NEEDS, PREFERENCES AND DECISION-MAKING REGARDING LONG-TERM RESIDENTIAL CARE: SOUTH ASIAN OLDER ADULTS' AND FAMILY CAREGIVERS' PERSPECTIVES

Dissertation Format: An Integrated Manuscript

by

Sherin Jamal

BSc, University of British Columbia, 1987
BMLSc, University of British Columbia, 1989
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Supervisory Committee

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Abstract

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The aging Canadian population is becoming increasingly ethno-culturally diverse primarily due to immigration. This, together with research indicating increased likelihood of long-term residential care (LTRC) use at older ages and challenges in providing these services, prompt important questions about whether LTRC services are prepared to provide culturally responsive and competent care to immigrant and ethno-cultural minority older adults (EMOA). This ethnographic study, informed by a critical theoretical perspective, explored these questions from the perspectives of South Asian older adults (SAOAs) and their family caregivers (FCGs). In-depth interviews with 18 SAOAs in LTRC, assisted living and those at home, their FCGs, and seven key informants from LTRC and the South Asian (SA) community (n=43) were undertaken. These interviews, in addition to 220 hours of participant observation in two LTRC facilities, provided information regarding the needs, preferences, experiences and situation of SAOAs in LTRC as well as how SA families make decisions regarding the use of such services. A select review of provincial policy, residential care regulation, health authority and facility documents, exposed taken-for-granted assumptions in how care and services are provided and the sociopolitical context of LTRC provision.

Study findings suggest that LTRC services are challenged to meet the needs of immigrant and EMOA and reflect unequal and inequitable care, illuminated by the differential impact of macro-policies and resource-constrained LTRC environments on SAOAs and their families and on the ability of existing LTRC services to provide person-centred care. This inequity in service provision has implications for immigrant and EMOA and their family members in light of findings that the decision to move to LTRC is essentially a (non) decision influenced by a range of social structural factors that interact to *necessitate* the move to LTRC. Study findings revealed the salience of socio-economic status and economic resources in particular, in the (non) decision for LTRC placement.

The findings from this study along with demographic shifts in the aging Canadian population call for LTRC service providers and policy makers to actively prepare for increasing ethno-culturally diverse resident populations and point to the need for equity informed approaches to the care of older adults.

Key words: Long-term residential care; Nursing homes; South Asian older adults; Immigrant older adults; Ethno-cultural minority older adults; Family caregivers; Decision-making

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Co-Authorship Statement

Sherin Jamal conducted this research under the supervision of Dr. Kelli Stajduhar, Dr. Karen Kobayashi, and Dr. Sheryl Reimer-Kirkham, who will be co-authors on the publications resulting from Chapters 4, 5 and 6.

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I have been privileged to work with and learn from an amazing Supervisory Committee. I would like to acknowledge my co-supervisors Dr. Kelli Stajduhar and Dr. Karen Kobayashi, for their unwavering support and mentoring over the years. Their trust in my abilities and excellent guidance led to pushing the boundaries of my thinking and comfort zone, continuous learning and improvement, which at times felt like my brain was going to explode. I would like to thank them for continually challenging my thinking, their words of encouragement, and being available when needed. I would also like to acknowledge Dr. Sheryl Reimer-Kirkham, for her thoughtful insights, comments and questions which led to exploring additional perspectives in my research. Through their expertise and mentorship, my Supervisory Committee taught me the difference between good and great.

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Dedication

This dissertation is dedicated to my late parents, Bahadur and Daulat Rahim, who believed in the power of education to improve people's lives, taught me the value of hard work and the ethic of service. They always encouraged me to pursue my educational aspirations and to use my knowledge and skills in service to others.

Chapter 1: Introduction

Long-term residential care (LTRC)[1] facilities are where some of our most vulnerable older adults live and die (Armstrong & Braedley, 2013; Estabrooks et al., 2020). The demand for these services is expected to increase in conjunction with the growth in the Canadian older adult population (Canadian Institute for Health Information [CIHI], 2017; Kary, 2019). In addition, it can be anticipated that these services will be required to care for increasing ethno-culturally diverse resident populations, reflecting demographic changes in the aging Canadian population, resulting primarily from immigration (Statistics Canada, 2016a). These trends, together with research indicating that ethno-cultural minority older adults (EMOA) in mainstream facilities face a number of challenges (Chan & Kayser-Jones, 2005; Kong, Deatrick, & Evans, 2010; Martinsson, Edberg, & Janlov, 2013; Rosendahl, Söderman, & Mazaheri, 2016; Runci, Eppingstall, van der Ploeg, & O'Connor, 2014; Wang, Wang, Cao, Jia, & Wu, 2016), which may further increase their vulnerability in these settings, raise important questions as to whether LTRC services are prepared to provide culturally responsive and competent care to meet the needs of an increasing population of EMOA.

This dissertation explored these questions from the perspectives of South Asian older adults (SAOAs) and their families given that South Asians (SAs) currently comprise, and may continue to be, the largest visible minority group in Canada and the second largest in British Columbia (Statistics Canada, 2010, 2013, 2016b). Although this research was conducted prior to the COVID-19 pandemic currently gripping the world, it is anticipated that the findings from this study will be amplified during the pandemic, given the way that social and health inequities have

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[1] In this dissertation, the term "long-term residential care" (LTRC) is used to refer to care of older adults with complex needs who require 24-hour professional supervision and care in a protective, secure environment. Synonymous terms are residential care, long-term care, care homes, and nursing homes.

been made visible and exacerbated globally (McNeely, Schintler, & Stabile, 2020; Yaya, Yeboah, Charles, Otu, & Labonte, 2020) and that the majority of deaths in Canada have occurred in LTRC (Estabrooks et al., 2020; Public Health Agency of Canada, 2020).

1.1 Background

Older adults are now living longer than ever before (Lee, Mason, & Cotlear, 2010; McGrew, 2000). As people age, the chances of experiencing health crises, physical disability, cognitive impairment and death all increase and these risks are increasingly compressed to older ages (Lee et al., 2010). The need for LTRC or other intensive forms of care is associated with advanced age, increased disability, and functional impairment (Lee et al., 2010).

The demand for LTRC services in Canada is projected to increase as the Canadian population ages (Canadian Institute for Health Information [CIHI], 2017; Kary, 2019). CIHI (2017) has noted that within the next 20 years, growth in the population of older adults aged 75 and over – who rely more heavily on continuing care services – is expected to accelerate resulting in a doubling in the size of that population (p.7). In addition to the growth of the older adult population, the aging Canadian population is becoming more diverse with respect to its ethno-cultural composition primarily due to immigration (Statistics Canada, 2016a). While historically immigration to Canada was from European countries, more recently, the largest immigrant populations are arriving from Asia and thus fit Statistics Canada’s definition of a “visible minority” (Statistics Canada, 2016a, 2016b, 2017a). Further, Statistics Canada projects that by the time the cohort of individuals born between 1997 to 2001 turns age 65, almost one-half of that cohort will be foreign-born with approximately 44% belonging to a visible minority group and 30% of those individuals coming from Asia (Statistics Canada, 2016b). More immediately, by 2031, 25-28 percent of the Canadian population will be foreign-born and one-third will belong to a visible minority group. In particular, SAs currently comprise, and may continue to be, the largest visible minority group in Canada and the second largest in British Columbia (Statistics Canada, 2010, 2013, 2016b).

The South Asian (SA) diaspora in Canada includes immigrants from India, Pakistan, Bangladesh, Nepal, Sri Lanka, Bhutan and the Maldives (Walton-Roberts, 2013). ‘South Asians’ also refers to Indians who have migrated to other parts of the world such as Fiji, Malaysia, Hong Kong, and East Africa (Nayar, 2004). In addition to the diversity in country of origin, there is also diversity in the religions practiced, with adherents to Sikhism, Hinduism, Islam, Christianity, and Buddhism amongst others (Coward, Hinnells, & Williams, 2000) as well as languages spoken, the most common being Punjabi, Tamil, Urdu, Gujarati, Hindi, and Bengali (Lindsay, 2007; Tran, Kaddatz, & Allard, 2005). Further, there is variation in the time since immigration with some SAs aging here in Canada and others immigrating in late life as Family Class[2] immigrants.

The shifts in the aging of the population at the national and provincial levels as well as the projected demand for LTRC services discussed above prompt important questions as to whether the current organization of LTRC services is designed to meet the needs of an increasing population of ethno-cultural minority older adults (EMOA). Research has indicated that EMOA face a number of challenges in accessing health and social services, including structural and individual level barriers, which often lead to an under-utilization of health services thus putting them at an increased risk of experiencing health disparities (Bookman & Harrington, 2007;

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[2] Canadian citizens and permanent residents may sponsor spouses/partners, dependent children, parents, grandparents and other close relatives to become permanent residents as Family Class immigrants. The Family Class sponsorship program, under which the majority of older adults immigrate to Canada, requires a signed agreement with the Minister of Immigration in which the sponsor promises to financially support and care for the sponsored older adult for a period of 20 years. During the support period, sponsored dependents cannot collect social assistance and are ineligible for public pensions, subsidized housing or housing subsidies or other local benefits such as reduced bus fare passes (Koehn, Spencer, & Hwang, 2010).

Bowes & Wilkinson, 2003; Keith, 2009; Koehn, 2001, 2009; Lai & Surood, 2010; Mold, Fitzpatrick, & Roberts, 2005). Structural challenges are further exacerbated by language and other cultural barriers which not only impact access to services, but also the type of services accessed, such as LTRC (Bowes & Wilkinson, 2003; Gupta, 2002; Koehn, 2009; Lai, 2008).

Relocation to a LTRC facility is a difficult transition for older adults and for EMOA, the associated losses are magnified considerably, often in relation to feelings of shame, being dishonored by the family and loss of face (Koehn, 2001; MacLean & Bonar, 1983). Most EMOA experience the intersecting barriers of older age with ethnicity, gender and immigration status at this stage. Researchers have found that EMOA in mainstream facilities face a number of challenges including a loss of their culture, difficulty communicating with care providers, cultural differences related to food and bathing, the approach and attitude of staff, the perceived responsiveness of staff as well as high turnover of staff which also impacts EMOAs' adjustment and care experiences in LTRC (Chan & Kayser-Jones, 2005; Kong et al., 2010; Martinsson et al., 2013; Rosendahl et al., 2016; Runci et al., 2014; Wang et al., 2016). And now with pandemic restrictions in place, social isolation and a lack of physical and emotional connectedness (Bergman et al., 2020; Office of the Seniors Advocate, 2020; Sizoo, Monnier, Bloemen, Hertogh, & Smalbrugge, 2020; Yeh et al., 2020). The broader context in which care is provided also influences the experiences of older adults in care homes (Bourgeault, Atanackovic, Rashid, & Parpia, 2010). The reluctance of ethnic populations to use certain services may be quite reasonable if appropriate culturally responsive care is not available.

In light of the above, this dissertation examined the needs, preferences, challenges, and decision-making processes of SAOAs and their families regarding LTRC as well as whether and how existing LTRC services met their needs. The focus was on the SA population given their increasing numbers and the expectation that as SAOAs age and with continued immigration (Statistics Canada, 2017b), there will likely be increasing numbers of SAOAs in LTRC facilities. Moreover, despite their growing presence in the population, research on SAs has not kept pace and the diversity among the population is seldom acknowledged leaving gaps in the understanding of their needs (Koehn, Neysmith, Kobayashi, & Khamisa, 2012; Tran et al., 2005).

For this study, I sought to address the following research questions: 1) What are the unique needs and preferences of South Asian older adults and their families regarding long-term residential care?; 2) How are decisions regarding the use of such services made in South Asian families?; and 3) To what extent are existing long-term residential care services prepared to provide culturally responsive and competent care to meet the needs of older adults from diverse ethnic and cultural backgrounds? An ethnographic methodology informed by a critical theoretical perspective was used to explore these questions. Ethnographic methods enabled exploration from the perspectives of SAOAs and their family caregivers (FCGs), what their needs, preferences and challenges were regarding LTRC, how they viewed their situations, as well as the decision-making processes they undertook regarding LTRC placement. A critical theoretical perspective allowed me to situate these individual experiences within broader social, political and cultural contexts, and to examine how larger social processes and structural factors influenced SAOAs' and their families' experiences and decision-making related to LTRC as well as the provision of culturally responsive and competent LTRC services. The findings from this study will help to inform the planning and delivery of LTRC services for the growing ethno-cultural minority population in Canada and policy decision-making related to service delivery in this area.

1.2 Dissertation Overview

This dissertation comprises seven chapters. In this first chapter I have provided a brief background to the study, and introduced the methodology and key questions guiding the study. Chapter 2 provides a review of selected literature relevant to the topic of inquiry including the social, political and cultural contexts of care, an overview of LTRC and research focused on person-centred care in LTRC and what this means for EMOA. I also provide a brief section regarding EMOA and LTRC as a more extensive review of this topic is provided in each of chapters 4, 5, and 6. In Chapter 3, I explain the methodology of the study and include the purpose and utility of using ethnographic methods informed by a critical theoretical perspective. I describe the use of interview, observation and document review methods for data collection, the sample and data analysis, and reflect on the methodology used and the methodological issues I encountered. The strategies utilized for study rigour are also explicated.

In keeping with the University of Victoria's format for a publications-based dissertation, Chapters 4, 5, and 6 present the study's key findings; each chapter is a stand-alone manuscript to be submitted for future publication and as such includes a review of the literature pertinent to the findings discussed. In Chapter 4, "Are Mainstream Long-Term Residential Care Facilities Prepared to Provide Culturally Responsive Care?" I illuminate the needs and experiences of SAOAs and their families related to LTRC and discuss whether and how their needs are met in existing mainstream LTRC facilities. In Chapter 5, "(Non) Decision Regarding Long-Term Residential Care Placement", I discuss SAOAs' and their families' consideration of, or decision making, regarding LTRC placement, to illuminate the complexity of LTRC placement for SA families and explicate the factors that influence a move to LTRC. Chapter 6, "Person-Centred Transition to Long-Term Residential Care for South Asian Older Adults", provides insights into the transition and adjustment experiences of SAOAs and their families in LTRC, the practices and/or strategies to support these processes as well as how policies may impact person-centred transitions for SAOAs in LTRC. Finally, in chapter 7, I highlight the major insights and key implications that have emerged from this study as well as discuss the study's strengths and limitations.

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Chapter 2: Review of Selected Literature

Political, social and cultural contexts influence how health care services, including long-term residential care (LTRC), are organized, provided and accessed, as well as which aspects of care provision are emphasized and which are marginalized thereby shaping the care experiences of older adults. In this chapter, I begin by discussing the current political and socio-cultural contexts of care provision in Canada. I then provide an overview of LTRC, including policy and legislation that governs LTRC as well as the culture and organization of care. This is followed by an exploration of research focused on person-centred care (PCC) in LTRC and what this means for immigrant and EMOA. I end the chapter with a brief high-level selective overview of care and caregiving in the SA population, the experiences of EMOA in LTRC, and practices suggested to facilitate their transition and adjustment. As previously mentioned, a more extensive review of these topics is provided in Chapters 4, 5, and 6.

2.1 Political and Socio-cultural Contexts of Care

The political philosophy of a society determines how aspects such as freedom, justice, individual rights and responsibilities, the distribution of societal resources, as well as the responsibilities of government amongst others, are viewed and enacted (Brooks, 2013; Dryzek, Honig, & Phillips, 2011). Hence, a society's political philosophy has everyday implications for people's lives which are not always recognized (Braedley & Luxton, 2014). In the following section, I provide an overview of neoliberalism, which dominates the current political context in Canada, and discuss its influence on the organization of care and implications for individuals and families.

2.1.1 Political Context

Neoliberalism has variously been described as an ideology, a project, a logic of governance, as well as a process, amongst others (Armstrong, 2013; Braedley & Luxton, 2014; Peck & Tickell, 2002). Constructed on the principles of classical 18th and 19th century liberalism, with its primary value of “human freedom from coercion and servitude” – which neoliberals believe is tied to capitalism as a system that promotes expansions of wealth and the freedom to pursue wealth and thus one’s desires (Braedley & Luxton, 2014, p.7) – neoliberalism initially emerged immediately after World War II under the intellectual leadership of Friedrich von Hayek, in response to “concern over the threats posed to individual freedom, moral standards, the rule of law, and private property by arbitrary state power” (Armstrong, 2013, p.188). However, it was not until the 1970s, during a period of economic stagnation and fiscal crisis that neoliberalism took on hegemonic status (Armstrong, 2013). Standing in opposition to socialism and as a defense of capitalism (Braedley & Luxton, 2014), neoliberalists “championed markets free of state intervention as the principal guarantor of individual freedom” (Armstrong, 2013, p.188). Further, neoliberalists perceive markets and market-like mechanisms as the fairest social arrangement through which to distribute social goods and “bads” (Braedley & Luxton, 2010; Connell, 2010 as cited in Armstrong & Braedley, 2013). Along with the primacy of the “free market” and individual freedom which goes hand-in-hand with personal responsibility, other aspects of neoliberal ideology include a reduction in public sector expenditures, commodification of services and privatization of public assets and institutions. And, ensuing from the latter, is an institutional and cultural change where for-profit corporations are considered to be the admired model for the public sector and business management principles are applied to public sector institutions referred to as the “new public management” (Connell, 2014; Rushton & Edvardsson, 2020). In addition, it is important to be aware of the contingent nature of neoliberalism (Connell, 2014; Peck & Tickell, 2002). Connell (2014) points to the variability and complexity of the neoliberal project when she notes:

> The neoliberal agenda cannot be regarded as a single doctrine or program, or even as a single package of policies. It is, rather, a sprawling family of related policies that get proposed and implemented in different sequences and in a variety of institutional forms. They are linked, however, even if imperfectly, through the mechanisms of global markets, the circulation of neoliberal doctrine…and the mutual support of neoliberal states, under the hegemony of the United States (p.32).

In a similar vein, Peck and Tickell (2002) speak about neoliberalism as a 'process' that is "transformative and adaptive" demonstrated by variability in the way it has been embedded in different "local neoliberalisms" within wider networks and structures of neoliberalism (p.380). Through tracing historical shifts in the process of neoliberalization in the North Atlantic zone, Peck and Tickell illustrate its transformative capacity noting that "[T]he process of neoliberalization then is neither monolithic in form nor universal in effect…in the course of the last quarter-century, there have been significant internal shifts in its institutional forms, its political rationality, and its economic and social consequences" (p.384).

Despite its variegated nature, neoliberalism has resulted in increased inequality, often in classed, gendered and racialized ways (Armstrong, 2014; Braedley & Luxton, 2014), greater health and health care inequalities (Chappell & Penning, 2009; Viens, 2019), and the offloading of care and costs from the state to individuals and families (Armstrong, 2014; Luxton, 2014). Neoliberalism has also influenced how care is organized and provided (Armstrong & Braedley, 2013; McGregor, 2001).

The neoliberal ideology of individualism and individual responsibility provides a rationalization for inequality through the assumption that we get what we deserve as a result of our efforts (Armstrong, 2014), but ignores the structural and other constraints that create inequalities (Braedley & Luxton, 2014; Luxton, 2014). Braedley and Luxton (2014) have argued that neoliberalism has produced benefits and losses on the basis of gender, race and class. The ideology of individualism and individual responsibility also places the responsibility for one’s health status on the motivations and behaviours of the individual rather than health status being the result of how society organizes the distribution of a variety of resources (Raphael, Curry-Stevens, & Bryant, 2008). This leads to a strong bias towards understanding health problems as individual problems rather than societal ones and specifies the cause of the health problem as residing with the individual (Raphael et al., 2008; Viens, 2019).

Services that were once provided by the state as citizens’ rights have been either “redrawn or withdrawn in the name of choice” (Armstrong, 2014), commodified or privatized (Connell, 2014). The claim that the market or for-profit organizations are more efficient and effective than the public sector in provision of services has been used to support a move to privatization (Armstrong, 2014; Polivka & Luo, 2017), despite researchers noting the lack of evidence supporting such claims (Armstrong, 2014; Polivka & Luo, 2017). Privatization has resulted in restricting access to services in unequal ways (Armstrong, 2014) and has forced people to rely on earnings, support from family and friends, voluntary organizations, or to “go without” (Luxton, 2014). In addition, more costs have been downloaded to individuals and families as governments add fees to services that were previously offered without them or as individuals are sent home “quicker and sicker” from hospital resulting in costs for prescriptions and other necessities that would have been covered in hospital (Armstrong, 2014).

Where services are still provided by the public sector including health care, they are often managed according to business-like managerial practices in a call to efficiency (Braedley, 2012; Rushton & Edvardsson, 2020). Managerialism involves the deployment of “techne” such as “technologies of performance” enacted through standardization, guidelines, targets, key performance indicators, audit compliance and reporting to mention a few and “technologies of agency” such as funding and incentivization schemes as well as professional development and appraisal (Rushton & Edvardsson, 2020). Such practices enable governance from a distance (Armstrong, 2013; Rushton & Edvardsson, 2020) and serve to guide the conduct of service providers (Baines, 2006). These practices also require significant work-time to be spent on gathering data and managing the technocracy, without necessarily resulting in increased efficiency (Baines, 2006), and, when implemented in health care organizations, such as LTRC facilities, can have an impact on resident care (Rushton & Edvardsson, 2020; Sharp, McAllister, & Broadbent, 2018).

The organization and delivery of LTRC services have been significantly influenced by neoliberal ideology (Armstrong & Braedley, 2013; Mercille, 2018; Polivka & Luo, 2017). In many countries, LTRC is increasingly organized along market lines with for-profit LTRC facilities, often part of large corporate chains, comprising a larger share of the complex institutional care for older adults (Mercille, 2018; Polivka & Luo, 2017). Privatization is also seen in LTRC facilities that are owned and operated by the state, where contracting out of certain services such as housekeeping and meals with a view to cost savings is not uncommon (Mercille, 2018). In addition, governments may also contract with the private sector to provide publicly funded LTRC services.

In British Columbia (B.C.), the province where this study took place, there are 293 publicly funded LTRC facilities, 62 percent of which are owned and operated by private sector contractors that are a combination of for-profit businesses and not-for-profit societies (Office of the Seniors Advocate, 2020). According to the Office of the Seniors Advocate (2020), the contracted long-term care sector in B.C. is a “$1.4 billion per year business, making it one of the largest financial transactions between government and the private sector" (p.7). The focus on profit of these businesses can have implications for staffing levels and direct care provision which can impact the quality of care and quality of life of older adults in these facilities (Armstrong & Armstrong, 2020; Armstrong, Armstrong, Choiniere, Lowndes, & Struthers, 2020; McGregor et al., 2005; McGregor & Ronald, 2011; Office of the Seniors Advocate, 2020). Further discussion about the organization of LTRC in B.C. is taken up in Section 2.2 "Overview of Long-Term Residential Care".

2.1.2 Socio-cultural Context

The socio-cultural and political context in Canada is imbued by a discourse of ageism. The rhetoric of the grey tsunami, apocalyptic demography and arguments for rationing of services to benefit younger 'productive' members of society continues to exist despite refutations about the grey tsunami and apocalyptic projections (Evans, McGrail, Morgan, Barer, & Hertzman, 2001). In a statement made on September 29, 2016 on the occasion of the "International Day of the Older Person" on October 1st, the B.C. Seniors Advocate noted that 85 percent of seniors over the age of 85 live independently, 80 percent of this cohort do not have a diagnosis of dementia and that "emergency departments are not flooded with seniors; in fact only 22% of emergency department visits are from those over 65" (https://www.seniorsadvocatebc.ca/wp-content/uploads/sites/4/2016/09/Seniors-Advocate-opinion-piece-Int.-Day-of-the-Older-Person-2016.pdf), further refuting claims of apocalyptic expenditure for older adults. Ageist notions are often seen and perpetuated in newsprint media, editorials, and opinion pieces (Baumbusch, 2008) and are sometimes articulated in more nuanced ways. One example of this is an opinion piece in the Vancouver Sun dated October 6, 2015 related to services and programs for older adults which opined that politicians favoured funding for seniors compared to young adults because more seniors vote compared to young adults. Couched in voter turnout lingo, this opinion piece can be seen as a nuanced example of ageism as it discounts the need for services and programs for older adults in their own right rather than in exchange for turning out to vote. Moreover, such opinion pieces also serve to incite generational divides based on gross generalizations. A blatant example of such divisive rhetoric was a column in the Globe and Mail by Margaret Wente, entitled “Time to Soak the Seniors”, dated June 10, 2016, in which Ms. Wente painted all seniors as affluent and as not needing the government pensions and services which are provided to them (http://www.theglobeandmail.com/opinion/time-to-soak-the-seniors/article30306595/). Ms. Wente argued that pensions and services were paid for by the younger working-age generation, who she said were earning less today, and referred to the phenomenon as “we’re robbing from the poor to give to the rich”. The B.C. Seniors Advocate was prompted to write a response in which she noted that the column was a “generally divisive and stunningly inaccurate generalization of a group of people based on their age” (https://www.seniorsadvocatebc.ca/osa-reports/seniors-advocate-responds-to-globe-and-mail-column/). Such rhetoric indiscriminately supports a lack of or reduced services for older adults (Ronch, 2004), or services when provided, that offer little choice or respect and which treat all older adults as a homogenous group. The Seniors Advocate has described this as “the social spending bias against seniors”.

Ageist notions are also reflected in neoliberal ideology revealed through contemporary positive aging discourses which are aligned with the neoliberal agenda of activation, responsibilization, and individualization (Laliberte Rudman, 2015). Laliberte Rudman (2015), utilizing a governmentality perspective to critically analyze how study participants talked about their aging bodies as part of preparing for and moving into retirement, found that the body was central to informants' understanding of oldness. She noted:

> …consistent with the positioning of the body as a marker of responsible citizenship and an object to be monitored and controlled as part of retirement within positive aging discourses, informants positioned those with 'old bodies' as irresponsible…and when talking about those they perceived as 'old', informants pervasively located oldness in undesired bodily signs and incapacities, distancing themselves from such bodily characteristics as well as from those they saw as 'old' (p.13-14).

She commented that "rather than combating ageist attitudes, positive aging discourses were taken up in ways that continued to position oldness as a state to be avoided both personally and socially" (p.14) and concluded that her informants "embodied positive aging discourses, and in turn, embodied neoliberal rationality as they prepared for and moved into retirement" (p.19).

At the time of writing, the world is in the midst of the COVID-19 pandemic. This unprecedented situation starkly illuminates in the public realm how society views and values its older adult population as well as how we care for them. With 80 percent of COVID-19-related deaths in Canada occurring in LTRC facilities and the need to deploy members of the Canadian Armed Forces to provide assistance in LTRC facilities in two provinces, the Prime Minister of Canada noted "[I]n Canada, we shouldn't have soldiers taking care of seniors" (Brewster, 2020). Further, on May 12, 2020 he stated "COVID-19 has exposed some 'uncomfortable truths' about Canadian society, including how we care for seniors" (Harris, 2020). The pandemic also brought to light the high degree of privatization of the LTRC "industry" and its dire consequences (Armstrong et al., 2020; Canadian Institute for Health Information [CIHI], 2021).

The socio-cultural context in which care is provided is also dominated by the ideology of the medical model with its orientation towards treating clinical problems, its hierarchical organization, notions of efficiency in the health care system and patriarchal view that healthcare providers know best (Froggatt, Hockley, Parker, & Brazil, 2011; Porter & Lee, 2013; Ronch, 2004). The medical model has influenced how LTRC facilities are organized and residents seen and cared for (Froggatt et al., 2011; Ronch, 2004). As Ronch (2004) noted when discussing the challenge of culture change in nursing homes, "a major barrier to culture change in nursing homes appears to be that the acute care medical model constitutes the defining core of the philosophical and operational blueprint of nursing home care" (p.65). The influence of the medical model and organization of LTRC is further discussed in the next section.

2.2 Overview of Long-Term Residential Care

2.2.1 Policy and Legislation

Long-term residential care (LTRC) provides 24-hour professional supervision and care in a protective, secure environment for people who have complex care needs and can no longer be cared for in their own homes or in an assisted living residence (British Columbia Ministry of Health, 2015; Office of the Seniors Advocate, 2015b). The services provided include personal care such as assistance with bathing, toileting, dressing; health care such as nursing care, medical coordination, rehabilitation; social work and dietician services as well as activities programs, meals and housekeeping (British Columbia Ministry of Health, 2015). British Columbia has 27,028 publicly funded residential care beds (Office of the Seniors Advocate, 2018) in 293 regulated facilities which are owned and operated either by health authorities, not-for-profit organizations or private companies (Office of the Seniors Advocate, 2018). There are also approximately 1,600 private-pay licensed residential care beds in the province (Office of the Seniors Advocate, 2015b). Approximately 3 percent of older British Columbians, the majority of whom are women (65%), live in publicly subsidized residential LTC facilities (Office of the Seniors Advocate, 2018, 2019). The average age of residents is 85 years, and 60% are 85 or older (Office of the Seniors Advocate, 2018). Older adults in LTRC have complex care needs with the majority having a diagnosis of dementia (63%), moderate to severe difficulties with memory and following direction (63%) and in independently performing daily living tasks (70%), with a little over one half primarily using a wheelchair (53%). On average, 45% of older adults are admitted to LTRC directly from hospital and the median length of stay in these facilities is 1.3 years (Office of the Seniors Advocate, 2019).

The British Columbia Ministry of Health provides funding to health authorities to plan and deliver publicly subsidized home and community care services which include LTRC facilities, and sets out its requirements for service provision in the *Home and Community Care Policy Manual*. While health authorities have flexibility regarding the organization and implementation of services, they have to ensure that adequate services of the types specified in the Policy Manual are delivered and that client needs are met. The Policy Manual outlines a range of requirements including eligibility for services, the management of access to services, assessment of client needs and referral, provision of information to the public about the services available and how to access them, as well as health authorities' responsibilities in applying a performance management approach to the planning and delivery of services using performance data such as bed sores, infection rates and other such clinical and medical data in monitoring improvements in quality of care and outcomes for service clients (B.C. Ministry of Health, 2013). Based on the requirements outlined in the Manual, it can be surmised that the expectations of health authorities in monitoring services is contextualized in a neoliberal model of business efficiency and on a medical model with no exploration of psychosocial outcomes or relational care. The performance management and reporting requirements as well as the context of efficiency and organization of care based on the medical model is extended to LTRC facilities in all health authorities.

Eligibility for LTRC services is established based on a standardized care assessment using an internationally researched and validated assessment instrument, the InterRAI-HC. Once an older adult is deemed eligible, access to a facility is prioritized based on care needs and/or level of risk and older adults are placed on a list (referred to as Assessed and Awaiting Placement). When an individual's turn comes up, which facility an older adult actually goes to is based on the *First Appropriate Bed Policy (FAB)* (ARCBC; Office of the Seniors Advocate, 2015b). The policy was developed in the context of the demand for LTRC services and to reduce hospital congestion as people waited for the residential care bed of their choice in addition to ensuring that those who are most in need of a residential care facility bed secure that bed as soon as possible. Under this policy, an older adult who has been assessed as ready for a move to residential care must accept and move to the first appropriate bed that becomes available in their geographic area within 48 hours or risk being removed from the priority list for the first available bed (Office of the Seniors Advocate, 2015b). During the writing of this dissertation, a policy shift was made where older adults would no longer have to accept the first available bed and would be able to choose up to three preferred care homes (British Columbia Ministry of Health, 2019). It is not yet clear how these changes were operationalized by the health authorities or the impact of the policy changes on older adults' eligibility for LTRC or on the demand for LTRC services and hospital congestion.

Long-term residential care facilities in British Columbia (both private and publicly subsidized beds) must meet provincial licensing standards and are required to provide a range of services that are specified in the *Community Care and Assisted Living Act or in the Hospital Act* (Office of the Seniors Advocate, 2015b). The legislation standardizes care and accountability and requires LTRC facilities to operationalize the legislation through institution-specific policies

(Kontos, Miller, Mitchell, & Cott, 2010). The legislation covers everything from facility requirements related to types of spaces and footage of floor space per resident, staffing requirements, operations (admission and continuing accommodation, general care requirement, nutrition, medication, use of restraints, matters that must be reported) to records and transitional facilities. While the Act is quite prescriptive in some areas such as detailing the floor space footage per resident or that a menu should be prepared for at least a 4-week period or dictating the times for a food service schedule (e.g., morning meal between 7-9am, noon meal between 11:45-1:00pm and evening meal after 5pm), in other areas there is a dearth of direction. For example, the directives on staffing requirements simply state that "employees on duty are sufficient in numbers, training and experience, and organized in an appropriate staffing pattern…" and refrains from specifying direct care hours per resident per day, leaving facilities to determine the staffing levels and scheduling patterns.

What becomes clear from the discussion above is that much of what facilities and staff can and cannot do is imposed on them externally through legislation and policy and procedures developed at the Ministry and health authority level and these standards of care and practice guidelines structure the day-to-day delivery of care (Kontos et al., 2010). While intended to ensure a high quality of care for residents, the externally imposed legislation can have unintended consequences such as limiting residents' autonomy, independence, choice and flexibility; restricting health care providers' ability to meet the individualized care and relational needs of residents (DeForge, van Wyk, Hall, & Salmoni, 2011; Kontos et al., 2010; Lopez, 2007, 2014); and creating a culture of surveillance and compliance (DeForge et al., 2011; Kontos et al., 2010). LTRC frontline workers in a study conducted by DeForge et al. (2011) in an urban LTC facility in Ontario, described how the rules and regulations worked for some residents and not others and that because the one size fits all did not work, the staff learned to work around the rules and regulations and sometimes broke rules to meet residents' individualized needs. The staff also reported feeling excessively monitored by supervisors in their attempt to ensure compliance with rules and regulations (supervisors also reported the same experience) and felt that blame was sometimes shifted onto them and thus were afraid when they broke rules. DeForge et al. concluded that the staff felt afraid to care and were unable to care and that their experiential knowledge of residents' needs was discounted in the regulated environment – the latter point also noted by other researchers (Holmberg et al., 2013). Kontos et al. (2010) similarly noted links between government regulations and institutional polices, supervisors' responsibility for compliance to regulations and surveillance of frontline workers, as well as frontline workers' articulation of the disjuncture between policy and resident preferences relating to personal care and the rule breaking that staff engaged in to meet residents' needs. Kontos et al. found that while supervisors had the responsibility to ensure compliance with legislative rules, they also felt that the regulatory structure of LTC restricted quality care and sometimes condoned rule breaking by frontline staff when this was perceived to be consistent with a resident's needs or preferences. However there was an upper limit to supervisors condoning the breaking of rules such that if the rule breaking resulted in interference with "the temporal order of institutional practices for the smooth operation of the facility" (p.124), then frontline workers were held accountable for breaking the rules. The risks that frontline workers were willing to take in breaking rules and which rules they decided to break in meeting residents' needs were found to also depend on the relationship of the frontline worker with a resident (Bowers, Esmond, & Jacobson, 2000).

2.2.2 Organization and Culture of Care

Long-term residential care continues to be organized and funded based on the dominant ideology of the medical model of care (Froggatt et al., 2011; Ronch, 2004). While this may seem logical and even necessary on one level given the increasing acuity of residents in the LTRC setting, Ronch (2004) asserts that this model of care is inappropriate to meet the needs of the residential care population which has multiple chronic rather than acute conditions and complex psychosocial needs. Further, he asserts that an approach to care which focuses on the clinical illness rather than the whole person makes for an inhumane environment and that the drive for culture change in LTRC is an attempt to humanize the care environment.

Similar to Ronch, Froggatt et al. (2011) also note that the biomedical model has infiltrated LTRC and that identities are ascribed to residents based on institutional templates such as the ‘embodied self’ where care practices and social interactions focus on the physical limitations of the person’s body, and the person is reduced to an object of care or the ‘dying self’ referring to residents deemed to be dying primarily defined by a biomedical discourse. The researchers contend that this ascription of identity to residents in LTRC facilities results in “the atomization and splitting down of the whole person to instrumental components, which deny dynamic social relationships which give meaning to residents’ experiences” (p.267).

Froggatt et al., also see LTRC facilities as ‘contested places’ for several reasons. First, these facilities are both homes for people and places where care is provided and contestation is seen in the variable terms used such as ‘resident’ or ‘patient’ to describe the older adults who reside there (and in this study, key informants have also used the term ‘customer’ reflecting the broader neoliberal market-oriented context in which LTRC facilities are situated). Second, given that LTRC facilities are considered both homes and places where care is provided, they are “located in an ambiguous position between, and drawing on, medical and domestic domains of care" (p.267), which have conflicting priorities that have to be managed within the facility. Third, LTRC facilities are not only places where people live but also where they die. The lengths of stay in these facilities is getting shorter with the median length of stay in a B.C. care home being approximately 1.3 years (Office of the Seniors Advocate, 2019). Thus the different foci on living and dying also adds another dimension to the care provided. And fourth, LTRC facilities are also contested places because of "the ongoing dissonance that arises from the application of the rules and regulations arising from the system that may not ally with the lifeworld priorities of residents, staff and relatives" (p.267). The consequences of these contestations are that the experiences of care of individuals and their families may not align with personal preferences and priorities (Froggatt et al., 2011).

The hierarchical nature of LTRC is apparent in the organization of care and staff with administrators holding the most power at the apex followed by regulated professions such as nurses (registered nurses and licensed practical nurses), social workers, and rehabilitation therapists. Resident care aides (RCAs), also referred to as health care workers (HCWs), certified nursing assistants (CNAs), or personal support workers (PSWs), who represent the majority of workers, do the bulk of the personal bodily care work and have the most interaction with residents are relegated to the bottom of the hierarchy (Banerjee et al., 2012; Baumbusch, 2008; Forbes-Thompson, Gajewski, Scott-Cawiezell, & Dunton, 2006; Holmberg et al., 2013; Jervis, 2002; Ronch, 2004). Care work is task-oriented with tasks allocated among job categories such that registered nurses (RNs) hold managerial roles, licensed practical nurses (LPNs) perform more medically oriented, supervisory and administrative tasks, and care aides handle the bodily care work (e.g., bathing, toileting, dressing, feeding, etc.) (Banerjee et al., 2012). Jervis (2002) has described the staff hierarchy in LTRC as a "chain of command" in the nursing department where “orders were passed down the chain of command, and problems and questions were directed upward for resolution and guidance” (p.14), and where top staff have a relatively large degree of autonomy and hold the most power, with nursing assistants having the least autonomy and seemingly no power. Jervis noted that some RCAs exerted power by engaging in low profile resistance such as giving the semblance of following orders but continuing to focus on residents’ preferences and limiting contact with nurse-supervisors.

Forbes-Thompson et al. (2006) discussed the disjuncture between administrators and care staff in LTRC regarding perceptions of communication, teamwork and leadership, with administrators rating these processes higher and care staff lower, and RCAs giving the lowest ratings to administrative leadership and teamwork. Holmberg et al. (2013), in focus groups with nursing assistants, found that nursing assistants felt disrespected by their supervisors and that their experiential knowledge of residents was discounted. Nursing assistants also felt that the organization of the work environment, particularly related to the absence of teamwork with nurse supervisors, and policies related to staffing levels and staff scheduling, inhibited their ability to provide quality care to residents which for them extended beyond the physical tasks of feeding or cleaning to include meeting the social and emotional needs of residents.

The relationship between staffing and quality in LTRC has been extensively explored in the literature. Frontline care workers report heavy workloads, the inability to complete tasks within the allotted time, feeling rushed, insufficient staffing levels, and having to work short-staffed, all of which result not only in physical and emotional stress for care workers, but also limits/constrains their ability to provide the quality of care that they felt they were capable of providing, including attention to both the physical and psychosocial aspects of care (Banerjee et al., 2012; Bowers et al., 2000; Knopp-Sihota, Niehaus, Squires, Norton, & Estabrooks, 2015; Lopez, 2006, 2007, 2014; McGregor et al., 2005; McGregor & Ronald, 2011).

While reviewing the literature in this area, a great deal of variation was noted in care aide to resident ratios ranging from a low of 1 RCA: 6 or 7 residents (Rockwell, 2012) to a high of 1:24 residents on a day shift (Baumbusch, 2008) and 1:25 residents on a night shift (Pemberton, 2016a). Banerjee et al. (2012), in their comparative survey of residential care workers across three Canadian provinces and four countries that followed a Scandinavian model of social care, found that Canadian frontline workers were responsible for twice as many residents as their Scandinavian counterparts. Banerjee et al., have cautioned that staff to resident ratios in and of themselves may not provide an accurate measure of workload because the ratios do not necessarily reflect the intensity and complexity of the care work provided to each resident. Further, Cooke (2015) has noted that it is not only the number of RCAs but also the extent to which RCAs on each shift work together as a team to meet residents' needs (which can be influenced by other factors such as whether they are regular or casual staff), that is important. Nonetheless, one can conceive of the impossibility of providing a high level of care to 25 residents during a day shift without cutting corners or feeling rushed, less so having the time to develop a relationship with residents.

McGregor et al. (2005) examined staffing ratios for direct-care and support staff in publicly funded not-for-profit and for-profit nursing homes in British Columbia which receive global funding from the provincial government. Findings indicated that significantly more direct care and support staff hours per resident-day were purchased in the not-for-profit sector than the for-profit sector with similar funding levels (0.34 more hours per resident-day provided by direct care staff and 0.23 more hours per resident-day provided by support staff). McGregor et al.

suggested that the difference in direct care and support hours noted between the two sectors may have implications for the provision of quality care given research showing that having more direct-care personnel is associated with better care. At the time of the study, there was no regulation by the government or regional health authorities regarding how funding should be allocated between staffing, administration, or property costs. Given their finding and that one of the principal ways to generate profit in the residential care sector is through lower staffing levels, McGregor and colleagues advocated for mandatory minimum staffing levels suggesting that 3.5 nursing hours per resident per day would be a reasonable first step (McGregor & Ronald, 2011).

A recent funding review of contracted long-term residential care in B.C. conducted by the Office of the Seniors Advocate similarly found a significant difference between for-profit and not-for-profit providers in the number of direct care hours delivered. With similar funding formulae, when comparing the number of direct care hours delivered relative to the number funded in 2017/2018, the review found that for-profit providers failed to deliver 207,000 hours of funded direct care hours while the not-for-profit care homes over-delivered by providing an additional 80,000 hours of direct care beyond what they were funded to deliver. The report noted “[W]hile the shortfall of 207,000 hours in the for-profit care homes represents only 2% of their funded hours, these hours would be enough to fully staff a 168-bed care home at 3.36 hours of direct care per resident, per day for one year” (p.33) (Office of the Seniors Advocate, 2020). Although the British Columbia Ministry of Health has set a guideline of 3.36 direct care hours per resident per day, this is not legislated and reports in the media suggest that almost 80 percent of government-funded nursing homes were below the government guideline and of those, 74 percent were owned and operated by private businesses (Pemberton, 2016a, 2016b).

In exploring the views of nurse aides regarding the relationship between staffing levels and quality in LTRC, Bowers et al. (2000) found that nurse aides described the link between staffing and quality based on staff-resident relationships. For these nursing assistants, delivering high quality care meant developing relationships with residents and then using those relationships to enhance residents' quality of life. Short-staffing resulted in nurse aides feeling rushed and collapsing routine care tasks into a series of procedures, eliminating tasks such as oral care, walking and range of motion exercises, abbreviating bathing procedures, not stopping to chat and reducing other activities that allowed for resident choice and a sense of reciprocity (p.60). However, Bowers et al. also found that the presence or absence of a relationship between the nursing assistant and resident had a strong influence in decisions related to which care tasks to leave out so they were not overly detrimental to the resident. For many nursing assistants, short-staffing meant missing breaks or feeling guilty if they took their regularly scheduled breaks. Inadequate staffing levels had detrimental effects on the physical and psychological experience of nursing assistants reflecting moral distress (Morley, Ives, & Bradbury-Jones, 2019).

Knopp-Sihota et al. (2015), in a cross-sectional survey of health care aides in western Canada, similarly found that most care aides (85%) reported feeling rushed and that 75 percent left at least one task missed due to insufficient time. Psychosocial aspects of care such as talking with residents were most often rushed or missed, followed by other physical activities or care tasks missed such as assisting with mobility, mouth care, toileting, hair care and bathing. Knopp-Sihota et al., concluded that lack of time and possibly how work was structured were barriers to providing necessary resident care and that the unit-level work environment was most important in terms of organizational association.

Lopez (2006, 2007), conducting an ethnographic study in a US nursing home, found that care aides recognized their inability to complete all tasks during morning care routines within the allotted time, especially if they followed official procedures. This led workers to break rules to get their work done on time and learn ‘unofficial’ skills in expediting care, thus compromising the quality of care provided. Lopez attributed this situation to policies being imposed on nursing homes by regulators without any regard for the reality of staffing levels, care aide job design, or how staff were organized as well as public funding constraints and limited budgets that resulted in a focus on efficiency – what Lopez described as the tension that nursing homes face between the bureaucratic mandates of efficiency and profit versus care, sensitivity and humanity (Lopez, 2006, 2007, 2014).

Banerjee et al. (2012), based on their study described earlier, assert that the current LTRC environment in which frontline staff work can be considered a form of structural violence. Canadian care workers in their study also reported being rushed to complete care tasks, had higher workloads, and were twice as likely to end the day feeling physically exhausted, three times as likely to experience back pain, and four times as likely to be mentally exhausted as their Scandinavian counterparts (p.395, 396). In addition to insufficient staffing levels, Banerjee et al. found that Canadian care workers were subjected to routine short-staffing where absent staff were not replaced and staff reported that low decision-making autonomy and insufficient opportunities to communicate with co-workers also contributed to violence. As they note: “[I]ndeed workers’ heavy workload, rigid work routines, low autonomy and low status were experienced as sources of physical and psychological distress. Focus group participants indicated that their working conditions contributed to conflict and violence” (p.395). Banerjee et al., therefore urged researchers to investigate the effects of macro-level social, political and economic choices on the conditions within LTRC facilities.

2.3 Person-centred Care

Thus far, I have discussed the political and socio-cultural contexts of care provision in Canada and provided an overview of LTRC, the policy and legislation governing these services, as well as how neoliberal ideology and the medical model have influenced the provision, delivery and organization of LTRC. In this section, I explore research focused on person-centred care (PCC) in LTRC, what PCC means for immigrant and ethno-cultural minority older adults (EMOA), and the factors that influence the delivery of PCC.

Person-centred care (PCC) at its core is an ethical and moral call to recognize and value the ‘person’ behind the ‘patient’ and respect the inherent dignity of each person (Edvardsson, Winblad, & Sandman, 2008; El-Alti, Sandman, & Munthe, 2019; Entwistle & Watt, 2013; Öhlén et al., 2017). McCormack et al. (2015) have suggested that PCC is a movement to humanize health services. In the LTRC context, PCC is seen as a reaction to the disempowering and dehumanizing institutionalized and medicalized environment with its many contestations and as a counterpoint to “efficiency” (Colomer & de Vries, 2016; Froggatt et al., 2011; McCormack et al., 2015).

PCC aims to place the person at the centre of their care, understanding their biography, taking account of their experiences, and supporting their values, preferences and needs in all aspects of caregiving; involving them in decision-making; attempting to understand behaviour from the perspective of the individual and assuming that there is meaning in all behaviour; and creating a positive social environment in terms of care that promotes relationships between people (Backman et al., 2016; Brooker, 2003; Colomer & de Vries, 2016; Crandall, White, Schuldheis, & Talerico, 2007; Donnelly & MacEntee, 2016; Edvardsson, Varrailhon, & Edvardsson, 2014; Edvardsson et al., 2008; McCormack, 2004; Nolan, Davies, Brown, Keady, & Nolan, 2004; Rockwell, 2012; Smebye & Kirkevold, 2013; Talerico, O'Brien, & Swafford, 2003). For immigrant and ethno-cultural minority older adults, PCC also entails the provision of culturally responsive and competent care (Cragg, 2017; Lehman, Fenza, & Hollinger-Smith, n.d.) based on values of inclusivity, respect, valuing differences, equity and commitment (Registered Nurses' Association of Ontario, 2007, p.19). At the interpersonal level, culturally responsive and appropriate care extends beyond cultural competence to the relationship between the care provider and care recipient with consideration of the multiple social identities/locations of the care recipient, and includes knowing and valuing the individual in their context of family and community and engaging with multiple aspects of the individual’s cultural makeup (Werkmeister-Rozas & Klein, 2009). At the organizational level, cultural responsiveness is reflected in a “congruent set of workforce behaviours, management practices and institutional policies” (Registered Nurses' Association of Ontario, 2007, p.19). Culturally responsive and competent organizations affirm and respect differences within and between groups, are committed to policies that enhance services to diverse communities, continually assess policies and practices regarding culture, expand cultural knowledge and resources, and adapt service models to better meet the needs of the communities served (Cragg, 2017, p.5). The Swedish National Board of Health and Welfare in its 2010 published guidelines for dementia care described person-centred care relative to culturally and linguistically diverse older adults as follows:

> Person-centered care means to especially consider needs related to people having different cultural or linguistic background. Allowing for cultural needs could for instance be about giving persons with dementia disease the opportunity to practice their religion, being served culturally appropriate food, keeping their cultural traditions and customs,

> and having access to nursing staff that communicate in the same native tongue as the person with dementia…To be cared for by nursing staff who communicate in the native tongue and who also have cultural competence could give the person with dementia disease who has a different ethnic background a sense of security, increased well-being, and a sense of feeling “at home” (Antelius & Kiwi, 2015, p.81)

While PCC is generally supported in the literature and among policy makers and residential care facilities’ management as important to implement (Colomer & de Vries, 2016), a number of challenges related to its understanding (Colomer & de Vries, 2016; Morgan & Yoder, 2012; Rockwell, 2012; Smebye & Kirkevold, 2013) and implementation have been discussed in the literature (Colomer & de Vries, 2016; Donnelly & MacEntee, 2016; Rockwell, 2012; Talerico et al., 2003) along with some critique related to the individualistic assumptions on which PCC is based (Greenwood, 2007; McCormack, 2004; Nolan et al., 2004; Smebye & Kirkevold, 2013).

PCC has been variously viewed as an approach to care, a practice philosophy, a value base, individualized care, a set of techniques, or a phenomenological approach (Brooker, 2003; Colomer & de Vries, 2016; Rockwell, 2012; Smebye & Kirkevold, 2013). This diversity in how PCC is viewed, the lack of clarity regarding what PCC entails, and the absence of prescriptive techniques or problem-solving procedures, as noted by Rockwell (2012), has had implications regarding how it has been operationalized, which aspects have been implemented, and its understanding among caregivers (Colomer & de Vries, 2016; Ells, Hunt, & Chambers-Evans, 2011; Rockwell, 2012). Most often, PCC has been seen to be operationalized at the micro patient-care provider level through elicitation and documentation of the patient’s narrative to establish a partnership, engagement in decision-making and development of care plans (Naldemirci et al., 2018; Ocloo et al., 2020). Ohlen et al. (2017) however, through their analysis of PCC in the palliative care context, have demonstrated that PCC can also be considered at the meso- and macro-levels thereby enabling critique of organizational frameworks and structures experienced by patients, families and professionals as well as the macro context which influences the micro- and meso-levels (p.7).

Taking a critical look at PCC in the context of gerontological nursing, several authors have taken issue with the assumptions of individualism, individual autonomy and independence on which PCC is based (Ells et al., 2011; Nolan et al., 2004; Rockwell, 2012), arguing that such a view is inadequate in meeting the needs of older adults and may actually inhibit quality care because it promotes an idealistic image of aging that dissociates older adults who are frail or dependent and neglects the reality and necessity of interdependence at all stages of life (Rockwell, 2012, p.244). Nolan et al. (2004) contend that one needs to understand individuals as belonging to a network of social relationships and value interdependence. Along similar lines, Ells et al. (2011) argue that the historical individualistic view of patient autonomy isolates the patient as decision maker and contributes to difficulties in implementing PCC. Instead, Ells et al., advocate for the explicit adoption of a concept of relational autonomy within patient-centred care. They explain that relational autonomy takes account of the fact that:

> …people are integrally connected with a social environment marked by economics, politics, ethnicity, gender, culture and so on. Their identity is formed and shaped by their social environment, as well as their experience of embodiment, interactions with others, and possibilities for a good life. Along with interconnection, the fact of interdependence pervades this relational understanding of self, as people are only dependent and independent relative to the circumstances in which they find themselves (Ells, 2001 as cited in Ells et al., 2011, p.86).

As a result, even if people’s circumstances constrain what autonomy can be achieved, one can be empowered and enabled to express oneself within one’s context (Ells et al., 2011; Spencer, 2003). Hence incorporating relational autonomy within patient-centred care:

> …reinforces the active guiding role of the patient and supportive relationships. This helps to prevent lapses into mechanistic (or programmatic) approaches that ignore important features of particular people and the need to involve them significantly in decision making. Further, this helps to avoid paternalistic approaches where the health professional’s perceptions of the patient’s good dominate decision making related to care

> while at the same time the health professional denies the patient control over the decision-making process" (Ells et al., 2011, p.90).

The notions of relational autonomy, interdependence and relationship within PCC (i.e., relational care), also speak to the importance of recognizing the personhood of care providers and the conditions of work that support or hinder their personhood and ability to provide PCC (Cooke, 2015; Nolan, Brown, Davies, Nolan, & Keady, 2006).

A number of structural and organizational factors have been found to challenge the implementation of PCC in LTRC. As noted previously, LTRC facilities are still organized and funded according to a traditional medical model with a hierarchical bureaucracy, and PCC is overlaid atop of this organizational structure (Rockwell, 2012). Such a structure together with the neoliberal tendency toward market-oriented LTRC services (Daly, 2013; Mercille, 2018; Polivka & Luo, 2017) reinforces financially standardized care (Campbell, 2013; Talerico et al., 2003), is concerned with objectively measurable and functional tasks rather than subjective wellbeing (Clemens et al., 1994 as cited in Rockwell, 2012; Cooke, 2015; Armstrong, 2013a), and does not allow for autonomy at the care provider level to meet person-centred needs (Rockwell, 2012; Talerico et al., 2003). Moreover, LTRC facilities are part of a larger health care system which sets regulations, funding priorities and policies related to the physical layout of facilities, regulations that govern food services, health and safety, admission to facilities, levels of care, and staffing, which further impose limitations on the implementation of PCC (Rockwell, 2012). Talerico et al. (2003) note that nursing homes' tendency to focus on minimum regulatory requirements may also contribute to a lack of adoption of PCC. Limited staffing resources, time pressures on staff and having to adhere to a timetable or schedule in which to complete tasks, lack of continuity in care related to staffing models, inadequate education and training of staff and high staff turnover (Colomer & de Vries, 2016; Ells et al., 2011; Talerico et al., 2003) as well as the institutionalized, routinized culture of LTRC (Rockwell, 2012) all contribute to challenges in supporting PCC. Researchers have also noted that competing priorities imposed on care workers enacted through managerialism and its associated techne mitigate the provision of PCC (Hillman et al., 2013; Ocloo et al., 2020; Rushton & Edvardsson, 2020; Sharp et al., 2018). Cooke (2015) and Sharp et al. (2018) have discussed how care staff in their studies prioritized the completion of documentation over care provision and Hillman (2013) discussed how the need for completion of managerial tasks offered alternate ways for staff to pursue diverse agendas. Leadership behaviour of managers also significantly impacts PCC practice (Backman et al., 2016). Backman et al. (2016) found that in situations where person-centredness of care was at a low level, leadership behaviour was particularly important in developing and supporting PCC practice. Talerico et al. (2003) maintain that successful implementation of PCC must address organizational, staff and individual factors and Edvardsson et al. (2008) contend that a great deal of flexibility is required in the clinical environment to meet the needs of the person.

2.4 Ethno-cultural Minority Older Adults and LTRC

In this section, I provide a brief and high-level selective overview of research regarding care and caregiving in the South Asian population, the experiences of immigrant and EMOA in LTRC and practices suggested to facilitate the transition and adjustment of EMOA in LTRC facilities. A more extensive review of the literature pertaining to these topics is provided in Chapters 4, 5 and 6.

South Asian norms of care and caregiving, rooted in religious beliefs regarding duty, respect and honor, encompass widespread traditional values among South Asians (Lamb, 2002, 2013; Mehta, 1997; Nayar, 2004). Filial piety, fulfilling one’s duty toward and respect for elders is highly revered in SA cultures and is generally operationalized through children providing support and care for their aging parents in later life and is a marker of intergenerational reciprocity (Lamb, 2002, 2013; Sharma & Kemp, 2011). Traditionally sons and daughters-in-law in a joint family system are expected to provide this support to older parents with the daughters-in-law typically providing the day-to-day care (Sharma & Kemp, 2011). As discussed in detail in Chapter 5, while this is the ideal, researchers have found shifts in traditional norms of caregiving and elder care in SA immigrant communities over time and have noted that social structural factors affect the type of support that is provided to older family members and the openness among SA families towards extra-familial care such as LTRC facilities (Andrews, 2012; Blakemore, 2000; Burholt & Dobbs, 2010; Gupta, 2002; Lal, 2003; Lamb, 2002; Sharma & Kemp, 2011; Speirs, Huang, & Konnert, 2017; Victor, Martin, & Zubair, 2012). Nonetheless, for many South Asians, institutional care for older adults continues to be associated with ambivalence and stigma (Brijnath, 2012; Lamb, 2013) and this can impact decision-making related to LTRC in diasporic communities.

The transition to LTRC is considered to be one of the most stressful and difficult life events for older adults, characterized by multiple losses, discontinuities, emotional upheaval and feelings of abandonment (Brandburg, Symes, Mastel-Smith, Hersch, & Walsh, 2013; Lane, Hirst, Hawranik, Reed, & Rokhman, 2017; Lee, Woo, & Mackenzie, 2002; Lee, 2010; Manion & Rantz, 1995; Martinsson, Edberg, & Janlov, 2013). For immigrant and EMOA, the transition and adjustment can entail additional difficulties as they move from a familiar social and cultural environment into one which is designed and run in accordance with Euro-centric norms and values with English being the predominant language (Koehn, Baumbusch, Reid, & Li, 2018). As briefly noted in Chapter 1 and discussed more extensively in Chapters 4 and 6, research regarding the experiences of immigrant and EMOA in LTRC indicate that these older adults may experience a range of issues or challenges including loss of family, culture and community (MacLean & Bonar, 1983; Martinsson et al., 2013; Rosendahl, Söderman, & Mazaheri, 2016), communication issues, the approach, attitude and perceived responsiveness of staff as well as high staff turnover (Chan & Kayser-Jones, 2005; Kong, Deatrick, & Evans, 2010; Martinsson et al., 2013; Rosendahl et al., 2016; Runci, Eppingstall, van der Ploeg, & O'Connor, 2014; Wang, Wang, Cao, Jia, & Wu, 2016). In addition, these older adults may also be dealing with feelings of shame and being dishonoured by the family (Koehn, 2001; MacLean & Bonar, 1983). Researchers have noted that while the transition to LTRC is already associated with loss for older adults generally, for immigrant and EMOA, the issues and challenges discussed above can put these older adults at risk for isolation and alienation, affecting their ability to adjust to the new environment and find a sense of belonging (Martinsson et al., 2013). Moreover, all of these challenges can disrupt the continuity of care that older adults feel is important to their quality of life in the LTRC setting (Chan & Kayser-Jones, 2005; Kong et al., 2010; Martinsson et al., 2013; Rosendahl et al., 2016; Runci et al., 2014; Wang et al., 2016).

Researchers have identified a number of factors that can help with the placement and adjustment of older adults in LTRC including being prepared for the move, the presence and active engagement of family, resident-staff relationships and staff support, and the provision of person-centred care (Bourgeault, Atanackovic, Rashid, & Parpia, 2010; Brandburg et al., 2013; Brownie, Horstmanshof, & Garbutt, 2014; Fraher & Coffey, 2011; Gorek, Martin, White, Peters, & Hummel, 2002; Iwasiw, Goldenberg, Bol, & MacMaster, 2003; Kokonya & Fitzsimons, 2018; Kong et al., 2010; Manion & Rantz, 1995; Mold, Fitzpatrick, & Roberts, 2005; Nay, 1995; Rosendahl et al., 2016; Sullivan & Williams, 2017; Sussman & Dupuis, 2012). In addition to these factors, the presence of staff who speak the same language and honouring residents’ and families’ cultural and ethnic preferences can facilitate the adjustment and transition of immigrant and EMOA (Bekhet & Zauszniewski, 2014; Brownie et al., 2014; Gorek et al., 2002; Kao, Travis, & Acton, 2004; Koehn, 2001; Rosendahl et al., 2016). These factors are elaborated upon in Chapter 6.

2.5 Summary of Literature Review

The organization and provision of LTRC services has been significantly influenced by the broader political and socio-cultural contexts of care characterized by neoliberalism, the medical model of care and ageist discourse.

Neoliberalism, with its market-based ideology and a drive toward profitization, and retrenchment of state services for citizens and individualism (Armstrong & Braedley, 2013; Chappell & Penning, 2009; Froggatt et al., 2011) ascribes little value to care work, (Armstrong & Braedley, 2013; Daly, 2013), places the responsibility for health and care on individuals by offloading care and costs to families (Armstrong & Braedley, 2013; Chappell & Penning, 2009) and reflects ageist notions in the level, type and eligibility for services for older adults and through contemporary positive aging discourses (Chappell & Penning, 2009; Laliberte Rudman, 2015). LTRC services, intended to meet the complex care needs of older adults who can no longer be cared for at home or in other community-based settings (British Columbia Ministry of Health, 2015; Office of the Seniors Advocate, 2015a), are increasingly organized along market lines, with a focus on efficiency and profit (Mercille, 2018; Polivka & Luo, 2017). The dominance of the medical model of care in this setting also influences the organization of care with a focus on the physical limitations of a person’s body which serves to treat older adults as objects of care and emphasizes clinical/medical outcomes rather than psychosocial outcomes (Froggatt et al., 2011; Ronch, 2004). This highly regulated, structured and routinized environment is characterized by insufficient staffing levels, high workloads and care that is standardized, role and task-focused (Banerjee et al., 2012; Bowers et al., 2000; DeForge et al., 2011; Knopp-Sihota et al., 2015; Kontos et al., 2010; Lopez, 2006, 2007, 2014; McGregor et al., 2005; McGregor & Ronald, 2011). Care providers are challenged to complete tasks within the allotted time without breaking rules or foregoing breaks and report feeling rushed in care provision and missing care activities, do not have time for relational care and do not attend to the psychosocial needs of residents having little or no autonomy in how care is provided (Armstrong & Braedley, 2013; DeForge et al., 2011; Knopp-Sihota et al., 2015; Kontos et al., 2010; Lopez, 2006, 2007, 2014). In addition, the application of business-like managerial practices in a call to efficiency (Braedley, 2012; Rushton & Edvardsson, 2020), together with the need to meet regulatory requirements, has led to a culture of surveillance, compliance and reporting (DeForge et al., 2011; Kontos et al., 2010; Rushton & Edvardsson, 2020) which has also been found to constrain care providers' autonomy in care provision (Baines, 2006) and has become a competing priority in the provision of quality care (Cooke, 2015; Rushton & Edvardsson, 2020; Sharp et al., 2018). The result of this is an inhumane environment for both residents and care providers (Banerjee et al., 2012; Ronch, 2004). The consequences of the above for residents of LTRC facilities are reduced quality of care and quality of life.

Efforts to improve quality of care and life in LTRC and the overall culture have included a move toward person-centred care (Colomer & de Vries, 2016). At its core, PCC is an ethical and moral call to value the 'person' behind the 'patient' and to place the person at the centre of their care by becoming familiar with their biography, supporting their values and needs in caregiving and involving them in decision-making (Colomer & de Vries, 2016; Edvardsson et al., 2014; Edvardsson et al., 2008; El-Alti et al., 2019; Entwistle & Watt, 2013; Öhlén et al., 2017; Rockwell, 2012; Talerico et al., 2003). For immigrant and EMOA, PCC also includes the provision of culturally responsive and competent care based on the values of inclusivity, respect, valuing difference, equity and commitment (Cragg, 2017; Registered Nurses' Association of Ontario, 2007).

The implementation of PCC in LTRC settings has had minimal success (Lopez, 2014) for many reasons including variations in understanding its principles and what it entails (Colomer & de Vries, 2016; Ells et al., 2011; Morgan & Yoder, 2012; Rockwell, 2012; Smebye & Kirkevold, 2013), as well as structural and organizational factors which have challenged its implementation (Campbell, 2013; Colomer & de Vries, 2016; Cooke, 2015; Ells et al., 2011; Hillman et al., 2013; Rockwell, 2012; Rushton & Edvardsson, 2020; Sharp et al., 2018; Talerico et al., 2003). Rockwell (2012) has noted that PCC has been laid atop of the existing organizational structure and Lopez (2014) has argued that structural changes related to the organization of care and staffing levels need to be instituted for successful implementation of PCC.

The literature reviewed regarding care and caregiving in the SA population indicates that cultural norms of filial piety, intergenerational reciprocity, appropriate family roles and respect for older adults figure significantly in decisions around care and caregiving for aging older adults at home. The review also highlights shifts in expectations for care and caregiving within SA immigrant communities over time, and that social structural factors affect the type of support provided to older family members and the openness among SA families towards extra-familial care such as LTRC facilities.

Finally, the transition to LTRC is considered to be one of the most stressful and difficult life events for older adults. Research on immigrant and EMOA has indicated that these populations face additional challenges in the LTRC setting that can affect their ability to adjust to and find a sense of belonging as well as impact their quality of care. Several practices/strategies have been suggested in the literature to facilitate older adults' transition and adjustment in LTRC.

In summary, the review of the literature has illustrated challenges in the provision of LTRC and the influence of macro-level contexts in how care is organized and services are provided. This together with the increasing ethno-cultural diversity of the Canadian older adult population discussed in the Introduction, prompt important questions as to whether the existing organization of LTRC services is designed to meet the needs of an increasingly diverse older adult population. The current study explored this question from the perspective of South Asian older adults and their families. Key questions guiding the inquiry were:

1) What are the unique needs and preferences of South Asian older adults and their families regarding long-term residential care?
2) How are decisions regarding the use of such services made in South Asian families?
3) To what extent are existing long-term residential care services prepared to provide culturally responsive and competent care to meet the needs of older adults from diverse ethnic and cultural backgrounds?

In the following chapter, I describe the research process in greater detail including the theoretical perspective, methods, and research strategies employed, sample characteristics, the analytic techniques, and steps taken to ensure scientific rigour.

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Chapter 3: Research Design

In this study, I sought to explore the needs, preferences and experiences of SAOAs and their families regarding LTRC, how SA families make decisions about the use of such services and whether and how existing LTRC facilities meet their needs. One of my key aims in conceptualizing this study was to involve SA older adults in the research process and to understand from their perspective how they viewed their situation. This was important as much of the research until relatively recently regarding access to care and the factors that predict placement in residential care for older adults in general, and for EMOA in particular, has been conducted from the perspective of family caregivers only (Dubois, Dubuc, & Caron, 2009; Gupta, 2002; Lai, 2008; Min, 2005; Sudha & Mutran, 1999). While families may play a key role in the decision to access services (Grewal, Bottorff, & Hilton, 2005), I felt it was essential to explore the experiences of both SAOAs and their family caregivers. I also felt that it was important to situate these individual level experiences within broader social, political and cultural contexts so as to gain a deeper understanding of the effect of these contextual factors on SAOAs' and their families' experiences and in order to be able to inform change at a systems level. Thus I required a methodology that would enable understanding and description at the individual level and a framework that enabled situating the individual experiences within the broader context. Hence, I conducted an ethnography informed by a critical theoretical perspective.

This chapter outlines the research methods that guided this study. I begin by exploring ethnographic and critical perspectives and discuss my philosophical and theoretical positioning. I then reflect on my multiple social locations as an adult child family caregiver, a woman, a student researcher and being South Asian. Following this I describe the process for gathering data, including negotiating access and entry to the study sites, participant recruitment and data collection methods (i.e., in-depth interviews, participant observation and document review). I then discuss the data management and analytic techniques and strategies for establishing the scientific rigour of the study, concluding with a review of the ethical considerations related to the study.

3.1 Ethnography

Ethnography is one of many qualitative approaches found in social research today (Creswell, 2013; Hammersley & Atkinson, 2007). Emerging within Western social and cultural anthropology in the early twentieth century, the focus of classical or realist ethnography was to accurately and objectively document ‘other’ cultures or societies through prolonged immersion in those communities (Creswell, 2013; Hammersley, 2018; Hammersley & Atkinson, 2007; Holloway & Todres, 2003; Mantzoukas, 2012) with the assumption that the ethnographer could present a neutral, objective and value-free description of the group under study (Hammersley & Atkinson, 2007; Koro-Ljungberg & Greckhamer, 2005; Mantzoukas, 2012). Over time and in various disciplinary contexts, ethnography has been “reinterpreted and recontextualized” in order to deal with particular circumstances and now takes a variety of forms such as critical ethnography, confessional ethnography, life history, autoethnography, and feminist ethnography, to mention a few (Creswell, 2013; Hammersley, 2018; Hammersley & Atkinson, 2007). Holloway and Todres (2003) suggest that the aim of ethnography in contemporary times is to reveal the structures and interactions in a society, and the meaning that people give to their action and interaction. It also reveals how people are situated within a particular cultural context. Creswell (2013) notes that ethnography as a methodology is appropriate to use if the needs are to explore the beliefs, language, behaviour and issues facing a particular group. The task is to investigate some aspect of the lives of the people who are being studied, and this includes finding out how these people view the situations they face, how they regard one another, and also how they see themselves (Hammersley & Atkinson, 2007).

Although there is no single, agreed-upon definition of ethnography (Hammersley, 2018), one can describe what ethnographers actually do, the sorts of data they usually collect, and what kind of analysis they deploy to handle those data (Hammersley & Atkinson, 2007). With regard to data collection, ethnography usually draws on a range of data sources including the researcher undertaking prolonged observation in the field (watching what happens, listening to what is said), and/or asking questions through informal and formal interviews, as well as collecting documents and artefacts that provide insights into the focus of inquiry (Hammersley & Atkinson, 2007; Mantzoukas, 2012). Hammersley and Atkinson (2007) suggest that ethnography is characterized by the following features, although variations in practice produced by differences in type of setting and/or in people studied as well as differences in philosophical or political orientation exist (Hammersley, 2018):

1. Research takes place in the field – that is, people’s actions and accounts are studied in everyday contexts, rather than under conditions created by the researcher.
2. Data are gathered from a range of sources including documentary evidence of various kinds, but participant observation and/or informal conversations are usually the main ones.
3. Data collection for the most part is unstructured in that it does not involve following a fixed and detailed research design specified at the start and the categories that are used for interpreting what people say or do are generated out of the process of data analysis.
4. The focus is usually on a few cases to facilitate in-depth study.

5. The analysis of data involves the interpretation of meanings, functions, and consequences of human actions and institutional practices, and how these are implicated in local and perhaps also wider contexts. The researcher relies on the participants' views as an insider emic perspective and reports them in verbatim quotes, and then synthesizes the data filtering it through the researchers' etic perspective (Creswell, 2013). What are produced for the most part are verbal descriptions, explanations, and theories (Hammersley & Atkinson, 2007).

Reflecting on classical ethnography, I came to realize that this approach was insufficient in meeting the aims of my research which extended beyond description of the experiences of SAOAs and their families regarding LTRC to critically examine how the broader social, political and cultural context may have shaped these experiences. With its positivist tendencies, classical ethnography also did not resonate with my worldview. It is now commonly understood that the researcher's worldview (i.e., values and belief systems) informs how the researcher approaches his or her research and the methodology chosen to conduct the research[3] (Crotty, 1998; Denzin & Lincoln, 2011; Hammersley & Atkinson, 2007). In addition, Denzin and Lincoln (2011) note that behind these terms stand the personal biography of the researcher, who speaks from a particular class, gendered, racial, cultural, and ethnic community perspective (p.11).

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[3] All qualitative researchers are guided by philosophical assumptions which define the qualitative research process – these are beliefs about ontology (i.e., the nature of reality, what can be known about reality); epistemology (refers to the nature of knowledge – what counts as knowledge, what is the relationship between the inquirer and the known. With the epistemological assumption, conducting a qualitative study means that the researcher tries to get as close as possible to the participants being studied; knowledge is known through the subjective experiences of people hence it becomes important to conduct studies in the "field", where participants live and work – these are important contexts for understanding what the participants are saying (Creswell 2013, p.20)); axiology (refers to values, what is the role of values – values can enter into the research process at a variety of points: the problem selected for study, choice of paradigm within which to study the problem, choice of theoretical framework, choice of major data-gathering and data-analytic methods, choice of format(s) for presenting findings) (Creswell, 2013; Crotty, 1998; Denzin & Lincoln, 2011; Guba, 1990; Heron & Reason, 1997).

Reflecting on my theoretical perspective, with the aid of substantive readings, particularly the works of Sandra Harding (2006) and Patti Lather (1991), I came to understand that research is a political endeavour, that it is value-laden and that all knowledge is socially constituted (Harding, 2006; Lather, 1991). The values that I bring to my research include respecting individual subjective reality, striving for social justice and equity and transforming practice. I also agree with Campbell and Bunting (1991) who note that understanding human patterns of behaviour involves developing an understanding of both the personal meanings of social structures and the communally agreed upon meanings and effects/influence of those structures (Campbell & Bunting, 1991, p.10).

Ontologically, I take a moderate realist perspective believing that reality is socially and historically constituted and that it is influenced by social, political, cultural, economic, ethnic, and gender values. I also agree with Thorne and Varcoe regarding balancing absolutist claims in the postmodern context and a respect for individual subjective reality thus taking a moderate realist position (Thorne & Varcoe, 1998).

I believe that knowledge is socially constituted, historically situated and value-based and that it is transactional. This means that the researcher and research participant construct knowledge together and thus it is important to have a dialogic and dialectical methodology that can enable participants to be actively involved and that invites reciprocal reflexivity and critique.

Given the above, I looked more closely at critical ethnography and critical theoretical perspectives as I continued to contemplate the methodology and theoretical framework for this study.

Mantzoukas (2012), in discussing the various forms of ethnography that have developed over time, argues that the development of ethnographic genres has been informed by a variety of epistemologies that have different aims, methods of data collection and analysis, and styles of presentation. Based on action and critical theory epistemologies (Erickson, 2011; Mantzoukas, 2012), critical ethnography emerged in response to the positivist tendencies of classical ethnography and the notion that the ethnographer could present a neutral, objective and value-free description of the group under study (Hammersley & Atkinson, 2007; Koro-Ljungberg & Greckhamer, 2005; Mantzoukas, 2012). It espouses a value-laden epistemology aimed at emancipation of marginalized groups who may not be able to speak for themselves (Creswell, 2013; Mantzoukas, 2012). While drawing from conventional ethnographic data collection methods, critical ethnographers differ from classical ethnographers in that they ask different questions and have different concerns related to their research projects (Koro-Ljungberg & Greckhamer, 2005). Critical ethnographers undertake a critical approach to interpretation and analysis where the ethnographer studies issues of power, empowerment, inequality, inequity, dominance, repression, hegemony and victimization (Creswell, 2013; Koro-Ljungberg & Greckhamer, 2005). The aim is to uncover patriarchal, gendered, racial and authorial voices and languages that are incorporated within the culture. As Mantzoukas (2012) puts it, “the mantra of ‘telling it as it is’ that summed up the epistemology of classical ethnography is now replaced by the mantra of ‘giving voice’” (p.424). While critical ethnography veers away from believing that objective and value-free research can capture the real, it accepts that there may exist a ‘true’ and ‘real’ reality, but that this reality is blurred, distorted and manipulated and thus we do not have direct access to it. Therefore, as Mantzoukas points out, the scope of research is not to discover what is true or real but to discover what or who is blurring, distorting and manipulating reality. The foreground of such research is a dialogue between the researcher and participant and a dialectic interaction which results in the empowerment of both the researcher and participant, and the eventual transformation of the lived reality (Mantzoukas, 2012). The final product of a critical ethnography as described by Mantzoukas is a provocative text that challenges the status quo, providing some form of social change and adding an explicit political purpose and social activist element to the research project.

Critical ethnography is not without its limitations. Mantzoukas (2012) notes the following: 1) the overemphasis on marginalized groups may lead to missing out on data as to how others who are not marginalized view this group of people (Thupayagale-Tshweneagae, 2008 as cited in Mantzoukas); 2) it may be difficult for the researcher to achieve de-familiarization of their research context (referring to researchers who conduct research in their own environments) (Bland, 2007 as cited in Mantzoukas); 3) critical ethnography can appear to position participants as 'the problem' and the researcher as 'the solution' provider (Lather, 1992 as cited in Mantzoukas), and may encourage participants to accept the truth of the researcher's preferred discourse[4]; and 4) involving participants in analysis may in fact put participants in a disempowering situation (Manias & Street, 2001 as cited in Mantzoukas).

In summary, ethnography is both a process and an end product. As a process it involves participant observation through immersion in the field, informal or formal interviews and collection of documents that are relevant to the issue of concern. There are many forms of ethnography, classical or realist ethnography and critical ethnography being the most common. The primary mode of data collection may vary depending on the ethnographic approach chosen. Classical ethnography is concerned with the description of cultures in an accurate and objective fashion, and espouses cultural and social reality as ahistorical and independent of human thought and values. In contrast, critical ethnography is a value-laden enterprise where the goal is

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[4] Lather, 1991, notes that the central challenge in praxis-oriented research is "how to maximize self as mediator between people's self-understandings and the need for ideology critique and transformative social action *without becoming impositional*" (p.64, emphasis in the original) (Lather, 1991)

emancipation of marginalized groups by uncovering patriarchal, gendered, racial and authorial voices and languages that are incorporated within the culture and that influence the positionality of individuals in society (Mantzoukas, 2012). While critical ethnographers challenge that a ‘true’ and ‘real’ reality can be accurately described in an objective fashion, they accept that an external reality may exist but that it is blurred, distorted and manipulated so we do not have direct access to it. Interviews are considered the primary form of data collection in critical ethnography (Mantzoukas, 2012) and the interviews take a dialogical and dialectical form that can lead to emancipation of both the researcher and participant. Researcher reflexivity is considered as extremely important so that the researcher can determine how his/her positionality impacts the research and the participants and should be practiced from the outset and throughout the research process to diffuse power across participants and researchers.

3.2 Critical Theoretical Perspectives

Critical theory grew out of the theoretical tradition of the Frankfurt School in the 1920s and 1930s as these intellectuals reappraised Marxist theory to move the notion of domination and oppression beyond economic and class struggles (Browne, 2000; Campbell & Bunting, 1991; Crotty, 1998). Criticalists use their work as a form of social or cultural criticism (Kincheloe, McLaren, & Steinberg, 2011) and advocate varying degrees of social action, from the overturning of specific unjust practices to radical transformation of entire societies (Lincoln, Lynham, & Guba, 2011). They aim to change social institutions’ policies and practice (Bernal, 2002 as cited by Lincoln et al., 2011) and attempt to improve social justice and remove barriers and other negative influences associated with social oppression (Giroux, 1982 as cited in Lincoln et al., 2011). Critical researchers interrogate commonly held values and assumptions, challenge conventional social structures and keep a focus on power relationships within society so as to expose the forces of hegemony and injustice (Crotty, 1998).

Critical theory is ideologically or praxis-oriented (Guba, 1990; Lather, 1991) and includes a number of critical inquiry approaches such as neo-Marxism, materialism, feminism, Freireism, participatory inquiry, and other similar movements as well as critical theory itself. It is best understood in the context of empowerment of individuals and attempts to confront the injustice of a particular society or public sphere within the society (Kincheloe et al., 2011).

Critical theory comes from an ontological position of historical realism which assumes an apprehendable reality that is shaped by social, political, cultural, economic, ethnic, and gender values (Guba & Lincoln, 1994; Lincoln et al., 2011). Thorne and Varcoe (1998) suggest a "moderate realism that balances absolute claims in the postmodern context and a respect for individual subjective reality that balances ideological primacy within critical social theory" (p.491).

Epistemologically, critical theory takes the position that knowledge is transactional and subjective and that its findings are value-mediated. The researcher and researched are thought to be interactively linked with the values of the researcher inevitably influencing the inquiry, thus the findings are value-mediated (Guba & Lincoln, 1994; Lincoln et al., 2011).

Critical theory is methodologically dialogic and dialectical (Lincoln et al., 2011). A dialogic research design is required to enable participants to be actively involved in the construction and validation of meaning (Lather, 1986b). Dialectical practices require an interactive approach to research that invites reciprocal reflexivity and critique, both of which guard against the central dangers to praxis-oriented empirical work: imposition and reification on the part of the researcher (Lather 1986b, p.265).

Critical theory is value-laden. The role of values is included and is formative in the research process (Guba & Lincoln, 2005 as cited by Lincoln et al., 2011) and researchers seek data that can be transformative and useful in imparting social justice (Giroux, 1982 as cited by Lincoln et al., 2011). A key concern of critical theory is to understand how taken for granted assumptions can serve to further marginalize or oppress disadvantaged groups and to consider how to address social justice issues. Its aim is to uncover how larger social processes shape the lives of individuals and to bring about necessary changes such that unequal relations of power that disadvantage marginalized groups, e.g., systemic racism, are accounted for and addressed. Thus critical researchers enter the research with their assumptions on the table (Kincheloe & McLaren, 1994).

Reflexivity is very important in critical research. It is described as a process of "reflecting critically on the self as researcher" (Guba & Lincoln, 1981 as cited by Lincoln et al., 2011); as "the chronic monitoring of one's actions and thoughts (internalized actions), which is an inherent feature of human life" (Hardcastle, Usher, & Holmes, 2006, p.158). Reflexivity should take place throughout the research process at multiple levels, some of which include: 1) at the level of the researcher him or herself and his or her positionality (which impacts not only how people in the field interpret and therefore respond to the researcher but also how the researcher himself or herself filters his or her observations) (Pachirat, 2009); 2) at the level of the underlying logic of inquiry used in the research (which channels a whole series of decisions beginning with the framing of the research question to the way the researcher counts certain things as facts or observations relevant to the research and others as coincidental or unimportant) (Pachirat, 2009); 3) at the level of the researcher-researched relationship (where an asymmetry in the power relationship between the researcher and researched may exist) (Erickson, 2011; Lather, 1991); 4) at the level of data and theory (the use of a priori theory in praxis-oriented research and ensuring that theory develops from the data and being critically aware of the effect of the data on a priori theory, i.e., how it has been changed) (Lather, 1991); and 5) during the presentation of the end product (issues of voice, representation, etc.) (Erickson, 2011; Frost et al., 2010; Mantzoukas, 2004). In summary, as Lather (1991) articulates, self-reflexivity throughout the research process enables the researcher to both render problematic and provisional his or her most firmly held assumptions, yet act in the world and take a stand (p.29).

As I reviewed the literature related to critical ethnography and critical perspectives, a tension arose related to the distinction between a critical ethnography and ethnography informed by critical theoretical perspectives. For me, the tension focused on both what I was setting out to do with my dissertation research and the level at which I hoped to influence change, as well as the notion of false consciousness, a key aspect of critical ethnography. I was not setting out to emancipate SAOAs and their FCGs from false consciousness per say as the primary goal of my research – rather, my goal was to understand their experiences related to LTRC and to situate these experiences within the broader social context in order to critically examine how social, political and cultural processes might impact their experiences and therefore obtain knowledge that may inform future service planning, delivery and policy. Thus, I aimed to focus my emancipatory intent on the larger objective of the research which was to inform service delivery and policy change in the LTRC sector[5]. Another concern related to the emancipatory intent aimed at research participants discussed by Campbell and Bunting (1991) is that the assumption that research participants begin the process less emancipated than the researcher results in an

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[5] As Thorne and Varcoe (1998) have cautioned, “focusing emancipatory intent on the participants of the research itself rather than the larger objective of the research can lead to a number of systematic errors in what gets studied and how. For example, such a position fails to recognize the social inequities that might render full partnership impossible” (p.488). However, focusing the emancipatory intent of my research on the larger objective of the research does not preclude an emancipatory outcome for the research participant (Thorne & Varcoe, 1998).

attitude of paternalism (p.6). The notion of false consciousness and what this meant for accepting as legitimate the knowledge of research participants themselves was also a tension for me. Browne (2000) brings to the fore concerns regarding the notion of false consciousness – the first is that false consciousness runs counter to the view that individual subjective positions are legitimate and necessarily valuable in their own right; and the second is the risk of imposition of the researcher's position on the participants. In light of these concerns and my philosophical and theoretical perspective, I felt that ethnography informed by a critical theoretical perspective allowed me to apply critical theoretical concepts to interpretation and analysis thereby enabling a critique of the broader social, political and cultural forces that impact the everyday lives of individuals and thus obtain knowledge that can inform change at the level of service planning, delivery and policy while respecting my concerns.

On a final note, key aspects of critical theoretical perspectives are the ability for researchers to account for their biases and to be reflexive throughout the research process. For me, this was comforting because I knew that I likely had biases and assumptions about LTRC upon entering into this research from my previous experience as an administrator of a research center focused on promoting evidence-based change for seniors in community and health care settings and having chosen the topic of my dissertation because of the personal experiences[6] I have had with my parents regarding LTRC and my personal biography.

The center, where I was employed as the operations leader, conducted research related to LTRC as well as organized and hosted annual educational programs for physicians and leaders in LTRC. Through my work at the center and particularly in overseeing the planning of the

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[6] While some researchers may frown upon personal experience being the impetus of research, feminist researchers have advocated invoking personal experience as a "standpoint on which to base analysis, formulate theory and motivate action" (Ray & Fine, 1999, p.174) and that "personal struggles and experiences offer an important touchstone for academic theorizing" (Twigg, 2004, p.62) as exemplified by Martin-Matthews (2007) in her research on the provision of in-home health and social support services to elderly clients in the context of home as the site of care.

educational programs, I learned about the LTRC environment, the challenges in the setting, including clinical and those related to the organization and provision of medical care. This, along with my other social locations, influenced the framing of my research questions. For instance, I became aware of the predominant biomedical focus of care and wondered about other aspects that might influence older adults' quality of life in that setting. I also noted that the older adult population in LTRC facilities were primarily of European and Canadian backgrounds and wondered how these services might meet the needs of older adults from different ethnic and cultural backgrounds. These questions also arose from being a daughter of South Asian parents who always told my sisters and I "please don't ever put us in a nursing home". The fear of 'being put away in a nursing home to die' was palpable, especially knowing that they would likely be in a facility where the culture and food were not what they were accustomed to and that they would likely be the minority in such settings. The fear of isolation and loneliness, being left 'alone', was strong as was the inability to practice their religion and other customs. The fear that I heard in my parents' voices and saw on my mother's face after my father, who was her primary caregiver, passed away was overwhelming. Their expressed fear juxtaposed with concerns that we would likely need to consider other care options, including residential care, if my mother's health deteriorated to a point where she might need more care than my sisters and I could provide at home, was a key reason for choosing this topic. In addition, my personal experience led to wondering about other SA families' views and experiences regarding LTRC and this together with the shift in the ethno-cultural composition of the Canadian older adult population discussed earlier contributed to the choice of dissertation topic. Thus, I am aware that my research is value-laden in that I wanted to raise awareness among health care providers and policy makers about the needs, preferences, and challenges of SA families (and EMOA) regarding LTRC with a view to informing service delivery and policy in this area and that I entered the research with assumptions and biases about LTRC, the organization and delivery of service and questioned whether these services met the needs of ethno-cultural minority older adults.

I worked through these issues by engaging in reflexivity throughout the research process facilitated by journaling, peer debriefing, and conversations with my dissertation committee. I tried to critically reflect on my reactions to what I was seeing once I entered the field. For instance, when I first began spending time in the residential care setting, I found myself feeling extremely sad, emotional, and indignant about the situation I saw some SA older adults in such as being left in dirty diapers which I could smell as I entered their rooms to take them to activities, or the response of some staff members when I brought to their attention that someone needed to use the washroom or required a diaper change. I wondered why I was experiencing such strong emotions. I became anxious and worried that I may not be able to think clearly about what I was seeing or complete my research. I did not know what was going on with me – whether it was tiredness or stress from juggling multiple responsibilities of work, school and family. Debriefing with some colleagues helped me to understand that I was personalizing things and experiencing moral distress. The advice I was given was to remind myself before every LTRC visit that I was conducting a research study and that it was not about me or my parents. I also began to reflect that such situations affected other older adults in the facility as well and considered what might be causing this to happen which helped me to contextualize what I was observing. Other researchers have noted the emotion work that qualitative researchers undertake when carrying out their research (Dickson-Swift, James, Kippen, & Liamputtong, 2009; Velardo & Elliott, 2018), particularly when researching sensitive topics or the topic of research is from their own life experience and even arguing that "it is appropriate for qualitative researchers to see their emotional and cognitive functions as inseparable from each other and that emotions should be central to the research process" (Dickson-Swift et al., 2009, p.64). The researchers have noted that by taking time to reflect on the emotional and physical aspects of research, qualitative researchers may be better prepared to both undertake the research and look after their own health while doing so.

Another way that I sought to challenge my assumptions and biases about LTRC was to extend the study to include key informant interviews. Initially when the study was conceptualized, it included interviews with only SAOAs and their FCGs (in order to obtain perspectives beyond my own). As the data collection progressed I noted participants consistently commenting that staff did not have time to provide care, seeming rushed, etc. I felt that it was important to obtain the perspectives of care providers regarding the situation of SAOAs in LTRC as well as the institutional perspective thus after discussion with my dissertation committee, I included care providers as well. The information provided by key informants helped me to question the assumptions I may have made about the organization of care and services in the LTRC setting and proved to be important in the final analysis. Also engaging in reflexivity as I wrote and reviewed my field notes, I wondered about some of the observations I had of staff and their rushing about during mealtimes for example and wondered about the factors that influenced their ability to provide care or why they did things the way that they did.

Insider and/or outsider status constituted through my social locations (as an adult child caregiver, woman, student researcher and South Asian) have had an impact on how data were collected and interpreted. These social locations situated me as 'insider' and/or 'outsider' during the research process conferring challenges and advantages. I was a young child when my family came to Canada as refugees in the early 1970s. While I have adopted many Western cultural values and beliefs having grown up and educated in Canada, I still have deeply embedded beliefs, actions and behaviours related to SA norms of respect accorded to parents and grandparents which may have facilitated the building of rapport with SAOAs. Oftentimes, I was treated by female older adults as a granddaughter or niece would be, leaving with blessings after a visit or the older adult being concerned about whether I would get home safely or freely offering advice on childbearing once ascertaining that I was married (the interaction with male older adults was more formal in keeping with patriarchal cultural norms). Yet at other times, I was situated as an ‘outsider’ when I could not communicate with older adults in Punjabi. Some older adults and family members required the interviews to be conducted in Punjabi and in these cases, the interviews were conducted by a multilingual research assistant with me present. While I could understand some of the conversation because I do speak and understand a little bit of Hindi which has some similar words in Punjabi, there were times when I did not understand what was being talked about. The inability to communicate in Punjabi was particularly challenging during episodes of participant observation when I was visiting with SAOAs on my own. During these times, the older adults would engage in informal conversation with me and I would not understand everything they said. This situation was particularly frustrating for me and many times throughout the study I lamented my inability to speak Punjabi knowing that I may have missed important information.

I connected with many family caregivers as an adult child caregiver of aging parents. Being of SA background also provided another point of connection. The intersection of being SA and an adult child caregiver became particularly salient during interviews with family members when discussing decision-making about LTRC and cultural norms of caregiving in SA cultures.

Many caregivers assumed that I knew these cultural norms when they made statements such as ‘you know how it is in our culture…’ and upon careful review of early interview transcripts I too noticed that I did not further probe such statements because I knew implicitly what they were referring to in response to a particular line of questioning. Once I became aware of this, in future interviews when such responses were provided, I would follow up with asking ‘can you tell me more about that?’ or ‘can you explain a little more?’ to ensure that I was not imposing my own interpretation. This was important because as Kanuha (2000) noted when writing about her experience of conducting research with a social group of which she is a member:

> …one must not assume that being an insider to a cultural group necessarily means that the insider researcher has intimate knowledge of the particular and situated experiences of all members of the group or that generalizations can or should be made about the knowledge the researcher holds about her own culture (p.443).

As a student researcher, I was situated as both an ‘outsider’ and ‘insider’ in the LTRC setting. Whenever I was in the LTRC facility, I wore a nametag that identified me as a student researcher so that both residents and staff knew who I was and what I was doing there. While this set me up as an ‘outsider’ in that setting, I was also able to negotiate some level of ‘insider’ status. I conducted participant observations at different times of the day during the week as well as on weekends and assisted as a volunteer might by helping staff to set up for and clean up after activities, bringing SA residents to the activities or to the dining room for lunch and returning them to their rooms afterward, and spending one-on-one time with SA residents. During these times, I was treated as an ‘insider’ by the staff as they updated me on how the older adults were doing or half-jokingly asked me to stick around until their shift was over because ‘Mrs. so and so is so calm when you are here’. However, this ‘insider’ status was tenuous as I experienced one morning while conducting observation during breakfast when a family caregiver participant who was upset to find that her family member was not eating and was not being fed by the staff turned to me and said loudly “write that they are short staffed and one person alone can't feed all residents together.”

In summary, given my theoretical perspective, my desire to explore the needs, preferences and decision-making processes of SAOAs and their families regarding LTRC from their perspectives, and to contextualize these individual experiences within the broader social context as well as to inform change at a systems level, ethnography informed by critical perspectives offered the necessary methodology and theoretical framework to answer the questions posed. The combination of ethnography with a critical theoretical perspective facilitated immersion in the field and co-construction of knowledge with research participants to understand from their perspectives their situations and situating individual descriptions within the broader social, political and cultural context. Furthermore, as we saw in the discussion of critical theoretical perspectives and critical ethnography, researchers using this methodology undertake a critical approach to interpretation and analysis, interrogating commonly held values and assumptions, trying to understand how taken for granted assumptions can serve to further marginalize or oppress disadvantaged groups and trying to uncover how larger social processes shape the lives of individuals and bring about necessary changes such that unequal relations of power that disadvantage marginalized groups are accounted for and addressed. Positioned through my multiple locations and identities, I held a fluid insider-outsider status (Dhillon & Thomas, 2019; Razon & Ross, 2012; Ryan, 2015), experiencing various degrees of insiderness and outsiderness (Chavez, 2008) and at times simultaneously being both insider and outsider. Through reflexivity, I was aware that negotiation of these identities may have an impact on data collection and my interpretations.

3.3 Data Gathering

Having laid out the methodology from which I proceeded, I now discuss the more practical aspects of the study. As an overview, the sample consisted of SAOAs residing in LTRC facilities and those contemplating placement (recruited from an assisted living facility and from the SA community at large) and their family caregivers (FCGs), as well as key informants. Fieldwork, encompassing negotiating access and entry, engaging in data collection, managing data – in essence, "doing" the research – took place over a total of twenty-nine months from September 2013 to mid-March 2015 and mid-June 2015 to May 2016 when I re-entered the field after taking a three-month break to focus on data analysis. The data analysis-focused break took place after data were collected in the first LTRC facility and before beginning data collection in the second LTRC facility enabling the development of additional questions to clarify and expand conceptualizations. Data were collected from multiple sources using the ethnographic techniques of in-depth interviewing, participant observations and the collection and review of relevant documents. Data collection began with SAOA and family member interviews in assisted living, followed by participant observation of and interviews with SAOAs residing in LTRC and with their family members. Interviews with SAOAs living at home in the community and their FCGs were conducted next followed by interviews with key informants. The collection of documents occurred simultaneously throughout the study. Thematic analyses of transcribed interviews, field notes, and documents were completed by the constant comparative method to create a composite description of SAOAs' and family caregivers' experiences regarding LTRC within the larger social context.

Being a novice ethnographer, I found the experience of fieldwork to be quite intensive in terms of the time spent in the field and managing the range of activities and tasks that needed to be completed, not to mention the emotions, both personal and those of study participants I encountered. Trying to manage multiple aspects simultaneously when in the field such as trying to operationalize what I had learned from my readings about "how to do" participant observation or write field notes or conduct interviews (with the assistance of an RA which added additional challenges discussed later), to being alert and sensitive to the needs of study participants not to mention managing my own emotions in the field was at times overwhelming. Additionally, managing the other aspects of the research process such as transcribing the English interviews I had conducted, listening to the transcribed and translated interviews for accuracy and other such activities often left me exhausted and always felt like there just was not enough time. In addition, given the length of time I was in the field, I was also challenged to find multilingual research assistants who could help with participant recruitment, conducting interviews in Punjabi or Hindi, and who could undertake transcription and translation of interviews conducted in those languages. Over the span of approximately two and a half years spent in conducting the research, I worked with five different RAs[7].

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[7] I was fortunate to obtain research funding for this project and was able to employ the research assistants required. All research assistants signed an agreement of confidentiality prior to employment. Early in the study I hired an RA to assist with all aspects of the study from translation of study materials into Punjabi and Hindi, to assisting with participant recruitment and conducting interviews in Punjabi and Hindi to transcription of interviews conducted in those languages. I had hoped that the RA would work with me over the course of the entire study. However, as we began to work together, I found that the RA did not have the skill level and flexibility indicated and that I required and thus had to be let go. I then employed another RA, a certified translator and interpreter, who translated all the study materials into Punjabi and Hindi and transcribed the bulk of the Punjabi and Hindi interviews but did not have the time availability to assist with recruitment and conducting interviews. Thus I employed three successive RAs to assist with participant recruitment and interviews mainly because of the availability and flexibility I required of the RAs to support these activities. As discussed in detail in the ensuing sections, recruitment of older adults from assisted living and LTRC required spending time in those settings to be seen, become familiar to the residents and to provide information about the study. I required RAs who had the availability and flexibility to join me when I spent time in the facilities at various times of the day during the week and on weekends so they could help to provide information about the study in Punjabi or Hindi. Similarly, when we set out to conduct the interviews, I required RAs who were available and flexible in order to accommodate older adults' and family caregivers' schedules as much as possible and particularly when we conducted interviews with older adults in LTRC, where many times the older adults would be unwell or sleeping when we attempted to meet with them and we then had to visit at a different time on the same day or on a different day. While I did eventually find RAs with some research experience that also had such availability and flexibility, this could not be sustained by the RA for the duration of the study as their life circumstances changed hence the need for three different RAs to assist with recruitment and interviews.

3.3.1 Negotiating Access

Given that I wanted to recruit SA older adult-family caregiver dyads from LTRC, assisted living and the SA community at large, negotiating access to the field required a multipronged approach. My supervisors, who had several contacts through their own research in the health authority where this study took place, facilitated an introduction to the Project Leader and Clinical Nurse Specialist for Residential Care in September 2013. Subsequently, I had discussions with these individuals regarding the study and obtained their support in identifying and facilitating access to LTRC facilities with SA residents in the region.

Access to the assisted living facility, which catered to the SA population, was facilitated by a well-respected and experienced researcher with the South Asian community who had done previous work with the assisted living site's operator and helped to set up a meeting in September 2013 with the Director of Seniors Care who subsequently agreed to provide access to the assisted living site.

With the assistance of the researcher, an Advisory Committee, comprising well-known and respected members of the SA community, was also set up for the study. The Advisory Committee members assured me of their support in facilitating access to seniors groups in the SA community where information about the study could be provided.

Once I had successfully negotiated support for access to the various study sites, I obtained ethics approval from the University of Victoria's Research Ethics Board and the Research Ethics Board of the health authority in which the study took place.

After obtaining ethics approval, I provided a Facility Information Letter (see Appendix 1) to the Project Leader and the Clinical Nurse Specialist for Residential Care to be distributed to

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Thus in total, I worked with five RAs over the course of the study. To maintain consistency throughout the study, each RA was oriented to the study, the semi-structured interview guide, and qualitative techniques. In addition, I debriefed with the RAs after each interview.

facility administrators in the region. When I met with both of them in November 2013, they had identified two LTRC facilities with SA residents and the Manager and Director of Care, respectively, of each facility had agreed to facilitate recruitment and I was subsequently introduced to these individuals by email. In December 2013, I met with the Manager/Director of Care of each facility and provided further information about the study as well as discussed the best approaches for recruitment.

In February 2014, I met with the Director of Care of the assisted living facility to provide further information about the study and discussed the best approach to recruitment.

3.3.2 Study Sites

The study sites included two LTRC facilities (one owned and operated by the health authority and the other a contracted facility), an assisted living facility and the SA community at large. The health authority owned and operated LTRC facility (Facility 1) had 190 beds organized in single and semi-private shared rooms. South Asian residents comprised 13-15 percent of the resident population. The contracted facility (Facility 2) had 120 beds, the majority of which were health authority subsidized, and was organized in single occupancy rooms. South Asian residents made up 17-21 percent of the resident population.

The assisted living facility had 49 subsidized units and catered to the South Asian population. Most residents were Punjabi Sikh, but an array of SA religions, languages and countries of origin were represented at this site.

3.3.3 Negotiating Entry and Participant Recruitment

Undertaking research in nursing homes can be challenging because of the frailty and functional and/or cognitive losses that older adults in this setting may have (Maas, Kelley, Park, & Specht, 2002). Gaining informed consent from older residents can be difficult and usually takes longer than for many other potential participants and researchers should be prepared to spend a substantial amount of time with the consent process in nursing homes. Older adults in nursing homes should give their own consent if at all possible and if a resident has dementia or a cognitive impairment, then assent to participate should be sought from the resident in addition to obtaining consent from an authorized decision-maker (Black, Black, Rabins, Sugarman, & Karlawish, 2010; Maas et al., 2002; Slaughter, Cole, Jennings, & Reimer, 2007). Other challenges include obtaining and maintaining an adequate sample for the study. Oversampling, ongoing recruitment and recruiting older adults from multiple nursing homes are strategies to consider (Maas et al., 2002). In qualitative research, if conducting interviews, older adults may be unable or unwilling to respond to lengthy interviews. The researcher needs to be sensitive to the needs of the older adults at all times and explain that the interview can be stopped at any time and continued later or on another day. In addition, spending sufficient time in the setting to establish trust with staff, family members and older adults and to become familiar with policies and routines can assist in completing the research (Maas et al., 2002).

Conducting research with ethnic minority communities adds a level of complexity to the research process. Researchers need to acquire cultural competency prior to embarking on such research. Recruitment of and access to study participants, cross-cultural interviewing, use of interpreters, and translation of materials into required languages adds additional complexity to research methods. Obtaining informed consent from minority ethnic groups can also be challenging, especially from those who are non-literate (Lloyd et al., 2008). Researchers need to take the time to ensure that participants fully understand the aims of the research, the voluntary nature of participation, how participants will remain anonymous and their responses will be kept confidential.

A number of strategies are suggested in the literature to assist researchers including using bicultural recruiters, interviewers, or research assistants to facilitate engagement and access to people from different cultural groups and to facilitate the building of trust and rapport as well as to enable interviewing in the participants' native language (Feldman, Radermacher, Browning, & et al., 2008; Neufeld, Harrison, Hughes, & et al., 2001; Rugkasa & Canvin, 2011); using gatekeepers to assist in recruitment (Alvarez, Vasquez, & Mayorga, 2006; Feldman et al., 2008; Neufeld et al., 2001; Rugkasa & Canvin, 2011); and translating materials into the required languages as well as obtaining verbal consent where participants are non-literate (Lloyd et al., 2008). In addition, researchers need to make a number of decisions when using interpreters to conduct interviews in the participants' native language such as clarification of the interpreter's role, whether a passive or independent interpretive style should be used[8], whether to use consecutive or simultaneous interpretation[9], as well as how the interview should be translated[10] (Wallin & Ahlström, 2006).

In negotiating entry into the field and participant recruitment, I attempted to take account of the above and utilized several of the suggested strategies including but not limited to spending time in the assisted living and LTRC facilities to establish trust and build rapport with older adults, staff and family members and observe the daily routines; working with the project advisory committee members to gain access to the SA community at large; working with a multilingual SA research assistant (RA) to help with recruitment, obtaining consent and

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[8] The passive interpretive style involves the interpreter simply acting as a conduit whereas in the independent style, the interpreter dominates the interview. The passive interpretive style is more common. Baker et al., 1981 (as cited in Wallin et al., 2006) suggests that the ideal style falls somewhere along the continuum allowing for the interviewer and interpreter to become a close team.

[9] The consecutive style of interpretation means that only one person speaks at a time while in the simultaneous style, the interpreter is translating and speaking at the same time as the respondent or interviewer. Simultaneous interpretation is not recommended in one-to-one interviews because it can be distracting for all involved.

[10] Verbatim translation is most commonly used to prevent the interpreter summarizing and explaining responses, which would make it difficult for the researcher to know whose perceptions are being expressed although some researchers note that it is impossible to provide an exact translation of the dialogue.

conducting interviews; and translating study materials into Punjabi and Hindi, two of the most commonly spoken languages among the study population.

As an overview, entry and participant recruitment in assisted living and LTRC occurred concurrently between February and May 2014 with entry and recruitment continuing in LTRC until August 2015 (as I was recruiting from two LTRC facilities). Entry and participant recruitment in the SA community took place between November 2015 and March 2016 after data collection had been completed in LTRC. Recruitment of key informants occurred between January and March 2016. Although articulated linearly here, in all study settings, participant recruitment and data collection proceeded concurrently as older adults and their family members were enrolled (i.e., I did not wait to start data collection until all participants were recruited in a particular setting).

Purposive sampling methods were used to recruit SAOAs and their FCGs. Purposive sampling is often used in qualitative research because researchers can purposefully inform an understanding of the research problem and central phenomenon in the study (Creswell, 2013). While there are various forms of purposive sampling, the common element is that participants are selected according to predetermined criteria relevant to a particular research objective (Guest, Bunce, & Johnson, 2006). The criteria for SAOA participation included: 1) being aged 65+ years; 2) being of South Asian descent; 3) currently residing in a LTRC facility or contemplating placement in a LTRC facility (recruited from Assisted Living or the SA community at large); and 4) having a FCG who also agrees to participate.

Recruitment in Assisted Living

In February 2014, when discussing recruitment from the assisted living facility, the Director of Care suggested that presenting information about the study to residents during activity time, which took place Monday to Friday between 10-11am, would be the best way to facilitate recruitment. I subsequently met with the activity coordinator to schedule the information sessions and he assisted in spreading the word to the residents. My research assistant and I together conducted several sessions providing information in Hindi, Punjabi and English about the purpose of the study, what would be required if older adults agreed to participate, the eligibility criteria and answered questions. At the end of each session we distributed the study information letters (see Appendix 2) which had been translated into Punjabi and Hindi and took down the names and telephone numbers of interested older adults to follow-up with later. Study information letters were also posted in visible areas such as the lobby bulletin board where information about other activities inside and outside the facility was posted. During the sessions, we emphasized that we were recruiting both older adults and their FCGs thus clarifying that in order to participate in the study interested older adults' FCGs would need to agree to participate. Although sessions were done on different days, we generally found that the same residents attended the morning activity and we were not capturing other residents who were not participating. I thus asked the Director of Care whether we could provide information about the study just before or after lunch or dinner when most residents would be present in the dining room. While we did not obtain permission to do that, he suggested that we 'hang around' the lobby area close to lunch or dinner time so residents could see us around as they headed to/from the dining room and on weekends. This approach helped as we became familiar to the residents and some stopped to chat and we were able to speak about the study. When older adults indicated their interest in participating, as mentioned earlier, we noted down their names and telephone numbers and then the RA followed up to confirm their interest, obtain the name and contact information of their family caregiver, and reminded the older adults to speak to their family members about the study and their interest in participating. The RA subsequently contacted the family caregivers and if they agreed to participate then the older adult was enrolled.

Recruitment in Long-Term Residential Care

As noted in the literature, entry and participant recruitment in LTRC took a considerable amount of time as it was important to establish trust and rapport with the older adults and staff in both facilities. In March 2014, I met with the Manager of Residential Care in Facility 1 who took me around to meet the SA residents in the facility. The manager had identified a few eligible SAOAs who might be interested and able to participate in the study and had spoken to them and their family members about the study and provided the study information letter (see Appendix 2). I also met the recreational coordinator who shared the monthly activity calendar with me and identified the activities that SA residents normally attended. In June 2014, I met with the Director of Care in Facility 2 and was introduced to the recreational coordinator and to SA residents as I was getting a tour of the facility. The Director of Care had also identified eligible SAOAs who might be interested and able to participate and had spoken to them and their family members about the study and provided the study information letter. Study information letters were also posted in visible areas of both facilities such as bulletin boards in the lobby and interested older adults and family members could contact me or the RA directly. In addition, I wrote about the study in the family and resident newsletter published in Facility 2. Following these meetings, I spent time in both facilities, visiting each bi-weekly and helping out as a volunteer would, transporting SA residents to/from activities or the Sikh service, helping with the setup and clean up before and after activities as well as serving refreshments during activities and visiting with SA residents one-on-one when requested. Although I was spending time in both facilities concurrently, I decided to actively focus on recruitment and data collection in Facility

1first and then focus on recruitment and data collection in Facility 2 as I realized that undertaking these activities concurrently would limit my ability to fully immerse myself at each site. A consequence of this decision was that by the time I moved to active recruitment in Facility 2 in December 2014, half of the older adults who had initially been identified as interested in the study in June 2014 had passed away and by June 2015, only one was still alive. Moreover, the Director of Care had mentioned to me that of the SA residents in the facility at that time, only a few were well enough to potentially participate. Thus, I became concerned about whether I would be able to recruit additional older adults from Facility 2 and spoke to the regional Clinical Nurse Specialist responsible for Residential Care about the possibility of recruiting from a third LTRC facility. I continued to spend time in Facility 2 and being seen regularly in the facility was helpful as I became a familiar face to the existing and new SA residents and managed to recruit additional older adults. Although a third LTRC facility had been identified and I had met with the Director of Care of the facility and obtained approval and support to recruit older adults, recruitment from the third facility was not required as saturation (that is the point where no new information emerges with additional interviews or observations and data replicates) (Guest et al., 2006; Morse, Barrett, Mayan, Olson, & Spiers, 2002) was achieved with the older adults recruited from the first two facilities. Hence, active recruitment and data collection in Facility 1 took place over nine months (from March 2014 to November 2014). Active recruitment from Facility 2 took place from December 2014 to February 2015 (although I was visiting since July 2014) and resumed together with data collection after a 3-month break from the field for coding and initial data analysis in June to November 2015. Recruitment and data collection in Facility 2 thus occurred over a total of nine months.

Recruitment from the South Asian Community

Entry into the SA community at large was facilitated by members of the advisory committee for this project who provided a number of contacts in the community. I followed up with those contacts and arranged to speak about the study with several SA seniors groups in November and December 2015. One contact, an organizer of a Hindu seniors group, requested that in addition to speaking about the study, I also do a presentation about LTRC providing information about the services, access, cost, etc. Once the date and time of the information session was confirmed, the organizer advertised widely, sending details about the session to a number of SA newspapers including The Asian Star, Asian Journal, Indo Canadian Voice, and The Link Paper. The information sessions were conducted in English, Punjabi and/or Hindi as needed and at the end of each information session, similarly to the recruitment in assisted living, my RA and I handed out the study information letters (see Appendix 2) and took down the names and contact information of older adults interested in participating for follow-up later. My RA then followed up with the older adults to confirm their interest, obtain the name and contact information of their family caregiver, and reminded the older adults to speak to their family members about the study and their interest in participating. The RA subsequently contacted the family caregivers and if they agreed to participate then the older adult was enrolled.

Recruitment of Key Informants

Key informants were purposively recruited from LTRC based on their clinical role and their experience with the transition, integration and/or care of SAOAs living in LTRC. Key informants were also recruited from the project advisory committee based on their knowledge of the SA community at large either as a member of the community or though their work with the SA community. By the time key informants were being recruited between January and March

2016, I had spent several months engaged in data collection in two LTRC facilities and through my time in the facilities, I had also made contact with health care providers in various clinical roles. Based on this, I sent a study invitation by email to health care providers in selected clinical roles inviting them to participate in a key informant interview (see Appendix 2). Similarly, an invitation was sent to selected members of the project advisory committee (see Appendix 2). Individuals were able to contact me directly to confirm their interest in participating in the study.

A significant challenge impacting recruitment in this study, in addition to the specific challenges discussed regarding recruitment in LTRC and assisted living, was the busyness of the older adults' FCGs. As I was recruiting SAOA-FCG dyads, even if older adults were interested in participating in the study, if their FCGs were not interested or did not have the time to participate, then the older adults could not participate. In some cases, even when FCGs had agreed to participate and we proceeded with conducting interviews with the older adults and then the RA reached out to secure appointment times with the FCGs for their interview, the FCGs did not respond to requests to return calls or would say to call back in a few weeks when they might be less busy and thus required multiple follow-ups to find time for the interview. In a couple of cases, when the RA was not successful in reaching the FCG or securing a time for the interview despite several attempts, I called the FCGs and often after leaving several messages and explaining that despite having completed the interview with their older family member, s/he could not be included in study if we could not interview the FCG, I managed to set up the interviews. The FCGs were sincerely interested in participating but we found that they were busy, most juggling paid work, child-rearing and the needs of aging parents. After discussion with my committee, we made a decision that while in-person interviews were ideal, if family members did not have the time but wanted to participate, we could conduct the interviews by telephone.

3.3.4 Study Sample

In this study, I sought SA older adult participants and their family caregivers who varied in age and gender, and represented a range of experiences related to LTRC and decision-making for consideration of LTRC and thus recruited from LTRC, assisted living, and the SA community at large.

As I mentioned earlier, originally I had planned to recruit only SAOAs and their FCGs but based on information emerging in interviews with older adults and their family members in LTRC, I extended the study to obtain organizational and health authority perspectives. Thus I purposively sampled administrators and health care providers in LTRC from different disciplines to obtain a range of views. I also recruited individuals from the advisory committee for this project who could provide insights related to the SA community at large and the perspective of the community related to residential care.

The final study sample comprised 18 SAOA-FCG dyads (7 from LTRC, 5 from assisted living, and 6 from the SA community) and seven key informants for a total of 43 participants. There is a great deal of variation in the literature regarding the number of participants required to generate sufficient data to enable in-depth interrogation of the phenomenon under study with recommendations of six to eight interviews for a homogenous sample and twelve to twenty “when looking for disconfirming evidence or trying to achieve maximum variation” (Kuzel 1992:41 as cited in Guest et al., 2006) to thirty to fifty interviews deemed adequate for ethnographic research (Baker & Edwards, 2012; Morse, 2000; Moser & Korstjens, 2018). Hence, a sample size of 43 participants which elicited 43 formal interviews was considered to be in line with recommendations.

I collected demographic data on the older adults and FCGs (see Appendix 3 for Demographic Data Collection Forms). The 18 older adults ranged in age from 68 to 94 years and 12 were female. Over one-half of the older adults (n=10) respectively were from India and were Sikh reflecting the large settlement of this immigrant group in B.C. The majority of older adults spoke little or no English (n=10), a surprising finding given that the median number of years in Canada was 38 years, with a range of 8-52 years. One-half of the older adults had less than High School education and two older adults had university level education (Master's Degree from India) (see Table 1).

Of the FCGs, 15 were female and the majority were daughters, granddaughters or great granddaughters (see Table 1). Of the three male family caregivers, two were sons and one a spouse. The family caregivers ranged in age from 20 to 86 years with a median age of 54.5 years. A large majority were fluent in English (89%) and 78 percent were educated at the Diploma level or higher. Twelve family caregivers were employed, one was a homemaker and five were retired.

The seven key informants included managers, clinical nurse specialists, social workers, and recreation coordinators from LTRC as well as highly respected members of the SA community and individuals with knowledge of the SA community through their work with the community.

Table 1: Older Adult and Family Caregiver Demographics

	Older Adults	Family Caregivers
Gender		
Female	12	15
Male	6	3
Age		
Range	68-94	20-86
Mean	78.2	55.1
Median	77.5	54.5
National Origin		
Burma	1	-
China	1	-
Fiji	2	2
India	10	9
Pakistan	2	1
Sri Lanka	1	1
Uganda	1	1
Canada	-	4
Religious Affiliation		
Agnostic	-	1
Christian	3	1
Hindu	3	4
Muslim	2	2
Sikh	10	9
N/A	-	1
English Language Ability		
No English	7	-
A little bit of English	3	2
Fluent in English	8	16
Education Level		
< than High School	9	2
High School graduation	3	2
Diploma	3	7
Bachelor's Degree	-	5
Master's Degree	2	1
PhD	-	1
Technical Program	-	-
Other	1	-

Income		
< $10,000	1	1
$10,000-$20,000	13	6
$21,000-$30,000	2	2
$31,000-$40,000	1	1
$41,000-$50,000	1	2
$51,000-$60,000	-	2
$61,000-$70,000	-	-
> $70,000	-	3
N/A	-	1
Period of Arrival		
1960s	3	1
1970s	6	8
1980s	3	1
1990s	4	2
2000s	2	2
N/A	-	4
Age at Immigration		
Long-term elders (landed in Canada aged 40-49 yrs & younger)	12	N/A
Short-term elders (landed in Canada aged 50-59 yrs)	1	N/A
Immediate elders (landed in Canada aged 60+ yrs)	5	N/A
Number of Years in Canada (at time of first interview)		
Range	8-52	8-52
Mean	33.4	34.4
Median	38	40
Caregiver Relationship to Older Adult		
Daughter		10
Granddaughter/Great granddaughter		2
Husband		1
Sister		1
Son		2
Wife		2
Employment Status		
Unemployed		-
Self-employed		1
Employed full-time		8
Employed part-time		3
Retired		5
Other		1

3.3.5 Data Sources

One of the key features of ethnography is studying people’s actions and accounts in their everyday contexts for extended periods of time drawing on a range of data sources (Hammersley & Atkinson, 2007; Mantzoukas, 2012). In keeping with ethnography, I utilized multiple data sources to explore the needs, preferences, experiences and decision-making processes of SAOAs and their families regarding LTRC including, in-depth interviews, participant observation and review of relevant documents (e.g., provincial, health authority, and facility-based policies and procedures) as elaborated in the following sub-sections.

In-depth Qualitative Interviews

Interviews are an important source of data in ethnographic and other research methodologies enabling the researcher to gather information that may be difficult to obtain otherwise both about events described and about participants’ perspectives of a particular topic or experience (Creswell, 2013; Hammersley & Atkinson, 2007; Mason, 2002), the aim being to reach a new understanding of the phenomenon under study (Taylor & de Vocht, 2011). In-depth interviews not only offer the opportunity to gain information about events beyond those that the researcher has direct access to, but since in-depth interviews can be focused by the researcher, it is also possible to collect similar information from many participants (Lofland, Snow, Anderson, & Lofland, 2006).

Semi-structured in-depth interviews were conducted with 18 SAOAs, 18 FCGs and seven key informants. Eight older adults and three FCGs required the interviews to be carried out in Punjabi or Hindi and thus were conducted by a SA multilingual research assistant with me present as a participant observer (Hikoyeda & Wallace, 2002). Although I lacked the fluency in those languages to be able to conduct the interviews myself, I can understand and speak some

Hindi so was able to participate in a limited way and was able to build rapport with these older adults and FCGs. Ranging from 20 to 103 minutes, the majority of interviews were recorded and transcribed. I conducted and transcribed the English interviews. Interviews conducted in Punjabi or Hindi were simultaneously translated and transcribed by a multilingual RA. Two SAOAs and two FCGs did not feel comfortable with the interviews being recorded, thus handwritten notes were taken during the interviews. In the case of one of these older adults who became extremely uncomfortable when any paper was visible, the RA and I conducted the interview without the recorder and paper and then immediately afterward wrote down everything we could recall from memory. In follow-up visits to complete the interview, we were able to confirm the answers to questions previously asked and continue with the interview. Field notes were written and typed up after each interview to note details such as date, location and time of interview, my general impression of the interview, and reflections on what occurred as well as my personal feelings to elicit any biases or preconceived assumptions.

Unlike the interviews with SAOAs in assisted living and in the community, which were scheduled in advance and were generally completed in a single visit in assisted living or the older adults' home, the interviews with SAOAs in LTRC were more challenging to organize and required considerable flexibility and time due to the older adults' frailty and vulnerability. Many times my RA and I would go to conduct an interview and would find that the older adult was ill, too tired, or asleep thus requiring several attempts. In addition, multiple visits were required to complete the interviews with these older adults because many became tired during the interview or were not well. The need for several visits provided an opportunity to verify what participants had said previously and to seek additional information or further elaboration.

The interviews with FCGs were conducted at a time and place that was convenient for them and included their homes, coffee shops and the LTRC facility where their family member resided. Interviews with two FCGs who lived outside Canada were conducted by telephone.

When interviews took place at study participants' homes and in the assisted living suites, in keeping with SA norms of hospitality and respect accorded to visitors, my RA and I were often asked to partake in refreshments prior to starting the interview or afterward or at the very least to accept a glass of water or cup of tea. We always accepted such gestures as it would have been rude to refuse. Even a few older adults in LTRC worried that they did not have anything to offer us and this concern was voiced often when I spent time with the older adults during periods of observation. The time spent sharing refreshments enabled the building of rapport and sometimes if we stayed after the interview, resulted in additional information that was later captured in the field notes.

The interviews were conducted using a semi-structured interview guide (see Appendix 4) which included open-ended questions to explore details in depth, and which enabled individual perspectives and experiences to emerge while also helping to keep interactions focused and facilitating some structure in the interview. The interviews with SAOAs and FCGs were conducted separately to enable them to speak freely (Taylor & de Vocht, 2011). All interviews started with asking participants to "tell me a little about your life to help me understand who you are" which helped to make the participants comfortable, build rapport and often facilitated moving to other interview questions. Topics covered included the older adult's living situation prior to institutionalization or current if in the community, reasons for the move to LTRC or consideration of LTRC, how the decision was made or would be made to move to LTRC, who was or would be involved in the decision-making process regarding institutionalization, the experiences of older adults who are currently in LTRC or what might be of concern if older adults were to move to LTRC, as well as older adults' needs and preferences for end-of-life care. In addition, given the salience of religion and spirituality in SA populations, the interview guide for older adults included questions related to personal beliefs and quality of life[11] in order to try and understand how these beliefs may affect SAOAs' quality of life. Although these questions were also translated into Punjabi and Hindi, some of the older adults in this study had considerable difficulty understanding the questions and some also had difficulty with the response scale resulting in variable completion of these questions.

Conducting interviews in another language requiring an interpreter/RA added additional complexity that became particularly salient when conducting interviews in LTRC where older adults were frail and some had mild cognitive impairment. Although I had oriented the RA to the study purpose, objectives, semi-structured interview guide, qualitative techniques and we had already conducted some interviews with older adults in assisted living where the interviews had progressed reasonably well, in the LTRC setting, the style, agility and patience of the interviewer as well as knowledge of how to conduct the interview and familiarity with the interview questions became extremely important. For instance, some older adults were slower to answer the questions posed by the RA or provided a response unrelated to the question posed or seemed

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[11] Although I was interested in assessing the quality of life of SAOAs in LTRC generally, I decided against applying a quality of life tool to facilitate this in the current study due to my need to set some boundaries around the scope of my dissertation if I had any hope of completing it in a reasonable amount of time. Nonetheless, given the salience of religion and spirituality in South Asian populations, I still wanted to get a sense of how these beliefs may support SAOAs and affect their quality of life. The WHOQOL-100 tool includes a dimension on personal beliefs and quality of life and provided an opportunity to explore this aspect. Thus I included the relevant questions from the English version of the tool in the older adult interview guide. However as I noted, some older adults had difficulty with these questions. One explanation for the difficulty older adults had with these questions may be that the questions were taken out of the context of the entire WHOQOL-100 questionnaire and thus lacked continuity and applicability as implemented. Another explanation may be related to the fact that the questions were adopted from the English version of the questionnaire and translated into the required languages which may have inadvertently made the questions more difficult to understand. Adopting the questions directly from the relevant language questionnaire may have been clearer (the WHOQOL-100 tool is available in over 20 languages including Hindi but not Punjabi). In addition, the cognition of older adults may have also influenced their ability to understand the questions and apply the response scale in answering.

confused or became distracted. In the initial interviews, these instances would cause the RA to become flummoxed, overwhelmed, and sometimes impatient and the RA did not know how to redirect the interview. At these times the inability to speak Punjabi/Hindi and conduct the interview myself (as I understood some of the conversation and observed the interaction) became particularly frustrating. I found myself interrupting and telling the RA what to say next or how else to ask the question which then resulted in the RA losing her train of thought. At this point, I considered conducting the interviews myself with the RA acting as a passive interpreter but decided against it knowing that it would make the interview much longer and more difficult for the older adults (Sin & Chih, 2004). I understood that this was a trade-off in terms of the researcher giving up some control to the interpreter/interviewer when doing research with populations who do not speak English. Nonetheless, to mitigate such a situation in future interviews, I conducted further training with the RA regarding sensitivity to the cognitive and physical status of the older adults. In addition, we discussed ways to support the older adult such as simplifying questions and adjusting the pace of the interview (Hikoyeda & Wallace, 2002), the importance of tone, patience, of active listening so we can judge understanding and the potential need to reframe the question. I also engaged in role play and debriefed with the RA after reviewing the transcript of every interview and before the next interview session with the older adult indicating how I would have responded, what I would have probed more or what I would have done next as well as the questions I wanted to ask again, how I wanted to ask them and the new questions to pose.

Another challenge working with an interpreter/RA in LTRC was that some older adults may have initially felt intimidated with two people. To manage this, I usually mentioned to the older adults that the next time I visited with them I would bring a friend who would help me to understand what they are saying as from my visits they knew I spoke limited Hindi and no Punjabi. In addition, whenever my RA accompanied me to conduct an interview in the facility, we made an attempt to spend a few minutes before or after the interview visiting with the other study participants so they could become familiar with the RA. And as I noted earlier, one older adult seemed particularly intimidated with the recorder and even simply having the questionnaire out and taking notes – this perhaps seeming quite ‘official’. In this case we refrained from using the recorder and taking notes during the interview and then immediately afterward wrote down everything we could recall from the conversation. The writing of field notes also helped in recalling parts of the conversation and this was noted.

The risks associated with conducting research on sensitive topics have been recognized in the literature (Butler, Copnell, & Hall, 2019; Dempsey, Dowling, Larkin, & Murphy, 2016). While many of the caregivers and older adults in the study spoke about how important they felt the research I was conducting was and some caregivers noted that the interviews helped them to consider the conversations they may want to have with their older relatives, I was aware that the interviews could bring forth strong emotional reactions. Many times family caregivers cried as they discussed their experiences of the decision-making and placement of their older relatives in LTRC as did some older adults in sharing their stories. In these instances, the caregivers and older adults were always asked with sensitivity whether they wanted to stop the interview. More often than not, the caregivers and older adults wanted to continue and just required a short pause to regain their composure. However, in one instance when I felt the interview was becoming too overwhelming, I took it upon myself to stop the interview and told the older adult that we could meet again on another day to continue if s/he wanted to. Given the frailty and vulnerability of the older adult population in LTRC, I also paid particular attention to their needs and if they got tired we stopped the interview and continued on another day. Other researchers have also implemented such approaches in their research with older adults (Davies et al., 2010; Zermansky, Alldred, Petty, & Raynor, 2007). While stopping the interview and resuming it on another day may potentially have affected the quality of the data collected, returning to complete the interview enabled verification of the responses previously provided and facilitated clarification and elaboration as needed.

All key informant interviews except one, which was conducted at the key informant's home, took place in their work settings.

The interview guide for key informants from LTRC (see Appendix 4) sought to obtain health care providers' and organizational leaders' perspectives of the needs, preferences and challenges of South Asian older adults and their families regarding residential care. The interviews started with asking participants how they came to work in LTRC and to describe their roles and responsibilities in the setting which helped to build rapport and facilitated moving to obtaining their perspectives regarding the needs and situation of SAOAs in the LTRC setting. Topics discussed included but were not limited to their perspectives of the reasons for SAOA placement in LTRC, what it is like for these older adults when they first move into the facility, factors that may impact SAOAs' adjustment in the setting and what may help. In addition, we asked informants about SAOAs' relationships and interaction with other residents and with staff as well as what LTRC facilities can do to provide culturally responsive care and whether and how prepared they felt LTRC facilities were to provide culturally responsive and competent care to older adults from diverse ethnic and cultural backgrounds.

The interview guide for key informants from the SA community (see Appendix 4) sought to obtain insights related to the SA community at large and the perspective of the community regarding LTRC. Topics covered included SAOAs' expectations of their families related to their care and support as they aged, SA families' perspectives regarding caring for their older family members, awareness of and perspectives regarding LTRC placement as well as what would be helpful or important in facilitating the transition and adjustment of SAOAs if they required LTRC placement. The final topic focused on what the informants believed LTRC facilities could do to provide culturally responsive care for older adults from diverse ethno-cultural backgrounds.

Participant Observation

A distinguishing feature of ethnography, participant observation generally refers to methods of collecting data in which the researcher immerses him/herself in the research setting so that s/he can observe first hand a range of dimensions in and of that setting. These can include watching the physical setting, participants, activities/events, social actions, interactions, behaviours, and conversations (Creswell, 2013; Emerson, Fretz, & Shaw, 2001; Gold, 1958). In essence, participant observation "involves the interweaving of looking and listening, of participating and asking…"(Lofland et al., 2006, p.18).

Funk and Stajduhar (2009) argue the importance of integrating interviews with observational methods which together can assist researchers in gaining deeper insight into the complexity of a phenomenon that interviews alone may be unable to provide. To that end, I conducted 220 hours of observational fieldwork in two LTRC facilities. As mentioned previously, entry into LTRC occurred over an extended period of time. While I spent time in both facilities concurrently to become familiar with the LTRC environment, the schedules and routines in the setting, the care providers and their roles, and to build rapport and trust with the SA residents and staff, focused participant observation of seven SAOAs who had consented to being interviewed and to the participant observation took place sequentially. I conducted participant observation in the first facility over a five-month period and I then took three months out of the field for analysis. I re-entered the field and conducted focused participant observation of SAOAs in the second facility over five months to extend the analysis and validate my evolving interpretations.

The degree of involvement that a researcher has in the field ranges from complete participant to complete observer (Creswell, 2013; Gold, 1958; Mason, 2002). During participant observation, I assumed the role of participant-as-observer – that is, I was known and recognized as a student researcher by the study participants and staff. I, and my RA whenever she accompanied me, wore a name tag identifying our names and position as student researchers. I participated in group (i.e., resident) activities particularly those catered to the South Asian residents such as the Sikh service held once a week in both facilities and assisted residents and staff as a volunteer might serving food and drink to residents during activities when asked, taking SA residents to the Sikh service and other activities and returning them to their rooms afterward, reading to SA residents who understood English, or walking those who were mobile with their walkers, as well as spending time visiting with them. My observations were conducted on weekdays and weekends, varying the times throughout the course of the day so as not to restrict myself to a limited view of life in LTRC. Observations took place in public areas of the facilities such as the lounge, activity room, dining room, etc. and were typically conducted in intervals of three to four hours as recommended by Lofland et al. (2006) to lessen the likelihood of my forgetting key details and I found that I was often too exhausted to stay longer. Guided by a participant observation guide (see Appendix 5), I watched how SAOAs interacted with the physical environment, fellow residents and staff, how they negotiated their care, the activities they attended, how they spent their time, their general appearance, behaviours, nonverbal communication patterns, etc., the goal being to gain insights regarding how SA older adults are located within the LTRC setting and their situation in the setting. During observational periods when I would be visiting with the older adults, I found that they wanted to engage in conversation. While I could somewhat understand and respond at a basic level when they conversed in Punjabi/Hindi, there were times when I found myself just nodding not having understood everything they were saying. The language barrier was quite frustrating for me as I was aware that I may have missed important information shared and it limited my ability to informally follow up on what was discussed during the interview or other items (though I did ask basic questions in my broken Hindi). Many times throughout this study I wished that I had learned those languages prior to starting this study.

The data collected through participant observation were recorded in the form of detailed field notes as were descriptions of the informal conversations I had with the older adults. For the most part, as described by Lofland et al. (2006), field notes are a running description of settings, events, people, things heard and overheard, and interactions among and with people, including conversations (p.112). In addition to providing description, field notes should also include a running record of the researcher's analytic musings and personal impressions and feelings although it is important to keep these separate from the descriptions of what is being observed (Emerson et al., 2001; Lofland et al., 2006). Generally field notes should be written as soon as possible after an observational session (if unable to take notes during observation).

As recommended by Emerson et al. (2001) and Lofland et al. (2006), I used a two-step process for developing field notes. I usually had my iPhone with me when in the field and when I was able to, I would pull out my phone and make quick jottings in the Notes Application about interactions I had observed, details about action and talk that I felt was important to help jog my memory when I later sat down to write the detailed field notes, as well as a personal note about my feelings of what I saw and was thinking. I also usually carried my iPad with me so immediately after an observation session I would find a quiet spot in the facility or go to my car and write a descriptive account of my observations, using the jottings to help remember details (on occasion when I was observing from a corner and not engaged in some activity or conversation, I was able to take notes during the observation). Then when I got home, I would transfer the notes from my iPad onto my desktop computer, review the notes and add other things that came to me. At this time, I also made analytic notes such as linkages between observations and interviews and reflexive notes about my impressions or feelings and aspects that I wanted to follow up on next time.

The narratives I wrote in my field notes tried to describe everything I saw in as much detail as I could, running through the scenes and interactions I observed and conversations I heard in the sequence they happened when writing to better recall. I included concrete and sensory descriptions of the physical setting, sometimes using diagrams, interactions and actions, behaviours, conversations heard as well as verbal and nonverbal emotional expressions (Emerson et al., 2001; Lofland et al., 2006). Admittedly however, my descriptive accounts were selective based on what seemed significant to me and my interpretation of the happenings through my personal lens. As such, I likely missed other things. Emerson et al. (2001) have noted that field notes are “inevitably selective…The ethnographer writes about certain things that seem ‘significant’, ignoring and hence ‘leaving out’ other matters that do not seem significant” (p.353).

Document Review

Review and analysis of relevant documents generated in the setting of interest and that are pertinent to the research questions being asked are important sources of information and data and help to provide a contextual understanding of the observational and interview data (Hammersley & Atkinson, 2007; Lofland et al., 2006; Mason, 2002). Given that in addition to exploring the needs, preferences and decision-making of SAOAs and their families regarding LTRC, I wanted to understand the challenges and situation of SAOAs in LTRC, whether and how LTRC facilities meet their needs, and factors that may influence these aspects, I collected and reviewed documents relevant to LTRC including provincial policy documents, provincial residential care regulation, and various documents prepared by the health authority and the LTRC facilities where the study took place (see Appendix 6). The documents were collected throughout the study and when study participants made reference to a particular document, it was included for review. The review of documents provided an understanding of the formal processes required for access to LTRC as well as how services are organized and provided in the LTRC setting. Findings from the review of the documents enabled uncovering of taken for granted assumptions in how care and services are provided and the sociopolitical context in which LTRC is situated. For instance, a review of the Home and Community Care Policy Manual (B.C. Ministry of Health, 2013), which sets out the Ministry of Health’s requirements of health authorities in planning and delivering these services as well as the Community Care and Assisted Living Act – Residential Care Regulation (Government of B.C.), which provides strict direction to residential care facilities regarding standards to be maintained in order to remain licensed and operate under the Act, illuminated that much of what LTRC facilities and staff can and cannot do is imposed on them externally through these mechanisms. In addition, such legislation and policy standardizes the way in which residents’ needs are measured and met, further illustrated by the use of tools such as the Minimum Data Set-Resident Assessment Instrument (MDS-RAI) which categorizes the characteristics of LTRC residents and the resource allocation that stems from them (Armstrong, 2013); challenges the provision of person-centred care; and limits residents' autonomy, independence, and choice. This along with terminology such as "client" and "services" used throughout the policy manual as well as the directive to apply a performance management approach to planning, delivering, and monitoring of services provided reveals the neoliberal context in which LTRC is provided as well as the neoliberal tendency to apply business-like principles to health care provision (Porter & Lee, 2013).

3.4 Data Analysis and Interpretation

Analysis in qualitative research is inductive in that the analysis is driven by the data themselves (Lofland et al., 2006). This inductive nature of qualitative analysis means that "researchers are the central agents in the analytic process" (Lofland et al., 2006, p.195) and this requires the researcher to be immersed in the data (similar to immersion in the field during fieldwork). Creswell (2013) notes that data analysis in qualitative research consists of preparing and organizing the data (i.e., text data in transcripts, field notes, photographs, etc.) for analysis, then reducing the data into themes through a process of coding and condensing the codes, and finally representing the data in figures, tables, or a discussion (p.180). He further notes that data analysis is not 'off-the-shelf' but is custom built and qualitative researchers often "learn by doing". Although outlined linearly here, the processes of data collection, analysis and report writing are interrelated and often go on simultaneously. As such, data analysis was conducted concurrently with data collection and was ongoing throughout the study. Every effort was made to have the interviews transcribed as soon as possible after they had been conducted. Immediately after each interview conducted in Punjabi/Hindi, the digital recording was provided to a multilingual RA for simultaneous translation and transcription while I transcribed the English interviews allowing me to begin rudimentary analysis. Once transcribed, I listened to the interview recordings (both English and Punjabi/Hindi) as I “checked” the transcripts to ensure accuracy. Listening to the recordings provided an opportunity to pick up nuances, emotions, tone and to note initial insights, as well as provided learning in the case of the Punjabi/Hindi interviews as I picked up words, phrases previously unfamiliar. I then read each transcript again to get a sense of the interview as a whole as well as ‘cleaned’ the transcript removing any identifiable information and replacing with pseudonyms, etc. Following this I reread a hard copy of the transcript along with the related field notes written right after the interview, writing margin notes and comparing interview and observational data (i.e., reading the field notes from my focused observation of the older adult interviewed). I also made a summary of each interview to help my thinking, interpretation and analysis.

To facilitate data management, all cleaned transcripts, interview summaries, and field notes were entered into NVivo 10, a computerized software program designed to assist with management and organization of qualitative data (Bazeley & Jackson, 2013). These data were then coded in NVivo using the constant comparative method (Boeije, 2002) and analytic memos were written to highlight key categories and to identify areas that required further elaboration and clarification. My first attempt at coding was quite elementary as I basically coded to each interview question posed which resulted in very detailed coding without any level of abstraction. I took to heart Creswell’s note that researchers often “learn by doing” and in addition, sought guidance from my committee. They highlighted that the analytic process is like taking apart what I have and re-conceptualizing it based on the interpretive lens I am putting on the data and the literature. They further noted that I should code the data trying to identify a bit more abstraction by creating larger bucket codes and to think about how my data is the same or different from other sources. With this in mind, I recoded the data using an analytic structure that mirrored the micro, meso and macro contexts[12] of SAOAs' and their families' decision-making and experiences related to LTRC. I printed out these coding sections and reviewed the hard copy, making margin notes and refining the codes/key categories as I compared within and between groups and from this evolved key themes. For example, I used codes called "food", "language" to depict study participants' experiences of these aspects in LTRC. As the study progressed, I collapsed these codes into a broader theme of 'difference' as these components reflected experiences of 'difference' that arose in the context of mainstream facilities discussed in Chapter 4 under "Contextualized Experiences of 'Difference'". I used the strategies of diagramming, analytic memos, and noting my thinking and interpretations in notebooks as I went along which served to further compare and verify my interpretations and as a visual representation of my evolving analytic thinking. Analysis and interpretation was a cyclical, iterative process and dialectical in nature as I moved between field notes and transcripts, evolving data analysis and the theoretical and research literature. Immersion in the literature helped me to ponder different explanations for the patterns I identified and also helped me to keep to my critical interpretive framework making the analytic phase both inductive and deductive. Analytic work in the final stages centered on writing and moving between transcripts, field notes and the research literature.

The various documents collected for this study were reviewed and then critically examined, paying particular attention to the language used and how dominant ideologies were

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[12] Aspects related to the individual such as beliefs, norms, values; ways of "being in the world" as well as identity relative to the individual i.e., how people saw and presented themselves was coded at the micro level. Experiences and aspects related to long-term care and the broader health care system in which the long-term care system is embedded, as well as interactions with and identity relative to others was coded at the meso level. Coding at the macro level reflected the broader social, political and cultural context. Identity relative to this broader societal context was also coded at the macro level.

reproduced in the text (Fairclough, 2003; MacCourt, 2009; McCloskey, 2008; Morgan, 2010). A summary of each document was written and coded. A critical analysis of the texts contributed to the development of theoretical arguments and to the analysis of the broader context of the study.

In summary, data analysis began in the initial stages of this project and evolved throughout the study. Guided by a critical theoretical perspective, the analysis was multilayered and enabled exploration and understanding of individual experiences of SAOAs and FCGs, comparison within and between groups in a systematic way and explication of how larger social processes influenced the decisions/considerations of and experiences in LTRC. In reviewing the findings, commonly held values and assumptions were interrogated with a view to understanding how these may influence LTRC service provision for SAOAs and SAOAs' role in decision-making for LTRC. For example, I posed questions such as: "How is the broader social political context influencing what is going here?"; "What is taken for granted?"; "Whose interests are served?"; "Who benefits and who is disadvantaged and in what ways?" Applying such questions when reviewing the findings related to decision-making for or consideration of LTRC, for instance, shed light on (among other things) the influence of social structural factors in SA families' LTRC placement decisions and assisted in questioning taken for granted assumptions regarding SA families' abilities to care for older family members at home as they age.

3.5 Establishing Scientific Rigour

The question of establishing scientific rigour in qualitative research is much debated (Creswell, 2013; Denzin & Lincoln, 2011; Mason, 2002). Many perspectives exist regarding the importance of validation in qualitative research, the definition of it, the terms used to describe it, and procedures for establishing it (Creswell, 2013; Cypress, 2017; Morse et al., 2002; Tracy, 2010). Nonetheless, as Denzin and Lincoln (2011) put it (and I agree with their perspective):

> Validity cannot be dismissed simply because it points to a question that has to be answered in one way or another: Are these findings sufficiently authentic (isomorphic to some reality, trustworthy, related to the way others construct their social worlds) that I may trust myself in acting on their implications? More to the point, would I feel sufficiently secure about these findings to construct social policy or legislation based on them? (p.120)

A number of strategies have been proposed in the literature to check the validity of qualitative research. As discussed by Bryman and Teevan (2005) and Creswell (2002, 2013), Guba and Lincoln propose member checking, prolonged engagement in the field, and triangulation of data sources, methods and investigators to help establish credibility; rich detailed accounts to help assess the transferability of findings between the researcher and those being studied and transferability to other milieus; and the use of an audit trail which helps to assess both dependability and confirmability of the research. In addition, researcher reflexivity, where the researcher self-discloses his/her assumptions, beliefs and biases also establishes confirmability (Bryman & Teevan, 2005; Creswell, 2013; Creswell & Miller, 2002; Maxwell, 1996). To these validity approaches, Creswell (2002, 2013) adds peer review or debriefing and disconfirming evidence. Creswell (2013) recommends that qualitative researchers engage in at least two of these various validity procedures in any given study. Below I outline how I drew on reflexivity, triangulation, member checking and auditability to establish the trustworthiness and authenticity of the findings[13].

3.5.1 Reflexivity

Reflexivity is considered to be one of the key approaches to establishing validity in qualitative research and particularly for critical ethnography (Bryman & Teevan, 2005; Creswell,

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[13] In addition to the validity approaches discussed, Lather (1986, 1991) is a proponent of a lesser known measure of validity termed "catalytic validity" which refers to the degree to which the research process serves to re-orient, focus and energize participants to some action. Lather suggests that catalytic validity has been achieved when "the research process has led to insight, and ideally, activism on the part of the respondents" (Lather, 1986a, p.78). While this measure resonated with me, the underpinning notion of emancipation was problematic for this study.

2013; Creswell & Miller, 2002; Cutcliffe, 2003; Maxwell, 1996). Social researchers are part of the social world they study (Hammersley & Atkinson, 2007) and bring their personal biographies to the research they conduct in addition to the worldview or theoretical perspective which informs how the researcher approaches his or her research and the methodology chosen to conduct the research (Creswell, 2013; Crotty, 1998; Denzin & Lincoln, 2011). As Hammersley and Atkinson (2007) explain, 'the concept of reflexivity acknowledges that the orientation of researchers will be shaped by their socio-historical locations, including the values and interests that these locations confer upon them' (p.15). Reflexivity should take place throughout the research process at multiple levels and critical researchers enter the research with their assumptions on the table.

While I have tried to be reflexive throughout the research process as discussed earlier, I am cognizant that I may not be completely self-aware and that a portion of my values and beliefs may remain outside of my consciousness and not be acknowledged in any reflexive account. Thus, as Cutcliffe (2003) notes, and I agree with him, "these reflexive accounts can be regarded as only "incomplete" or "partial" processes, in that achieving complete knowledge of self is unrealistic and, possibly, unattainable" (p.144). Peer debriefing and discussions with my dissertation committee were therefore key strategies in addition to journaling, to facilitate reflexivity.

3.5.2 Triangulation

In social research, if researchers rely on a single piece of data, there is the danger that undetected error in inferences made may render the analysis incorrect. Thus in qualitative inquiry, triangulation – the comparison of data relating to the same concept or phenomenon but derived from different data collection techniques or participants with different perspectives – is often used to check the validity of inferences (Hammersley & Atkinson, 2007). However, it is important to be aware that aggregation of data from different sources may not necessarily produce a more accurate picture and the role of triangulation may be to check for additional information or provide a different angle to the answering of research questions (Mason, 2002). In this study, triangulation was achieved by utilizing a combination of different data generation procedures (e.g., interviews, participant observation and document analysis) as well as collecting data from participants with differing viewpoints (e.g., older adults in LTRC and those in assisted living and in the community; family members, health care providers). I used triangulation as a way to look for congruence/incongruence within the data and to check for additional information.

3.5.3 Member Checking

Member checking (also known as respondent validation, informant feedback, member validation or dependability checking) involves returning to study participants with interview transcripts or data interpretations for their comments (Morse et al., 2002; Thorne & Darbyshire, 2005; Varpio, Ajjawi, Monrouxe, O'Brien, & Rees, 2017) and relates to the credibility of the research (Bryman & Teevan, 2005). Although member checking was originally described as a continuous process during data analysis, it is more commonly conducted post hoc as researchers have interpreted and used it for verification of overall results with participants (Morse et al., 2002). In this study, I asked some study participants to comment on my early analysis and initial interpretations. However, being cognizant of the inherent challenges associated with returning to study participants for checking (Morse et al., 2002; Thorne & Darbyshire, 2005; Varpio et al., 2017), I used the new interviews I conducted after taking a break from the field to extend my analysis and to also check the data. Data trustworthiness was further established by supporting my theoretical arguments with ethnographic data from this study.

3.5.4 Auditability

The use of an audit trail where the researcher maintains clear documentation of all decisions and activities undertaken in the course of the research endeavour helps to assess both dependability and confirmability of the research (Bryman & Teevan, 2005; Creswell, 2013; Creswell & Miller, 2002; Maxwell, 1996). Throughout this study, I maintained a log of all activities that took place as well as decisions that were made, including how and why they were made.

3.6 Ethical Considerations

Ethics approval was received from the University of Victoria Research Ethics Board and the health authority where the study took place. As previously mentioned, study information letters for SAOAs and FCGs (see Appendix 2) outlining the purpose of the study, what the research would entail, and emphasizing the voluntary nature of participation and the ability to withdraw from the study at any time were prepared in English, Punjabi and Hindi. These were distributed to SAOAs in LTRC, and in assisted living and the SA community following information sessions in the latter settings. Prior to formally beginning data collection, I sought informed consent from study participants. Separate consent forms were prepared for key informants, FCGs and older adults (see Appendix 7). The consent form for older adults in LTRC included consent for both the interview and participant observation while the consent forms for older adults in assisted living and those in the community as well as for FCGs and key informants requested consent for interviews only. To ensure that older adults and family members understood the aims of the research, the voluntary nature of participation and that they could discontinue their participation at any time as well as how they would remain anonymous and their information kept confidential and any risks associated with the study, consent forms were translated into Punjabi and Hindi. I also worked with a multilingual RA who assisted in explaining the informed consent process and obtaining consent where necessary. While written consent was sought, where this was not possible, in line with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 2014, p.46), verbal consent was obtained and documented in field notes along with documentation of the procedures used to seek consent. Given the continual nature of participant observation and the need for multiple visits to complete some interviews, informed consent was seen as an ongoing process and I continually negotiated and renegotiated this with each participant paying attention to any hesitation from them. During fieldwork, I constantly reminded participants of who I was and why I was in the setting and confirmed that they were comfortable with me being there at the time. When participants indicated that it was not a good time I thanked them and said I would visit another time. We did not complete the interview with one older adult in LTRC who had consented to and participated in the interview but required another visit to complete it. Although the older adult agreed to speak with the RA and me when we subsequently visited twice to try and complete the interview, when we began to ask questions, the older adult did not engage or pretended to fall asleep. Despite consenting to speak with us, I interpreted the disengagement as dissent (which can be indicated behaviourally (e.g., not cooperating, being agitated, wanting to leave)) (Black et al., 2010; Slaughter et al., 2007), and thus did not pursue additional encounters to complete the interview.

Given the nature of the study, it was difficult to ensure confidentiality of participation particularly in LTRC as staff, other residents and family members saw me spending one-on-one time with SAOAs in the common areas of the facility and some older adults preferred to speak with the RA and myself in the lounge or dining room. Consequently, we tried to have conversations with the older adults at a time when few people were around or when there was less activity going on such as using the dining room at off meal-time periods. While in assisted living we were better able to protect confidentiality of participation as the interviews took place in older adults' suites, it was not completely possible as other residents not participating in the study heard about the study through 'word of mouth' and saw the RA and I 'hanging around' and were interested in what we were doing there.

To protect the anonymity of study participants, a numerical code was assigned to each study participant and was used on all materials pertaining to them. All data (i.e. typed transcripts and field notes) were de-identified by removing any markers such as names and locations or replacing them with pseudonyms. Only the anonymized data was shared with my dissertation committee for the purposes of analysis. To further protect anonymity, pseudonyms were used in written reports and I also altered the circumstances in some instances to protect the identity of participants. All consent forms and data were stored in separate locked cabinets accessible only to me.

3.7 Introduction to the Study Findings

Having detailed the theoretical perspective and research methods guiding the study, I now turn to the key findings which are presented in the subsequent three chapters. Following the University of Victoria's format for a publication-based dissertation, each chapter is a stand-alone manuscript to be submitted for publication.

Chapter 4 provides insights about the needs, preferences and experiences of South Asian older adults and their families regarding LTRC services and discusses whether and how mainstream LTRC facilities meet their needs. The significance of this discussion becomes further apparent as Chapter 5 illuminates the (non) decision regarding LTRC placement and examines the factors that lead to the decision-making/consideration of LTRC as a care option in SA families. Chapter 6 then explores the transition and adjustment experiences of SA older adults and their families in LTRC as well as the factors that may facilitate or hinder a person-centred transition for SAOAs. Following these three chapters, a final discussion chapter draws out the key insights and associated implications and recommendations emerging from the research.

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Chapter 4: Are Mainstream Long-Term Residential Care Facilities Prepared to Provide Culturally Responsive Care? An Ethnographic Study of Long Term Care in Western Canada

4.1 Introduction

The aging Canadian population is becoming more diverse with respect to its ethno-cultural composition primarily due to immigration (Statistics Canada, 2016a). While historically immigration to Canada was from European countries, more recently, the largest immigrant populations are arriving from Asia and thus fit Statistics Canada's definition of a "visible minority" (Statistics Canada, 2016a, 2016b, 2017). In exploring the contribution of immigration to the size and ethno-cultural diversity of future cohorts of older adults in Canada, Statistics Canada projects that by the time the cohort of individuals born between 1997 to 2001 turns age 65, almost one-half of that cohort will be foreign-born with approximately 30% coming from Asia. Further, 44% at age 65 will belong to a visible minority group (Statistics Canada, 2016b). More immediately, by 2031, 25-28 percent of the Canadian population will be foreign-born and one-third will belong to a visible minority group. In particular, South Asians (SA) currently comprise, and may continue to be, the largest visible minority group in Canada and the second largest in British Columbia (Statistics Canada, 2010, 2013, 2016b).

These shifts in the aging of the population at national and provincial levels prompt important questions as to whether the current organization of long-term residential care (LTRC)[14] services are designed to meet the needs of an increasingly diverse population of ethno-cultural older adults.

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[14] In this paper, the term "long-term residential care" (LTRC) is used to refer to care of older adults with complex needs who require 24-hour professional supervision and care in a protective, secure environment. Synonymous terms are residential care, long-term care, care homes, and nursing homes.

Long-term residential care provides 24-hour professional supervision and care in a protective, secure environment for older adults with complex care needs who can no longer be cared for in their own homes or in an assisted living residence (British Columbia Ministry of Health, 2015; Office of the Seniors Advocate, 2015). The services provided include personal and health care, social work and dietician services as well as activities programs, meals and housekeeping (British Columbia Ministry of Health, 2015). British Columbia provides subsidized, licensed LTRC services through facilities both owned and operated by health authorities (8,814 beds in 110 facilities) and contracted facilities owned and operated by either a not-for-profit society or a private company (18,328 beds in 183 facilities) (Office of the Seniors Advocate, 2017, 2018). In addition to publicly subsidized residential care, there are facilities that offer some or all of their beds on a completely private basis (4,000 beds) (Office of the Seniors Advocate, 2017). Approximately 4% of older British Columbians, the majority of whom are women (65%), live in publicly subsided LTRC facilities (Office of the Seniors Advocate, 2016). The average age of residents is 85 years, and 60% are 85 or older. On average, 45% of older adults are admitted to LTRC directly from hospital and the median length of stay in these facilities is 1.3 years (Office of the Seniors Advocate, 2015, 2016, 2019). While no information was found about the ethno-cultural mix of residents in B.C. LTRC facilities, researchers have noted that immigrant older adults are increasingly moving into LTRC facilities (Koehn, Baumbusch, Reid, & Li, 2018).

This paper presents findings from an ethnographic study examining the needs, preferences and experiences of South Asian older adults (SAOAs) and their families regarding LTRC services and discusses whether and how mainstream LTRC homes meet their needs.

The South Asian diaspora in Canada includes immigrants from India, Pakistan, Bangladesh, Nepal, Sri Lanka, Bhutan and the Maldives (Walton-Roberts, 2013). ‘South Asians’ also refers to Indians who have migrated to other parts of the world such as Fiji, Malaysia, Hong Kong, and East Africa (Nayar, 2004). In addition to the diversity in country of origin, there is also diversity in the religions practiced with adherents to Sikhism, Hinduism, Islam, Christianity, and Buddhism amongst other religious traditions (Coward, Hinnells, & Williams, 2000) as well as languages spoken including Punjabi, Tamil, Urdu, Gujarati, Hindi, and Bengali to mention the most common (Lindsay, 2007; Tran, Kaddatz, & Allard, 2005). The focus is on the SA population given their increasing numbers and the fact that despite their growing presence in the population, the volume of research on SAs has not kept pace and the diversity among the population is seldom acknowledged, leaving gaps in the understanding of their needs (Koehn, Neysmith, Kobayashi, & Khamisa, 2012; Tran et al., 2005).

4.2 Literature Review

Research focused on immigrant and ethno-cultural minority older adults (EMOA) and their access to care and experiences related to LTRC was undertaken. The first section explores the challenges faced in accessing care and the availability of culturally responsive care followed by studies focused on what is known about EMOAs’ experiences and challenges upon relocation to a LTRC home.

4.2.1 Ethno-cultural Minority Older Adults and Access to Care

Research on immigrant and EMOA indicates that these populations face a number of challenges in accessing health and social services including structural barriers, cultural issues and attitudinal barriers. Research shows that these barriers often lead to an under-utilization of health services and health disparities (Bookman & Harrington, 2007; Bowes & Wilkinson, 2003;

Feng, Fennell, Tyler, Clark, & Mor, 2011; Keith, 2009; Koehn, 2001, 2009; Konetzka & Werner, 2009; Lai & Surood, 2010; Mold, Fitzpatrick, & Roberts, 2005a). Often it is the family caregivers of older adults who assist in accessing such services for their family members as well as playing a key role in coordinating care, advocating for older adults' needs and providing personal care (Bookman & Harrington, 2007; Keith, 2009).

The structural barriers to accessing care include systemic barriers such as the need for and access to information, knowledge about ways to access care, as well as the organization and delivery of health services themselves including perceptions of discrimination or racism (Bookman & Harrington, 2007; Brotman, 2000, 2003; Johnson et al., 2004; Keith, 2009; Koehn, 2009; Lai & Surood, 2010; Oxman-Martinez & Hanley, 2005; Pollock, Newbold, Lafreniere, & Edge, 2011; Wright & Perry, 2010). In addition, the Family Class[15] immigrant status of many EMOA and the imposed dependency on family as well as the ineligibility for some services during the period of dependency (Koehn, Spencer, & Hwang, 2010; McLaren, 2006; McLaren & Black, 2005), impacts access to services that may be needed. For EMOA, the structural challenges are exacerbated by language barriers, the inability to communicate with care providers and cultural issues (Bowes & Wilkinson, 2003; Koehn, 2001; Lai & Surood, 2010; Mold et al., 2005a).

Cultural issues not only impact access to services but also the types of services accessed. In particular, studies from the U.S. have consistently shown disparities in the use of nursing

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[15] Canadian citizens and permanent residents may sponsor spouses/partners, dependent children, parents, grandparents and other close relatives to become permanent residents as Family Class immigrants. The Family Class sponsorship program, under which the majority of older adults immigrate to Canada, requires a signed agreement with the Minister of Immigration in which the sponsor promises to financially support and care for the sponsored older adult for a period of 20 years. During the support period, sponsored dependents cannot collect social assistance and are ineligible for public pensions, subsidized housing or housing subsidies or other local benefits such as reduced bus fare passes. As a result, immigrant older adults are not only legal dependents according to immigration policy, but the sponsorship program also enforces their dependency which is made more salient by virtue of their income insecurity and inability to access social resources that benefit most older Canadians.

homes among minority older adults even when they were found to be more disabled than Whites, on average, at the time of admission to a nursing home (Akamigbo & Wolinsky, 2007; Feng et al., 2011; Howard et al., 2002; Konetzka & Werner, 2009; Wallace, Levy-Storms, Kington, & et al., 1998). In many Asian cultures, family structure and responsibility (filial piety), the stigma associated with accessing formal care, and the availability of culturally responsive care may impact the types of services accessed or not accessed (Bowes & Wilkinson, 2003; Gupta, 2002; Koehn, 2009; Kong, Deatrick, & Evans, 2010; Lai, 2008; Mold et al., 2005a). Koehn (2009) and Lai (2008) caution that the underutilization of some services by EMOA as a consequence of cultural issues, norms of family responsibility and the perception that ‘ethnic families take care of their own’ should not be construed as an absence of need for such services. Often EMOA and their families continue to live with high unmet needs. In a study conducted by Bowes et al. (2003) exploring SA experiences of dementia in the UK, the researchers found that when people were asked about the services they needed, they always referred to services at home and expressed strong views against residential care (although some in the study indicated that this might be changing). In addition, service support appeared limited in that none of it involved mainstream non-National Health Service services or voluntary sector services for people with dementia. Further, Bowes et al. found that SAs were continuing to care for family members with dementia even when the dementia became advanced to a point where others may have sought placement in residential care. Similarly, Kong et al. (2010) found that Korean immigrant caregivers’ negative perceptions about nursing home placement resulted in them taking care of their parents with dementia at home for several years before a nursing home placement, experiencing strong feelings of guilt, making frequent visits to nursing homes, and labelling themselves as “unfilial” or “bad” children (p.326-27). Other researchers have also reported that a lack of knowledge about the care services available for immigrants with dementia (Daker-White, Beattie, Gilliard, & Means, 2002; Kosloski, Montgomery, & Karner, 1999; van Wezel et al., 2016) or the fear of leaving a family member with dementia in a foreign residential care facility (Kosloski et al., 1999; Mold, Fitzpatrick, & Roberts, 2005b; Rosendahl, Söderman, & Mazaheri, 2016; van Wezel et al., 2016) can be reasons for seeking professional care later.

Attitudinal barriers to accessing care relate to individual perceptions on seeking help or using services (Lai & Surood, 2010). Lai and Surood (2010), in their study exploring the types and factor structure of barriers to utilization of health services among aging SAs in Calgary, commented that researchers have discussed that beliefs regarding use of services often play an important role in determining health service use and access. Koehn (2009) discusses this in relation to the candidacy model put forth by Dixon-Woods et al. where the first step in gaining access to health care is determining that “you need and deserve it” (p.590). As Koehn (2009) discussed, Dixon-Woods et al. found that “the desire to protect individual and cultural identity, which seniors and immigrants may perceive as threatened by health-care providers and practices, could be a barrier to access” (Dixon-Woods et al., 2005 as cited in Koehn, 2009, pp.590-591). For seniors, this may translate into the ideal of ‘being healthy, independent and active’ and ‘responsible and unselfish’ in their use of services (Koehn, 2009).

4.2.2 Ethno-cultural Minority Older Adults and Challenges in Long-Term Residential Care

Relocation to a LTRC facility is typically a difficult transition for older adults, requiring them to adapt to a new environment and removing them from all that is familiar, and thus may evoke feelings of isolation and accelerated mental and/or physical deterioration (Koehn, 2001). For EMOA, the losses in moving from their own home to a care facility are magnified and may entail feelings of shame and loss of face and feelings of being dishonoured by the family.

Further, EMOA in mainstream long-term care facilities suffer a loss of their culture with regard to food, music, literature and folklore, the ability to communicate in their own language as well as a loss of community, all of which provide a sense of care and respect for ethnic older adults (MacLean & Bonar, 1983). Most EMOA are confronted with the triple barriers of old age, increasing loss of a second language with age and adherence to a minority culture (Koehn, 2001; Kong et al., 2010). Unlike the majority of older adults in Canadian LTRC facilities, EMOA are limited in their ability to re-establish a sense of community with fellow residents as they may not share a common political history, religious traditions or community values with those around them (Koehn, 2001; MacLean & Bonar, 1983). Maintaining family and kinship ties are important factors for many residents in care homes as most often, families continue to assist with personal care, offer social and emotional support and serve as advocates and brokers of services (Koehn, 2001; Mold et al., 2005a). For EMOA, families also attend to dietary and spiritual needs that are not provided by institutions (Koehn, 2001; Kong et al., 2010) and which serve to maintain ties to their cultural heritage (Martinsson, Edberg, & Janlov, 2013).

Given the salience of religion and spirituality for EMOA, it is important for LTRC to be culturally responsive to the spiritual practices of ethno-cultural older adults in their facilities. Often religious and spiritual traditions are conflated with cultural practices (Ng & Northcott, 2010) and this can result in religious and spiritual practices being overlooked or ignored because they are seen as different and not important. Reimer-Kirkham and Sharma (2012) argue that it is important not to subsume religion under culture because of the power of religion and spirituality for inclusion and exclusion thus affecting people’s experiences. Regan (2014) makes a case for religion and culture to be recognized as two distinct entities because of the potential of religion, as distinct from culture, to influence healthcare practice. Moreover, a review of the literature conducted by Reimer-Kirkham et al. (2018) found that the health outcomes of prayer and spiritual support for older adults in residential care included higher reported quality of life among residents getting prayer as an intervention, and that prayer may buffer against cognitive decline, restore a sense of control and connections, and provide comfort and calm among other things. In addition to the health outcomes of prayer, Reimer-Kirkham et al. (2018), in their investigation of the ways in which prayer is manifest in residential care homes, found that prayer can be an opportunity for connection and understanding even when there are linguistic differences (Reimer-Kirkham et al., 2018, p.81). Thus meeting the religious and spiritual needs of EMOA in LTRC has been reported to be important and residential care facilities can meet their needs in various ways (Reimer-Kirkham et al., 2018). Reimer-Kirkham and colleagues (2018), in their study exploring expressions of prayer in residential care homes, found that often the specific mission of each organization influenced opportunities for prayer. For example, some residential care facilities in their study integrated daily prayer into communal activities for residents and staff, others permitted volunteers to create opportunities for prayer on a weekly basis, and in yet other facilities, volunteers came in regularly to pray with residents (pp.75, 80).

Several researchers have explored the specific experiences of EMOA in LTRC. Key issues or challenges include: 1) communication with care providers and with those around them; 2) cultural differences related to food and bathing; 3) the approach and attitude of staff; 4) the perceived responsiveness of staff; and 5) the high turnover of staff. All of these challenges impact EMOAs' adjustment and care experiences in the LTRC setting (Chan & Kayser-Jones, 2005; Kong et al., 2010; Martinsson et al., 2013; Rosendahl et al., 2016; Runci, Eppingstall, van der Ploeg, & O'Connor, 2014; Wang, Wang, Cao, Jia, & Wu, 2016).

Communication issues stemming from the inability of EMOA to speak the dominant language have been reported as a major challenge in their adjustment and care experience in LTRC. The inability to speak the dominant language resulted in older adults not being able to express their difficulties, needs and preferences for care, difficulties in receiving care, and importantly sometimes resulted in the potential for misdiagnosis and not receiving needed care such as pain management (Chan & Kayser-Jones, 2005; Kong et al., 2010; Martinsson et al., 2013; Rosendahl et al., 2016). In addition, Martinsson et al. (2013) found that if care staff were stressed or busy then immigrant and minority older adults were hesitant to ask staff for help. They found that when care staff spoke the same language as the older adult, this provided a sense of comfort for the resident. Similarly, Rosendahl et al. (2016) found that if the care provider and immigrants with dementia spoke the same language, then there was the possibility of more nuanced communication between them, enabling persons with dementia to socialize and develop social relationships; they found that even for immigrant persons with dementia who could no longer communicate verbally, their mother tongue seemed to still be important in that they listened and reacted when they heard words in their mother tongue. Small et al. (2015) found that communication between care staff and residents in ethno-culturally and linguistically diverse long-term care settings involved both verbal and nonverbal ways of communicating with nonverbal communication behaviours being quite prevalent in mismatch interactions. Certain types of nonverbal behaviours from staff such as sustained eye gazing appeared to have a significant impact on the relational dimension of communication and in facilities where there was a critical mass of ethno-cultural older adults, care staff's attempts to speak in the language of the residents enhanced staff's approach to initiating interactions with residents and to supporting them through a task or activity (Small et al., 2015). Communication and language barriers not only affected EMOA’s ability to express their needs for care but along with cultural differences, also impacted their ability to socialize with those around them or to attend/participate in activities, often leading to feelings of alienation resulting in isolation and loneliness (Chan & Kayser-Jones, 2005; Kong et al., 2010; Martinsson et al., 2013; Rosendahl et al., 2016). Rosendahl et al. (2016) and Martinsson et al. (2013) found that immigrant and ethnic older adults spent a lot of time watching television and expressed a wish to have access to channels and music in their own language.

Cultural differences particularly related to food were also challenging and are the basis for a common complaint of older adults and their families from diverse ethno-cultural backgrounds (Chan & Kayser-Jones, 2005; Kong et al., 2010; Mold et al., 2005a; Rosendahl et al., 2016). Older adults often did not like the food, which was prepared based on the mainstream resident population, and thus depended on family to bring food from home. The importance of provision of culturally appropriate food for ethno-cultural minority older adults in institutional settings has been noted by other researchers (Kayser-Jones, 1996; Koehn, 2001; Train, Nurock, Manela, Kitchen, & Livingston, 2005). As discussed by Hanssen and Kuven (2016), food is not only important in terms of physiologic needs of adequate nutrients and liquids but is also important to psychosocial health, well-being and quality of life. Kayser-Jones (1996) notes that dietary habits are established early in life and may be difficult to change, and Harris-Davis and Haughton (2000), note that “food habits are developed based on ‘ethnicity’, religion, group affiliation, socio-economic status and world view” (p.1180). Moreover, culture influences how individuals perceive food and the meanings they attach to food. Hanssen and Kuven (2016), in their research exploring what people with severe dementia experience as good nursing care found through interviews with patients’ family members and nurses that serving traditional dishes to people with severe dementia in institutional care enhanced their sense of identity, belonging and joy, revived memories and improved their appetite. They note that “one should not underestimate the importance of serving patients with dementia traditional dishes” (p.871) and that “there is a significant need for a greater focus on serving dishes that patients recognize from their childhood and youth as tastes and smells from earlier years may create joy and improve appetite, which again improve nutritional status” (p.872).

With regard to staffing and the interaction with staff in nursing homes, Korean immigrant caregivers of non-English-speaking older relatives with dementia in American nursing homes in Kong et al.’s (2010) study discussed the attitude and approach of staff to care, the perceived responsiveness of staff and the high turnover of staff as problematic. They noted differences in the approach to care between Korean American and North American staff and expressed a desire for bilingual Korean American nursing staff to facilitate communication, detect discomforts directly from patients, provide more comforts, and better understand Korean culture (p.325). Some study participants also pointed out the high turnover rate of nurse aides which prevented continuous care for their older adults from nursing home staff. As a result of these concerns, informants requested strategies to facilitate better understanding of cultural differences among nursing home staff. Of note, Kong et al. acknowledge that there are few studies that have explored the experiences of nursing home staff themselves in providing care to non-English-speaking older people in facilities. Bourgeault et al. (2010), in their investigation of relations between immigrant care workers and older persons in home and long-term care in three provinces in Canada, found that the cultural competency of immigrant care workers and language barriers (on both the immigrant care workers’ and older adults’ sides) impacted their relationship as did the broader context of care such as staff shortages and workload. They also found that immigrant care workers were prone to racism and that this played out differently in different work contexts. They concluded that health care reforms in Canada have a disproportionate negative impact on visible minority health care workers and older adults that in turn influenced the quality of care. Based on their findings they suggested increased education for immigrant care workers regarding Canadian older adult cultural issues and more situation-specific conversational English language classes; more anti-racist campaigns along the same lines as anti-violence campaigns in health care settings; and recruitment of immigrant care workers to match older adults so as to better match language and cultural needs (Bourgeault, Atanackovic, Rashid, & Parpia, 2010).

In summary, the literature reviewed indicates that the Canadian older adult population is becoming increasingly ethno-culturally diverse primarily due to immigration (Statistics Canada, 2010, 2013, 2016a, 2016b, 2017). The SA population currently comprises and may continue to be the largest visible minority group in Canada and the second largest in British Columbia (Statistics Canada, 2010, 2013, 2016b). Given this, it can be expected that there will be increased numbers of SAOAs in residential LTC facilities in the future.

Researchers have found that EMOA in mainstream facilities face a number of challenges including a loss of their culture, difficulty communicating with care providers, cultural differences related to food and bathing, the approach and attitude of staff, the perceived responsiveness of staff as well as high turnover of staff all of which impact EMOAs’ adjustment and care experiences in LTRC (Chan & Kayser-Jones, 2005; Kong et al., 2010; Martinsson et al., 2013; Rosendahl et al., 2016; Runci et al., 2014; Wang et al., 2016). In addition, the move to LTRC may also entail feelings of shame and loss of face and feelings of being dishonoured by the family. The broader context in which care is provided also influences the experiences of older adults in care homes (Bourgeault et al., 2010). The reluctance of ethnic populations to using certain services may be quite reasonable if appropriate culturally responsive care is not available. In light of the above, this paper aims to provide insights about the needs, preferences and experiences of South Asian older adults and their families regarding LTRC services and discusses whether and how mainstream LTRC facilities meet their needs.

4.3 Study Design and Methods

This analysis is based upon data collected for an ethnographic study that, through a critical theoretical perspective, aimed to explore the needs, preferences and challenges of SAOAs and their families regarding LTRC as well as whether and how mainstream LTRC facilities meet their needs. Studies using ethnographic methodologies focus on qualitatively exploring the beliefs, language, behaviours and issues facing a particular group (Creswell, 2013). The task is to investigate some aspect of the lives of the people who are being studied, and this includes finding out how these people view the situations they face, how they regard one another, and also how they see themselves (Hammersley & Atkinson, 2007). Ethnography also reveals how people are situated within a cultural context (Holloway & Todres, 2003).

Ethnographers employing critical perspectives aim to generate knowledge that helps to understand how taken for granted assumptions can serve to further marginalize or oppress disadvantaged groups and to consider how to address social justice issues. The aim is to uncover how larger social processes shape the lives of individuals and to bring about necessary changes such that unequal relations of power that disadvantage marginalized groups are accounted for and addressed (Creswell, 2013; Kincheloe & McLaren, 1994; Koro-Ljungberg & Greckhamer, 2005; Mantzoukas, 2012; Norander, 2017; O'Reilly, 2009).

This study employed the ethnographic methods of participant observation, interviews and document review. Funk and Stajduhar (2009) argue the importance of not simply relying on interview data to understand study participants' situations but integrating interviews with other methods such as observational research which together may tell the researcher more about the phenomenon being studied and provide insight into the complexity of the phenomenon. Basing conclusions only on interpretations of what is said in interviews may result in erroneous conclusions as study participants' responses may reflect social desirability and reactivity (Funk & Stajduhar, 2009) and in the case of interviews with participants from minority cultures, what may be a desire to please and answer questions with what the study participants think the researcher wants to hear or attempts to give what they consider might be the "right answers" (Birks, Chapman, & Francis, 2007; Neufeld, Harrison, Hughes, & et al., 2001; Sands, Sands, Bourjolly, & Roer-Strier, 2007). Observational research requires the researcher to spend time being immersed in the field and thus facilitates the collection of longitudinal data (Creswell, 2013; Emerson, Fretz, & Shaw, 2001; Funk & Stajduhar, 2009; Gold, 1958). As the researcher spends more time in the field and builds trusting relationships with study participants, the need for participants to respond in ways that they think the researcher wants may be reduced. The review and analysis of relevant documents generated in the setting of interest and that are pertinent to the research questions being asked are also important sources of information and data (Hammersley & Atkinson, 2007; Lofland, Snow, Anderson, & Lofland, 2006; Mason, 2002) and help to provide a contextual understanding of the observational and interview data (Hammersley & Atkinson, 2007).

4.3.1 Sample and Recruitment

The study sample comprised 18 South Asian older adult (SAOA)-family caregiver dyads purposively recruited from two LTRC facilities, an assisted living facility, and from the South Asian community at large. Seven key informants were also recruited including managers, clinical nurse specialists, social workers, and recreation coordinators from LTRC as well as individuals from the SA community at large and individuals with knowledge of the SA community through their work with the community. The criteria for recruitment of SAOAs included 1) aged 65 years and above, 2) being of South Asian descent, 3) currently residing in a LTC facility or contemplating placement in a LTC facility (recruited from Assisted Living or the SA community at large), and 4) having a family caregiver who also agrees to participate. The 18 older adults ranged in age from 68 to 94 years and 12 were female. Fifty-six percent (n=10) of older adults respectively were from India and were Sikh reflecting the large settlement of this immigrant group in B.C. The majority of older adults spoke little or no English (n=10). The median number of years in Canada was 38 years, ranging from 8 to 52 years. One-half of the older adults had less than High School education and two older adults had university level education (Master's Degree from India) (see Table 1).

Of the family caregivers, 15 were female and the majority were daughters, granddaughters or great granddaughters (see Table 1). Of the three male family caregivers, two were sons and one a spouse. The family caregivers ranged in age from 20 to 86 years with a median age of 54.5 years. A large majority were fluent in English (89%) and 78% were educated at the Diploma level or higher. Twelve family caregivers were employed, one was a homemaker and five were retired.

Key informants were purposively recruited from LTRC based on their clinical role and their experience with the transition, integration and/or care of SAOAs living in LTC as well as from the advisory committee for the project based on their knowledge of the SA community at large either as a member of the community or through their work with the SA community.

Following ethics approval from the Research Ethics Board at the University of Victoria and the regional health authority involved, LTRC and assisted living facility managers assisted in distributing study information letters prepared in English, Punjabi and Hindi to SAOAs in their facilities. Interested older adults and family caregivers contacted the researcher or the multilingual research assistant directly. SAOA-family caregiver dyads from the South Asian community at large were recruited with the assistance of the advisory committee members for the study who provided linkages to the community through their networks. Information sessions were conducted with various seniors groups in the community and older adults interested in participating in the study contacted the researcher or the research assistant directly. Key informants were invited to participate in a key informant interview via email and contacted the researcher directly to confirm their interest.

4.3.2 Data Collection

Data were collected from March 2014 to May 2016 using multiple data sources that included in-depth qualitative interviews, participant observation and document review, and consisted of 220 hours of observational fieldwork. To facilitate data management, all interviews and field notes were entered into NVivo 10 software, a computerized software program designed to assist with management and organization of qualitative data (Bazeley & Jackson, 2013).

Interviews

Semi-structured, in-depth interviews were conducted with eighteen SAOAs, eighteen family caregivers and seven key informants. The interviews with SAOAs in LTRC required multiple visits to complete because they became tired during the interview or were not well. One family caregiver required two visits to complete the interview because she had only short timeframes available and thus required a second visit to complete the interview. Eight older adults and three family caregivers required the interviews to be carried out in Punjabi or Hindi and thus were conducted by a South Asian multilingual research assistant with the researcher present. Ranging from 20 to 103 minutes, the majority of interviews were recorded and transcribed. Interviews conducted in Punjabi or Hindi were simultaneously translated and transcribed. Where SAOAs or family caregivers did not feel comfortable with the interviews being recorded, handwritten notes were taken during the interviews. Field notes were written after all interviews.

Focused Participant Observation

Focused participant observation of seven SAOAs living in two LTRC facilities was conducted between March 2014 and April 2016. This time in the LTC setting allowed the researcher to become familiar with the LTRC environment and enabled observation of SAOAs' interactions with fellow residents, formal care providers, the physical environment and how they negotiated their specific needs and preferences as well as any relationships they developed in the setting. Observations were conducted on weekdays and weekends, varying the times throughout the course of the day and took place in public areas of the facilities such as the lounge, activity room, dining room, etc. and were recorded in the form of detailed field notes.

Document Review

Eight documents relevant to LTRC were collected and reviewed including provincial policy documents, provincial residential care regulation, and various documents prepared by the health authority and the LTRC facilities where the study took place. The review of documents provided an understanding of the formal processes required for access to LTRC as well as how services are organized and provided in the LTC setting. Findings from the review of the documents enabled uncovering of taken for granted assumptions in how care and services are provided and the sociopolitical context in which LTRC is situated.

4.3.3 Data Analysis

Data were analyzed using the constant comparative method (Boeije, 2002) which involves comparison of themes within and between groups of study participants. Each interview transcript was read several times to obtain an understanding of the general ideas expressed by the participants with regards to the research questions. Each transcript was then coded by comparing passages within the transcript resulting in provisional codes/categories and this process was followed for all interviews and field notes. The next step involved comparing between interviews of the same group, e.g., older adults, to identify higher level themes, followed by comparison of interviews from different groups, e.g., interviews with older adults and those with family caregivers. The latter step was aimed at deepening the insights and completing the information about the group of older adults that has been the focus of interest. This process was multi-layered and enabled exploration and understanding of individual experiences of older adults and family caregivers and comparison within and between groups in a systematic way. A critical theoretical perspective was applied to the findings to explicate how larger social processes shape the lives of older adults and their needs and preferences in LTRC. In reviewing the findings, commonly held values and assumptions were interrogated with a view to understanding how these may serve to marginalize SAOAs in facilities.

The documents collected for this study were reviewed and then critically examined, paying particular attention to the language used and how dominant ideologies were reproduced in the text. A brief summary of each document was written, coded and then these coded sections were included in the overall analysis. A critical analysis of these texts contributed to the development of theoretical arguments and to the analysis of the broader context of the study.

4.4 Findings

The findings from interviews with SAOAs, family members and key informants as well as from observation of SAOAs residing in LTRC are presented under the main themes of "Contextualized Experiences of 'Difference'," "Differential Effects of Time Constraints," and "Expectations Placed on South Asian Staff". These themes illuminate the needs and experiences of SAOAs and their families related to LTRC and whether and how their needs are met in existing mainstream LTRC facilities.

4.4.1 Contextualized Experiences of 'Difference'

The SAOAs residing in mainstream LTRC facilities felt a sense of being 'different' from those around them. They spoke about the ways in which they experienced this 'difference' in terms of language and the challenges in communicating with staff and others, and how the food they are served is not what they are familiar with and/or accustomed to eating – the food is "not like ours".

'Difference' is denoted in singular quotations to indicate that it is socially constructed and materially experienced in the context of LTRC facilities. SAOAs in mainstream LTRC facilities profoundly experience 'difference,' articulated through their inability to communicate with staff and others and the lack of culturally appropriate food. This 'difference' materializes when the context shifts for these older adults; when their needs and preferences do not match those of the institution.

Language

Language issues and difficulty communicating with staff and others are a key challenge for many SAOAs in mainstream LTRC facilities. For example, when a 72-year-old SA male in a residential care facility who cannot speak English was asked how he communicates with those who care for him, he answered that he calls his son and his son communicates with them. When prompted further and asked whether those who bathe him and bring him food talk to him, he said:

> They speak in English and we communicate in Punjabi…We just keep mum [i.e. keep quiet] while they talk in English. We are unable to talk to them, they ask one thing and we tend to answer something else…

The above illustrates not only the challenge of communicating with staff who do not speak the same language as the older adult, but also the dependence of SAOAs on family to help communicate. In everyday situations, the language barrier can lead to SAOAs not being able to articulate their preferences for care, misunderstanding of what is needed, and challenges in building relationships with SA residents.

The communication is different when the staff is SA. SAOAs felt known and understood by SA staff. The same SA older adult mentioned above makes a distinction when he is being cared for by Punjabi-speaking care aides, in this instance related to being bathed:

> Interviewer: Do they talk to you nicely when they come to bathe you?
> Akil[16]: Yes they do. They do talk. They are our own people.

Family members of older adults, including those of older adults who are fluent in English, commented on the importance of having SA staff in the facility so that their family members can talk to them and communicate their needs in their own language. A family caregiver of an 80-year-old SA female in residential care said:

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[16] Pseudonyms have been used to protect the anonymity of study participants.

> Yeah, important thing they have Punjabi people there…that's be good thing. She's be talk them, what she have problem then they talk with her, right…that's the good things…Otherwise nobody Punjabi then is very hard right

And a family caregiver of an 85-year-old SA male who is fluent in English, when discussing the adjustment of her father in the LTC facility spoke about the difference it makes having SA staff in the facility who can speak to her father in Punjabi:

> …he knows that this is the best place for him now and we visit when we can. And plus the help having Indian people around is a huge difference because they'll speak a little bit of Punjabi to him and there's one nurse from Burma and she speaks in what is it Burmese, I can't remember, so they speak the same language too he can speak that too so they're doing that and yeah so having the Indian people I think makes a huge difference too right.

Even SAOAs who are considering LTRC as an option sometime in the future, who are acculturated to Canadian norms, who immigrated early in life and have lived and worked in Canada for 30+ years and are fluent in English, when asked about their needs and preferences in LTRC, discussed the importance of being able to speak to staff in their native languages. They worried that they may lose their ability to speak English with age and that there is comfort in being able to articulate their needs in their native language. A 72-year-old SA female living at home in the community explained:

> …though I know the language, but if I don't know the language somebody who can talk to me in the language I know…and that I came across with my husband when he has a brain tumor, he totally went back to his original language…his mother tongue…and it just happened so naturally that there was nobody could understand except me…or somebody who can speak in Hindi then I realized that you need people in the system with different language ability to be able to communicate with the person who is in a dire need of it.

Key informants also described how the communication between SAOAs and SA staff is different compared to that with non-SA staff. Debbie, a social worker in LTRC explained that there is more communication, communication is fluid and not a struggle. Observational fieldwork in LTRC confirmed that many SAOAs were at ease in communicating with SA staff. During breakfast one Saturday morning, the interaction between Akil, the 72-year-old SA male mentioned earlier, and a SA registered nurse who was helping with feeding residents in the dining room showed the naturalness of the interaction and the rapport that existed between the older adult and SA staff member who spoke to him in Punjabi. This observation also illustrates through the dialogue how the inherent cultural familiarity between the SAOA and SA RN facilitated the eating behaviours of the older adult:

> … She [SA RN] then went over and spoke to Akil in Punjabi and asked how he was. He said good. She said to him 'chenga legta hai' meaning you are looking good. Akil was laughing...Earlier when the RN spoke to him and she went to talk to another resident he was saying something conversationally to her as she was heading to the other resident…and she too was joking with him.
>
> Breakfast consisted of toast, porridge, tea, and milk…the RN came to him and asked if he wanted milk or tea to drink. He asked for tea. He said to her that for Punjabi people milk and tea are the staples of a meal…she gave him the tea cup in his left hand and he was able to drink by himself. After he took the first sip he told her that it needs more sugar. The nurse added more sugar then gave it to him again and he said it was fine now. Once he was done he placed the cup back on the table. He then used his bib to clean his mouth. Then the nurse came to him and asked him whether he wanted to drink his milk. He shook his head no. Then she said that milk is good for you, it makes you strong and has calcium so he should drink it. He said that he is strong as a horse and said okay. So she took the glass of milk and held it to his mouth as he also was using his left hand to hold the glass. He drank the entire glass of milk in one gulp.

When the resident is cared for by staff who can speak the language, SA residents seemed more at ease in communicating with staff, seemed to be able to express their needs and preferences and there seemed to be a sense of being known due to cultural familiarity and inherent cultural knowledge of what is important to the older adult. In comparison, when a resident is cared for by staff who do not speak their language, this can result in minimal communication, a dependence on family to interpret, the inability of older adults to articulate their preferences, and the potential for misunderstanding of what is needed and in extreme cases even the potential for misdiagnosis. As Rachael, a key informant who has worked extensively with the SA population notes:

> Sometimes people have been identified as having dementia but it's only because they couldn't communicate their needs and their wishes because there was a language barrier…because the staff didn't speak the language of the person …

One of the ways in which LTC facilities have tried to attend to language differences is to offer interpretation services. According to study participants, this works well when there are staff 'on site' who speak the language and can provide 'on the spot' interpretation. However, more often than not, interpretation services are centralized, with interpreters available, but not often on site when needed. One key informant spoke of the challenges in accessing the interpretation service:

> …we do have a translation service program in (name of health authority 1) however, it is very difficult to get a translator to come here, to come off-site and I think the system has changed a bit to the point where I don't even bother…I think there needs to be improvement on the translation services umm because our seniors are not going to talk through a telephone for a translator it just doesn't, they are not going to trust, you know it is hard enough for them to talk to a stranger to translate for them, but at least if they are in person there can be an engagement whereas over the telephone so that's one area that I think there needs to be some improvement on and I don't know if, there's been a lot of this centralizing services between (name of health authority 1) and (name of health authority 2) and that what's it called…(name of health authority 3) and uh so maybe they're just having growing pains right now but it would be nice to have uh more readily available translators if we need them especially for languages we don't have covered right [i.e., covered by staff in the facility who speak those languages].

Another key informant noted that while interpreters are readily available for social interactions (referring to SA staff in the facility), if she needed to spend a longer time with a SA resident to hear his/her concerns, she would need to schedule an interpreter and that might be more difficult. She also wondered how difficult it would be to get an interpreter if she needed to help someone who was in a crisis situation suggesting that she may have to ask a SA staff member or rely on family to interpret which may not be appropriate:

> But if I needed to spend let's say an hour with someone I'd have to make sure I could get somebody and that might be a little more difficult… In social work a lot of the needs arise because of a crisis so if you are needing, if I am needing to help someone in a crisis, then it, how hard is it going to be to get somebody in to interpret. And I know I can obtain interpreters, but I mean realistically I am sure I could get somebody from here

> especially in a crisis…or a family member…but family member might be part of the problem.

Language issues and difficulty communicating with staff and others in mainstream LTRC are challenges for many SA residents. This results in the dependence of SAOAs on family to help with interpretation and can lead to SAOAs not being able to articulate their preferences for care, misunderstanding of what is needed and challenges in building relationships. While LTRC facilities may have formal interpretation services available, the findings indicate that these services are often centralized and not readily accessible leading to challenges in obtaining appropriate and timely access to interpreters.

Food

Food was another important place of ‘difference’. SAOAs and their family members spoke about how the food is not what they are familiar with and accustomed to eating and that there is no choice when one is hungry. Gurjit, a 94-year-old SA female says “the food is not like ours…There is nothing to like; one just has to fill the belly. Everything is good when one is hungry”. Observations in LTC revealed that sometimes, even if South Asian/Indian food was served, SAOAs did not eat it. The excerpt below from observation with Gurjit during dinner illustrates this:

> Gurjit was eating a peanut butter sandwich. She did not touch the daal and rice. She had some tea. I said to her, “you have not eaten your daal and rice” and she said she is “full”. She will “eat it later”. She then had more tea. She then took her menu and put it in her lap. She had more tea. She picked up her spoon and had her canned oranges. ….
>
> The menu today for dinner was peanut butter sandwich, vegetable daal rice and boiled mixed vegetables. Gurjit ate the peanut butter sandwich and some mixed vegetables but did not eat the daal and rice.

SA family members spoke about the importance of food in the SA culture, how many SAOAs in LTRC remain hungry and that facilities should provide culturally appropriate food, and when not provided how it then falls to the family to bring food from home so their family members will eat. The latter not only adds more work for families but also results in feelings of guilt. The daughter of a 79-year-old female in residential care said about the importance of food in the SA culture:

> Food. I mean the food – I cannot express even how much that means to you know culturally food is everything I think for each culture. And here I mean they just don't offer Indian food at all. And that's really unfortunate. I mean the vegetarian – she's not a vegetarian – but the vegetarian meals that they do offer or sometimes the things that they do bring and kind of have an Indian I guess component to them are awful (laughs).

Another family caregiver of an 89-year-old SA female in the same facility who visits the facility twice a day to bring lunch and supper for her mother says:

> She can't eat uh English food, (First and Last name of mother), she not eat Canadian food so I bring food from home. This is the reason I need close by so I worry about she not eating food…I have to go maybe two times a day because she not eat food in facility in care home…I see lots of others they stay like hungry…They don't have a taste, they don't eat. Like my mom is especially you know. So I, what I recommend is government should do something for the old people. You know end of life they stay hungry then how we feel?

The importance of having culturally appropriate food for many SAOAs is also related to their religious proscriptions. As Rachael, a key informant introduced earlier notes:

> …Food is extremely important because that is say integral to the religion so a lot of people are vegetarian and often in care facilities things that are said to be vegetarian are not necessarily, I've heard seniors say that you know somebody is served a broth and it is made out of gelatin or like jello or some kind of stock and the stock comes from meat or the gelatin in jello is made from uh you know the hooves of pigs and so on so you know things aren't strictly vegetarian or vegan and there's that kind of thing. But I mean it's even just eating foods that you have been accustomed to your whole life and it's really hard to change at that point and their stomachs have a hard time accommodating those different types of foods you know…

Danvir, a 71-year-old Hindu male living at home in the community and contemplating placement in LTC at some time in the future, when asked about his needs and preferences for LTC, spoke emphatically about the religious proscription for strictly vegetarian food to the extent of saying that he would not be comfortable to move to a LTRC facility where both vegetarian and non-vegetarian meals were prepared in the same kitchen:

> Especially because we are totally vegetarian family, first priority will be that where that type of vegetarianism that is the main point for me…Actually if in the same kitchen non-veg is cooked I shall not be comfortable whatever the facility it may be…I shall not be comfortable to live there.

Several key informants also spoke about the importance of serving culturally appropriate food as a key factor in the adjustment of SAOAs in the facility. Gori, a manager in a LTC facility, mentioned the challenge of providing culturally appropriate food and her frustration in not being able to accommodate this given that approximately 15% of residents in the facility were SAOAs:

> ... and especially the food I am trying my best to bring the South Asian food but (name of health authority) they have so many restrictions uh so uh that's what my next move is to bring the South Asian food. Um they started butter chicken already I think (laughs)…but not a lot of variety for the vegetarian. A lot of South Asian population, the older population, they are vegetarian so they like roti and you know daal and other stuff but we are not able to, unfortunately, not able to provide that…because we have a regional menu so I don't know in the future probably they are able to do something about it but uh.

She later explains that a "regional menu" is a 28-day meal menu created at a regional level and implemented in all thirteen or fourteen LTRC facilities across the health authority. There seems to be little flexibility and ability at the facility level to alter the regionally imposed menu regardless of the ethno-cultural mix of residents that may be in a facility.

> SRJ: Um so when you say a regional menu, essentially it's a menu that the entire region is expected to implement
>
> Gori: so from here to (name of area 1) or to (name of area 2), you know…yeah all thirteen or fourteen facilities, yeah…
>
> SRJ: …I am wondering about … nuances around different facilities and the populations
>
> Gori: yeah they don't…because you know I am thinking in east probably lot of we don't have a lot of South Asian population but here like in (name of city 1 in Lower Mainland) and probably (name of city 2 in Lower Mainland) or (name of city 3 in Lower Mainland) you know a lot of South Asian population so especially in (name of city 1 in Lower Mainland).
>
> SRJ: Hmm, hmm. And uh, is there a rationale for the regional
>
> Gori: no they are, I don't know, they have a twenty eight day cycle so uh you know it's hard for them and they have a sea board system, some kind of system, computerized

> system and it's complex right to switch them around I guess I don't know. Maybe with new technology somebody can come up with (laughs). And acute care menu is different I think from residential care too. Because I have seen in acute care, one day like they get daal and pita and stuff like that and I ask my manager here and she said no we can't provide because it is a regional menu so there are some restrictions.

Overall, the findings in this theme illustrate how food, language and religion are inter-connected and encompassing aspects of everyday life for SAOAs and have deep meaning for them. Experiencing 'difference' surfaces for SAOAs in LTRC when there is a disconnect between these intersecting needs and preferences and those of the institution. The 'difference' is contextual – on the one hand, when SAOAs are in their own homes, this 'difference' does not exist. On the other hand, the institution does not acknowledge the 'difference' in the way services are organized. Yet, in the LTC context, the 'difference' matters profoundly. The lack of accommodation by LTRC facilities for meeting the language and dietary needs of SAOAs is experienced by these older adults, not as inconveniences or preferences, but as foundational to their experience and way of life. Food preferences are both cultural and religious in nature, such that the intersectional nature of 'difference', ethno-cultural and religious beliefs makes the experience of being positioned as 'different' very encompassing for SAOAs.

4.4.2 The Differential Effects of Time Constraints

SAOAs and key informants spoke about the time constraints on staff and the impact this can have on residents including the building of relationships. While all residents may feel the negative impact of staff not having the time to care, this can be exacerbated for SAOAs in mainstream facilities who do not speak the same language and thus may require a longer time to communicate their needs and build relationships with staff.

Mansukh, an 85-year-old male, fluent in English, shared during a participant observation, his dissatisfaction with meal times and how staff rush from resident to resident, in effect making the entire experience mechanistic. When he tells the staff about the way they help residents, they reply that they do not have time and have too much to do, as the following excerpt from observational field notes demonstrate:

> Mansukh then moved to talking more about his experience in LTC. He talked again about meal times and the fact that staff do one thing for one resident and then rush to do something else for another resident and then another instead of finishing with one resident. He said that the 'staff are splitting their time not their work so they rush between multiple residents while not serving anyone satisfactorily'. He said that 'the staff should focus on completing one task at a time or managing only a few residents at a time not 10 or 12'. He said that when he mentioned this to the staff they say that they don't have time and have too much to do. He then told them that they should tell their employer to hire more staff.

During an interview, Mansukh also discussed how staff multitask to save time. He described an incident when staff tried to toilet him and dress him at the same time, demonstrating how a normally private activity can become uncomfortable and undignified:

> Another bad thing that's happening is while I'm sitting at the toilet the workers try to dress me up. I'm still at the toilet sitting on the commode and someone is putting socks and also putting the shoes on and put the dress on pants undershirt etc. while I'm sitting on the toilet. It's a very bad scene….Well when you dress someone you don't say okay sit on the toilet seat and I will dress you up. I mean that is awful.

These experiences illustrate attempts by staff to save time in order to gain time for additional tasks that are required of their jobs. Participants also talked of how staff need to rush care and multitask in order to complete their work and the impact this has on residents. Moreover, with staff rushing to complete tasks, there is little or no time to communicate with residents and build relationships. Key informants discussed how staff are "supposed to act like a robot" or explained that working in LTRC is "like working in a factory":

> Today care aides, I think I went to this symposium not long ago in Vancouver Library, and a care aide of thirty years' experience, very compassionate person…she was saying she got no time (emphasizes time) to talk to the, she is given no time to have a few minutes to talk to the person she is caring for…extremely task, extremely task focused…compassion is taken out of it completely. You know like a robot. Actually she mentioned that, supposed to act like a robot.

The above key informant elaborates on the situation of care aides today and comments that this is a result of the system. He noted: "…Well I say, if I look at the care aide's point of view…they've got other pressures… they're being told to do this [work] in a certain number amount of time and so on so forth. So in a way it goes back to the system."

A key informant who has a region-wide education role for frontline staff in residential care facilities noted:

> … We can do a lot Sherin but we cannot afford to do those ideas because everybody is too busy. Nurses, for example LPNs (licensed practical nurse) have twenty-five resident and they have to finish all those medication, they're attached to the med cart. They don't even have time to spend time and talk to new resident. It's like working in the factory I am sorry to say that.

The challenges with the lack of time can be exacerbated because of language issues. The minimal time that staff has to communicate with residents also affects the ability of staff and SAOAs to develop relationships. It takes more time and is more difficult compared to the time required if the staff and resident can speak the same language and they come from the same culture. The same key informant above notes:

> …and to be fair with the other staff, I'm sure they get close to that resident too but it could be harder to have to build that relationship because they don't you know resident don't understand them. … Yeah it could happen but definitely takes more time and it is more difficult compared to the time if the staff and resident can speak the same language and they come from the same culture.

As the findings in this theme show, residents (and staff) feel the negative impact of staff not having the time to care, and this can be exacerbated for SAOAs in mainstream facilities who do not speak the same language.

4.4.3 Expectations Placed on South Asian Staff

The findings discussed in this theme indicate that South Asian staff in mainstream facilities may directly or indirectly have expectations placed on them that are different from their non-SA colleagues. As seen from the findings discussed thus far, SAOAs and family members spoke about the importance of having SA staff in LTRC facilities so that their family members can communicate their needs in their own language. Key informants also talked about the 'saving grace' of having SA staff in their facilities as they helped with interpretation and the adjustment of SAOAs in the facility because the older adults felt that they had someone they could talk to. As noted by a recreation therapist employed at one of the sites:

> …the only thing that we find here is for me, is a language barrier and that um fortunately enough we are able to work with a lot of co-workers who speak the language and we're able to communicate through our and work as teamwork to understand what our residents are saying and what their needs are… so I am sure when they [SAOAs] know that they have that staff person here that they can speak to, that they feel like okay this is okay because I have that communication um so I think that they are very happy they have that communication… they have someone to talk to, I can't imagine if we were all Caucasian here and everybody was Sikh

Key informants also noted that there is an expectation among SAOAs and families that if a staff member is SA then s/he will be able to speak the language fluently and if this is not the case, then residents and families will go and find a staff member who can speak the language or the SA staff member who cannot speak the language will go and find someone who can. In addition, key informants noted that SA residents and their families may also have higher expectations of SA staff than non-SA staff to solve their problems. This can be frustrating for SA staff as they work in the same system with the same constraints as their non-SA colleagues.

> SRJ: …in terms of the South Asian staff who can speak their language it sounds like there is more interaction and communication
>
> Gail: yeah and more expectations… I would say more expectations for them to solve the problem, right and they are working within a system and not necessarily can change the system, right. I can't give you examples but generally that's and uh I think that's their frustration [referring to SA staff], I hear, um…yeah because the family are coming to them all the time for this for that and expecting them to go outside their role so to speak and um and they can't they can't…and they're time limited, they have got their job to do, that kind of thing and so that's...but I think that that is something I have observed over the years uh that some staff get frustrated.

Observations in LTRC supported the contention that some SAOAs also have expectations that SA staff will adhere to cultural norms such as acknowledging elders if they are present. This was illustrated in the extract below from observations with Gurjit, a 94-year-old SA female:

> As we were sitting together one staff member (Caucasian) came over and sat at the table to fold laundry…Gurjit looked over at her and asked her in Punjabi if she was working. Then the staff member asked me what Gurjit had said and I told her she was asking if you were working. While the staff member was folding the laundry another SA staff person came into the dining room area with a resident. The two staff members interacted and then the SA one went off. There was no interaction between Gurjit and the SA care aide. After the SA care aide left Gurjit said to me that she felt bad that the SA care aide did not acknowledge her. She said 'she sees I am sitting here by myself and she did not call [speak to] me.'

Despite having myself and another care aide sitting at the table and chatting with her, Gurjit had the expectation of being acknowledged by the SA care aide and felt slighted when this did not happen.

Key informants also mentioned that some SAOAs only want SA staff to care for them because they can communicate their needs and SA staff know what SA residents want:

> …Some of them, we have a lady just came in, she only likes East Indian girls…so whenever she see a new staff, I don't know because of the language she is not able to explain what she really wants, so you know she always say oh I like you know these three people…. So they tend to like you know the South Asian girls because they feel more comfortable with you know they can talk to them and they know exactly what they want, right. …Specially the music you know they have little radios now they can you know hear the prayers and stuff like that and yeah and certain time of the day you know they know okay they specially for Sikh population and they like to hear paat (prayer) in the morning and do their prayers, so they know exactly what they want compared to the other staff.

Residential care regulations may also implicitly (and unwittingly) set up expectations for ethno-cultural staff in LTC facilities to work outside their role descriptions to assist with interpretation and for their colleagues to call upon them for assistance when required in caring for ethno-cultural older adults. The Community Care and Assisted Living Act – Residential Care Regulation, which provides strict direction to residential care facilities regarding standards to be maintained in order to remain licensed and operate under the Act, states in Section 42, Subsection 3 (an amendment added to the regulation in 2016): "A licensee must ensure that, at all times, there are employees on duty who can communicate effectively with all of the persons in care." This asserts the need for ethno-cultural staff who can communicate with ethno-cultural residents to be on duty during all shifts and sets the expectation for them to assist with communication if needed (as facilities do not have trained interpreters on staff). In practice, this translates into a situation described by one key informant where ethno-cultural staff, in this case SA staff, can have higher demands on them and can end up with more work:

> …They are also if there is more Caucasian or other cultural background staff on duty and then there is one staff that's South Asian then they get they get their… all the work right, because they have got the communication skills and to address so and so's problem and address so and so's problem, and address so and so's problem even though that's not the number of residents that they have on their workload that day (clears throat) or those people are not on their workload that day…yeah, so they do get more work…or the staff are saying could you go see Mrs. so and so I don't know what she is trying to tell me…so the demands are greater.

Physicians may also rely on SA staff for interpretation when they visit the facility. The legislation remains silent on the implications of this expectation on ethno-cultural staff in terms of the additional and uncompensated work that they undertake beyond the roles that they are hired for.

The expectations of SA families and older adults for SA staff to meet their needs beyond what would be expected of other staff, as well as expectations from non-SA colleagues to interpret and help care for SA residents, results in additional work for SA staff and increased workload if they are the only SA staff on shift. Moreover, residential care regulation may also set up expectation for SA staff to act as interpreters and help with resident communication. There seems to be expectations of SA staff that are different than their non-SA counterparts – to interpret and help non-SA staff to care for SAOAs, to understand cultural norms, to go beyond their roles to meet SAOAs' and families' needs. This might have the potential to place extra pressure on SA staff in an already time constrained environment and could potentially result in moral distress and precarious work on the part of SA staff. The utilization of SA staff in this manner reflects the hidden, unaccounted and unpaid work of SA staff in facilities, and, in the process, may save the system money by reducing the need for interpretation services.

The challenges discussed by study participants are the result of being in an environment that is structured around Euro-centric norms and values and where the predominant language of care is English. The LTRC system is also situated in a neoliberal political economy which treats people as if they are the same and offloads responsibility for "care" onto families and those who are culturally congruent (i.e., poorly paid care aides). The lack of provision of culturally appropriate food and the minimal availability of formal interpretation services despite increasing numbers of SAOAs in mainstream LTRC facilities are examples of this. There is limited accommodation for 'difference' and the system has little ability to adapt to 'difference'. Person-centred and relationship-centred care for SAOAs is accomplished through the unseen and unpaid work of SA staff, mainly care aides, in the facilities and family members (in the case of food provision).

4.5 Discussion

Research on immigrant and ethno-cultural minority older adults has shown that these populations face a number of challenges in mainstream LTRC facilities including communication with care providers and those around them, cultural differences related to food, the approach and attitudes of staff, the perceived responsiveness of staff as well as the high turnover of staff, especially those on the front line who occupy the lowest pay categories (Chan & Kayser-Jones, 2005; Kong et al., 2010; Martinsson et al., 2013; Rosendahl et al., 2016; Runci et al., 2014; Runci, O'Connor, & Redman, 2005; Wang et al., 2016). This is in addition to the losses suffered when EMOA transition to mainstream LTRC facilities including a loss of their culture with regard to familiar foods, music, literature and folklore, the ability to communicate in their own language as well as a loss of community which provides a sense of care and respect for ethnic older adults which may be different in a LTC environment that privileges mainstream culture (MacLean & Bonar, 1983). The move to LTRC may also entail feelings of shame and loss of face and feelings of being dishonoured by the family (Koehn, 2001).

Long-term residential care services in Canada, comprising a mixed model of public and for-profit facilities, are provided in a neoliberal, market-oriented, for-profit context. This influences how care is organized, and what services are provided and not provided under the rubric of public health care. The diminishing role of the state in citizen provision of resources has been associated with program reductions and limiting eligibility for a wide range of benefits and services often through increasingly stringent eligibility criteria as well as implementation of other policies designed to minimize need for access to certain more expensive services. The health care system is expected more and more to work within a “business efficiency model” which privileges transaction-based care with hospitals being restructured to their business focus of acute care, which is more narrowly defined, and other services either being contracted out, not offered, or offered under the rubric of home care which already falls outside of medically insured services (Armstrong & Braedley, 2013b; Chappell & Penning, 2009; Porter & Lee, 2013). This results in inequitable access to services and increased demands on family and friends for caregiving as well as increased acuity of individuals when they do access services (Armstrong & Braedley, 2013b; Chappell & Penning, 2009; Daly, 2013; Froggatt, Hockley, Parker, & Brazil, 2011; Porter & Lee, 2013). For example, the “Home is Best” policy instituted by the B.C.

Ministry of Health with the goal of supporting high-needs older adults to live in their homes while waiting for residential care, to avoid residential care if possible, and to avoid acute care use if not appropriate (British Columbia Ministry of Health, 2015), touted as a reflection of the preferences of older adults to remain at home for as long as possible, has resulted in making it more difficult for older adults and their families to access LTRC. Anecdotal evidence from key informants in LTRC suggests that the consequence of this policy has been deferring needed care resulting in higher acuity of older adults when they are eventually admitted to LTRC, increased complexity of care required and increased care demands on families. Armstrong and Braedley (2013), based on data from the Canadian Institute for Health Information (CIHI), have also noted that as it becomes more difficult to access LTRC and more intensive care is provided in individual households, “residents have more complex health care needs than did residents in the past and, as a result, require more intensive kinds of care” (Armstrong & Braedley, 2013a, p.13).

The neoliberal ideology of market domination, reducing costs and increasing profitization places little value on care work, privileges transaction-based care (Armstrong & Braedley, 2013b; Daly, 2013) and results in inadequate staffing levels and not replacing staff who are sick or on vacation (Banerjee et al., 2012; Bowers, Esmond, & Jacobson, 2000; Knopp-Sihota, Niehaus, Squires, Norton, & Estabrooks, 2015; Lopez, 2006, 2007, 2014). The consequences of this for existing staff include having to work in a mode of efficiency with limited time to complete tasks, having to be more task focused, rushing from resident to resident, leaving little or no time for the relational compassionate aspect of care (Armstrong & Braedley, 2013b; Banerjee et al., 2012; Bowers et al., 2000; DeForge, van Wyk, Hall, & Salmoni, 2011; Knopp-Sihota et al., 2015; Kontos, Miller, Mitchell, & Cott, 2010; Lopez, 2006, 2007, 2014) resulting in what one key informant describes as working in a factory. As made abundantly clear in this study, this LTRC environment differentially impacts SAOAs in mainstream facilities who may require additional time to communicate their needs to staff due to language barriers and may be reluctant to ask for what they need if staff are rushed and seem abrupt. These constraints of LTRC facilities imposed by neoliberal ideology is a form of systemic discrimination where there is a lack of designated time for effective communication between service providers and users (Pollock et al., 2011).

Neoliberal ideology also influences the types of services that are provided in LTRC facilities and services that are the first to be reduced or cut when needing to save costs. For instance, the minimal availability or unavailability of formal interpretation services or centralizing such services for cost savings to the point where it requires too much effort on the part of staff to access the service or the service is not available in a timely or appropriate manner results in not meeting the needs of ethno-cultural older adults furthering inequality. Such changes in service provision differentially impact SAOAs and other ethno-cultural older adults in LTRC facilities. Moreover, the lack of formal interpretation services also has a differential impact on SA staff in that the demands on them are greater compared to non-SA staff. Not only do the SA residents want to speak to that one person if s/he is the only one on duty and have expectations for SA staff to go beyond their role descriptions to meet their needs, but non-SA staff often ask that one person to go and see or help with such and such SA resident because they do not understand what the SA resident is trying to say. SA staff are often conscripted into doing hidden, unaccounted and unpaid work, compared to their non-SA colleagues illuminating the precarious nature of their work. Long-term residential care facilities not providing culturally appropriate food or interpretation services offloads those services on to SA families so that they need to bring food from home and be available to communicate their family member’s needs once the older adult is in residential care. In short, ethno-cultural populations in mainstream LTRC facilities experience systemic discrimination – they pay the same as everybody but have to bring food from home and family has to be available to interpret. This discrimination leads to unequal and inequitable care for ethno-cultural populations in facilities compared to the mainstream population, and could be understood as a form of institutional racism (Anthias, 1999; Atkin, 2004; Forbat, 2004; Griffith, Childs, Eng, & Jeffries, 2007; McKenzie, 2017; Thorne, 2017; Wight, 2003), which often occurs unwittingly and unconsciously rather than intentionally (Brotman, 2003; Forbat, 2004), and reflects the collective failure of an organization to provide appropriate and professional service to people of different ethno-cultural backgrounds; a failure that can be detected in the processes, attitudes and behaviour of institutions (Forbat 2004, p.316).

While the rhetoric of a multicultural and pluralistic society is common in Canada, often this does not get translated into operational service delivery. The examples related to the provision of culturally appropriate food and interpretation services are illustrative of this. Kirkham (2003), in her study exploring intergroup relations in health care, notes that "public and political discourse affirms pluralistic society but at the same time resists the demands that articulation of cultural and ethnic differences makes on dominant society" (p.769). She further comments regarding the widespread acceptance among staff in her study of the lack of available interpretation services that [this] "suggests a preference for English and an expectation of linguistic assimilation" (p.772) and:

> when viewed in the contexts of a national history sustained by discourses of "us versus them" that create Other health care discourses of fiscal austerity and crisis and the hegemonic influences of biomedicine, the slow introduction of language services becomes a reflection of the larger linguistic domination of the English language and imperialist Western culture both in Canada and around the globe (p.772).

The findings from this study are also reflective of the expectation of and reliance on ethno-cultural staff, who may be employed as managers, nurses and care aides, etc. to fill the gap in meeting the language needs of ethno-cultural residents.

Despite the increasing diversity in the Canadian population, the rhetoric related to multiculturalism, a pluralist and inclusive society, and continued plans for both economic and family reunification under immigration as well as acceptance of refugees and protected persons (Citizenship and Immigration Canada, 2016), health care institutions to date are struggling to meet the needs of diverse populations. As seen in this study, the struggle is particularly evident in mainstream LTRC facilities which are recently seeing increasing numbers of ethno-cultural residents in their midst. As Kirkham (2003) notes, “health care institutions (along with other fundamental structures of society) have not been transformed to reflect the different groups that make up Canada and thus remain Eurocentric and classist, designed for middle-class, English-speaking Canadians who have Euro-Canadian backgrounds” (p.772). While the policies and practices in LTRC are meant to treat all residents similarly, and any cost cutting measures are thought to impact the residents in the same way, SAOAs in mainstream facilities are differentially impacted. The health authority mandated menu catering to the mainstream population and the absence of flexibility in offering other culturally familiar menu items irrespective of increased numbers of SA residents in a facility differentially impacts SAOAs and their families. They pay the same as everyone else but have to bring food from home so their family members will eat. The cost cutting measures and centralization of formal interpretation services also differentially impacts SAOAs in mainstream facilities who require these services compared to mainstream populations who do not. These are examples of institutional racism. The system has little ability to adapt to difference and accommodates for difference in superficial ways such as serving an inedible Indian component to meals, by offloading services on to SA families, and by relying on the invisible and unpaid work of SA staff.

Long-term residential care facilities are sites where a considerable amount of unpaid work is provided by informal care providers such as volunteers, family members, and students (Baumbusch & Phinney, 2014; Daly & Armstrong, 2016; Lowndes, Daly, & Armstrong, 2018). Examples of this include volunteers and family members assisting residents to eat during mealtimes to students and volunteers assisting with social activities in the facility or visiting one-to-one with residents. The work and contribution of families, volunteers and students as well as privately paid companions to the care of residents are not officially recorded in the LTC facility statistics (Daly, Armstrong, & Lowndes, 2015) and thus their contribution and work remains invisible (Laxer, 2013) even though as these researchers argue, the work they do fills the care gap in publicly funded care. Laxer (2013) also notes the absence of data on paid facility staff who contribute extra time to care in addition to their paid time. I contend that the issues discussed by these researchers also extend to the unseen and unpaid work by SA staff in facilities. While one can observe the unpaid care work of informal care providers such as family, volunteers or private care companions in residential care for example during meal times, it is difficult to measure and account for the hidden and unpaid work done by SA staff in facilities that is outside their role descriptions. In addition to the absence of data on the unpaid labour force that provides care for people in facilities, Daly et al. (2015) note that there is “almost no research documenting informal care in LTCF *unpaid nursing home care* (by family, volunteers or students), or the other wage labour of privately private companions” (p.260). To the researcher’s knowledge, the hidden and unpaid work undertaken by SA staff including expectations of SAOAs and their families for SA staff to solve their problems in the facility has also not been explored to any great degree.

The absence of data and the typical depictions of the labour force, including the failure to map some forms of LTRC work (Laxer, 2013) results in the promotion and maintenance of invisible work in LTRC facilities and serves to keep hidden the gaps in the publicly funded system brought about by austerity measures and neoliberal ideology (Baumbusch & Phinney, 2014; Daly & Armstrong, 2016; Daly et al., 2015; Lowndes et al., 2018). Furrow (1997 as cited in Daly et al., 2015) suggests that private companions paid for by families can be seen as a resource for facilities that can lead to savings (and thus profits) and I suggest the same of the hidden, unaccounted and unpaid work of SA staff in facilities which saves the system money and gives the impression of meeting the needs of SA populations. Lowndes et al. (2018) note that this utilization and reliance on the invisible work of family members, volunteers and students underscores the need for more staff in LTRC facilities. They also argue that there needs to be less reliance on these individuals and on paid companions to augment care provision (p.141), the latter resulting in inequitable care where those who can afford private companions can augment care while those who cannot, do without.

4.6 Conclusions

This paper brings to light the unintentional and differential impact of policies, procedures and processes meant to be equitable on SA older adults and their families in mainstream long-term residential care facilities. It also uncovers the hidden, unaccounted and unpaid work undertaken by SA staff in mainstream facilities including the expectations of SA older adults and families for SA staff to meet their needs. Finally the paper discusses how keeping the work that SA staff do outside of their formal role descriptions, along with other work undertaken by informal care providers, results in perpetuating the use of unpaid care work and serves to meet the neoliberal goals of the system in reducing costs and increasing profits.

With continued plans for immigration according to economic and family reunification goals (Citizenship and Immigration Canada, 2016) as well as data showing that the largest source of family class immigrants is from India (Immigration Refugees and Citizenship Canada, 2017; McLaren, 2006), it can be anticipated that LTRC facilities will continue to see increased numbers of SA older adults utilizing their services. If the system truly wants to provide person-centred and relationship-centred care for the current and expected increase of SA older adults in its LTRC facilities, it is incumbent upon policy makers and service providers to recognize and take account of the gaps in culturally responsive service provision as well as the hidden and unpaid work of SA and other ethno-cultural staff in facilities to fill existing gaps in service.

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Chapter 5: "(Non) Decision Regarding Long-Term Residential Care Placement" South Asian Older Adults' and Family Caregivers' Perspectives Regarding Decision-making about Long-Term Residential Care

5.1 Introduction

Older adults are now living longer than ever before (Lee, Mason, & Cotlear, 2010; McGrew, 2000). As people age, the chances of experiencing health crises, physical disability, cognitive impairment and death all increase and these risks are increasingly compressed and primarily affect those at older ages (Lee et al., 2010). Adult children are the primary source of informal care as older adults age (Fowler & Fisher, 2009; McGrew, 2000). The need for long-term residential care (LTRC)[17] or other intensive forms of care is associated with advanced age (McGrew, 2000) and increased disability and functional impairment measured by limitations in activities of daily living (ADLs) and instrumental activities of daily living (IADLs), with the former indicating more profound limitations (Lee et al., 2010). The probability of any nursing home use is high with estimates in the United States (U.S.) ranging from 35%-64% (Hurd, Michaud, & Rohwedder, 2017; Kemper, Komisar, & Alecxih, 2005). Hurd et al. (2017) predict the lifetime risk of any nursing home use among 57-61 years olds to be 56% and the lifetime risk of nursing home use by females in this age category to be 64%, considerably higher than for males primarily due to the increased life expectancy of women compared to men (Hurd et al., 2017).

Research has shown that thinking about future care needs, along with concrete planning to implement plans for future care, promotes subjective wellbeing among older adults (Pinquart

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[17] In this paper, the term "long-term residential care" (LTRC) is used to refer to care of older adults with complex needs who require 24-hour professional supervision and care in a protective, secure environment. Synonymous terms are residential care, long-term care, care homes, and nursing homes.

& Sörensen, 2002). Yet many older adults and their families do not make such plans (Fowler & Fisher, 2009; McGrew, 2000), resulting in these important decisions being made under pressure at a point of crisis without much input from those affected the most, the older adults themselves (Fowler & Fisher, 2009; McGrew, 2000). Importantly, the negative perception about nursing homes and in the U.S., misperceptions of the costs involved have been found to be deterrents for families and older adults thinking about LTRC as an option for care (Biedenharn & Normoyle, 1991; Speirs, Huang, & Konnert, 2017). Beliefs and assumptions about the role of family members in the care of their significant others and the decision-making process may also influence care discussions (Fitzgerald, Mullavey-O'Byrne, & Clemson, 2001; Fowler & Fisher, 2009).

In many Asian cultures, family structure and sense of responsibility (filial piety), the stigma associated with accessing care, and the availability of culturally responsive care may impact the types of services accessed or not (Bowes & Wilkinson, 2003; Gupta, 2002; Koehn, 2009; Kong, Deatrick, & Evans, 2010; Lai, 2008; Mold, Fitzpatrick, & Roberts, 2005a). Moreover, decision-making around placement in an institution is highly stressful as this decision is often irreversible and brings into question older peoples’ sense of identity, independence and autonomy (Fitzgerald et al., 2001; Mold et al., 2005a). Furthermore, for ethno-cultural minority families, this decision can be even more challenging knowing that most of the existing facilities may not have the cultural and language capacity to meet their family member’s unique needs (Dubois, Dubuc, & Caron, 2009; Gupta, 2002; Koehn, 2001; Lai, 2008; Mold et al., 2005a). Disagreement about what should be done can lead to family conflicts, and if the older adult is not involved in the decision making process it can impact the adjustment and quality of life of the older adult in the new environment (Dubois et al., 2009; Fraher & Coffey, 2011).

Drawing from an ethnographic study examining the needs, preferences and experiences of South Asian older adults (SAOAs) and their families regarding LTRC as well as their decision making about LTRC placement, this paper reports on the findings about how South Asian (SA) families make decisions about LTRC placement and the role of SAOAs in such decisions. The focus is on the SA population given that South Asians (SAs) currently comprise, and may continue to be, the largest visible minority group in Canada and the second largest in British Columbia (Statistics Canada, 2010, 2013, 2016), and as SAOAs age and with continued immigration (Statistics Canada, 2017), the prediction is that there will be increasing numbers of SAOAs in LTRC facilities. Moreover, despite their growing presence in the population, the volume of research on SAs has not kept pace and the diversity among the population is seldom acknowledged leaving gaps in the understanding of their needs (Koehn, Neysmith, Kobayashi, & Khamisa, 2012; Tran, Kaddatz, & Allard, 2005). Understanding how SA families make decisions about placement and the challenges they face may assist care providers in supporting SAOAs and their families during the decision-making process and post-placement period.

5.2 Literature Review

5.2.1 Care and Caregiving in the South Asian Population

The South Asian diaspora in Canada includes immigrants from India, Pakistan, Bangladesh, Nepal, Sri Lanka, Bhutan and the Maldives (Walton-Roberts, 2013). The category of ‘South Asians’ also refers to Indians who have migrated to other parts of the world such as Fiji, Malaysia, Hong Kong, and East Africa (Nayar, 2004). In addition to the diversity in country of origin, there is diversity in the religions practiced, with adherents to Sikhism, Hinduism, Islam, Christianity, and Buddhism amongst other religious traditions (Coward, Hinnells, & Williams, 2000), as well as languages spoken, including Punjabi, Tamil, Urdu, Gujarati, Hindi, and Bengali to mention the most common (Lindsay, 2007; Tran et al., 2005). Duty, respect and honor, rooted in religious beliefs, are widespread traditional values among SAs (Lamb, 2002, 2013; Mehta, 1997; Nayar, 2004). Duty refers to the "fulfillment of one's wide range of responsibilities within the household" (Nayar, 2004, p.51) and is related to respect in that "one shows respect by fulfilling one's duty, and expects respect for having fulfilled one's duty" (Nayar, 2004, p.51). Honor is understood as protecting one's honor at the personal level and the level of the community and is expressed by action in conformance with traditional norms. At the community level, honor is expressed as behaving properly, to save face, be it of the family or the community and there is an "orientation toward behaving in accordance with what others say or will say" (Nayar, 2004, p.166), which traditionally was a means of social control. Fulfilling one's duty and respecting and honouring one's elders is highly regarded in SA cultures (Lamb, 2002, 2013; Mehta, 1997; Nayar, 2004).

The values of duty toward and respect for elders in South Asian cultures is generally operationalized through children providing support and care for their aging parents in later life and is considered a marker of intergenerational reciprocity (Lamb, 2002, 2013; Sharma & Kemp, 2011). A number of modes of exchanges make up this system of intergenerational reciprocity including material support (food, clothing, money, shelter), services of caring (cooking, serving food, cleaning, etc.), sentiments (forms of love coupled with hierarchical respect), and performing key life cycle rituals (Lamb, 2002, 2013). Traditionally, sons and daughters-in-law in a joint family system, (especially the eldest son and his wife), are expected to provide this support to older parents with daughters-in-law typically providing the day-to-day care (Sharma & Kemp, 2011). Daughters generally move out of their natal homes when they marry and take on obligations to their parents-in-law (Lamb, 2002; Sharma & Kemp, 2011).

While the notion of intergenerational reciprocity described above is the ideal, researchers have found variation in how this is enacted in immigrant communities. Blakemore (2000) in his research with SAs in the United Kingdom (UK) questioned the sustainability of Asian patterns of caregiving in immigrant populations noting that:

> …cultural, economic and employment changes are likely to result in the gradual 'Westernization' of family life and patterns of care, especially in the better off Asian communities, though it is also likely that some distinctly 'Asian' attitudes towards the care of older people – mirroring, perhaps, the distinctiveness of other minority ethnic groups' approach to care-giving, such as that of the Jewish community in Britain or the United States (p.140-141).

Further, Burholt and Dobbs (2010) investigated prevailing family values, the provision and receipt of help and emotional closeness among Indian Gujratis and Punjabis, and Bangladeshi Sylhetis living in the UK or South Asia. Their findings showed that there were differences between the SA groups in the extent to which they acculturated, remained separate or enculturated in the host society and that this also had an impact on the caregiving and care receiving norms of each group (Burholt & Dobbs, 2010).

Research from the UK and U.S. has shown a shift in intergenerational exchange expectations in SA immigrant families. Victor et al. (2012) in their research with Pakistani and Bangladeshi older adults in the UK found that while all participants expressed unambiguous expectations that their children would provide care for them in their old age, not all participants were entirely sure that this would become a reality and concerns were expressed about things changing within the SA community with articulated examples of placement of older adults in nursing homes. Victor et al. noted that the family networks of participants were highly dispersed with resultant implications for the provision and receipt of care (Victor, Martin, & Zubair, 2012). Lamb (2002) in her research with Indian American families in the San Francisco/San Jose and Boston areas found that intergenerational exchange expectations in SA families were transformed from an “Indian” to a hybrid “Indo-American” mode of exchange and expectations. She explained that many of the exchanges that her informants felt constituted an “Indian” system of intergenerational reciprocity became halted, reversed, and displaced onto the state in the U.S. (p.309). One example of such a modification was in the realm of transactions of material support. She noted that where older adults had been in the U.S. for a period of time and were eligible for seniors’ services, they used those to support themselves rather than be dependent on their children and that they were averse to being “burdens” on their children (Lamb, 2002). Another example related to the provision of services such as cooking and serving food, tending to household chores, and providing care when older adults became ill. Lamb explained that the perception among Indian older adults in America was that their children did not end up reciprocating such services to their parents (or at least to the extent that the older adults expected and would have liked). Both older adults and their children expressed the main issue to be that the children were too busy working and they did not have the time to provide such services including the intensive care required when an older parent became ill, bedridden, or incontinent. Lamb noted that many older adults themselves, older women in particular, ended up providing the lion’s share of the household labour including childcare, thus not only reversing the expected direction of transactional flows and extending their phase of giving into old age, but also facilitating the external paid work of their daughters or daughters-in-law with the latter also resulting in a reversal of the mother-in-law/daughter-in-law relationship which is the norm in India (p.314). Older adults who ended up needing more extensive care hoped to be able to return to India if they had a remaining relative who could care for them or where the older adult may be able to afford to hire servants, but they worried about not being able to carry out such plans and some ended up in nursing homes (Lamb, 2002).

Sharma and Kemp (2011), in their research on expectations of and experiences with family support among older adults in Atlanta, Georgia, found that SA older adults aligned their expectations of their children with their perceptions of reality and their understandings about what was possible. They referred to this modification in expectations as “individualized filial piety” (Sharma & Kemp, 2011, p.138). Sharma and Kemp found that older adults extended support to their families sometimes in the form of financial support and in the housework that parents did. They also found, in line with Lamb (2002), that older adults who were receiving financial support from the state felt respected by having their own financial resources thereby demonstrating a modification in expectations.

Another example provided by Sharma and Kemp (2011) related to older adults who had both sons and daughters and these older adults brought their daughters into their support networks thus reducing dependence on sons and by association, daughters-in-law. A few older adults in their study also noted that, though not their first choice, if their children were unable to meet their care needs, they would consider formal long-term care including assisted living or nursing homes. Sharma and Kemp found that the older adults in their study attributed any lack in support practices mostly to work practices in the U.S. and to the changing work culture in India (participants identified ongoing social changes in India as a major factor affecting the cultural practices in the U.S.). The researchers noted that the variability seen in how support practices were enacted were on a continuum from continuing with traditional ways to modifying some of the practices and filial expectations and/or abandoning certain practices altogether or some combination of the two (p.138). They further illustrated that the exchange of support between generations was individualized in each family context in response to social change, as well as family and individual influences and that this also illustrated the fluidity of cultural values (Sharma & Kemp, 2011, p.137).

Although shifts in traditional norms of caregiving and elder care are being seen in SA immigrant communities and even in India where there has been a proliferation of for-pay care homes particularly in urban centres (Brijnath, 2012; Lamb, 2013), for many in the community, institutional care for older adults is associated with ambivalence and stigma (Brijnath, 2012; Lamb, 2013). Brijnath (2012) noted in her review of the literature "…such sites are interpreted as symbols of social degeneration, where aged relatives are 'dumped', and love and *seva*[18] (italics in original) commercialized" (p.700). Lamb (2013) noted, "…old age home living is profoundly associated with stigma, shock, and – especially for those with sons – an acute sense of having been thrown away or abandoned by families" (p.72). Such sentiments can impact decision-making related to LTRC in diasporic communities.

5.2.2 Decision-making for Long-term Residential Care

The decision to enter a nursing home is difficult for older adults and their families regardless of ethnic origin as this decision is often irreversible, brings into question the older adult's sense of independence and autonomy (Fitzgerald et al., 2001; Mold, Fitzpatrick, & Roberts, 2005b), results in many discontinuities and is considered to be the most significant relocation affecting older adults' wellbeing (Lee, Woo, & Mackenzie, 2002). Such decisions are not simply made between older adults and their primary caregivers – both are likely to be influenced in their views by siblings, partners, other informal caregivers and formal care providers (Dubois et al., 2009) and, as noted above, by cultural[19] norms and perceptions.

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[18] *Seva* means service and the term is often used to describe care provided to parents in Indian families.

[19] "Cultural" in reference to norms is being used with the understanding that these norms are to a degree rooted in religious beliefs and values.

Fitzgerald et al. (2001) in their cross-cultural study exploring issues associated with nursing home placement in Australia found cross-cultural distinctions related to the reasons for the difficulty in placement decision-making. They found that while the decision-making process of family members took into account the needs of the older adult and others in the family, issues such as role expectations and responsibilities as well as the opinions of social others such as family members and the community may be more critical factors. They noted that for some in the study, the issue was embedded within a personal sense of responsibility and self-opinion and for others it was embedded in a sense of social responsibility and social opinion. Hence, understanding the reasons for the difficulty in the decision to place an older adult in a care facility is important as they influence the kinds of strategies required to help families and older adults make a decision that will meet the needs of all the people involved.

Similarly, Caldwell et al. (2014) in their study comparing caregivers from Chinese and English-speaking backgrounds with regard to the decision-making process for placement of older adults with dementia in nursing homes found that while the decision-making process was similar for both cultural groups, the Chinese caregivers spoke more about their sense of duty, the need for a Chinese specific facility, and declining a place because of family disagreement. They concluded that placing a family member in a nursing home is stressful for all caregivers and that caregivers from ethnic minority groups face additional difficulties that service providers and health care professionals should consider when supporting the decision-making process (Caldwell, Low, & Brodaty, 2014).

Research has shown that the interaction of a range of factors leads to thinking about/decision-making related to nursing home placement. These include declining health and functional ability of the older adult, the inability of family caregivers to manage escalating care needs even when there is community support available, lack of medical knowledge or skills to provide adequate support at home, and insufficient homecare support (Chen, 2015; Kiwi, Hydén, & Antelius, 2018; Sussman & Dupuis, 2012; Tinker & Liu, 2001; Wee et al., 2015; Yeboah, Bowers, & Rolls, 2013). In addition, the availability of family members to provide care due to challenges related to geographic proximity, work, changing attitudes about caregiving (Chen, 2015; Tinker & Liu, 2001; Yeboah et al., 2013), the availability, ease of access, and cost of LTRC services (Speirs et al., 2017; Wee et al., 2015) and awareness and knowledge of such services (Kiwi et al., 2018), all influence decision-making and thinking about LTRC placement. Research has also shown that placement often occurs at a time of distress and crisis related to a change in health status, for example following an acute illness or hospitalization (Fraher & Coffey, 2011; Lee et al., 2002; Tinker & Liu, 2001).

There is a paucity of research on the factors that influence the consideration of nursing home placement for older SAs. Gupta (2002) in her study with a diverse sample of SA households in the Dallas-Fort Worth area found that caregivers who experienced greater role conflict, who were providing care to older adults who had stayed in the U.S. for a longer time, and who were caring for significantly mentally confused older adults, were more likely to consider nursing home placement for their family member. Factors that prevented an older adult from being placed in a nursing home included the caregiver’s level of adherence to cultural norms of filial piety and the older parent’s marital status (as widowed). Gupta also found that SA females were more likely to consider nursing home placement for older family members compared to male caregivers.

Lal (2003) in her study exploring the culture of aging among SA communities in Vancouver, Canada, found that caregivers (as well as older adults) articulated the need to have more long-term care homes for SAOAs. These caregivers worried about the deterioration of their older family members' health and the impact this would have on the type of care they would need in the future. Role conflict, family dynamics, the expectation of women caring for older parents (in law), caregiver burden, being part of the sandwich generation, tension of upholding cultural norms and the reality, and stigma around placement of older parents in LTRC were all concerns influencing placement decisions. Lal noted "[W]hen primary caregivers begin to consider the use of 'outside' services such as long-term care facilities a process of delicate negotiation begins. These decisions tend to be influenced by the availability of the services, the level of endorsement of the option by the family, and the relative authority of the caregiver within the family" (Lal, 2003, p.26).

Andrews (2012) in her investigation of ethnic specific Anglo-Indian residential care homes in Melbourne, Australia and Kolkata found that family caregivers in Australia spoke about their parents needing to be in a home (in this case an ethnic specific facility) because there was no one at home all day to look after them and expressed concern that their parents would have a fall, or just be lonely all day on their own (Andrews, 2012, p.92).

Speirs et al. (2017) in their study examining the perceived probability among young adults in Alberta, Canada, of future caregiving activities such as the probability of becoming a caregiver for their parents or providing assistance in relocating to a nursing home found that Asian or SA participants rated the probability of being a caregiver significantly higher than Caucasian participants, and the probability of placing a parent in a nursing home as significantly lower. They found that filial piety was the strongest predictor of the probability of these life events, and that it mediated the relationship between ethnicity and probability ratings (Speirs et al., 2017). They also noted however, that the probability of placing a parent in a nursing home depends on multiple factors including the availability, affordability and ease of access to nursing home care, as well as structural and socialization variables such as geographic mobility, future jobs and incomes of these potential caregivers, and the impact of acculturation on values such as filial piety (Speirs et al., 2017).

Involving older adults in the decision-making for LTRC placement and providing information about the move to a care home have been found to assist in the transition and adjustment in the setting (Fraher & Coffey, 2011). However, research has shown that older adults are often not involved in the decision to relocate to LTRC or only minimally involved (Fraher & Coffey, 2011; Johnson, Popejoy, & Radina, 2010; Kiwi et al., 2018; Nay, 1995; Tinker & Liu, 2001). The lack of involvement of older adults in the decision-making process among some ethno-cultural groups has been attributed to decision-making being the duty of the family or eldest son with the wellbeing of the older adult a primary concern (Kiwi et al., 2018; Tinker & Liu, 2001). Even when older adults are directly involved in the decision, their participation may be blocked because they are not enabled to fully communicate their concerns and desires regarding their decisions, for instance during discharge planning from hospital (Efraimsson, Sandman, Hydén, & Holritz Rasmussen, 2006; Huby, Stewart, Tierney, & Rogers, 2004). Often there is little agreement between older adults and their informal caregivers for institutionalization (Dubois et al., 2009).

In summary, the literature reviewed indicates that cultural norms of filial piety, intergenerational reciprocity, appropriate family roles and respect for older adults in SA cultural contexts figure significantly in decisions around care and caregiving for aging older adults at home. The review also highlights shifts in expectations for care and caregiving within SA immigrant communities over time, and that social structural factors affect the type of support provided to older family members and the openness among SA families towards extra-familial care such as LTRC facilities.

The decision to place a family member in LTRC is difficult and complex, involving a range of factors that lead to the decision-making or consideration of LTRC placement. Cultural perceptions about LTRC placement can add to the difficulty of such decisions. Involvement of older adults in decision-making regarding LTRC placement has been found to assist in their transition and adjustment in the setting (Fraher & Coffey, 2011). Yet, older adults are often not involved in the process.

In light of the above, and the importance of future care planning for older adults, this paper aims to provide insights into how SA families make decisions about LTRC and the role of the older adult in the decision-making process. The paper also examines factors that lead to the consideration of LTRC as a care option in SA families.

5.3 Study Design and Methods

This analysis is part of a larger ethnographic study that, through a critical theoretical perspective, aimed to explore the needs, preferences and challenges of SAOAs and their families regarding LTRC, as well as how SA families make decisions about LTRC placement and the role of the older adult in the decision-making process. Data were collected using the ethnographic methods of in-depth qualitative interviews, participant observation and document review. For the purpose of this paper, the analysis is based on interviews conducted with SAOAs residing in LTRC, in assisted living and those living at home in the community and their family caregivers. Findings from the participant observations of SAOAs in LTRC are not included in this analysis as these observations were focused on understanding the situation of SAOAs in the facility post decision-making and placement.

Ethnographic methods enable researchers to qualitatively explore the beliefs, language, behavior and issues facing a particular group (Creswell, 2013), as well as explore aspects of the lives of the people who are being studied, including finding out how these people view the situations they face (Hammersley & Atkinson, 2007). Ethnography also reveals how people are situated within a cultural context (Holloway & Todres, 2003). Ethnographers employing critical perspectives aim to uncover how larger social processes shape the lives of individuals. Their objective is to generate knowledge that helps audiences to understand how taken for granted assumptions can serve to further marginalize or oppress disadvantaged groups with a view to improving social justice (Creswell, 2013; Kincheloe & McLaren, 1994; Koro-Ljungberg & Greckhamer, 2005; Mantzoukas, 2012; Norander, 2017; O'Reilly, 2009).

Interviews are an important source of data in ethnographic and other research methodologies (Creswell, 2013; Hammersley & Atkinson, 2007; Mason, 2002). They allow the researcher to gather information that may be very difficult to obtain otherwise – both about events described and about perspectives and discursive strategies (Hammersley & Atkinson, 2007). In-depth interviews offer the opportunity to gain information about events beyond those the researcher has direct access to. Furthermore, since in-depth interviews can be structured according to the research objectives, it is possible to collect similar information from many participants (Lofland, Snow, Anderson, & Lofland, 2006).

5.3.1 Sample and Recruitment

The study sample was comprised of 18 South Asian older adult (SAOA)-family caregiver dyads purposively recruited from two LTRC facilities, an assisted living facility, and from the South Asian community at large. Seven key informants were also recruited including managers, clinical nurse specialists, social workers, and recreation coordinators from LTRC as well as individuals from the SA community at large and researchers with knowledge of the SA population through their work with the community. The criteria for recruitment of SAOAs included: 1) being aged 65+ years; 2) being of South Asian descent; 3) currently residing in a LTC facility or contemplating placement in a LTC facility (recruited from Assisted Living or the SA community at large); and 4) having a family caregiver who also agrees to participate. The 18 older adults ranged in age from 68 to 94 years and 12 were female. Fifty-six percent (n=10) of older adults respectively were from India and were Sikh, reflecting the large settlement of this religious group in B.C. The majority of older adults spoke little or no English (n=10). The median number of years in Canada was 38 years, ranging from 8 to 52 years. One half of the older adults had less than High School education and two older adults had university level education (Master's Degree from India) (see Table 1).

Of the family caregivers, 15 were female and the majority were daughters, granddaughters or great granddaughters (see Table 1). Of the three male family caregivers, two were sons and one a spouse. The family caregivers ranged in age from 20 to 86 years with a median age of 54.5 years. A large majority were fluent in English (89%) and 78% were educated at the college diploma level or higher. Twelve family caregivers were employed, one was a homemaker and five were retired.

Key informants were purposively recruited from LTRC based on their clinical role and their experience with the transition, integration and/or care of SAOAs living in LTC as well as from the project advisory committee based on their knowledge of the SA community at large either as a member of the community or through their work with the SA community.

Following ethics approval from the Research Ethics Board at the University of Victoria and the regional health authority involved, LTRC and assisted living facility managers helped to distribute study information letters prepared in English, Punjabi and Hindi to SAOAs in their facilities. Interested older adults and family caregivers contacted the researcher or the multilingual research assistant directly. SAOA-family caregiver dyads from the SA community at large were recruited with the assistance of the advisory committee members for the study. The committee provided linkages to the community through their networks. Information sessions were conducted with various older adult groups in the community and those who were interested in participating in the study contacted the researcher or the research assistant directly. Key informants were invited to participate in a key informant interview via email and contacted the researcher directly to confirm their interest.

5.3.2 Data Collection

Data were collected from March 2014 to May 2016 using multiple data sources that included in-depth qualitative interviews, reviews of provincial policies, residential care regulation and other documents prepared by the health authority and LTRC facilities, and 220 hours of observational fieldwork in two LTRC facilities. To facilitate data management, all interviews and field notes were entered into NVivo software, a computerized software program designed to assist with management and organization of qualitative data (Bazeley & Jackson, 2013).

Semi-structured, in-depth interviews were conducted with 18 SAOAs, 18 family caregivers and seven key informants. The interviews with SAOAs in LTRC required multiple visits to complete because many became tired during the interview or were not well. One family caregiver required two visits to complete the interview because she had only short timeframes available and thus required a second visit to complete the interview. Eight older adults and three family caregivers required the interviews to be carried out in Punjabi or Hindi and thus were conducted by a South Asian multilingual research assistant with the researcher present. Ranging from 20 to 103 minutes, the majority of interviews were recorded and transcribed. Interviews conducted in Punjabi or Hindi were simultaneously translated and transcribed. Where SAOAs or family caregivers did not feel comfortable with the interviews being recorded, handwritten notes were taken during the interviews. Field notes were written after all interviews.

The interviews were conducted using a semi-structured interview guide which included open-ended questions to explore details in depth, and which enabled individual perspectives and experiences to emerge while also helping to keep interactions focused and facilitating some structure in the interview. The interviews with SAOAs and family caregivers (the focus of this paper) were conducted separately to enable them to speak freely. Topics covered included, but were not limited to, the older adult's living situation prior to institutionalization or current if in the community, reasons for the move to LTRC or consideration of LTRC, how the decision was made or would be made to move to LTRC, who was or would be involved in the decision-making process regarding institutionalization, and the experiences of older adults who are currently in LTRC or what might be of concern if older adults were to move to LTRC.

5.3.3 Data Analysis

Data were analyzed using the constant comparative method (Boeije, 2002) which involves comparison of themes within and between groups of study participants. Each interview transcript was read several times to obtain an understanding of the general ideas expressed by the participants with regards to the research questions. Each transcript was then coded by comparing passages within the transcript, resulting in provisional codes/categories. This process was followed for all interviews and field notes. The next step involved comparing between interviews of the same group, e.g., older adults, to identify higher level themes, followed by comparison of interviews from different groups, e.g., interviews with older adults and those with family caregivers. The latter step was aimed at deepening the insights and completing the information about the group of older adults that has been the focus of interest. This process was multi-layered and enabled exploration and understanding of individual experiences of older adults and family caregivers and comparison within and between groups in a systematic way. A critical theoretical perspective was applied to the findings to explicate how larger social processes influenced the decision for or consideration of LTRC. In reviewing the findings, commonly held values and assumptions were interrogated with a view to understanding how these may influence LTRC service provision for SAOAs and SAOAs' role in decision-making for LTRC.

The documents collected for this study were reviewed and then critically examined, paying particular attention to the language used and how dominant ideologies were reproduced in the text. A brief summary of each document was written, coded and these coded sections were included in the overall analysis. A critical analysis of the texts contributed to the development of theoretical arguments and to the analysis of the broader context of the study.

5.4 Findings

The findings from interviews with SAOAs and family members are presented in the overarching theme of "(Non) Decision Regarding Long-Term Residential Care" and sub-themes of "Power and Agency in Family Negotiations of LTRC", "Negotiation of Knowledges" and "Social Political Context". The "(non)" preceding "decision" in the overarching theme opens up the space to illustrate that the decision to move to a LTRC facility may not be a 'decision' at all. Instead, the 'decision' may be triggered by a range of factors that interact to *necessitate* the move to LTRC thereby rendering it a (non) decision. In the context of the overarching theme of (non) decision, the sub-themes illuminate the complexity of LTRC placement for SAOAs and their families and explicate the factors that influence the necessity for consideration of or a move to LTRC.

5.4.1 (Non) Decision Regarding Long-term Residential Care

"(Non) Decision Regarding Long-term Residential Care" was the overarching theme that emerged from the analysis of interviews with SAOAs and their family caregivers. SAOAs residing in LTRC and assisted living felt that they had no choice or option about the move to LTRC and no say in the decision to move. Either their children told them that they needed to move to a care home or a health care provider said they needed to move.

The family caregivers of SAOAs in residential care and assisted living also felt that they had no choice about placing their family members in LTRC. The family caregivers of older adults in LTRC could no longer manage the care of their family member at home and had to place their family member in LTRC. The family caregivers of older adults in assisted living also reported not having much choice in the decision if the assisted living facility could no longer care for their family member and made the decision that the older adult needed to move to LTRC.

In contrast to older adults living in LTRC and in assisted living, community-dwelling older adults were thinking about LTRC as an option for care in the future and hoped to be able to make the decision when the time came. By thinking about LTRC as a future care option now, these older adults hoped to maintain their power and agency in the future.

The family caregivers of community-dwelling older adults while thinking about the potential need for their older family members for LTRC in the future also saw it as a last option particularly if they were adult child caregivers.

The decision to place older adults in LTRC is influenced by many factors that interact to necessitate the move including socio-economic status and particularly the economic resources of the family which impacts the decision to place as well as to access other options. The availability of, access to and level of community-based care as well as other supports, also influences placement decisions.

Power and Agency in Family Negotiations Regarding LTRC Placement

South Asian older adults residing in LTRC felt that they had no choice or option about the move to LTC and little or no say regarding the decision to move. Chann[20], an 89-year-old female says "…[In this country] if one is unwell, even if a little bit, one is thrown into the hospital [referring to the facility she is in]" and 71-year-old Dana when asked whether she had ever thought about what it might be like for her if she had to move to a care home said, "No. I had to do it. It happened I had to come. No choice in life." When Jasmeet, a 79-year-old female was asked why she moved to the LTC facility she responded, "My family big, because everybody working and uh nobody care me. Because I want somebody care me. My daughter she say you so much care here."

Regarding the decision to move to LTRC, Mansukh, an 85-year-old male, when asked whether he had any involvement in the decision to move to the care home replied, "Well I was told that I cannot be looked after at home. This is proper residential place." When Gurjit, a 94-year-old female, was asked how she came to be in the care home she replied, "The doctor had given something. He gave his consent that I should come here. It was not so easy to adjust here." Even when an older adult indicated that they had been involved in or consulted about the decision to move to LTRC, they seemed to have acquiesced to the family as seen in the interview excerpt below with Jasmeet:

> SRJ: So Mrs. (name) how did you decide to come here? How did you decide? Did somebody help you to make the decision to move here?

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[20] Pseudonyms have been used to protect the anonymity of study participants.

> Jasmeet: Myself.
>
> SRJ: You made the decision yourself?
>
> Jasmeet: No, because my daughter, my whole family she say ‘you okay? you okay?’ I say okay. I be anytime go back. We already happy here.

The SAOAs in LTRC noted being sick and needing care and the inability of their children to look after them because they work as reasons for LTRC placement. Some older adults noted that a health care provider said they needed to be in care. The older adults residing in LTRC seemed to lack power and agency in the decision to move, whether it was the family who decided they needed to move because they could not be cared for at home or a health care provider suggested the move.

Discussions with the family caregivers of SAOAs in LTRC also indicated that the older adults did not have much say in the decision to move to LTRC. All the SAOAs in LTRC lived with their family caregivers prior to LTRC placement. In most cases, the need for the move to LTRC was raised by the family caregiver him/herself or the children together after a discussion with the family caregiver; the decision was difficult for the caregiver and household, and was often accompanied by feelings of guilt. In some cases, not all family members were supportive of the decision. The older adult in most cases had no choice or say about the decision. In the excerpt below, Priya explained how the decision was made to move her mother to LTRC:

> Well I talked to my sisters and they know how hard it was for me. I said you know I just can’t do it anymore. This is not working. I can’t do it anymore and we can’t even share all of the responsibility because it’s not everyone’s - one’s in (name of city in Northern BC), one’s in (name of city on Vancouver Island) - I said it’s not like we’re in the same town we could help a little bit. I said so I really don’t care what it costs now at this point this is it (half laugh). We need to do something. And my one sister is pretty supportive, the other one’s not as much but this one is and she said yes of course we have to place her we have to do whatever we have to do. So I told her I said “mom this is what we have to do if you come home this is the scenarios could happen, this is what’s gonna happen and you need to I need you to be safe so I can work properly.” Um so (emotional, crying we take a pause I hand over the box of tissue) (while still emotional) because even at work I couldn’t concentrate cause then she’d call me and uh she’d phone and she says well I

> can’t she’s saying a bunch of stuff at work and I’m like well what do you want me to do I can’t leave I can’t just leave like that so that was kind of hard you get a phone call and go in the back and it’s like oh my god okay. So anyways yeah so that was (still emotional but talking) it I said “you need to go to a place, you need to go for me, the family and for yourself. We have to go there.”

While family caregivers told the older adults that they could no longer be cared for at home and had to move to a care home, and thus seemingly held the power regarding making the placement decision, family caregivers also felt that they had no choice about placing their family members in LTC facilities. The decision to move their family member to residential care occurred only after they could no longer manage their family member’s care needs at home and as a last resort when other options considered were not feasible. Some family caregivers mentioned that there was stigma associated with LTRC placement in the SA community and said that they could not care for their older adult at home and had no choice about placement. Aarav, the son of a 72-year-old male in LTRC noted:

> It is indeed hard. But we have no choice. He is very advanced in years and everyone works. I too am working. Also is my wife. Kids go to school. Mom she’s a heart patient and she got the bypass surgery. So she cannot handle. Hard to take him to washroom, take a shower; right. It is hard…I know mostly it is not liked in the South Asian community to be put in a senior home. It is considered to be a taboo that your parents are in day care. I know people don’t like it but this system is good. We can’t handle at home. So it is the best option to put them in the senior home.

Family caregivers cited many factors that precipitated the decision-making for and move to LTRC including the deteriorating health and functional ability of the older adult, progressively increasing care needs of the older adult including after hospitalization, the complexity and intensity of the care required, and the inability of the family caregiver to cope with the increasing needs. Amanjot, the daughter of a 79-year-old female in a LTC facility, described the multiple health issues and needs of her mother and her inability to continue to meet those needs which led her to think about placement in residential care:

> Well her care at home it was getting to the point where it was too much just to give her all her needs and the proper care she needed at home. It was starting to you know we thought about a live-in caregiver but she kind of needed things day and night because her health was - there wasn't any consistency. She had many things going on – um she suffers from anxiety when her health, her medical issues were on the rise and she had many; she suffers from rheumatoid arthritis so that would go into many different types of problems because she's had it for so long, we're talking; she also suffers from she would get mouth ulcers, she would bleed out of her nose – that would cause her extreme (emphasize extreme) anxiety; not being able to and then her foot was is very damaged from her arthritis not being able to get up and go to the washroom which she goes to the washroom many times at night, bed wetting, forgetfulness, she has vascular dementia, still wanting the desire of trying to do things on her own but it was becoming dangerous at home – falls, breaking things, not understanding that certain things she did caused her danger. A wide spectrum of things were happening and it was getting to the point where it no longer was healthy for her that situation and as well as I wasn't able to manage all the needs that were coming at me very quickly…it was escalating and it had been for a while. You know it felt it was manageable few years prior but the last year was a real struggle.

In addition, most of the family caregivers were employed, had their own families and constraints; some were aging themselves and had health issues which also made it challenging to care for their older adult at home. In many cases, other family members were not available or able to provide care and support and all of the family caregivers noted that the homecare support hours that they may have been offered or had was insufficient to meet the needs of their family members. Further, some family caregivers also spoke about the costs of private homecare being prohibitive and thus contributed to the consideration for LTRC support. Priya, introduced earlier, a single mother employed full-time in a job requiring shiftwork and whose mother is significantly visually impaired and moved to residential care after hospitalization, explained the challenges she faced in caring for her mother at home, the reasons for the move to a facility and her concern about how she would cope if her mother had been sent home after her hospitalization. Priya's situation illustrates how in addition to the increasing care needs of her mother, the intersection of family formation (single motherhood) and low income/ precarious employment influenced her ability to care for her mother and was a significant factor in the decision-making process:

> Because I was full time and I work days and evenings and my son is here he helped when he was here but uh in the morning like she (referring to her mother) had her own routine where she likes to sleep till 10 or whatever right. I'm at work, my son's at school, there's nobody here…She can't pour a glass of water or anything and she can't find anything in the fridge and she can't turn the stove on like there's nothing so I used to make the breakfast ahead of time…I set up her breakfast and then I'd set up her lunch and her drinks during the day and everything would be sitting here [referring to the dining table]. So she would come up and feel around and she'd know everything was there…That worked for a while and then but she was alone all day …And then the safety concern. Um going up and down stairs. That was a concern as well. And then not only that, she's got glaucoma so the medication how could we put all the drops in every day. You know there is breakfast, lunch, supper you know so many drops. That's impossible she can't do it herself and I was not able to put them all in so she might get maybe twice a day instead of the recommended drops right. …[Then in the hospital] the physios also doing their assessment, the OTs doing their, everyone's doing their assessments but they're all thinking that she can go home. At that time they all think that she can go home. And I'm the one getting worried like how I'm going to manage her because for one thing she didn't have the I knew she used to have some accidents where she'd wet everything…so I was a little bit worried that you know how am I going to take care of that if anything happens during the day, what's going to happen to her because I can't stop my job here. Um so I was worried about that part…

In the situation with Priya, as with others in the study, the older adults' children were geographically dispersed which also influenced decision-making for LTC placement.

The discussion with the family caregivers of older adults in LTRC illustrates that factors related to the older adult him/herself and social structural factors including the availability and feasibility of other options and supports influenced family caregivers' decisions to place their family members in to care. These structural constraints on family caregivers' choice hence complicate simple understandings about the individual power of the family caregiver in placement decisions.

In contrast to older adults living in LTRC who felt they had no choice or option about the move to LTC and little or no say, the community-dwelling older adults were thinking about LTRC as an option for care in the future and some requested information about LTRC from the researcher. One older adult was actively exploring facilities. Most of these older adults hoped to be able to make the decision to move to LTC or at least be involved in making the decision when the time came. As 68-year-old Jisha said:

> I am not sure if the decision would be mine or my children's but I hope it would be my decision um or if I am not able to care for myself and think for myself or know what's happening then they'll have to make the decision I guess for me….Yeah I think it would be basically my three daughters and maybe you know their spouses. They would probably besides me who would make that decision. …I would like them to be involved… I would consult with them, I would discuss with them, and if I decide that I should move into a long term care I would like to have their okay or if they are deciding to put me in a long term care I would like to know why (laughs), yeah.

The community-dwelling older adults articulated numerous reasons for thinking about LTRC as a care option in the future including that they are aging, the unpredictability of one's health and the future, the busy working and family lives of their children and that their children cannot quit their jobs to look after them, and that they did not want to be a burden for their children or have their children sacrifice their lives for them. In addition, for some older adults, their children did not live in the same city as them which led to them considering other care options and one older adult spoke emotionally about how her daughter had indicated to her that she should not depend on her for care. The experiences of others in their networks also prompted thinking about their own care in the future. Gurshant, a 77-year-old female spoke about how her children help her now but she is not sure if they will be able to in the future if her health deteriorates and the reason she is thinking about LTRC:

> Gurshant: Till today my children help me, I can't say whether they help me tomorrow.
>
> Jatinder: Have you thought to go to LTC facility?
>
> Gurshant: I don't know, if I fall sick tomorrow I may go. I can, if I fall sick and children can't look after, they cannot leave job. I can't guarantee. Nobody can guarantee life, you also know.

Jisha, introduced earlier, while speaking about the uncertainty of her health in the future and what would happen if she needed care, also explained in the interview excerpt below, that the experience with the care of her parents, the family dynamics involved and not wanting her children to sacrifice their lives were other reasons for her considering LTRC as an option in the future:

> Hmm, a good question. What's causing me to think about that is seeing my parents. You know my dad had lung cancer and my mother has Parkinson's disease and they are in (name of country) and able to afford several caregivers. So they are in the home with immediate family actually, my brother, his wife and I have another brother who also lives in the same city and his wife and the grand children who are also grown up now, they have their family there and still the feeling of loneliness, still the feeling of insecurity, still the feeling of fear to ask anything in case you know, you upset their feelings. Even with the caregivers you know uh so I felt that I don't want to put my children through that over here. Maybe the long term care facility would be the answer. I would be very happy to move to a long term care facility uh to avoid so that my children don't have to sacrifice their lives for me. Their quality of life for they are living uh with their families.

Though not articulated, it seems that Jisha also did not want to put herself in similar family dynamics with her own children that her parents experienced and wanted to maintain her power and agency into the future.

Jaspinder, a 78-year-old female with multiple chronic conditions who was having difficulty managing her daily activities and who had been actively exploring private retirement facilities, when asked about who would be involved in the decision for her to move to a care home, emotionally spoke about not being able to depend on her daughter for care:

> First it would be us [referring to her husband and herself], but my daughter is already suggesting me to move to the facility, so that means she is telling me that she won't be able to help me …she is already giving the indication that you better make some plan, don't depend on me… it to tell you the truth, it really hurts me (getting emotional, heavy voice) … Even sometimes (speaking with quivering voice) when I had all this cancer and all this open heart surgery and sometimes she used to say I can't take you to the doctor, you better talk to your son (emotional, softly crying).

In considering LTRC as an option for care in the future, community-dwelling older adults articulated both personal and external factors that could influence the need for their move into LTRC and were actively engaged in the decision-making at this time. Consideration and exploration of LTRC as a future care option may also be an attempt to maintain power and agency in the future when such decisions may be required.

The family caregivers of community-dwelling older adults had thought about LTRC for their family member as a potential option in the future for a variety of reasons. The family caregivers varied in their thinking about LTRC placement for their older family members depending on whether they were children or spouses. Adult child family caregivers often evoked cultural norms of not putting family members in residential care, said that LTRC placement would not be their preference and generally viewed LTRC as a last option when other care options were tried or exhausted. Alka, the daughter of a community-dwelling older adult, when speaking about how the decision would be made if her mother needed to be moved to a LTC facility, said that she would rather move her mother to her home in a different province than move her to a LTC facility. Further, Alka stated that if she was not able to care for her at home because of work, she would bring in private care, reflecting her ability to afford private care to supplement any publically funded care/support and indicating that LTRC would be a last resort after other options had been tried:

> And more than likely to be really honest with you, depending on what it was, we would bring her to (name of city in Alberta) um because I just can't even really imagine it. Like if, that's the other thing that it boils down to is that if my mom was unwell, I think probably what would work better for us is to bring her to our home and if my work didn't allow me to care for her in the home then we would hire a caregiver, you know.

Yet, some of the same caregivers also spoke about not wanting to be full time caregivers for their parent. For instance when Nitu was asked whether she had ever thought about her mother moving to a LTRC facility, she replied:

> I have thought about it. If it came to that it wouldn't be my preference; I don't think it would be her preference either, but it's a conversation I should probably have with her. Um I don't, you know I have thought about it…but I gotta tell you that I would much prefer her to stay at home and have the care come to her than her being in somebody else's facility. Culturally speaking, it's not what we do; it's just not what we do. I mean

> that's not been my experience. When I think about my grandparents they were cared for at home, they are cared for at home, my grandmother, my surviving grandmother is cared for at home. Not one person has gone to a long-term care facility to receive care. It does present a challenge because it means affording care at home though culturally this would be you know the most appropriate fit. I mean if I wanted to be honest about that, culturally speaking all this should you know sort of, we would have a better way of managing her care between us as an extended family network, but I don't think we're gonna manage that too well because we're a small family unit…if my mom's health required more professional attention then we could provide her at home or that a visiting nurse could provide her at home then we'd have to think about a long-term care facility simply to make sure that she is getting the best care.

Nitu evoked the cultural values regarding care and caregiving for SA older adults but then noted the challenges to upholding those norms such as the affordability of in-home care and that her family was a small nuclear family which would impact their ability to meet her mother's potential future care needs. Later in the interview, Nitu elaborated about her availability and willingness to care for her mother if she needed more care:

> …and when it comes to my availability unless I move there I'm not in a position to care for her in a substantial way and as much as I would like to, I also don't want to. I mean I don't want to I don't have it in me to be a nine-to you know like a twenty-four hour care person for her. Emotionally, I don't have it in me to do that and you know professionally, I don't have it in me, I don't have the skills that she would need to take care of her. That's the challenge.

In contrast to adult child family caregivers, family caregivers who were spouses did not evoke cultural norms. They spoke about the reasons that they would seek placement and how the decision would be made. For instance, Meeta spoke about the fact that she was aging and worried that she may not be able to look after her husband if he became ill and that her children are all busy and have little availability to assist:

> JD: what do you think, why, because of what reasons you will take him there (LTRC)?
>
> Meeta: Because I will get old and I will not be able to take care of him health wise then he has to go [to nursing home]… even I can't drive, because I didn't learn. He takes me to hospital whenever there is need but I can't take because I don't know car and children don't have time.

When it came to decision-making about placement, Meeta said that she would speak to the children and ask them what to do:

> I will also discuss with children, discuss with children that I can't do, you don't have time and my children, one daughter lives in (city in Ontario) my one son lives in (city in U.S.), my one son is here. He is very busy with his children, very busy in his work, discuss with all children that I can't do you tell how to do, where to send him.

The family caregivers of community-dwelling older adults articulated social structural factors that would impact their ability to provide care for their family member at home and which would influence any decision for LTRC placement. The family's ability to afford other options that could support upholding cultural norms of caregiving was also discussed. Social structural factors may mitigate any power that family caregivers are thought to have in the placement decision. In light of this, family caregivers of community-dwelling older adults may in fact hope that their family members have the agency (implicit in this is consideration of financial resources) to make their own care decisions in the future.

Negotiation of Knowledges

When health care providers suggest LTRC as an option for care, as seen with some SAOAs in residential care, or the decision to place an older adult in residential care is made by health care providers, as in the case of older adults residing in assisted living, the question of negotiating these decisions or shared decision-making arise. The findings indicate that these negotiations regarding placement happen in the space of (non) decision and reflect an asymmetry of power, agency and knowledges between health care providers and SA families/older adults.

As noted earlier, for the majority of SAOAs in LTRC, the need for the move was raised by the family caregiver him/herself or the children together after a discussion with the family caregiver. In two cases, health care providers in the hospital suggested residential care as an option. In these cases, the SAOAs felt they had no choice or option and no say in the decision to move. The family was able to explain the reason for placement as professionally driven which may have eased the guilt of the family somewhat while simultaneously being perceived as not having a choice. This is illustrated by the following discussion with Kavita who was told in the hospital that her mother had lost her memory and was not capable of being left alone at any point in time:

> …one day she (mother) is waiting for the bus stop then she fell down then they you know somebody call to the ambulance they take to the hospital then ah they find she is lost little bit memory well not that much just may be 10% she lost the memory otherwise she is very good…I feel so bad she have to stay there [i.e. LTRC] because I am not home that's why. We have to have somebody stay with her even (clears throat) all day time then is good, right. The night time is no problem then I am coming around 10 – 11 clock (clears throat) to home…No I know she is lost memory only 10%, 5% otherwise memory is very good but then because social worker there said 'no she lost all the memory' then we don't have choice to send her (to LTRC)…otherwise someone, that time my husband is not that great to take care for her right…then we can't do. My brother he goes out then he doesn't know what time he comes home and I can't depend on him – just only me and my children that's it right then that very hard.

The discussion with Kavita illustrates how the health care provider's perceived scientific knowledge / expertise offsets the cultural knowledge of families and gives authority to the decision-making which translates into a lack of power and choice for the family regarding LTRC placement. However, the suggestion of LTRC placement by a healthcare provider can also be helpful when families can no longer manage the care of their family member or when other circumstances make it challenging to care for their older family member at home. As seen in the excerpt above, Kavita, while stating that the family had no choice about sending her mother to LTRC because the social worker said she needed to be in LTC, she also speaks about how her husband was not supportive of having his mother-in-law cared for in his home and that her brother could not be depended upon to care for their mother. Hence the social worker suggesting LTRC placement may have provided an "out" for the family in terms of explaining the placement as professionally driven rather than due to family dynamics and inability of the family to provide the care needed thus saving face.

Similarly to older adults in LTRC who felt they had no choice when a health care provider said they needed to go to LTC, the older adults residing in assisted living were aware at some level that if their health deteriorated, the assisted living facility would send them to LTRC and that they would have no choice. They knew that this had happened to others. The excerpt from a conversation with Saanvi, an 83-year-old female illustrates this point. The excerpt also illustrates how Saanvi, in the space of (non) decision, evokes God’s will as a way to cope with such a situation should it arise:

> Interviewer: Do you have any problems with the kind of care that you get here? Do you worry about anything that if you have more (health) problem, how would that be taken care of here?
>
> Saanvi: If the condition aggravates, these people won’t keep me here. They will send me to another place.
>
> Interviewer and PhD candidate: Long-term care?
>
> Saanvi: Yes, long-term care.
>
> Interviewer: In case you are required to move to long-term care, what do you think about that?
>
> Saanvi: I haven’t thought about that.
>
> Interviewer: Does the thought bother you? Do you get worried about how you would go there?
>
> Saanvi: We’ll see when the situation arises. I leave it to God. Who knows what is in store. There is no certainty about life. When the long-term care (facility) is ready, maybe I would be shifted there (referring to a South Asian LTC facility being fundraised for by the Umbrella organization running the assisted living facility).
>
> Interviewer: Since these people would take some time to build the LTC, if you need to get into LTC, what do you think about going to any other facility?
>
> Saanvi: They would shift me to another one. There is another one somewhere…Many other residents have also gone there from this facility. Many have also gone to God’s abode.

The references by Saanvi to God's will juxtaposition the influence of professional knowledge by healthcare professionals with divine knowledge, where it may be easier to acquiesce to the change if it is seen as in the hands of God.

The older adults in assisted living had no choice or power to change the decision to move to LTRC if the assisted living facility could no longer provide the care that they required. These older adults exercised agency by trying to stay healthy while in the assisted living facility to avoid the need to move to LTRC. Saanvi notes this later in the interview when she is discussing a fundraising event for a SA ethno-specific LTRC facility that she attended which was organized by the operators of the assisted living facility:

> … I didn't eat much. I didn't even go to get it [i.e. food]…said that I might fall down, we went and got from the fridge samosa etc. but I didn't eat. I don't eat these sort of things. Exercises are conducted for five days for us here [i.e. at assisted living]. He (exercise instructor) advises us not to eat oily food and says that salad, cucumber would be beneficial. If I don't follow his advice, I would face problems later. When I go for shopping, I bring all such stuff, fruit etc. They also give some fruit here but I bring my own also like papaya. I like all this.

The family caregivers of older adults in assisted living were aware that the assisted living facility would decide if there was a need to place their family member in residential care and that the older adult and family would not have much choice in the matter. Yasmin, whose 83-year-old father is in assisted living, described how the decision would be made to move her father to LTRC:

> Uh as far as (name of AL) is concerned, it's the nurse over there that makes the decision that the client has to move to long-term care. If the client needs more than half an hour of the allocated nursing time, there are more needs than they can they are funded for. And once the administration decides he has to move, he has to move, there's no choice. The family's left without a choice in that… At this point in time, I don't think the family would have much of a choice. The only choices would be to accept whatever was available at the time or to bring him home.

Many of the family caregivers hoped that the day would never come when such a decision needed to be made for their family member. Sunita, whose 72-year-old mother is in assisted living, articulated the difficulty she would have and the reasons for the difficulty in making the decision for her mother to move to LTRC from the assisted living facility:

> From here to a nursing home, oh my. (Deep breath). I don't know, she has her mind, you know, I don't know if I'll ever be able to put her in a care home. You know, it's going to be very not easy, you know um. It's not going to be easy for me…it's gonna be hard for her because we don't have any East Indian care homes. I've seen people in a care home; I have a guy right now and he's always isolated because nobody talks to him, he might say a few words, but the most hard things are the food, you know it's always Western food, they're not going to make one Indian food, right? And culture wise it will be very hard for her because even though she is a bit Western, she's not Western. So those are the things will be very difficult for me to even prepare her… It will be a very, very hard decision to make and if she is ever there, it won't be easy. It will not be easy (each word punctuated).

Sunita then expressed her hope that such a decision would not be needed to be made and explained the impact it would have on her if the decision was needed and the option she would consider:

> I wish that day never come to tell you the truth. I wish this, this is fine, I never worry about it, but I will be stressed out and keep her at home. I've already thought about it. Me and my sister have talked about it, didn't say anything to her (mom). But as I said, I hope the day don't come. As us people, you know like all these people who have elderly people all worry about things like that. We do talk, yeah.

Sunita's reaction regarding not having an ethno-cultural specific LTRC facility for the South Asian population was not unique. Even the older adults who resided in the assisted living facility hoped that if they had to go to LTRC that they would go to one that was like the assisted living facility they were in which catered to the South Asian population.

Like the family members of some SAOAs in LTRC who felt they were powerless and had no choice when a health care provider suggested the move to residential care, family caregivers of SAOAs in assisted living also felt powerless regarding the decision made by the assisted living provider for their family member to move to LTRC. The asymmetry in power and knowledges between health care provider and family is also observed in this instance. The health care provider's scientific /technical knowledge and policy regarding the level of care that can be provided in assisted living offsets the family's desire for a cultural-specific facility which would at least make the move to LTRC for their family member more tolerable. Some family caregivers spoke about other options they would consider before sending their family member to LTRC if the assisted living facility made the decision that it could no longer care for their family member. As seen above, Sunita said that she would consider keeping her mother at home with her and Yasmin, when discussing how her father might cope with a move to LTRC if it was required, said that she would try to supplement the care in the assisted living facility with private support in order to keep her father in the assisted living facility:

> I don't know but historically what had happened is there's been some of his friends that have moved uh and they've not lived for more than three months. So I don't know. It would be very hard for me to predict. But for me if it really came down to it, I would try and privately fund as much support as he needed to stay at (name of AL) as long as (name of AL) was agreeable.

In summary, when a health care provider suggested a move to LTRC or made the decision that an older adult could no longer be cared for in assisted living, SAOAs and their families felt they had no choice or option about the placement decision. The health care provider's expert knowledge and authority translated into no choice and a lack of power in the decision-making for families and older adults. Families exercised agency on behalf of their older family members by considering and exploring other options. Meanwhile, older adults in assisted living worked to remain healthy in order to avoid a move to LTRC. In some cases, the health care provider's suggestion of LTRC placement may have served as an "out" for families in terms of making the decision and referencing God's will also became a way to soften the placement decision.

Social Political Context

As seen from the findings shared above, when discussing how the decision was made or would be made for LTRC placement, SAOAs and their family caregivers cited the deteriorating health and functional ability of the older adult, the inability of family caregivers to manage care needs, as well as external factors in the social political environment that impacted or would impact placement decision-making. These external factors not only affected the decision about placement but also consideration of other options that could defer placement.

Both older adults and family caregivers noted work as a reason for the inability of family caregivers to care for their family members at home. Family caregivers could not quit their jobs to care for older family members at home. Family caregivers of older adults in LTRC also noted that the homecare support that was offered or provided was insufficient to meet the care needs of their family members and spoke about the affordability of in-home private care. These factors, a consequence of neoliberal ideology, added to the inability of family caregivers to manage caregiving at home.

Most family caregivers indicated that LTRC placement of their family members was not their preference and would be considered as a last resort. Some family caregivers of community-dwelling older adults said that they would consider other options before placing their family members in LTRC. One such example was of a daughter who said she would rather move her parent to her own home in a different province and bring in private care if necessary before moving her family member to LTRC. Similarly, some family caregivers of older adults in assisted living said they would consider other options such as taking their family member to their home or exploring whether they could supplement the facility care with private support before sending their family member to LTRC. At the meso level, the choices that families have are constrained by class-related experiences.

Other micro-level factors such as smaller nuclear families, the proximity, availability and willingness of other family members to assist with caregiving, as well as shifts in attitudes about care and caregiving also influenced the decision to place older adults in LTRC.

SA older adults' and family caregivers' discussions regarding decision-making for or consideration of LTRC illuminate the salience of socio-economic factors, particularly economic resources, in placement decisions and the accessibility of other options. Those with economic means have more options and choice, while for those without, LTRC may be the only and most economical option. While at the meso level, it appears that family caregivers may exert power in placement decisions, factors in the social political environment may be more powerful in influencing these decisions. At the health care system level, SA families' cultural knowledge is offset by formal care providers' scientific knowledge supported by policy outlining the level of care and support that can be provided in the community and in assisted living facilities. In some cases, care providers' suggestion regarding LTRC placement served as an "out" for some families enabling them to explain placement of their family member in LTC as professionally driven thereby reducing the guilt and stigma that often accompanies such decisions.

5.5 Discussion

South Asian families' decision-making for LTRC placement is occurring at the intersection of the current neoliberal social political context in Canada and in the context of SA cultural norms regarding care and caregiving for older adults. Neoliberalism is characterized by its ideology of individualism and individual responsibility, dominance of the free market, retrenchment of public services, and the increased privatization of remaining public services (Armstrong & Braedley, 2013b; Chappell & Penning, 2009; Polivka & Luo, 2017). The diminishing role of the state in citizen provision of resources has been associated with program reductions, a narrowing focus of provided services and limiting eligibility for a wide range of benefits and services often through increasingly stringent eligibility criteria as well as implementation of other policies designed to minimize need for access to certain more expensive services (Chappell & Penning, 2009; Polivka & Luo, 2017). This has been accompanied by an increase in for-profit care services which aim to fill the gap left by public services. The result of this is inequitable access to services and increased demands on family and friends for caregiving as well as increased acuity of individuals when they do access services (Armstrong & Braedley, 2013b; Chappell & Penning, 2009; Daly, 2013; Fine, 2012; Froggatt, Hockley, Parker, & Brazil, 2011; Polivka & Luo, 2017). The orientation toward individualism and individual responsibility "…privileges individual freedom to compete for economic prosperity and accumulate property through participation in markets…" (Armstrong & Braedley, 2013a, p.14). This, along with globalized economic and financial systems have been associated with social changes, such as the geographic dispersion of family members for work and more women in the workforce where they make up the largest proportion of the precarious work force (Duxbury, Higgins, & Schroeder, 2009; Fine, 2012) and hence are more easily displaced in times of austerity.

South Asian cultural norms regarding care and caregiving for older adults are rooted in religious beliefs and reflect moral authority (Lamb, 2002, 2013; Mehta, 1997; Nayar, 2004) . Duty, respect and honour are widespread traditional values (Lamb, 2002, 2013; Mehta, 1997; Nayar, 2004) and refer to the fulfillment of one's responsibilities within the household, attaining respect for having fulfilled one's duty and honoring the family and community by conformance with traditional norms (Nayar, 2004). Fulfilling one's duty to and respecting and honouring one's elders is highly regarded in South Asian cultures (Lamb, 2002, 2013; Mehta, 1997; Nayar, 2004) and is generally operationalized by children providing material support (food, clothing, money, shelter), services of caring (cooking, serving food, cleaning, providing care when the parent becomes ill, bedridden, or incontinent, etc.), sentiments (forms of love coupled with hierarchical respect), and performing key life cycle rituals for their aging parents in later life (Lamb, 2002, 2013). Traditionally, sons and daughters-in-law in a joint family system, especially the eldest son and his wife, are expected to provide this support to older parents with daughters-in-law typically providing the day-to-day care (Sharma & Kemp, 2011).

The current neoliberal context challenges South Asian families in upholding traditional caregiving norms and sets the stage for (non) decision regarding LTRC placement whether the decision is made by the family or health care providers. In the family context, both SAOAs in LTRC and their family members felt they had no choice about the decision to move to LTRC and SAOAs felt they had no say in the decision to move. The older adults in LTRC attributed the need for the move to being sick, that their children were working and not available to look after them and that in LTRC they would get the care that they needed (as told to them by their children). Even older adults who may have been consulted about the move to LTRC seemed to have acquiesced to their children's situations and concerns for their wellbeing. However, in the space of (non) decision, older adults who appeared to acquiesce to their family's decision to move to LTRC, may in fact have exercised their agency by agreeing to the move in order to maintain family harmony, considered a moral imperative in SA cultures (Gilbar & Miola, 2015). While it may appear that family caregivers asserted their power and choice in the decision to place their family members in residential care, this observation is complicated by the interaction of a range of factors that led to thinking about and decision-making related to LTRC. Similar to findings from other research, SA family caregivers cited the declining health and functional ability of the older adult, the inability of the family caregiver to manage the escalating care needs, lack of medical knowledge or skills to provide support at home, and insufficient homecare support (Chen, 2015; Kiwi et al., 2018; Sussman & Dupuis, 2012; Tinker & Liu, 2001; Wee et al., 2015; Yeboah et al., 2013) as factors that influenced LTC placement. The prohibitive cost of private in-home care was also articulated by family caregivers in the study. In addition, the availability of family members to provide care due to multi-level factors such as geographic dispersion, work, changing attitudes about caregiving (Chen, 2015; Tinker & Liu, 2001; Yeboah et al., 2013), the availability of LTRC services and awareness and knowledge of such services (Kiwi et al., 2018; Speirs et al., 2017; Wee et al., 2015) all influenced placement. Despite having managed the care of their older parents at home for as long as possible, meso- and macro-level factors in the neoliberal context including socio-economic status, particularly the economic resources of the family, inadequate homecare support and the cost of private in-home care led to (non) decision about placement. Economic resources influenced not only the family's ability to continue to look after their older family members at home as their health declined but also to supplement insufficient publicly-provided homecare support with private in-home care. Family caregivers could not quit their jobs to provide more care and there is a lack of paid eldercare leave for adult children caring for older parents (Duxbury et al., 2009; Fine, 2012; Martin-Matthews, 2007). The placement of their family member in LTRC was found to be very difficult for SA family caregivers and was accompanied by feelings of guilt and/or shame. There was an added weightiness to the guilt because of the moral imperative to care for parents as they age, which originates in religious beliefs (Lamb, 2002, 2013; Mehta, 1997; Nayar, 2004). Some family caregivers felt that they had abdicated their duty to their parents but felt they had no choice. Regardless of the lack of choice, the guilt and/or shame associated with placement decisions can have long lasting impacts on the mental health and wellbeing of adult children, particularly women in midlife.

Both community-dwelling SAOAs and their family caregivers had thought about LTRC as an option for care in the future. The older adults hoped they could make the decision or at least be actively involved in making the decision to move. In thinking about LTRC as a future care option, these older adults seemed to have aligned their expectations of care with the reality of their children's life in Canada and the current social political context. They could not or did not want to be dependent on their children for their future care. The busy working and family lives of their children and whether they would be available and able to care for them or in some instances even wanted to care for them and not wanting to be a burden for their children contributed to their thinking about and in some cases actively exploring LTRC as a care option. For some older adults, their children did not reside in the same city as themselves resulting in the need to explore other care options. Other researchers from the U.S. and Canada also found that SAOAs aligned their own expectations with that of their children's experiences and understandings about what was possible, and therefore some SAOAs considered LTRC as an option for future care (Lal, 2003; Lamb, 2002; Sharma & Kemp, 2011). In fact, SAOAs in Lal's study articulated the need for LTC homes for South Asian older adults (Lal, 2003). By considering LTRC as a future care option, community-dwelling older adults may be working to avoid the negative social obligation consequences of ill health such as being a burden to and unable to fulfill responsibilities towards loved ones and to maintaining family harmony (Betsch et al., 2016). Consideration of LTRC now may also be an attempt to reduce the decision-making burden on their children in the future if such a decision was required while ensuring their own agency in the future.

The family caregivers of community-dwelling older adults, while thinking about the potential need of their older family members for LTRC in the future, also saw it as a last option, particularly the adult child caregivers who evoked cultural mores of not placing aging family members in care homes. Some adult child caregivers noted that they did not want to be 24-hour caregivers and some older adults mentioned that their children had already indicated that the older adults should not depend on them for care. Like the family caregivers of older adults in LTRC, these family caregivers noted practical challenges to caring for their older family members at home such as having small family networks, the prohibitive cost of in-home care, the geographic dispersion of family members and their own availability to provide care. Spousal caregivers, who were themselves aging, seemed more open to placement decisions because they felt that they may not be able to look after their family member and that their children had minimal availability to assist. Hence the question arises as to whether the decision for LTRC placement will in fact be enacted differently for community-dwelling older adults given the social political context in which such decisions are necessitated and community-based services are provided (or not).

When the decision to place SAOAs in LTRC was suggested or made by health care providers as in the case of some SAOAs in LTRC or for SAOAs residing in assisted living facilities, both the older adults and their family caregivers felt they had no choice about the placement decision. The decision to move to a LTRC facility for these older adults and their families was for all intents and purposes a (non) decision. Family caregivers of older adults in assisted living hoped that decisions would not have to be made particularly because their family member would be moving from an ethno-cultural specific assisted living facility to a mainstream LTRC facility where their cultural-specific needs may not be met. Some family caregivers articulated other options they would consider if the assisted living provider decided their family member could no longer be cared for in the facility and had to move to LTRC. The consideration of other options was influenced by the socio-economic status of families. While family caregivers were able to explain the reason for placement in LTRC as professionally driven or in some way in God’s will which may have eased the guilt of the family somewhat, this was simultaneously perceived as not having a choice. In these situations, the religious knowledge of SA families about care for older adults was offset by the perceived authority of health care providers as experts with scientific or technical knowledge (Klassen, 2018; Pattison, 2013) and any negotiation regarding placement occurred in the space of (non) decision. However, health care providers suggesting or making the decision for LTRC placement may also have provided an “out” for adult child caregivers both in terms of not having to make an exceedingly difficult decision and in providing a buffer against the stigma associated with the placement of aging parents in care homes.

The findings illuminate the salience of socio-economic status and economic resources, in particular, in the (non) decision for LTRC placement and access to other care options. Those with economic resources could consider supplementing the public homecare support offered or provided or consider other options for care for their older parent that may enable upholding cultural norms of caregiving while those without would ‘default’ to LTRC. The lack of access to ethno-cultural specific LTRC facilities then adds to the tension of LTRC placement for SAOAs and their families and to the difficulty of such decisions. Other research has also shown that the lack of ethno-cultural specific LTRC facilities adds to the difficulty of decision-making around LTRC placement for ethno-cultural minority families (Andrews, 2012; Caldwell et al., 2014). Moreover, Antelius et al. (2015) and Kiwi et al. (2018) found in their studies of dementia caregiving and decision-making for LTRC among Iranian family caregivers in Sweden, that choosing an ethno-cultural facility seemed to relate to living up to the ideals of filial piety and eased family caregivers' guilt of LTRC placement of older family members with dementia (Antelius & Kiwi, 2015; Kiwi et al., 2018).

5.6 Conclusions

The context in which decisions for LTRC placement and health care in general are made matters (Murtagh, 2009; Rapley & May, 2009). Murtagh (2009) in discussing health care decision-making and the doctor-patient relationship noted:

> …decisions are also contextual, both materially and symbolically. The socioeconomic and cultural environment, the experience of health and health care *matter* in decision-making; the meanings attached to health and illness *matter* (p.82, italics in original).

While South Asian cultural norms indicate care and caregiving for older family members at home as they age, structural and meso-level factors in the Canadian neoliberal context impact the ability of SA families to meet these caregiving norms. The busy working and family lives of children resulting in reduced availability, smaller family networks, the geographic proximity of children, affordability of in-home care and insufficient homecare support affect SA families' ability to care for their older family members at home. Moreover, with more and more care for older adults being provided in the community, an increasing proportion of the cost of caring is borne by families (Chappell, 2011; Chappell & Penning, 2009; Duxbury et al., 2009; Purewal & Jasani, 2017; Struthers, 2013; Sussman & Dupuis, 2012). Even with the focus on community-based care, there is a paucity of resources in the community (Purewal & Jasani, 2017). Income has been found to be a major determinant of whether and how many services are purchased by family caregivers; the higher one's income, the more options and flexibility caregivers have to obtain services to meet their needs (Duxbury et al., 2009, p.42). If families do not have the economic resources to supplement publicly provided homecare support or afford other options for care, there is no viable way for families to care for their family members at home. For many families and older adults, LTRC placement is a (non) decision whether it is the family who suggests this or health care providers. As Armstrong (2013) notes about older adults in LTRC: "…most are in residential care because their physical, social, and economic circumstances give them no alternative" (Armstrong & Braedley, 2013a, p.13).

Despite having cared for their older family members at home for as long as possible, there is often significant guilt and/or shame associated with institutional placement for SA families and older adults stemming from the religious authority in which SA norms of caregiving originate, and consequent feelings of not having fulfilled their duty towards their parents (Brijnath, 2012; Lamb, 2013). The inability of families to provide care at home can be hidden behind the narrative of a family's unwillingness to take care of their own, both in the South Asian and mainstream communities. When health care providers suggested or made the decision for LTRC placement, this may have somewhat eased the guilt of family caregivers but was simultaneously perceived as not having a choice. In these cases, the religious and laic knowledge of SA families is offset by the perceived expertise of health care providers in the space of (non) decision (Klassen, 2018).

Variation in expectations for care and caregiving was observed among SAOAs and family caregivers. As in any society, there is diversity in the extent of adherence to religious beliefs and cultural norms (Betsch et al., 2016; Gilbar & Miola, 2015; Pattison, 2013). As Gilbar and Miola (2015) note when discussing patient autonomy, medical decision-making and the impact of culture:

> The reality is that societies are not one-dimensional and static, but rather their members 'pick and choose from its beliefs'. This is particularly true in our context, where patients

> from some backgrounds may be influenced by the cultural values of their origin *and* the values of the society they live in (p.383 italics in original).

In this, South Asians are no different. Research from the UK and U.S. also found shifts in intergenerational expectations for care and caregiving among SA immigrant families (Lamb, 2002; Sharma & Kemp, 2011; Victor et al., 2012) with these shifts being variously described as a transformation from an "Indian" to a hybrid "Indo-American" mode of exchange and expectations (Lamb, 2002) and as "individualized filial piety" (Sharma & Kemp, 2011). SA older adults in these studies were found to align their expectations of their children with their perceptions of reality and their understandings about what was possible. Sharma & Kemp (2011) noted that the variability seen in how support practices were enacted in SA families in their study was on a continuum from continuing with traditional ways to modifying some of the practices and filial expectations and/or abandoning certain practices altogether or some combination (Sharma & Kemp, 2011). They further noted that the exchange of support between generations was individualized in each family context in response to social change, as well as family and individual influences and that this reflected the fluidity of cultural values (Sharma & Kemp, 2011). In addition, one could argue that there is a secularizing shift in SA communities where families become increasingly accustomed to offsetting religious knowledge with other sources of knowledge (Klassen, 2018) be it laic knowledge gathered from consultations with significant others and other sufferers, medical texts, radio, television, internet, print media etc. (Rapley & May, 2009) or the knowledge of health care providers.

Given the above, assumptions about South Asian families' ability and willingness to provide care for their older family members at home are problematic. It is important for policy makers and formal LTRC providers to recognize that SA families face the same challenges in caring for their older family members as mainstream Canadians and thus they should be prepared to provide culturally responsive care for SAOAs in LTRC facilities. Other researchers also caution against stereotypical assumptions of ethno-cultural minority families and their ability to care for older family members (Harper & Levin, 2003; Purewal & Jasani, 2017; Sharma & Kemp, 2011). Harper and Levin (2003) note that stereotypes about the extended family, about their ability and willingness to provide care ignore the possible diversity of attitudes and behaviours as well as structural influences that might affect how families offer support (Harper & Levin, 2003). Sharma and Kemp (2011) similarly note that “stereotypical views of ethno-cultural minority families as the preferred and sole site of eldercare requires critical scrutiny given the work demands and busy lives of their children, and that care providers and policy makers should recognize that older parents in such families cannot necessarily rely on their children to provide care” (p.138). In this sense, aging in ethno-cultural minority groups may not be vastly different from aging in the mainstream. Sharma and Kemp suggest that formal long-term care services should prepare for increasing cultural diversity and that care providers should prioritize cultural competency both in the services they provide and among the staff they hire (p.138).

In light of the overarching theme of (non) decision regarding LTRC placement found in this study, when placement of SAOAs in residential care is necessitated, implementing shared decision-making in the context of person-centred care (Bunn et al., 2018; McCance, McCormack, & Dewing, 2011) can support SA families in this difficult situation. Health care providers’ awareness of the macro-, meso, and micro-level factors influencing placement decisions, understanding the reasons for the difficulties in decision-making for LTRC placement in SA families and acknowledgement of the cultural and laic knowledges of SA families in the shared decision-making process can assist in supporting families in the decision and placement process. Moreover, variation in decision-making and attitudes towards care and caregiving in each family context require micro- and meso-level understandings in the context of changing/shifting structural (political) contexts and indicate a need for a person-centred approach to decision-making regarding LTRC.

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Chapter 6: Person-Centred Transition to Long-term Residential Care for South Asian Older Adults: Challenges and Facilitators

6.1 Introduction

The move to long-term residential care (LTRC)[21] is considered to be one of the most stressful and difficult life events for older adults and their family members (Lane, Hirst, Hawranik, Reed, & Rokhman, 2017; Lee, Woo, & Mackenzie, 2002; Lee, 2010; Manion & Rantz, 1995; Martinsson, Edberg, & Janlov, 2013; Sussman & Dupuis, 2012). For older adults the move may be accompanied by multiple losses, discontinuities, emotional upheaval and feelings of abandonment (Brandburg, Symes, Mastel-Smith, Hersch, & Walsh, 2013; Lee et al., 2002); family members experience guilt, sadness, and regret along with relief and peace of mind (Caldwell, Low, & Brodaty, 2014; Lane et al., 2017; Sussman & Dupuis, 2012).

Transition and adjustment to LTRC is a complex process (Brandburg et al., 2013). For immigrant and ethno-cultural minority older adults (EMOA), the transition and adjustment can entail additional difficulties (MacLean & Bonar, 1983; Martinsson et al., 2013; Mold, Fitzpatrick, & Roberts, 2005) as they move from a familiar social and cultural environment into one which is designed and run in accordance with Euro-centric norms and values with English being the predominant language (Koehn, Baumbusch, Reid, & Li, 2018). These older adults have to adjust not only to a new environment, regimented schedules, rules and regulations, expectations of staff and norms of resident behaviours (Diamond, 1992), but also to a new socio-cultural context of communal living with others from different ethno-cultural backgrounds (Koehn, 2001; MacLean & Bonar, 1983; Martinsson et al., 2013; Mold et al., 2005; Rosendahl, Söderman, & Mazaheri, 2016; Westbrook & Legge, 1992). Moreover, relocation to LTRC may

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[21] In this paper, the term "long-term residential care" (LTRC) is used to refer to care of older adults with complex needs who require 24-hour professional supervision and care in a protective, secure environment. Synonymous terms are residential care, long-term care, care homes, and nursing homes.

be perceived differently “depending on the meaning and importance of the original and new home to the mover and on his or her life-situation” (Danermark & Ekstrom, 1990, p.45). For immigrant older adults, the meaning of home may differ from that of mainstream older adults as their notion of what constitutes home has been formed in a culture and influenced by life circumstances that are often different from the culture in which they now live (Lewin, 2001). In addition, as immigrant older adults are not a homogenous group, the meaning associated with home may also differ across immigrant groups according to ethnicity and time since immigration.

This paper explores the transition and adjustment experiences of South Asian older adults (SAOAs) and their families in LTRC, as well as the factors that may facilitate their transition and adjustment. The analysis, framed in the context of person-centredness[22], is drawn from a larger ethnographic study that took place in western Canada that explored the needs, preferences and experiences of SAOAs and their families regarding LTRC and how SA families make decisions regarding placement. The South Asian diaspora in Canada includes immigrants from India, Pakistan, Bangladesh, Sri Lanka, Nepal, Bhutan and the Maldives (Walton-Roberts, 2013) and also refers to Indians who have migrated to other parts of the world including Malaysia, Fiji, Hong Kong, and East Africa (Nayar, 2004). In addition to the diversity in country of origin, there is also diversity in the religions practiced (e.g., Sikhism, Hinduism, Islam, Christianity, Buddhism (Coward, Hinnells, & Williams, 2000)), in the languages spoken (e.g., Punjabi, Hindi, Tamil, Gujarati, Urdu, and Bengali (Lindsay, 2007; Tran, Kaddatz, & Allard, 2005)), as well as

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[22] Person-centredness is widely referenced in health care, characterized by respecting the inherent value and dignity of each individual in the care context. Person-centred care (PCC) places people at the centre of their care and responds to their needs in humane and holistic ways (McCormack et al., 2015).

time since immigration, with some aging here in Canada and others immigrating in late life as Family Class[23] immigrants.

6.2 Literature Review

To situate this analysis within the larger body of research, literature pertaining to placement and adjustment experiences of older adults in LTRC is reviewed, followed by a synthesis of the limited research on the experiences of immigrant and ethno-cultural minority older adults. Research on the practices and/or strategies that can facilitate adjustment and transition is also reviewed.

6.2.1 Placement and Adjustment Experiences of Older Adults in LTRC

Research has shown that the placement and adjustment of older adults in LTRC is stressful and fraught with emotions for them and their families (Brandburg et al., 2013; Caldwell et al., 2014; Lane et al., 2017; Lee et al., 2002; Sussman & Dupuis, 2012). The experience is characterized as one of loss (Brownie, Horstmanshof, & Garbutt, 2014; Nay, 1995; Sullivan & Williams, 2017) – loss of home, identity, independence, autonomy, privacy, possessions, relationships, and continuity of former roles (Brownie et al., 2014; Riedl, Mantovan, & Them, 2013; Sullivan & Williams, 2017). The processes prior to transition can impact the subsequent adjustment of older adults and their families (Sussman & Dupuis, 2012); when older adults are involved in the decision to move, research has shown they are better able to adjust in a new setting (Brownie et al., 2014; Kokonya & Fitzsimons, 2018; Koppitz et al., 2017).

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[23] Canadian citizens and permanent residents may sponsor spouses/partners, dependent children, parents, grandparents and other close relatives to become permanent residents as Family Class immigrants. The Family Class sponsorship program, under which the majority of older adults immigrate to Canada, requires a signed agreement with the Minister of Immigration in which the sponsor promises to financially support and care for the sponsored older adult for a period of 20 years. During the support period, sponsored dependents cannot collect social assistance and are ineligible for public pensions, subsidized housing or housing subsidies or other local benefits such as reduced bus fare passes.

Sussman and Dupuis (2012) explored interventions, conditions and systems that contribute to or hinder a positive transitional experience for families prior to, during, and immediately following their relative's move to LTRC and found that time to process the decision to move with their older family members helped with the transition. Koppitz et al. (2017) investigating unplanned admissions to nursing homes found that transparency of the reasons for admission as well as communication about the admission process were crucial to helping older adults adjust to the new setting (Koppitz et al., 2017). However, both Sussman and Dupuis and Koppitz et al., noted that often older adults and their families lacked adequate time to process the decision to move, particularly when the move occurred from acute care. Sussman and Dupuis also noted the absence of adequate information regarding the facility and admission processes.

After admission to a nursing home, older adults may feel challenged and unable to cope with the new situation, experiencing feelings of helplessness, abandonment, and vulnerability (Kao, Travis, & Acton, 2004; Riedl et al., 2013). Kao et al. (2004) found that it can take from 6-8 weeks to three months from the day of admission for older adults to settle into their new environment and adjust to life in the facility. Iwasiw et al. (2003), in their longitudinal study exploring the perspectives, needs and expectations of residents and their family members during their first year in LTRC, found that residents tried to adjust mainly by accepting and adapting to the institutional routines and following staff instructions. Brownie et al. (2014) found that for some older adults, adjusting to the rules and regulations added stress and anxiety, reflecting their loss of autonomy.

Several researchers have also noted the importance of social connections with other residents and with staff in establishing a sense of belonging and hence adjustment (Altintas, De Benedetto, & Gallouj, 2016; Brownie et al., 2014; Lee, 2010; Sullivan & Williams, 2017;

Sussman & Dupuis, 2012). Participating in activities also facilitates adjustment, with high leisure participation predicting better adaptation to the long-term care environment (Altintas et al., 2016). Researchers have suggested that older adults may be considered to be adjusted to the long-term care setting when they feel as if it is their “home” or they “feel at home” in the new place of residence (Koppitz et al., 2017).

Placement and Adjustment of Immigrant and Ethno-cultural Minority Older Adults (EMOA)

A few researchers have explored the transition and adjustment experiences of immigrant and EMOA in LTRC (Bekhet & Zauszniewski, 2014; Lee, 2010; MacLean & Bonar, 1983; Martinsson et al., 2013; Mold et al., 2005; Rosendahl et al., 2016; Yeboah, Bowers, & Rolls, 2013). Researchers have noted additional issues that these older adults face when moving to residential care which may make it more difficult for them to adapt to institutional living, including loss of family, culture and community (MacLean & Bonar, 1983; Martinsson et al., 2013; Rosendahl et al., 2016).

For immigrant and EMOA, the need for respect and intimacy is most often provided by the immediate and extended family (Lamb, 2002, 2013; MacLean & Bonar, 1983) and is operationalized by the family caring for older family members’ physical and material needs as they age (Lamb, 2002, 2013; MacLean & Bonar, 1983). Placement, therefore, can lead to these older adults developing feelings of isolation, rejection, dishonour and disrespect with regard to their family. These older adults are also likely to experience a sense of family loss and may need to cope with feelings of shame, in addition to the normal feelings of anxiety related to the institutionalization process (MacLean & Bonar, 1983).

Immigrant and EMOA also face a loss of their culture. The loss of familiar foods, folklore, music and language has been found to contribute to a sense of isolation in the facility (Koehn, 2001; MacLean & Bonar, 1983; Martinsson et al., 2013; Rosendahl et al., 2016). The inability to communicate with staff in their native languages can lead to misunderstandings. Moreover, these older adults may be challenged to develop a sense of community and belonging in LTRC as they may not share a common political history, religious traditions or community values with those around them (Koehn, 2001; MacLean & Bonar, 1983).

In their investigation of older immigrants' and their family members' experiences of moving to residential care in Sweden, Martinsson et al. (2013) and Rosendahl et al. (2016) found that immigrant older adults felt alienated in the new context where they missed their culturally influenced food and possessions, felt unfamiliar with the other residents, had difficulty communicating their needs to staff and were unable to socialize with others due to language difficulties. The researchers found these older adults spent a lot of time watching television and expressed a wish to have access to channels from their native country, in their own language. If staff who spoke the same language were on duty, these immigrant older adults felt safe, understood, and could participate in conversation. In addition, family members brought traditional food and assisted in interpreting for their older family members. The researchers noted the importance of family visits and involvement more so for immigrant older adults as family members could interpret, bring culturally appropriate food, and for immigrant persons with dementia, could assist in recalling memories in a way not possible in a foreign care environment (Martinsson et al., 2013; Rosendahl et al., 2016). Martinsson et al. (2013) concluded that the transition to residential care can already be associated with a sense of loss, but for immigrant older adults, there was the additional risk of isolation and alienation. Thus they noted the importance of sustaining previous relationships in order to retain a sense of meaning and identity (Martinsson et al., 2013).

6.2.2 Facilitators of LTRC Placement and Adjustment

Researchers have identified a number of factors that can help with the placement and adjustment of older adults in LTRC including: 1) being prepared for the move (Kokonya & Fitzsimons, 2018); 2) the presence and active engagement of family (Brownie et al., 2014; Iwasiw, Goldenberg, Bol, & MacMaster, 2003; Kokonya & Fitzsimons, 2018; Manion & Rantz, 1995; Mold et al., 2005; Nay, 1995; Sussman & Dupuis, 2012); 3) resident-staff relationships and staff support (Bourgeault, Atanackovic, Rashid, & Parpia, 2010; Brandburg et al., 2013; Brownie et al., 2014; Gorek, Martin, White, Peters, & Hummel, 2002; Iwasiw et al., 2003; Kokonya & Fitzsimons, 2018; Kong, Deatrick, & Evans, 2010; Nay, 1995; Rosendahl et al., 2016; Sullivan & Williams, 2017); and 4) the provision of person-centred care (PCC) (Fraher & Coffey, 2011; Iwasiw et al., 2003; Kokonya & Fitzsimons, 2018; Sussman & Dupuis, 2012). In addition to these factors, research on immigrant and EMOA has shown that presence of staff who speak the same language (Rosendahl et al., 2016) and honouring residents' and families' cultural and ethnic preferences facilitate adjustment and transition (Bekhet & Zauszniewski, 2014; Brownie et al., 2014; Gorek et al., 2002; Kao et al., 2004; Koehn, 2001; Rosendahl et al., 2016).

Once the decision to move to LTRC has been made, several strategies have been identified to assist older adults and their families in their preparation for the move, including facilitating an anticipatory period where information about the care home is provided to the older adult and family (Fraher & Coffey 2011; Sussman & Dupuis 2012), having a transitional plan or transition team in place (Brownie et al., 2014; Lee, 2010), enabling a progressive introduction and orientation program for both the resident and family, as well as planning overnight stays pre-admission (Brownie et al., 2014; Kao et al., 2004; Kokonya & Fitzsimons, 2018).

Involvement of older adults’ family during the transition and adjustment period by providing stay time for families while the older adult settles into the facility and having family/significant others be present at the time of the move has been found to promote a sense of connectedness for older adults, reduce feelings of abandonment, and lessen anxiety, confusion and dissatisfaction for both the older adult and their family (Kokonya & Fitzsimons, 2018; Manion & Rantz, 1995; Sussman & Dupuis, 2012). Family visitation and involvement in decision-making and in the provision of physical, social, and emotional care has been found to be crucial to the quality of care and life of the residents post-placement (Iwasiw et al., 2003). For EMOA, family involvement was found to be essential. The support provided by family and kinship ties helps EMOA not only maintain their sense of identity and continuity (Koehn, 2001; Mold et al., 2005), but family members also provide for cultural needs that may not be met in mainstream LTRC (Koehn, 2001; Rosendahl et al., 2016).

Resident-staff relationships have also been found to be key to successful transitions (Sullivan & Williams, 2017). Matching health care providers to older adults on admission day and a few days afterward or appointing a primary nurse to the new resident along with bilingual and bicultural health care providers to match language and cultural needs of immigrant older adults in LTRC can help to build trust and lessen the stress involved (Bourgeault et al., 2010; Gorek et al., 2002; Kokonya & Fitzsimons, 2018; Kong et al., 2010; Rosendahl et al., 2016). LTRC staff supporting older adults to work through feelings of loss and grief upon moving (Nay, 1995; Sullivan & Williams, 2017) and facilitating social connections with other residents and staff, as well as with family, have been found to help older adults build a sense of belonging in the facility (Brownie et al., 2014).

Health care providers can further support transition and adjustment with the provision of person-centred care (Fraher & Coffey, 2011; Iwasiw et al., 2003; Kokonya & Fitzsimons, 2018; Sussman & Dupuis, 2012), acknowledging personal histories, values and preferences, and sustaining a sense of continuity with residents' personal histories (Iwasiw et al., 2003). In addition, honouring residents' and families' cultural and ethnic preferences (Kao et al., 2004) for culturally appropriate food (Brownie et al., 2014; Gorek et al., 2002; Koehn, 2001; Rosendahl et al., 2016), interpretation services (Bekhet & Zauszniewski, 2014; Gorek et al., 2002; Rosendahl et al., 2016), culturally meaningful activities (Runci, Eppingstall, van der Ploeg, & O'Connor, 2014), and having a place for prayer (Bekhet & Zauszniewski, 2014) have been identified as important for supporting the adjustment and quality of life of EMOA.

In summary, the literature indicates that transition to and adjustment in LTRC is often an emotional and difficult experience for older adults. For immigrant and EMOA, transition and adjustment may entail additional difficulties (MacLean & Bonar, 1983; Martinsson et al., 2013; Mold et al., 2005; Rosendahl et al., 2016). At the same time, research focused explicitly on immigrant and EMOA is limited and most of the research is done outside of Canada. In addition, there is little research that provides an in-depth ethnographic description of the transition and adjustment experiences of these older adults. As the numbers of SAOAs in LTRC are expected to increase with continued immigration (Statistics Canada, 2017) and the aging of the population, this study provides important insights into the transition and adjustment experiences of SAOAs and their families in LTRC and the practices and/or strategies suggested by participants to support these processes.

6.3 Study Design and Methods

This analysis draws on data from an ethnographic study examining the needs, preferences and challenges of SAOAs and their families regarding LTRC. Ethnographic methodologies enable exploration of the beliefs, language, behaviours and issues facing a particular group (Creswell, 2013; Hammersley & Atkinson, 2007) as well as how people are situated within a cultural context (Holloway & Todres, 2003). Employing a critical theoretical perspective, as done in this study, enables the contextualizing of individual subjective experiences within the broader social context and facilitates the development of an understanding of how larger social processes shape the lives of individuals (Creswell, 2013; Kincheloe & McLaren, 1994; Koro-Ljungberg & Greckhamer, 2005; Mantzoukas, 2012; Norander, 2017; O'Reilly, 2009). Ethnographic methods of participant observation, interviews and document review were employed, taking direction from Funk and Stajduhar (2009) who argue that observational methods can assist researchers in gaining deeper insight into the complexity of a phenomenon that interviews alone may be unable to provide. The review and analysis of relevant documents generated in the setting of interest and that are pertinent to the research questions being asked are also important sources of information and data (Hammersley & Atkinson, 2007; Lofland, Snow, Anderson, & Lofland, 2006; Mason, 2002) and provide the context for the observational and interview data (Hammersley & Atkinson, 2007).

6.3.1 Sample and Recruitment

The sample was comprised of 18 South Asian older adult (SAOA)-family caregiver dyads purposively recruited from two LTRC facilities, an assisted living facility, and from the South Asian community at large. Seven key informants were also recruited including managers, clinical nurse specialists, social workers, and recreation coordinators from LTRC as well as individuals from the SA community and researchers with knowledge of the SA community through their work with the community. The criteria for SAOA recruitment included: 1) being aged 65+ years; 2) being of South Asian descent; 3) currently residing in a LTC facility or contemplating placement in a LTC facility; and 4) having a family caregiver who also agrees to participate. The 18 older adults ranged in age from 68 to 94 years and 12 were female. Fifty-six percent (n=10) of older adults respectively were from India and were Sikh. A little over half of the older adults spoke little or no English (n=10), a surprising finding given that the median number of years in Canada was 38 (with a range of 8 to 52 years). One half of the older adults had less than high school education and two older adults had university level education (Master's Degree from India) (see Table 1).

Of the family caregivers, 15 were female and the majority were daughters, granddaughters or great granddaughters (see Table 1). Of the three male family caregivers, two were sons and one a spouse. The family caregivers ranged in age from 20 to 86 years with a median age of 54.5 years. The majority were fluent in English (89%) and 78% were educated at the college diploma level or higher. Twelve family caregivers were employed, one was a homemaker, and five were retired.

Key informants were purposively recruited from LTRC based on their clinical role and their experience with the transition, integration and/or care of SAOAs living in LTC as well as from the project advisory committee, based on their knowledge of the SA community at large either as a member of the community or through their work with the SA community.

Following ethics approval from the Research Ethics Board affiliated with the primary author's university and the regional health authority involved, LTRC and assisted living facility managers distributed information letters prepared in English, Punjabi and Hindi to SAOAs in their facilities. Interested older adults and family caregivers contacted the researcher or the multilingual research assistant directly. SAOA-family caregiver dyads from the South Asian community at large were recruited with the assistance of the project advisory committee members who provided linkages to the community through their networks. Information sessions were conducted with various older adult groups and interested older adults contacted the researcher or the research assistant directly. Key informants were invited to participate in an interview via email and contacted the researcher directly to confirm their interest.

6.3.2 Data Collection

Data were collected from March 2014 to May 2016 by in-depth qualitative interviews, document review, and observational fieldwork. To facilitate data management, all interviews and field notes were entered into NVivo 10 software, a computerized software program designed to assist with management and organization of qualitative data (Bazeley & Jackson, 2013).

Semi-structured, in-depth interviews were conducted with 18 SAOAs, 18 family caregivers and seven key informants. Eleven study participants required the interviews to be carried out in Punjabi or Hindi and were conducted by a South Asian multilingual research assistant with the researcher present. Ranging from 20 to 103 minutes, interviews were recorded and transcribed. Interviews conducted in Punjabi or Hindi were simultaneously translated and transcribed. Two SAOAs and two family caregivers did not feel comfortable with the interviews being recorded, thus handwritten notes were taken during the interviews. Field notes were written after all interviews.

Participant observation of seven SAOAs living in two LTRC facilities was conducted between March 2014 and April 2016. Observational fieldwork, comprising 220 hours, took place in public areas of the facilities at varying times on weekdays and weekends, and focused on the observation of SAOAs' interactions with fellow residents, formal care providers, the physical environment and how they negotiated their specific needs and preferences as well as any relationships they developed in the setting. All observations were recorded in the form of detailed field notes.

The review of provincial policies, residential care regulations and other documents prepared by the health authority and LTRC facilities provided an understanding of the formal processes required for access to LTRC as well as how services are organized and provided in the LTRC setting.

6.3.3 Data Analysis

Interview and field note data were analyzed using the constant comparative method (Boeije, 2002) – a multi-layered process which enabled exploration and understanding of individual experiences of older adults and family caregivers and comparison within and between groups in a systematic way. A critical theoretical perspective guided the analysis to explicate how larger social processes influenced the decision/consideration of and experience in LTRC. In reviewing the findings, commonly held values and assumptions were interrogated with a view to understanding how these may influence LTRC service provision for SAOAs and SAOAs' role in decision-making for LTRC.

The documents collected for this study were reviewed and then critically examined, paying particular attention to the language used and how dominant ideologies were reproduced in the text. A critical analysis of the texts contributed to the development of theoretical arguments and to the analysis of the broader context of the study.

6.4 Findings

The results from observation of and interviews with SAOAs residing in LTRC, their family members and key informants, as well as from document review are framed in the context of person-centredness and focus on SAOAs as they transition to LTRC, practices that support transition, and policies that challenge the implementation of person-centred practices.

6.4.1 Transitional Experiences

Participants spoke of the significance of family, describing family as “home”. More than the loss of a physical space or “place”, participants reported that being separated from their families was one of the most difficult aspects of transitioning to residential care. Gurjit[24], a 94-year-old female shared how she felt alone and worried and wished she was still living with her family:

> If I am sitting alone I just worry everyone is at home or that they have gone away to different places – that we have all been separated. This thought does nag me sometimes…staying alone makes a lot of difference. It is good to stay in the family only. The family, if one lives with the family. What else do I want? Nothing more than that.

Similarly, family members articulated the difficulty when this separation from family occurs, indicating how their older relatives had never lived apart from their families. Aahna, whose family member had been in a care home for approximately three months noted that the move to LTRC was a difficult change:

> …The change is quite harsh for her … Since she’s moved to Canada she’s never been alone. She’s always lived with a family member and it was usually not just one person she was living with. She always lived with multiple people. And mostly she stayed with my family. Like, she had her son here as well and he moved to (U.S. state) but she wanted to stay with us instead. And so obviously she’s never been alone and even when she would sleep at night there would always, she would sleep with me and my sister so even now when she sleeps she has a hard time sleeping alone by herself.

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[24] Pseudonyms have been used to protect the anonymity of study participants.

Some older adults felt they had no home and were ambivalent about moving to residential care. Chann, an 89-year-old female, articulated a sense of being homeless, replying, “My house is nowhere” and Jasmeet, a 79-year-old female, articulated feelings of ambivalence saying, “I not happy sometimes – sometimes sad. Sometimes sad because all my children are my home. After everybody got house and my house is here.”

Key informants noted that for some SAOAs, their family comprised their social world. Debbie, a LTRC social worker explained that sometimes it “just takes time and patience” and said that those who experience most difficulty are the residents that feel they have been “displaced” or who were reluctant about being admitted to LTRC. Separation from family seemed to be one of the most difficult aspects of the transition, impacting SAOAs’ sense of self and adjustment in the new environment. Jane, an educator in LTRC described the difficulty that many older adults have when they transition to LTRC and suggested that the transition may be even more difficult when a resident is from a non-western country:

> …Many times those South Asian older adult cannot speak English…and many times they used to live at home with their kids and it seems that they were not even in the society so they don’t know enough about the Canadian culture Western culture either… So I could say for sure it’s very hard for them in the beginning. Again it’s not even for South Asian, for older adult it’s very hard to come to residential care because it’s new environment, but in particular for South Asian, since they have different culture, I can say it is very difficult … The environment is different, they don’t speak English enough, they don’t know the culture, they are used to eat different food, you know everything is different for them. Lots of adjustment, lots of new experience yeah...People, residents could have delirium only for relocation and moving-in day so never mind having different culture and different language…I cannot even imagine how difficult it is.

Moving to LTRC can therefore be disorienting for SAOAs as they navigate multiple new experiences and cope with unfamiliar environments. Challenges in communicating with LTRC staff (due to language barriers) and not having access to foods that they are accustomed to create issues for SAOAs trying to find a sense of belonging in the facility. Additionally, the absence of others with similar backgrounds can also affect SAOAs’ ability to find a sense of belonging.

Akil, a 72-year-old male spoke about being among strangers and the lack of commonality he felt with others around him:

> Everybody is a stranger here. [I] don’t know anybody here. People here are from different places. We don’t know anybody here. Neither do they know about us nor do we have any clue about them.

The transitional experiences of SAOAs illuminate additional challenges that these older adults may have upon moving to LTRC indicating the need for a person-centred approach to supporting their adjustment in residential care.

6.4.2 Practices to Support Transition to LTRC

Several key informants spoke about the importance of person-centred care in facilitating the transition and adjustment of SAOAs in LTRC; they noted that the existing transition process is not person-centred, being constrained by policies and limited resources. Key informants suggested a number of practices and/or strategies to facilitate a more person-centred approach including strategies related to orientation and transition, resident co-location, staff-resident concordance, and linguistic, cultural and religious services. In suggesting these practices, however, key informants admitted that system constraints (as discussed in Chapter 4) often preclude implementation.

Orientation and Transition

Orientation to the LTRC facility prior to move-in day was suggested by key informants to help ease older adults’ and their families’ transition to the new environment. Information about the facility and an on-site visit were considered important so families could view the layout of the facility, resident rooms, etc. A phased-in transition where older adults and families could participate in the facility activities during various times as well as enabling a gradual move into the facility would allow for older adults and their families to spend time in the facility, becoming oriented with the routine, staff, and activities. Jane describes her ideas for this more extensive type of orientation while noting that in the current context of health care affordability and scarce resources, this type of an orientation is likely a dream:

> To have a good orientation makes transition easier as much as possible… maybe resident can have a visit for few hours and go back the other way around, I don't know…I don't know but this transition that I am seeing definitely is not a good transition. I understand why we are doing that because we have no other choices, but definitely is not person-centered care and we cannot afford to spend lots of time with new resident because everybody is busy doing the task....I hope maybe they for first week they can come only for meals with family you know and following week they can come for AM care, HS[25] care you know, get ready for bed, get ready for the day and following week they can come only for activities, but it's a dream I know that we cannot afford doing that, but one day hopefully you know health care can afford doing that.

While recognizing the helpfulness of a good orientation in the transition to LTRC, key informants also noted the reality that older adults and families have very little time between a facility being found for them and when they need to move in and that this timeframe may be even shorter for those transferring from acute care.

Key informants suggested that having the family accompany the older adult on move-in day as well as visiting more often in the first few weeks after the move would help the older adult with the transition and not feel as if they have been forgotten. Debbie explained how family is the one constant for the older adults during this time of change:

> …How else can the family support or facilitate … they are the common, they are what they [the resident] are used to so even though the walls have changed the family is still the same.

Gail, a social worker in a different LTRC facility, explained that encouraging family to visit more in the first couple of weeks would reassure the older adult that their family is still there for them, that they are not forgotten and that the older adults have a voice as they adjust to the new environment:

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[25] "HS care" refers to evening or bedtime care; it comes from the Latin 'hora somni' meaning 'at bedtime'.

> We encourage family, and this is also across the board because we don’t know how everyone copes, but, we encourage family to visit more in the first couple of weeks and then gradually wean off, like reduce their visits so they [older adults] have company and reassurance that they are not forgotten. That they [family] are there still for them and that they [older adults] have a voice as they adjust to new situations.

For SAOAs, active engagement of family is even more important as family members may assist in interpreting for their relatives, bringing culturally familiar food and providing a sense of connection with their cultural heritage.

Resident Co-Location

The presence of other SAOAs in LTRC facilities was also considered by key informants and family members to be helpful for SAOAs’ adjustment in LTRC. Having other older adults of the same faith/cultural background, who spoke the same language and shared common beliefs enabled communication and social interaction. Aahna, a family member, described what it is like for her older relative to move to residential care:

> I also find that language could be a problem here just because there’s not as many Punjabi speaking ladies here. There is a few but some of them are in a state where they can’t talk…there’s a few nurses upstairs in that area they’re really kind … they’ll be like aunty come sit with us, talk to us. That’s not a problem but I feel like if there is more people of the same culture I think it would be much easier for her in that sense…

Should there happen to be residents of the same backgrounds in the facility, key informants suggested that co-locating these residents close together would help them to have a sense of community and belonging. Nuala, a recreation coordinator, spoke about how in her facility, they tried to group SAOAs together in one area. However, she noted that this was not always possible because beds may not become available:

> …We try to group them together so they have a sense of community, so putting residents together of the same faith and beliefs are important. Sometimes that can’t happen though because beds don’t always come up … so you know, that’s not always easy to do. But, in general here we try to put a lot of the Sikh community together so they have a sense of community. So putting the folks together so they can speak together, they can feel like this is home.

Staff-Resident Concordance

The presence of SA staff was considered to be a ‘saving grace’ by several key informants and family members as SA staff helped with interpretation and the adjustment of SAOAs in their facilities. Having a SA staff member working on the day a SAOA moves into a facility and a few days afterwards helps with the older adult’s transition to the new environment. While Gail made this suggestion, she also noted that it is not always possible:

> I think when we have staff that are Punjabi speaking or whatever language speaking on duty when they [older adult] arrive, it makes a huge difference because then there is more of a welcoming and there is dialogue, you can interact … I think that sets the stage and it’s even better if that person can be on duty for the first two or three days. But it doesn’t always work like that.

Scheduling SA staff on the day SAOAs move in can be challenging in facilities with few SA staff. As Gori, a LTRC manager noted about her facility, “We do have a lot of South Asian staff members, but not a lot of them, like not on every shift…” Thus, the likelihood of being able to schedule a SA staff member on move-in day and the same staff member on the following few days is minimal.

While staff-resident ethnic concordance is considered to be helpful in the transition and adjustment of SAOAs it is not without problem. Some key informants noted the potential for increased workloads for SA staff both from requests of other non-SA staff for assistance and from expectations of SAOAs and their families for SA staff to meet their needs beyond what is possible for them to do.

Linguistic, Cultural and Religious Services

Key informants suggested that the provision of culturally appropriate food, enabling SAOAs the space to carry out their religious observances and providing access to SA radio and television are key to help these older adults transition to and adjust in LTRC and are important components of person-centred care. As Rachael notes, food and religion are interconnected and encompassing aspects of everyday life for SAOAs and have deep meaning for them. Moreover, the practice of their religion provides a sense of calm for SAOAs:

> Food is extremely important because that is integral to the religion so a lot of people are vegetarian and often in care facilities things that are said to be vegetarian are not necessarily…I would say observations as well about people's religion you know having a space where people can observe you know face in the right direction toward Mecca, this kind of thing or a lot of seniors that I know like to listen to, if they can't sleep, they like to listen to religious programs very early in the morning, like two, three in the morning and that needs to be accommodated …it's something that's very comforting to them, very calming so you know you'd think it is worth it. Those things are quite central, I mean I think the religion and the food which go together, are probably the key things…

Person-centred care places the person at the centre of their care and encompasses the provision of holistic care that respects the person's beliefs, values, and needs (McCance, McCormack, & Dewing, 2011; McCormack et al., 2015). In this study, strategies that would promote person-centred transitions for SAOAs were sometimes present, but more often than not, person-centred approaches were challenging to achieve in the context of resource constraints, structural issues in the care environment, and policies regarding access to care.

6.4.3 When Policies and Person-Centred Care Collide

Health care workers strive to provide person-centred care. The policy context in which health care services are provided, however, can influence the provision of person-centred care. A collection and review of key documents relevant to this study may shed some light on the challenges encountered in enacting person-centredness and provide some explanation for why strategies suggested by key informants to help SAOAs transition is difficult. For example, the province in which this study occurred operates a First Appropriate Bed (FAB) policy. The FAB policy requires older adults who have been deemed eligible for LTRC to accept and move to the first appropriate bed that becomes available in their geographic area within 48 hours, or risk being removed from the priority list (Office of the Seniors Advocate, 2015). This type of macro-level policy creates a situation for SAOAs and their families whereby the elements that would facilitate a smooth transition to LTRC are challenged. Katri, a family member, noted how her older relative being placed in a facility that was geographically distant (as a result of having to accept the first available bed) was challenging given that she had to visit the facility multiple times in a day to bring culturally appropriate meals:

> …then social worker give me a facility, but they not give me this place (name of current facility) …for me is hard to go far away. She [mother] can't eat English food, she not eat Canadian food so I bring food from home. This is the reason I need close by … I have to go maybe two times a day because she not eat food in facility.

Having to accept a bed in a facility that may not be in close proximity to family can affect family members' ability to support their older relatives when they transition to LTRC and, as seen in the excerpt above, this can take on greater significance for SA families when older relatives are in a facility where their ethno-cultural needs are not met.

The FAB policy also impacts whether there are other older adults of the same faith/cultural background in LTRC facilities. While the policy is meant to allow those who need residential care services quick access, by not considering other criteria such as cultural needs or ethno-cultural background, the FAB policy may unwittingly affect the adjustment and quality of life of ethno-cultural minority older adults in LTRC. With the FAB policy, SAOAs may end up in facilities where they are the only person from that ethno-cultural background, which could result in feelings of isolation and lack of belonging impacting their adjustment and quality of life in the setting.

Should there happen to be residents of the same ethno-cultural/religious backgrounds in a facility, attempts to co-locate these residents close together are affected by whether beds become available in the same area within the facility as well as the FAB policy. Even if a bed did become available in areas where residents of the same backgrounds are co-located, based on the FAB policy, the available bed would be offered to the next older adult on the waitlist for LTRC regardless of ethno-cultural background. This, then, mitigates the ability of facilities to maintain such co-location and may in fact be uncomfortable for the new resident.

While attempting to be efficient by requiring that eligible older adults accept the first available bed, the FAB policy can result in facilities having only a few residents of the same ethno-cultural background with the unintended consequence that if there are not adequate numbers of older adults of the same backgrounds in a facility, they are unlikely to have their ethno-cultural and religious needs met by the facility.

During the writing of this paper, shifts in policies regarding access to LTRC were made where older adults would no longer have to accept the first available bed and would be able to choose up to three preferred care homes (British Columbia Ministry of Health, 2019). It is not clear at this time how these changes will influence the transition process, however such shifts may open up the space for implementation of practices and/or strategies suggested in this study and point toward a promising direction that may better reflect person-centredness.

6.5 Discussion

The transitional experiences of SAOAs and their families illustrate additional factors that may need to be considered in helping older adults transition and adjust to LTRC. Separation from family was one of the most difficult aspects of the transition, affecting older adults’ sense of self and home. For many SAOAs, home is a felt concept, generated within the context of being with one’s family and community (Nayar, 2004). In SA cultures, the traditional family structure is the joint family and older adults are highly respected. Respect for and duty toward older family members have religious origins and thus hold a great deal of authority (Mehta, 1997). Families show their respect for and fulfill their duty toward older family members through the provision of care and caregiving as their family members age (Lamb, 2002, 2013; Nayar, 2004). Thus, of the various dimensions of home described by Cooney (2012), the most salient for SAOAs is home being “the centre of family life, togetherness, belonging and connection” (p.189). SAOAs’ identities are intertwined with family, thus, separation from family can result in a deep loss of home and identity. SAOAs in this study articulated feelings of ambivalence and feeling a loss of home when they moved to LTRC. The loss of their family, who comprised their social world and promoted a sense of home, was lost. This loss was exacerbated by moving into a context where LTRC services are organized around Euro-centric norms and values (Koehn et al., 2018; Mold et al., 2005; Reimer-Kirkham, Sharma, Smith, Schutt, & Janzen, 2018). Living among others with whom they may not have commonality and not having access to customary food or people that speak their language challenged SAOAs’ ability to find a sense of belonging in the facility and hence a sense of home. Some SAOAs spoke about being among strangers and the lack of commonality they felt with those around them. Other researchers have found similar experiences among immigrant older adults relocating to residential care facilities organized around the mainstream population in their countries (Martinsson et al., 2013; Rosendahl et al., 2016).

The transitional experiences of SAOAs described in this study indicate that policies and practices may not be consistent with the person-centred approach espoused by most LTRC facilities in Canada. While key informants and family members provided several actionable suggestions to promote more person-centered approaches to facilitate transition and adjustment, many of which have also been proposed by other researchers, the policy context, along with several other trends in Canadian long-term care practice (i.e., staff shortages and turnover, increased workloads, lack of resources, time constraints, regulated environment and culture of efficiency (Banerjee et al., 2012; Coughlan & Ward, 2007; DeForge, van Wyk, Hall, & Salmoni, 2011; Donnelly & MacEntee, 2016; Harrington et al., 2012; Kontos, Miller, Mitchell, & Cott, 2010; Lane et al., 2017; Lopez, 2007, 2014; McGregor et al., 2005; McGregor & Ronald, 2011)) suggests that these types of strategies may not be realistic to achieve.

The lack of accommodation of the person-centred needs of SAOAs in LTRC facilities results in families having to fill the gap post-placement and hence place additional demands on SA families compared to non-SA families, which could be interpreted as a form of institutional racism (as discussed in Chapter 4). Moreover, as seen from the findings in this study, the policy context, in addition to hindering the ability of LTRC facilities to implement person-centred care approaches, can also impact the ability of SA families to attend to the unmet needs of their older relatives in LTRC. Some family members articulated the challenge of meeting their family member's dietary needs when the facility their older relatives were placed in was not in close proximity.

In summary, several practices and/or strategies have been suggested by key informants and family members to support the transition and adjustment of SAOAs in LTRC. However, the context in which LTRC services are provided challenge the ability to implement many of these practices and/or strategies which ultimately are about the provision of person-centred care. Macro-level policies and processes which are meant to treat everyone the same differentially impact ethno-cultural minority older adults when they transition to LTRC. Moving to a care home where there may not be others like oneself, not having access to the foods that one is familiar and accustomed to eating, the inability to communicate with care staff and others, as well as the inability to practice one's religion make the transition to LTRC increasingly difficult for older adults.

6.6 Conclusion

The current conceptualization of person-centred care underpinned by the neoliberal Western notion of individualism does not align with other populations who rely on relational/social networks as well as membership in groups to thrive and for self-definition (Betsch et al., 2016). The findings from this study illuminate the salience of family and community networks for SAOAs and the challenges faced when moving to LTRC facilities which may not be organized to facilitate the re-establishment of a sense of community and thus belonging for these older adults. Ohlen et al. (2017) have discussed the importance of broadening person-centred care to encompass population and societal perspectives and advocate extending person-centred care to “people-centred care” noting that “the person is always socially and societally contextualized” (p.7).

The people-centred approach to care espoused by the World Health Organization, rooted in universally held values and principles such as non-discrimination, access and equity, points to planning and delivering care based on the needs and expectations of people and communities rather than a biomedical focus (World Health Organization, 2007, 2013, 2015). It describes people-centred health services as:

> an approach to care that consciously adopts the perspectives of individuals, families and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways (World Health Organization, 2015, pp.10-11).

The LTRC system is challenged to provide not only person-centred but also people-centred care. While individual facilities may attempt to implement person-centred practices and/or strategies to meet residents’ needs, the findings from this study illuminate how macro-level policies can collide with person-centredness, and indicate the need for policy-makers to assess the impact of policies on the delivery of person-centred care. In addition, as discussed by

Koren (2010), and Berta, Laporte, and Kachan (2010), and noted by Donnelly and MacEntee (2016), policy makers need to acknowledge the limitations imposed by insufficient public funding and a culture of efficiency:

> Policy needs to emphasize contextual sensitivity to the needs of residents, and acknowledge the limitations imposed by insufficient public funding in a climate of cost-containment and operational efficiency (Donnelly & MacEntee, 2016, p.157).

For immigrant and EMOA, person-centred care includes access to culturally appropriate food, the ability to practice one's religion, and participate in culturally meaningful activities, all of which have been found to support the adjustment of these older adults in LTRC (Brownie et al., 2014; Riedl et al., 2013). The Swedish National Board of Health and Welfare in their 2010 published guidelines for dementia care described what person-centred care means relative to culturally and linguistically diverse older adults (as discussed in Antelius and Kiwi, 2015, p.81):

> Person-centered care means to especially consider needs related to people having different cultural or linguistic background. Allowing for cultural needs could for instance be about giving persons with dementia disease the opportunity to practice their religion, being served culturally appropriate food, keeping their cultural traditions and customs, and having access to nursing staff that communicate in the same native tongue as the person with dementia…To be cared for by nursing staff who communicate in the native tongue and who also have cultural competence could give the person with dementia disease who has a different ethnic background a sense of security, increased well-being, and a sense of feeling "at home."

Extending the concept of person-centred care to people-centred care per the WHO description may mean the need for addressing both the impact of macro-policies and structural constraints on person-centredness and consideration of the broader question of population-specific needs. In this vein, policy makers and health authorities could be called upon to consider other approaches to LTRC service delivery for immigrant and ethno-cultural minority older adults that could more comprehensively meet their holistic needs. A discussion of potential approaches will be picked up in the final Chapter.

6.7 References

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Chapter 7: Discussion and Conclusion

In this chapter, I provide a brief overview of the study goals and methods and summarize the key findings. I then highlight the major insights and key implications that have emerged and conclude with a discussion of the study's strengths and limitations.

7.1 Study Overview

The goals of this study were to provide insights regarding the needs, preferences, challenges, and decision-making of SAOAs and their families regarding LTRC and to explore the extent to which existing LTRC services are prepared to provide culturally responsive and competent care to older adults from diverse ethnic and cultural backgrounds.

I entered the study believing that I would need to understand individual experiences in the current social, cultural and political context in order to generate knowledge that could effect change at a systems level. I also felt it important to hear from SAOAs and family members themselves, what their needs, preferences and challenges were regarding LTRC. In addition, I was interested in understanding how they made decisions about the use of such services and whether and how existing LTRC services met their needs. Ethnography informed by critical perspectives offered the necessary methodology and theoretical framework to both listen to these voices and contextualize individual experiences within the macro and meso contexts. In-depth interviews conducted with SAOAs in LTRC, assisted living as well as those living at home in the community and their family caregivers yielded information-rich data. Participant observation of SAOAs residing in two LTRC facilities provided insight about how these older adults are located within the LTRC setting and their situation in the setting. The review of documents relevant to LTRC including provincial policy documents, residential care regulation, and various documents prepared by the health authority and the LTRC facilities where the study took place enabled uncovering of taken for granted assumptions in how care and services are provided and the sociopolitical context in which LTRC is situated. The application of a critical theoretical perspective during data analysis enabled explication of how larger social processes influenced the decision-making and experience of SAOAs and their families regarding LTRC as well as the provision of LTRC services.

7.2 Summary of Study Findings

Study findings suggest that LTRC services, as they are currently organized, are challenged to meet the needs of immigrant and EMOA and reflect unequal and inequitable care. These findings have implications for immigrant and EMOA and their family members in light of the finding that the decision to move to LTRC may in fact be a (non) decision. Strategies to facilitate person-centred care are hindered by the macro context of care provision.

Chapter 4, “Are Mainstream LTRC Facilities Prepared to Provide Culturally Responsive Care?” reveals the minimal ability of existing LTRC facilities to acknowledge and accommodate ‘difference’ in the way services are organized. SAOAs in mainstream LTRC facilities experienced a contextualized sense of ‘difference’ which materializes when the context shifts for these older adults. For instance, ‘difference’ was experienced when there was a disconnect between their intersecting needs and preferences for language, food and religion, which are interconnected and encompassing aspects of everyday life for these older adults, and those of the institution. While individual facilities may attempt to meet these needs, study findings indicate that policies and practices imposed through detailed regulations and legislation as well as neoliberal-driven cost savings results in standardized care limiting flexibility at the facility level to provide culturally responsive care. Examples of this included the lack of SA menu items despite 15-20 percent of the resident population comprising of SAOAs (and if provided, seemed to be of poor quality) and the difficulty for care providers to access the centralized formal interpretation services. The lack of culturally appropriate food and interpretation services served to offload those services on to SA families. Other researchers have also noted the adoption of a ‘difference-blind’ approach in the provision of services to immigrant and ethno-cultural minority groups (Guo & Guo, 2011). Henry et al. (2006) argue that “failure to provide immigrants with services that are “racially sensitive, culturally appropriate, and linguistically accessible” can be attributed to the liberal universalism which assumes that “people are essentially the same” (Henry et al., 2006, as cited in Guo & Guo, 2011, p.68).

In addition to experiencing a contextualized sense of ‘difference’, SAOAs were also differentially impacted by the structural and resource constrained LTRC environment. While all residents may feel the negative impact of time constraints on staff to provide care, this can be exacerbated for SAOAs in LTRC who may require more time to communicate their needs and preferences for care and build relationships with staff due to language differences. The expectations placed on staff to complete tasks within certain timeframes results in staff having to rush care activities and leaves little time for communication and relationship building with residents (Armstrong & Braedley, 2013; DeForge, van Wyk, Hall, & Salmoni, 2011; Knopp-Sihota, Niehaus, Squires, Norton, & Estabrooks, 2015; Kontos, Miller, Mitchell, & Cott, 2010; Lopez, 2006, 2007, 2014). The combination of rushed caregiving and communication challenges may contribute to staff foregoing these aspects of care (Barnett, 1988; Reimer-Kirkham, 2000). Moreover, SAOAs may be reluctant to ask for help if staff are rushed and seem abrupt.

Study findings also illuminate the expectation and reliance on SA staff to fill the gap in meeting the language needs of SAOAs. As discussed in Chapter 4, direct and indirect expectations were placed on SA staff by SAOAs and their families as well as residential care regulations to go beyond their role descriptions to meet SAOAs' needs and assist their non-SA colleagues with interpretation and care of SAOAs. This results in increased workload for SA staff, can cause moral distress and precarious work on their part (Hadziabdic, Lundin, & Hjelm, 2015; Morley, Ives, & Bradbury-Jones, 2019), and reflects the hidden, unaccounted and unpaid work of SA staff in facilities which may save the system money by reducing the need for formal interpretation services. Other researchers have similarly noted expectations placed on ethno-cultural staff in mainstream facilities to assist with interpretation which reduces the need for facilities to organize interpretation services with resultant cost savings (Hadziabdic et al., 2015; Martin, Woods, & Williams, 2018).

The experiences of SAOAs and their families in mainstream LTRC facilities are the result of being in an environment that is structured around Euro-centric norms and values and where the predominant language of care is English. The LTRC system is also situated in a neoliberal political economy which treats people as if they are the same and offloads responsibility for "care" onto families and those who are culturally congruent (i.e., poorly paid care aides). Moreover, the neoliberal ideology of market domination, reducing costs and increasing profitization privileges transaction-based care (Armstrong & Braedley, 2013; Daly, 2013), results in inadequate staffing levels and not replacing staff who are sick or on vacation (Banerjee et al., 2012; Bowers, Esmond, & Jacobson, 2000; Knopp-Sihota et al., 2015; Lopez, 2006, 2007, 2014). Consequently, existing staff have to work in a mode of efficiency with limited time to complete tasks, thus becoming more task focused, rushing from resident to resident, leaving little or no time for the relational compassionate aspect of care (Armstrong & Braedley, 2013; Banerjee et al., 2012; Bowers et al., 2000; DeForge et al., 2011; Knopp-Sihota et al., 2015; Kontos et al., 2010; Lopez, 2006, 2007, 2014). As explicated in Chapter 4, this LTRC environment differentially impacts SAOAs in mainstream facilities. The constraints of LTRC facilities imposed by neoliberal ideology where there is a lack of designated time for effective communication between service providers and users, the lack of provision of culturally appropriate food and the minimal availability of formal interpretation services despite increasing numbers of SAOAs in mainstream LTRC facilities results in experiences of systemic discrimination (Pollock, Newbold, Lafreniere, & Edge, 2011). South Asian families pay the same as other residents but have to bring food from home and family has to be available to interpret. This discrimination leads to unequal and inequitable care for ethno-cultural populations in facilities compared to the mainstream population, and could be understood as a form of institutional racism (Anthias, 1999; Atkin, 2004; Forbat, 2004; Griffith, Childs, Eng, & Jeffries, 2007; McKenzie, 2017; Thorne, 2017; Wight, 2003), which often occurs unwittingly and unconsciously (Brotman, 2003; Forbat, 2004), and reflects the collective failure of an organization to provide appropriate and professional service to people of different ethno-cultural backgrounds; a failure that can be detected in the processes, attitudes and behaviour of institutions (Forbat 2004, p.316).

Chapter 5, "(Non) Decision Regarding Long-Term Residential Care Placement" reveals that the decision to move to LTRC may in fact be a (non) decision. Study findings uncover a range of social structural factors in the current neoliberal context that interact to *necessitate* the move to LTRC, thereby rendering it a (non) decision. Similar to findings from other research, SA family caregivers cited the declining health and functional ability of the older adult, the inability of the family caregiver to manage the escalating care needs, lack of medical knowledge or skills to provide support at home, and insufficient homecare support (Chen, 2015; Kiwi, Hydén, &

Antelius, 2018; Sussman & Dupuis, 2012; Tinker & Liu, 2001; Wee et al., 2015; Yeboah, Bowers, & Rolls, 2013) as factors that influenced LTC placement. The prohibitive cost of private in-home care was also articulated by family caregivers in the study. In addition, the availability of family members to provide care due to multi-level factors such as geographic dispersion, work, changing attitudes about caregiving (Chen, 2015; Tinker & Liu, 2001; Yeboah et al., 2013), the availability of LTRC services and awareness and knowledge of such services (Kiwi et al., 2018; Speirs, Huang, & Konnert, 2017; Wee et al., 2015) all influenced placement. Study findings illuminate the salience of socio-economic status and economic resources, in particular, in the (non) decision for LTRC placement and access to other care options. Economic resources influenced not only the family's ability to continue to look after their older family members at home as their health declined but also to supplement insufficient publicly-provided homecare support with private in-home care and consideration of other options. Family caregivers could not quit their jobs to provide more care and there is a lack of paid eldercare leave for adult children caring for older parents (Duxbury, Higgins, & Schroeder, 2009; Fine, 2012; Martin-Matthews, 2007).

Chapter 5 also explicated the difficulty and complexity of LTRC placement for SA families in the space of (non) decision. Despite having managed the care of their older parents at home for as long as possible and variation in expectations for care and caregiving observed in this study, for many SA families, LTRC placement is accompanied by significant feelings of guilt and/or shame arising from the religious authority in which SA norms of caregiving originate (Lamb, 2002, 2013; Mehta, 1997; Nayar, 2004). Consequently, many experience feelings of not having fulfilled their duty towards their parents. Study findings suggest that when health care providers recommended or made the decision for LTRC placement, this may have somewhat eased the guilt of family caregivers while simultaneously being perceived as not having a choice. In these cases, the religious knowledge of SA families about care for older adults was offset by the perceived expertise of health care providers in the space of (non) decision (Klassen, 2018; Pattison, 2013). In some cases, health care providers' suggestion regarding LTRC placement served as an "out" for some families enabling them to explain placement of their family member in LTC as professionally driven thereby reducing the guilt and stigma that often accompanies such decisions. The lack of access to ethno-cultural specific LTRC facilities also added to the tension of LTRC placement for SAOAs and their families and to the difficulty of such decisions. Other research has also shown that the lack of ethno-cultural specific LTRC facilities adds to the difficulty of decision-making around LTRC placement for ethno-cultural minority families (Andrews, 2012; Caldwell, Low, & Brodaty, 2014).

Chapter 6, "Person-Centred Transition to Long-term Residential Care for South Asian Older Adults: Challenges and Facilitators" illuminates the influence of the macro context in which LTRC services are provided on person-centred care. The transition experiences of SAOAs revealed a deep sense of loss of home and identity upon separation from family which was exacerbated by moving into a context where services are organized around Euro-centric norms and values (Koehn, Baumbusch, Reid, & Li, 2018; Mold, Fitzpatrick, & Roberts, 2005; Reimer-Kirkham, Sharma, Smith, Schutt, & Janzen, 2018). Living among others with whom they may not have commonality and not having access to customary food or people that speak their language challenged SAOAs' ability to find a sense of belonging in the facility and hence a sense of home. Other researchers have found similar experiences among immigrant older adults relocating to residential care facilities organized around the mainstream population in their countries (Martinsson, Edberg, & Janlov, 2013; Rosendahl, Söderman, & Mazaheri, 2016).

While key informants and family members provided several actionable suggestions to promote more person-centered approaches to facilitate the transition and adjustment of SAOAs in LTRC, study findings illustrated how the policy context, along with several other trends in Canadian long-term care practice (i.e., staff shortages and turnover, increased workloads, lack of resources, time constraints, regulated environment and culture of efficiency (Banerjee et al., 2012; Coughlan & Ward, 2007; DeForge et al., 2011; Donnelly & MacEntee, 2016; Harrington et al., 2012; Kontos et al., 2010; Lane, Hirst, Hawranik, Reed, & Rokhman, 2017; Lopez, 2007, 2014; McGregor et al., 2005; McGregor & Ronald, 2011)) may hinder the ability of facilities to implement such person-centred strategies. In addition, study findings illuminated how the policy context could impact the ability of SA families to attend to the unmet needs of their older family relatives in LTRC.

7.3 Major Insights and Key Implications/Recommendations

Several major insights can be drawn from study findings. In this section, I discuss the insights and associated implications/recommendations.

The decision to move to LTRC is essentially a (non) decision influenced by the interaction of a range of factors. Meso and macro-level factors in the neoliberal context, particularly economic resources of the family, inadequate home support and the prohibitive cost of private in-home care led to (non) decision. In addition, micro-level factors such as variation in expectations for care and caregiving observed among SAOAs and family members, smaller family networks, availability of family members to care due to busy work and family lives, geographic dispersion of family members all influenced placement decisions. Thus assumptions about SA families’ ability and willingness to provide care for older family members at home are problematic. SA families face the same challenges caring for older family members as mainstream Canadians. This finding, along with continued immigration and aging of the SA population, calls for LTRC service providers and policy makers to actively prepare for increasing ethno-culturally diverse resident populations and consider how best to provide culturally responsive and competent care to meet their needs. This may require taking a pluralistic approach to service planning and provision as both populations and conditions vary and context matters (Armstrong, 2018; Armstrong, Armstrong, Choiniere, Lowndes, & Struthers, 2020). A pluralistic approach to service provision means consideration of promising practices (Baines & Armstrong, 2015) rather than one single right way and understanding that implementation strategies may vary in different contexts.

Study findings illuminated the complexity and difficulty of LTRC placement for SA families in the space of (non) decision. This, along with the variation in decision-making and attitudes towards care and caregiving found in this study, indicates that when placement of SAOAs in LTRC is *necessitated*, shared decision-making in the context of person-centred care (Bunn et al., 2018; McCance, McCormack, & Dewing, 2011) can support SA families during this difficult time. Health care providers' awareness of the macro-, meso and micro-level factors influencing placement decisions, understanding the reasons for the difficulties in decision-making for LTRC placement in SA families and acknowledgement of the cultural and laic knowledges of SA families in the shared decision-making process can assist in supporting families in the decision and placement process. The importance of shared decision-making in a context where patients and their families can discuss the value and effectiveness of proposed care options without feeling judged has been noted in the literature (Bunn et al., 2018). This requires both the systems at the meso-level to support shared decision-making and communication and interpersonal skills at the micro-health care provider level (Bunn et al., 2018; McCance et al., 2011).

LTRC services as they are currently organized have little ability to adapt to difference and there is limited accommodation of difference. Services, predominantly organized around Eurocentric norms and values, are standardized so that care for everyone is the same and any changes in service provision or policy are expected to impact everyone similarly. But Canada does not have a standardized population – the Canadian population is more ethno-culturally diverse now than ever before, a trend that is expected to continue with immigration – and this study explicates the differential impact of policies based on equality and constraints on service provision imposed by neoliberal ideology on SAOAs and their families at the site of LTRC. LTRC services as they are currently provided have not kept pace with changes in the Canadian population and reflect unequal and inequitable care for ethno-cultural populations in facilities compared to the mainstream population (Um, 2016). Given the demographic shift in the Canadian population and findings regarding decision-making for LTRC, there is a need for equity-informed approaches to the care of older adults. A pluralistic ethos can facilitate the pursuit of equitable care. Such a stance results from "the daily decisions taken by institutions…and individuals to recognize and value human differences" (Global Centre for Pluralism, 2020). Kymlicka (2017) has noted that both "institution work" (referring to legislation and policy at the macro- and meso-levels) and "culture work" (referring to "cultural habits" or a "public mindset") are required to build pluralist societies/organizations since these aspects continually interact and condition each other (p.1). Despite the rhetoric related to multiculturalism, a pluralist and inclusive society, as discussed in Chapter 4, health care institutions to date are struggling to meet the needs of diverse populations. Reimer-Kirkham and

Cochrane (2016) have offered a call to responsible pluralism in our health care system and have summarized the qualities associated with this across micro, meso and macro levels. At the micro – patient and provider level – responsible pluralism entails person-centred, respectful care, seeking common ground while respecting differences. Qualities associated with responsible pluralism at the meso – administration and health care services – level include diversity services as an ethical obligation, an equity lens, and inclusiveness while paying attention to particularities. And, at the macro – community and society – level, responsible pluralism entails acknowledgement of and addressing inequities, viewing faith/[cultural] communities as social capital, and a public space for multiple voices, balancing competing views (Table 6.1) (Reimer-Kirkham & Cochrane, 2016).

Assessing whether and how new and existing policies and practices or changes in policies and practices differentially impact immigrant and ethno-cultural minority older adults (and I would submit other older adult populations such as LGBTQ) can be a starting point toward equitable access and care, and responsible pluralism in LTRC services. Health equity impact assessment tools, which have been adopted in several international jurisdictions and used and advocated by the World Health Organization (Ontario Ministry of Health and Long-Term Care, 2019) can facilitate such assessments. Moreover, there are no reliable statistics on ethnic diversity in long-term care (Durst & Barrass, 2014). The current study did not find any information regarding the number of EMOA in LTRC. Estabrooks et al. (2020) have noted the importance and need to collect data such as race, ethnicity, language, and religion among others for both residents and staff to facilitate service planning. This study affirms the importance of and need to collect such data. In addition, there is a need to analyze the findings of the survey research conducted by the B.C. Office of the Seniors Advocate in LTRC facilities by ethnicity/culture/language/religious affiliation to better understand the quality of life of EMOA in B.C. LTRC facilities. Good evidence can inform effective equity strategies in care provision.

An unanticipated finding of this research was the hidden and uncompensated work that SA staff provide in LTRC. Critical analysis uncovered a taken for granted ‘expectation’ of the system for ethno-cultural staff to go beyond their formal roles to assist with interpretation and meeting the needs of EMOA in facilities. Further exploration of this finding and the implications for ethno-cultural staff in LTRC is warranted.

The macro context in which LTRC services are provided inhibit the accommodation of person-centred care, a much espoused value of health care. This study illustrated how macro-policies and structural constraints imposed by neoliberal ideology challenged suggested approaches to facilitate person-centred transitions to LTRC for SAOAs and impacted the ability of SA families to attend to the unmet needs of their older relatives in LTRC. Further, study findings illuminated the salience of family and community networks for SAOAs and the challenges faced when moving to LTRC facilities which may not be organized to facilitate the re-establishment of a sense of community and thus belonging for these older adults. This suggests that the current conceptualization of person-centred care underpinned by the neoliberal Western notion of individualism does not align with other populations who rely on relational/social networks as well as membership in groups to thrive and for self-definition (Betsch et al., 2016). Extending the concept of person-centred care to people-centred care espoused by the WHO (World Health Organization, 2007, 2013, 2015) may mean the need for addressing both the impact of macro-policies and structural constraints (e.g., adequate staff and appropriate staff mix, a stable workforce, time to complete work and how care is distributed over time (Armstrong, 2015)), on person-centredness and consideration of the broader question of population-specific needs. In this vein, policy makers and health authorities could be called upon to consider other approaches to LTRC service delivery for immigrant and ethno-cultural minority older adults that could more comprehensively meet their holistic needs. Ethno-specific LTRC facilities/homes and the clustering model are other approaches most often discussed in the literature.

Ethno-specific LTRC facilities/homes are generally structured to cater to particular ethno-cultural groups (Andrews, 2012; Antelius & Kiwi, 2015; Kanitsaki, 1999). Not only are ethno-cultural staff who speak the same language as the residents employed, but the ethno-specific cultural context is derived from the physical, architectural, decorative aspects of the home, the types of activities conducted in the home, the general ambiance of the home embodied by the interactions between residents and residents and staff, what is heard (such culturally specific radio and television as well as language spoken), and the type of food that is cooked and served along with the aroma the foods bring about – all essentially aimed at creating a familiar environment reminiscent of their native home where older adults may feel a sense of community and belonging (Andrews, 2012; Antelius & Kiwi, 2015; Kanitsaki, 1999). These facilities are generally initiated by members of the ethno-cultural community who have identified an unmet need and are able to fundraise the capital funding required to build (Andrews, 2012). Hence, such facilities may only be possible for larger, well established communities (Durst & Barrass, 2014; Low & LoGiudice, 2018).

The clustering model (Arnold, Rowland, & Petrov, 2000; Runci, Eppingstall, van der Ploeg, & O'Connor, 2014; Westbrook & Legge, 1992) is another approach discussed in the literature. Clustering involves an agreement by the management of a nursing home to provide a percentage of beds to people from a specific language or ethno-cultural group. The nursing home makes a commitment to attempt to employ staff who are bilingual in the appropriate language, to provide the preferred food, to provide culturally acceptable leisure activities and to encourage visits from medical practitioners, clergy and other members of the ethnic community e.g., volunteers, social groups (Westbrook & Legge, 1992, p.13). There are examples of LTRC facilities in Canada which have implemented this type of model to some degree. For instance, the Yee Hong Centre for Geriatric Care in Toronto, Ontario features a South Asian floor in their Markham facility. The majority of staff caring for the residents on the floor are South Asian and SA meals for lunch and dinner are served daily. Similarly, the Scarborough Finch facility presents a Japanese unit with Japanese décor, staffed by Japanese-speaking health care professionals and Japanese meals.

The demand for ethno-specific LTRC is evidenced by the long wait times and waiting lists for such facilities. For instance, figures from Ontario, which is thought to have between fifty and sixty ethnic-specific homes (Kwong, Buchanan, & Smith, 2018) have indicated that those waiting for placement in an ethno-specific home can wait approximately six months longer than those who applied to mainstream homes and some may wait up to 12 years (Kwong et al., 2018; Um, 2016). The benefits of ethno-specific LTRC for EMOA extend beyond meeting their socio-cultural needs. Research in Yee Hong facilities for instance has shown significant health benefits with lower rates of depression, falls, skin ulcers and hospitalizations compared to mainstream facilities (Bascaramurty, 2012). Ethno-specific facilities have also noted lower rates of antipsychotic medication and restraint use (Runci, Eppingstall, & O'Connor, 2012). Yee Hong has attributed its success in meeting the needs of its ethno-cultural minority residents to several factors including paying attention to residents' cultural needs, high staff retention and a staff culture that aligns with the philosophy of care in the facility such as respect for older adults, attentiveness, as well as the center's interdisciplinary team approach to care. Innovation at the facility level where best practices are actively sought out and implemented also assists in improving the health of residents (Bascaramurty, 2012; Yee Hong Centre for Geriatric Care, n.d.).

Ethno-specific facilities, however, are not without controversy or challenges. At the macro societal level, the establishment of such facilities/organizations often raises the issue of segregation (Andrews, 2012; Curry-Stevens, Deloney, & Morton, 2019; Guo & Guo, 2011), can be perceived as a threat to national unity and disloyalty to the nation state (Curry-Stevens et al., 2019; Guo & Guo, 2011), and also raises issues regarding immigrant and minority rights, immigration policy and discourses of "us and them" (Todd, 2016). At the meso-level, once ethno-specific facilities have been built, operating funds to provide culturally sensitive services may be an issue as this may exceed what is provided by the Ministry of Health (Kwong et al., 2018) and the recruitment of ethno-cultural/bilingual staff can be challenging (Director of Resident Care, Yee Hong Centre for Geriatric Care – Markham, personal communication, May 2019). Research has shown that structural factors in the meso context can also influence care provision (Hikoyeda & Wallace, 2002; Kanitsaki, 1999; Shippee, Ng, & Bowblis, 2020) and hence culturally congruent environments alone may not be sufficient to enabling a good quality of life (Hikoyeda & Wallace, 2002). In addition, most of these facilities are subsidized by the government, and government policies regarding admission can challenge the ability of facilities to maintain their communities and can also be challenging for those of a different background who may be placed in these facilities (Armstrong, 2018; Durst & Barrass, 2014). And, as noted in the discussion above, access to existing facilities is an issue with the high demand. In-depth discussion of these issues is beyond the scope of this dissertation but further research regarding these issues and the efficacy of these models is warranted. Other researchers have also noted the need for research regarding ethno-specific LTRC (Andrews, 2012; Durst & Barrass, 2014; Martin et al., 2018; Montayre, Montayre, & Thaggard, 2018).

In summary, the findings from this study along with demographic shifts in the Canadian older adult population call for LTRC service providers and policy makers to actively prepare for increasing ethno-culturally diverse resident populations and consider how best to provide culturally responsive and competent care to meet their needs. Equity informed approaches, underpinned by a pluralistic ethos, together with the collection of data such as race, ethnicity, language, and religion, can facilitate service planning and provision.

7.4 Study Strengths and Limitations

A major strength of the current study was the fit between the methodological approach, ethnography informed by a critical theoretical perspective, and the topic of inquiry. Ethnographic methods of in-depth interviews and participant observation enabled exploration from the perspective of SAOAs and their family caregivers themselves, what their needs, preferences and challenges were regarding LTRC, how they viewed their situations, as well as the decision-making processes they undertook regarding LTRC placement. A critical theoretical framework enabled situating these individual experiences within the broader social, political and cultural context and examination of how larger social processes and structural factors influenced SAOAs' and their families' experiences and decision-making related to LTRC as well as the provision of culturally responsive and competent LTRC services. One of the goals of ethnographies informed by critical perspectives is to reveal how larger structures and processes influence and shape individual experiences (Thomas, 1993).

The inclusion of SA older adults in the study and facilitating the sharing of their experiences, needs and preferences as well as role in decision-making/consideration of LTRC was also important given that much of the research until relatively recently regarding access to care and the factors that predict placement in residential care for older adults in general and for EMOA in particular has been conducted from the perspective of family caregivers only (Dubois, Dubuc, & Caron, 2009; Gupta, 2002; Lai, 2008; Min, 2005; Sudha & Mutran, 1999). Moreover, SAOAs' views/opinions may not often be voiced given SA norms of care and caregiving where families may make care decisions for their older family members.

As a qualitative study, I was not aiming for representativeness across the entire SA population or across all LTRC facilities but the common findings among the diverse study population speaks to the legitimacy of issues and experiences. The triangulation of findings with older adults and family caregivers helped to confirm the findings as does the triangulation between study participants from different sectors i.e., assisted living, residential care and community. However, despite its diversity, the study is limited by its location in one health region (albeit one reflecting ethnic and religious diversity in its population) in one province in Canada and results may differ in other health authorities or Canadian jurisdictions.

In sharing the key insights and recommendations emanating from this study, I am cognizant that knowledge is always partial and put forth from a particular social location (Reimer-Kirkham et al., 2009). It is important to acknowledge the role that my own positioning, experience and education played in documenting and interpreting SA older adults' and family caregivers' experiences. However, ongoing input from my supervisors and colleagues during the analytic process helped broaden the lens with which the data were viewed, thus moderating the potential of my positioning from disproportionately guiding interpretations presented in the preceding chapters.

7.5 Conclusion

This dissertation examined the needs, preferences, challenges, and decision-making processes of SAOAs and their families regarding LTRC as well as whether and how existing LTRC services met their needs. The focus was on the SA population given their increasing numbers and the expectation that as SAOAs age and with continued immigration (Statistics Canada, 2017), there will likely be increasing numbers of SAOAs in LTRC facilities. Specifically, I sought to address the following research questions: 1) What are the unique needs and preferences of SAOAs and their families regarding LTRC?; 2) How are decisions regarding the use of such services made in SA families?; and 3) To what extent are existing LTRC services prepared to provide culturally responsive and competent care to meet the needs of older adults from diverse ethnic and cultural backgrounds?

In exploring these questions, study findings explicated the influence of the broader social political context and structural factors on decision-making for LTRC in SA families as well the ability of LTRC services, as they are currently organized and provided, to meet the needs of SAOAs. At a deeper level, the findings from this study raise questions about equitable service provision for SAOAs (and I submit for ethno-cultural minority older adults) in LTRC facilities.

As previously noted, the world is in the midst of the COVID-19 pandemic. The disproportionate impact of the pandemic on older adults in LTRC (Public Health Agency of Canada, 2020) has put a spotlight on the conditions of care and work in this setting, which have existed for many years and have impacted care provision (Estabrooks et al., 2020). Inadequate staffing levels, an unstable LTRC workforce, resource constraints, the organization of care and care work as well as the pursuit for profit amongst other factors have resulted in poor quality of care and quality of life for the older adults who live in these facilities (Armstrong & Armstrong, 2020; Armstrong & Braedley, 2013; Canadian Health Coalition, 2018; Estabrooks et al., 2020). However, this LTRC environment does not impact all residents equally. This study has illuminated the differential impact of this structural and resource-constrained environment as well as egalitarian policies regarding care and service provision on SA older adults and their families in LTRC.

Estabrooks et al. (2020) have discussed not only how the long-standing conditions noted above "sabotage ongoing quality of care, quality of life and a good death, quality of work life for staff, and health and safety of residents, caregivers, family and staff" (p.655), but also how these conditions compromised the ability of LTRC facilities to respond to the pandemic resulting in over 80 percent of total COVID-19 deaths in Canada occurring in nursing homes (Estabrooks et al., 2020; Public Health Agency of Canada, 2020). Given the findings from this study regarding the differential impact of these conditions on SAOAs in care, it can be surmised that ethno-cultural minority older adults in LTRC may be disproportionately impacted by the pandemic in terms of care provision, having their needs met and potentially higher fatality rates. Research from the U.S. has found that the pandemic has exacerbated racial/ethnic disparities in long-term services and supports (Shippee, Akosionu, et al., 2020). However, without the collection of data on race/ethnicity/language/religion, etc. it is not possible to determine the impact of the pandemic on the different populations residing in LTRC facilities (Estabrooks et al., 2020).

Estabrooks et al. (2020) have noted that while the causes for the failure of LTRC services to meet the needs of our most vulnerable older adults are multiple and complex, "their core is systemic and deeply institutionalized implicit attitudes about age and gender" (p.652) and I would submit race as discussed in Chapter 4.

In light of the findings from this study, as policy makers and LTRC service providers work to reform and redesign LTRC services, it is essential to keep in mind the increasing diversity in resident populations and to ensure a system that equitably meets the needs of all residents. As noted by Armstrong and Daly (2012):

> Equity is about carrying out all state activities in ways that promote appropriate responses to different needs and create conditions that allow individuals as well as groups to participate to the extent of their abilities. Such conditions include those that allow people to live with dignity and respect (p.50).

7.6 References

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Appendix 1: Facility Information Letter

Date

Facility Director’s Name

Name of Facility

Address

<u>RE: Research Study entitled “Access to Residential and End-of-Life Care: Exploring South Asian Older Adults’ and Family Caregivers’ Perspectives</u>

<u>Principal Investigators:</u> [*Name of Health Authority contact person*], (XXX) XXX-XXXX and Sherin Jamal, MSc, PhD (Candidate), (XXX) XXX-XXXX.

Dear Mr./Ms.

My name is Sherin Jamal. I am a PhD student at the University of Victoria. I will be conducting a study with South Asian older adults residing in residential long-term care and assisted living facilities in the [*Name of Health Authority*] and their family caregivers. South Asian older adults living at home and their family caregivers will also be part of the study. The purpose of my research with South Asian older adults and their family caregivers is to explore, from their perspectives, what their needs and preferences are regarding residential long-term care and end-of-life care in these settings as well as the challenges faced in accessing these services. I will also explore how South Asian families make decisions regarding placement of their older family members in residential long-term care and the role that older adults themselves play in the decision-making process. This research is being conducted as part of my doctoral degree requirements at the University of Victoria and is funded by a Canadian Institutes of Health Research Doctoral Research Award.

In carrying out the research, I am supported by a supervisory committee consisting of nationally and internationally recognized researchers including Drs. Kelli Stajduhar, Karen Kobayashi, and Sheryl Reimer-Kirkham. In addition, key [*Name of Health Authority*] staff including [*Name of Staff Member*] and [*Name of Staff Member*] are also supportive of this research.

The research will involve interviews with South Asian older adults and their family caregivers in three study settings (i.e., residential long-term care, assisted living, and older adults living at home in the community). In addition, South Asian older adults residing in residential long-term care who agree to participate in the interviews will also be requested to participate in focused participant observations. The older adult will be the focus of participant observation enabling me to gain insight regarding how they are located within that setting, their situation in the setting, their relationships with fellow residents, formal care providers and the physical environment. I will spend up to four hours at a time, ‘hanging out’ observing the older adult as he/she goes about his/her daily activities in public areas of the facility (e.g., lounge, activity room, dining room, etc.). With the assistance of a Punjabi/Hindi speaking research assistant I will conduct interviews with ten to twelve South Asian older adults currently residing in residential long-term care facilities and five to seven South Asian older adults residing in assisted living. Interviews will also be conducted separately with their family caregivers in a location that is convenient for them.

Information letters regarding the research study have been prepared for South Asian older adults and their families. These letters are available in English as well as Punjabi and Hindi. I request your assistance in distributing these information letters to South Asian older adults residing in your facilities for discussion with their family members. Older adults and their families interested in participating in the research can contact me or the research assistant directly. I also request your permission to post the study information letters in visible areas of the facility as well as approval to speak at family and resident council meetings regarding the study. In addition, I request that you inform the care staff about the study so that they are aware and have an opportunity to ask any questions of me. I would be pleased to attend a staff meeting to provide more information and answer any questions.

Ethics approval for this study has been obtained from the University of Victoria Research Ethics Board and from the [*Name of Health Authority*] Research Ethics Board.

The findings from my study will provide important insights into the needs and preferences of South Asian older adults and their families regarding residential long-term care and end-of-life care. This is significant given that South Asians comprise the largest visible minority group in Canada and the second largest in British Columbia. In addition, the findings from this research will inform future service delivery and policy related to residential long-term care and end-of-life services to meet the needs of an increasingly diverse older adult population.

I thank you in advance for your assistance. For more information on this study or if you have any questions or concerns, please do not hesitate to contact me at (XXX) XXX-XXXX or by email at XXXX@XXXXXX.

Sincerely,

Sherin Jamal, PhD Candidate

Centre on Aging, University of Victoria

Appendix 2: Study Information Letters

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Principal Investigators
[*Name of Health Authority Contact Person*], (XXX) XXX-XXXX
Sherin Jamal, MSc, PhD (Candidate), (XXX) XXX-XXXX

Dear Sir or Madam:

We would like to invite you to participate in an important study about the experiences of South Asian families in accessing residential long-term care for their older family members and about how families make decisions regarding the use of this service. Sharing your experiences with us will help in designing better services for South Asian older adults and other older adults from diverse ethnic and cultural populations.

The research is funded by a Canadian Institutes of Health Research Doctoral Research Award and will form part of a graduate student's doctoral studies at the University of Victoria.

<u>The title of our study</u> is "Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives". It is being conducted in the [*Name of Health Authority*].

<u>Why are we conducting this study?</u> We would like to understand what it is like for older South Asian people when they need to live in a care home (the health authority calls this "residential long-term care") and the difficulties they and their families may face when they access this service. We are also interested in how older South Asians make the decision to move into these homes and if and how their families get involved in that decision. In addition, we would like to understand the needs and preferences of older South Asians and their families regarding end-of-life care.

<u>Who can participate?</u> We are looking for South Asian older adults (65 years and older), who are currently living in a long-term care facility, in assisted living, or who are living at home and may be thinking about placement in residential care. We would also like to speak separately about these issues with their family caregivers.

Participation in this study is entirely voluntary. You may refuse to participate or withdraw from the study at any time and your decision will in no way affect the care you receive.

<u>What can you do?</u> If you decide to participate, we will arrange an interview with you in the language that you prefer. This will take a maximum of one and a half hours of your time and may be done over two sessions if needed. The doctoral candidate and a research assistant can come to meet you at the long-term care facility. The doctoral candidate will also spend up to four hours at a time over several months in public areas of the facility such as the lounge, dining room, and activity room, observing as you go about your daily activities. This will help her to see and understand what it is like for you to live in the care home. We will also arrange an interview with your family caregiver at a location convenient for him or her.

The information you provide will be kept strictly confidential and any identifying information will be removed or replaced by pseudonyms to protect your anonymity.

If you are interested in participating or would like more information, please contact Sherin (English) at (XXX) XXX-XXXX or [*Name of Research Assistant*] (Punjabi/Hindi) at (XXX) XXX-XXXX.

University of Victoria | Centre on Aging

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Principal Investigators
[*Name of Health Authority Contact Person*], (XXX) XXX-XXXX
Sherin Jamal, MSc, PhD (Candidate), (XXX) XXX-XXXX

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Why are we conducting this study? We would like to understand what it is like for older South Asian people when they need to live in a care home (the health authority calls this "residential long-term care") and the difficulties they and their families may face when they access this service. We are also interested in how older South Asians make the decision to move into these homes and if and how their families get involved in that decision. In addition, we would like to understand the needs and preferences of older South Asians and their families regarding end-of-life care.

Who can participate? We are looking for South Asian older adults (65 years and older), who are currently living in a long-term care facility, in assisted living, or who are living at home and may be thinking about placement in residential care. We would also like to speak separately about these issues with their family caregivers.

Participation in this study is entirely voluntary. You may refuse to participate or withdraw from the study at any time and your decision will in no way affect the care you receive or your access to care in the future.

What can you do? If you decide to participate, we will arrange an interview with you in the language that you prefer. This will take a maximum of one and a half hours of your time and may be done over two sessions if needed. We will also arrange an interview with your family caregiver. The doctoral candidate and a research assistant can come to meet you at the assisted living facility or if you are at home, your home or other location convenient for you. They will also meet with your caregiver at a location convenient for him or her. The information you provide will be kept strictly confidential and any identifying information will be removed or replaced by pseudonyms to protect your anonymity.

If you are interested in participating or would like more information, please contact Sherin (English) at (XXX) XXX-XXXX or [*Name of Research Assistant]* (Punjabi/Hindi) at (XXX) XXX-XXXX.

University of Victoria | Centre on Aging

Date

Key Informant’s Name

Position

Invitation to participate in Research Study entitled “Access to Residential and End-of-Life Care: Exploring South Asian Older Adults’ and Family Caregivers’ Perspectives

Principal Investigators: [*Name of Health Authority Contact Person*], (XXX) XXX-XXXX and Sherin Jamal, MSc, PhD (Candidate), (XXX) XXX-XXXX

Dear Mr./Ms.

We are writing to invite you to participate in a key informant interview that seeks to obtain your perspective on the needs, preferences and experiences of South Asian older adults and their families regarding residential long-term care. The interview activity is a key component of a research study with South Asian older adults residing in residential long-term care and assisted living facilities in the [*Name of Health Authority*] and their family caregivers. South Asian older adults living at home and their family caregivers are also part of the study. The purpose of the research with South Asian older adults and their family caregivers is to explore, from their perspectives, what their needs and preferences are regarding residential long-term care and end-of-life care in these settings as well as the challenges faced in accessing these services. The study also explores how South Asian families make decisions regarding placement of their older family members in residential long-term care and the role that older adults themselves play in the decision-making process. The research is funded by a Canadian Institutes of Health Research Doctoral Research Award and will form part of a graduate student’s doctoral studies at the University of Victoria.

We are inviting you to participate in this research study because you are a health care provider in residential long-term care and you have some experience with the transition, integration and/or care of South Asian seniors living in residential care. If you decide to participate in the study, Sherin Jamal, PhD (Candidate), will arrange an interview with you at a time and place that is convenient for you. The interview will take a maximum of 60 minutes of your time. During the interview, based on your experience in providing care to South Asian older adults in residential care, you will be asked to share your perspective regarding the needs, preferences and experiences of South Asian residents in residential care and their families. The information you provide will be kept strictly confidential and any identifying information will be removed or replaced by pseudonyms to protect your anonymity.

Participation in this study is entirely voluntary. You may refuse to participate or withdraw from the study at any time and there will be no penalty or loss of benefits to which you are otherwise entitled.

Ethics approval for this study has been obtained from the University of Victoria Research Ethics Board and from the [*Name of Health Authority*] Research Ethics Board.

The findings from the study will provide important insights into the needs and preferences of South Asian older adults and their families regarding residential long-term care and end-of-life care. This is significant given that South Asians comprise the largest visible minority group in Canada and the second largest in British Columbia. In addition, the findings from this research will inform future service delivery and policy related to residential long-term care and end-of-life services to meet the needs of an increasingly diverse older adult population.

If you are interested in the opportunity to participate in this study and/or would like additional details about the interview, please contact Sherin Jamal at (XXX) XXX-XXXX or by email at XXXX@XXXXXX.

University of Victoria | Centre on Aging

Date

Key Informant's Name

Invitation to participate in Research Study entitled "Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Principal Investigators: [*Name of Health Authority Contact Person*], (XXX) XXX-XXXX and Sherin Jamal, MSc, PhD (Candidate), (XXX) XXX-XXXX

Dear Mr./Ms.

We are writing to invite you to participate in a key informant interview that seeks to obtain your perspective on the needs, preferences and experiences of South Asian older adults and their families regarding residential long-term care. The interview activity is a key component of a research study with South Asian older adults residing in residential long-term care and assisted living facilities in the [*Name of Health Authority*] and their family caregivers. South Asian older adults living at home and their family caregivers are also part of the study. The purpose of the research with South Asian older adults and their family caregivers is to explore, from their perspectives, what their needs and preferences are regarding residential long-term care and end-of-life care in these settings as well as the challenges faced in accessing these services. The study also explores how South Asian families make decisions regarding placement of their older family members in residential long-term care and the role that older adults themselves play in the decision-making process. The research is funded by a Canadian Institutes of Health Research Doctoral Research Award and will form part of a graduate student's doctoral studies at the University of Victoria.

We are inviting you to participate in this research study because you are a member of the Community Advisory Committee for this research study and are knowledgeable about the South Asian community either as a member of the community or through your work with the community and can share your insights related to the perspectives of the South Asian community regarding residential long-term care. If you decide to participate in the study, Sherin Jamal, PhD (Candidate), will arrange an interview with you at a time and place that is convenient for you. The interview will take a maximum of 60 minutes of your time. During the interview, based on your knowledge of the South Asian community, you will be asked to share your insights related to the South Asian community at large and the perspective of the community related to residential long-term care. The information you provide will be kept strictly confidential and any identifying information will be removed or replaced by pseudonyms to protect your anonymity.

Participation in this study is entirely voluntary. You may refuse to participate or withdraw from the study at any time and there will be no penalty or loss of benefits to which you are otherwise entitled.

Ethics approval for this study has been obtained from the University of Victoria Research Ethics Board and from the [*Name of Health Authority*] Research Ethics Board.

The findings from the study will provide important insights into the needs and preferences of South Asian older adults and their families regarding residential long-term care and end-of-life care. This is significant given that South Asians comprise the largest visible minority group in Canada and the second largest in British Columbia. In addition, the findings from this research will inform future service delivery and policy related to residential long-term care and end-of-life services to meet the needs of an increasingly diverse older adult population.

If you are interested in the opportunity to participate in this study and/or would like additional details about the interview, please contact Sherin Jamal at (XXX) XXX-XXXX or by email at XXXX@XXXXXX.

Appendix 3: Demographic Data Collection Forms

Demographic Information for Older Adults

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Code Number: ____________

Site Code: ____________

Date: ____________

Interview Conducted in: ____________________ Name of Interpreter: __________________

Year of Birth: ____________ Gender: Male ____________ Female _________

Country of Birth: ________________________________

Year of Arrival in Canada: __________

Immigration sponsored by family member? Y/N ________ If yes, who (relationship)? _________

Religious Affiliation: __________________________________

Mother Tongue: __________________________________

Knowledge of Official Languages: English and/or French ____________

Neither _______

Fluency in other languages (besides English/French): ______________________________________

Education Level:
- Less than high school _______
- High school graduation _______
- Post secondary education
  - Diploma _______
  - Bachelor's Degree _______
  - Masters _______
  - PhD _______
  - Technical program _______
  - Other ____________________

Income Level:	< $10,000	____________	$41,000 - $50,000	__________
	$10,000 - $20,000	____________	$51,000 - $60,000	__________
	$21,000 - $30,000	____________	$61,000 - $70,000	__________
	$31,000 - $40,000	____________	> $70,000	__________

Demographic Information for Family Caregivers

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Code Number: ____________

Site Code: ____________

Date: ____________

Interview Conducted in: ______________________ Name of Interpreter: _________

Year of Birth: _____________ Gender: Male ____________ Female

Country of Birth: ________________________________ Year of Arrival in Canada:

Immigration sponsored by family member? Y/N ________ If yes, who (relationship)?

Religious Affiliation: ________________________________

Caregiver Relationship to Older Adult: ______________________________

Mother Tongue: ________________________________

Knowledge of Official Languages: English and/or French ____________

Neither _______

Fluency in other languages (besides English/French): ____________________________

Education Level:

- Less than high school _______
- High school graduation _______
- Post secondary education
  - Diploma _______
  - Bachelor's Degree _______
  - Masters _______
  - PhD _______
  - Technical program _______
  - Other ____________________

Employment Status:	Unemployed	____________		
	Self-employed	____________		
	Employed full-time	____________		
	Employed part-time	____________		
	Retired	____________		
	Other	________________________________		
Income Level:	< $10,000	____________	$41,000 - $50,000	_________
	$10,000 - $20,000	____________	$51,000 - $60,000	_________
	$21,000 - $30,000	____________	$61,000 - $70,000	_________
	$31,000 - $40,000	____________	> $70,000	_________

Appendix 4: Interview Guides

INTERVIEW GUIDE FOR OLDER ADULTS

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Questions for older adults living in residential LTC

I am a PhD student at the University of Victoria and I am interested in understanding what the needs and preferences are of South Asian older adults regarding living in LTC. I would like to talk to you about how you came to be here, what it is like for you to live here, whether you had any difficulties in getting into LTC. What you say to me will help me understand how we can improve access to LTC for South Asian older adults and how we can improve the experiences of South Asian seniors once they are in LTC.

The first few questions are about your life in LTC.

- Can you tell me a little about your life to help me understand who you are?
- How long have you lived here?
- Where were you living before you came here?
- Why did you move to LTC?
- How was the decision made to move to LTC?
    - Who was involved in making the decision?
    - What role did your family and/or friends play in making the decision to move to LTC?
    - Did you consider different options for your care or did you explore different LTC facilities before moving to this one (e.g., private versus health authority-run facilities)?
    - How did you feel about the decision to move to LTC?
- Did you have any difficulties in getting into a LTC facility?
- Before you moved here, what did you think it would be like to live in a LTC facility?
- What was it like for you when you first moved here?
- What is it like for you now to live here?
    - What do you like about being here?
    - What don't you like about being here?
    - What kinds of things do your friends and family do for you that help you here?
    - Who do you speak to if you have some difficulty or have a problem here in the care home?
- Is there anything that you feel is important for you to have here that you don't have?
- Is there anything that you worry about related to your care here?
    - How would you like to be cared for here?

The next questions ask about your needs and preferences for care at end-of-life.

- Are there things that are important for you at end of life (at time of death)?
    - Are there any specific practices that are important to you at the time of death or afterward?
    - Is there anything that you worry about related to your care at end of life?

Prompts

- Can you tell me more…
- Can you provide me with an example…
- What I hear you saying is…
- What was that like for you…
- The experience was…
- You felt like…

The following questions are concerned with your ***personal beliefs****, and how they affect your quality of life. These questions refer to religion, spirituality and any other beliefs you may hold. The questions refer to the* ***last two weeks*** *and are answered using a range such as 'Not at all' to 'An extreme amount'.*[26]

- Do your personal beliefs give meaning to your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

- To what extent do you feel your life to be meaningful?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

- To what extent do your personal beliefs give you the strength to face difficulties?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

- To what extent do your personal beliefs help you to understand difficulties in life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

The next questions relate to how you see the ***overall quality of your life*** *and ask you to say how satisfied, happy or good you have felt about various aspects of your life and to rate these aspects. Again, these questions refer to the* ***last two weeks****.*[27]

- How satisfied are you with the **quality of your life**?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

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[26] These questions have been adopted from the WHOQOL-100 tool.
[27] These questions have been adopted from the WHOQOL-100 tool.

- How would you rate your **quality of life**?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

- In general, how satisfied are you with your life?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

<u>Questions for older adults living in an assisted living facility</u>

I am a PhD student at the University of Victoria and I am interested in understanding what the needs and preferences are of South Asian older adults regarding living in LTC. I would like to talk to you about how you came to be here, what it is like for you to live here, whether you have thought about moving to a LTC facility. What you say to me will help me understand how we can improve access to LTC for South Asian older adults and how we can improve the experiences of South Asian seniors once they are in LTC.

The first few questions are about your life in Assisted Living.

- Can you tell me a little about your life to help me understand who you are?
- How long have you lived here?
- Where were you living before you came here?
- Why did you move to assisted living?
- How was the decision made to move to assisted living?
    - Who was involved in making the decision?
    - What role did your family and/or friends play in making the decision to move to assisted living?
- Did you have any difficulties in getting into an assisted living facility?
- What is it like for you to live here?
    - What do you like about being here?
    - What don’t you like about being here?
- Is there anything that you feel is important for you to have here that you don’t have?
- Is there anything that you worry about related to your care here?
- What would cause you to move to a LTC facility?
- How would you make the decision to move to a LTC facility?
    - Who else would be involved in the decision making?
    - What role would your family and/or friends play in the decision for you to move to a LTC facility?
    - What would be important for you to have in a LTC facility if you had to move to one?
    - Would you explore different LTC facilities (e.g., private versus health authority-run facilities) before making a decision?
- Is there anything that would worry you about moving to a LTC facility if you had to move to one?

The next questions ask about your needs and preferences for care at end-of-life.

- Are there things that are important for you at end of life (at time of death)?
    - Are there any specific practices that are important to you at the time of death or afterward?
    - Is there anything that you worry about related to your care at end of life?

Prompts

- Can you tell me more…
- Can you provide me with an example…
- What I hear you saying is…
- What was that like for you…
- The experience was…
- You felt like…

The following questions are concerned with your ***personal beliefs****, and how they affect your quality of life. These questions refer to religion, spirituality and any other beliefs you may hold. The questions refer to the* ***last two weeks*** *and are answered using a range such as 'Not at all' to 'An extreme amount'.*[28]

- Do your personal beliefs give meaning to your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

- To what extent do you feel your life to be meaningful?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

- To what extent do your personal beliefs give you the strength to face difficulties?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

- To what extent do your personal beliefs help you to understand difficulties in life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

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[28] These questions have been adopted from the WHOQOL-100 tool.

*The next questions relate to how you see the **overall quality of your life** and ask you to say how satisfied, happy or good you have felt about various aspects of your life and to rate these aspects. Again, these questions refer to the **last two weeks.*** [29]

- How satisfied are you with the **quality of your life**?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

- How would you rate your **quality of life**?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

- In general, how satisfied are you with your life?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

<u>Questions for older adults living in the community (alone, with spouse, or with extended family)</u>

I am a PhD student at the University of Victoria and I am interested in understanding what the needs and preferences are of South Asian older adults regarding living in LTC. I would like to talk to you about whether you have thought about moving to a LTC facility, what would be important for you if you ever had to move to LTC. What you say to me will help me understand how we can improve access to LTC for South Asian older adults and how we can improve the experiences of South Asian seniors once they are in LTC.

The first few questions are about your current living situation and your thoughts about living in a LTC facility.

- Can you tell me a little about your life to help me understand who you are?
- What is your current living situation?
    - Do you currently live alone?
    - Who else lives with you?
- Who is involved in providing care for you?
    - If respondent mentions family members living in the same house then ask: Is there anyone else that provides care for you?
- If you have ever thought about or are now thinking about living in a LTC facility, what is causing you to think about it?
- How would you make the decision to move to a LTC facility?
    - Who else would be involved in the decision making?
    - What role would your family and/or friends play in the decision for you to move to a LTC facility?
    - What would be important for you to have in a LTC facility if you had to move to one?

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[29] These questions have been adopted from the WHOQOL-100 tool.

  - Would you explore different LTC facilities (e.g., private versus health authority-run facilities) before making a decision?
- Is there anything that would worry you about moving to a LTC facility if you had to move to one?

The next questions ask about your needs and preferences for care at end-of-life.

- Are there things that are important for you at end of life (at time of death)?
  - Are there any specific practices that are important to you at the time of death or afterward?
  - Is there anything that you worry about related to your care at end of life?

Prompts

Can you tell me more…

Can you provide me with an example…

What I hear you saying is…

What was that like for you…

The experience was…

You felt like…

*The following questions are concerned with your **personal beliefs**, and how they affect your quality of life. These questions refer to religion, spirituality and any other beliefs you may hold. The questions refer to the **last two weeks** and are answered using a range such as 'Not at all' to 'An extreme amount'.*[30]

- Do your personal beliefs give meaning to your life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

- To what extent do you feel your life to be meaningful?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

- To what extent do your personal beliefs give you the strength to face difficulties?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

- To what extent do your personal beliefs help you to understand difficulties in life?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

---

[30] These questions have been adopted from the WHOQOL-100 tool.

The next questions relate to how you see the ***overall quality of your life*** *and ask you to say how satisfied, happy or good you have felt about various aspects of your life and to rate these aspects. Again, these questions refer to the* ***last two weeks.*** [31]

- How satisfied are you with the **quality of your life**?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

- How would you rate your **quality of life**?

Very poor	Poor	Neither poor nor good	Good	Very good
1	2	3	4	5

- In general, how satisfied are you with your life?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
1	2	3	4	5

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[31] These questions have been adopted from the WHOQOL-100 tool.

INTERVIEW GUIDE FOR FAMILY CAREGIVERS (FCGs)

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Questions for FCGs of older adults living in residential LTC

I am a PhD student at the University of Victoria and I am interested in understanding the perspectives of South Asian older adults and their families regarding access to residential and end-of-life care. So I will be asking you questions related to decisions about LTC, what would be important to have in LTC, etc. What you tell me will help me understand how we can improve access to LTC for South Asian older adults and how we can improve the experiences South Asian seniors once they are in LTC.

The first few questions are about your family member's life in LTC.

- Can you tell me a little about your life to help me understand who you are and what you think and feel about the questions I'm going to ask you?
- How long has your family member lived in this LTC facility?
- Where was your family member living before he/she moved to the LTC facility?
- Why did your family member move to LTC?
- How was the decision made for your family member to move to LTC?
    - Who was involved in making the decision?
    - What role did your family member himself/herself play in making the decision to move to LTC?
    - Did you consider different options for your family member's care or did you explore different LTC facilities before choosing this one (e.g. private versus health authority facilities)?
    - How did you feel about the decision to move your family member to LTC?
- Did you have any difficulties in getting your family member into a LTC facility?
- What was it like for your family member when they first moved to the LTC facility?
- What is it like for your family member to live in a LTC facility?
    - What does your family member like about being in a LTC facility?
    - What doesn't your family member like about being in a LTC facility?
- Now that your family member is in LTC, are there things that you or your family do to support him/her there?
- Is there anything that you feel is important for your family member to have in the LTC facility that he/she doesn't have?
- Is there anything that you worry about related to your family member's care at the LTC facility?
    - How would you like your family member to be cared for in the facility?

The next questions ask about your family member's needs and preferences for care at end-of-life.

- Are there things that are important for your family member at end of life (at time of death)?
    - Are there any specific practices that are important to your family member at the time of death or afterward?
    - Is there anything that you worry about related to your family member's care at end of life?

Prompts

- Can you tell me more…
- Can you provide me with an example…
- What I hear you saying is…
- What was that like for you…
- The experience was…
- You felt like…

Questions for FCGs of older adults living in an assisted living facility

I am a PhD student at the University of Victoria and I am interested in understanding the perspectives of South Asian older adults and their families regarding access to residential and end-of-life care. So I will be asking you questions related to decisions about assisted living and LTC, what would be important to have in AL and LTC, etc. What you tell me will help me understand how we can improve access to LTC for South Asian older adults and how we can improve the experiences of South Asian seniors once they are in LTC.

The first few questions are about your family member's life in Assisted Living.

- Can you tell me a little about your life to help me understand who you are and what you think and feel about the questions I'm going to ask you?
- How long has your family member lived in assisted living?
- Where was your family member living before he/she moved to assisted living?
- Why did your family member move to assisted living?
- How was the decision made to move to assisted living?
    - Who was involved in making the decision?
    - What role did your family member himself/herself play in making the decision to move to assisted living?
- Did you have any difficulties in getting your family member into an assisted living facility?
- What is it like for your family member to live in assisted living?
    - What does your family member like about being in assisted living?
    - What doesn't your family member like about being in assisted living?
- Is there anything that you feel is important for your family member to have in assisted living that he/she doesn't have?
- Is there anything that you worry about related to your family member's care in assisted living?
- If your family member had to move to a LTC facility, what would be important for him/her to have in a LTC facility?
- Is there anything that would worry you about your family member moving to a LTC facility if he/she had to move to one?
- How would the decision be made for your family member to move to a LTC facility?
    - Who would be involved in the decision making?
    - What role would your family member himself/herself play in the decision for him/her to move to a LTC facility?
    - Would you explore different LTC facilities (e.g., private versus health authority facilities) before making a decision?

The next questions ask about your family member's needs and preferences for care at end-of-life.

- Are there things that are important for your family member at end of life (at time of death)?

  - Are there any specific practices that are important to your family member at the time of death or afterward?
  - Is there anything that you worry about related to your family member's care at end of life?

Prompts

- Can you tell me more…
- Can you provide me with an example…
- What I hear you saying is…
- What was that like for you…
- The experience was…
- You felt like…

Questions for FCGs of older adults living in the community (alone, with spouse, or with extended family)

I am a PhD student at the University of Victoria and I am interested in understanding the perspectives of South Asian older adults and their families regarding access to residential and end-of-life care. So I will be asking you questions related to decisions about LTC, what would be important to have in LTC, etc. What you tell me will help me understand how we can improve access to LTC for South Asian older adults and how we can improve the experiences of South Asian seniors once they are in LTC.

The first few questions are about your family member's current living situation and thoughts about your family member living in a LTC facility.

- Can you tell me a little about your life to help me understand who you are and what you think and feel about the questions I'm going to ask you?
- What is your family member's current living situation?
  - Does your family member currently live alone?
  - Who else lives with him/her?
- Who else is involved in providing care for your family member?
- If you have you ever thought about or are now thinking about your family member living in a LTC facility, what is causing you to think about it?
- How would the decision be made for your family member to move to a LTC facility?
  - Who would be involved in the decision making?
  - What role would your family member himself/herself play in the decision for him/her to move to a LTC facility?
  - Would you explore different LTC facilities (e.g., private versus health authority facilities) before making a decision?
- What would be important for your family member to have in a LTC facility if he/she had to move to one?
- Is there anything that would worry you about your family member moving to a LTC facility if he/she had to move to one?

The next questions ask about your family member's needs and preferences for care at end-of-life.

- Are there things that are important for your family member at end of life (at time of death)?
  - Are there any specific practices that are important to your family member at the time of death or afterward?
  - Is there anything that you worry about related to your family member's care at end of life?

Prompts

Can you tell me more…

Can you provide me with an example…

What I hear you saying is…

What was that like for you…

The experience was…

You felt like…

INTERVIEW GUIDE FOR KEY INFORMANTS

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

<u>Questions for Institutional Key Informants</u>

- How did you come to work in residential long-term care?
- Can you describe your role for me? Your responsibilities here?
- From your experience, why do South Asian older adults come to live in residential long-term care?
    - What do you think causes them to move to residential care?
- From your experience and observations, what is it like for South Asian older adults when they first move into the facility?
    - Does this change over time? If so, how?
- How would you describe South Asian residents' relationships/interaction with other residents in the facility?
    - With other South Asian residents?
- How would you describe South Asian residents' relationships/interaction with facility staff?
    - Are these interactions different if a staff member is of South Asian background?
    - If yes, how is it different/are they different?
- From your experience, what factors may impact South Asian residents' adjustment in residential long-term care?
    - Is this different than other older adults' experiences who move to residential care?
- What things do you consider helpful or important in facilitating the adjustment of South Asian residents in the facility?
- How would you describe South Asian residents' relationships with their families?
- How would you describe South Asian families' engagement/involvement related to their family members' care in the facility?
- From your perspective, what can residential LTC facilities do to provide culturally responsive care to older adults from diverse ethnic and cultural backgrounds?
- In your opinion, how prepared are residential LTC facilities to provide culturally responsive and competent care to older adults from diverse ethno-cultural backgrounds?

Questions for Community Key Informants

- How would you describe South Asian older adults' expectations of their families related to their care and support as they age?
- How would you describe South Asian families' perspectives regarding caring for their parents and grandparents as they age?
- From your perspective, are South Asian seniors and families generally aware that there are residential long-term care facilities in their cities/health authorities?
- From your perspective, how does the South Asian community generally feel about placing family members in residential long-term care?
    - Under what circumstances would it be acceptable or unacceptable to place a family member in a care home?
    - Is there any stigma related to placing a family member in residential care? Is this changing? How is it changing?
- If a family member had to be placed in a residential long-term care facility, what would you consider to be helpful or important in facilitating this transition?
    - What do you think would be helpful in facilitating their adjustment once they have moved into that setting?
- From your perspective, what can residential LTC facilities do to provide culturally responsive care to older adults from diverse ethnic and cultural backgrounds?
- Is there any information related to residential long-term care that you think would be helpful for the South Asian community to have to (increase awareness, facilitate transitions, etc.?)?

Appendix 5: Participant Observation Guide

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

I am a PhD student at the University of Victoria and I am interested in understanding what the needs and preferences are of South Asian older adults regarding living in LTC. I will undertake **focused observations of South Asian older adults residing in residential LTC facilities who consent to being interviewed and to the participant observation** in order to gain insights into how South Asian older adults are located within that setting, their situation in the setting, and their relationships with fellow residents, formal care providers and the physical environment. By focusing my observations on South Asian older adults, I will have the opportunity to observe them in their current environment as well as the activities that they participate in so that I can understand the experiences of the resident and the socio-cultural context they are a part of.

The observations will take place in residential LTC facilities where consenting South Asian older adults reside and will be conducted on weekdays and weekends, varying the times throughout the course of the day. Observations will take place in public areas of the facility such as the lounge, activity room, dining room, etc. and will be limited to intervals of 3-4 hours.

Participant observation will allow me to answer the following questions:

1. How are South Asian older adults situated in the residential LTC facility vis-à-vis the environment, other residents and their formal care providers?
2. How do South Asian older adults interact with fellow residents, care providers and the physical environment?

During the participant observation, I will do the following:

- Describe where the observation takes place (e.g., lounge, dining room, activity room, etc.)
- Describe the setting at the time of observation (e.g., who is present, what time of day is it, layout of the space, etc.)
- Describe the general appearance of the South Asian older adult, including clothing, physical appearance, etc.
- Describe the environment (the facility itself, location of spaces within the facility)
- Describe interactions between South Asian older adults and others in the facility (who speaks to whom and for how long; who initiates interaction; languages or dialects spoken; tone of voice; physical behaviour and gestures) – focused on SA older adult

- In observing interactions between the South Asian older adult and care providers, I will attempt to describe how care is negotiated (e.g., describe how questions are asked and answered, describe who initiates conversations around care, etc.) – focused on SA older adult
- Describe any nonverbal communication patterns
- Describe the activities that the South Asian older adult participates in and his/her ability to participate in facility/resident activities (e.g., coffee groups, resident meetings, music groups, etc.)
- Describe the informal conversations that occur between myself and the South Asian older adult

Appendix 6: List of Documents Reviewed

- **BC Ministry of Health Home and Community Care Policy Manual** – sets out the BC Ministry of Health requirements for health authorities in planning and delivering subsidized home and community care services. The manual includes sections on eligibility and access to assisted living and long-term residential care facilities among other things.
- **B.C.’s New Residential Care Access Policy** – outlines the residential care access policy.
- **Community Care and Assisted Living Act** – Residential Care Regulation – provides strict direction to residential care facilities regarding standards to be maintained in order to remain licensed and operate under the Community Care and Assisted Living Act.
- **Residents’ Bill of Rights** – informs adults in care of their rights in residential care facilities. Added to the Community Care and Assisted Living Act Residential Care Regulations in December 2009.
- **Resident and Family Handbook** – prepared by each of the long-term residential care facilities where the research was conducted. Provides information to new residents and their families about the facility, rules and regulations, residents’ rights and responsibilities, financial information, care in the facility, etc.
- **Family Information Bulletin** – prepared by the health authority owned and operated facility. Forms part of the Welcome Package provided to new residents and their families. Provides families with information about who to contact if they have concerns about the care of their family member in the facility.
- **Move Checklist** – prepared by the health authority owned and operated facility. Provides a checklist for older adults moving into the facility including such things as belongings, particularly clothing, to bring with them; connection of phone or internet; what to do if the older adult wants a TV; how to change address; provide the funeral home contact information etc.
- **Residential Care Social Work Assessment** – purpose is to obtain personal information about the resident and to get a sense of who the resident is. Captures information such as social profile/history, religious affiliation, immigration/citizenship status, advance care planning (financial and health care), funeral home contact, income sources, health insurance benefits, family, transitions to care etc.

Appendix 7: Consent Forms

Participant Consent Form

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Principal Investigators	[*Name of Health Authority Contact Person*], [*Designations*] [*Name of Health Authority*] (XXX) XXX-XXXX Sherin Jamal, MSc, PhD (Candidate), Centre on Aging, University of Victoria (XXX) XXX-XXXX
Co-Investigators	Kelli Stajduhar, PhD, Associate Professor, School of Nursing, UVIC Karen Kobayashi, PhD, Associate Professor, Dept. of Sociology, UVIC Sheryl Reimer-Kirkham, PhD, Professor, School of Nursing, TWU

Introduction

You are invited to participate in a research study (funded by a Canadian Institutes of Health Research Doctoral Research Award) because you are a South Asian older adult (65 years and older), living in a long-term care facility. The purpose of this study is to explore the needs and preferences of South Asian older adults and their families regarding residential long-term care and end-of-life care. The study will also explore how decisions regarding the use of such services are made in South Asian families.

Voluntary participation

Taking part in this study is entirely up to you. Nobody can make you participate. If you decide that you do not want to participate, you do not have to give any reason for your decision, and you will not lose or be prevented from obtaining any benefits to which you are entitled; it will not affect the care or services you receive if you are living in a residential long-term care or assisted living facility, nor will it affect your chances of getting into one in the future.

If you decide to participate and sign this consent form, you can stop participating at any time. Signing this consent form does not limit your legal rights against the sponsor, investigators, or anyone else in any way. If you do decide to stop participating in the study for any reason, the information you have provided will only be used if you give your permission.

Background

The Canadian older adult population is becoming increasingly diverse with respect to its ethno-cultural mix. By 2031, approximately one-third of the Canadian population will belong to a visible minority group and the South Asian population will comprise the largest visible minority group in

Canada and the second largest in British Columbia. Between 2006 and 2031, the proportion of the population belonging to a visible minority group in the 65 and older age category will double from 9% to 18%. These shifts in the aging Canadian population prompt important questions as to whether the current organization of residential long-term care and end-of-life services are designed to meet the needs of increasingly diverse ethno-cultural older adults.

Goals and purpose of the study

We want to understand what it is like for older South Asian people when they need to live in a care home (the health authority calls this "residential long-term care"). We are also interested in how they make the decision to move into these homes and if and how their families get involved in that decision.

Importance of this Research

Focusing on South Asian families in later life is important because South Asians are currently the largest visible minority group in Canada and the second largest in British Columbia. Information from this study will help us to make recommendations to the health authority about how services in care homes could be designed or re-designed to meet their needs. The study findings will also provide additional questions for research in the future.

Participant Selection

You are being invited to participate in this study because you are a South Asian older adult (65 years and older), living in a long-term care facility.

What does the study involve?

You will be asked to share your experiences, opinions and feelings about care homes in an interview with the doctoral candidate and a research assistant who speaks Punjabi and/or Hindi as well as English. During the interview, we will also collect information such as when you arrived in Canada, your religious affiliation, ethnicity, education and income level. This information is important because research has shown that these factors may influence a person's health, aging and access to care. The interview will take place over one or two sessions, lasting a maximum one and a half hours, depending on how much you have to say. You can speak in Punjabi, Hindi or English. The interview will take place at a time and place that is convenient for you. The interview will be audio-taped to make sure we do not miss anything you say. A transcript will be made of the interview. Your name and other references that may identify you will be removed from this written record.

In addition, to learn more about your living situation in the care home, the doctoral candidate will spend up to four hours at a time in public areas of the care home such as the lounge, dining room, activity room, observing as you go about your daily activities. She will write down what she sees and hears so that she doesn't forget. However, the notes she takes will remain private and confidential; no real names will appear in the notes (only code names will be used) and all identifying information will be removed so that there is no link to you directly. As the study will take place over several months, she will likely observe you a number of times. The information she will collect in this way will help her to see and understand what it is like for you to live in the care home.

Anonymity, Confidentiality and Data Storage

If you are currently living in a care home or assisted living, others may know that you have participated in this research from their observations. However, we will do everything possible to make sure this is not the case.

We will also make sure that the information you provide is kept confidential to the full extent permitted by law. You will be assigned a unique study number. Only this number will be used on any research-related information collected. To protect the anonymity of participants, no reference will be made in oral or written reports which could link the participants to the study. Your real name will not appear on the transcripts of our interviews. Your name or any other identifying information will not appear in any of the reported results from this study.

The audio recordings and computer records of transcripts and participant identities (codes assigned to transcripts instead of names) will be kept on password-protected computers and will be downloaded to an external password protected hard drive. This will be kept with any hand-written notes and printouts of transcripts in a locked filing cabinet in the doctoral candidate's office for at least five years. Only the research team will have access to this data (which for the research team will always be de-identified). Consent forms will be kept in a separate locked cabinet, to which only the doctoral candidate will have access.

The data from the interviews and from observations (with no identifying information from any of the participants) will be kept for a minimum of five years in accordance with the University of Victoria research policy. The data may also be used for future analysis by the doctoral candidate to answer other research questions related to residential and end-of-life care and South Asian older adults and their families. All copies will be destroyed after such usage.

Benefits and Risks

By participating in this study, you will be able to share your feelings, opinions and experiences about care homes with the doctoral candidate. Although taking part in this study may not benefit you directly, the information you provide may help us to make recommendations to the health authority about how services in care homes should be designed or re-designed to meet the needs of other older South Asians and older adults from different ethno-cultural groups in the future.

If you agree to participate in this interview, there is a potential risk that you may feel emotional when you are sharing your experiences, opinions or feelings. We will take a break if this happens until you feel ready to continue. You can stop the interview at any time without having to give any reason for your decision.

If you agree to being observed, there is a potential loss of privacy. The doctoral candidate will take special care to make sure that her presence does not upset you. If at any time during the observations you appear to be upset by her being there, she will stop the observation and leave. You can also ask her to stop the observation at any time without giving her a reason. At the start of each observation interval, she will ask you whether you are okay with her being there.

Study Results

We will summarize the information you provide and share the main findings with you and others who work or have an interest in residential long-term care for ethno-culturally diverse older adults. The study findings will also be reported in the doctoral candidate's thesis, presented at conferences, published in academic journals and chapters, and reports written for policy makers and health care decision makers.

Ethics Approval
We have obtained ethics approval from the University of Victoria Research Ethics Board and from the [*Name of Health Authority*] Research Ethics Board to conduct this study.

For more information
If you have any questions or concerns about the research study, you can contact the Principal Investigators [*Name of Health Authority Contact Person*] at (XXX) XXX-XXXX or XXXX@XXXXXX or Sherin Jamal at (XXX) XXX-XXXX or XXXX@XXXXXX. You may also contact the Co-investigator Dr. Kelli Stajduhar at (XXX) XXX-XXXX or XXXX@XXXXXX. If you have any concerns about your rights or treatment during the study, you can also contact the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca), **or** the [*Name of Health Authority*] Research Ethics Board by calling (XXX) XXX-XXXX.

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Consent to Participate

Your signature, below indicates that you:

- have had a chance to review and have understood all of the above conditions,
- have had an opportunity to talk about it with people that you trust and/or a research team member for clarification,
- understand that you will receive a dated and signed copy of this form for your own records,
- are willing to participate in this study.

Name of the participant (print)	Signature	DD/	MM/	YY
Name of the witness (print)	Signature	DD/	MM/	YY

A copy of this consent will be left with you, and a copy will be taken by the researcher.

University of Victoria | Centre on Aging

Participant Consent Form

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Principal Investigators	[*Name of Health Authority Contact Person*], [*Designations*] [*Name of Health Authority*] (XXX) XXX-XXXX Sherin Jamal, MSc, PhD (Candidate), Centre on Aging, University of Victoria (XXX) XXX-XXXX
Co-Investigators	Kelli Stajduhar, PhD, Associate Professor, School of Nursing, UVIC Karen Kobayashi, PhD, Associate Professor, Dept. of Sociology, UVIC Sheryl Reimer-Kirkham, PhD, Professor, School of Nursing, TWU

Introduction

You are invited to participate in a research study (funded by a Canadian Institutes of Health Research Doctoral Research Award) because you are either a South Asian older adult (65 years and older), living in an assisted living facility, or you are living at home and may be thinking about moving to a care home at some time in the future. The purpose of this study is to explore the needs and preferences of South Asian older adults and their families regarding residential long-term care and end-of-life care. The study will also explore how decisions regarding the use of such services are made in South Asian families.

Voluntary participation

Taking part in this study is entirely up to you. Nobody can make you participate. If you decide that you do not want to participate, you do not have to give any reason for your decision, and you will not lose or be prevented from obtaining any benefits to which you are entitled; it will not affect the care or services you receive if you are living in an assisted living facility, nor will it affect your chances of getting into one in the future.

If you decide to participate and sign this consent form, you can stop participating at any time. Signing this consent form does not limit your legal rights against the sponsor, investigators, or anyone else in any way. If you do decide to stop participating in the study for any reason, the information you have provided will only be used if you give your permission. However, if you participated in focus group discussions, your data will be used in summarized form with no identifying information.

Background

The Canadian older adult population is becoming increasingly diverse with respect to its ethno-cultural mix. By 2031, approximately one-third of the Canadian population will belong to a visible minority group and the South Asian population will comprise the largest visible minority group in Canada and the second largest in British Columbia. Between 2006 and 2031, the proportion of the population belonging to a visible minority group in the 65 and older age category will double from 9% to 18%. These shifts in the aging Canadian population prompt important questions as to whether the current organization of residential long-term care and end-of-life services are designed to meet the needs of increasingly diverse ethno-cultural older adults.

Goals and purpose of the study

We want to understand what it is like for older South Asian people when they need to live in a care home (the health authority calls this "residential long-term care"). We are also interested in how they make the decision to move into these homes and if and how their families get involved in that decision.

Importance of this Research

Focusing on South Asian families in later life is important because South Asians are currently the largest visible minority group in Canada and the second largest in British Columbia. Information from this study will help us to make recommendations to the health authority about how services in care homes could be designed or re-designed to meet their needs. The study findings will also provide additional questions for research in the future.

Participant Selection

You are being invited to participate in this study because you are either a South Asian older adult (65 years and older), living in an assisted living facility, or you are living at home and may be thinking about moving to a care home at some time in the future.

What does the study involve?

You will be asked to share your experiences, opinions and feelings about care homes in an interview with the doctoral candidate and a research assistant who speaks Punjabi and/or Hindi as well as English. During the interview, we will also collect information such as when you arrived in Canada, your religious affiliation, ethnicity, education and income level. This information is important because research has shown that these factors may influence a person's health, aging and access to care. The interview will take place over one or two sessions, lasting a maximum one and a half hours, depending on how much you have to say. You can speak in Punjabi, Hindi or English. The interviews will take place at a time and place that is convenient for you. The interview will be audio-taped to make sure we do not miss anything you say. A transcript will be made of the interview. Your name and other references that may identify you will be removed from this written record. In addition, once the study results have been summarized, you may be invited to provide feedback on the results either individually or through focus groups.

Anonymity, Confidentiality and Data Storage

If you are currently living in an assisted living facility, others may know that you have participated in this research from their observations. However, we will do everything possible to make sure this is not the case.

We will also make sure that the information you provide is kept confidential to the full extent permitted by law. You will be assigned a unique study number. Only this number will be used on any research-related information collected. To protect the anonymity of participants, no reference will be made in oral or written reports which could link the participants to the study. Your real name will not appear on the transcripts of our interviews. Your name or any other identifying information will not appear in any of the reported results from this study.

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The data from the interviews (with no identifying information from any of the participants) will be kept for a minimum of five years in accordance with the University of Victoria research policy. The data may also be used for future analysis by the doctoral candidate to answer other research questions related to residential and end-of-life care and South Asian older adults and their families. All copies will be destroyed after such usage.

Benefits and Risks

By participating in this study, you will be able to share your feelings, opinions and experiences about care homes with the doctoral candidate. Although taking part in this study may not benefit you directly, the information you provide may help us to make recommendations to the health authority about how services in care homes should be designed or re-designed to meet the needs of other older South Asians and older adults from different ethno-cultural groups in the future.

If you agree to participate in this interview, there is a potential risk that you may feel emotional when you are sharing your experiences, opinions or feelings. We will take a break if this happens until you feel ready to continue. You can stop the interview at any time without having to give any reason for your decision.

Study Results

We will summarize the information you provide and share the main findings with you and others who work or have an interest in residential long-term care for ethno-culturally diverse older adults. The study findings will also be reported in the doctoral candidate's thesis, presented at conferences, published in academic journals and chapters, and reports written for policy makers and health care decision makers.

Ethics Approval

We have obtained ethics approval from the University of Victoria Research Ethics Board and from the [*Name of Health Authority*] Research Ethics Board to conduct this study.

For more information

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Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Consent to Participate

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- understand that you will receive a dated and signed copy of this form for your own records,
- are willing to participate in this study.

Name of the participant (print) Signature DD/ MM/ YY

Name of the witness (print) Signature DD/ MM/ YY

A copy of this consent will be left with you, and a copy will be taken by the researcher.

University of Victoria | Centre on Aging

Participant Consent Form

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Principal Investigators	[*Name of Health Authority Contact Person*], [*Designations*] [*Name of Health Authority*] (XXX) XXX-XXXX Sherin Jamal, MSc, PhD (Candidate), Centre on Aging, University of Victoria (XXX) XXX-XXXX
Co-Investigators	Kelli Stajduhar, PhD, Associate Professor, School of Nursing, UVIC Karen Kobayashi, PhD, Associate Professor, Dept. of Sociology, UVIC Sheryl Reimer-Kirkham, PhD, Professor, School of Nursing, TWU

Introduction

You are invited to participate in a research study (funded by a Canadian Institutes of Health Research Doctoral Research Award) because you are either a family member and provide some care to a South Asian older adult (65 years and older), living in a long-term care or assisted living facility, or you live with and provide some care for an older adult (65 years and older), who may be thinking about moving to a care home at some time in the future. The purpose of this study is to explore the needs and preferences of South Asian older adults and their families regarding residential long-term care and end-of-life care. The study will also explore how decisions regarding the use of such services are made in South Asian families.

Voluntary participation

Taking part in this study is entirely up to you. Nobody can make you participate. If you decide that you do not want to participate, you do not have to give any reason for your decision, and you or the family member you care for will not lose or be prevented from obtaining any benefits to which you are entitled; it will not affect the care or services your family member receives if he or she is living in a residential long-term care or assisted living facility, nor will it affect your family member's chances of getting into one in the future.

If you decide to participate and sign this consent form, you can stop participating at any time. Signing this consent form does not limit your legal rights against the sponsor, investigators, or anyone else in any way. If you do decide to stop participating in the study for any reason, the information you have provided will only be used if you give your permission. However, if you participated in focus group discussions, your data will be used in summarized form with no identifying information.

Background

The Canadian older adult population is becoming increasingly diverse with respect to its ethno-cultural mix. By 2031, approximately one-third of the Canadian population will belong to a visible minority group and the South Asian population will comprise the largest visible minority group in Canada and the second largest in British Columbia. Between 2006 and 2031, the proportion of the population belonging to a visible minority group in the 65 and older age category will double from 9% to 18%. These shifts in the aging Canadian population prompt important questions as to whether the current organization of residential long-term care and end-of-life services are designed to meet the needs of increasingly diverse ethno-cultural older adults.

Goals and purpose of the study

We want to understand what it is like for older South Asian people when they need to live in a care home (the health authority calls this “residential long-term care”). We are also interested in how they make the decision to move into these homes and if and how their families get involved in that decision.

Importance of this Research

Focusing on South Asian families in later life is important because South Asians are currently the largest visible minority group in Canada and the second largest in British Columbia. Information from this study will help us to make recommendations to the health authority about how services in care homes could be designed or re-designed to meet their needs. The study findings will also provide additional questions for research in the future.

Participant Selection

You are being invited to participate in this study because you are either a family member and provide some care to a South Asian older adult (65 years and older), living in a long-term care or assisted living facility, or you live with and provide some care for an older adult (65 years and older), who may be thinking about moving to a care home at some time in the future.

What does the study involve?

You will be asked to share your experiences, opinions and feelings about care homes in an interview with the doctoral candidate and a research assistant who speaks Punjabi and/or Hindi as well as English. During the interview, we will also collect information such as when you arrived in Canada, your religious affiliation, ethnicity, education and income level. This information is important because research has shown that these factors may influence a person’s health, aging and access to care. The interview will last a maximum one and a half hours, depending on how much you have to say. You can speak in Punjabi, Hindi or English. The interview will take place at a time and place that is convenient for you. The interview will be audio-taped to make sure we do not miss anything you say. A transcript will be made of the interview. Your name and other references that may identify you will be removed from this written record. In addition, once the study results have been summarized, you may be invited to provide feedback on the results either individually or through focus groups.

Anonymity, Confidentiality and Data Storage

We will make sure that the information you provide is kept confidential to the full extent permitted by law. You will be assigned a unique study number. Only this number will be used on any research-related information collected. To protect the anonymity of participants, no reference will be made in oral or written reports which could link the participants to the study. Your real name will not appear on the transcripts of our interviews. Your name or any other identifying information will not appear in any of the reported results from this study.

The audio recordings and computer records of transcripts and participant identities (codes assigned to transcripts instead of names) will be kept on password-protected computers and will be downloaded to an external password protected hard drive. This will be kept with any hand-written notes and printouts of transcripts in a locked filing cabinet in the doctoral candidate's office for at least five years. Only the research team will have access to this data (which for the research team will always be de-identified). Consent forms will be kept in a separate locked cabinet, to which only the doctoral candidate will have access.

The data from the interviews (with no identifying information from any of the participants) will be kept for a minimum of five years in accordance with the University of Victoria research policy. The data may also be used for future analysis by the doctoral candidate to answer other research questions related to residential and end-of-life care and South Asian older adults and their families. All copies will be destroyed after such usage.

Benefits and Risks

By participating in this study, you will be able to share your feelings, opinions and experiences about care homes with the doctoral candidate. Although taking part in this study may not benefit you or the family member you care for directly, the information you provide may help us to make recommendations to the health authority about how services in care homes should be designed or re-designed to meet the needs of other older South Asians and older adults from different ethno-cultural groups in the future.

If you agree to participate in this interview, there is a potential risk that you may feel emotional when you are sharing your experiences, opinions or feelings. We will take a break if this happens until you feel ready to continue. You can stop the interview at any time without having to give any reason for your decision.

Study Results

We will summarize the information you provide and share the main findings with you and others who work or have an interest in residential long-term care for ethno-culturally diverse older adults. The study findings will also be reported in the doctoral candidate's thesis, presented at conferences, published in academic journals and chapters, and reports written for policy makers and health care decision makers.

Ethics Approval

We have obtained ethics approval from the University of Victoria Research Ethics Board and from the [*Name of Health Authority*] Research Ethics Board to conduct this study.

For more information

If you have any questions or concerns about the research study, you can contact the Principal Investigators [*Name of Health Authority Contact Person*] at (XXX) XXX-XXXX or XXXX@XXXXXX or Sherin Jamal at (XXX) XXX-XXXX or XXXX@XXXXXX. You may also contact the Co-investigator Dr. Kelli Stajduhar at (XXX) XXX-XXXX or XXXX@XXXXXX. If you have any concerns about your rights or treatment during the study, you can also contact the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca), **or** the [*Name of Health Authority*] Research Ethics Board by calling (XXX) XXX-XXXX.

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Consent to Participate

Your signature, below indicates that you:

- have had a chance to review and have understood all of the above conditions,
- have had an opportunity to talk about it with people that you trust and/or a research team member for clarification,
- understand that you will receive a dated and signed copy of this form for your own records,
- are willing to participate in this study.

Name of the participant (print)	Signature	DD/	MM/	YY
Name of the witness (print)	Signature	DD/	MM/	YY

A copy of this consent will be left with you, and a copy will be taken by the researcher.

University of Victoria | Centre on Aging

Participant Consent Form

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Principal Investigators	[*Name of Health Authority Contact Person*], [*Designations*] [*Name of Health Authority*] (XXX) XXX-XXXX Sherin Jamal, MSc, PhD (Candidate), Centre on Aging, University of Victoria (XXX) XXX-XXXX
Co-Investigators	Kelli Stajduhar, PhD, Associate Professor, School of Nursing, UVIC Karen Kobayashi, PhD, Associate Professor, Dept. of Sociology, UVIC Sheryl Reimer-Kirkham, PhD, Professor, School of Nursing, TWU

Introduction

You are invited to participate in a research study (funded by a Canadian Institutes of Health Research Doctoral Research Award) because you are either a health care provider in residential long-term care and have some experience with the transition, integration and/or care of South Asian older adults (65 years and older) living in a long-term care facility, or you are a member of the Community Advisory Committee for this research study and are knowledgeable about the South Asian community either as a member of the community or through your work with the community and can share some insights related to the perspectives of the South Asian community regarding residential long-term care. The purpose of this study is to explore the needs and preferences of South Asian older adults and their families regarding residential long-term care and end-of-life care. The study will also explore how decisions regarding the use of such services are made in South Asian families.

Voluntary participation

Taking part in this study is entirely up to you. Nobody can make you participate. If you decide that you do not want to participate, you do not have to give any reason for your decision, and there will be no penalty or loss of benefits to which you are otherwise entitled.

If you decide to participate and sign this consent form, you are still free to withdraw at any time and without giving any reasons for your decision. If you do decide to stop participating in the study for any reason, the information you have provided will only be used if you give your permission.

Background

The Canadian older adult population is becoming increasingly diverse with respect to its ethno-cultural mix. By 2031, approximately one-third of the Canadian population will belong to a visible minority group and the South Asian population will comprise the largest visible minority group in Canada and the second largest in British Columbia. Between 2006 and 2031, the proportion of the population belonging to a visible minority group in the 65 and older age category will double from 9% to 18%. These shifts in the aging Canadian population prompt important questions as to whether the current organization of residential long-term care and end-of-life services are designed to meet the needs of increasingly diverse ethno-cultural older adults.

Goals and purpose of the study

We want to understand what it is like for older South Asian people when they need to live in a care home (the health authority calls this “residential long-term care”). We are also interested in how they make the decision to move into these homes and if and how their families get involved in that decision.

Importance of this Research

Focusing on South Asian families in later life is important because South Asians are currently the largest visible minority group in Canada and the second largest in British Columbia. Information from this study will help us to make recommendations to the health authority about how services in care homes could be designed or re-designed to meet their needs. The study findings will also provide additional questions for research in the future.

Participant Selection

You are being invited to participate as a key informant in this study because you are either a health care provider in residential long-term care and have some experience with the transition, integration and/or care of South Asian older adults (65 years and older) living in a long-term care facility, or you are a member of the Community Advisory Committee for this research study and are knowledgeable about the South Asian community either as a member of the community or through your work with the community and can share some insights related to the perspectives of the South Asian community regarding residential long-term care.

What does the study involve?

As a health care provider in residential long-term care and based on your experience in providing care to South Asian older adults in residential care, you will be asked to share your perspective regarding the needs, preferences and experiences of South Asian residents in residential care and their families in an interview with Sherin Jamal, PhD (Candidate). As a member of the South Asian community or because of your work with the South Asian community and your knowledge of the South Asian community, you will be asked to share your insights related to the South Asian community at large and the perspective of the community related to residential long-term care. The interview will last a maximum of one hour and will take place at a time and place that is convenient for you. With your permission the interview will be audio-taped to make sure we do not miss anything you say. A transcript will be made of the interview. Your name and other references that may identify you will be removed from this written record. In addition, once the study results have been summarized, you may be invited to provide feedback on the results either individually or through focus groups.

Anonymity, Confidentiality and Data Storage

We will make sure that the information you provide is kept confidential to the full extent permitted by law. However, research records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of the [*Name of Health Authority*] Research Ethics Board for the purpose of monitoring the research. You will be assigned a unique study number. Only this number will be used on any research-related information collected. To protect the anonymity of participants, no reference will be made in oral or written reports which could link the participants to the study. Your real name will not appear on the transcripts of our interviews. Your name or any other identifying information will not appear in any of the reported results from this study.

The audio recordings and computer records of transcripts and participant identities (codes assigned to transcripts instead of names) will be kept on password-protected computers and will be downloaded to an external password protected hard drive. This will be kept with any hand-written notes and printouts of transcripts in a locked filing cabinet in the doctoral candidate's office for at least five years. Only the research team will have access to this data (which for the research team will always be de-identified). Consent forms will be kept in a separate locked cabinet, to which only the doctoral candidate will have access.

The data from the interviews (with no identifying information from any of the participants) will be kept for a minimum of five years in accordance with the University of Victoria research policy. The data may also be used for future analysis by the doctoral candidate to answer other research questions related to residential and end-of-life care and South Asian older adults and their families. All copies will be destroyed after such usage.

Benefits and Risks

There are no anticipated benefits to you from taking part in this study. Participating in this study and sharing your insights regarding the needs, preferences, experiences and perspectives of South Asian older adults and families related to residential long-term care may help us to make recommendations to the health authority about how services in care homes should be designed or re-designed to meet the needs of older South Asians and older adults from different ethno-cultural groups in the future.

There are no anticipated risks to you if you agree to participate in this interview. You can stop the interview at any time without having to give any reason for your decision and you do not have to answer any questions you do not want to.

Study Results

We will summarize the information you provide and share the main findings with you and others who work or have an interest in residential long-term care for ethno-culturally diverse older adults. The study findings will also be reported in the doctoral candidate's thesis, presented at conferences, published in academic journals and chapters, and reports written for policy makers and health care decision makers.

Ethics Approval

We have obtained ethics approval from the University of Victoria Research Ethics Board and from the [*Name of Health Authority*] Research Ethics Board to conduct this study.

For more information

If you have any questions or concerns about the research study, you can contact the Principal Investigators [*Name of Health Authority Contact Person*] at (XXX) XXX-XXXX or XXXX@XXXXXX or Sherin Jamal at (XXX) XXX-XXXX or XXXX@XXXXXX. You may also contact the Co-investigator Dr. Kelli Stajduhar at (XXX) XXX-XXXX or XXXX@XXXXXX. If you have any concerns about your rights or treatment during the study, you can also contact the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca), **or** the [*Name of Health Authority*] Research Ethics Board by calling (XXX) XXX-XXXX.

Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives

Consent to Participate

Your signature, below indicates that you:

- have had a chance to review and have understood all of the above conditions,
- have had an opportunity to talk about it with a research team member for clarification,
- understand that you will receive a dated and signed copy of this form for your own records,
- are willing to participate in this study.

Name of the participant (print)	Signature	DD/ MM/ YY

Name of the witness (print)	Signature	DD/ MM/ YY

A copy of this consent will be left with you, and a copy will be taken by the researcher.