so I wasn't happy there. The difference is that when you have a for-profit you have somebody at the top wanting to make money. When you are working for a not-for-profit at the end of the year they're not allowed to have money left. It has to be spent. It has to be put back into the residents. At a for-profit it's like I want to cut costs, so now I give less briefs (adult incontinence product) or less gloves. You start getting less care. I have other friends that work in for-profit organizations and they say the same thing. They all have safety guidelines; it's just that you have some that want to be penny pinchers. It's like if I give you an extra box of gloves that's the money out of my pocket. In a not-for-profit it's like well, it's not my money anyways. The guy in the for-profit sees it as a profit. They see it as that will be my money if I don't give it to you.

Janet claimed that money in for-profit facilities is strategically invested in order to maximize profit for the company, whereas non-profit facilities put any profits made back into the care of the residents. Janet argued that this results in support staff being provided with fewer supplies to care for residents, including briefs and gloves, both critical for maintaining sanitary living conditions. Janet's assertion that non-profit facilities tend to provide better care to residents than for-profit facilities supports Hillmer et al.'s (2005) research findings that non-profit facilities do better on most quality indicators for resident care.

As someone involved in the provision of home care, Jane made a special effort to read through all of the policies outlined by the home care agency that she works for when she was hired, despite the fact that it was not a part of her training as a PSW. She did not find anything that promoted diversity, but there was information on anti-discrimination policies. While this shows a willingness to provide equal service to all prospective clients, it does not necessarily indicate any serious steps taken towards inclusivity, particularly for those who have been historically marginalized.

Oh, I would say they are accessible. Like, I didn't see any evidence of them limiting, in other words not giving access to, people from diverse backgrounds. I read their policies and procedures when I was hired and there were statements saying that they would not discriminate. I thought that was important.

Jane felt that the agency she works for is open to diversity because it does not restrict access to care for people from diverse backgrounds. Six interview participants reiterated Jane's belief that a lack of direct discrimination demonstrates accommodation. However, this assumption contradicts Jiwani's research, which concludes that the mainstream health care system contains systemic barriers that effectively restrict access to immigrants by ignoring the impact of historical discrimination that is built into the system itself. For

example, services provided only in Canada's official languages are based on the assumption that those engaging with the health care system are Canadian-born. Consequently, those with a language barrier are inadvertently excluded.

### **5.3 Client Diversity**

A first step in addressing the health care needs of older immigrants and their informal caregivers is identifying *who* the immigrants are. This is necessary in order to accommodate the needs of older adults in a way that moves beyond a single-axis framework that focuses on age alone, by attending to variables like ethnicity. This claim is consistent with Phillimore's (2011) argument that identifying the ethnicity of older immigrants makes room for creating programs that are responsive to complex diversity among and between different ethnic groups. Phillimore's argument is based on two qualitative research studies of health service provision in the West Midlands, United Kingdom where she explored the challenges in meeting the needs of new immigrants within the existing health care system. Phillimore concluded that existing health care provision in the West Midlands, United Kingdom does not meet the needs of diverse immigrants. For example, immigrants lack access to appropriate language supports and information, which leaves them without the treatment that they require, including unequal access to specialist services. Phillimore argues that policies that take a race blind approach are ineffective because, in reality, they result in diverse groups of immigrants trying to fit themselves into a health care system that does not suit their needs, and that they do not understand. In order to identify what steps home care and long-term care facilities in Southern Ontario have taken to respond effectively to the needs of diverse residents/clients, each participant in phase two of the research was asked how the organization that he or she works for identifies a client who is ethnically diverse.

The results reveal that one of the major ways that immigrant residents are identified is through initial assessment tools used in many long-term care facilities. Lisa explained that asking about a client's background is part of the admissions process, which helps to identify any special needs that a new resident may have.

Well it's on the assessment tool at the time of referral. As I said, we also learn some of that through discussion with the individual and with the family. Our Chaplain will also meet with them. The social worker also—we have a social worker who is part of the team, so she might pick up some of that as well. The social workers are part of the initial conference and then they'll go from there, so it will depend on what the needs are. She's one person who works part-time. You know what; most people don't have a need for a social worker. I'm just saying that over the course of a conversation when she's meeting with people she may pick up that that's an issue.

Ontario's Long-term Care Act mandates that each incoming resident, and their informal caregivers, must take part in a care conference with facility staff upon admission. Lisa noted that information about a resident's ethnic background often comes up informally during this process. However questions about ethnic background are not a standardized part of the care conference. Lisa revealed the fact that, in addition to the initial assessment, the needs of residents with diverse backgrounds are gleaned from conversations with the Chaplain or the part-time social worker. Again, there is no guarantee that the resident will have these conversations because meeting with the Chaplain and the social worker on an ongoing basis is often not part of a care plan. This is a troubling finding given that existing research indicates that the ability of institutions to accommodate the needs of those with multiple marginalities is precarious where programs are implemented situationally rather than through standard regulations (Ward, 2004). For example, based on a study of a Latino health organization focusing on HIV/AIDS prevention and education in Los Angeles, Ward (2004) found that lesbian women who are HIV positive fare poorer on health indicators

compared to other groups because there is a lack of standard regulations around programming that meets their needs. Specifically, lesbian women are excluded from programs that target gay men, and are not adequately served by programs that target heterosexual women. The current research findings signal areas where a resident's ethnicity is not being considered when making a care plan as a matter of course, which could impact his or her overall wellbeing.

Nancy, who works as a Chaplain at facility five, admitted that because it is not part of the information she is given as standard practice, she is not always aware of the background of the immigrant residents. This is particularly challenging for Nancy where a resident is not a racialized minority. "This area is an area of immigrants so I can't always tell if somebody was born here or not, although sometimes the accent will tell me." Nancy noted that the area where her facility is located is highly populated by immigrants, although who is and is not an immigrant may not be readily apparent. She said that she often relies on clues, such as an accent, to identify whether or not someone is an immigrant. This kind of guess work was also used by others who were interviewed. For example, Jane also listens to the accents of her clients to determine their country of origin.

Um, a lot of times I like to make conversation with people. If I hear their accent I will ask if they were born in Canada. I will maybe say what country were you born in? Then they will say like England or wherever. I get them talking about where they came from and their memories because elderly people like to talk a lot about their memories. They like to talk about where they come from.

Jane made a special effort to engage with clients about their backgrounds when she detected an accent even though it is not part of the information that she is routinely provided. She indicated that she asks about her client's backgrounds because older adults feel that where they come from is an important part of who they are. The above indicates that race

may intersect with ethnicity in a unique way for white immigrants. Specifically, without additional effort made on the part of formal care providers, it is possible that white European-born immigrants will have ethnic preferences overlooked, and subsequently unmet, because they are not visibly different from white Canadian-born clients/residents. When asked about what information she is given through the initial assessments conducted by the CCAC, Jane said she is only given information that is relevant to the medical concerns of her clients.

It is pretty much medical information, and name and birth date. It will tell you if they have just come out of the hospital, what they are currently diagnosed with and any special requirements. For example, if they are diabetic and they've just come out of the hospital they will need to follow a diabetic diet and you will need to test their blood sugar. They tell you information like that.

Jane argued that as a PSW she is typically told her client's names, birth dates, what they are diagnosed with, and what care requirements they have. In contrast, background information, such as country of origin, is not generally collected by the CCAC during an assessment. Deanna, a care coordinator at facility five, confirmed this saying that the CCAC assessment focuses on medical information.

Yeah, a lot of that medical information would already be made available to us through the CCAC. I've not had so much come across for ethnicity but lately we've had diets come across, like for people who have special dietary concerns. That sort of thing is certainly identified by the CCAC. There is not so much for ethnics just yet.

Deanna acknowledged that the facility relies on the CCAC client assessment for designing a care plan. She noted that she has not seen very much information included about a resident's ethnic background, although information about dietary concerns is a routine part of the assessment. She later added that there needs to be more information included on ethnic background because it is an important part of delivering appropriate care. These

findings indicate that the lack of appropriate programming for immigrants in long-term care and home care is perpetuated by the assessment strategy employed for evaluating the needs of prospective residents/clients, including what information is even considered noteworthy. The challenges created by overlooking resident/client diversity are more acute for support staff who work directly with residents/clients without access to needed information on variables such as ethnic background or language proficiency. In addition, Claire, an RPN at facility one, noted that even if additional background information is collected from immigrant residents during the facility's initial assessment, it is not always made available to support staff. For example, a person's language proficiency is not something that is posted for PSWs or RPNs.

Um, it is not on their charts and it is not on their walls that their first language isn't English. We don't have like a dot to say that they're Portuguese speaking. You know, we have dots for other things, like for people who are diabetic. We don't have specific flags, you know? We don't have anything that says they're from another country. We just know. You know the residents very well because you always work on the same unit. You know your residents very well.

Claire argued that a resident's language proficiencies are not included in his or her medical chart. However, she claimed that charting the resident's background is not necessary because the staff members are well aware of whom they are taking care of through daily interactions. But, this overlooks the fact that many support staff in long-term care facilities work part-time or casually. For example, in Ontario 41.3% of nurses are employed on a part time or casual basis. The Registered Nurses' Association of Ontario (2006) argues that this results in a compromised ability for nurses to perform their duties as a result of fewer opportunities to engage in a meaningful way with clients/residents. It is worth noting that the situation is worse in Canada than the United States, where 71.6% of nurses are



employed full time. Armstrong, Armstrong and Scott-Dixon (2008) argue that the work arrangements of nurses continue to be precarious due to the fact that these “low skilled” roles are not seen as a vital part of health care provision by those in positions of power. In addition, Baines, Evans and Neysmith (1991) add that these jobs do not offer security or high pay because they continue to be devalued as an extension of women’s unpaid labour in the home.

Esi’s experiences as a casual RPN at facility four serve as an important example of the difficulties experienced by casual staff in providing quality care to residents. She argued that it is difficult for her to know a patient’s background because she works as a casual staff member. As a result, Esi goes long periods of time without working at the facility. “I may only be there once every two or three weeks. I don’t remember everything about a person. The next time I am scheduled to work I might be working with people I have never worked with before. They need to do more charting on background and things like that, so that the casual staff know what is going on.” Esi said that because she only works at the facility approximately twice per month, there are many things about a resident that she may not remember. There have also been times when she is working with a recently admitted resident for the first time. Esi suggested that additional charting about background would make providing appropriate care easier. According to Irena, a nurse from facility five, the demographics of the facility have shifted over time.

It has changed. When the facility first opened we had more Mennonites. Now, through the years, you can see more people from other religious groups and people from other ethnic backgrounds. Now we have Germans and people from the former Yugoslavia even. There are also some people from Holland, Germany, Yugoslavia. There are not too many people from China and Arab countries, but there are some.

Irena said the Mennonite facility she works at is now more likely to have non-Mennonite and immigrant residents than when it originally opened in 1963. For example, the facility has residents from Holland, Germany, the former Yugoslavia, China and South Asia. The growing ethnic diversity of long-term care facilities in Southern Ontario makes sense given that Ontario has experienced a shift in immigration patterns, leading to increased numbers of immigrants from non-traditional source countries. It is reasonable to expect that religious, ethnic and racial diversity will continue to increase in long-term care facilities as immigrants in Ontario age. Joanne, an Executive Director from facility four, also felt there had been a small increase in the number of racialized minority residents at her facility. “We were predominantly Anglo-white for sure. That has changed a little bit. I couldn’t say that with any conviction or stats to back me up. I don’t know exactly how the composition has changed. We have some residents who are East Indian for sure.” Joanne claimed that while she believes there are more immigrant residents now than when the facility originally opened, she does not know for certain because exact records are not kept. She relies on anecdotal evidence, such as familiarity with several East Indian residents at the facility, for this information. Esi believed that the facility she works for has become increasingly diverse, based on the fact that she also sees more racialized minority residents. “They have different cultures over there. They have different nationalities. It has increased over the past 12 years that I’ve worked there. We have Chinese, Jamaicans, Indians, Canadians and people from Europe.” Esi noted that the facility now has residents from China, Jamaica and India. However, without being provided with exact numbers it is difficult to determine how diverse the facility actually is, or if there has been a marked increase in diversity over the past 12 years.

Kakra who works as a PSW at the same facility as Esi, did not feel that the facility is very diverse. “We have Chinese people come but there are not a lot. We have a lot of Canadians and then there are Europeans from Hungary, Romania and those countries.” Kakra argued that there are a few residents from China, but did not mention residents from Jamaica or India. Aside from this, she claimed that the facility has mainly white Canadian-born residents and some white European-born residents. Other participants also felt that the facilities they work for have not become any more diverse over the years. Oliwia, a registered practical nurse at facility one, argued that most residents are Canadian-born, with only a few exceptions. “When I first started it was pretty much the same as it is now. I don’t really see much of a difference. There are a few people from different places. I actually don’t really know because we don’t always pay attention to that.” Oliwia argued that she has seen very little change in diversity at facility one, although she admits that she has not paid specific attention. The disagreement as to whether or not the participating facilities have become more diverse highlights the need to collect information beyond direct medical concerns. Tracking information about the ethnicity of residents may contribute to a broader understanding of patterns, which is necessary for creating inclusive long-term care programming. Specifically, this information is required for an analysis that effectively identifies who is left out of existing programming.

There was only one long-term care facility included in the research that kept track of the ethnic background of residents, which was the designated multicultural facility. Immigrant residents are the norm rather than the exception at this facility. According to Executive Director Qiao, encouraging ethnic diversity is a part of the facility’s original design.

So, there were three groups that we kind of targeted but, of course, we wouldn't leave any bed idle. We targeted the Chinese, Filipino and South Asian communities. We admitted a lot of Chinese, but still at this point in time the Filipino seniors have a priority. If there is a Filipino application to the specific designated area, and if the application is vetted by the CCAC to be eligible and we accept the application, then this Filipino senior's application will have priority over other applications. A majority, 90% of our residents, are Chinese. It's kind of multicultural like the community, but the majority is Chinese.

Qiao discussed the fact that her facility targets older adults from the surrounding Chinese, Filipino and South Asian communities, although she admitted that most of the residents are Chinese. Unlike mainstream long-term care facilities, the wait list at the designated multicultural facility allows priority placement for older adults from the targeted ethnic communities. Qiao noted that even in a designated multicultural facility, at times matching the services to the resident's ethnicity is problematic.

Most of the residents are still very much Chinese oriented, but there are an increasing number of Mandarin speakers among the Chinese group. There are also an increasing number of Vietnamese applications. We have now about, I think, 20 to 30 applications of resident seniors who are from Vietnam, or have some Vietnamese origins. It's hard to tell because some of them are Vietnamese-Chinese. The Vietnamese-Chinese—they sometimes identify with the Chinese culture more than the Vietnamese culture. Sometimes we can only tell from their last names that they are part Vietnamese. It may not necessarily be correct in terms of their ethnicity. It could be a Vietnamese-Chinese person but the last name is Vietnamese, so we group them as Vietnamese.

Qiao argued that she and her staff often rely on clues like last name to determine a person's ethnic background. However, she admitted that this may not always be a clear-cut method for identifying a resident's ethnicity. For example, she acknowledged the challenge presented by those with hybrid ethnic identities, such as those who are Vietnamese-Chinese. According to Satzewich (2006), those with hybrid ethnic identities do not rely on essentialized constructions of ethnicity or a single homeland, which makes it difficult to fit

them into established categories. This finding offers an example of “intersectionality invisibility” discussed by Purdie-Vaughns and Eibach (2008). People with multiple subordinate statuses who do not fit the standard model of their respective categories of difference are ignored by programs that only address the ideal model. Because residents with hybrid ethnic identities do not fit exclusively into a single ethnic category, their experiences and needs are ignored by even designated multicultural facilities that do not acknowledge diversity within immigrant groups. Incorporating an analysis of diversity within groups can help to ensure that long-term care facilities are responsive to complex diversity among aging immigrants in the future. The findings offer a warning that relying on identifiers like last name may be misleading and result in the allocation of inappropriate resources. Qiao’s response shows that she has begun to move beyond seeing Vietnamese immigrants as a unified group. Because Qiao works at a designated multicultural facility that is designed to meet the needs of Chinese and Filipino immigrants, she is more attuned to the diversities that exist among immigrants.

#### **5.4 Expectations for Caregivers**

One of the key underlying assumptions in the early stages of this research was that cultural differences contribute to the support needs of aging immigrants. A number of the long-term care staff believed that the needs of aging immigrants were exclusively met by informal caregivers. Yet, the findings in phase one of this research indicate that immigrant informal caregivers are increasingly receptive to using formal supports. Oliwia, a PSW from facility one, claimed that people from India and China care for their parents at home. She argued that the cultural and religious practices of these groups would make adapting to living in long-term care difficult.

I just think they have different expectations for caring for their parents. I have never had residents that were from East Indian or Chinese backgrounds. I'm not sure it would be but, I mean, we would try our best to facilitate them and meet their needs as much as we can. I mean, there are certain things that we can't do. When you move into a nursing home there is a safety committee. You can't have Buddhas displayed and candles all over the place. They are into that stuff and that's what they do. That's their tradition. I think that they pretty much only care for their family members at home.

Oliwia argued that people from an East Indian or Chinese background would have different expectations for care, which would impact their needs. As a result, Oliwia claimed that the mainstream long-term care facility where she works would do the best they could, but that they would have certain limitations. It is important to reiterate that the findings show that while programs may need to be designed with aging immigrants in mind, the basic needs of aging immigrants are no different than older Canadian-born adults. Oliwia's assertion that it would be difficult to integrate the (non-Christian) religious practices of Indian or Chinese residents, although she has never cared for one, may impact her ability to provide appropriate care. She has already concluded that mainstream long-term care facilities are unsuitable for racialized immigrants based on a surface level knowledge of certain religious practices. For example, while Buddhists make an offering of light to Buddha to symbolize the light of wisdom that drives away the ignorance of darkness, the light can be in the form of a candle or a lamp (Buddha Dharma Education Association, 2008). In contrast to Oliwia's contention that Chinese people only care for their family members at home, the Chinese-born Executive Director of facility two argued that Chinese people are actually far more likely to consider long-term care in Canada today than in the past.

Nowadays some Chinese families would consider putting their loved ones in a nursing home because, you know, mom is getting too frail to take care of herself. It's not that she needs a lot of medical attention; it's just that it's not safe for her to be

home by herself or if she fell no one would be there for her. She probably had fallen once and the family realized how critical it could be.

Qiao argued that Chinese families are more open to considering long-term care for aging FFN because as people get frailer they demand constant supervision. As discussed in chapter four, many families require a dual income to pay for household expenses, which leaves no one at home. While it may not be the cultural norm, certain realities supersede expectations that an aging FFN will be cared for in the family home. However, Qiao said that South Asian caregivers remain less likely to consider long-term care facilities for their aging FFN. She believes that South Asian families only consider long-term care in very extreme cases.

The South Asian community is very—they don't like the idea of putting their seniors in nursing homes. They are more conservative than the Chinese community. Unless it is absolutely impossible to take care of the family member at home, due to serious illness, they don't put their family members in a nursing home. For the South Asian community it is only because the loved one had diabetes, heart problems and all kinds of complications that they would consider long-term care. It had to be something that they really, really couldn't take care of at home.

Although Qiao was aware that Chinese families are more likely to view long-term care as a possible option, she appears to hold the same belief as Oliwia when it comes to South Asian immigrants. While Nadia, the Executive Director of the Muslim senior's centre, agreed that the South Asian community is reluctant to consider long-term care, she felt that this reluctance was partly due to the fact that long-term care facilities have not evolved to meet their needs.

If you are at home and they are at work then they need someone to look after you. I said I know this myself through my own experience. I have an older brother who is diabetic. He became really sick and he couldn't walk. He had to be in a wheelchair. It was me, my mother and my sister-in-law at home with him. My brother wanted to come out of the bed and sit on this wheelchair. The three of us could not do anything. We just had to just prop him up with pillows and wait until my son got home. So, I

tell them is it better to keep him home? But, long-term care facilities still need to change. They aren't made for people who are South Asian.

Nadia used her own personal experience in caring for her brother as an example of when it may be necessary to consider long-term care, despite the fact that it contradicts cultural expectations of care. She noted that because her brother is wheelchair bound, and there is no dedicated caregiver available at home who can lift him, he would be better served in a long-term care facility. However, because mainstream long-term care facilities in Southern Ontario were created with the needs of older Canadian-born adults in mind, they do not present a good alternative at present for aging South Asian immigrants. Nadia's experience indicates that developing culturally appropriate long-term care is important because some older adults require more care than can be provided by informal caregivers in the home. Moreover, in certain cases the idea that people from a particular ethnic background prefer to care for their FFN at home may actually regress program development in Ontario.

A number of staff in mainstream facilities were aware that long-term care facilities have become more of an option for people of diverse ethnic backgrounds. For example, Irena, a nurse at facility five, stated that people from China are now more willing to consider long-term care. "For people from China, their parents usually stay with them. But, because they moved to Canada their habits are changed. It's different here. They are more adapting to Canadian ways of doing things." Irena was aware that adherence to cultural expectations of care for aging FFN in the home begins to decrease after immigrants acculturate to Western standards, supported by other research (Knight et al., 2002). Nancy, the Chaplain from facility five, also discussed the process of acculturation. "As immigrants age, they will



probably acculturate practices of looking after the elderly. They will give that care over to the professionals just as Canadians have. They will take less care of their people at home.” Nancy argued that after some time in Ontario, immigrants are more likely to rely on the use of formal care supports for their aging FFN because they see that this is more acceptable in Canada. While immigrants may be more likely to use long-term care due to a process of acculturation, this does not mean that they can simply be successfully integrated into existing long-term care facilities without any changes being made. Claire assumed that the acculturation of immigrant residents means that facilities do not have to have targeted programs to meet their needs. “I don’t think there’s any difference. A lot of the people that are, you know, from Portugal or wherever have lived in Canada for quite a long time. They are used to the Canadian way of life. They are established immigrants.” Claire argued that the program needs of aging immigrants are no different. But, most of the interviews with other long-term care staff revealed that the program requirements of people born outside of Canada do differ. This was particularly emphasized by long-term care staff who were themselves born outside of Canada, and thus have an insider’s viewpoint of structural barriers to long-term care. For example, when discussing if she would choose a long-term care facility for her own grandmother, Hazel, who is a home care PSW born in Zimbabwe, agreed that she would consider this option. Nevertheless, Hazel felt that mainstream long-term care facilities do not accommodate aging immigrants well, especially those with language barriers.

I think some cultures prefer to take care of their own people. For example, where I come from we would rather take care of our own people. I would rather have my grandma at home, take her to the hospital and take her home. I would rather do that than take her to a nursing home. Because I’m in Canada and there is only me, I would need somebody to help relieve me. However, if there was myself, my sister

and my cousin then I know we would take turns to take care of that person. It's also a matter of language barriers. People with language barriers can't go to nursing homes even if they need them. People are afraid that maybe they are not expressing themselves. It might not be fear—it could just be that when they express themselves they are misunderstood, so they just don't get the services they need.

Hazel's statement provides further support for Gupta's (1999) research, which indicates that even in countries where cultural expectations dictate that care should be provided in the family home, it is typically shared by more than one primary caregiver. Specifically, Hazel argued that if she were in Zimbabwe she would have support from her sister and cousin to help care for her grandmother. However, in Canada this support would be unavailable to her, which would make using home care or long-term care necessary. Many immigrant informal caregivers remain heavily involved after long-term care placement in order to ensure that proper care is provided. Like other support programming in Canada, mainstream long-term care facilities are designed to accommodate those who are white Canadian-born. Long-term care facilities that fail to keep pace with changing demographics will not be able to respond to the needs of aging immigrants. According to Esi, a nurse from Ghana, immigrant informal caregivers visit more frequently than those who are Canadian-born.

People born outside of Canada have different cultures, right? Normally it's (putting a FFN in a long-term care facility) because of work, you know? They just can't manage at home. Their family members have bad dementia or maybe a bad stroke. It would be difficult for their family to take care of them and then work as well, so they bring them here. Those people—what they do is make sure they come after work to just come and see them. They visit more often because they know the family members don't like it here. They seem like they feel more guilty about putting their family member in a nursing home, but they can't do anything about it. They have to work.

Esi confirmed that the need to work makes relying on long-term care essential for many immigrant informal caregivers. However, she argued that because mainstream long-term care facilities are not designed for diverse residents, immigrant informal caregivers often feel guilty about making this decision. Like Esi, Kakra also said that Canadian-born people visit their FFN less often compared to immigrant informal caregivers. “I would say those who were not born in Canada spend a lot more time than Canadians. A lot of the Canadians don’t really come to see their family members often. They still come, but not really that often.” This finding indicates that even after an aging FFN enters long-term care, it may be more time consuming for an informal caregiver to care for an aging immigrant than for an aging Canadian-born adult. Zhenzhen, a Chinese PSW working at facility two, said that Chinese caregivers visit more frequently because the cultural expectation is that they will provide more hands-on care. “I don’t know, but maybe their traditions are different. Our Chinese people, not all of them of course but some of them, really give a lot of time to their parents. They come every day.” Zhenhen noted that cultural expectations of care do still influence the amount of hands-on care provided by many informal caregivers in some ethnic groups, such as Chinese. Although many of the staff at the long-term care facilities felt that immigrant informal caregivers are more involved in the lives of their aging FFN, this was not uniformly the case. For example, the Care Coordinator from facility five argued that the granddaughter of the Japanese resident does not visit often.

The one Japanese lady, her—I actually don’t think her children are living here; it’s her granddaughter that looks after her. I very seldom see her in here. She works out of town and has a young family. It is hard for her. She’s still available on the phone if there’s a problem. The other thing that we run into is people who have older families. There is a Chinese lady who is in her 90’s, so her children that look after her are in their 70’s. They are starting to have health problems as well. You also see that. You can see at both ends. They are either still working, busy with their

families, or they are aging themselves. When our residents get into their 90's their own children are elderly. They don't have as much energy or strength to help out. Those are some of the challenges that you sometimes see.

Deanna stated that she rarely ever sees the granddaughter of the Japanese resident because she works out of town and has a young family. This particular case illustrates the time pressures experienced by young and middle aged adults who are part of the sandwiched generation (Williams, 2005). In addition, Deanna discussed the fact that because the average life expectancy is increasing, many informal caregivers of residents are aging themselves. It may be very difficult for informal caregivers in their 70's to provide all needed medical care to aging FFN in their 90's, regardless of whether or not they would like to adhere to cultural expectations of care in the home. The above results highlight the fact that the ability to fulfill expected caregiving roles is mediated by life circumstances. At best it may be misguided, and at worst negligent, to assume that immigrant informal caregivers will be more involved in providing care to FFN because of traditional caregiving expectations.

While categories of difference, such as gender, do not preclude the use of formal support services for aging immigrants, they have a powerful influence on the interactions between immigrant residents/clients and formal health care workers. For example, according to Kakra, there are a number of immigrant residents who do not feel comfortable working with male PSWs or nurses.

I can say we have noticed some difference in those Europeans. I don't know what part of Europe, maybe Eastern European or Hungarian, but one female resident who is there will not work with male PSWs. We have male PSWs, but they don't like male PSWs to give them care. Those people don't like that. They like females to do the care. If a male PSW has a Hungarian resident then they have to switch. He would maybe have to take a different male resident.

Kakra noted that there are Hungarian women residents at her facility who do not feel comfortable with male PSWs doing personal care, such as bathing. She argued that this reluctance is attributable to cultural care preferences among Hungarian women. As a home care PSW, Hazel also noticed that women from certain ethnic backgrounds do not like male PSWs doing their care.

There were some clients who would specifically request a male caregiver. Women from Germany don't like male PSWs. They really tried to make sure the client was happy and that they got what they need. It was not always possible but they always tried to match the client with the worker who they thought would really be able to meet their needs. A lot of immigrants just feel like men don't really care the same way that women do.

Hazel identified women from Germany as being particularly reluctant to accept care from a man. Hazel's statement reflects the fact that people from certain ethnic groups continue to hold the belief that women are naturally imbued with an ethic of care, wherein they believe that women have a genuine desire to ensure the welfare of others (Gilligan, 1982). She said that many German women say that men do not *really* care, in the way that a woman would. In certain cases, the belief in different moral orientations for men and women guides who is seen as suitable for providing informal *and* formal support to older adults. According to Hazel, the organization that she works for does its best to accommodate requests for female PSWs. In other circumstances, participants felt that aging immigrants and their informal caregivers have unreasonable expectations for care. For example, Mark discussed his interactions with a high income informal caregiver from India.

We do have some immigrant clients that have differing expectations than what a Canadian would have. Recently we had a client who was looking more for a housekeeper. This person, I think, was from India. They had money in India and they brought their money with them to Canada. They had servants in India that looked after them. We had this one case where the wife was trying to use our personal support worker to serve food at her party. We just said no we don't do that.

She wanted the personal support worker to go in the next day and clean up after the party. The personal support worker was put in to care for their elderly mom who was living with them, but then they had these expectations. We do get some unrealistic expectations from some of the different cultural backgrounds.

Mark explained that the informal caregiver in this situation expected that the PSW would come to her home and clean up after her party. He argued that she was used to having maids clean for her in India as someone from a high income background. Mark was adamant that PSWs are put in place by the CCAC to fill the personal care needs of the client. He claimed that the expectations held by the informal caregiver from India differ from expectations held by someone who is Canadian-born, regardless of income, because someone born in Canada would not expect a PSW to offer extensive housekeeping services. Mark indicated that he felt the client's unrealistic expectations were caused by a combination of culture and income. Claire also felt that some immigrants have higher expectations for care. But, for her this seemed to be the result of the pressure that immigrant informal caregivers feel themselves.

There is a difference in the way that people from different cultures do things probably. I'm just going to use the Asian culture as an example because Asians tend not to put their loved ones in long-term care because that's their culture. You just look after your elders. Unfortunately, sometimes you have to use long-term care. Their standards tend to be higher, you know? They want things done all the time because they would have done it all the time. They feel like if they are paying for care it should be the same as what they would do.

Claire argued that for some immigrant informal caregivers who choose long-term care for their aging FFN, there is an expectation that the same level of care will be provided by paid staff. She claimed that maintaining these standards is not always possible because the standards are too high. In contrast, there were participants who argued that the expectations of Canadian-born caregivers were harder to manage than those who were born

outside of Canada. For example, Esi, who is a nurse from Ghana, felt that white Canadian-born caregivers are far more demanding.

Sometimes the demands of family members are unreasonable. You know what I mean? It's your people (white people who are Canadian-born)! Okay, normally they are fine to deal with. Some of them are very good and they understand, you know? Some whites are very good and they understand, you know? Some of them think you are not providing good care. They think you are not doing what you are supposed to do, right?

Esi argued that although some white Canadian-born caregivers understand that support staff in long-term care facilities cannot dedicate all their time to one resident, many feel that this means their aging FFN is not receiving good care. In her experiences, immigrants have much more reasonable expectations. It is noteworthy that Esi was initially reluctant to admit this during her interview, possibly because I myself am a white Canadian-born woman. Like Esi, Mark admitted that certain ethnic groups are easier to deal with than those who are Canadian-born.

We have some cultures that are not used to any services. We can say we can give you a personal support worker twice a week. They say this is fantastic! That's great, you know? They're so appreciative and so thankful because the services were never available to them before. We usually see that for people from the Slovak countries. There they never had that service and they are usually appreciative of anything that we give.

Mark argued that immigrant informal caregivers who did not have access to formal caregiver supports in their home country are very thankful to have home care available through the CCAC. He discussed the fact that this was the case particularly for immigrants from Eastern European countries. This finding indicates that access to home care or long-term care facilities can be a welcome resource for those who have not had any support in informal caregiving. This is especially the case for those who do not have the income to pay

for care out-of-pocket. Unlike the above participants, Jane argued that a client's expectations for home care are determined more by income background than ethnic background.

The wealthier clients just expected more of what I would call service, rather than what would be deemed personal care or health care. They wanted health care too, but they almost wanted to treat you like 'the help'. They wanted you to clean up after them more. Where they were from really didn't seem to make the difference. I think it was more how much money they had and how much they were used to having things done for them.

Jane argued that in her experience, high income informal caregivers from any ethnic background tend to demand higher levels of service. She equated her experience working with high income clients to being treated as one of the "help", rather than a health care professional. Jane's argument that high income people tend to be more demanding of PSWs underscores the need for an analysis that does not artificially conflate one category of difference with another. Because race and ethnicity are more visible in a white dominant society, it is easy to associate the traits of one member of a group with the entire group. However, a contextual analysis reveals that income may play a larger part in determining the level of demands that will be placed upon home care staff than ethnicity. Therefore, an analysis that looks at race or ethnicity alone cannot adequately capture the full picture. It is essential for those involved in making policies for long-term care and home care to be aware of these nuances.

## **5.5 Language Barriers**

Each participant was asked if the facility has programs in place to meet the needs of diverse residents. As a result, a number of challenges to accessing care were discussed during the interview process. Communication issues were overwhelmingly identified as the main challenge to providing appropriate care. This barrier was common among all



immigrants who could not speak English or French, regardless of ethnic background.

According to Ying, a PSW working at the designated multicultural facility, even where there is no language barrier communication can be difficult.

The biggest problem is whether or not they (residents) understand what you are saying. Communication is sometimes more difficult than the actual task of the duties. It's not always the different languages—sometimes communication is not very easy even when someone speaks the same language as you. Even if you think something is good, maybe people will not think something is good for them.

Ying stated that in her experience communicating with residents may at times be more difficult than performing direct care. While language barriers present a very large problem, communication moves beyond this to include deeper meanings, and an interpretation of what is in the resident's best interest. In Nadia's experience, the wishes and needs of those who have a language barrier are often overlooked in long-term care facilities because not all staff can communicate with them.

We started going to long-term care homes because we see that the people who cannot speak—it doesn't matter what ethnicity they are, they cannot access even little services that they need. Even the staff ignores them because either they don't understand them or they are just over worked. In this society children are working and they are not able to go to visit their parents or grandparents regularly. They are double isolated because they cannot speak.

Nadia argued that residents who cannot communicate with staff due to a language barrier are often ignored because they cannot speak the same language. This provides a very tangible example of how older adults who do not conform to the white-Anglo standard become invisible to formal care providers in Southern Ontario. As the Executive Director of a Muslim Senior's Centre, Nadia has made a concerted effort to reach out to Muslims in

long-term care facilities in order to help address isolation. According to Oliwia, language barriers are the only issues that residents born outside of Canada have.

The only thing that I see is the language barrier. For them to communicate with the staff and communicate their needs they need a translator. Some of them do and some of them don't need that. Some of them understand enough because they have been here very long. They are able to communicate in simple ways, you know? They can say I need this or I have pain and that sort of thing. Some of them—they come in and they haven't been here for a very long time. They need somebody there to translate for them because they just can't speak. They speak only in their own language.

Oliwia acknowledged that some residents born outside of Canada need additional help with language translation if they have not been in Canada for very long. She argued that those who have been in Canada for some time can speak some English and communicate basic information, such as where they are experiencing pain. However, communication can become problematic due to the progression of diseases like Alzheimer's or dementia, even for immigrants who have lived in Canada for a long time. Many immigrants with dementia lose their second language skills as their cognitive abilities decline. This is troubling given that 60% of long-term care residents in Ontario have some form of dementia, and an additional 30% are diagnosed with some kind of cognitive impairment. Moreover, within the next 20 years the number of Ontarians with dementia is expected to double (Alzheimer's Society of Ontario, 2013). Qiao was particularly aware of the impact of dementia on acquired language skills.

When you get older you kind of regress—you don't necessarily regress, but you prefer to use your own language. You forget your acquired language, the second language, when you age if you have dementia. You also find comfort in your own food and mingling with your own people. That is the idea behind promoting culturally and linguistically appropriate care for seniors.

Qiao noted that she knows many residents in her facility who have forgotten how to speak English. In addition, she claimed that many older immigrants even without dementia simply prefer to use their first language, and find comfort in interacting with others of their own ethnic background. Qiao stated that culturally and linguistically appropriate care for older adults can promote better health. She spoke about a resident with Alzheimer's disease whose condition improved dramatically after being admitted to the designated multicultural facility.

I have stories—there was this resident who passed away maybe three years ago. She was admitted when we first opened as a transfer from another home. She was diagnosed with Alzheimer's and soon after she was admitted into the other nursing home she stopped talking. The staff members at the facility and the woman's family thought it was the progression of Alzheimer's. She was there for three years before she came here to us. Soon after she came here she started to speak simple words. It's likely because she probably realized that, you know, there were people who could understand her. She thought that previously people didn't understand what she said, so why bother?

Qiao claimed that the woman's family assumed that she stopped speaking as a result of the progression of her Alzheimer's disease. However, after three years of not speaking, the woman began to talk when she was admitted into the designated multicultural facility. Qiao reasoned that the woman stopped speaking at the mainstream long-term care facility because she knew that no one understood what she was saying. Qiao's example shows that providing linguistically appropriate care can have a notable impact on a resident's quality of life. It provides a valuable warning about the potential of overlooking the impact of a language barrier. It also shows that while immigrants may face certain structural barriers as a group, the programs required to overcome these barriers must be responsive to differences among immigrants. The diversity among immigrants may not shape the form of the programs in long-term care facilities, for instance many residents need assistance with

activities of daily living, but it will unquestionably guide the content in inclusive facilities. For example, the woman Qiao referred to benefited from interactions with staff who could speak Mandarin. Without targeted programming at mainstream long-term care facilities, staff members described various techniques for overcoming a resident's language barrier. According to Claire, families are often asked to assist with translation.

We've asked families to write out a list of what the words are in their language for what we need them to know. For example, we would want to be able to tell them that it's their bath and they are going to have a bath. We need to know the special words that we are able to speak to them. We want to be able to say that this is what we want, or need, for you to do.

Claire explained that at her facility the families of immigrant residents with language barriers are asked to provide staff with a list of words for basic needs, such as bath. Claire indicated that this facilitates all needed interactions between immigrant residents and staff. While the use of a small number of simple commands shows that support staff are doing their best to integrate immigrants with language barriers into existing mainstream long-term care facilities, it does not reflect a move towards breaking down structural barriers. Immigrant residents are simply required to adjust to a model of care based on the needs of white-Anglo residents. Using a list of simple commands was also a method used by Kakra at facility four.

Some residents come in speaking a little English, but as the time goes on their condition progresses and they would go back to their mother tongue. I remember that with my Hungarian resident. I had to learn one or two words in Hungarian to interact with her. I had to learn a few Hungarian words so that if she wanted to use the bathroom I would know what she was saying. It's very hard when they don't speak English because you don't know what they want. Sometimes we have to ask the family.

Kakra noted that she has learned one or two important Hungarian words to interact with the Hungarian resident in her charge. For example, she knows the word for bathroom. She argued that it is difficult to interact with this resident based on these limited commands, and that the resident's family is often contacted for additional translation. Increased dependence on a resident's family members was brought up numerous times by formal care staff. For example, Nancy mentioned making many telephone calls to family members to help communicate with immigrant residents with language barriers.

It's always very sad when we have a resident who no one can speak to in their first language except their family members. Then there are lots of phone consultations with family members. We say this is what we need to say to your mom and then they say it and hand the phone back and forth to translate. It's hard.

Nancy said that family members are asked to listen to what their aging FFN is requesting and pass this information on to the staff. However, upon reflection she stated that it is sad when residents cannot easily communicate their needs to the staff. Lisa, the Executive Director at facility one, also admitted to asking family members for help where a language barrier was an issue. "We rely on family members to help too. They will bring a niece, a friend, or they will bring somebody to get the message through." Unlike Nancy, Lisa did not appear to think language barriers presented a large challenge in providing suitable care to an immigrant resident with a language barrier. However, in Janet's experience as a PSW for facility five, relying on family members as translators can be problematic.

The language barrier alone, you know, is a huge challenge. When you have somebody pointing at something or yelling about something and you have no idea what they want it's hard. A lot of times if we don't know what someone is saying we will call the family and ask will you speak to your loved one to tell us what they want. The problem is they might have dementia. Sometimes we would get a case where we don't know what they're saying because there's a language barrier, but then

the family doesn't understand because there is dementia. They are upset because their family member is saying something that can't be true, but they're saying it so it must be true. They don't understand, so there is this whole big can of worms that opens up there. The family doesn't have the skills to deal with dementia.

Janet recalled that immigrant informal caregivers have been upset in the past as a result of having to translate for their aging FFN because what their aging FFN was saying did not make logical sense. According to Janet, family members may be unprepared to act as translators because they do not possess the required medical training or background to deal with aging FFN with dementia. The previous chapter supports these findings, as a number of the immigrant informal caregivers had experienced difficulty with translating complex medical information for an aging FFN. This finding also corroborates findings from the Canadian Research Network for Care in the Community (2011). Having to translate medical information on behalf of aging FFN can create additional stress for immigrant informal caregivers. In cases like those discussed by Janet, the involvement of informal caregivers can be unhelpful, or even damaging. The reliance on informal caregivers may not be a good option, especially given the fact that many people only consider long-term care for their FFN because they feel that they can no longer meet their needs.

Other participants said that they relied on fellow staff members who spoke the resident's language in order to communicate. According to Executive Director Lisa, overcoming language barriers is not a problem because a number of staff members speak the same language as the residents who do not speak English. "Where that is an issue we have a list of all of the staff and a list of languages that they write and speak." Lisa noted that she keeps a file of the languages that all staff members speak in order to have the information on

hand when it is needed. Oliwia, a nurse at the same facility, agreed that staff members are available to help with residents who have a language barrier.

With translating, there is always someone within the facility that speaks that language. I don't personally speak Portuguese, but if I get somebody that I cannot communicate with there are always two or three girls that can help. We just had a lady actually who came down a few months ago and she is Polish. She has been here only for six years and she was basically kept at home by her son. She can't speak any English. I have gone downstairs and I have helped translate at least the background. As soon as I started talking Polish to her she was happy.

Oliwia explained that she knows of two or three staff who can help her to translate what the Portuguese residents are saying. She added that she is available to translate for the recently admitted Polish resident who cannot speak any English. While the Polish resident is not on her assigned floor, Oliwia goes downstairs to translate for her on a routine basis. Given the hectic schedules of staff in long-term care facilities, the reliance on a small number of staff may be problematic during very busy times. According to Mark, the CCAC makes an effort to match home care clients with PSWs who can speak the same language.

We will try to match them up (clients and PSWs with specific language backgrounds). We don't have a problem with that because obviously some of these families that are new to Canada, or new to Ontario, may not speak the language very well. We would ask them (the contracted home care agency) if they had anybody who spoke that language available. We ask could they switch schedules around to try to accommodate that. We do our very best.

Mark argued that as a CCAC manager he is aware that language barriers present a problem, particularly for newcomers to Canada. While the CCAC makes an effort to request home care support in the client's language, it is not always something that can be accommodated because of staff availability. Despite Mark's efforts at the CCAC, many caregivers in phase one of the research indicated that they were not assigned a PSW who

spoke their FFN's language. As a PSW at facility four, Kakra had previously relied on a fellow PSW to communicate with a Hungarian resident.

I remember we had one Hungarian PSW, but she has retired, so she's not there anymore. The Hungarian woman is hard to interact with. I cannot talk to her easily anymore because there are no PSWs or nurses who speak Hungarian. Without that we are just trying—we are just trying to figure out what she wants.

Kakra noted that she has recently begun to face communication issues with the Hungarian resident because the Hungarian PSW has retired. She appeared to be somewhat at a loss as to how to move forward with the resident without this support. When asked if she made a direct attempt to hire staff who spoke the same languages as immigrant residents, Lisa said that such a practice would be against the facility's policies.

No, that would be discriminatory. If you are looking at a job there is a union contract that guides you to start with. Outside of that we would be looking at credentials. You would be put through the interview process if we were interested. At this point in time we don't really have a group that we would hire anyone of a specific language background for. There is not a group big enough. One or two people doesn't justify recruiting someone with a particular background.

Lisa explained that anti-discrimination hiring policies in Ontario restrict long-term care facilities from hiring staff based on language backgrounds. She emphasized that hiring was done based on credentials. In addition, Lisa argued that at her facility there currently is not a large enough group of immigrant residents from any one ethnic background to justify such recruitment. In contrast, Qiao argued that the language of applicants is considered an asset alongside of credentials at the designated multicultural facility.

Language is always an asset. It is definitely considered during hiring. I would say there is a natural gravitation to us. People like working in an environment where you see familiar faces and where there is a similar cultural background. But, we do have



staff members who are from a Jamaican background. Quite a few of our colleagues are from the Philippines, some from South Asia and some from Vietnam as well. I think we are used to this multicultural environment so it is not something that people have a lot of problem with.

According to Qiao, language is considered during hiring as an asset, but it is definitely not used to unfairly exclude those who come from other ethnic backgrounds. Qiao argued that her designated multicultural facility has many staff who reflect the ethnic backgrounds of the residents because people like to work in an environment with others of the same ethnicity. However, Qiao noted that the facility also attracts staff members of all backgrounds. She suggested that the diversity of the staff is a result of the multicultural environment of the facility itself. Ying, who works as a PSW at facility two, argued that people from Hong Kong are particularly attracted to working at the designated multicultural facility because it meets their language needs.

Of course people from Hong Kong would prefer to go here because people will find it more comfortable when they meet the people who speak the same language. They would trust them more and believe—it's just easier to understand. I think language is one of the main points. Besides language I would say it's the style of daily life, you know? What I think is that maybe the first impression of the residents is different. They trust you because it's like you are my people and you speak my same language. They won't be scared because they can tell you the truth, you know?

Ying claimed that older adults from Hong Kong prefer the designated multicultural facility because they find it comfortable to work with staff who speak the same language. In addition to language, Qiao argued that residents feel more trusting of staff and other residents who have the same ethnic background and lifestyle as themselves. This is an important finding, given that existing research indicates that higher levels of trust of health care providers on the part of immigrants increases the utilization of health services overall, which

reduces the overuse of expensive emergency medical services and hospital treatments (Phillimore, 2011).

A number of participants working in the mainstream long-term care facilities argued that relying on staff for translation is unreliable. For example, the Care Coordinator of facility five said that there are times she has to rely on a PSW to help with an initial assessment because of a language barrier.

I find that it makes it more of a challenge when you're trying to do assessments on residents if English is not their first language because it's difficult when you don't understand. Sometimes we'll have staff that will speak the resident's language. But, then you're always wondering do they really understand what is being said to them? If you have a PSW asking an assessment type question you're just hoping that it's all being comprehended. That's a challenge. PSWs don't necessarily know what information is relevant during an assessment if they are translating.

According to Deanna, PSWs do not have the training required to do assessments. Consequently, there is a risk that PSWs may not fully understand all of the information that they are being told, or even what information is relevant to pass on to the care coordinator. This is cause for concern because the initial assessment is used to develop the care plan for each resident. In addition, volunteers were often relied on where staff members were not available to translate. According to Irena, the facility where she works makes an effort to recruit volunteers to communicate with residents who have a language barrier.

There are volunteers who would come and they help us out too. The volunteers are intentionally sought out. There is one person with a Russian background downstairs in the Alzheimer's unit. They were seeking a volunteer person who speaks Russian to help her and us.

Irena recalled a specific situation where a volunteer was sought out to communicate with a Russian speaking resident. She noted that this resident also had Alzheimer's. As previously noted, people who do not have specific training in dealing with older adults with cognitive impairments may not be able to accurately understand or convey what they are being told. Esi has also seen her facility address the language barriers of residents with the help of volunteers.

We have two residents, one speaks Cantonese and the other speaks Mandarin. We have a volunteer who is actually able to communicate with these two ladies. It's been really nice to have this volunteer. There is a different connection there. It's amazing how the staff is able to figure out what the residents want, but it must be so difficult to not have anybody who speaks your language.

Esi noted that her facility sought volunteers who speak Cantonese and Mandarin in order to communicate with two residents with language barriers. She saw that despite the fact that staff members could generally understand what a resident's immediate needs were, they could not make a personal connection with residents who had a language barrier. Esi indicated that for this reason, having the volunteers has been a very positive thing for the two residents. Volunteers help to bridge a gap by providing language support free of charge. Nadia, who is the Executive Director of a Muslim centre for older adults, is actively involved in recruiting volunteers on behalf of local mainstream long-term care facilities. "They (residents) don't speak English. Somebody needs to be there to translate, so that's why our volunteers go to long-term facilities. We shouldn't need to send volunteers. It's not fair to rely on volunteers for what they should be doing themselves. They are paid to provide the right care." Nadia felt that it is essential for older Muslim adults to be able to communicate their needs, especially in regards to health concerns. However, she argued that it is unfair

that her organization has to send volunteers to fill the role of paid staff members, particularly because residents in long-term care pay for their services. Nadia concluded that relying on unpaid volunteers is not necessarily the best way to manage the needs of older immigrants.

## **5.6 Religious Differences**

After discussing language as a main barrier for immigrant residents, several additional concerns emerged. The need for religious accommodation was discussed in a number of the interviews, particularly at the three facilities with strong religious affiliations. The facility that Joanne manages was originally opened with the help of the Lutheran Church. The facility is unique because it is for-profit, but the profits are reinvested into other areas of a larger non-profit organization, such as youth and mental health services. Joanne said that the affiliation to the Lutheran Church was a main selling point for residents when the facility was first opened.

It was really more of the religious affiliation with the Lutheran Church of Canada which was the greatest draw. We are very much built on the fact that even though our facility is for profit, the larger organization is a non-profit organization. We are very closely affiliated with the Lutheran Church of Canada. They are instrumental in us being able to purchase the land. That was the biggest draw from there in terms of ethnicity.

Joanne argued that the affiliation with the Lutheran Church has been instrumental in the facility's success. For example, in addition to drawing in an initial resident base, the Lutheran Church also donated funds to build certain parts of the facility. However, Joanne added that the involvement of the Lutheran Church is no longer as necessary because of the growing client base. "We have evolved a little bit. I think in terms of our strong relationship to the Lutheran Church of Canada it's not quite as present." She argued that the direction of the facility has changed over time and moved away from a central focus on the Lutheran

church. As previously stated, the facility is now focused largely on drawing in high income residents. Janet, who works as a PSW at facility five, has seen a move away from the facility's Mennonite traditions.

We are a Mennonite home, so we were Mennonite-based. We're not anymore though. It's been very receptive to the community's needs. I think the difference nowadays is that they don't actually get to pick who comes into long-term care. There is a waiting list and they come as they go. It used to be like well, my aunt is here so I want to be here now. They used to say okay, we'll take you instead of you, but it doesn't work that way anymore. That's across the board in long-term care because there are so many needs. You can't pick and choose anymore; you just get the next on the list.

Janet reported that the facility has moved away from being a strongly Mennonite-focused home in response to the needs of the increasingly diverse surrounding community. However, she added that part of the move towards a more secularly-run facility is because of government regulations around long-term care set out in the Long-term Care Act, which prohibit mainstream long-term care facilities from selecting residents based on religious background. Janet argued that prior to the regulations implemented by the Long-term Care Act, mainstream long-term care facilities in Ontario could choose residents much more selectively. Nancy, a Chaplain at the same facility, went into greater detail about these regulations and how they have shaped the facility.

By law we have to be open to everyone. It's like every other nursing home in the province. All of our dollars come from the Ontario Ministry of Health and Long-term Care. We don't get to say that we only want to take Mennonite people. We try to give the very best care to everybody that we can.

Nancy argued that because funding for long-term care facilities in Ontario come from the Ontario Ministry of Health and Long-term Care, facilities adhere to standard guidelines for admissions. For example, admission is provided to people who require assistance with

activities of daily living at frequent intervals when this care is not adequately provided by publicly funded community-based services (Service Ontario, 2010). Nancy claimed that now the facility is open to people of all religious backgrounds because of the regulations set out by the Ontario Ministry of Health and Long-term Care. The Ontario Ministry of Health and Long-term Care has clearly made a concerted effort to encourage equality of access for all religious groups. However, there have been fewer efforts made to address ongoing structural barriers related to religious accommodation for residents once they enter a mainstream facility. The findings indicate that religiously-based facilities continue to rely on their religious traditions, which leads to the indirect exclusion of others. Care Coordinator Deanna noted that the Mennonite community has contributed large amounts of money to help develop the facility's infrastructure, even though day-to day-funding comes from the government.

We have supporting churches, and their money goes more into the structure. It doesn't really get transferred into hiring another PSW. That funding all comes through the ministry because it's very regulated. The church money comes in through fundraising for special projects. There is a fellowship hall that we have out there, which would be very unusual in most nursing homes. Those are all private dollars primarily from the Mennonite community.

Deanna explained that while the funding provided through the ministry itself is very regulated, in terms of what it can be used for, the money donated through the local Mennonite community can be used for things such as building renovations. For example, a large sum of money has been used to create a fellowship hall where church services are routinely held. Nancy noted that the non-profit Mennonite-based facility also places a greater importance on her role as a Chaplain than other non-religious facilities would.

There is a real openness to having pastoral care. The Mennonite homes in the area all have Chaplains and very little social work help. That's mainly because we've

decided to spend those kinds of social work dollars all in Chaplaincy. For example, I run the spouse support group. That is something that would typically come more from social work, rather than from my office. Because we don't have a social worker, that falls to me. We've always spent more money on pastoral care.

In addition to her work as a pastor, Nancy runs a spousal support group for the spouses of residents at the facility. This type of programming would typically be run by social workers in mainstream long-term care facilities without a religious affiliation. Nancy noted that her role expands beyond what other Chaplains do because the facility has intentionally redirected funding away from social work and towards her. Nancy spoke about the religiosity of her facility in a positive way. However, she also raised concerns about past issues caused by religious differences between staff members and residents. Specifically, she talked about her role in discussing death with families. In her experience, the discussion around death varies depending on the religious and cultural background of the resident. For example, Nancy explained that people from certain Asian cultures do not want to be told directly that they are dying by a health care provider because it is typically the role of a family member.

The thing to watch out for is that there are some—I think there are some Asian cultures where you don't directly tell the person that they are dying. That is always handled by the family. I have a book that I'll turn to for some of that. This will tell me how Buddhists or Muslims handle death. That will give me some clues. I use the book designed for multi-faith populations in hospital. There is a section on rituals and practices regarding death, which is always the part that I read. I use it to talk to staff. It might be a bit of staff education around what you do when a person dies. That is something that I have found helpful to use for people from different faiths. It gives me a kind of jumping off point. It's just the basics for what to do when somebody dies.

Nancy said that she relies on a book about various religious practices around death and dying in order to approach such issues in an appropriate and sensitive way. The book

offers details about things like rituals around the time of death for Buddhists and Muslims. In addition to reading this book herself, Nancy uses the information that she learns to educate other staff at the facility on an as needed basis. Through Nancy's own admission, this book provides only a basic summary of different religious practices around death. It does not serve as a comprehensive information resource that is part of a regulated training program for all staff at the facility. Phillimore (2011) concludes that a regulated training program that accommodates diversity is best practice for the provision of health care services in a multicultural community. Consequently, while the informal measures used by Nancy show her genuine interest in accommodating the religious needs of diverse residents, they do not ensure widespread inclusion of immigrant residents in mainstream long-term care facilities. The religious needs of aging immigrants from ethnic minorities are largely overlooked in Southern Ontario because they are situated within a health care institution that favours those who are Canadian-born. According to Qiao, the staff at the designated multicultural facility where she works do their best to accommodate the different religious and spiritual needs of the residents.

One of the assessments we do is a spiritual care assessment. We would like to know the person's religious background. We have religious activities run by faith communities in this area. We have a lot of Christian programs. There is only one Chinese Catholic church in Mississauga, so that group comes once a week to do a mass. We also have a Buddhist program that is done once a month only. That's the sort of religious programs that we have.

Unlike the mainstream long-term care facilities included in the research, Qiao argued that her designated multicultural facility has residents complete a separate spiritual care assessment as part of their admissions process. In addition to Protestant Christian programs, Qiao's facility accommodates the needs of Catholics (in Mandarin) and Buddhist. The fact



that the designated multicultural facility facilitates religious services in three different religions was unique among all of the other long-term care facilities included in the research. The designated multicultural facility has taken steps to move beyond an integration model by responding to the religious needs of diverse immigrant residents in a proactive way. This challenges the standard model of providing religious accommodation only for the dominant group. In all of the mainstream long-term care facilities where interviews were conducted there was typically only one type of religious service offered for residents. For the facilities that were religiously-based, these services were oriented towards that particular religion. Joanne, the Executive Director of facility four, sees no reason to apologize for offering limited religious programming.

It's a Christian chapel that we have here. It's non-denominational but we do say it's Christian service. We are pretty upfront with that as well. Certainly you don't have to be Christian to live here, but in terms of our spiritual programming it is Christian-based. We do have a Chaplain on staff who works about 22 hours a week. Again, you don't need to be Christian to seek his guidance and support, but he is a Christian chaplain. He will give answers consistent with that. It's not that we need to apologize for that, right? It's a balance because there's some tension around being inclusive and being true to that part of our history. We have had those discussions about going forward. Depending on the residents that we're serving, we've discussed how we will meet their spiritual needs. I don't think we know what we are going to do if the clients become more religiously diverse. I think we are going to sort of cross that bridge when we get there because I don't know.

Joanne explained that her facility has a Christian chapel and that it offers specifically Christian services. A chaplain who provides Christian guidance is hired by the facility and paid for by the fees collected from the residents. Joanne admits that her facility has not made any moves towards diversifying religious programming because maintaining a Christian tradition is part of the facility's heritage. Joanne's comments reflect a dichotomy between those who are Christian and a homogenized non-Christian 'other'. By refusing to respond to

religious diversity, Joanne fails to challenge normalized religious standards in her facility. Joanne upholds a model of integration by implicitly encouraging residents to fit in with the status quo, in terms of religious practices. She added that her staff has discussed the need to consider religious accommodation for immigrant residents in the future, but no concrete solutions have been proposed. Her reference to addressing the need for diverse residents as they arise indicates that she views diversity as a problem to be solved, rather than as an asset. Deanna, Care Coordinator of facility five, admits that encouraging the integration of immigrants into existing religious services has been difficult in the past. For example, Deanna talked about a woman whose religious and cultural background was unknown until she passed away.

We had a lady who was native and we didn't know it. We did not know this lady had a native background and the day before she died her daughter had said she wanted to do the smudging ceremony. There was some ceremony where at the time of the death there would be some smoke. The resident had not shared any of her background, and neither did the family. At the end of care the daughter really wanted these traditional things to happen. Now what we do—when we have somebody that's dying we try to have a palliative care meeting to make sure we know their religious practices. One of the questions we ask is, are there any traditions that you would like us to follow?

This particular case provides an example of how race intersects with ethnicity and religion to create structural exclusion for those with religious needs that do not conform to the status quo, but who otherwise appear to be white Canadian-born Christians. According to Deanna, the facility's staff had wrongly assumed that the resident would not require any special ceremonies at the time of death because she was not part of a visible minority, nor was she visibly Aboriginal. However, the daughter of the resident informed the staff that because her mother was Aboriginal she wanted to complete a smudging ceremony. Mens-Verhulst and Radtke (2006) found that informal caregivers with multiple marginalities

frequently confront established rules that work against them when trying to access resources for FFN in the health care system. If this information had been known earlier, accommodating this request would have been much easier. However, no arrangements had been made to allow for the use of smoke. The facility has since implemented a routine palliative care meeting in response to this situation. Nancy has been instrumental in implementing this program, and in conducting subsequent staff training sessions. Without regulated training, she has taken it upon herself to learn about different religious traditions, such as Judaism.

I've been in touch with the synagogues for the Jewish folks. Again, I think that part of my job is religious care and care after death. One thing for those who are Jewish is that the body cannot be left unattended for 24 hours after death. A group of people, either men or women depending on the sex of the person who has died, come in and wash and prepare the body. Preferably I think that burial is done within 24 hours. We've had to do some training for staff around that. We want to make sure that nothing goes wrong when someone dies.

Nancy explained that because there are Jewish residents at her facility, she has actively sought information about Jewish practices related to death in order to meet the needs of these residents. For example, she has learned that the body of a Jewish person cannot be left unattended for 24 hours after death, and that burial is done within 24 hours, if possible. She has imparted this knowledge to her staff as well ensured that nothing goes wrong when a Jewish resident passes away. However, this kind of staff training is not mandated by the Ontario Ministry of Health and Long-term Care, which indicates that there have been no widespread moves to dismantle systemic barriers associated with ensuring religious accommodation. Staff members at other facilities were much less knowledgeable about the religious traditions of diverse residents. For example, Oliwia, who works as a nurse at facility one, did not consider the fact that the facilities Christian-based services may not meet

the needs of all of the residents. “The religious services are for everybody. Residents could get involved in a simple thing like hymn sing that we have every Friday. It’s not specific religion, it’s just you go and they sing. We have non-denominational services. The hymns are non-denominational, but they are Christian-based.” Oliwia was aware that language barriers could present a problem, but felt that the Christian-based religious programming was suitable because it was non-denominational. The type of programming provided included singing Christian hymns. Oliwia could not provide much detail when probed about the needs of the few Muslim residents at the facility. One of the few things she noted, incorrectly, was dietary restrictions. “I mean—I know that Muslims don’t eat beef and stuff like that. Even as we go on into the future, because of their traditions, values, and the way they are—I don’t think we will have many residents like that because of the way they are raised.” Oliwia claimed that Muslims do not eat beef, which shows that she is not aware that pork is one of the main dietary restrictions for Muslims. Oliwia concluded that she is unlikely to need any additional information about the religious practices of Muslims because their traditional expectations of care do not include the use of long-term care facilities. However, this statement contradicts existing research (Wong, Yoo and Stewart, 2006 and Knight et al., 2002) and interviews with Muslim informal caregivers discussed in chapter four, which indicate that immigrants are increasingly receptive to the use of long-term care for their aging FFN. For this reason, it is essential for long-term care staff to understand the religious practices and requirements of immigrant residents. Nadia echoed the fact that being aware of the religious traditions of Muslims living in long-term care facilities is essential.

You need to know the background of people. That’s what makes people unique—especially Muslims. The problems that they have, when they go to long-term care, need to be addressed. For example, before their prayers they have to do certain things. Muslims have to do the washing and everything properly. This is alien to

normal people you know. In a long-term care facility Muslims may not get to wash before prayers because the nurses don't have time to help them wash. They don't know how important it is because they don't understand.

Nadia argued that it is very important to accommodate a person's religious needs because religious beliefs are part of what makes people unique. She explained that Muslims must take certain steps before they pray, such as washing properly. Nadia concluded that nurses who are not aware of these practices will not understand the importance of washing before prayer, and may therefore be less willing to help. Many participants discussed relying on the resident's FFN to provide needed religious guidance. For example, Janet said that she leaves it up to the family of Muslim residents to make sure that they pray when they need to. "A lot of that we leave to the family to do just because, I mean, I don't know your religion. I don't know when you are supposed to be praying. We do allow our families to do that." Janet confirmed that she does not know when Muslim residents are supposed to pray, or how, because she is unfamiliar with Islam.

A number of staff members said that they had not sought out additional information about diverse religious practices because only a small number of residents from a particular religious group live at the facility. Providing programming that meets the needs of the majority was a recurring theme. For example, Lisa said that the facility that she manages does extensive programming around holidays and celebrations. The facility routinely celebrates Christian holidays in particular.

In terms of celebrations, we don't cater to any particular group, but what we do try to do is a cross-section of different activities that represent the different special days. For example, for Easter we have something and for Christmas there's something—there's always something. We try to do different activities. We try to do things that represent the interests of the people we have here.

Lisa felt that her facility accommodates a wide range of holidays because they celebrate Christmas and Easter. Although these celebrations are largely religiously based, in Lisa's opinion the facility does not cater to any specific religious group. Like Lisa, Nancy organized religious and cultural celebrations based on the number of residents who would be participating. For example, this year she did not organize a Passover meal because one of the three Jewish residents had died.

In the past we had three Jewish residents. Now we only have two, but when we were at three I helped the families to organize a Passover meal. It worked out really well. It is the biggest celebration in the Jewish year. I thought three was a lot because we had never had that many Jewish people. There are only two now, but the families are still welcome to have their own Passover dinner if they want to. They never did follow-up on that because maybe they did just need that extra help of somebody organizing it.

According to the International Fellowship of Christians and Jews (2014), the Passover meal is a very important celebration for Jews because it "commemorates Israel's deliverance from bondage in Egypt. The Jews cried out to God in their oppression, and God sent Moses to deliver them". Despite the significance of Passover for the remaining Jewish residents, Nancy argued that the smaller number of residents did not warrant preparing a Passover meal. In contrast to the mainstream facilities that hosted mainly Christian celebrations, facility two celebrates Chinese New Year as a big event.

For the social and recreational programs Chinese New Year is coming up and it is one of the biggest, if not the biggest, events of the whole year. On the first day of Chinese New Year we would all dress up. We wouldn't dress up in the full Chinese attire but just something more festive. We have a lion dance. We do the lion dance and then we hand out lucky packets and an orange. Fruit is a symbol of liveliness and freshness. We would go to each floor to say greetings to every senior. If they are not able to come to the activity room we would go into their rooms individually and say greetings. There would also be a program with Chinese songs and all those things.

Qiao described an elaborate celebration of Chinese New Year, including dressing up in traditional Chinese clothing and a traditional lion dance. The designated multicultural facility was more equipped overall to address both the cultural and religious needs of aging Chinese and Filipino immigrants because it was designed with them in mind. Facilities of this type show how diversity may be seen as an asset, which is consistent with Fleras' (2012) model of inclusivity. The move towards inclusivity is facilitated by the fact that multicultural facilities are predicated on the assumption that culture and ethnicity shape resource needs. This makes way for exploring differences among residence in a more engaged way.

### **5.7 Food Preferences**

A number of participants talked about the challenge of accommodating the different food requirements or preferences of immigrant residents. For example, Jane has noticed that her British home care clients prefer a tea time in the afternoon. “The couple I would deal with from England liked tea at a certain time. That was something I would notice across the board—you break and you have tea time. They would always like you to have tea time. That was the same for all of the British clients I have had.” Jane argued that the desire for a tea time was something that she has seen in all of her British clients to date. She was able to fulfill this request because there is greater flexibility in her role as a home care PSW compared to the more structured schedule of a PSW working in a long-term care facility. There are also more strict regulations, in terms of food distribution and food type, for those who work in long-term care facilities. The mainstream long-term care facility that Nancy works at serves mainly North American food, which she sees as problematic for residents who are not used to this type of diet.

Food is a big thing too. If we get people from an Asian culture then this food is just not what they're used to. We cook sort of middle of the road North American food. We make casseroles and soups, you know? We cook very little ethnic food, so that has to be hard. For someone who is used to eating a rice diet it has to be hard to only be able to get rice twice a week rather than three times a day. That's hard for people.

Nancy stated that food is a very large issue for the residents that she cares for. She added that very few ethnic food options are available, which would be a difficult adjustment for someone who is used to eating food that does not conform to Canadian standards. Nancy used rice as an example, because her facility rarely serves it, relying heavily on foods like casseroles and soups. In contrast, the designated multicultural long-term care facility where Qiao works tailors the food to the cultural background of the residents. The long-term care facility where Qiao works is one of four run under the same organization. Each facility caters to a different ethnic group.

At the second home we have a designated wing for South Asian seniors. We are the third home, so we have a designated wing for Filipino seniors and Chinese seniors. The fourth home has a designated wing for Japanese seniors. For those designated ethnic groups we would provide the food that they are used to. We would cook South Asian curry, for example. The other home for Japanese seniors would have miso soup, tempura, teriyaki and that sort of thing. We give the residents the foods that they are used to eating.

Qiao explained that each of the four facilities provides services designed to meet the needs of older adults from the surrounding ethnic communities, including Filipino, Chinese, Japanese and South Asian communities. For example, she argued that the facility designed for older Japanese adults serves traditional Japanese foods, such as miso soup, tempura and teriyaki. Janet feels that the dietician at the facility she works for is responsive to the needs



of residents, even though the dietician does not plan food based on the cultural or ethnic background of the residents.

I don't think they are sitting down and saying okay now if we get somebody that is this background, what do we do? I mean, if they do get somebody then they try to be accommodating. You're not always going to get certain things but they do their best. It all depends on who's on the top end, you know? We can order rice and we can do little prepackaged frozen rice because you just microwave it. We did that here for somebody who requested rice.

Janet argued that the management staff at the facility where she works do not proactively consider how to meet the needs of diverse residents. However, she claimed that the staff do try their best to address concerns as they arise. According to Janet, whether or not the food preferences of immigrant residents are accommodated is based on those who are in charge. This may pose a potential barrier to inclusion for aging immigrants because existing data (Zeytinoglu and Muteshi, 1999) and the current research indicate that those in positions of power are more likely to be white-Anglo Canadian-born men and women. As such, they may be less likely to understand the needs of older adults with multiple marginalities because they do not share a similar social location. However, Janet noted that in the past the cooks at her facility have responded to requests for foods like rice by preparing prepackaged rice for those who request it. Oliwia agreed that her facility would be responsive to the different food preferences of immigrant residents. "Well, I'm sure we would because we do it for others, you know? We have different diets for renal failure patients and people who have to eat low sodium diets. I think that would be fine." Oliwia reasoned that the management staff at her facility would accommodate requests for different foods based on cultural preferences because they approve of special foods for residents with restricted diets, such as for those who require low sodium meals. However, the Executive

Director of Oliwia's facility, Lisa, stated that special diets would not be considered based on the cultural preferences of immigrant residents.

In terms of special diets or meals we have a dietician on staff. First of all, in terms of diets, we can do all of those. We have all different sorts of diets that are available. The second thing is that if they had a preference for a particular food, would we cater to it? Not likely. That's not our mandate.

Lisa felt that it was not in the facility's mandate to satisfy the preferences of immigrant residents because the facility has to cook for many people. As a result, the immigrant residents at this facility must conform to the Canadian-style menu offered. Lisa's reference to following the facility's mandate confirms that regulations established by the Long-term Care Act have a very definite impact on what resources/programs are routinely offered in long-term care. For example, while Lisa is willing to ensure individualized menus for residents who are on special or restricted diets for medical reasons, as per the Ontario Long-term Care Act, 2007 (Service Ontario, 2010), she does not feel inclined to offer individualized meal plans based on cultural food preferences because no such regulation exists. This provides an example of the ways in which current regulations in Ontario's Long-term Care Act overlook the needs of those with multiple marginalities, as culturally based food preferences are not considered in mainstream long-term care. Joanne, Executive Director of facility four, also pointed out that large batch cooking is one of the main reasons for not being able to meet the dietary preferences of immigrant residents. Unlike Lisa, Joanne saw this as an area for future improvement.

When we look at the way we deliver food it is batch cooking. You can make some modifications and we can prepare some special meals, but it is harder. Again with dietary needs there's no question—we will accommodate that. For more ethnic preferences, that's tougher. We've looked at our entire food services model over the

last few years and we haven't made any substantial changes at this point. We have talked about whether or not we want to continue on with that food delivery model, where it is more like batch cooking. If we had a different model, what would that look like? What does that look like in terms of staffing and cost? It is less feasible.

Joanne argued that batch cooking limited the freedom to make modifications for special meal requests, although again she confirmed that such accommodations would be made immediately for those with dietary restrictions based on health concerns. She expressed concerns that the budget limits her ability to change the way food is prepared and served, and added that no clear alternatives are available. Budgetary limitations were also mentioned by the Care Coordinator of facility five.

Food is one of the biggest challenges. That is a challenge because we're only given so much money in our food budget. We already have to offer two choices for every meal and, I mean, that's hard. That's a challenge—the food. You need to increase funding to buy the ingredients. It would be another staff member to prepare it. It's not just buying the stuff—it's also preparing it.

Deanna explained that offering more than the two standard food choices would mean not only extra money for the food itself, but also funding to pay for staff to prepare it. Regardless of the fact that many staff members at mainstream long-term care facilities were aware that the food did not meet the needs of aging immigrants, it is simply not possible to accommodate all preferences because of the current batch cooking approach. Food cannot be made to satisfy the needs of a small number of immigrant residents, particularly where a number of different ethnic groups may be present. Beyond different preferences for foods, some staff members discussed food restrictions for residents based on religious beliefs. For example, Irena mentioned a resident who did not eat pork due to religious reasons.

I would say dietary is a big thing. For example, some religious backgrounds do not eat pork. We have to remember when we serve food if pork is one of the options that they get the chicken. We try to remember that. I mean, when they are cognitive they will automatically choose but as they decline they don't remember that they don't eat pork anymore. We kind of have to remember that they don't eat pork. We had a Muslim lady years ago and Muslims don't eat pork. She knew when she was cognitive that she didn't eat pork. As she declined we would remember that she didn't eat pork. She might not even realize that she was eating pork. As your dietary needs change you might be getting all your food diced or minced, so it doesn't even look like what it should look like. Depending on how it's cooked pork could taste like chicken.

In Irena's experience, it is very important for staff to be aware of religiously-based dietary restrictions on behalf of residents. For example, if the staff were not aware of the fact that Muslim residents do not eat pork they may inadvertently eat it because cognitive decline may impact a person's memory of what he or she will not eat. Also, for those with a minced food diet, pork may not be recognizable as such. As previously noted, not all staff in long-term care facilities are aware of different religiously-based food restrictions, particularly for Muslim and Jewish residents. This means that this type of safeguarding does not occur in all mainstream long-term care facilities. This finding provides support for Van Herk et al.'s (2011) argument that intersectionality research could improve nursing care practice for those with multiple marginalities in Canada. For example, if a nurse's educational training included information about diverse religious practices derived from intersectionality research, every nurse would be aware of things like common dietary restrictions. Currently, informal caregivers are relied upon heavily to make sure that immigrant residents are getting the food that they need or want. For example, Esi said that the families of immigrants are frequently encouraged to bring in food that they know the resident will like.

The food that they prepare here is different from maybe what they normally eat at home. If the immigrant residents have family members—what they do is to bring in some kind of food that their loved one would like. A lot of the time the families bring different kinds of food, like soup and all that. We have a fridge that we store them in with their names labeled and all that. In the afternoon you can just heat it and give it to that person. You can bring in food or anything. We tell people to do that all the time if they want to.

Esi explained that the facility has a fridge specifically set aside for informal caregivers to bring in foods that their FFN prefer. For immigrant residents who do not have informal caregivers who frequently visit, this option would of course be unavailable. Janet said that her facility also encourages informal caregivers to help out with their FFN's food preferences. For example, Janet said that they encouraged the caregiver of an immigrant resident to bring in spice to add to her meals.

We try to ask family. We do have somebody who wasn't eating their food and the daughter had said I think it's because the food doesn't have flavor. I mean, that's true. When you cook for 96 residents you have to make it dull because lots of people don't like spice. They try to tell family to help out. For this example they said to the daughter if you want to bring spices that can be added after then you can. They don't get the supplies all the time necessarily, but they will encourage family to bring in whatever it is they need.

Janet argued that the staff members at the facility where she works try to accommodate the food preferences of immigrant residents by encouraging the involvement of informal caregivers. Although Janet realized that food preferences are important, there are few other options available to accommodate different dietary preferences or needs in large mainstream facilities.

## 5.8 Recreational Activities

Many of the staff members stated that they did not feel that immigrant residents needed specifically designed recreational activities. Instead, a number of participants provided a list of activities that they felt were suitable to all residents. For example, Esi said that there were a number of games that everyone was involved in during the daily activity programs. “We have life skills workers over there who also have some programs every day for them from Monday to Friday. The programs are for everybody. They play games, they do spelling drills and history trivia. It’s all basically Canadian history questions.” Although she was not necessarily aware of it, Esi confirmed the trivia games she mentioned were geared to those who were Canadian-born. These trivia games indirectly exclude those who are not familiar with Canadian history. Hazel also thought that the long-term care facility where she works provides suitable recreation for people of all backgrounds. “Every week there was a movie day. They didn’t have specific kinds of movies that they targeted but they did show American movies. They didn’t really have any recreation geared to any culture that I can think of.” Hazel was unaware that the facility’s entertainment is geared to English-speaking Canadian-born residents, despite the fact that the movies shown are all in English and generally made in the United States. Unlike Hazel and Esi, Claire was aware that some residents had issues with language barriers when making use of available recreational programming. However, Claire said that many of the activities at facility one are interactive, which makes them suitable for all residents.

I don’t think there are any specific recreational programs. A lot of the activities that are done here are interactive. The resident with a language barrier can still go. He doesn’t need to be told in his language what’s going to happen. You are sitting there and you know they are throwing the ball at bowling pins. A lot of the activities don’t need to be explained. He can go to those activities. He likes to do those things.

Claire argued that the resident with the language barrier was able to play the bowling game that they offered because he could pick up on what was going on without much direction. Kakra talked about residents who could not speak English, but she felt that having a language barrier did present a problem for those who wished to participate in recreational activities.

Sometimes there is movie watching. They would go downstairs to watch movies. They would play movies that they like from their time. They would play Hollywood classics. They like it and all that. It's sad for the ones that can't understand though. For people who don't speak English—it would be better if there were more people who spoke their language. It would be better too if they could watch TV in their own language. It would be good if they could understand what they are hearing. If it was in their language, then they could follow the movie. If they are able to do that it would be better.

Kakra argued that the fact that her facility only plays English language movies is sad for residents with language barriers because they clearly cannot enjoy the films to the same degree as the residents who speak English. She concluded that it would, of course, be preferable if the residents with language barriers could understand what they were hearing in the movies. Staff at the designated multicultural facility made an intentional effort to provide accessible recreation. Qiao said that the facility's recreational schedule includes a program designed for residents to reminisce about China. "When we run a reminiscence program they would be talking about China. We would talk about scenery in Hong Kong or where they came from. We do things they are familiar with in the language that they would understand." Qiao noted that the recreational programs are held in the language that the residents will understand. A PSW from facility two talked about the tailored recreational programming without realizing that it was unique.

They do lots of things. They sing songs and watch TV. They sing mostly Chinese songs because, to tell you the truth, I'm working on the fifth floor and 99% of the people are Chinese. They have all sorts of activities. If they watch movies they watch all kinds of movies. Sometimes they watch programs on TV. They are, of course, Chinese shows. They will also play games. Some of them play Mahjong. Chinese people like Mahjong. It's very good for them to use their mind and their hands.

Ying took for granted the fact that the songs and movies are language appropriate, and that games like Mahjong are played. This provides a valid explanation as to why the rates of depression were reported to be much lower (25%) at the designated multicultural long-term care facility included in the research compared to mainstream long-term care facilities in Ontario (44%) (Gorham, 2012). Hall (2010) supports this finding by showing that providing suitable recreation for older adults living in long-term care facilities decreases feelings of unhappiness and increase satisfaction with overall living conditions. In contrast, the mainstream long-term care facilities offered English language music and movies, and games like Canadian trivia or bingo. As discussed in chapter four, without suitable recreation many aging immigrants do not feel comfortable in long-term care, which leaves long-term care out of reach for many immigrant informal caregivers. As with the food, Executive Director Lisa geared recreational programming to the majority. "We try to tailor programs to fit the residents. That's the way we try to deal with this. Because we track attendance and everything else we know when people are losing interest. Again, the entertainment caters to the masses." Lisa explained that the recreational programming is determined based on attendance. If a program is not being well attended it is cut in favour of a new program. This leaves few options for those who are not interested. Janet, who works as a nurse, also said that programming in mainstream long-term care facilities is designed



with the majority in mind, leaving others to choose from what is available, or not participate at all.

I think that they just do things across the board. I mean, if somebody has a specific thing that they do then the activity director would look into seeing if there is something they could do. It would have to be something that everybody would enjoy, just because of funding. They don't do things like knitting right now, but all of a sudden if you get three ladies that love knitting they'll come in and do knitting with them. They do ask family what they like to do, but whether it's possible is another story. We have lots of bingo here and games like that.

Janet reiterated the ability of staff to incorporate the recreational preferences of residents is limited by funding. Although families are routinely consulted about what their aging FFN enjoys, these responses may be ignored if other residents do not support the suggested activity. Staff members discussed a number of methods that facilities use to meet the recreational needs of immigrant residents when they cannot be included in existing programs. For example, Esi said that the facility's activities director looks for groups in the community that immigrant residents can attend.

Sometimes the immigrant residents have programs in the community that some of them are registered for. From time to time they go there for activities and all that. It's the nursing home's activity director that registers them for that. The nursing home looks for things that they can do in the community if there are no suitable programs here. It's not like for every kind of nationality, but there are a few. I know there are about three people who go to the community groups every week for a program. It's not for their language, it's just for entertainment.

Esi noted that there are currently three immigrant residents in her facility who attend recreational programming for older adults run by their respective ethnic communities. In this case, the activities director at the facility is actively involved in seeking out opportunities for culturally appropriate recreation in order to ensure that the needs of the immigrant residents are met. The use of recreational activities offered by ethnic community groups was also

discussed by informal caregivers in chapter four, which further supports the important role that such groups fill for aging immigrants in Southern Ontario. Luh (2003) also found that connection to the wider ethnic community protects against a loss of ethnic identity and sense of belonging for older immigrants living in mainstream long-term care facilities in Ontario.

In addition to ethnic community groups, informal caregivers were also called upon to provide recreation for immigrant residents. For example, Irena noted that the family of an Indian resident brings in Bollywood movies for her. “Families can bring in movies and that. We have an Indian woman and her family brings her Indian movies. She doesn’t go to the lounge or anything to watch movies though. She stays in her room because she has what she wants to watch in her room.” Irena noted that the movies put on by the facility are neither culturally nor linguistically suitable for the Indian resident at the facility. In response, the resident’s family has made sure she has access to the movies that she wants to watch in her room but, in doing so, the woman is isolated from other residents. The above findings indicate that while the recreation offered at mainstream long-term care facilities *is* equally available to all residents, it is certainly not inclusive.

## **5.9 Staff Burden**

The interviews reveal that many staff can accurately identify the significant barriers that immigrants face in accessing appropriate long-term care. As discussed in chapter four, language barriers and a lack of accommodation for religion, food preferences and suitable recreation were all identified by immigrant informal caregivers as the main challenges to accessing suitable care for their aging FFN. This necessitates an investigation into why there is a persistent disconnect between the care needs of aging immigrants and current home care and long-term care provision in Southern Ontario. A lack of sufficient funding appears to be

the primary reason that mainstream home care and long-term care facilities have been unable to address the needs of aging immigrants. One of the largest problems caused by low levels of funding is an insufficient number of support staff assigned to care for a large number of clients/residents. When asked what the biggest barrier to providing appropriate care for immigrant residents was, the overwhelming majority of the participants discussed having too many residents to care with too little time. According to Oliwia, the stress and workload is very difficult to handle.

The hardest part is not having enough time for everything. Sometimes between things happening and being busy you just don't have enough time. That is stressful. This is just a busy place. Every day it is a busy day. It has to do with the ministry a little bit because when you do something you have to chart it. I also get frustrated when I'm working short. That's a very big part because, you know, when you have 29 residents to take care of and you are short one staff it makes a big difference. Everything falls back.

Oliwia reported that the ministry regulations require RPNs and PSWs to chart all of their work. While this ensures the safety of the clients and consistency of care, the need to keep meticulous records has not been compensated by an increase in staffing levels. For example, Oliwia noted that as an RPN she is responsible for 29 residents during the course of one shift. The workload becomes more hectic when the facility is short staffed. For Claire, the workload is especially difficult to handle around meal times. "I would say we don't have enough staff. I would like to see more staff. That's particularly at meal times because we have a lot of people who have to be fed." Claire argued that there needs to be more staff to ensure that people get fed in a timely manner. According to Esi, the amount of individual attention given to each resident is very low because there are not enough staff.

You have to do everything within the eight hours. Most of the time you can't get it done, and if you can't get it done the next shift will have to finish up. We need more time and more staff. The workload is too much, so we need more staff so that we will be able to finish whatever we have to do. If we had more staff then we would be able to have more one-on-one time with the patients.

Esi admitted that in most cases she is unable to finish her assigned work tasks because there simply is not enough time. As a result, the next shift is typically left trying to finish what the last shift could not do. This creates an ongoing cycle. Esi concluded that there is a need for more staff in order for residents to actually get the one-to-one care that they need. When asked how many residents she would prefer to work with during a shift, Kakra said that she would like to be responsible for a maximum of ten.

It's difficult when you have to work short. That is stressful for everybody. You have 12 people to take care of even when you aren't working short. I would say that eight residents would be nice. A maximum of ten would be nice. That way, I believe if you have eight, you would have enough time to interact with them and talk to them. With the 12 people you don't even have much time to spend with them. You only have time to talk a minute or two because then you have to go and do somebody else.

Kakra explained that as a PSW she is routinely responsible for providing personal care to 12 residents, including bathing, dressing and toileting. With the heavy workload, Kakra has only one to two minutes to talk with each resident. Such a limited time frame clearly does not leave room for meaningful interaction, or even the possibility of disclosing emerging medical issues. During her interview in phase one of the research, Shannon argued that one of the reasons she has chosen to care for her mother-in-law at home is because she has witnessed the results of neglect in long-term care facilities through her role in admissions in a local hospital's emergency room department.

Probably more one to one care is needed in nursing homes. I've heard of situations from the hospital. There have been patients who have come in from the nursing homes and patients who have fallen. They may not have been looked after properly, based on the condition the patient was in. If you know that the patient may get out of bed because they are a wanderer then you need to be more alert and have a sitter with that patient. I think they need to, um...then again...with the government, are they willing to pay more nurses in these nursing homes? They're not. They're going to do as little as they can. If they can have two nurses for a whole ward then that's what they're going to do. There are just not enough employees there to care for the patients and that's why things happen. That's why the patients fall and that's why they don't get the medical care that they need. That's why their health goes down, because they may not be getting the stimulation or walks. They just don't have the time. They have time to change them and see that they eat. A lot of the times we have patients come in and the nursing home has put in a feeding tube and they didn't need too. Other times the feeding tube is blocked and I'm thinking, how long has this been blocked? This patient was not getting any food. If the tube has been blocked all day then they haven't been getting any food. Did they even realize it was blocked? Then they end up staying at the hospital for a long time because then they're dehydrated.

Shannon recalled situations where residents from long-term care facilities have been admitted to the hospital after falls and blocked feeding tubes. Blocked feeding tubes can result in older adults becoming dehydrated. She argued that this sort of thing occurs because the government is only willing to provide enough funding for a small number of nurses for an entire ward of residents in a long-term care facility, which corroborates the claims of many of the long-term care staff who were interviewed. Shannon concluded that the Ontario government is unwilling to increase funding to a level that would ensure enough staff to properly feed and care for all residents. Consequently, she felt that the health status of many older adults in long-term care facilities in Ontario will continue to decline. Janet argued that increased Ministry regulations have contributed to staff burden.

Over the years the ministry demands are the only things that change. The demands have really increased. My personal opinion is that it has sometimes gotten ridiculous. We tried to ask what ministry actually says we get to put someone to bed and we never got an answer out of that. You could say you get 15 minutes per resident but all of a sudden this resident has diarrhea or something, so it takes me twice as long to

clean them up then. Then do I take ten minutes off the next guy? No, I've got to find that time. The government only gives us so much money. If I say I need more help and there is no more funding, I'm not going to get more help. I'll just use nights for example. I work alone at night. Me—I think that's ridiculous that I work alone at night because that's 26 changes that I have to do by myself. That's rolling people, because they don't roll, and doing whatever they need to do. I have to bring them to the toilet—for the ones that actually do walk. If they are a lift then we just don't toilet at night because we don't have the man power to do it. You know, we can yell until we're blue in the face, but if they don't feel the money is there then we're not going to get extra help. I mean, how can I worry about meeting all the different needs if I can't even get everybody changed? Sometimes things have to go. If I'm running behind there's certain things that are going to get cut out. Unfortunately that's the nature of the beast.

Janet claimed that the ministry guidelines established in the Ontario Long-term Care Act have greatly increased the pressure placed upon RPNs and PSWs without substantial funding levels to increase the number of staff. For example, during a night shift Janet is responsible for changing 26 residents, which includes changing residents who are not functionally mobile. According to Janet, the Ontario Ministry of Health and Long-term Care has been reluctant to give staff working in long-term care specific guidelines around how much time it should take to put a resident to bed. Working within a very limited time frame means that certain care standards are not being met because more immediate tasks, such as toileting and bathing, must be completed. This indicates that the regulations set by policy makers and management in mainstream long-term care in Southern Ontario are unrealistic. Irena also claimed that staff are overburdened due to unrealistic expectations from the Ontario Ministry of Health and Long-term Care. “We're struggling—like every home. I'm hoping in the future that something good is going to come up. We always need more staff. We need more money and more funding from the Ministry.” According to Irena, every long-term care facility is facing the same struggles with staffing because of a lack of funding.

Irena is hopeful that funding will increase in the future to keep up with the increasing demands.

The fact that all of the staff involved in the provision of home care and long-term care in the current research argued that increasing regulations are being met with an unsafe reduction in funding and staffing supports Armstrong , Armstrong and Scott-Dixon (2008) claim that the cutbacks made to health care across Canada since the 1990's are creating unsafe conditions. In addition, the fact that most support staff positions in Ontario long-term care facilities are filled by women means that women in particular are left scrambling to provide patchwork care to older adults. However, the increasing privatization of necessary health care supports does not create a lack of appropriate care for all older adults to an equal degree. For example, those with higher incomes are able to supplement funded home care and care received in long-term care facilities with privately hired PSWs and RPNs. In addition, the findings indicate that funding is allocated to serve the needs of the majority, which means that those with multiple marginalities are even more vulnerable as services are eroded.

## **5.10 Conclusion**

This chapter explored the challenges that home care and long-term care facility staff in Southern Ontario face in addressing the needs of aging immigrants and their informal caregivers. My data support the main thesis argument that immigrant informal caregivers lack needed resources in caring for aging FFN due to the informal caregivers multiple marginalities. Although many home care and long-term care facility staff in Southern Ontario can effectively identify the barriers that older immigrants and their informal caregivers face in accessing care, they lack the resources needed to implement programs that

would facilitate the inclusion of older immigrants. Rather than making small changes, full inclusion would necessitate a substantial change to the existing system. The pressing concern for many support staff members is completing necessary physical care, such as feeding and changing residents.

The use of feminist theories related to care work helped to explain the gendered nature of paid care work, and directed specific attention to the structure of this work in long-term care facilities. The fact that those in management are disproportionately white Canadian-born men and women means that they may not be aware of the exclusion of aging immigrants with multiple marginalities. I then moved to an analysis of the barriers to long-term care for aging immigrants. I applied an intersectionality analysis throughout, which revealed that categories of difference do in fact interact and intersect to shape the exclusion of aging immigrants from mainstream home care and long-term care facilities in Southern Ontario. While the barriers experienced by aging immigrants and their informal caregivers were similar across many groups, complex diversities among immigrant groups, based on variables such as ethnicity, culture, race and religion, were also present. For example, it is apparent that not all immigrant residents speak the same language or require the same recreational activities. At a majority of the facilities, management and support staff have made concerted efforts to address the needs of immigrant residents and their informal caregivers. Specific solutions include relying on immigrant staff, immigrant informal caregivers, volunteers and the ethnic community to meet the needs of immigrant residents. While these measures offer a smoother transition into mainstream long-term care, they do not provide enough support to eliminate existing systemic barriers. In contrast, the multicultural facility is more prepared to address the needs of the immigrant residents because it was



designed with their needs in mind. The following chapter offers a general summary of the findings from chapters four and five, and recommended directions for future research based on these findings.

## **Chapter 6: Conclusion**

### **6.1 Intracategorical Analysis and Complex Diversity, Inclusion and Inclusivity**

This dissertation is predicated on the argument that, due to their multiple marginalities as gendered and racialized newcomers, immigrant informal caregivers lack needed resources in caring for aging FFN in Southern Ontario. Since the early 1990's, Ontario's health care system has experienced drastic cuts and overall reductions in the social safety net. As a result of the growing trend towards privatization of health care services in a political and economic climate shaped by the goals of fiscal conservatism, the role of unpaid informal caregivers has become increasingly vital to the sustainability of the health care system in Canada. Care previously provided in hospitals at great expense to the health care system is increasingly downloaded to informal caregivers. A report recently released by Statistics Canada claims that immigrant informal caregivers contribute between \$5-25 billion through their labour each year, depending on how estimates are calculated (Sinha, 2012). Regardless of the exact figures, the importance of the work of unpaid informal caregivers in Canada is undeniable. Yet, the value of this unpaid labour both economically, and in terms of nation building, is largely invisible. The fact that most of this care is provided to older adults, along with rising concerns the rising concern about Canada's aging population, highlights the need to create a system wherein informal caregivers are supported in their roles. This research indicates that services are lacking in their support of informal caregivers in Southern Ontario.

The theoretical framework used to analyze the data in this dissertation combines feminist theories related to care as work with intersectionality theories. Feminist theories related to care as work focus a broader analysis to the specific experiences of informal

caregivers within the current political context in Southern Ontario. Programs created to support informal caregivers implicitly, and at times explicitly, rely on the care provided by the nuclear family without considering the considerable economic, emotional and physical burdens associated with providing that care. While men have taken up a greater share of instrumental care, many policies continue to use gender neutral language which overlooks the fact that a majority of the primary direct care continues to be provided predominantly by women. Women appear to have internalized the expectation of providing unpaid informal care for aging FFN, as there have been very few widespread calls for increased caregiver support.

Unpaid informal caregivers as a group lack the needed financial and direct care support to provide care to aging FFN in a sustainable way. The data indicate that an increased pressure is placed upon informal caregivers to provide care independently of formal external support. The notion of individual responsibility touted under the current neoliberal agenda has translated into the requirement that each informal caregiver become a responsible caregiver for his or her aging FFN. Any support provided formally through the government is temporary. This conclusion is supported by Statistics Canada data, which indicate that in 2012 only 7% of caregivers received financial support from a government program (Sinha, 2012). With little support for informal caregivers in general, the Government of Ontario has not yet begun to acknowledge care as a good in and of itself, which is a major foundational principle of care-focused feminist theories. While the above challenges appear to be shared by all informal caregivers, regardless of background characteristics, immigrant informal caregivers face even greater difficulties with accessing

support designed for informal caregivers because they are unfamiliar with the health care system and do not have access to needed information.

Beyond basic access to critical information, immigrant informal caregivers caring for aging FFN in Southern Ontario face four main challenges in providing care to aging FFN including language barriers, access to programs that meet culturally based food preferences, programs that meet culturally based recreational needs and programs that accommodate religious differences. Rather than serving as an exhaustive list, these challenges signal the systemic bias that works in favour of white Canadian-born older adults and their caregivers. This conclusion is supported through application of the multidimensional theoretical framework. The two theoretical strands used in this dissertation work in tandem to direct needed attention to the experiences of immigrant informal caregivers in particular. After care-focused feminist theories direct needed attention to the context of care in Ontario, intersectionality theories offer a method to analyze the ways in which categories of difference interact and intersect to shape access to formal support resources for immigrant informal caregivers due to their social positions as gendered and racialized newcomers. Intersectionality theories offer a critique of existing research that uses a cultural competency framework, because it overlooks key variable such as gender. An analysis that looks beyond single variables is able to address previous critiques that existing caregiver research has simplified caregiver experiences.

The intracategorical approach within intersectional theories provides the needed methodological basis to inform the collection of data. The intracategorical approach effectively draws attention to the experiences of those who exist at the margins of a health care system nested in a Eurocentric notion of who an informal caregiver is. The Ontario

health care system, including support offered to informal caregivers, is based on a Eurocentric model that addresses the needs of those who are Canadian born to the exclusion of other ethnicities. When differences between Canadian-born and immigrant caregivers are taken into consideration by health policy makers, there is often very little attention given to the complex diversity within immigrant populations.

The theoretical framework effectively supports a reciprocal relationship between the intracategorical approach and the empirical data. While the intracategorical approach informs the focus of analysis, the data reinforces its utility. Variables including race, class, ethnicity, gender, and immigration status interact and intersect to exclude immigrant informal caregivers and amplify the burdens associated with providing unpaid informal care to an aging FFN. A multidimensional analysis confirms that immigrant informal caregivers confront systemic bias by being “squeezed in” to Canada’s health care system. Within this approach differences are framed as a problem to be solved, rather than as an important and useful addition to an evolving multicultural Canada. Differences among immigrants are not being taken seriously and very little efforts towards substantive inclusivity are being made, as evidence by the fact that there have been few steps taken towards responding to the differences between Canadian-born and immigrant informal caregivers at a system wide level. At the same time, immigrant informal caregivers continue to be squeezed between cultural expectations of care taken from their home country and the reality of life in Southern Ontario, which may make caring for an aging FFN at home impossible once separated from established social support networks. The application of an intracategorical approach lends itself to problematizing inclusion and calling for inclusivity that addresses the challenges that are unique to immigrant informal caregivers.

Building upon an intracategorical approach that explores the experiences of those existing at the margins, the concept of complex diversity directs attention to the differences within highly heterogeneous immigrant communities. The data reveals that although immigrant informal caregivers have the same general needs when accessing resources, the substance of the programs differ substantially based on factors such as ethnic background. As a result, complex diversity provides a more in-depth understanding of differences that are only initially uncovered through the use of an intracategorical approach. An application of the concept of complex diversity provides a feasible explanation for why immigrant informal caregivers continue to be invisibilized and excluded from programs that have been created to provide at least some measure of support to immigrant informal caregivers as a group. It opens an avenue for moving towards a health care system based on inclusivity. Immigrant informal caregivers have complex motives in providing care to aging FFN.

Although some immigrant informal caregivers provide care for an aging FFN out of a genuine desire to do so, others are bound by a set of cultural expectations. This may mean that immigrant informal caregivers may actually require more formal support from outside sources. Regardless of cultural pressures, immigrant informal caregivers appear willing to modify patterns around the provision of informal care for aging FFN. Despite the readiness of immigrant informal caregivers to adapt to Canadian standards of older adult care provision, policy makers have done little to respond to their needs. Many formal care providers rely on the assumption that immigrant informal caregivers will not access supports, which regresses program development and stalls meaningful changes to the system itself.

Just as immigrant informal caregivers are facing challenges in the caring for aging FFN at home, mainstream home care and long-term care providers face challenges in caring

for older immigrants because health care provision for older adults was not developed to advance immigrant interests. For the most part, formal care providers were able to identify the fact that the current model of care provision for older adults is ill suited to meet the needs of aging immigrants and their informal caregivers. The same four main challenges were identified by many of the formal care providers included in the research. However, those in positions of power appear to be unwilling to acknowledge the extent of the problem. As a consequence, formal care providers continue to implement programming that essentializes older immigrant adults. Eurocentric programming is provided as a matter of course with stop-gap measures put in place when crises occur in response to inadequacies that fail to respond to basic differences. As the Canadian population continues to diversify there is very little indication that the problems associated with providing one-size fits all care for older adults will subside. Those involved in the provision of care for older adults, including support for informal caregivers, have not yet reached a point of questioning or addressing challenges associated with providing care in a Canadian context. As a result, the system itself is far from being able to respond to complex diversities among immigrant informal caregivers and their aging FFN.

In order to facilitate a move towards inclusivity for immigrant informal caregivers and their aging FFN, the system itself needs to be rethought. This means challenging the basic organizing principles of formal supports designed to complement or offer an alternative to ongoing informal care. A major barrier to shifting from inclusion to inclusivity in the provision of care for immigrant older adults in Southern Ontario is resistance on the part of Canadian-born older adults and their caregivers. The data indicate that there is some push back to reworking a system designed to meet the needs of those who are white and Canadian

born. Additional informal education for those who are white and Canadian born may be necessary in order to create the necessary support for a system level change. In practice, a move towards inclusivity would also require a problematizing of Canada's foundational Eurocentricity in a broader sense. Because the health care system is tied to many other programs, including Canada's Employment Insurance through the Compassionate Care Benefits Program, inclusivity cannot be achieved in an isolated vacuum without looking at the broader social context. As a result, any move to inclusivity would require collaboration of the various levels of government in Ontario and Canada. A shift to full inclusivity represents an unlikely scenario in Southern Ontario, given current fiscal realities. The data indicate that there is insufficient funding in mainstream home care and long-term care to meet basic needs of older adults, let alone offer inclusive care to aging immigrants. This dissertation provides evidence of the negative impact that the increased privatization of care for older adults has had in Southern Ontario. The lack of funding for long-term care has been met with increased demands on formal care staff through the Ontario Ministry of Long-term Care.

Based on the results of this research, developing a hybrid approach to providing care to older adults in Southern Ontario is a preferred method because it offers a more realistic compromise. A hybrid system would operate based on a model of inclusion that treats all older adults and their caregivers the same as a matter of course, but respond by taking differences seriously and provide reasonable accommodation when these differences present themselves. Failing a more substantial change to the existing system, health care professionals should, at the very least, receive training about the needs of aging immigrants and their caregivers mandated through the Ontario Ministry of Health and Long-term Care to



ensure greater consistency across all organizations. While such training is not likely to create completely respectful, reflective and responsive care for older adults with multiple marginalities, it will encourage greater critical reflexivity on the part of staff. Formal care providers should be given space to reflect on how their perspectives on care may differ from aging immigrants and their caregivers because there is a tendency for those in positions of power to assume a universal experience.

## **6.2 Direction for Future Research**

Several research areas emerge from the current study that were not included due to the nature and scope of the dissertation. Future research directions posed here will add to the empirical research on immigrant informal caregivers and related health care service provision. This study focused on the experiences of caregivers and direct service providers. One of the goals of this research was to explore what programs in long-term care facilities and in the community have been implemented to meet the needs of older immigrants and their caregivers. The findings indicate that in many cases, immigrant caregivers are implicitly expected to integrate their aging FFN into existing programming that is not responsive to complex diversities among immigrants. Most programs at long-term care facilities targeted to immigrant residents are largely based on the discretion of management staff. In order to add to this discussion, future research involving representatives from the Ministry of Health and Long-term Care should be conducted. Such research would help to confirm whether or not any policies directed towards aging immigrants are in the planning stages. For example, does the Ontario Ministry of Health and Long-term Care intend to implement policies that specifically address the barriers experienced by immigrant caregivers identified in this research, such as language barrier, differences in recreational and food

preferences and need for religious accommodation? Given the apparent ability of culturally tailored services, such as designated multicultural facilities or ethnically based senior's centres, to better address the needs of aging immigrants, future research should explore the perspectives and plans of those working with large scale policy and program development.

Moreover, research conducted in other geographic locations would be beneficial. In certain cases, the findings related to service accessibility for informal caregivers may be unique to those living in Southern Ontario. Data from other parts of Ontario would offer a broader picture. For example, services provided by ethnic communities may be more available in larger city centres, and nonexistent in smaller more homogenous towns. In addition, long-term care facilities situated in more ethnically diverse communities will likely have programs and resources that smaller and more heterogeneous communities do not. The designated multicultural facility in this research was designed for the ethnic groups which represented the surrounding demographics. The programs and services offered in other designated multicultural long-term care facilities would differ depending on the geographic location.

As an in-depth qualitative study, this research provides an important source of information for understanding the barriers to sustainable informal care for aging FFN experienced by Canadian-born and immigrant caregivers. More research of this kind is needed to capture additional complexity. It is likely that other hidden barriers to accessing caregiver supports exist. For example, future research that explores the perspective of immigrant and Canadian-born caregivers who refuse to take on the caregiver role would be useful. The current research focused on high intensity caregivers, as these caregivers face the largest burden and greatest need for support. Low-intensity caregivers and those who chose

not to take on any caregiving duties at all may offer additional insights into the challenges or barriers that led them to play only a minor role in caregiving, or refuse it entirely. If the Canadian government continues to encourage informal care, it will be necessary to tap into the perspective of those who are reluctant to provide care because more caregivers will be needed as the population continues to age.

The current research points to opportunities for further exploration among specific types of immigrant caregivers, or those in particular circumstances. For example, a number of female participants interviewed in this research were caring for their husband's parents. Future researchers may wish to interview both the sons and daughter-in-laws in these circumstances in order to provide a more complete analysis. In addition, only immigrant informal caregivers who spoke English were included in the research. It is more than likely that caregivers with a language barrier would face additional barriers in accessing caregiver supports, including accessing information about supports. Research that specifically compares English-speaking caregivers with those who cannot speak English would add to caregiver research in Ontario. Moreover, this research included representation from immigrants who had settled in Ontario from 1980 to 2011. As date of settlement has an impact on the level of knowledge that immigrants have about available supports, future research may wish to include a more direct comparison between those who have recently settled and those who are better established. Although the difference in settlement time was included in the analysis of this research it was not a direct focus.

Finally, through this research, I discovered that many informal caregivers consider addressing the mental health concerns of their aging FFN to be the most significant challenge. I interviewed a number of Executive Directors at long-term care facilities who

said that dealing with mental health concerns has been problematic. The behavioural issues associated with dementia can often make providing needed care difficult. Resource needs associated with mental health concerns were an underdeveloped area in this research because it was not a main focus.

According to the Mental Health Commission of Canada (2011), access to appropriate mental health services for older adults is especially lacking. There is nowhere in Canada where proposed benchmarks are currently being completely met. For example, the commission argues that a minimum of 7.5 residential mental health beds per 10,000 elderly are needed. Providing appropriate services would reduce fragmentation, improve the overall health of the older adult population and reduce climbing health care costs. According to a report prepared by the Alzheimer's Society of Canada (2010), if changes are not made to how mental health services for the elderly are allocated, the proliferation of diseases like dementia could have a devastating impact on the economy and the health care system. By 2038 the number of Canadians living with dementia is expected to be double from that of 2008.

The government of Canada has shown a growing interest in further developing mental health services targeted towards the elderly. For example, the Canadian Coalition for Senior's Mental Health received funding from the Public Health Agency of Canada in 2005 for a National Project designed to establish evidence-based guidelines around the treatment of mental health issues in long-term care homes. The project team concluded that there are significant levels of diversity among those living in long-term care. One of the main recommendations of the final project report was to create programs for the long-term care population that was targeted to meet individual needs, rather than a one size fits all approach

(Conn et al., 2006). Members of racialized immigrant communities are least likely to have their needs met by existing mental health services. Sadavoy, Meier and Mui Ong (2004) conducted research in 2004 to explain barriers to mental health services met by ethnocultural seniors. They concluded that mainstream services need to be redesigned to meet the needs of Canada's increasingly multicultural population, particularly in areas with large numbers of immigrants. Mental health issues are shaped by a number of factors, including ethnic and immigrant background. I intend to capitalize on these areas for future research in order to expand on empirical research on caregiving and address gaps in health care policy in Ontario. The objective of my future research goals will be to establish an action plan that can be used to alter health care services and support programs in a way that make them inclusive to all aging Canadians.

### **6.3 Last Words**

The expectation that immigrant informal caregivers will “take care of their own” without any support is not reasonable given increasing pressure to acculturate to a Canadian way of life; nor is the expectation that older immigrants will be able to integrate themselves into existing programs. Designated multicultural long-term care facilities and ethnic communities are well suited to fill in the gap in service provision for immigrants caring for aging FFN, failing a complete redesign of mainstream care provision for older adults. Because complex diversities drastically impact the resource needs of immigrant caregivers and their aging FFN, in terms of the need to tailor specific content, existing ethnic and cultural communities are poised to shape and inform these resources. There are distinct differences among caregivers based on cultural background and immigrant status. The differences between immigrant groups go beyond their status as a racialized minority.

Programs designed for a Somali woman will not necessarily accommodate a Jamaican woman simply because they share membership in a racialized category. The data reveal that mainstream programs and long-term care facilities are not well-equipped to address the diversities among immigrants caring for aging FFN. This is because there is a systemic bias embedded in the provision of long-term care for older adults extending from a health care system that is based on a Eurocentric model. Immigrant informal caregivers who exist outside of this model risk becoming invisible through interactions with mainstream formal care providers. Without evidence of a widespread move towards addressing foundational biases, the data reveal that many immigrant informal caregivers rely on ethnic and cultural communities to provide needed services. A more formal arrangement that includes funded support may help to better address the gap in service provision. Going forward long-term care policy makers in Southern Ontario must acknowledge the value of inclusion into existing programming as a useful first step, but move beyond this by incorporating the principles of inclusivity and accommodation. Given Canada's dedication to official Multiculturalism, the government has an obligation to take the needs of immigrant informal caregivers and their aging FFN seriously.

## Appendix A. Interview Guide for Informal Caregivers

**YOU MAY DECLINE TO ANSWER ANY OF THE INTERVIEW QUESTIONS.**

**YOU MAY ALSO DECIDE TO WITHDRAW FROM THIS STUDY AT ANY TIME WITHOUT ANY NEGATIVE CONSEQUENCES BY ADVISING THE INTERVIEWER. PSEUDONYMS WILL BE USED FOR BOTH THE CAREGIVER AND CARE RECEIVER'S NAME IN THE DISSERTATION AND ALL RELATED WORK.**

1. Tell me about yourself.
  - a. Where are you from?
  - b. Where have you lived?
  - c. Why did you decide to come to Canada?
  - d. Who did you come with?
  - e. When did you move to your current city?
  - f. How many people do you live with and how are they related to you?
2. Tell me about your role as a caregiver.
  - a. Apart from your children, who do you care for?
  - b. When did you first start looking after (care receiver's name)?
  - c. What is (care receiver's name) relationship to you? E.g. friend, spouse, parent
  - d. Why did you decide to start looking after (care receiver's name)?
  - e. Did (care receiver's name) ask you for help?
  - f. Where does (care receiver's name) live? E.g. in your home, in their own home, in another FFN home
3. How has caring (care receiver's name) changed between the time when you first started looking after him/her and now? E.g. does he/she need more medical tests, does he/she need more help with activities of daily living?)
4. What do you have planned for this month for (care receiver's name)? (Provide participant with a blank schedule to fill in and ask the following:
  - a. What activities do you do?
  - b. How often?
  - c. How long does the activity take?
  - d. Do you do this activity by yourself, or do you need help with it?

5. We have just looked at the activities required to care for (care receiver's name). Are there other aspects of looking after (care receiver's name) that you do, and that you find important to do? E.g. giving (care receiver's name) a hug, reading, talking, and taking them for a walk. Make a list of activities and for each one ask the following questions
  - a. How long does it take?
  - b. How often do you do it?
6. Do you personally think that you do enough for (care receiver's name)? In an ideal situation would you do more for (care receiver's name)? If yes, which activities would you do more? Is there someone else who could do some of these activities with (care receiver's name)?
7. Do you find that you have to give up some of the more caring activities (e.g. talking, and back rub), in order to perform the more immediate tasks (e.g. giving medication, bathing, and doctor's visits)?
8. How is the care for (care receiver's name) shared?
  - a. Are you the only person providing ongoing care?
  - b. If not, then who else helps? How often?
  - c. What type of help? E.g. financial, taking to doctor's visits, PSW home care, meals on wheels
  - d. What help do you need that you are not getting at present?
9. How has caring for (care receiver's name) impacted other aspects of your life?
  - a. Has taking care of (care receiver's name) interrupted any paid work that you did before you decided to take on a caregiver role? If yes, how? E.g. stopped working, reduced number of working hours, refused a promotion
  - b. Has taking care of (care receiver's name) increased your stress level? If yes, how? E.g. feeling guilty for not spending enough time with other loved ones, not enough time for yourself, stress because of financial strain
  - c. Do you think that you have become less healthy since you've started to care for (care receiver's name)? If yes, How? E.g. less time for physical activity, less time for doctor's visits, eating less well
  - d. Has your relationship with (care receiver's name) changed since you've started taking care of him/her? If yes, how? E.g. feel closer to them, feel more frustrated with them
  - e. Have your other relationships with family, friends, and neighbours changed since you've started taking care of (care receiver's name)? If yes, how? E.g. feel like you have less time for them, feel like you enjoy spending time with them more, feel resentful because they do not help out enough.
10. What are the biggest benefits that you receive by caring for (care receiver's name)? E.g. feeling better connected to the care receiver, feeling appreciated in the community, or feeling like you have an important role.



11. What are the biggest difficulties that you have faced caring for (care receiver's name)?
12. How were you able to overcome these difficulties? Are there any difficulties that are still ongoing? If so, what are they?
13. Who should provide care for an aging FFN in need of support?
  - a. Who do you think is responsible for caring for an aging family member, friend or neighbor? E.g. a spouse, a child, an entire community
  - b. What factors should impact a person's decision to provide care? E.g. gender, income, time.
14. How should caregivers be supported?
  - a. Who should provide support to someone caring for an aging family member, friend or neighbor (FFN)? E.g. the government, volunteers, other family members, church
  - b. What kind of support should be given to someone caring for an aging FFN? E.g. financial support, training, information
15. How has the government of Canada helped you take care of (care receiver's name)?
  - a. Have you used home care, Compassionate Care Benefits, the Caregiver Amount Tax Credit, or other programs?
  - b. Are there programs offered through the government to support those who are taking care of an aging FFN that you haven't used? Explain
  - c. How did you first find out about the programs available through the government?
  - d. How adequate are these programs? Explain.
16. How effective do you think long-term care facilities are at in providing care?
  - a. In what circumstances is it suitable or preferable to put an aging FFN in a long-term care facility?
  - b. What would you look for in a long-term care facility to make sure that it would meet the needs for your FFN? E.g. recreational programs, people with common interests, level of care available
  - c. Do you think that long-term care facilities provide good overall care? If no, why not?
  - d. How do long-term care facilities need to be improved? E.g. more one-on-one attention, more recreational programs, newer equipment
17. Do you feel like it is important for long-term care facilities to have specific programs for older immigrant adults? If yes, what kind of programs? E.g. language programs, recreational activities.

18. Do you think that the experiences of immigrants taking care of FFN differ from those who are Canadian born? If yes, how? E.g. more difficult to access support services, different expectations, more support networks
19. Are there long-term care facilities currently in the Region of Waterloo that provide you with an alternative to caring for (care receiver's name) if you could no longer take care of him/her?

**THANK YOU SO MUCH FOR TAKING THE TIME TO ANSWER MY QUESTIONS. I WILL PROVIDE YOU WITH A TRANSCRIPT OF YOUR ANSWERS FOR YOU TO REVIEW AND A SUMMARY OF THE RESULTS OF THE STUDY ONCE IT IS COMPLETED.**

## **Appendix B. Demographic Information Questionnaire for Informal Caregivers**

You may decline to answer any of the questions. You may also decide to withdraw from this study at any time without any negative consequences by advising the interviewer. The information that you provide will be used to generally describe study participants. This information will not be used to identify any participant.

### **1. What is your age range?**

- a) 18-30
- b) 31-45
- c) 46-55
- d) 56 +

### **2. What is your income range?**

- a) under \$10 000
- b) 10 000- 25 000
- c) 26 000- 35 000
- d) 36 000- 60 000
- e) 61 000 +

### **3. What is your highest level of education?**

- a) Some elementary school/elementary school
- b) High school
- c) College
- d) Trade school
- e) University
- f) Post-graduate school

### **4. What is your marital status?**

- a) Single
- b) Married
- c) Widowed
- d) Divorced
- e) Common-law

### **5. How many people live in your house?**

- a) 1
- b) 2-3
- c) 4-6
- d) 7+

### **6. What is your employment status?**

- a) Part-time
- b) Full-time
- c) Unemployed
- e) Other \_\_\_\_\_

### **7. What is your first language?**

- a) English
- b) French
- c) Arabic
- d) Other (Specify)  
\_\_\_\_\_

### **8. How many children do you have?**

- a) 0
- b) 1-3
- c) 4-6
- d) 7 +

### **9. How many people do you provide care for?**

- a) 1
- b) 2
- c) 3
- d) 4 +

### **10. What is your ethnic background?**

---

## **Appendix C. Interview Guide for Long-term Care Facility Staff**

**YOU MAY DECLINE TO ANSWER ANY OF THE INTERVIEW QUESTIONS.**

**YOU MAY ALSO DECIDE TO WITHDRAW FROM THIS STUDY AT ANY TIME WITHOUT ANY NEGATIVE CONSEQUENCES BY ADVISING THE INTERVIEWER.**

1. Tell me about the facility you work at.
  - a. When did this facility open?
  - b. What demographic was the facility originally intended for?
  - c. Have the demographics changed since the facility opened? If yes, how? How has the facility changed to accommodate changing demographics?
  - d. How is the facility funded? E.g. publicly through the government, or privately
  - e. Describe the various levels of care available at the facility. E.g. nursing home, palliative care, ventilators
  - f. How many clients does the facility accommodate? Is it currently full?
  - g. Is there a wait list for the facility?
  - h. Does the facility have clients from diverse ethnic backgrounds? (If so, provide details).
  - i. Does the facility make any special efforts to attract clients from diverse ethnic backgrounds? If yes, how? E.g. marketing campaigns, special programs
2. Do clients from diverse ethnic background have special needs? If yes, what are they? E.g. special diets, different recreational activities.
3. If yes to question 2, does the facility have programs in place to meet these needs? If yes, provide details. If no, what programs should be implemented?
4. How do you identify a client who is ethnically diverse?
5. Tell me about your role at the facility.
  - a. What is your job title?
  - b. What is your education and training background?
  - c. How long have you been working at the facility?
  - d. Has your job changed since you started working at the facility? If so, how? E.g. started as a nurse and now a director, started as a volunteer now a PSW
  - e. What is your role when interacting with a client's family? E.g. do you have to tell them about patient care, discuss payments, and listen to complaints?
  - f. What is the most stressful part of your job at the facility? E.g. time constraints, too many clients.

6. Describe your current workload, on an average week.
  - a. What activities do you do?
  - b. How often?
  - c. How long does the activity take?
  - d. Do you do this activity by yourself, or do you need help with it?
  - e. How many patients are you responsible for?
7. Do you feel like the facility gives you the resources that you need to do the best job possible in your current role? If no, what resources do you need? E.g. more support from other staff, more time to do each task.
8. Please discuss your interactions with FFN (family, friends, and neighbours) of clients at the facility.
  - a. What is your role in communicating with FFN of clients at the facility? E.g. discussing patient care, discussing concerns of FFN, getting information from FFN about care preferences.
  - b. What concerns are most frequently raised by FFN of clients at the facility?
  - c. Are the concerns of immigrant FFN different than Canadian born FFN? If yes, how?
  - d. Do you feel like the concerns raised by FFN of clients living at the facility are generally reasonable? If no, which concerns are not reasonable? E.g. families demand too much time, families demand services that you do not provide
  - e. How do you deal with the most frequently raised concerns?
  - f. What could be done to help you deal with these concerns better in the future?
9. What role do FFN typically have in taking care of clients living in the facility? E.g. bathing, talking to them, advocating for more care
10. Do you feel that FFN should be more involved in providing care for clients living at the facility? If so, please explain how. E.g. more visits, help with bathing, more day trips out of the facility

**THANK YOU SO MUCH FOR TAKING THE TIME TO ANSWER MY QUESTIONS. I WILL PROVIDE YOU WITH A TRANSCRIPT OF YOUR ANSWERS FOR YOU TO REVIEW AND A SUMMARY OF THE RESULTS OF THE DISSERTATION ONCE IT IS COMPLETED.**

## **Appendix D: Information Letter for Informal Caregivers**

University of Waterloo

Dear **(insert participant's name)**:

This letter is an invitation to consider participating in a study I am conducting as part of my PhD degree in the Department of Sociology and Legal Studies at the University of Waterloo under the supervision of Professor Alicja Muszynski. I would like to provide you with more information about this project and what your involvement would entail if you decide to take part.

While the feasibility of maintaining informal care is a growing concern for many families in Canada, caregiving expectations are not the same for everyone. Family caregiving expectations and care relationships are shaped by a number of factors, including immigrant background. Research indicates that many immigrant informal caregivers experience burden as a result of taking on the caregiver role. They find themselves sandwiched between the immediate short term demands of an increasingly diverse minority population and the long term consequences of financial instability. In response to this growing evidence of burden, the Canadian government has attempted to provide supports and resources to assist informal caregivers. The purpose of this study is to examine the needs of informal caregivers and to assess the accessibility and suitability of existing resources in addressing caregiver burden.

I believe that because you are actively involved in providing older adult care, you are best suited to speak to the various issues, such as what resources are needed, what caring for aging Canadians entails, and what role long-term care facilities have in assisting with care.

Participation in this study is voluntary. It will involve an interview of approximately an hour and a half in length to take place in a mutually agreed upon location. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising the researcher. For your participation in the study you will receive a \$15 gift certificate from Tim Horton's. Even if you choose to withdraw from the study at any time, the gift certificate is yours to keep. The amount received is taxable. It is your responsibility to report this amount for income tax purposes. With your permission, the interview will be audio recorded to facilitate collection of information, and later transcribed for analysis. Shortly after the interview has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. All information you provide is considered completely confidential. Your name will not appear in any dissertation or report resulting from this study, however, with your permission anonymous quotations may be used. Data collected during this study will be retained for two years in my locked office at the University of Waterloo in the PAS building. Only researchers associated with this project will have access. It is possible that certain details that you provide about your caregiving experiences in the interview could put your anonymity at risk because of the small sample size. During the interview you can refuse to answer any questions that you feel could threaten your anonymity. You will also be

given the opportunity after your interview to review your transcript and omit any information that you do not wish to include.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at 519-502-1960 or by email at [jflagler@uwaterloo.ca](mailto:jflagler@uwaterloo.ca). You can also contact my supervisor, Professor Alicja Muszynski at 519-888-4567 ext. 35187 or email [alicja@uwaterloo.ca](mailto:alicja@uwaterloo.ca).

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin in the Office of Research Ethics at 1-519-888-4567, Ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca).

For this study, I plan to provide a list of policy recommendations for better addressing the needs of immigrant caregivers I hope that the results of my study will be of benefit to long-term care facilities, health care policy makers, as well as to the broader research community.

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Yours Sincerely,

Jenny Flagler

## **Appendix E: Information Letter for Long-term Care Facility Staff**

University of Waterloo

Dear **(insert participant's name)**:

This letter is an invitation to consider participating in a study I am conducting as part of my PhD degree in the Department of Sociology and Legal Studies at the University of Waterloo under the supervision of Professor Alicja Muszynski. I would like to provide you with more information about this project and what your involvement would entail if you decide to take part.

While the feasibility of maintaining informal care is a growing concern for many families in Canada, caregiving expectations are not the same for everyone. Family caregiving expectations and care relationships are shaped by a number of factors, including immigrant background. Research indicates that many immigrant informal caregivers experience burden as a result of taking on the caregiver role. They find themselves sandwiched between the immediate short term demands of an increasingly diverse minority population and the long term consequences of financial instability. In response to this growing evidence of burden, the Canadian government has attempted to provide supports and resources to assist informal caregivers. The purpose of this study is to examine the needs of informal caregivers and to assess the accessibility and suitability of existing resources in addressing caregiver burden.

I believe that because you are actively involved in providing older adult care, you are best suited to speak to the various issues, such as what resources are needed, what caring for aging Canadians entails, and what role long-term care facilities have in assisting with care.

Participation in this study is voluntary. It will involve an interview of approximately an hour and a half in length to take place in a mutually agreed upon location. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising the researcher. For your participation in the study you will receive a \$15 gift certificate from Tim Horton's. Even if you choose to withdraw from the study at any time, the gift certificate is yours to keep. The amount received is taxable. It is your responsibility to report this amount for income tax purposes. With your permission, the interview will be audio recorded to facilitate collection of information, and later transcribed for analysis. Shortly after the interview has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. All information you provide is considered completely confidential. Your name will not appear in any dissertation or report resulting from this study, however, with your permission anonymous quotations may be used. Data collected during this study will be retained for two years in my locked office at the University of Waterloo in the PAS building. Only researchers associated with this project will have access. It is possible that certain details that you provide about your caregiving experiences in the interview could put your anonymity at risk because of the small sample size. During the interview you can refuse to answer any questions that you feel could threaten your anonymity. You will also be



given the opportunity after your interview to review your transcript and omit any information that you do not wish to include.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at 519-502-1960 or by email at [jflagler@uwaterloo.ca](mailto:jflagler@uwaterloo.ca). You can also contact my supervisor, Professor Alicja Muszynski at 519-888-4567 ext. 35187 or email [alicja@uwaterloo.ca](mailto:alicja@uwaterloo.ca).

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin in the Office of Research Ethics at 1-519-888-4567, Ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca).

For this study, I plan to provide policy recommendations for better addressing the needs of immigrant caregivers I hope that the results of my study will be of benefit to long-term care facilities, health care policy makers, as well as to the broader research community.

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Yours Sincerely,

Jenny Flagler

## Appendix F: Consent Form

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Jenny Flagler of the Department of Sociology and Legal Studies at the University of Waterloo under the supervisor of Dr. Alicja Muszynski. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses. I am also aware that excerpts from the interview may be included in the dissertation and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher. This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

YES    NO

I agree to have my interview audio recorded.

YES    NO

I agree to the use of anonymous quotations in any dissertation or publication that comes of this research.

YES    NO

Participant Name: \_\_\_\_\_ (Please print)

Participant Signature: \_\_\_\_\_

Witness Name: \_\_\_\_\_ (Please print)

Witness Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix G: Feedback Letter

University of Waterloo

Dear (*Insert Name of Participant*),

I would like to thank you for your participation in this study entitled “The Sandwiched Generation: The Intersecting Paradoxes of Care for Immigrant Informal Caregivers”. As a reminder, the purpose of this study is to examine the needs of informal caregivers and to assess the accessibility and suitability of existing resources in addressing caregiver burden.

The data collected during interviews will contribute to a better understanding of the appropriate direction of future development in long-term care facilities, and for informal caregiver support programs.

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or would like a summary of the results, please provide your email address, and when the study is completed, anticipated by August 31, 2014, I will send you the information. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email or telephone as noted below. You may also contact my supervisor Professor Alicja Muszynski at [Alicja@uwaterloo.ca](mailto:Alicja@uwaterloo.ca) or by telephone at 519-888-4567 extension 35187 if you have any questions about the study findings or results. As with all University of Waterloo projects involving human participants, this project was reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca).

Jenny Flagler

University of Waterloo  
Department of Sociology and Legal Studies

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## Appendix H: List of Acronyms Frequently Used in the Dissertation

CCAC	Community Care Access Centre
CCB	Compassionate Care Benefits
<b>FFN</b>	<b>Family, friends and neighbours</b>
PSW	Personal support worker
RPN	Registered practical nurse

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