# “Even if we want help, there is no help”

# Exploring Perceptions and Barriers in Home Care Services within the South Asian Communities

by

Krithika Subbiah

A thesis

presented to the University of Waterloo

in fulfillment of the

thesis requirement for the degree of

Master of Science

in

Public Health Sciences

Waterloo, Ontario, Canada, 2024

© Krithika Subbiah 2024

# Author’s Declaration

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

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

# Abstract

**Background**: In Canada, the demand for home care services continues to increase due to the ongoing growth of the aging population. This aging population is marked not only by the increase in the number of older adults but also by its significant diversity (National Advisory Council on Aging, 2005). There is a growing need to address disparities in the utilization of home care services among immigrant older adults (Wellesley Institute, 2016). Despite the importance of home care services, little is known about how ethnic minorities perceive home care services in Ontario, specifically South Asian communities – who are the largest minority in Canada. Therefore, recognizing this overarching context, my research aimed to explore South Asian communities' nuanced perceptions about home care services in Ontario, barriers they face when accessing these services and recommendations on how home care services in Ontario can be structured to address their unique needs.

**Specific Aims:** The study aimed to explore South Asian communities' nuanced perceptions about home care services in Ontario and the barriers they experience when they access home care services. Additionally, it sought recommendations from these communities on how to enhance home care services for older adults, aiming to improve the provision of culturally aligned home care services for South Asian communities in Ontario.

**Methods**: This study employed an exploratory qualitative research design to investigate the nuanced perceptions about home care services in Ontario, barriers they face when accessing these services and recommendations on how home care services in Ontario can be structured to address their unique needs. Thirteen participants, including seven care partners, three South Asian older adults, and three social workers who engaged with South Asian older adults, contributed to the study. A Reflexive Thematic Analysis (RTA) was utilized to engage with the data and generate themes for the study.

This method facilitated a rigorous and reflexive examination of participants' narratives, enhancing the depth and richness of the study findings.

**Results:** The participants emphasized a significant demand for home care services within South Asian communities. In shedding light on the barriers faced by these communities in accessing home care services, various challenges experienced by care partners and older adults in Ontario were revealed. The findings also revealed the impact of duration of residency in Canada on openness to formal home care, the presence of stigma hindering care-seeking, and a lack of awareness about available home care services. Evolving gender roles and care partner burdens were discussed, emphasizing the necessity of culturally tailored support services. Preferences for culturally competent and humble care, language concordance, and alignment with care providers' gender and ethnicity emerged as significant themes. Additionally, the study participants offered valuable recommendations to improve home care services for South Asian communities. These suggestions, ranging from enhancing accessibility to customizing services, aim to align with the cultural needs of the South Asian communities.

**Discussion**: The study reinforced the notion that the South Asian communities are a diverse and heterogeneous group. Perceptions of home care services differed based on the extent of Western cultural adaptation and lived experiences. The research also underscored that while the general population faces obstacles in accessing home care, these challenges are more pronounced within the South Asian communities due to factors like cultural expectations, language barriers, and financial constraints. Additionally, it highlighted the need for culturally tailored home care services to meet the specific needs of an increasingly diverse aging population.

**Conclusion:** This study significantly contributed to ethnogerontological knowledge by examining South Asian communities' nuanced perceptions about home care services in Ontario, barriers they

faced when accessing these services and recommendations on how home care services in Ontario can be structured to address their unique needs. Recommendations included targeted awareness strategies and culturally sensitive services for South Asian communities. The study advocated for a holistic home care model, patient-centered care, and cautioning against reliance on cultural stereotypes. Future research suggestions included exploring perceptions among recent immigrants, those with dementia, and an intersectional analysis. Additionally, investigating cultural factors like filial piety and their impact on long-term care decisions within the South Asian communities is recommended.

# Acknowledgements

I extend my heartfelt gratitude to Dr. Elena Neiterman for her unwavering support throughout my academic journey. Your consistent encouragement and guidance have played a crucial role in helping me write this thesis. Navigating the challenges of my academic path wouldn't have been as manageable without your support. The way you lead with kindness has genuinely left a mark on me. I am deeply grateful for the invaluable life lessons you've imparted. Your mentorship extends beyond the academics, and I am truly thankful for your existence.

I'd also like to express my sincere gratitude to Dr. Suzanne Tyas, Dr. Samantha Meyer, Dr. Catherine Tong, and Dr. Paul Stolee for their invaluable guidance in shaping my thesis into something meaningful. Each and every one of you has played a pivotal role in enriching my academic experience, and I am genuinely grateful for the valuable insights you've shared along the way.

I'd also like to thank my dear family and friends for their unwavering support. Your presence has been a constant source of strength, celebrating my successes and standing by me during challenges. I truly appreciate the meaningful connections we've built, and each of you holds a special place in my heart.

Lastly, I would like to express my appreciation to the participants for generously sharing their stories with me. This thesis would not have been possible without their valuable contributions.

# Land Acknowledgement

I wish to acknowledge that I am an international student currently residing in the traditional territory of the Neutral, Anishinaabeg, and Haudenosaunee Peoples. My academic endeavors for the past two years have been based at the University of Waterloo, located on the Haldimand Tract, a territory granted to the Six Nations, encompassing six miles on each side of the Grand River.

## Table of Contents

*Abstract* ........ *iii*

*Acknowledgements* ........ *vi*

*Land Acknowledgement* ........ *vii*

*List of Tables* ........ *xi*

*List of Abbreviations* ........ *xii*

*Chapter 1: Introduction* ........ *1*

**1.1 Canada - The Land of Immigrants** ........ **1**

1.1.1 South Asia - Unity in Diversity ........ 2

**1.2 Impacts of Culture on Caring at Home** ........ **3**

**1.3 Cultural Considerations in Provision of Care to South Asian Communities** ........ **4**

**1.4 Provision of Home Care Services in Canada** ........ **7**

1.4.1 The Gap in the Provision of Home Care Services in Canada ........ 10

*Chapter 2 : Study Aims* ........ *13*

*Chapter 3: Methodology* ........ *14*

**3.1 Research Design** ........ **14**

*Chapter 4: Methods* ........ *16*

**4.1 Study Sample** ........ **16**

**4.2 Ethics** ........ **17**

**4.3 Recruitment** ........ **18**

**4.4 Participants** ........ **18**

**4.5 Data Collection** ........ **21**

**4.6 Translation ........ 22**

**4.7 Reflexivity and Positionality ........ 23**

**4.8 Data Analysis ........ 24**

***Chapter 5: Results ........ 26***

**5.1 The Current Need for Home Care Services within the South Asian Communities: "Illuminating Cultural Depths in Home Care." ........ 28**

5.1.1 Perceptions of Home Care Services within South Asian Communities ........ 28

5.1.2 Evolution of Blended Gender Roles in a South Asian Families ........ 38

**5.2 Barriers Encountered by the South Asian Communities While Accessing Home Care Services: "Echoing the Voices of the Unheard." ........ 44**

5.2.1 Lack of Cultural and Language Considerations in Home Care Services ........ 44

5.2.2 Increased Waiting Times in Receiving Culturally Aligned Services ........ 49

5.2.3 Lack of Awareness About Home Care Services ........ 50

5.2.4 Lack of Interpersonal Connection and Consistency of Home Care Services ........ 51

5.2.5 Racism and Inherent Trauma ........ 53

5.2.6 Lack of Funding and Service Hours ........ 54

5.2.7 Challenges in Coordination of Home Care Services ........ 57

5.2.8 Lack of Support for PSWs ........ 59

**5.3 Recommendations to Improve Home Care Services for the South Asian Communities: "Weaving Cultural Threads in the Tapestry of Home Care." ........ 61**

5.3.1 Focus on Gender, Ethnicity and Language Concordance in Home Care Services ........ 61

5.3.2 Enhance Cultural Humility in Home Care Services ........ 65

5.3.3 Foster Kindness and Compassion in Home Care Services ........ 67

5.3.4 Promote Awareness About Home Care Services ........ 68

5.3.5 Prioritize Building Rapport with Older Adults ........ 71

***Chapter 6: Discussion ........ 73***

**6.1 Implications for Policy and Practice ........ 80**

**6.2 Implications for Future Research ........ 83**

**6.3 Limitations and Strengths ........ 84**

*Chapter 7: Conclusion* ........................................................................................ *87*

*References* ........................................................................................................ *88*

*Appendix A: Recruitment Materials* ................................................................... *107*

*APPENDIX B: Letter of Information and Consent Form* .................................................. *110*

*APPENDIX C: Interview Guide*......................................................................................... *117*

*Appendix D: Feedback Form*.......................................................................................... *122*

# List of Tables

Table 1: Description of the study participants ........................................................................ 19
Table 2 : Themes generated during the data analysis ............................................................ 26

# List of Abbreviations

| | |
|---|---|
| ALC | Alternate Level of Care |
| HCCSS | Home and Community Care Support Services |
| HHC | Home Health Care |
| LHIN | Local Health Integration Networks |
| NIA | National Institute of Ageing |
| OHIP | Ontario Health Insurance Plan |
| PSW | Personal Support Workers |
| RTA | Reflexive Thematic Analysis |

# Chapter 1: Introduction

## 1.1 Canada - The Land of Immigrants

Canada is a multicultural country with almost one-third of its population born overseas (Canada, 2022). In 2018, immigration accounted for approximately two-thirds of the country's population growth (Statistics Canada, 2018). According to the 2021 census, more than 23% of the total population of Canada are immigrants, and by 2041, this number is projected to increase to 34% (Statistics Canada, 2021a). This is the highest proportion of immigrants in the population since Canada was founded in 1867 (Statistics Canada, 2021b). In 2021, over 2.5 million Canadian immigrants originated in South Asia (7.1% of the total population), making it the largest visible minority group in Canada (Statistics Canada, 2021b).

A parallel demographic development in Canada is the growth of multigenerational households. This trend is largely attributed to the practice of sponsoring older parents to live with their families (Statistics Canada, 2022; Turcotte and Schellenberg, 2007). In 2012, Citizenship and Immigration Canada (2012) reported that India and Sri Lanka were the top source countries with the highest number of parent and grandparent sponsorships (Citizenship and Immigration Canada, 2012). According to Battams (2016), immigrants are twice as likely as non-immigrants to live in multigenerational households. These demographic developments have significant implications for the provision of culturally competent care for immigrant South Asian families, especially for older adults (Battams, 2016).

### 1.1.1 South Asia - Unity in Diversity

South Asia is a geographically extensive and populous region characterized by profound social and cultural variation. Geographically, South Asia encompasses six countries: Pakistan, India, Nepal, Bhutan, Bangladesh, and Sri Lanka (Mann, 2014). This region is particularly known for its linguistic and religious diversity. The diversity within the South Asian communities in Canada is evident through the extensive range of South Asian languages spoken in the country (Statistics Canada, 2021a). The 2021 Canadian census illustrated the multilingual nature of the South Asian communities in Canada, with English (36.4%), Punjabi (29.4%), Urdu (11.3%), Hindi (8.2%), Tamil (7.1%), and Gujarati (6.4%) being the most commonly reported languages, either spoken alone or in combination with other languages (Statistics Canada, 2021a). With regards to religion, Hinduism, Sikhism, and Islam make up the top three religions practiced by South Asian communities in Canada (29.9%, 29.6%, and 23.1%, respectively) (Statistics Canada, 2021a). It is essential to be cognizant that the terminology "South Asian" includes a wide range of sub-groups that might differ in their religious beliefs as well as sociocultural views (Zaidi et al., 2014).

Despite these geographic, religious, and linguistic differences, the distinctive cultural norms and social values that are shared by the South Asian communities may have an impact on their healthcare values and practices (Ramaswamy et al., 2019). One such cultural norm is *filial piety*. Filial piety is a practice of honoring and caring for one's parents in their old age and is based on a moral obligation that offspring owe their parents (Sharma and Kemp, 2011; Sharma et. al, 2011; Acharya and Northcott, 2007). Among South Asian communities, the concept of filial piety holds a significant importance, requiring offspring to shoulder the responsibility of caring for their parents and other older family members (Jamuna, 2000; Gupta and Pillai 1996). Furthermore, it is common in South

Asian cultures to anticipate that family members will be in charge of making significant healthcare decisions for their parents (Biondo et al., 2017).

## 1.2 Impacts of Culture on Caring at Home

The Eastern and Western cultural value systems seem to considerably differ from one another (Shariff, 2008). Western individualistic culture places high importance on independence and individualism (Perez, 1997). These values set the individual's interests and wants above those of the family of origin (Ogihara, 2014). On the other hand, the needs and the expectations of the family are prioritized over those of any individual family member in collectivist cultures. This type of culture seems to be prevalent in Eastern countries (Huisman, 1996). According to Wardak (2000), in Eastern societies, the family structure and function are prioritized over all other relationships (Wardak, 2000). Furthermore, in Eastern cultures, family members discuss all decisions, big or small, and they always consider how they might affect their significant others (Ayyub, 2000). Overall, this shared collectivistic cultural value system can have significant implications on healthcare decisions made by South Asian communities, including those related to the older adults in the family (Lucas et al., 2013).

In Western culture, the primary responsibility to care for aging parents is expected to be fulfilled by a female child. On the other hand, in South Asian communities it is often the responsibility of the son or male family relative to make important healthcare decisions for their parents (Radhakrishna et al., 2017). Meanwhile, daughters and daughters-in-law typically engage in household activities and provide hands-on care and companionship (Radhakrishna et al., 2017; Sharma et al., 2011; Weerasinghe & Maddalena, 2016). Acknowledging the differences in decision-making and care practices within the Eastern and Western value systems emphasizes the need to tailor healthcare approaches for ethnic minorities in Canada, whose cultural values may differ from the Western norm

(Surood & Lai, 2010). Therefore, adapting healthcare provision to account for these cultural variations is essential to ensure the delivery of inclusive and culturally aligned health services.

## 1.3 Cultural Considerations in Provision of Care to South Asian Communities

When addressing cultural considerations in the provision of healthcare services, a central concept that surfaces is cultural competence. Coined in the 1980s, the term "cultural competency" underscores the importance of specific skills in delivering care, rooted in an understanding of the customs and beliefs of various cultural groups (Pistole, 2004). Culturally competent care is characterized by its sensitivity and responsiveness to cultural beliefs, values, family norms, and obligations (Guberman & Maheu, 2002). The implementation of cultural competency in healthcare delivery has been identified as a factor contributing to improved health and well-being among patients (Narayana, 2016).

However, the concept of cultural competency has faced criticism from multiple researchers for several reasons. A literature review conducted by Grenier (2020), showed that cultural competency has a reductionist and static approach to culture that neglects its dynamic nature (Azzopardi & McNeill, 2016; Beagan, 2018; Grenier, 2020). Additionally, framing cultural competency within the objectivist paradigm as a skill to be acquired through learning and training, and subject to assessment, oversimplifies the complexities of cultural understandings (Kumas-Tan et al., 2007). Furthermore, the criticism of cultural competency is centered on its simplistic, liberal approach to addressing racism, consequently overlooking the broader systemic and structural factors contributing to discrimination (Azzopardi & McNeill, 2016; Furlong & Wight, 2011; Kumas-Tan et al.,2007). Finally, there's a neglect of intersectionality and the lack of consideration of healthcare professionals' social location and positionality (Kumas-Tan et al., 2007; Beagan, 2018). Therefore, these critiques underscore the

necessity of adopting a more nuanced and systemic approach to cultural competency, one that acknowledges and addresses the underlying structures contributing to disparities and discrimination.

Given the limitations of the term “cultural competence”, researchers introduced the term “cultural humility” (Lekas, 2019). Cultural humility is a lifelong process of self-reflection, designed to deepen the understanding of cultural differences and to effectively conduct research involving vulnerable groups (Tervalon, & Murray-García,1998; Yeagar, 2013). Cultural humility is the practice of recognizing one's limited knowledge and being open to learning from patients about their experiences (Yeagar, 2013). It also entails being mindful of one's own cultural context and how it shapes one's perspectives (Tervalon, & Murray-García,1998). One of the advantages of cultural humility is that it takes into account the dynamic nature of cultures and acknowledges the consideration of other social-identity factors, including sexual orientation and gender (Tervalon & Murray-Garcia, 1998). Moreover, it does not require the healthcare providers to be experts on the culture of care recipients (Lekas, 2019). Nonetheless, a primary criticism directed at cultural humility stems from a perceived lack of conceptual clarity, creating a challenge for healthcare providers to ascertain if they are effectively practicing cultural humility (Danso, 2018).

Another term, which has gained attention and momentum in the health setting is “person-centered care” (Howard et al., 2018). The primary aim of person-centered care is to individualize care and adapt care delivery to unique sociocultural values and perspective, incorporating a holistic approach to care (McMillian 2013). Moreover, person-centered care promotes viewing each individual as a “unique human being,” decreasing physicians' often unconscious racial or ethnic biases (Marrelli, 2017). This approach to care has significance in home care as healthcare providers become “guests” in the care recipient’s personal space, requiring them to adapt and be flexible to the individual's lifestyle and surroundings (Marrelli, 2017).

Cultural competence provides a general framework for understanding client's cultural needs, while cultural humility adds an essential layer of ongoing learning and adaptation (Greene-Moton, 2020). Meanwhile, person-centered care ensures that each care recipient's overall individual preferences are prioritized irrespective of their cultural background. Although person-centered care offers a comprehensive framework that includes elements of cultural competence and humility (Saha, 2008; Kelsall-Knight, 2022), this section will delve deeper into cultural humility. Cultural humility is important for effectively catering to the nuanced cultural dynamics of ethnic minority groups in healthcare, ensuring that care is not only personalized but also truly aligned with the cultural values and norms of the individual.

In Canada, the concept of cultural humility is increasingly considered as significant components for addressing culturally specific healthcare needs of diverse population. It is a key concept for enhancing the quality of care and reducing racial disparities in health outcomes and healthcare access (Yeagar, 2013). This is particularly crucial when delivering treatment to older immigrants who face language barriers and strongly adhere to their culture, values, and health beliefs (Wang & Kwak, 2015; Sheikh et al., 2009; Ginde et al., 2009). Furthermore, some older immigrants from South Asian communities in Canada may find that certain aspects of Western healthcare systems do not always fully respect their traditional health beliefs (Surood & Lai, 2010). It is also indicated that cultural differences between care providers and patients can affect communication and treatment due to misinterpretation of patients' symptoms and difficulty conveying mainstream Western medical knowledge to patients from traditional ethnic communities (Brown et al., 2014; Rooney, 2011; Waheed et al., 2015; McDonald & Kennedy, 2007).

Healthcare providers in Canada sometimes may have a limited awareness of the sociocultural context of ethnic populations, and this may impact their ability to provide culturally competent

healthcare service (Sadavoy, et al. 2004; Jongen et al. 2018; Pentaris and Thomsen 2020). This raises greater concerns in the context of home care compared to other types of care, given that home care services are often perceived as more intimate (Milligan, 2009). The fact that care is provided in one's home, within the private spheres of an individual, can significantly influence how an older adult perceives the experience of receiving home care services (Martin-Matthews, 2007). According to Milligan (2009), alterations in physical routines and control over access to one's home may have a profound impact on older adults' sense of security. Therefore, in order to provide culturally aligned home care services, it is important to understand the unique ethnocultural needs of those who receive them (Milligan, 2009).

### 1.4 Provision of Home Care Services in Canada

In 2004, the Canadian Home Care Association developed a comprehensive definition of home care that is widely accepted throughout the country (Canadian Home Care Association, 2016). Home care services refer to "a range of services offered in both home and community environments, covering health education and promotion, therapeutic measures, end-of-life assistance, recuperative care, assistance and upkeep, societal adjustment and inclusion, as well as support for informal (family) caregivers" (Canadian Home Care Association, 2016). In contrast to receiving care in a hospital or long-term care facility, a comprehensive range of services are provided to people of all ages in their homes through home care services. Home care services can be further divided into home health care (HHC) services and support services (Ayalon et al., 2010; Government of Canada, 2016). Typically, healthcare professionals offer HHC services, which encompass nursing care and various medical services, including physiotherapy, occupational or speech therapy, nutritional counselling, and assistance with medical supplies or equipment (Government of Canada, 2016). On the other hand, Personal Support Workers (PSWs) and volunteer agencies offer support services to assist people with

daily activities like bathing, meal preparation, housekeeping, and transportation (Government of Canada, 2016). In this study, the term “home care” is used to refer to support services provided by PSWs, as these services comprise the majority of home care services (Home Care Sector Study Corporation, 2003).

Home care is not included in the so-called “Medicare core,” a collection of provincial and territorial health insurance plans which adhere to national standards (Marchildon, 2004). Due to exclusion of home care services from Medicare, there is neither equality nor transferability in the delivery of home care among the 13 provinces and territories. Home care programs are provided by various provincial, territorial, and municipal governments, and they differ in how they are financed and managed (Johnson et al., 2017).

In Ontario, Home and Community Care Support Services (HCCSS) is responsible for the administration and delivery of publicly funded home care services. Comprising of 14 decentralized units, Home and Community Care Support Services operates under the oversight of Ontario Health (Connecting Care Act, of 2019; Marani, 2023). Until April 1, 2021, Home and Community Care Support Services was previously referred to as Local Health Integration Networks (LHINs). HCCSS encompasses a broader scope including responsibilities for home and community care, long-term care, and hospital care. Nevertheless, in both the LHIN and HCCSS settings, the procedure for accessing home care services remains unchanged (Marani, 2023).

Older adults in Ontario who need home care services, irrespective of their prior hospitalization, have the option to self-refer or be referred by their primary care physician to their local Home and Community Care Support Services (Marani, 2023). Following this, a care coordinator or case manager is assigned, collaborating closely with primary care physicians, care recipients, and their

care partners to evaluate needs and coordinate essential services (Government of Ontario, 2023; Marani 2023). Home-based services provided by home care workers, such as PSWs, nurses, or social workers, are covered under Ontario Health Insurance Plan (OHIP) for eligible home care recipients. The extent of service, including the number of hours of personal support visits, is determined based on an assessment of needs conducted by the care coordinator. Home care recipients, or their care partners on their behalf, are responsible for any additional private services that exceed the service maximum set by local Home and Community Care Support Services (Government of Ontario, 2023).

Home care helps seniors to optimize their level of independence in their own homes in addition to decreasing the need for long-term care (Canadian Medical Association, 2016). Additionally, home care is found to be more affordable than institutional care, as noted by Home Care Ontario (Home Care Ontario, 2019; Chappell, 2004). Moreover, the vast majority of Canadians intend to stay in their homes for as long as possible (CIHI, 2020). To further emphasize the older adults' stronger preference to home care compared to institutionalized care, the National Institute of Ageing (NIA) survey found that nearly 100% of older adults wish to remain independent in their own home (NIA, 2020).

In 2007, the Ontario government introduced the "aging at home" strategy, which aims to reduce the number of patients receiving Alternate Level of Care (ALC) in hospitals in Ontario. Patients receiving ALC are those who are admitted to an acute care hospital bed but are not critically sick or do not require the level of resources or services that are typically provided in a hospital (e.g., may no longer need treatment or hospital care). The aging at home strategy was to assist older adults and their care partners to maintain their health and live independently and with dignity in their own homes (MOHLTC, 2007).

Home care services effectively reduce the financial burdens on the healthcare system related to hospitalization for older adults, encompassing palliative care, emergency visits, and hospital stay durations (Canadian Home Care Association, 2016). Moreover, research suggests that the early utilization of home care services by older adults results in a delayed admission to long-term care institutions (Gaugler, 2005). According to a Wellesley Institute study, the provincial government covers home care expenses in Ontario, which amount to about $45 per day, significantly contrasting with the daily costs of $450 for hospital stays and $135 for long-term care (Wellesley, 2017). Hence, home care services stand out not only as a preferred choice for older adults but also as a cost-effective solution for the healthcare system.

In Ontario, about 900,000 people receive home care every year, including 730,000 in the publicly funded system (Sinha, 2012). According to Romanow (2002), continuous budget cuts to healthcare services and a focus on community care, along with advancements in treatment, medication, and home technology, have led to a greater need for formal home care services in Canada. Despite the importance of home care services, in 2015-2016, slightly more than a third of adults living in communities felt their perceived home care needs were unmet (Gilmour, 2018).

### 1.4.1 The Gap in the Provision of Home Care Services in Canada

The concept of “home” in the context of home care delivery is complex because it is tied to a person’s identity, independence and sense of familiarity in a private environment (Hidalgo and Hernandez, 2001; Marcus, 1995; Rowles, 2003; Rubinstein, 1989). Considering the complex nature of delivery of care at home, it is imperative to understand how older adults and their care partners conceptualize home care to receive quality care. One of the most crucial patient factors that impact care delivery at home for older adults is culture, as it can significantly influence how individuals interpret their

environment (Torres 2006). The term *culture* refers to a "constellation of shared meanings, values, rituals, and modes of interacting with others that determines how people view and make sense of the world" (Krakauer et al., 2002; p.184). It includes components like religious values, beliefs, norms and traditions (Belvins and Papadatou, 2006).

The conventional biomedical model, which seeks to lessen disability and provide medical treatment, forms the basis of current home care programs in Canada (Government of Canada, 1999). This model places less importance on the significance of cultural aspects, such as language, religion, ethnicity, and race, in the provision of home care services. As a result, individual perspectives or cultural considerations in the provision of home care are rarely taken into account (Walsh, 2014). This holds particular significance for older adults from ethnically diverse backgrounds, as their life experiences, cultural heritage, traditional values, and beliefs profoundly influence how they perceive and approach the idea of receiving care within their homes (Hernandez & Gibb, 2020)

Several international research studies have indicated that despite the equal financial accessibility of home care services in the majority of Western European healthcare systems, older ethnic minority individuals utilize home care services less frequently than their counterparts from the host population, even when their needs are comparable (Crist et al., 2009, Denktaş et al., 2009, Kadushin, 2004). Given the immigration patterns in Canada, there are limited studies that focus on the utilization of home care services by ethnic minorities in the country (Johnson et al., 2017). According to the Wellesley Institute Report (2016), there is a disparity between the racialized immigrant older adults and non-immigrant older adults in the receiving of government-funded home care services (Wellesley Institute, 2016). The report also adds that more evidence is needed to understand the reason behind the significant variation in utilization of home care services by racialized older adult immigrants. To address this gap, my research aimed to explore South Asian communities' nuanced perceptions about

home care services in Ontario, barriers they face when accessing these services and recommendations on how home care services in Ontario can be structured to address their unique needs.

Understanding the perceptions and challenges that South Asian communities encounter while accessing home care services becomes pivotal not only for tailoring home care services but also for recognizing the potential impact on the broader healthcare system, including long-term care facilities and emergency department visits.

# Chapter 2: Study Aims

Addressing the existing gap in literature regarding home care services among ethnic minorities and recognizing the significance of home care services in Canada, this study aimed to address the following research questions:

1. How do South Asian communities perceive home care services in Ontario?
2. What are the barriers encountered by the South Asian communities while accessing home care services in Ontario?
3. What recommendations do South Asian communities have for improving home care services for older adults in Ontario?

The study aimed to explore South Asian communities' nuanced perceptions about home care services in Ontario and the barriers they experience when they access home care services. Additionally, it sought recommendations from these communities on how to enhance home care services for older adults, aiming to improve the provision of culturally aligned home care services for South Asian communities in Ontario. By conducting this study, the main goal was to provide insights for policy development and improve the delivery of culturally aligned home care services for South Asian communities in Ontario.

# Chapter 3: Methodology

## 3.1 Research Design

My interest in investigating South Asian communities' nuanced perceptions about home care services and the barriers they experience when they access home care services, led me to select an exploratory qualitative approach for my thesis. The focus of qualitative research is to gain a better knowledge of how people perceive and identify with their surroundings (Delamont & Atkinson, 2016). An exploratory study was suitable to gain additional insights into how South Asian communities viewed home care and also highlighted areas for future investigation.

**Theoretical Standpoint**

The ontological stance utilized in this study is constructivism. Constructivism is defined by Crotty (2003:42) as “the view that all knowledge and therefore all meaningful reality as such is contingent upon human practices, being constructed in and out of the interaction between human beings and their world and developed and transmitted within an essentially social context.” As a result, meaning is created or “constructed” rather than discovered.

In this study, aligned with the constructivist paradigm, qualitative methods, specifically semi-structured interviews, were employed to capture the nuanced and subjective perceptions of South Asian communities surrounding home care services. With regards to data analysis, I employed Reflexive Thematic Analysis (RTA) which is a method known for its theoretical adaptability in systematically analyzing and interpreting patterns within a qualitative dataset. It involves an ongoing, self-reflective, and iterative exploration of the dataset (Braun and Clarke, 2019). The reflexive nature of RTA seamlessly aligned with the constructivist stance, recognizing the co-construction of

knowledge in the dynamic interplay between the researcher and participants. RTA allowed for a rigorous and reflexive examination of participants' narratives, contributing to the depth and richness of the study findings. Furthermore, through RTA, I was prompted to engage in critical reflection on my own perspectives and biases at every stage of the data analysis process. This approach served to enrich the depth and authenticity of the interpretation, resonating with the constructivist belief that researchers actively contribute to shaping the understanding of participants' experiences.

# Chapter 4: Methods

## 4.1 Study Sample

To address my research questions, I purposefully recruited three distinct groups, namely South Asian older adults who were 60 years and above, care partners who were caring for South Asian older adults and key informants who had experience working with the South Asian communities. This strategy was employed to incorporate diverse perspectives on home care services within the South Asian communities in Ontario.

Firstly, the inclusion criteria for South Asian older adults included individuals aged 60 years or older, adhering to the age limit set by the World Health Organization for the older adult (World Health Organization (WHO), 2021). This age criterion was also chosen to capture the demographic most likely to seek home care services. Furthermore, to ensure a thorough understanding, both older adults currently receiving home care and those not receiving home care were recruited. This approach aimed to capture diverse perspectives and insights regarding home care services within the South Asian communities in Ontario.

Secondly, care partners, aged 18 years or older, were intentionally selected to focus on adult care partner experiences, providing a nuanced understanding of their perspectives. Finally, key informants, including social workers and PSWs, were strategically included to offer valuable insights into South Asian communities' perceptions of home care services. PSWs, chosen for their role as care providers with intimate knowledge about home care services, played a crucial role in understanding the practical aspects of care delivery. Social workers, selected for their involvement in the assessment and referral of home care services, play a crucial role as advocates for this population. The inclusion of three distinct participant groups—South Asian older adults, care partners, and key informants—

was intentional to triangulate the data and ensure a comprehensive understanding of experiences and perceptions related to home care services among the South Asian communities.

The older adults and care partners were required to have residency of at least three months in Ontario. This requirement was implemented to align with eligibility for OHIP, ensuring participants had a sufficient duration of residence to be eligible for government-funded health services. Additionally, they needed to be proficient in one of the following languages: Tamil, Punjabi, Telugu, Hindi, Urdu, Gujarati, Bengali, or English. These language criteria were selected based on the representation of the majority of languages spoken in different South Asian countries, facilitating a diverse recruitment that considered linguistic preferences. Overall, these criteria were meticulously chosen to provide a nuanced perspective on home care within the South Asian communities in Ontario.

## 4.2 Ethics

This study was reviewed and received ethics clearance from the University of Waterloo Research Ethics Board (ORE #45218). Once ethics approval was obtained, I began to recruit participants and then schedule interviews. Prior to the interviews taking place, participants were encouraged to ask any questions they may have had regarding the study or to discuss the consent form. Participants were informed about the confidentiality of their identity throughout the study. To ensure the utmost confidentiality, anonymizing strategies, such as assigning pseudonyms and blinding the transcripts, were implemented to conceal their identity.

## 4.3 Recruitment

I began the recruitment process by sharing the study posters with my personal connections who were South Asians (see Appendix A). After that, I contacted the local mosque, temples, and churches to share the information about the study. Moreover, I promoted the study poster on LinkedIn with the aim of targeting specific key informants, particularly social workers. Those who were interested in the study reached out to me via email (refer to Appendix A). Those indicating interest received an email comprising the information letter (see Appendix B) and the consent form, which outlined the study's purpose and procedures.

Before coordinating the interviews, potential participants were given the opportunity to get in touch, to get further information and clarification about the study. It was consistently emphasized to participants that their participation in the study was entirely voluntary. Upon commencing the interviews, I applied a snowball sampling approach. At the end of our informal conversations or interviews, participants were encouraged to share information about the study within their social networks. I interviewed a total of 13 participants consisting of South Asian older adults, care partners to a South Asian older adult, and social workers who engage with South Asian communities. The decision to conclude the recruitment with 13 participants was based on the recognition that further interviews were unlikely to yield substantially new insights.

## 4.4 Participants

Table 1 describes the characteristics of this study's participants. Of the 13 participants in the study, seven were care partners of South Asian older adults, three were South Asian older adults aged 60 or above, and the remaining two were social workers and a former PSWs working with South Asian older adults in Ontario. None of the older adults who took part in the study had received home care

services at the time of the interview. However, almost all (n=6) care partners had experience with accessing home care. It is noteworthy that all participants were proficient in English, except for an older adult named Sathya. While Sathya could communicate in English, he occasionally used Hindi to articulate insights that he found challenging to express in English.

**Table 1: Description of the study participants**

| Name | Age | Country of Origin | Gender | Role | Employment | Language Interview conducted in | Relationship to the older adult | Length of Residency in Canada |
|---|---|---|---|---|---|---|---|---|
| Sathya | 70 | India | M | Older Adult | No | Hindi and English | N/A | 4 years |
| Fatima | 60 | Pakistan | W | Older Adult | Yes | English | N/A | 25 years |
| Davida | 62 | Bangladesh | W | Older Adult | No | English | N/A | 5 years |
| Grace | 25 | Sri Lankan-Canadian | M | Care Partner | Yes | English | Grand daughter | 25 years |
| North | 29 | Indian-Canadian | W | Care Partner | Yes | English | Grand daughter | 29 years |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Sarah | 32 | Pakistan | W | Care Partner | Yes | English | Daughter | 25 years |
| Maya | 35 | Bangladesh | W | Care Partner | Yes | English | Daughter-in-law | 9 years |
| Carol | 52 | Pakistan | W | Care Partner | Yes | English | Wife | 25 years |
| Sandra | 54 | India | W | Care Partner | Yes | English | Daughter | 20 years |
| Helena | 55 | India | W | Care Partner | No | English | Daughter-in-law | 18 years |
| Hope | 40 | India | W | Social Worker/ PSW | Yes – Previously as a PSW, currently working in Community support services sector | English | - | 15 years |
| Maan | 55 | India | M | Social Worker | Yes- Home Care Sector | English | - | 12 years |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Kunal | 56 | Canada | M | Social Worker | Yes – Not-For Profit, Community support services sector | English | - | 20 years |

## 4.5 Data Collection

Interviews took place between April 2023 and July 2023. The length of the interviews ranged from 25 minutes to an hour and a half, with most interviews lasting roughly 40 minutes. I arranged a date, time and platform to connect with the participants after they agreed to volunteer in the study. I conducted a total of 13 semi-structured interviews in English and Hindi. Out of the total interviews, five were conducted via Zoom, and eight were held over the phone.

The study utilized an interview guide (Appendix C) that had received clearance from the ethics board. The semi-structured interview guide prompted participants to share their perceptions about home care, discuss encountered barriers in accessing home care, and provide recommendations for improving these services. Prior to conducting the interview, participants reviewed the information letter and provided their consent either verbally or through a signed document. A verbal consent log, recording participants' names and consent dates, was meticulously maintained. This log was securely stored in a locked cabinet to uphold confidentiality.

The chosen method for data collection involved the utilization of semi-structured interviews. This enabled me to ask questions that were open-ended, encouraging participants to share detailed and comprehensive responses. The interview sessions commenced with a series of general demographic questions, focusing on factors such as gender, occupation, and the duration of residency in Canada. Participants were asked to share their views on seeking help from professional health and support services to provide care to aging parents at home, about their knowledge about availability of home care services in Ontario. Furthermore, participants were asked to identify features of South Asian communities that are important to consider when delivering home care for older adults. Additionally, participants were asked to consider cultural and language factors, as well as the gender of the PSWs, and whether it would matter to them.

After the interviews were concluded, participants were provided with a letter expressing appreciation for their involvement (refer to Appendix D). To accommodate participants who provided verbal consent, the details of the appreciation letter were verbally explained. Throughout the interview, comprehensive notes were made to document the participant's mood and demeanor, in addition to themes. Furthermore, to maintain confidentiality of the participants during the data analysis, pseudonyms were allocated.

## 4.6 Translation

In our study sample, only one participant spoke a combination of Hindi and English, necessitating translation. Following McKenna's (2022) guidelines, I utilized a forward translation method, translating original transcripts into English, the language used for analysis and reporting. All transcripts were subsequently uploaded into NVIVO. The researcher's proficiency in the South Asian

languages was essential for conducting interviews in participants' native languages, allowing for a more authentic expression of their experiences, as emphasized by Creswell (2014).

### 4.7 Reflexivity and Positionality

Throughout the study, I engaged in the iterative process of reflexivity. Reflexivity is the process of self-reflection and self-examination. It involves revealing our identities as individuals and researchers, acknowledging the potential impact of our biases on the research process (Berger, 2015; Creswell, 2014; Pillow, 2003). Reflexivity is an ongoing process, wherein the researchers establish their position within the analytical process, which includes acknowledging social positions and locations like age, gender identity, color, and ethnicity (Thurairajah, 2018).

As a younger daughter of an older Indian couple, I understand and am aware of all my roles and responsibilities as a daughter in an Indian family. I have been in Canada for almost two years, and I believe I have some familiarity with the cultural and religious differences between Western and South Asian cultures and how these may shape the experiences of caring practices in a South Asian Family. My set of beliefs, values and my background may help me to build rapport with my participants, but they could also impact the interpretation of the data during data analysis.

To mitigate this, I created a reflexive diary where I recorded the thoughts and interpretations I had about the data. This played a vital role in addressing potential biases and enhancing the reliability of the research. Before initiating the interviews, I recorded my own experiences, albeit limited, working within the South Asian communities in Ontario. My thoughts, feelings, and perceptions about caring for South Asian older adults and about seeking formal care to take care of them were outlined. This process allowed me to externalize and reflect on potential biases.

Throughout the interviews, efforts were made to create a conducive environment for participants to openly share their opinions and thoughts without interruptions or judgments. I refrained from sharing or discussing my own thoughts during the conversations. Instead, I documented the participants' reactions as they articulated their experiences. Despite expressing my own set of beliefs when it comes to providing care to South Asian older adults, I am confident that my positionality enhanced the research process by fostering deeper connections and empathy with the study participants.

## 4.8 Data Analysis

Following the interviews, I utilized the otter.ai software to transcribe each one. I then carefully listened to the recordings and made necessary corrections to the transcriptions prior to starting the analysis. Once each interview was transcribed, I imported the transcripts into NVivo (version 12), a widely used qualitative data analysis software in qualitative research (Woods et al, 2016). I conducted a Reflexive Thematic Analysis (RTA) developed by Braun and Clarke (Braun and Clarke, 2019). The data analysis process involved a thorough familiarization with the transcribed interviews through repeated readings. During this process, I was mindful of my reflexive position. Before the coding procedure began, I went over each transcript once again to gain a general understanding of the data. The main goal of this familiarization and immersion stage was to think of and discover patterns within the data.

After the familiarization stage, initial codes were generated to effectively organize the data (Braun & Clarke, 2006). These initial codes, more condensed than the subsequent themes, helped in organizing significant groups of data (Tuckett, 2005). Some of these initial codes were theory-driven, guided by research questions, while others were data-driven, relying solely on the data itself (Braun & Clarke, 2006). A recursive coding technique was employed which involved continuously revisiting,

refining, and adjusting codes as the analysis unfolded. The analysis delved into the explicit (semantic) aspects of the data, adopting a constructivist perspective. Using an inductive approach, codes, themes and sub-themes were derived directly from the content of the data. Examples of inductively generated themes and sub-themes include perceptions of home care services within South Asian communities, care partner burden, barriers to accessing home care services, enhancing cultural humility in PSWs, and increasing awareness of home care within South Asian communities.

Finally, I developed meaningful and descriptive names for the themes, aiming to capture the essence of the analysis (Braun & Clarke, 2013 p. 258). These theme names were derived directly from quotations or reflected analytical interpretations and the primary focus of the data (Braun & Clarke, 2013). These themes will be discussed in more detail in the upcoming section.

# Chapter 5: Results

Table 2 describes the key themes and subthemes which were generated during the data analysis. The three major themes were (1) The current need for home care services for South Asian communities, which outlined the pronounced need for home care services as expressed by the participants; (2) Barriers encountered by South Asian communities while accessing home care services, which focused on various challenges faced by care partners and South Asian older adults while accessing home care in Ontario; and (3) Recommendations to improve home care services for South Asian communities, which centers on various suggestions proposed by the study participants to improve access and tailor home care services to meet the cultural needs of the South Asian population. These themes will be further discussed in the following section.

**Table 2 : Themes generated during the data analysis**

| **5.1 The Current Need for Home Care Services Within the South Asian Communities** | **5.2 Barriers Encountered by South Asian Communities While Accessing Home Care Services** | **5.3 Recommendations to Improve Home Care Services for South Asian Communities** |
|---|---|---|
| 5.1.1 Perceptions of Home Care Services among South Asian Communities<br><br>5.1.1.1 Perceived important activities for older adults at home | 5.2.1 Lack of Cultural and Language Considerations in Home Care Services | 5.3.1. Focus on Gender, Ethnicity and Language Concordance |

| | | |
|---|---|---|
| 5.1.2 Evolution of Blended gender roles in South Asian Families<br><br>5.1.2.1 Care Partner Burden | 5.2.2 Increased Waiting Times in Receiving Culturally Aligned Services | 5.3.2 Enhance Cultural Humility Among the PSWs |
| | 5.2.3 Lack of Interpersonal Connection and Consistency | 5.3.3 Foster Kindness and Compassion in Home Care |
| | 5.2.4 Lack of Awareness About Home Care Service | 5.3.4 Promote Awareness About Home Care Services Within South Asian Communities |
| | 5.2.5 Racism and Inherent Trauma | 5.3.5 Prioritize on Building Rapport with Older Adults. |
| | 5.2.6 Lack of Funding and Sufficient Service Hours | |
| | 5.2.7 Challenges in Coordination of Home Care Services | |
| | 5.2.8 Lack of Support for PSWs | |

## 5.1 The Current Need for Home Care Services within the South Asian Communities: “Illuminating Cultural Depths in Home Care.”

Study participants expressed the need and recognized the significance of home care services in providing quality care for South Asian older adults. While some highlighted its importance, others mentioned its cultural implications. This section provides a nuanced exploration of the diverse perceptions on home care services present within the South Asian communities.

### 5.1.1 Perceptions of Home Care Services within South Asian Communities

The majority of South Asian older adults, whose care partners participated in this study, received a minimum of two hours of publicly funded home care services. Some participants also additionally utilized privately funded home care services. In all cases, these participants supplemented home care with informal support at home. Importantly, all participants recognized the vital role of home care services in providing quality care to South Asian older adults.

Study participants highlighted that some South Asian older adults prefer home care over informal care. For instance, when asked about her perceptions of home care services, Hope, a former PSW, currently working as a social worker, said:

> *“A lot of them [older adults] would prefer having someone come and care for them rather than depending on their family members, because that has a professional relationship rather than obligation, whereas a family member is obligated to help that person. But if an outsider comes, it’s more of a professional relationship, and they get all the things done on time rather than waiting for this family member to come back from work. And both sides have that guilt, right? So, the adult is feeling that I am burdening this person and their kids or grandkids, whoever that may be, feels that they are neglecting their older person because they don’t have enough time or the energy. So those two clashes and both parties are never happy or in a positive framework most times.”*

*-Hope*

Hope's statement illustrated three key messages. Firstly, Hope linked the cultural expectation of caring to the emotions of guilt and neglect that both older adults and their care partners may encounter within the context of this informal care arrangement. Secondly, older adults seem to be inclined to resort to home care services in order to alleviate the perceived burden that caring might bring to their family members. Finally, accessing home care services, according to Hope, would translate the relationship between an older adult and the PSW to the formal exchange, which can be termed as "a professional relationship" rather than a cultural obligation.

Similarly, some study participants believed that South Asian older adults preferred home care as it could help preserve their sense of dignity and independence. For instance, Helena, an immigrant who came to Canada over two decades ago, is currently caring for her 75-year-old mother-in-law, in conjunction with home care services. She said:

> *"So, if you have some outside help, it makes it relatively easy because you're not directly involved, you're not having any arguments. It's very stressful and sad when you can't do things which she doesn't want to do. But if there's a third person, an outsider, she's more comfortable than a family member. So, diaper change with an outsider is something she feels okay, but with the family member, she gives a lot of resistance. So that is also there the stigma of the embarrassment."*

*-Helena*

According to Helena, her mother-in-law seemed more accepting of home care, especially when it involved personal hygiene practices. This underscored how home care services may not only uphold the dignity of some South Asian older adults but also could potentially reduce the burden on their care partners.

Older adults who participated in the study also expressed their preference for home care services.

Fatima, a 60-year-older adult who immigrated from Pakistan to Canada 28 years ago, emphasized that she would seek assistance from home care services if she ever required professional support for daily activities in the future. She said:

> *"I wouldn't want to disturb my children because they would have a life, too. And God forbid if I get that condition [frailty], I would really want that support worker to come and help me out over there and move me around and make sure that my joints don't get jammed and help me with getting all these things that I like to do. I like to do puzzles to keep my mind fresh. I like to do different things, go out and get some fresh air. So definitely I would want someone to do that."*
>
> *-Fatima*

This quote implies that certain South Asian older adults wish to maintain their independence without imposing the cultural expectation of being cared for by their children. Furthermore, it is interesting to note that while traditional home care services primarily offer support with personal care and household tasks, Fatima viewed home care as a means to facilitate her involvement in activities like puzzles and outdoor walking. This statement highlighted the study participant's holistic perceptions of care at home.

While older adults in the study expressed a clear preference for home care, other participants, notably care partners, emphasized the importance of these services. For example, Carol, a 52-year-old full-time worker, moved to Canada 25 years ago. Two years prior to receiving home care services, she managed full-time work alongside caring for her bedridden husband. When asked about her opinions on home care services, she said:

> *"I always think professional help is better than taking care of someone on your own. So, when we get professional help, I'm relieved that way I don't need to worry*

*about him all day at work, right? So that way I feel relieved. Now, when I'm at work, I'm only at work.  Otherwise, my mind is constantly worrying over there (at home), right?"*

*-Carol*

This quote implied that home care may offer care partners a sense of security, enabling them to focus on their work responsibilities without constantly worrying about their loved ones at home. Similarly, Grace, who is a Sri Lankan Canadian, is currently caring for her 75-year-old grandmother. When asked about her opinions on home care services, she said:

*"Because as a working woman now and with other responsibilities and priorities, we're always trying to find ways to make sure that we are using our time at its wisely. So, making sure that rather than spending 3 hours to make sure that my grandmother's medical needs have been addressed, it only takes an hour because they (PSWs) take care of travel time and such. And in terms of allowing them to come inside our home and stuff, at the end of the day, I consider it like this. They're all healthcare professionals that are trying to do their job by addressing their patient's needs. And that patient happens to be my grandmother. I really don't mind when they come into the home to take care of my grandmother."*

*-Grace*

The quotes from both Carol and Grace illustrated that the importance of home care is recognized not only by those who are currently receiving it but also by those who have not yet accessed such services. This quote seemed to suggest the possibility that South Asian care partners, such as Grace, who have resided in Canada for an extended period, might be more receptive to the idea of utilizing home care services.

Following the discussion about the preference and need of home care services, study participants also identified some of the cultural challenges that may be present while accessing home care. To

illustrate, North, a 29-year-old Indo-Canadian, whose family moved to Canada 30 year ago, when asked about her opinions about home care services, said:

> *"Without any question we do need home care services. But it's very difficult from various perspectives because in the South Asian culture, I'm not going to generalize, but filial piety, where the children look after their parents, is very strong. And then this also trickles into the health care system where, again, not generalizing, but most healthcare professionals usually assume that just because this person is Indian or Pakistani, they don't need help because their family is going to take care, right? So, they don't end up providing those resources just because of this assumption."*
>
> *-North*

This quote captured two key points. First, North underscored the perceived importance of filial piety within the South Asian communities. Secondly, she also highlighted the healthcare providers' misconceptions about strong informal support systems present within the South Asian communities. These two aspects could potentially result in delayed access to home care services, impacting the health of both the care partner and the older adult. Similarly, Kunal, a South Asian social worker, who is also a care partner to his parents, said:

> *"They (mother and father in-law) give excuses like, "I'm not comfortable with the stranger coming into the house or I'm not sure whether that person is going to do a good job." And so it's really about comfort and belonging and having somebody in the house. But they've (parents) built a relationship with the PSWs. They have a good relationship. So, they've taken the time, whereas my in-laws refuse to even open that door. And that's the key problem."*
>
> *-Kunal*

According to Kunal, his in-laws expressed concerns about trust, comfort, and the presence of strangers in their house, and on the other hand, his parents have developed an understanding relationship with the PSWs. This indicated that contrasting perceptions about home care services may co-exist in the same family. In addition to reluctance expressed by some older adults in accepting home care, others highlighted feelings of guilt experienced by the children for considering these services, as exemplified by Fatima, a 60-year-old older adult. She said:

> *"Children will feel guilty about seeking external help because remember, we come from a society that makes sure that the children are always close to us (parents). We come from South Asia... we do not push the children out of the houses when they turn 18. So, it's embedded in the majority of the families. It's embedded in the children that we are going to take care of our parents at old age. And when that comes in, it also comes with that price of giving them the time. And if we are bringing in someone else do it, then really we have failed our parents. That's the attitude they have."*
>
> *-Fatima*

Fatima's statement implied the perceived cultural importance of familism, indicating that children may feel guilty when they fail to meet the cultural expectations of providing care for older adults in South Asian communities. Although some participants indicated guilt, others also mentioned that they initially hesitated to accept professional help due to the societal stigma tied to seeking such services. To illustrate this, Carol said:

> *"The challenge was accepting that personal support worker coming to my house for my husband and same for him, that it means you are not doing anything for me (husband). Because I was thinking I can do work and manage everything. But on the other hand, I have two sons. They said, "Mom, I know you are saying you will do everything for your husband but you know how challenging it is." And staying*

*in hospital, we had seen his needs are getting difficult and his needs are getting high priority for us."*

*-Carol*

This quote highlighted the collective decision-making within Carol's family to seek assistance from home care services to support the older adults at home. While care partners disclosed challenges in accepting home care, key informants, such as social workers, shared their experiences with South Asian older adults who were receiving home care services. For example, Maan, a social worker, described a situation of an older adult who was a retired University professor. He said:

*"The PSW would sit there, and she (older adult) wouldn't let her do anything. She wouldn't let her cook. She said, "no, I can cook. You just stand here and watch me cook". She (PSW) wants to clean the washroom. She said no, I'm used to cleaning the washroom. I'll do it. So after a week or so, the PSWs just gave up. She (PSW) said, okay, this is not working out because this woman doesn't want help."*

*-Maan*

This quote illustrated that even when the home care is being provided, it might not be utilized by some South Asian older adults. In addition to certain participants discussing feelings of guilt and their reluctance to accept assistance from home care services, others focused on a different aspect: the community's tendency to exhibit judgmental attitudes towards individuals seeking professional help for taking care of their older adults. For example, Sathya, a 70-year-old older adult who immigrated to Canada 5 years ago, said:

*"First of all, what is the community going to say? It's safekeeping. The children could not take care of the parents. We are not doing it for us, but we're doing it for what is the community going to say? What are our relatives going to say? What are our friends going to say?"*

*-Sathya*

According to Sathya, in a typical South Asian family, there is often a focus on "safeguarding" the family reputation and honor within the community. This quote illustrates that sometimes South Asian individuals may be compelled to conform to societal norms and cultural expectations.

Although participants voiced their preference for receiving home care, others discussed their preference for specific type of activities at home that could enhance the quality of care for older adults. These activities will be discussed in-detail in the next session.

#### 5.1.1.1 Perceived Important Activities for Older Adults at Home

Study participants identified various activities that they considered the most important for their older adults at home. Most participants believed that older adults' emotional needs were just as important as physical needs. For instance, when asked about the most important activity for her mother, Sarah said:

> *"I think the companionship for my mother is the most important. I live near the lake shore, so it's just really nice. We take our chairs and then we take our books, and then we just kind of hang out. Not real much conversation, but just the fact that we're spending time together and we do errands together sometimes when she's up for it. Also, I enjoy going out to dinner as well, and she does too. We do those types of activities. I take her for walks just to enjoy the weather around the block."*

*-Sarah*

Sarah's statement highlighted the importance of companionship for her mother. This not only seems to emphasize a strong family bond but also might reflect a broader cultural emphasis on the emotional aspect of providing care in the participant's family. Older adults, like Fatima, also voiced a similar

opinion when asked about important activities at home. She emphasized exercise as the most important activity:

> *"So if you're just saying what are the important activities, then I would say that exercise and mental activities are just to keep my mind fresh. Because I know that people just restrict themselves to listening or watching TV or something like that. Because not all the people would be the same. Some might be vision impaired people, some might have had stroke. So, they have their individual needs to find activities to stimulate them, to put it politely, to keep them alive. I would say it will differ from person. If you talk about me, I would really want to continue with exercising in some form mental or physical."*
>
> *-Fatima*

The quote illustrated the importance of mental stimulation and physical fitness, illustrating the value of psychological and physical activities for elderly individuals in a home setting. In addition to those who mentioned perceived important activities, some participants also explained the need for additional emotional support among South Asian older adults. Hope, who is also a care partner to her mother, emphasized that emotional engagement with older adults is just as crucial as meeting their physical needs. She said:

> *"You can have cooked food of their choices, take care of their medications and their physical comfort. But the most important thing which is I think is important is to be emotionally available for them. You can't live in your own silo and just give them food and clothing and everything and just dissociate yourself from them. No, you have to be engaged. You have to see whether they need you and you have to keep them involved in your day-to-day life. Because seniors can feel very isolated because they have been uprooted from their own home country, they had their own friend group, they had their own control over their household, their finances and pretty much they had a whole life for them. You have uprooted them from their home*

*environment and the environment they were so used to and then you bring them out here and then you just lock them in a you expect them to be happy that's not there."*

*-Hope*

Hope's quote emphasized that foreign-born older adults are more susceptible to isolation, requiring additional emotional support. While some participants discussed providing emotional support, other care partners talked about other issues such as fear of falling in older adults. Sandra said:

*"My mother has mobility issues, so she needs assistance to go to the washroom. That is the biggest challenge for her to go alone because my father, when he was here, he fell down and then he had a hip surgery. He couldn't survive it. So that's also one of the reasons why she's very scared of…a fear of fall. So that is one of the most important activities during the day because there could be several times in the day that she uses the washroom. For that activity, definitely I have to be with her or someone has to be with her at that time. And that's the only reason why I pick it out as the most important."*

*-Sandra*

This quote highlighted two key aspects: First, it shows how previous traumatic experiences related to falls can deeply impact an older adult's mental state and their perception of safety in routine activities. Second, it illustrates the psychological strain on care partners, who must remain constantly alert to prevent future fall-related incidents. Therefore, it is necessary to cater to both the physical and psychological care needs of the older adults and their care partners.

To summarize, although some study participants accessed home care and acknowledged its importance, they still experienced feelings of guilt and reluctance due to cultural expectations of providing care to older adults. This guilt for accessing home care could be due to individual factors such as a sense of obligation, or community factors such as peer pressure from friends and relatives.

Furthermore, participants highlighted various home activities which they considered important for providing care to South Asian older adults at home. The range of activities mentioned for home care demonstrates the multifaceted approach to providing care within South Asian communities, embracing a holistic perspective. While certain participants expressed their preferences for specific types of home care, others indicated that traditional caring roles in South Asian families are undergoing a transformation. These evolving gender roles will be further explored in the next section.

### 5.1.2 Evolution of Blended Gender Roles in a South Asian Families

There are various roles present within the provision of care for older adults, such as household activities, decision-making, financial management, hands on care and emotional support. Traditionally in South Asian families, sons are anticipated to take on a central role in decision-making and financial management, whereas daughters and daughters-in-law are engaged in household activities, hand-on care and companionship.

However, according to our study participants, the gender landscape within the context of caring for South Asian older adults is constantly evolving. For instance, Maan reflected upon his personal observations, where daughters are progressively engaged in taking on a more central role in supporting older adults. He said:

> *"Definitely the daughters [are primary caregivers]. I think the misconception in South Asian communities is that the sons will look after their parents. But from my lived experience and personal experiences with friends and family and just seeing who visits their parents when they're living in long term care, majority, it's the daughters who are supporting financially and providing companionship, whether it is in-person visits or whether it's phone calls. So, I think that's a big misconception that South Asians have that, oh, my son will take care of me. It's really not."*

*-Maan*

Maan's quote exemplified that there is a gradual shift towards blended gender roles within the context of providing care to older adults. While some participants indicated that daughters take on a primary role in supporting South Asian older adults, other participants emphasized that responsibility of providing care was also contingent on the gender of the older adult. For instance, North's father had to take care of her grandfather's hygiene practices while her mother was involved in managing the household activities. She said:

> *"But there was a time before my grandfather passed away, that he was bedridden. So, in that case my mom still did most of the caretaking in terms of cooking the food, feeding him. But when it came to personal hygiene and stuff, it was my dad who changed him, bathed him and stuff like that."*

*-North*

This quote illustrated the collaborative approach of providing care to an older adult within the South Asian families, with various family member taking on specific care roles based on their abilities and comfort level. On the other hand, some younger participants, like Maya, a 35-year-old care partner from Bangladesh who came to Canada 7 years ago, said that the household responsibilities in the context of providing care to older adults were equally distributed with her husband. She said:

> *"I'm just talking about my family. My family is kind of half and half. For example, I'm serving her (mother-in-law) food whenever my husband is cooking food, because we are kind of doing half and half of household work, me and my husband. So, we are not a typical family that I would do everything."*

*-Maya*

Maya's quote exemplified that her family is not a traditional South Asian household that adheres to conventional gender roles. This quote exemplified that gendered roles in proving care within South Asian families maybe fluid and could vary based on the unique dynamics of each household.

Helena, a 55-year-old care partner, mirrored a similar opinion about equal allocation of caregiving responsibilities in her family. She said:

> *"But it depends. It's not a hard and fast rule. I see a lot of sons taking care of their parents. Sometimes, I see both the husband and wife working and they share the responsibilities of caregiving also, at least in my circles. I don't know, maybe we are more aware or more educated, but I think depends on the socioeconomic group and also, we hire a lot of outside help. You have to see the different scenarios."*
>
> *-Helena*

This statement highlighted how the difference in gender roles while caring for older adults maybe significantly influenced by the family's educational background and socioeconomic status. While some participants indicated evolution of gender roles in the context of providing care, others talked about the implications of being employed along with responsibilities of caring for older adults at home. This will be further elaborated in the next section, which discusses care partner burden.

#### 5.1.2.1 Care Partner Burden

Care partner burden can be defined as "the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time" (Liu, Heffernan, & Tan, 2020). Care partner burden is characterized by physical, emotional, and mental exhaustion, accompanied by a shift from a positive to a negative and detached attitude while caring for an individual (Parkinson Foundation, 2022).

Participants reported experiencing stress and exhaustion from constantly caring for their older adults at home. In our study, all the care partners were women over the age of 25, each of whom were employed either full-time or part-time in Ontario.

Care partners indicated the challenges emerging from simultaneously managing their professional work and caring responsibilities at home. For instance, Grace explained how her social and personal life profoundly changed after she took on the responsibility of caring for her grandmother. She said:

> *"It's definitely a time crunch. I remember how social and outgoing I was able to be when I was younger before these responsibilities hit. And then once these responsibilities fell on me, I feel like there's been more of like a time crunch. I have less time for myself to reflect on and definitely a strain. It really does strain the other commitments and priorities that I have as well. Because even in the time when you're not full-on taking care of them, you still are thinking about them. So I'm always constantly trying to figure out and refigure out what my schedule is and how I will go about it to make sure that my work [caring responsibilities] gets done and my job gets done."*
>
> *-Grace*

This quote highlighted the challenges care partners might experience in continuously adjusting their schedules to accommodate the needs of the older adults, potentially impacting their physical and psychosocial well-being. Some participants emphasized that the responsibility of caring for an older adult might have direct impacts on their employment. For example, Sandra, a 54-year-old care partner to her mother, said:

> *"So that's why all my activities are centred around home. And I work from home because of that (providing care). I'm a musician as well. So that's my basic profession in terms of working remotely on virtual platforms. It has given me a lot of like irritability, the frustration that I'm not able to go out as much as I would*

*wish to, just hop into a car and drive myself and go shopping or do basic groceries sometimes."*

*-Sandra*

Sandra's quote illustrated that caring for an older adult may impact both the social and professional spheres of a care partner's life. This was evident when Sandra started to work from home, further impacting her social life. Study participants also voiced their distress during the COVID-19 pandemic, when it was challenging to provide care to older adults:

*"COVID was very difficult because the borders were closed, and with the borders closed, there were no siblings able to visit. So, for those three years, it was just me having to juggle everything without having much respite. I think that was just a little bit difficult because there was no off time. Before COVID a sibling would come at least once a month. And then another sibling would come for, like, six weeks. So, they were hanging out with her. They were doing errands with her. They were doing the family visits with her. So, it gave me time for myself, like, for self-care. But during COVID it was very hard to balance that because I was just on all the time."*

*-Sarah*

This quote illustrated the dual impact of the COVID-19 pandemic: it not only may have deprived care partners of much-needed respite, but also might have negatively impacted older adults, who experienced decreased social engagement due to the lack of connection with their community and social networks.

While some care partners highlighted lack of respite during the pandemic, others emphasized the fear of COVID-19 infection and transmitting it to older adults. For example, Helena said:

*"I was really frustrated especially during the pandemic. And in the past two, three years, that was very stifling because I was more scared of contracting anything and*

*I would pass it on to my mom with no support systems in place. So, I was literally caged at home."*

*-Helena*

Helena's statement emphasized how the preexisting stress from providing constant care, coupled with the anxiety of potentially contracting and spreading COVID-19 to the older adult and feeling of entrapment at home, significantly exacerbated the burden on her during the COVID-19 pandemic.

While certain participants acknowledged the physical and emotional challenges from providing for older adults, others proposed the implementation of home care services as a potential means to ease the burden on these care partners. To illustrate this, Maya, a 35-year-old care partner said:

*"If you can make sure that even though I am not with her 24/7, she can still get some support, can make your life easier, right? So, I can go for my work, I can do the job that I'm doing, and I can come back home. So as the caregiver, you don't feel overwhelmed, right? Like sometimes if it is too much for you, then you feel overwhelmed or you could feel burdened if you are always there and always supporting that person (older adult). But then if you get a PSW service during the time that you are not at home, then you come back and then you can assist your parents for remaining of the day. And in that way, the parents could still be here with us at home. They don't feel they're out of the family (in a long-term care home) and they're still getting the care from us. And also they're not feeling they are a burden on us because I can still go for work."*

*-Maya*

According to the participant, utilizing home care services can create a more sustainable and balanced care arrangement that benefits both her and her mother-in-law, ensuring that the older adult

receives the necessary care while allowing the care partner to manage their personal and professional life more efficiently.

To summarize, the participants recognized the changing gender dynamics within South Asian families, highlighting the blended roles of both sons and daughters in the context of providing care for older adults. On the other hand, these care partners reported increased burden arising from managing their caring responsibilities with their work commitments. As a result, they emphasized the importance of home care services as a much-needed respite. Although participants recognized the significance of home care, they also highlighted some barriers to accessing home care services which will be discussed in the next section.

## 5.2 Barriers Encountered by the South Asian Communities While Accessing Home Care Services: "Echoing the Voices of the Unheard."

While some study participants indicated a need for home care services to alleviate care partner burden, others highlighted the barriers they experienced while accessing these services. Some of these barriers are common across the general population, whereas others are unique to the South Asian communities. A detailed explanation of these barriers will be presented in the subsequent section.

### 5.2.1 Lack of Cultural and Language Considerations in Home Care Services

Participants who were receiving home care expressed that some PSWs may not fully understand or appreciate the cultural norms, traditions, and values that are important to South Asian families. According to them, lack of cultural considerations could lead to misunderstandings, miscommunication, and a disconnect in the PSW-older adult relationship. For example, care partner Sarah indicated that her mother was particular about selecting a care provider who had cultural compatibility. She said:

*"But it's difficult to find culturally competent care that's I think the biggest issue is how much my mother is willing to accept. So, my mother will not allow anybody to bathe her. Even my father wouldn't. So, finding the right people who do understand the way things are done, depending on the person's background. Example, okay, so she's practicing in her faith and so, there is a very specific way of doing things and having somebody who comes into the home who's supporting her understanding that there's a way to do things like religious hygiene or touching certain things and washing hands before alcohol. Not coming into the house with alcohol or pork products or things like that. If one of the people is coming into the house with their lunch that they're not bringing, like a ham sandwich into the house. I think that cultural incompetence is a big thing."*

*-Sarah*

Sarah's quotes illustrated the lack of culturally aligned service as a crucial barrier, illustrating the importance of having a care provider who possessed a nuanced understanding and respect for her mother's cultural values. This might involve factors such as sharing the same gender, ethnicity, and language. She also suggested that in the absence of considering these factors, her mother might not be willing to accept home care. Using the term "cultural competence," the participant emphasized the need for PSWs to adapt to her mother's specific cultural and religious practices. This highlighted the importance of cultural humility, where PSWs should continuously learn, adjust their approach, and respect the unique cultural context of each household, ensuring their care aligns with the older adult's cultural values and norms. While certain participants highlighted the significance of taking cultural aspects into account, others pointed out the negative implications of the absence of cultural considerations in home care. For instance, North said:

*"So, the PSW that we had, she didn't know how to dress my grandmother in her traditional clothes. That was a big issue because that frustrated my grandmother. And then my grandmother had just finished her prayers and her book, her holy*

*book, was lying on the side, and the PSW just picked it and kept it on the side. So, if she (PSW) understood the culture, understood the values, you would have known that you keep the book at a certain place. And then the way she gets her hair done, understanding the type of food she eats, understanding what kind of recreational activities she likes. Not just playing cards or coloring."*

*-North*

This quote exemplified the significance of providing culturally aligned care by actively engaging with care recipients to understand their preferences for receiving care which aligns with their socio-cultural values. On the other hand, some participants indicated language as a major barrier to receiving home care services. For example, Carol indicated the use of certain phrases that might be inappropriate for a South Asian older adult. For context, "bear with me" phrase carries a negative connotation when translated to Hindi language. She said:

*"The way I look at the professional staff is they are not trained how to work with South Asian community. They're born in Canada and coming from different countries sometimes we don't use those slang language or we don't use those idioms. But some of the things that we take it differently than it's meant. "You have to bear me for the next five days". What does it mean in our culture now? So, it means something was wrong. And she's saying that sentence to my husband. As a staff, if you are a happy staff, why do you need to say those kinds of things, right?"*

*-Carol*

In Hindi, "bear with me" implies a sense of burden or inconvenience, which may not align with the intended patience or understanding conveyed in the English phrase. It shows that language can shape cultural perceptions and interpretations as the same words may hold diverse connotations in different languages, affecting how messages are received and comprehended. Similarly, Maya explained that

she preferred a PSW who is capable of providing support to someone like her mother with limited understanding of the English language. She said:

> *"And even the language, speaking simple language (will help). Sometimes if I think about our older adults... I have my mother here, she does not know a lot of English. And I'm not saying we only need our language speaking staff (PSW), but at least understanding how to provide a service even with the low language person [limited English proficiency]. And when it comes to accommodation, what kind of accommodation we are doing to provide that service?"*
>
> *-Maya*

Helena provided a unique perspective, highlighting that effective communication extends beyond simply sharing a common language. Carol said:

> *"They need training about the ethnicity of the person. See, some of them do not speak the language. And even if they speak English, their accents are different. So, the clients are not able to understand the accents. So, these are the roadblocks that I see, I have discussed with other people who have PSWs coming in."*
>
> *-Helena*

Carol's quote emphasized that language encompasses more than the mere ability to converse in a mutual language; it points to the nuanced and multifaceted nature of communication.

Some participants indicated the subtleties within languages, while others highlighted the negative impacts of not having language concordance with the PSW. In healthcare, language concordance entails effective communication between patients and healthcare providers through the use of a shared language (Hsueh et al., 2019). North explained that the assigned PSW, who was not of South Asian origin, needed assistance for translation from her mother when performing various caring tasks while assisting her grandmother. She said:

> *"My mom had to teach the PSW how to put on the Salwar Kameez, which is the traditional Indian dress. She had to explain how to tie the Salwar, which is with a drawstring. She had to explain and translate everything for my grandmother. So, we didn't really see the point of having a PSW because the whole point of her being there would have been that my mom is able to take some time off and relax. But it just kind of increased her work so much. Now she had to translate and kind of console my grandmother because Grandma couldn't understand why there was a stranger trying to bathe her."*
>
> *-North*

North's quote indicated that even with home care provided for South Asian older adults, in the absence of language concordance, care partners might still not receive sufficient respite. This could ultimately compromise the care partners' health and well-being.

In addition to the language barriers expressed by the study participants, some care partners shared their experiences of certain home care agencies making an implicit assumption that any older adult from India spoke Hindi. Sandra said:

> *"Hindi is not the main language, of course, of India, but there are several other languages which are predominantly spoken and not Hindi alone. This is something that the home care services should understand because when they ask me, okay, I've had this conversation with one person, I think in the private care sector. They told me that person (PSW) speaks Hindi. They told me that should be ok. They presume that my mother would know Hindi."*
>
> *-Sandra*

This quote implied the importance of home care agencies not making assumptions about the spoken language of South Asian care recipients.

### 5.2.2 Increased Waiting Times in Receiving Culturally Aligned Services

While some participants highlighted barriers related to lack of cultural and language considerations, others voiced concerns about the potential increase in waiting times due to accommodating these preferences. North said:

> *"It is a struggle with PSWs to come at home because we would need someone who speaks Punjabi and it's a long wait. We did try someone who did not speak Punjabi and was from a different cultural background, but it was kind of null and void having her because then my mom still had to be present to explain to her what to do."*
>
> *-North*

This quote underscored that, although extended waiting times are a concern for the general population (Yakerson, 2019), they present additional challenges for South Asian older adults. These challenges emerge from having specific preferences related to the gender, ethnicity, and language of PSWs. Additionally, some participants voiced similar challenges related to the ethnic matching of PSWs. For instance, Kunal, a social worker, explained that most South Asians preferred PSWs of the same ethnicity, as they would have a better understanding of South Asian cultural nuances, languages, and religious practices. He said:

> *"Supports and services are very hard to get on a consistent basis and depending on where you live. So, for example, in Waterloo, how many South Asian PSWs are you going to get for seniors in your local area? If you're in north part of York region, in Toronto, certain areas you may be able to get it. Brampton for example you'll be able to get, but certain areas you won't. And that's the reality of things. It'd be nice to maybe even have people that check in on them [Older Adults] who may be South Asians."*
>
> *-Kunal*

The quote illustrated that despite the preference for South Asian PSWs, their availability is highly influenced by the geographic area, which can result in extended wait times to obtain the preferred PSW. This highlighted a regional constraint in accessing culturally competent home care.

### 5.2.3 Lack of Awareness About Home Care Services

Some participants believed that there was no awareness of home care services among South Asian communities. For example, Carol said:

> *"Sometimes in our community, some people, they are not fully aware of it. Like, I got a call from my neighbor. She said one of her friend's mother, she is sick and they don't know what to do and how to do anything. So those kinds of things, [awareness] people still feel as a barrier. And then I guided, and I said, "first thing is talk to your family doctor and discuss the situation and ask for suggestion, tell them that this is the situation and what can we do". So, I help them"*
>
> *-Carol*

According to Carol, there is limited awareness about home care services among South Asian communities, resulting in individuals relying on their community for information and assistance when required.

Although some participants indicated a lack of awareness, others suggested that South Asian individuals not only seek assistance during "crisis mode", but also may not be fully aware of the available services. North said:

> *"Having that lack of resources in South Asian communities, they usually ask for help in crisis mode. So, they don't ask for help or have a plan of action or advanced care planning. In the beginning everything is manageable. It's usually when they're like, "Okay, this is overwhelming, I can no longer do this" That they start looking*

*for help and don't know what to do. So that's another thing I've noticed with my parents was that they asked for help in crisis mode, which isn't really helpful for anybody"*

*-North*

The quote not only exemplified a significant gap in knowledge about accessing these services but also illustrated how cultural barriers might contribute to delayed access to home care.

### 5.2.4 Lack of Interpersonal Connection and Consistency of Home Care Services

Some study participants conveyed the cultural barriers in accessing home care, and others voiced the challenges in cultivating an interpersonal connection between the PSW and the older adult. Maan said,

*"You need people who are patient with seniors generally if they're in it just to kind of get a job and get them done and out of the way, they're not going to build those meaningful connections with them [Parents]. They find the caregivers that are most effective with my parents are the ones who actually take the time to get to know my parents. And I've seen PSWs who are just there to do their job and they're on their phones when they're not doing the work and they're not taking the time to build connections with my parents. And my parents say, "well I don't like this person because they're not caring for me even though they're doing the job".*

*-Maan*

This quote highlighted the pivotal role of PSWs in establishing a meaningful interpersonal connection with older adults. It also highlighted the significant distinction between a PSW who simply fulfilled their responsibilities and one who invested time and the effort to actively engage with the older adult. Furthermore, Maan underscored a significant obstacle restricting personal connections between PSWs and older adults: technology. Kunal presented a different perspective regarding virtual engagement by both family members and PSWs. He said:

*"I think technology has not made it easy for people to connect. Although we're able to connect, but we're not making connections. I don't know how many families and support workers would be connecting with them [older adults]. I think that disconnecting from virtual space to physical space will help. Because of that, I think people have also forgotten how to make personal connections. I think with that stress of life priorities, a face pace of work and fast pace of life has all surmounted into a situation where often seniors get side-lined. Although they're taken care of, but they're side-lined from participating in life, you know what I mean?"*

*-Kunal*

The quote emphasized the importance of the care partner's and PSW's physical presence and meaningful engagement in maintaining the social and emotional health of South Asian older adults.

While some participants expressed concerns about the absence of meaningful interactions with older adults, others pointed out a different issue that could hinder meaningful connections: the inconsistency in the home care services provided. Davida said,

*"Also, I would say the thing that I have witnessed with someone who is receiving this home care, is that there are different PSWs coming in morning, afternoon, and evening. There might be someone repeating after maybe two weeks. But if there's a consistency of one worker coming for the week or at least one of them is consistent for the week, where they can develop a rapport and they can say, " Okay, next week when I come in, we'll talk about that." Or "Okay, you think about it or you read about it, or you can hear this podcast and we'll discuss it next week." So it's more like a friendly encounter. So, when they're going to end, they're able to talk about something besides eating, drinking, cleaning. It's something more for the client to look forward to."*

*-Davida*

According to Davida, a lack of consistency in home care could potentially exacerbate the issues of limited interpersonal connections, negatively impacting the mental well-being of older adults.

### 5.2.5 Racism and Inherent Trauma

In addition to some participants indicating challenges such as lack of cultural competency and increased waiting time, others disclosed a systemic challenge: Racism and inherent trauma. Kunal said:

> *"For the most part, I think many of our last generation of seniors have had to face trauma of some sort or another, integration and racial discrimination in Canada. So there's a lot of apprehension about going outside because they always relied on their own faith based communities and their own communities to support. That nut is very hard to crack."*
>
> *-Kunal*

This quote exemplifies that most South Asian older adults may depend on faith-based community supports, which means supports provided by a group of people who share the same religion, faith or spiritual beliefs. According to Kunal, this support seems to act as a vital support system for older adults for psychological support, and a sense of belonging.

Later on, during the conversation, Kunal said he believed that there still exists "inherent trauma" in South Asian older adults. He said:

> *But there's a lot of inherent trauma of many of our seniors that have come so for (to Canada) example, in Sri Lankan Tamil, a lot of them have come here from civil war or they've had to flee because of their circumstances. So Afghanistan, for example. I think many of our seniors have not gone through the healing process of the trauma that they've faced leaving their country, their home country that they*

*knew all their lives and coming to migrate in Canada. So, some may be more open (home care) than others, but for the most part, it's just too late.*

*-Kunal*

According to Kunal, the presence of inherent trauma in South Asian older adults supposedly makes them susceptible to the psychological impacts of racism, potentially acting as a barrier to the utilization of home care services.

### 5.2.6 Lack of Funding and Service Hours

Most participants of this study mainly received publicly funded home care services. Only a few received additional services through private home agencies by paying out-of-pocket. Several participants voiced that one of the most significant obstacles encountered by South Asian older adults when accessing provincially funded home care services is the difficulty in receiving sufficient service hours. For example, Hope, a former PSW, who is currently working as a social worker, said:

> *"So that is the biggest hurdle right now, because I have a lot of people who do have access for the PSW, but they come for just 1 hour a day or three times a week sometimes. That is the only support they are given. Those things need to be addressed and changed. But everyone is struggling with the funding. So it takes a long time to bring all this into place."*

*-Hope*

On the other hand, participants also mentioned how COVID-19 impacted their ability to afford privately financed home care. Maan, who managed a home care agency, believed that the increase in hourly wages for PSW due to COVID-19 resulted in older adults not being able to afford hourly care:

> *"Before COVID we used to charge if a PSW goes, they get $15 an hour, we charge $18 an hour and 3 hours are minimum. So, it's like 36 plus 18 is $54 a day or 3 hours they have to spend. Now after COVID, the government itself has increased*

*the salaries of PSW to approximately $20. Now, if you want to add taxes and this and that, then it's going to be like 25, $28. It's like a catch 22 situation where there is also poverty in the community. So not many people can afford hourly care."*

*-Maan*

Maan's statement conveyed two key points: Firstly, the increase in hourly wages for PSWs is a positive development that recognizes their essential role in home care. Secondly, this increase has led to higher costs for home care services, making them less accessible for individuals with limited financial resources. Similarly, Sandra stated that due to the inadequate service hours provided by publicly funded home care, she had to resort to expensive private home care services. She said:

*"These home care services are very expensive. Very expensive when you go private. So as in Canada, we are known for getting free health services. We have paid into the tax system for so many years. And I think legitimately speaking, it would be appropriate if the same pattern continues. But if at all you're going to have out of pocket services, which I do take care of because it's just impossible, with just 1 hour respite in a 24 hours day is not enough. Right? So, for a caregiver I need, definitely I would go for out of pocket. But it should be reasonable. Also, it should be something that the government should step up to pay some families because not everyone can afford it"*

*-Sandra*

Sandra's statement illustrated the necessity for increased home care service hours and highlighted the disparities in accessing these services, emphasizing the challenge of ensuring equal provision of home care across different socioeconomic groups. Some participants said financial help from the children is instrumental in accessing home care for South Asian older adults. For example, Sarah, a care partner, emphasized that her mother would be unable to afford home care services with her limited financial resources. She said:

*"It helps that the program that I found is subsidized. So, like, the cleaning person who comes in for my mother every two weeks, it's 2 hours, but she doesn't pay $20 an hour for her services, so she pays according to her income. So, whatever my mother could afford, they do whatever the math that they need, then my mother pays for it. But in all honesty, my mother, we all chipped in, like, all my siblings and I financially support my mother because she wouldn't be able to without our support."*

*-Sarah*

The cost of home care can vary depending on the level of support required and the duration of care needed. As a result, some individuals may struggle to cover these expenses on their own. While some participants highlighted the financial barriers, other participants talked about the subjective experiences of receiving private and public home care services. For example, Maan said:

*"So, it's like cleaning your house so you can call the best cleaner in the world and ask them to clean your house, but you might end up saying, oh, she didn't do a good job. Because it's not objective, it's subjective. One spot she misses, then she didn't do a good job. So, the same way with PSW or home care, it's subjective work. And it becomes very difficult to convince South Asians that PSWs can only do so much. Again, if it's coming from CCAC or LHINs because it's free, it's kind of looked at it differently. If it comes through a private agency, a home care agency, it's looked at differently because naturally you're paying a lot of money for that 1-hour service."*

*-Maan*

Maan's quote underscored that home care services from private agencies are often perceived to be of higher quality compared to publicly funded services from HCCSS. This difference in perception, influenced by the funding source, can significantly affect both the expectations of the service and the satisfaction with the home care provided.

### 5.2.7 Challenges in Coordination of Home Care Services

Study participants revealed the intricacies involved in applying for home care services, expressing challenges in coordinating and managing the various aspects of the application process. For instance, Hope, the former PSW said:

> *"You need to put in a lot of effort too, especially when you apply for home care. You have to go through a lot of things. Don't just fill out an application and you say, oh, tomorrow the PSW will come. No, it doesn't happen that way. There are a lot of steps you need to go through, a lot of interviews you need to sit on. You need to prove your financial situation (for publicly funded home care). You need to prove that you need the service. Some of them can't advocate for themselves. So, the kids have to do the advocacy and they fail in that because they take the easy way out. Sometimes you really have to fight for the care and services you need. You'll only get the bare minimum. If you need anything extra, you need to fight for that. You have to prove that you need that service. So that is what they don't understand. You really have to fight for it in that way. Older adults slip through the system sometimes because there is no one there to take up that challenge."*
>
> *-Hope*

This quote highlighted that the combination of complex administrative procedures for accessing publicly funded home care and the limitations some older adults face in self-advocacy, together may result in receiving minimum home care support or completely "slipping" through the system.

On the other hand, care partners explained that their responsibilities extended beyond providing care to South Asian older adults. Some participants said that they assumed a "managerial role," where they coordinated home care services, ensuring that the needs of South Asian older adults are met. For instance, Sandra, a 54-year-old care partner, expressed that individuals who required additional assistance through privately funded home care services end up navigating through extensive bureaucratic processes. She said:

*"If you can afford it, you can go for private home care and everything. It is expensive and there is a lot of bureaucracy, there's a lot of documentation, lot of things that you need to get in place. You have to wait on the phone, you have to coordinate, and the logistics have to be worked out all over the phone."*

*-Sandra*

The comments shared by both Hope and Sandra emphasized that additional home care services, whether they are publicly or privately funded, entail a significant amount of administrative work. Ultimately, these coordination tasks might impact both the South Asian older adults and their care partners by delays in accessing home care. While some participants indicated extensive administrative process involved in applying for home care, the key informants, on the other hand, offered ideas about how to "beat the system". For example, Maan said:

*"So, we do a lot of advocacies and do a lot of guidance. So, I tell people how to kind of beat the system, how to get into the line of CCAC. So by the time your parents are 90, 91, or they have a situation where they need care, if you are in the system already, you are a few steps ahead of others, right? So rather than waiting for that day till another five years before they register with CCAC or wait for the family doctor to calls CCAC and to tell them, this lady needs help; we suggest that you start talking to CCAC right now and say, talk to a case manager. Even if they say she won't get any care today, that is fine because you are in the system. So, when you need care, when they go back to the database and say, see, they will already know because you're already in the system. So, you'll be a little bit ahead of others."*

*-Maan*

Maan's statement not only highlighted the extensive wait times for home care in Ontario but underscored the importance of utilizing community centers to obtain advice and guidance from fellow community members on how to effectively navigate the Canadian healthcare system.

### 5.2.8 Lack of Support for PSWs

Although study participants highlighted the challenges encountered by the older adults and their care partners, others underscored the struggles faced by the PSWs. To exemplify this perspective, Davida said:

> *"I've seen older adults becoming very difficult because they are frustrated because their self-esteem and their self-respect is put to a test over here. Now they are not and that frustrates people. It frustrates me if I have to ask someone to do something for me and I am losing my self-esteem. So, that in turn really affects the PSW. The PSW comes in, and the client is frustrated, and they take it out on that poor PSW. It becomes challenging for them because now they have to put up with someone like, If I'm supposed to clean you, I know I'm getting paid for that, but why do I have to hear all this from you? So, I will not be doing it with the same passion as I would do to someone who is obliged of what I'm doing. I'm okay. I have experience, because I have done it for older adults back home, and I've helped them out quite a few of them."*
>
> *-Davida*

This quote illustrated two key messages. Firstly, it highlighted that receiving home care might represent a significant emotional adjustment for older adults as they must come to terms with the perceived "loss of self-esteem", often leading to feelings of irritation. Secondly, it underscored that PSWs, in addition to their constrained time schedules, may also face the frustration of the older adults they are assisting, which adds another layer of complexity to their work. On the other hand, some participants talked about the mistreatment of the PSWs by other community members. Carol said:

> *"Sometimes people from our community even mistreat personal support workers and disrespect them. I heard from my relatives, "We had the personal support worker visit at our house. She was doing all my cleaning." So that is also wrong*

*or saying in our language Punjabi "oh Kamu" (Maid). Respect is in both ways. If I respect the staff, they will respect me also. But some don't."*

*- Carol*

In the context of Punjabi language and culture, the term "Kamu," which translates to "maid," carries a connotation of inferiority or low status. While some participants encountered instances of ill-treatment of PSWs, others shared stories where immigrant PSWs faced poor treatment from their own colleagues. For instance, Hope said:

*"I have seen the Canadian staff who is working as a Personal Support Worker and when they have new staff who is a newcomer like us [immigrant], they are not respecting even the staff to staff. In the same way, I notice those challenges and I address those challenges also at the same time."*

*-Sandra*

This quote underscored the importance of providing support to PSWs, as it becomes increasingly evident that when intersecting factors like gender and race are involved, the vulnerability of PSWs is magnified.

To summarize, participants highlighted some important barriers in receiving and accessing home care services. These barriers included cultural factors like consideration of clients' religious practices, language, and logistical factors such as taking up a "managerial role" for coordination of home care along with lack of funding and service hours. While some participants disclosed barriers and challenges, others suggested some recommendations to improve home care, which will be discussed in the next section.

## 5.3 Recommendations to Improve Home Care Services for the South Asian Communities: "Weaving Cultural Threads in the Tapestry of Home Care."

Study participants offered recommendations for improving home care services for South Asian older adults. These suggestions were made to tailor the current home care services to meet the distinct cultural and linguistic needs of South Asian older adults.

### 5.3.1 Focus on Gender, Ethnicity and Language Concordance in Home Care Services

Most participants emphasized that gender mattered when it comes to providing care to a South Asian older adult, highlighting the significance of gender matching in home care. For instance, Grace emphasized that her grandmother tends to prefer female healthcare providers. She said:

> *"Considering my grandma would prefer female doctors over male or like my grandfather would prefer male doctors over female, that sort of thing. Just for the sake of their comfort or being able to be a little bit comfortable in their environment and then speak about their personal needs in a much more understanding tone so that their needs are better met and the doctor (who is female) is able to better understand them at the same time."*
>
> *-Grace*

According to Grace, in South Asian culture, modesty and cultural norms often make older adults more comfortable discussing sensitive health issues with healthcare providers of the same gender, thereby creating a safe environment. This underscores the need for PSWs to undergo cultural competency training that takes into account the cultural significance of gender preferences among South Asian older adults.

On the other hand, Grace elaborated that older men are often more open to receiving assistance from a PSW of the opposite gender, as they are accustomed to women traditionally fulfilling caring roles within a South Asian family context. She said:

> *"So then again, it boils down to the fact that it's a women's area (PSWs jobs), so they are more like nurses. They're considered that this is a job that women can do better because a lot of men, majority of the men will not hesitate to get women to do their things because they're sort of used to it. But women refrain from having men take care of them."*
>
> *-Grace*

This statement highlighted the strict adherence to the "same gender" rule in providing care for older women, in contrast to a more flexible approach when it comes to providing care for older men. While certain participants emphasized the importance of gender preferences rooted in cultural values, others indicated that the gender of the PSWs was not a significant concern. However, those participants who claimed to be indifferent about gender acknowledged the existence of a stigma associated with interactions between opposite genders within the South Asian communities. For example, Fatima said:

> *"I don't believe in gender because it could be females, it could be males. I see all kinds of good people in the males and kinds of other people in females. It doesn't matter. I think it should be promoted in both the genders, this job, because in many cultures and religions, women will not allow men to touch them. They prefer to die, but not to be touched by men other than their husbands and their children. And men would have their own ego not to be touched by women, but it's mostly with the women. So, if you look at it at it from that context, then women prefer women."*
>
> *-Fatima*

The quote underscored the need for a more inclusive approach in training PSWs, advocating for both male and female care providers. According to Fatima, this approach would ensure that the home care provided to older adults is in alignment with the specific cultural values prevalent in South Asian communities. Some participants also explained that the same gender preferences in PSW consideration is prevalent across various other communities in Canada and is not specific to the South Asian communities. Maan said:

> *"Gender matters. As I said in the beginning, some male clients don't like female PSWs. And that's kind of not just in South Asian, but it's almost in every community. Some male members don't like female PSWs, some females don't like male PSW, but mostly there is dearth of male PSWs. And so we really don't focus on that area. So if somebody says they need a male PSW, we tell them that we cannot find you anyone because comes too much dependency on one person. If you're specific about a male PSW or with specific requirements, they say (clients) like, no, we need somebody who can only speak Italian, who must come from Italy and all that, then we say, we cannot provide this service."*
>
> *-Maan*

Maan's statement illustrated the need to enhance gender diversity among PSWs through training professionals of different genders for adequately serving not only South Asians but also for addressing the needs of various other cultural groups across Canada. In addition to some participants highlighting the significance of gender matching of the PSWs, others discussed the importance of ethnic and language concordance. Participants reported that South Asian older adults would likely prefer a PSW who shared cultural similarities. According to some participants, having shared life experiences fosters a sense of familiarity and trust with an older adult. Kunal said:

> *"I think the person would like it if the person who looks like them a little bit. They're able to speak the language, they're able to interact and understand the cultural*

*context. Ideally, if they've been through similar type of a life journey their parents have gone through, for example, me, if somebody had also had an exodus or a refugee, they understand that context. The dynamics of complexities of that, knowing their food, their diets, that kind of stuff, stuff like that I think would break barriers in being able to access services. It's culturally and socially aligned."*

*-Kunal*

This statement exemplified that when care providers and recipients share similar cultural or ethnic backgrounds, the care is likely to be more empathetic and effective. The quote also emphasized the importance of recruiting South Asian PSWs who can effectively provide care that aligns with the cultural needs of South Asian older adults. Helena, on the other hand, illustrated a unique perspective on preferring a PSW of different ethnicity. She said:

*"I tell you it's better to have a person of a different culture than to have a person of the same culture. In fact, it works better. And I'll tell you why. Because my mother-in-law would try to be on her best behavior with somebody who's not brown. If it's somebody of her own color and race, then she will take her for granted. It's better to have somebody of a different culture because they feel a bit guarded, because they still bother even that age, even when her mind is all clouded, she still wants to make a good impression."*

*-Helena*

The quote implied that while a non-South Asian PSW caring for an older adult who behaves well might be advantageous for the care partner and the PSW, it could cause the adult to feel "guarded" in their own care. Besides ethnicity, some participants also highlighted the significance of language concordance between the older adult and the PSW. For instance, Hope conveyed that language concordance is essential for effective communication, building trust, and encouraging active client participation in their care. She said:

*"Again, language is also an issue. If we have more South Asian PSWs. It does help. Speaking their language really helps because of the comfort level and understanding each other. Then doing a little bit extra, always puts them in a very comfortable space where they can share with you what they need. Sometimes what happens is, when language is an issue, the person wants things done in a certain way because you're used to a certain way right. And a new person comes in and does the exact opposite of what you wanted."*

*-Hope*

This quote illustrated the importance of recruiting multilingual PSWs who are proficient in South Asian languages to enable active engagement, as it may also allow the South Asian older adult to establish a stronger interpersonal connection to the PSW. In addition to the importance placed on gender ethnicity and language, some participants also talked about cultural humility training for PSWS who provide home care services for South Asian older adults, which will be discussed in the next section.

### 5.3.2 Enhance Cultural Humility in Home Care Services

Participants emphasized the necessity of integrating cultural humility training for PSWs, advocating for comprehensive training that covers various traditions and values present in South Asian cultures. To illustrate this, Sandra said:

*"I guess being able to teach all PSWs the diversity of cultures that we have here in Canada, if you look down our streets, there's about 30 houses, but 30 of them are from 30 different parts of the world. And each one has its own unique different practice. Like having a nurse understand the needs of Muslim people during Ramadan, or Hindu people during Diwali, or that sort of thing. Like being able to culturally understand where they're coming from so we don't step on their cultural boundaries or barriers. So providing a medication that might clash with what they*

*practice at home or a treatment plan of such that would clash with something that they practice at home. So having that kind of knowledge and insight for all PSW would be not just amazing, but very tailored to towards our current population of people."*

*-Sandra*

Sandra's statement highlighted the importance of integrating the concept of cultural humility while providing care to South Asian older adults. Her quote highlighted the significance of cultural humility in ensuring that the understanding of diverse cultural practices is applied through continuous learning and adaptation to the unique cultural context of each South Asian household. Furthermore, this approach ensures that the home care provided is respectful, culturally appropriate, and sensitive to the specific needs and preferences of Canada's diverse aging population.

While some participants emphasized the importance of cultural humility training for PSWs, others suggested that home care agencies should implement a brief survey to better understand and incorporate the unique cultural needs of their clients into the home care services provided. Davida, a 64-year-old participant, said:

*"First of all, when a PSW enter someone's home, anyone's home, regardless, they should understand that there will be things that they don't agree with over there. You need to be mindful and be respectful of various cultural practices of that home and then should not comment on their food or the smell of spices. Those are the things that they need to be aware of. If it's a Muslim household, they need announce in advance that they are arriving at home because maybe if it's a male PSW and they're going into a Muslim family, the girls around might be observing some religious attire that they need to get into. They cannot expose their maybe hair or they need to wear... They might be wearing a skirt and they need to wear pants underneath because they cannot come in the regular way. This is called, what you call Cultural competence? So, knowing when PSWs get a case, they need to know...*

*The agency should give them an awareness of where they are going. Yes. And that could happen by a short survey before they provide services to that family. So, it's what they would like, what are their preferences, what restrictions do they have in their home."*

*-Davida*

This statement illustrated the importance of making home care agencies aware of the unique cultural requirements of the recipient's household before commencing service. According to Davida, this can be accomplished by distributing a questionnaire providing care service. Such an approach would enable PSWs to gain a deeper understanding and offer quality care specifically tailored to each South Asian older adult.

### 5.3.3 Foster Kindness and Compassion in Home Care Services

Most participants consistently suggested that kindness and compassion are essential qualities for a PSW. For example, a 55-year-old care partner, Helena, explained how she had a pleasant experience with the PSW who was not only culturally sensitive but also compassionate towards the older adult. She said:

*"Just a compassionate PSW. Somebody who's culturally sensitive, who can give you the respect to your elder the way you respect your elder and who understands where that person is coming from. I have had excellent experience with all the PSWs. They are very compassionate. The PSWs, they have come have been exceptional even though they were Caucasian and some of them were not belonging to the same culture. But they learned some words like "Asalam alikum" (Greetings in Urdu) with the greeting. To say all those things and greet my mother-in-law with those kind words and words of respect which made a huge difference in the caregiving."*

*-Helena*

This quote illustrated that even in the presence of ethnicity or language incompatibility, a PSW's ability to provide kind and compassionate care could greatly enhance the perceived satisfaction and quality of care received by older adults. Similarly, some older adults also mirrored Helena's response regarding the significance of having a compassionate PSW. For instance, Fatima said:

> *"The most important thing is the person should be trained to be compassionate and be able to (take care of me) because I've seen the personal support workers who go the extra mile, but I've also seen those who really don't even come in and they complain a lot in the environment where everything is available. Like they really don't have to do much over there and they complain. It's sort of like you cannot have people who are not compassionate in this work."*
>
> *-Fatima*

This quote not only emphasized the importance of receiving compassionate care from PSWs, but also underscored the need for rigorous training in compassionate care for PSWs, to ensure enhanced care for South Asian older adults. In addition to some participants indicating their preferences for an ideal PSW, some participants also proposed strategies to enhance awareness of home care services within South Asian communities, which will be discussed in the next section.

### 5.3.4 Promote Awareness About Home Care Services

Study participants recommended various ways to increase awareness about home care services in Ontario. Maan said:

> *"During COVID, we did like a flyer which was basically designed in English but was translated into Hindi, Kanada, Tamil, Telugu, Bengali, Gujarati, Chinese, Korean. That gave a lot of confidence because when you read in your own language or when you listen in your own language it has more value than in English. So that's something also that could be done by creating flyers in different languages because here people cannot differentiate between Hindi and Urdu and they think that Urdu*

*and Hindi is the same. So most of your flyers, if you see most of the public service announcements are in Urdu, not in Hindi. We have to educate the locals before we try to educate our people. So language barrier is one of the things that plays a major part in this whole thing."*

*-Maan*

This statement also underscored the need to not only increase awareness of home care services in a range of South Asian languages but also to inform the broader public about the diversity of these languages, given that they are frequently mistakenly interchanged. Some participants also highlighted the importance of community outreach and engagement in the South Asian communities. For example, Sarah said:

*"There are just so many different festivals and social gatherings, especially in the Peel region. And for these community services to set up a booth there or something. To tell them what all their services are. Because otherwise people don't know. People won't know until they need it, right? And when they need it, they don't know where to go. I think to do outreach social gatherings that happen across the city where there's a lot of South Asians for them to go and tell them what services they provide and all that stuff. Spiritual leaders can also have booths at different social events. Those are all really important."*

*-Sarah*

The quote illustrated the potential value of utilizing South Asian community gatherings as a platform for reaching a wider audience within these communities. It also emphasized the influential role that spiritual or community leaders could play in raising awareness and communicating the significance of home care services to South Asian communities. While some participants proposed methods to raise awareness about home care among the general South Asian communities, others

emphasized the need to specifically target new immigrants, who often face challenges in accessing these services. For instance, Hope said:

> *"If new commers (new immigrants) don't have that knowledge, how can you advocate or how can you ask for services? So, getting involved in the community, involved in community centers really help because most of our community centers has some kind of an older adult program going on. So they will have more information about programs, services, where to reach out for what. And that really is the key. Get educated, get information from different organizations, speak to people in the centers, see what challenges they have gone through and see how you can improve from them there."*

*-Hope*

The quote exemplified the significance of community centers for newer immigrants serving as vital resources for connecting with others and obtaining guidance on navigating the healthcare system, thereby enabling them to be more effective advocates for themselves and their older adults. While some participants talked about promoting awareness about home care resources among South Asian communities, some indicated technical difficulties in accessing information about home care from websites. For instance, Sandra, said:

> *"Everybody says go look at the websites. I feel that that is not a solution to the problem. When you ask for help, please go to www dot you should understand that there are seniors here and there are caregivers who are taking care of seniors who may not be internet friendly. So I think the responsibility that they give the phone numbers, the contact person's name first, rather than saying go to www, dot something. I think that is a very important I think because I know families here where the parents do not even know how to speak English and the children are the caregivers or even to maneuver through the entire system be taxation, be it medical or being going to the groceries, buying things, everything."*

*-Sandra*

Sandra's quote emphasized the importance of providing alternative contact methods, such as personalized support assistance, which could be particularly beneficial for older adults and their care partners who may not be adept with technology.

### 5.3.5 Prioritize Building Rapport with Older Adults

While some participants suggest ways to enhance awareness of home care services among South Asian older adults, others suggested various ways to improve the interpersonal relationship between PSWs and the older adults. For instance, Davida, a 62-year-old participant, recommended training for PSWs on rapport-building techniques to care for South Asian older adults. She said:

> *"The PSWs should have also been trained in asking some other questions like, can I read to you? Yeah? Do you want to hear a podcast? Let's listen to a podcast. You know, how being more like a friend to them. What are you thinking about today? Those questions that are not relevant to eat, food, and how are you, and that's it. No. Something deeper, something more meaningful than just those typical questions. What did you do? Do you want to hear music today? Should I put on music today while we are doing all this? More than just that very, I won't say non-professional, but I would say "a little bit more human."*

*-Davida*

The quote implied that training for PSWs should extend beyond the fundamentals of care tasks and should include methods to engage more meaningfully with their clients. This approach could entail initiating conversations and activities that go beyond just providing care, aiming to create a connection that is rooted in genuine human interaction. Similarly, Hope, who had experience previously working as a PSW said:

*"I've worked in this field for a long time, and I know older adults want a person who can come in, sit with you for five minutes, and check on you, how you're doing to start off, just socializing for five minutes yeah, right? And just chatting with you and have a comfortable space where they can share with you what they need."*

*-Hope*

The quote illustrated that engaging meaningfully with older adults not only builds strong interpersonal relationships but also empowers them to voice their needs and preferences effectively in home care. Such engagement is crucial for enhancing the overall quality of the care provided.

To summarize, the study's participants recommended different ways to improve home care for South Asian older adults. Some highlighted the necessity of cultural humility training for PSWs, while others underscored the importance of training them to be compassionate towards older adults. Study participants also advocated for home care services that facilitated social engagement for older adults. Finally, in order to improve awareness and access to home care, several study participants recommended awareness initiatives which were tailored to South Asian communities.

# Chapter 6: Discussion

In Canada, the demand for home care services continues to increase due to the ongoing growth of the aging population. This aging population is marked not only by the increase in the number of older adults but also by its significant diversity (National Advisory Council on Aging, 2005). There is a growing need to address disparities in the utilization of home care services among immigrant older adults (Johnson, 2017). Despite the importance of home care services, little is known about how ethnic minorities perceive home care services in Ontario, specifically South Asians - who are the largest visible minority in Canada. Therefore, recognizing this overarching context, my research aimed to explore South Asian communities' nuanced perceptions about home care services, barriers they face when accessing these services and recommendations on how home care services in Ontario can be structured to address their unique needs.

In this study, South Asian care partners and older adults expressed a pronounced need for and recognized the importance of home care services in enhancing the provision of care to the older adults. It is well documented that ethnocultural groups are known to voluntarily offer informal support to older adults (National Advisory Council on Aging (NACA) 2005; Ajrouch, 2005; Ahmad and Walker, 1997). These expectations arise from assumptions regarding the resilience of family ties, cultural traditions emphasizing the care of older adults, and the natural caregiving skills embedded within ethnic minority communities (Atkin & Rollings, 1996; Parveen & Morrison, 2009; Dorazio-Migliore et al., 2005). Consequently, these underlying assumptions result in erroneous predictions of care and a decrease in the entitlement of home care among ethnic older adults (Brotman, 2002). In the study, almost every South Asian older adult whose care partner participated in this study received a minimum of 2 hours/week of provincially funded home care services. This study finding aligned with Purewal's (2017) research, which challenges the assumption that South Asian families are entirely

self-reliant and do not require external support in providing care to older adults (Purewal, & Jasani, 2017). Therefore, this study reinforced the notion that each South Asian family may have unique dynamics, and care providers should avoid making assumptions about families not requiring formal support to provide care for older adults (Swihart et al., 2023).

The findings of this study suggested that the length of residency in Canada may potentially influence participants' preferences for home care services. To illustrate, nearly all study participants had immigrated to Canada at least two decades ago. Additionally, existing literature has documented that immigrants from non-Western backgrounds who have lived in their host countries for an extended period of time tend to be more open to adopting Western-style formal services (Needham et al., 2017; Calderon-Rosado,2009; Surood & Lai, 2010). In the study, every participant, including those not currently receiving home care services, were receptive to the notion of utilizing such services. Furthermore, the study participants' preference for home care aligned with the findings of Brijnath (2012), who found that South Asian families often favor in-home care models. This preference is influenced by cultural concepts like 'seva' (voluntary service), reciprocity, duty, and affection of (Brijnath, 2012). Therefore, this study emphasized the dynamic nature of culture and cross-cultural variations in the expression of South Asian cultural values by care partners in Canada. This variation illustrated that traditional values evolve through exposure to and interaction with the Western sociocultural environment, resulting in diverse health behaviors among South Asians (Surood & Lai, 2010).

While certain participants emphasized the importance of home care services, others highlighted cultural barriers such as stigma associated with utilizing such services. Study participants highlighted the prevalence of stigma while seeking formal care, largely due to the cultural expectations of providing care to the older adults within the South Asian communities. For example, Carol revealed

that she initially refused to seek home care due to a sense of guilt, from being perceived as giving up on her filial obligation to care for her husband. Furthermore, South Asians in Canada place significant importance on their ethnic customs and traditions, and this value attached to cultural traditions remains constant over time. According to Statistics Canada (2005), more than two-thirds of South Asian immigrants who arrived between 1991 and 2001 considered the preservation of their cultural heritage as most important (Statistics Canada, 2005). Hence, any deviation from traditional filial expectations might result in stigma, which in turn, could potentially cause delayed access to home care services in Canada.

Due to the stigma and consequent delayed access to home care, study participants also highlighted the importance of increasing awareness of home care services among South Asians in Ontario. According to the study participants, a significant number of South Asian individuals are not adequately informed about the available home care services, and those in need often seek assistance from other South Asian community members to navigate the healthcare system. This finding is consistent with the results of Yakerson's (2019) study, which indicated that informal care partners in need of publicly funded home care were often unaware of the available services in Ontario. While it might be challenging for the general population to be aware of home care services, it could be even more difficult for ethnic minorities due to several compounding factors, such as low health literacy, language barriers, and familial expectations. (Suurmound, 2016; Brotman, 2003). Therefore, considering the additional challenges encountered by South Asians, it is essential to tailor home care awareness strategies for disseminating information in a way that efficiently engages and supports these communities in accessing home care services.

The study's findings highlighted constantly evolving gender roles within the provision of care for older adults in a South Asian family. In a typical South Asian family structure, distinct roles have

traditionally existed in the realm of provision of care for older adults, encompassing various aspects such as household responsibilities, decision-making, financial management, self-care practices, and emotional support. Within this traditional framework, sons are anticipated to take on a central role in decision-making and finance, whereas daughters and daughters-in-law are engaged in household and self-care activities, and emotional support (Bhattacharyya & Shibusawa 2008; Jutlla, 2015; Hossain, 2020).

However, according to the study participants, in recent times, there has been a noticeable shift towards more blended gender roles while caring for older adults. For instance, some participants conveyed that sons within the South Asian families were assuming primary caring roles for the older adults, whereas others highlighted that daughters and daughters-in-law are responsible for providing overall care for older adults. This finding aligned with a recent study conducted by Hussain (2020) on South Asian care partners in Britain, which concluded that the traditional caring roles within South Asian families are continuously evolving due to modernization, cultural integration, and the increased involvement of women in the workforce (Hossain, 2020).

While certain participants indicated shifts in gender dynamics, others talked about care partner burden associated with caring for South Asian older adults. We already know that caring for older adults affects all races, but the negative impacts are exacerbated in ethnic minorities (Greenwood et al., 2015; Parveen & Obyebode, 2018). A recent study conducted by Hussain (2020) on Bangladeshi care partners in the UK underscored the multifaceted roles played by daughters and daughters-in-law in South Asian households, who are responsible for caring not only for their husbands and children but also for their parents-in-law. These multifaceted roles often result in significant physical and emotional burden (Godfrey & Townsend, 2001; Jutlla, 2011; Lawrence et al., 2008). This burden is further amplified by the prevailing cultural norms that imply that seeking formal care is deemed

"unfilial," thus leading to feelings of shame (Livingston et al., 2017; Hossain et al., 2020). For instance, some participants expressed that they encountered a significant challenge in accepting formal care, as it evoked feelings of guilt due to not meeting their cultural caring obligations.

Furthermore, study participants indicated that within the South Asian communities, a tendency exists to exhibit judgmental attitudes towards individuals seeking home care, further causing “shame” to the family. These findings correspond with recent studies (Parveen & Oyebode, 2018; Hossain et al. 2020) which found that the moral obligation of caring for their older adults is strictly observed by the South Asian community and negatively judged when the expectations are not fulfilled, impacting the mental health of the care partner. Therefore, to alleviate care partner burden experienced by South Asian care partners, culturally tailored support services are essential for South Asian care partners to enable effective care for their older adults at home.

In examining participants' narratives on the type of care they wished to receive, it is noteworthy that some participants explicitly used the term 'cultural competence.' However, an in-depth analysis revealed that their articulated expectations aligned more closely with the concept of cultural humility. This distinction is crucial, considering the broader critiques of the term 'cultural competence' outlined in the background section. The participants' emphasis on mutual respect, understanding, and a dynamic approach to cultural interactions suggested a nuanced perspective that extends beyond the traditional understanding of 'cultural competence.' For instance, North believed that the PSW, even in the presence of potential language barriers, should not only possess respect and understanding for her grandmother's religious and cultural preferences but also actively incorporate and accommodate the cultural nuances into her care. A recent study finding showed that the demonstration of cultural humility by care providers helps reduce power imbalances in the patient-provider relationship, promoting a more equitable dynamic which enhances communication and care quality (Lekas, 2020).

Cultural humility holds particular importance in home care because care is provided within the older adult's private sphere of life, demanding an approach that respects and aligns with their cultural values and preferences.

While some study participants talked about cultural humility in the provision of home care, others indicated a preference for a holistic approach to conventional home care services. A holistic approach to care considers the entire well-being of an individual, addressing not only their physical health but also their mental, emotional, social, and spiritual needs (Jasemi, 2017). Firstly, the older adults in the study wanted home care to facilitate their social engagement. To illustrate, Fatima perceived home care as a means to enable her participation in socialactivities like puzzles and outdoor walking, emphasizing the importance of social engagement for South Asian older adults. On the other hand, care partners sought home care as a way to offer companionship to the older adults at home. For instance, some care partners underscored the significance of companionship for their parents, reflecting the importance attached to the emotional aspect of caring within South Asian communities. This finding is distinct from the traditional biomedical model of home care services, which focuses on minimizing the overall disability (Smart & Smart, 2006). Therefore, it is important to consider tailoring the Western biomedical model of home care services to better cater to the holistic needs of South Asian older adults.

Participants emphasized several cultural factors when delivering formal care to South Asian older adults in their home, including gender, ethnicity, and language concordance. First, participants indicated a preference for a PSW who is of the same gender as the South Asian older adult. This corresponded to Sathish's (2023) study, where British South Asian care partners rejected opposite-gendered support workers, which was conflicting with the South Asian cultural expectation for same-gender care providers. For example, participants stated that some older women would “rather die”

than to be touched by other men except their husbands. However, this study also found that the adherence to the "same gender rule" is more stringent for female older adults, while there is greater flexibility in the case of male older adults. This preference for "same gender" care for South Asian older women maybe grounded in cultural and religious values, specifically to honor modesty and respect gender norms (Attum, 2023).

Secondly, participants expressed a strong preference for a PSW who shares the same language as the older adult. This can be illustrated in the case of Helena, who believed that effective communication facilitated by shared language is essential for building trust between the PSW and the older adult. This aligns with Suurmond's (2016) Dutch home care study, where ethnic minority individuals were dissatisfied with Dutch support workers due to language barriers which impeded effective communication between care provider and the client. A language barrier is commonly cited as a barrier to accessing general healthcare services (Scheppers et al., 2006), and it is particularly a barrier in the context of home care as language proficiency empowers older adults to articulate their needs effectively, fostering a person-centered approach to care.

While certain participants emphasized the importance of linguistic concordance in providing care to older adults, others expressed that shared ethnicity also played a significant role. For example, Maan stated that most South Asian individuals preferred PSWs of the same ethnicity, as they would better understand South Asian cultural nuances, languages, and religious practices. Research findings have consistently shown that patients tend to view ethnic alignment between care providers and patients as advantageous (Cooper-Patrick et al., 1999; Pérez-Stable et al., 1997; Saha et al., 1999; Sue et al., 1995). Therefore, offering culturally sensitive services that take into account factors like gender, language, and ethnicity can greatly improve the quality of home care for South Asian older adults.

## 6.1 Implications for Policy and Practice

This study significantly contributed to ethnogerontological knowledge by examining South Asian communities' nuanced perceptions about home care services in Ontario, barriers they faced when accessing these services and recommendations on how home care services in Ontario can be structured to address their unique needs. The research findings hold the potential to provide insights that can be beneficial for governmental organizations, healthcare professionals, and home care agencies seeking a deeper understanding of the preferences and expectations of South Asian older adults receiving home care.

The study's findings highlighted participants' strong preference for home care, acknowledging its pivotal role in caring for older adults within South Asian communities. This finding has two important implications on the broader healthcare continuum. First, the inclination towards home care within the study participants may act as a crucial factor that may potentially influence the delay in accessing long-term care facilities. This delay not only aligns with participants' preferences but also offers economic benefits to the healthcare system by potentially postponing the need for institutionalization. Moreover, an increase in uptake of home care services within South Asian communities may lead to a notable reduction in frequent emergency department visits (Canadian Home Care Association, 2016). This ensures a continuous support system, ultimately improving health outcomes for older adults and care partners. Therefore, it is imperative for policymakers to prioritize providing home care services in a culturally appropriate manner, catering to the diverse cultural needs of the South Asian population.

Over the last few decades, healthcare restructuring along with technological advancements have transitioned acute care into homes (Simms, 2010; Crossen-Sills 2020). This has led to an increase in

demand for home care services and confusion on how to obtain them (Landry et al., 2008). This study highlighted the need to increase awareness of home care services among South Asian communities in Ontario, especially because they encounter additional challenges related to language and resources. The study participants proposed several strategies to enhance awareness, such as dissemination of home care resources in multiple local languages through pamphlets and posters within community centers, establishment of awareness centers during festivals or communal gatherings, and utilizing spiritual or community leaders as ambassadors to relay health information. These strategies could be used by governmental and home care agencies to disseminate home care related information effectively catering to South Asian communities in Ontario.

Furthermore, this study indicated a need to incorporate cultural humility into the PSWs training modules within the home care sector. Policy recommendations should prioritize a shift from a traditional cultural competence framework to one that emphasizes ongoing education, self-reflection, and collaborative learning for PSWs. This approach would ensure that PSWs not only possess cultural knowledge but also develop adaptive skills for engaging effectively with diverse populations. Policymakers should consider revising existing PSW training standards with the principles of cultural humility, fostering an environment that encourages continuous learning and a deeper understanding of the intricate cultural dynamics influencing home care experiences. This shift in policy could lead to significant improvements in PSW training, enhancing the quality of home care services for individuals from diverse cultural backgrounds.

The study's findings indicated that South Asian care partners experienced profound burden due to their multifaceted roles, along with the feelings of guilt and shame attributed to cultural barriers such as familial expectations. Furthermore, in South Asian communities, mental health issues related to life's challenges are often considered natural responses, resulting in the underestimation of these

symptoms when expressed by individuals (Sathish, 2023). It was also found that South Asian care partners often neglect their own mental health and hesitate to seek help, ultimately amplifying care partner burden (Islam, 2017; Sathish 2023). Therefore, it is essential to develop culturally appropriate psychosocial support services for South Asian care partners, with the objective of enhancing their capacity to care effectively for both themselves and the older adults they provide care for.

The current home care model in Ontario is biomedical, which has its roots in Eurocentric traditions. There have been numerous studies critiquing the reductionist biomedical model (Rocca, 2020). One such criticism is that it does not address the psychosocial determinants of health (Rocca, 2020). Participants of this study envisioned home care to be more holistic, incorporating both physical and emotional needs of the older adults. My research underscored the significance of adopting a holistic approach to home care that goes beyond purely addressing physical needs, emphasizing the importance of addressing psychological and social aspects in the provision of care. These insights could serve as valuable input for guiding policy and practice reforms at local and national levels.

Consistent with previous research (Marrelli, 2017), this study also reinforced the notion of patient-centered care, where the care recipient plays an active role in receiving care. Understanding and recognizing the cultural nuances and differences present among South Asian cultures could aid PSWs and other health providers in providing care according to the needs of the care recipient instead of depending on cultural misconceptions. It is evident from our study how each participant’s experiences and perceptions of home care varied depending on their lived experiences, socio-economic status, educational level and duration of stay in Canada. Therefore, care providers must exercise caution before solely relying on cultural stereotypes.

## 6.2 Implications for Future Research

In this study, an unexplored participant characteristic is the perceptions of home care among South Asian older adults with dementia living in their own homes. It's worth noting that none of the participants in our study were diagnosed with dementia or were care partners for individuals with dementia. Given the increasing prevalence and the stigma attached to dementia in South Asian communities (Blakemore, 2018), it is recommended for future studies to conduct research on South Asian individuals who are living at home with dementia.

Additional research is required to gain insight into how South Asian communities perceive home care services, particularly considering different waves of immigration and their countries of origin. Given that our current sample comprised of participants who arrived in Canada approximately 20 years ago, it would be valuable to investigate the perspectives of South Asian individuals who have immigrated within the last decade. This would help us better understand how the perception of home care services may vary among South Asian individuals based on more recent immigration experiences.

Furthermore, expanding this study through an intersectional lens could offer a valuable opportunity to delve into the nuanced experiences of specific groups within the home care, considering the interplay of gender, race, and age. This exploration could include understanding the perspectives of women care partners, older women, and women serving as PSWs regarding home care services. While Yakerson's (2019) study examined access to home care in Ontario through a feminist political ecology framework, it did not specifically address the experiences of racialized women under neoliberal healthcare reform, specifically home care. Neoliberal restructuring of home care entails decentralization, shifting authority from central government to local and regional levels (Yakerson, 2019). This aims to reduce administrative duplication, lower costs, and cater to the specific needs of

local contexts (Yakerson, 2019). Nevertheless, neoliberalism health reforms have been shown to increase health inequalities (Yakerson, 2019). Future research could build on this foundation by exploring the intersections of gender, race, and caregiving roles in the context of home care. An in-depth intersectional analysis has the potential to illuminate the unique challenges faced by racialized women in both care partner and PSW roles, highlighting how neoliberal home care policies may impact their experiences differently.

Finally, along the healthcare continuum, a pivotal direction for further exploration could involve understanding how cultural factors such as filial piety could contribute to the delay in admission to long-term care facilities. This presents a significant opportunity to explore the resulting impact on the demands placed on home care services within the South Asian communities. Moreover, the exploration takes on added significance as there appears to be a greater stigma surrounding admission to long-term care facilities within the South Asian communities compared to home care (Brijnath, 2012). The additional stigma surrounding institutionalized care adds layers of complexity to the decision-making process, influencing not only the utilization of home care services but also shaping perceptions and choices related to long-term care admissions.

## 6.3 Limitations and Strengths

There were several limitations to this qualitative research study. Due to limited existing research on home care services on South Asian communities, this study employed an exploratory qualitative study design. The exploratory qualitative approach provided in-depth insights but lacks broader generalizability. A longitudinal or survey-based study design could offer a more comprehensive understanding of the views and preferences of home care within South Asian communities, thereby enhancing the applicability of its findings to a broader South Asian population.

The decision to include participants from diverse South Asian communities was aimed to capture a broad range of perceptions about home care services. However, this approach limited the in-depth exploration of specific needs and perceptions unique to distinct subgroups, such as those from Sri Lanka, India, or Bangladesh. Given that South Asian communities encompass individuals from diverse socioeconomic statuses, faiths, and regions, a separate analysis for distinct South Asian countries, could have deepened the understanding of their unique sociocultural nuances and, healthcare experiences. Ultimately, this would have enhanced the overall specificity of the study findings. Therefore, future studies might benefit from focusing on specific communities within the broader South Asian context.

Similarly, the study's inclusion of three distinct groups limited the in-depth exploration of differences and similarities in perceptions among care partners, older adults, and key informants. To gain a more comprehensive understanding of how views on home care are perceived by South Asian care partners and older adults, future research should focus on exploring the perceptions of each group individually. This targeted approach will allow for a thorough exploration of their unique perspectives and experiences with home care services.

Additionally, the lack of a phone number in the recruitment material created a bias by excluding individuals who did not have access to email. This limitation may have restricted the sample to those with technology access, potentially reducing the depth of diversity in perceptions captured in the study. Moreover, this study employed snowball sampling. Therefore, individuals with similar socioeconomic status and social or professional networks might have shared similar perspectives, potentially influencing the breadth of perceptions in the study.

Another limitation of this study is that the sample was limited to individuals who were proficient in English. Further research on home care should be focused on understanding the experiences and

perceptions of new immigrants from low socio-economic backgrounds who are not proficient in English. Furthermore, interviews were conducted with only three older adults, all of whom were not receiving home care services. It would have been beneficial to acquire additional insights from older adults who were receiving home care services in Ontario. This would have aided in understanding any preferences or barriers from an end-user perspective. In addition to limited older adults receiving home care, the study's limitation lies in the lack of male representation, particularly among care partners. To address this gap, future research should delve into the perceptions and experiences of South Asian male care partners in navigating home care services.

The study predominantly included participants from India, Bangladesh, Sri Lanka, and Pakistan, aligning with the current demographic composition of Ontario. Future studies should specifically investigate the perceptions and experiences of individuals from Nepal and Bhutan, given their unique histories marked by a lack of British colonization, distinguishing them from the other South Asian countries.

While this research is not without its limitations, it possesses some notable strengths. Firstly, to the best of our knowledge, this is the first study to focus on South Asian communities' perceptions and barriers on home care services. Secondly, despite recruitment challenges, the triangulation of data from three distinct groups elicited diverse perceptions about home care services within South Asian communities. Furthermore, the research lays the groundwork for future studies to explore perceptions across various ethnic and linguistic backgrounds. Finally, this research holds significant implications for policy and practice, offering valuable insights that can inform reforms at both local and national levels.

# Chapter 7: Conclusion

This study employed an exploratory qualitative research design to investigate the nuanced perceptions about home care services in Ontario, barriers they face when accessing these services and recommendations on how home care services in Ontario can be structured to address their unique needs. Through semi-structured interviews, it was found that while most participants view home care to be an important support for older adults, there's also an acknowledgment of the stigma associated with seeking such services due to cultural expectations present in South Asian communities. The study reinforced the notion that the South Asian communities are a diverse and heterogeneous group. Perceptions of home care services differed based on the extent of Western cultural adaptation and lived experiences. The research also underscored that while the general population faces obstacles in accessing home care, these challenges are more pronounced within the South Asian communities due to factors like cultural expectations, language barriers, and financial constraints. Additionally, it highlighted the need for culturally tailored home care services to meet the specific needs of an increasingly diverse aging population. This study significantly contributed to ethnogerontological knowledge by examining South Asian communities' nuanced perceptions about home care services, barriers they faced when accessing these services and recommendations on how home care services in Ontario can be structured to address their unique needs. Recommendations included targeted awareness strategies and culturally sensitive services for South Asian care partners. The study advocates for a holistic home care model, patient-centered care, and cautioning against reliance on cultural stereotypes. Future research suggestions included exploring perceptions among recent immigrants, those with dementia, and an intersectional analysis. Additionally, investigating cultural factors like filial piety and their impact on long-term care decisions within the South Asian population is recommended, addressing associated stigma.

# References

Acharya, M. P., & Northcott, H. C. (2007). Mental distress and the coping strategies of elderly Indian immigrant women. *Transcultural Psychiatry, 44*(4), 614–636. https://doi.org/10.1177/1363461507083901

Ahmad, W. I. U., & Walker, R. (1997). Asian older people: housing, health and access to services. *Ageing and Society*, *17*(2), 141–165. https://doi.org/10.1017/S0144686X96006344

Ajrouch, K. J. (2005). Arab American immigrant elders' views about social support. *Ageing and Society*, *25*(5), 655–673. https://doi.org/10.1017/S0144686X04002934

Atkin, K., & Rollings, J.(1996). Looking after their own? In family care giving among Asian and Afro-Caribbean communities 'race' and community care*. Open University Press, Buckingham*, pp. 73–86.

Ayalon, L., Fialová, D., Areán, P. A., & Onder, G. (2010). Challenges associated with the recognition and treatment of depression in older recipients of home care services. *International Psychogeriatrics, 22*(4), 514–522. https://doi.org/10.1017/S1041610209991797

Attum, B., Hafiz, S., Malik, A., & Shamoon, Z. (2023). Cultural competence in the care of Muslim patients and their families. *StatPearls Publishing.* http://www.ncbi.nlm.nih.gov/books/NBK499933/

Ayyub, R. (2000). Domestic violence in the South Asian Muslin immigrant population in the United States. *Journal of Social Distress and the Homeless, 9*(3), 237–248. https://doi.org/10.1023/a:1009412119016

Azzopardi C, McNeill T. From Cultural competence to cultural consciousness: Transitioning to a critical approach to working across differences in social work. *Journal of Ethnic & Cultural Diversity in Social Work*. 2016;25(4):282-299. doi:10.1080/15313204.2016.1206494

Battams, N. (2013). In it Together: multigenerational living in Canada. *Transition, 43* (3), 11-13.

Beagan BL. A critique of cultural competence: assumptions, limitations, and alternatives. *Springer International Publishing*; :123-138. doi:10.1007/978-3-319-78997-2_6

Bhattacharya, G., & Shibusawa, T. (2009). Experiences of aging among immigrants from India to the United States: Social work practice in a global context. *Journal of Gerontological Social Work*, *52*(5), 445–462. https://doi.org/10.1080/01634370902983112

Berger. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research : QR, 15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Blakemore, A., Kenning, C., Mirza, N., Daker-White, G., Panagioti, M., & Waheed, W. (2018). Dementia in UK South Asians: a scoping review of the literature. *BMJ Open*, *8*(4), e020290–e020290. https://doi.org/10.1136/bmjopen-2017-020290

Biondo, P. D., Kalia, R., Khan, R., Asghar, N., Banerjee, C., Boulton, D., Simon, J. E. (2017). Understanding advance care planning within the South Asian community. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy, 20*(5), 911-919.doi:10.1111/hex.12531

Blevins, D., & Papadatou, D. (2006). The effects of culture in End-of-Life Situations. In *Psychosocial issues near the end of life: A resource for professional care providers* (pp. 27–55). American Psychological Association. https://doi.org/10.1037/11262-002

Braun, & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., Clarke, V. (2019). Reflecting on reflexive thematic analysis. Qual. Res. *Sport Exerc. Health 11*(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Brijnath, B. (2012). Why does institutionalised care not appeal to Indian families? Legislative and social answers from urban India. *Ageing and Society*, *32*(4), 697–717. https://doi.org/10.1017/S0144686X11000584

Brotman, S. (2002). Primacy of family in elder care discourse: Home care services to older ethnic women in Canada. *Journal of Gerontological Social Work*, 38(3), 19-52.

Brotman, S. (2003). The limits of multiculturalism in elder care services. *Journal of Aging Studies*, *17*(2), 209-22

Brown G. E., Woodham, A., Marshall. M., Thornicroft. G., Szmukler .G., Birchwood. M., Waquas.A., Farrelly .S., Waheed.W. (2014). Recruiting South Asians into a UK mental health randomised controlled trial: Experiences of field researchers. *Racial Ethn Health Disparities.* https://doi.org/10.1007/s40615-014-0024-4

CalderÓn-Rosado, V., Morrill, A., Chang, B.-H., & Tennstedt, S. (2002). Service utilization among disabled Puerto Rican lders and their caregivers: Does acculturation play a role? *Journal of Aging and Health*, *14*(1), 3–23. https://doi.org/10.1177/089826430201400101

Canadian Home Care Association. (2016). A better home care in Canada. Retrieved from https://cdnhomecare.ca/wp-content/uploads/2020/03/Better-Home-Care-Report-web-EN.pdf

Canadian Medical Association. (2016). The state of seniors' healthcare in Canada. Available from, the- state-of-seniors-health-care-in-canada-september-2016.

Chappell, N., Dlitt B.H., Hollander, M. J., Miller, J. A., & McWilliam, C. (2004). Comparative costs of home care and residential care. *The Gerontologist, 44*(3), 389–400. https://doi.org/10.1093/geront/44.3.389

Citizenship and Immigration Canada. (2012). Permanent and temporary residents, 2011. (2012, July 30). Retrieved on August 2022, from: https://open.canada.ca/data/en/dataset/f7e5498e-0ad8-4417-85c9-9b8aff9b9eda

Connecting Care Act, c. 5, Sched. (2019). https://www.ontario.ca/laws/statute/19c05

Cooper-Patrick, L., Gallo, J. J., Gonzales, J. J., Vu, H. T., Powe, N. R., Nelson, C., & Ford, D. E. (1999). Race, gender, and partnership in the patient-physician relationship. *JAMA, 282*(6), 583–589. https://doi.org/10.1001/jama.282.6.583

Creswell, J. W. (2014). Research design qualitative, quantitative and mixed methods approaches (4th ed*.). Thousand Oaks, CA Sage. - References - Scientific Research Publishing.*

Crist, J. D., Kim, S.-S., Pasvogel, A., & Velázquez, J. H. (2009). Mexican American elders' use of home care services. *Applied Nursing Research*, *22*(1), 26–34. https://doi.org/10.1016/j.apnr.2007.03.002

Crotty, M. (2003): The foundations of social research: Meaning and perspectives in the research process*, London: Sage Publications, 3rd edition, 10.*

Crossen-Sills, J., Toomey, I., & Doherty, M. E. (2009). Technology and home care: implementing systems to enhance aging in place. *The Nursing Clinics of North America*, *44*(2), 239–246. https://doi.org/10.1016/j.cnur.2009.03.003

Danso R. (2018). Cultural competence and cultural humility: A critical reflection on key cultural diversity concepts. *Journal of Social Work, 18*(4):410-430. doi:10.1177/1468017316654341

Delamont, S., & Atkinson, P. (2016). Editorial. *Qualitative Research*. https://doi.org/10.1177/146879410100100301

Denktaş, S., Koopmans, G., Birnie, E., Foets, M., & Bonsel, G. (2009). Ethnic background and differences in health care use: a national cross-sectional study of native Dutch and immigrant elderly in the Netherlands. *International Journal for Equity in Health*, *8*(1), 35–35. https://doi.org/10.1186/1475-9276-8-35

Dorazio-migliore, M., Migliore, S., & Anderson, J. M. (2005). Crafting a praxis-oriented culture concept in the health disciplines: Conundrums and possibilities. *Health, 9*(3), 339-360.

Furlong, M., & Wight, J. (2011). Promoting "critical awareness" and critiquing "cultural competence": Towards disrupting received professional knowledges. *Australian Social Work, 64*(1), 38–54. https://doi.org/10.1080/0312407X.2010.537352

Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). Early communitybased service utilization and its effects on institutionalization in dementia caregiving. *Gerontologist, 45*(2), 177–185. https://doi.org/10.1093/geront/45.2.177

Gilmour, H. (2018). ***Unmet home care needs in Canada*. Statistics Canada.** Unmet home care needs in Canada (statcan.gc.ca)

Ginde, A. A., Clark, S., & Camargo, C. A. (2009). Language barriers among patients in Boston emergency departments: Use of medical interpreters after passage of interpreter legislation. *Journal of Immigrant and Minority Health, 11*(6), 527–530. doi: 10.1007/s10903-008-9188-5

Godfrey M., Townsend J. (2001). Caring for an elder with dementia: The experience of Asian caregivers and barriers to the take up of support services. Nuffield Institute for Health, University of Leeds, UK

Government of Canada. (1999). Home care in Canada 1999: An overview. Available from, https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/home-continuing-care/home-care-canada-1999-overview.html#a3_6

Government of Canada. (2016). Home and community health care. Available from, https://www.canada.ca/en/health-canada/services/home-continuing-care/home-community-care.html

Government of Ontario. (2023). Home and community care. Available from, https://www.ontario.ca/page/home-community-care#:~:text=Call%20your%20Home%20and%20Community,2222%20(no%20area%20code%20required)

Greene-Moton, E., & Minkler, M. (2020). Cultural competence or cultural humility? Moving beyond the debate. *Health Promotion Practice*, *21*(1), 142–145. https://doi.org/10.1177/1524839919884912

Grenier ML. Cultural competency and the reproduction of White supremacy in occupational therapy education. *Health Education Journal. 2020;79*(6):633-644. doi:10.1177/0017896920902515

Guberman, N., & Maheu, P. (2002). Conceptions of family caregivers: Implications for professional practice. *Canadian Journal on Aging, 21*(1), 27-37.

Gupta, & Pillai, V. K. (2002). Elder caregiving in South Asian families: implications for social service. *Journal of Comparative Family Studies, 33*(4), 565–576.

Hernandez, M., & Gibb, J. K. (2020). Culture, behavior and health. *Evolution, Medicine, and Public Health*, *2020*(1), 12–13. https://doi.org/10.1093/emph/eoz036

Hidalgo, M.C., & Hernandez, B. (2001). Place attachments: Conceptual and empirical questions. *Journal of Environmental Psychology*, *21*(3), 273–281. https://doi.org/10.1006/jevp.2001.0221

Home Care Ontario. 2019. Staying home and Staying healthy. Retrieved from: https://www.homecareontario.ca/docs/default-source/position-papers/1-staying-home-staying-healthy-home-care-in-the-time-of-covid-19-and-beyond_pages_sm.pdf?sfvrsn=17

Home Care Sector Study Corporation. (2003). *Canadian home care human resources study*. Ottawa: Canadian Health Human Resources Network (CHHRN). https://www.hhr-rhs.ca/en/?option=com_mtree&task=viewlink&link_id=5228&Itemid=109%E2%8C%A9=en

Hossain, M. Z., Stores, R., Hakak, Y., & Dewey, A. (2020). Traditional gender roles and effects of dementia caregiving within a South Asian ethnic group in England. *Dementia and Geriatric Cognitive Disorders*. https://doi.org/10.1159/000506363

Howard, M. C., & Hoffman, M. E. (2018). Variable-centered, person-centered, and personspecific approaches: Where theory meets the method. *Organizational Research Methods, 21*(4), 846–876. https://doi.org/10.1177/1094428117744021

Hsueh, L., Hirsh, A. T., Maupomé, G., & Stewart, J. C. (2021). Patient-provider language concordance and health outcomes: A systematic review, evidence map, and research agenda. Medical Care Research and Review: MCRR, *78*(1), 3–23.

Huisman, K. A. (1996). Wife battering in Asian American communities. Identifying the service needs of an overlooked segment of the U.S. population. *Violence Against Women, 2,* 260–283.

Islam, F., Multani, A., Hynie, M., Shakya, Y., & McKenzie, K. (2017). Mental health of South Asian youth in Peel Region, Toronto, Canada: a qualitative study of determinants, coping strategies and service access. *BMJ Open*, *7*(11), e018265–e018265. https://doi.org/10.1136/bmjopen-2017-018265

*Jamuna. (2000). Ageing in India: Some key issues. Ageing International, 25(4), 16–31. https://doi.org/10.1007/s12126-000-1008-8*

Jasemi, M., Valizadeh, L., Zamanzadeh, V., & Keogh, B. (2017). A concept analysis of holistic care by hybrid model. *Indian Journal of Palliative Care*, *23*(1), 71–80. https://doi.org/10.4103/0973-1075.197960

Johnson, C.S., Bacsu, J., McIntosh, T., Jeffery, B., & Novik, N. (2017). Home care in Canada: An Environmental Scan. Regina, SK: Saskatchewan Population Health and Evaluation Research Unit, University of Regina and University of Saskatchewan

*Jongen, McCalman, J., & Bainbridge, R. (2018). Health workforce cultural competency interventions: a systematic scoping review. BMC Health Services Research, 18(1), 232–232. https://doi.org/10.1186/s12913-018-3001-5*

Jutlla, K. (2013). Ethnicity and cultural diversity in dementia care: Review of the research. Journal of Dementia Care, 21, 33–39.

Kelsall-Knight, L. (2022). Practising cultural humility to promote person and family-centred care. *Nursing Standard.* https://doi.org/10.7748/ns.2022.e11880

Kadushin, G. (2004). Home Health Care Utilization: A review of the research for social work. *Health & Social Work*, *29*(3), 219–244. https://doi.org/10.1093/hsw/29.3.219

Krakauer, E. L., Crenner, C., & Fox, K. (2002). Barriers to optimum end-of-life care for minority patients. *Journal of the American Geriatrics Society (JAGS)*, *50*(1), 182–190. https://doi.org/10.1046/j.1532-5415.2002.50027.x

Kumaş-Tan Z, Beagan B, Loppie C, MacLeod A, Frank B. Measures of cultural competence: examining hidden assumptions. *Academic Medicine. 2007;82*(6):548-557. doi:10.1097/ACM.0b013e3180555a2d

Landry, M. D., Jaglal, S., Wodchis, W. P., Raman, J., & Cott, C. A. (2008). Analysis of factors affecting demand for rehabilitation services in Ontario, Canada: a health-policy perspective. *Disability and Rehabilitation, 30*(24), 1837-1847

Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK. British *Journal of Psychiatry*, 192, 240–246.

Lekas, H.-M., Pahl, K., & Fuller Lewis, C. (2020). Rethinking cultural competence: shifting to cultural humility. *Health Services Insights*, *13*, 1178632920970580–1178632920970580. https://doi.org/10.1177/1178632920970580

Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International Journal of Nursing Sciences*, *7*(4), 438–445. https://doi.org/10.1016/j.ijnss.2020.07.012

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D.,Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, C., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Larson, E. B., Ritchie, K., Rockwood, K., Sampson, E. L., Samus, Q., … Mukadam, N. (2017). Dementia prevention, intervention, and care. *Lancet (London, England), 390*(10113), 2673–2734. https://doi.org/10.1016/S0140-6736(17)31363

Lucas, A., Murray, E., & Kinra, S. (2013). Heath beliefs of UK South Asians related to lifestyle diseases: A review of qualitative literature. *Journal of Obesity,* 2013, 1–13. https://doi.org/10.1155/2013/827674

Maddalena, V. (2016). Negotiation, mediation and communication between cultures: End-of-life care for South Asian immigrants in Canada from the perspective of family caregivers. *Social Work in Public Health, 31*(7), 665- 677.https://dx.doi.org/10.1080/19371918.2015.1137521

Mann, M. (2014). South Asia's modern history: Thematic perspectives (1st ed*.). Routledge.* https://doi.org/10.4324/9781315754550

Marani H, Shaw J, Marchildon GP. Challenges navigating publicly funded home care in Ontario, Canada: Perspectives from unpaid caregivers of persons living with dementia. *Dementia (London, England)*. *2023;22*(7):14713012231190580-14713012231191644. doi:10.1177/14713012231190579

Marchildon G. P. (2004). The public/private debate in the funding, administration and delivery of healthcare in Canada. *HealthcarePapers, 4*(4), 61–84. https://doi.org/10.12927/hcpap.2004.16855

Marrelli, T. (2017). Delivering person-centred care in people's homes: Adapting to patients' lifestyles and meeting their needs can be challenging for nurses who feel as if they are guests. *Nursing Management (Harrow, London, England)*, *24*(4), 16–16. https://doi.org/10.7748/nm.24.4.16.s19

Martin-Matthews, A. (2007). Situating 'Home' at the nexus of the public and private spheres: Ageing, gender and home support work in Canada. *Current Sociology, 55*(2), 229-249.

McDonald, J. T., & Kennedy, S. (2007). Cervical cancer screening by immigrant minority women in Canada. *Journal of Immigrant and Minority Health, 9*(4), 323–334.

McKenna, L. (2022). Translation of research interviews: Do we have a problem with qualitative rigor? *Nurse Author & Editor, 32*(1), 1–3. https://doi.org/10.1111/nae2.31

McMillan, S. S., Kendall, E., Sav, A., King, M. A., Whitty, J. A., Kelly, F., & Wheeler, A. J. (2013). Patient-centered approaches to health care: A systematic review of randomized controlled trials. *Medical Care Research and Review*, *70*(6), 567–596. https://doi.org/10.1177/1077558713496318

Milligan. (2009). There's no place like home : place and care in an ageing society. *Ashgate*.

Ministry of Health and Long-Term Care (MOHLTC). 2007. Backgrounder: Aging at Home Strategy.

National Advisory Council on Aging Canada. (2005). Seniors on the margins: Seniors from ethnocultural minorities.  Available online at https://publications.gc.ca/collections/Collection/H88-5-1-2005E.pdf

Narayan, M. C. (2016). Six Steps toward cultural competence: A clinician's guide. *Home Health Care Management & Practice*. https://doi.org/10.1177/108482230101400106

National Institute of Aging. Almost 100 per cent of older Canadians surveyed plan to live independently. [Story] Accessed November 12, 2022.

Needham, B. L., Mukherjee, B., Bagchi, P., Kim, C., Mukherjea, A., Kandula, N. R., & Kanaya, A. M. (2017). Acculturation strategies among South Asian immigrants: The Mediators of Atherosclerosis in South Asians Living in America (MASALA) Study. *Journal of Immigrant and Minority Health, 19*(2), 373–380. https://doi.org/10.1007/s10903-016-0372-8

Ogihara, Y., & Uchida, Y. (2013). Does individualism bring happiness? Negative effects of individualism on interpersonal relationships and happiness. *Frontiers in Psychology.* https://doi.org/10.3389/fpsyg.2014.00135.

Parkinson Foundation. (2019). Caring for the care partner. Accessed from: https://www.parkinson.org/resources-support/carepartners/caring-for-self

Parveen, S., & Morrison, V. (2009). Predictors of familism in the caregiver role: A pilot study. *Journal of Health Psychology*, *14*(8), 1135–1143. https://doi.org/10.1177/1359105309343020

Parveen, S and Oyebode, J. (2018). Dementia and minority ethnic carers. A Race Equality Foundation Briefing Paper.

Pentaris, P., & Thomsen, L. L. (2020). Cultural and religious diversity in hospice and palliative care: A qualitative cross-country comparative analysis of the challenges of healthcare professionals. *Omega, 81*(4), 648–669. https://doi.org/10.1177/0030222818795282

Perez, J.D. (1997). Differences in Social Support: A Comparison of Individualist and Collectivist World-Views Including Asian, Hawaiian, and European- American Cultures. PhD Dissertation, Loyola University Chicago.

Pérez-Stable, E. J., Nápoles-Springer, A., & Miramontes, J. M. (1997). The effects of ethnicity and language on medical outcomes of patients with hypertension or diabetes*. Medical Care, 35(*12), 1212–1219. https://doi.org/10.1097/00005650-199712000-00005

Pillow, W. (2003). Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodo-logical power in qualitative research. *International Journal of Qualitative Studies inEducation, 16(*2), 175–196. https://doi.org/10.1080/0951839032000060635

Pistole MC. Editor's note of multicultural competencies. Journal of Mental Health Couns. 2004;26(1):39–40.

Purewal, N., & Jasani, R. (2017). South Asian women elders and everyday lives of "care in the community" in Britain: the neoliberal turn in social care and the myth of the family. *South Asian Diaspora*, *9*(2), 111–127. https://doi.org/10.1080/19438192.2017.1339381

Radhakrishnan, K., Saxena, S., Jillapalli, R., Jang, Y., & Kim, M. (2017). Barriers to and facilitators of South Asian Indian-Americans' engagement in advanced care planning behaviors. *Journal of Nursing Scholarship, 49*(3), 294-302. https://dx.doi.org/10.1111/jnu.12293

Ramaswamy, P., Joseph, M., & Wang, J. (2020). Health beliefs regarding cardiovascular disease risk and risk reduction in South Asian immigrants: An integrative review. *Journal of Transcultural Nursing, 31*(1), 76–86. https://doi.org/10.1177/1043659619839114

Romanow, R. (2002). Building on values, the future of health care in Canada, final report. Retrieved October 18, 2022 from http://www.hcsc.gc.ca/english/pdf/romanow/pdfs/HCC_Final_Report.pdf

Rooney, L.K., Bhopal, R., Halani L., Levy, M. L., Partridge, M. R., Netuveli, G., Car, J., Griffiths, C., Atkinson, J., & Lindsay, G. (2011). Promoting recruitment of minority ethnic groups into research: qualitative study exploring the views of South Asian people with asthma. *J Public Health, 33*(4)*,* 604–15. 10.1093/pubmed/fdq100

Rubinstein, R. L. (1989). The home environments of older people: a description of the psychosocial processes linking person to place. *Journal of Gerontology (Kirkwood)*, *44*(2), S45–S53. https://doi.org/10.1093/geronj/44.2.s45

Sadavoy, J., Meier, R., & Ong, A. Y. M. (2004). Barriers to access to mental health services for ethnic seniors: The TorontoStudy. *Canadian Journal of Psychiatry, 49*(3), 192–199. https://doi.org/10.1177/070674370404900307

Sathish, A. (2023). Caring for the Caregivers: Exploring the Experiences of South Asian Carers of People with Dementia in Greater Manchester Area: An IPA study. [Doctoral Dissertation, Manchester Metropolitan University]

Saha, S., Beach, M. C., & Cooper, L. A. (2008). Patient centeredness, cultural competence and healthcare quality. *Journal of the National Medical Association.*, *100*(11), 1275–1285. https://doi.org/10.1016/s0027-9684(15)31505-4

Scheppers, E., van Dongen, E., Dekker, J., Geertzen, J., & Dekker, J. (2006). Potential barriers to the use of health services among ethnic minorities: a review. *Family Practice*, *23*(3), 325–348. https://doi.org/10.1093/fampra/cmi113

Shariff, F. D. (2008). The liminality of culture: Second generation South Asian Canadian Identity and the potential for postcolonial texts. *Journal of Teaching and Learning, 5(*2). https://doi.org/10.22329/jtl.v5i2.251

Sharma, & Kemp, C. L. (2011). "One should follow the wind": Individualized filial piety and support exchanges in Indian immigrant families in the United States. *Journal of Aging Studies, 26*(2), 129–139. https://doi.org/10.1016/j.jaging.2011.10.003

Sharma, R., Khosla, N., Tulsky, J. A., and Carrese, J. A. (2011). Traditional expectations versus US realities: first- and second-generation Asian Indian perspectives on end-of-life care. *Journal of General Internal Medicine, 27* (3), 311-317.

Sheikh, A., Halani, L., Bhopal, R., Netuveli, G., Partridge, M. R., Car, J., Griffiths, C., & Levy, M. (2009). Facilitating the recruitment of minority ethnic people into research: qualitative case study of South Asians and asthma. *PLoS medicine*, *6*(10), e1000148. https://doi.org/10.1371/journal.pmed.1000148

Simms, C. (2010). Health reform in Canada. *International Journal of Clinical Practice (Esher)*, *64*(4), 426–428. https://doi.org/10.1111/j.1742-1241.2010.02321.x

Sinha M. Portrait of caregivers, 2012. Ottawa: Statistics Canada; 2012. [cited 2022 October 31]. Available from: https://publications.gc.ca/site/eng/454428/publication.html

Smart, J. F. and Smart, D. W. (2006). Models of Disability: Implications for the counseling profession. *Journal of Counseling and Development*, 84, 29-40

Statistics Canada. (2005). South Asians in Canada: Unity through diversity. Available from: https://www150.statcan.gc.ca/n1/pub/11-008-x/2005002/article/8455-eng.pdf

Statistics Canada. (2018). Population growth: Migratory increase overtakes natural increase. Ottawa, ON. Available from: https://www150.statcan.gc.ca/n1/pub/11-630-x/11-630-x2014001-eng.htm

Statistics Canada. (2021a). The Canadian census: A rich portrait of the country's religious and ethnocultural diversity. Retrieved on October 26, 2022 from: https://www150.statcan.gc.ca/n1/daily-quotidien/221026/dq221026b-eng.htm

Statistics Canada. (2021b). Immigrants make up the largest share of the population in over 150 years and continue to shape who we are as Canadians. Ottawa, ON. Retrieved from: https://www150.statcan.gc.ca/n1/daily-quotidien/221026/dq221026a-eng.htm

Statistics Canada. (2022). Census family status and household living arrangements, household type of person, age group and gender: Canada, provinces and territories, census metropolitan areas and census agglomerations (Table 98-10-0134-01). https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=9810013401

Suurmond, J., Rosenmöller, D. L., el Mesbahi, H., Lamkaddem, M., & Essink-Bot, M.-L. (2016). Barriers in access to home care services among ethnic minority and Dutch elderly – A qualitative study. *International Journal of Nursing Studies*, *54*, 23–35. https://doi.org/10.1016/j.ijnurstu.2015.02.014

Surood, S., & Lai, D. (2010). Impact of culture on use of Western health services by older South Asian Canadians. *Canadian Journal of Public Health, 101*(2), 176–180.

Swihart, D. L., Yarrarapu, S. N. S., & Martin, R. L. (2023). Cultural religious competence in clinical practice. In StatPearls. StatPearls Publishing. http://www.ncbi.nlm.nih.gov/books/NBK493216/

Tervalon, & Murray-García, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved, 9*(2), 117–125. https://doi.org/10.1353/hpu.2010.0233

Thurairajah, K. (2018). The person behind the research": Reflexivity and the qualitative research process. *The Craft of Qualitative Research: A handbook*, 10-16.

Torres, S. (2006). Elderly immigrants in Sweden: "Otherness" under construction. *Journal of Ethnic and Migration Studies*, *32*(8), 1341–1358. https://doi.org/10.1080/13691830600928730

Tuckett. (2005). Applying thematic analysis theory to practice: A researcher's experience. Contemporary Nurse : *a Journal for the Australian Nursing Profession, 19*(1-2), 75–87. https://doi.org/10.5172/conu.19.1-2.75

Turcotte, M. and Schellenberg, G. (2007). A Portrait of seniors in Canada, 2006. Available from: https://www150.statcan.gc.ca/n1/en/pub/89-519-x/89-519-x2006001-eng.pdf?st=9K43kJBs

Waheed, W., Hughes-Morley, A., Woodham, A., Allen, G., & Bower, P. (2015) Overcoming barriers to recruiting ethnic minorities to mental health research: a typology of recruitment strategies. *BMC Psychiatry 15*, 101. https://doi.org/10.1186/s12888-015-0484-z

Walsh, A. (2014). Cultural Considerations in the Delivery of Homecare Services: "Beyond 2 kitchens and a disability/ più di due cucine e disabilità [Doctoral Dissertation, University of Toronto]

Wang, L., & Kwak, M. (2015). Immigration, barriers to healthcare and transnational ties: A case study of South Korean immigrants in Toronto, Canada. *Social Science & Medicine, 133*, 340–348.

Wardak, A. (2002). The mosque and social control in Edinburgh's Muslim community. Journal of Culture and Religion, 3, 201‐219.

Weerasinghe, & Maddalena, V. (2016). Negotiation, mediation and communication between cultures: End-of-life care for South Asian immigrants in Canada from the perspective of family caregivers. *Social Work in Public Health, 31*(7), 665–677. https://doi.org/10.1080/19371918.2015.1137521

Wellesley Institute. 2016. Ensuring Healthy aging for all. Accessed on October 2022. https://www.wellesleyinstitute.com/wp-content/uploads/2016/07/Ensuring-Healthy-Aging For-All_Wellesley-Institute.pdf

Wellesley Institute. 2017. Diversity, Aging, and Intersectionality in Ontario Home Care. Accessed on October 2023. https://www.wellesleyinstitute.com/wp-content/uploads/2017/05/Diversity-and-Aging.pdf

World health Organization (2021) Ageing and health. https://www.who.int/news-room/factsheets/detail/ageing-and-health

Woods, M., Paulus, T., Atkins, D. P., & Macklin, R. (2016). Advancing qualitative research using qualitative data analysis software (QDAS) reviewing potential versus practice in published studies using ATLAS.ti and NVivo, 1994–2013. *Social Science Computer Review*, *34*(5), 597–617. https://doi.org/10.1177/0894439315596311

Yakerson, A. (2019). Home Care in Ontario: Perspectives on Equity. *International Journal of Health Services*, *49*(2), 260–272. https://doi.org/10.1177/0020731418804403

Yeager, & Bauer-Wu, S. (2013). Cultural humility: Essential foundation for clinical researchers. *Applied Nursing Research, 26*(4), 251–256. https://doi.org/10.1016/j.apnr.2013.06.000

Zaidi, A. U., Couture-Carron, A., Maticka-Tyndale, E., & Arif, M. (2014). Ethnic identity, religion, and gender: An exploration of intersecting identities creating diverse perceptions and experiences with intimate cross-gender relationships amongst South Asian youth in Canada. *Canadian Ethnic Studies, 46*(2), 27–54. https://doi.org/10.1353/ces.2014.0019

# Appendix A: Recruitment Materials

RECRUITMENT EMAIL:

Dear [name]:

My name is Krithika Subbiah and I am currently working on a research study for my Master's thesis at the University of Waterloo titled: How do South Asian communities perceive home care services.

The objective of this study is to explore how South Asians living in Ontario view caring for older adults in the home. Additionally, this study will be exploring the attitudes towards home care services among South Asian individuals living in Ontario and their recommendations for a culturally competent home care services. The study will ask to share your experiences with caregiving roles and responsibilities in a South Asian household. It will also ask about your views on home care services available to individuals in Ontario and their suitability for the needs of South Asian communities. Lastly, I will ask for some suggestions and recommendations for the development and improvement of culturally sensitive home care services in Ontario.

Conducting this study, I hope to improve our understanding of South Asians' experiences with the provision of care in the home for older adults and identify how South Asians view home care. My overall goal is to provide recommendations on the type of home care services that can ultimately meet the needs of South Asian communities.

I am currently looking for volunteers to take part in an individual, semi-structured interview. For purposes of this study, I am seeking participants who meet the following criteria:

The participants are eligible for the interview if they satisfy the following criteria:

- South Asian Older adult OR
- Care partner *to a South Asian older adult OR

- Community members/key-informants, members of South Asian communities, such as representatives of local community centres, leaders in cultural centres, spiritual leaders, as well as health care providers, social workers and personal support workers who work with South Asian communities and have ability to comment on these communities' perceptions about and attitudes towards home care services.
- Age 18 or above
- Reside in Ontario for at least three months
- Speak Tamil, Malayalam, Telugu, Hindi, Urdu, Gujarati, Bengali, or English.
- Able to provide informed consent.

Your participation will remain confidential.

I have attached a Letter of Information and Consent Form where you can learn more about the study and its procedures. Please do consider sharing with your contacts who you think might be interested in participating in this study.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #44858). If you have any questions for the Board, please contact the Office of Research Ethics at (519) 888-4567 ext. 36005 or reb@uwaterloo.ca

Please feel free to reach out to me regarding participation or any questions you may have at ksubbiah@uwaterloo.ca

Sincerely,

Krithika Subbiah

MSc Candidate
School of Public Health Sciences

Faculty of Applied Health Sciences

University of Waterloo

RECRUITMENT POSTURE:

# APPENDIX B: Letter of Information and Consent Form

**Title of the study**: CARE IN THE HOME AND HOME CARE: How do South Asian communities perceive caring for older adults in the home.

**Faculty Supervisor**: Elena Neiterman, PhD, School of Public Health and Health Systems, University of Waterloo. Phone: (519) 888-4567 ext. 38221, Email: eneiterman@uwaterloo.ca

**Student Investigator**: Krithika Subbiah , MSc Candidate, School of Public Health Sciences, University of Waterloo. Email: ksubbiah@uwaterloo.ca

Dear Potential Participant,

To help you make an informed decision regarding your participation, this letter will explain what the study is about, your rights as a research participant, and the possible risks and benefits associated with participating in this research. If you do not understand something in the letter, please ask Krithika Subbiah prior to consenting to the study. You will be provided with a copy of the information and consent form if you choose to participate in the study.

**What is the study about?**

You are invited to participate in a study conducted by Krithika Subbiah, as part of her Master's thesis research at the University of Waterloo.

The objective of this study is to explore how South Asians living in Ontario view caring for older adults in the home. Additionally, this study will be exploring the attitudes towards home care services

among South Asian individuals living in Ontario and their recommendations for a culturally competent home care services. The study will ask to share your experiences with caregiving roles and responsibilities in a South Asian household. It will also ask about your views on home care services to South Asian communities. Lastly, I will ask for some suggestions and recommendations for the development and improvement of culturally sensitive home care services in Ontario. The overall goal is to inform practice and provide policy recommendations to improve the quality of home care services for South Asian older adults.

**Your responsibilities as a participant**

If you decide to volunteer, you will be asked to take part in an individual interview that will last 30-60 minutes. The interview will be scheduled at a date and time that is convenient for you and will take place online (e.g., Skype, WhatsApp, MS Teams) , via telephone or in-person. Privacy cannot be guaranteed when information is transmitted over the Internet. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you. If you prefer not to participate using this online method, please let the researcher know so you can participate using an alternative method such a telephone call.

At the beginning of the interview, you will be asked to introduce yourself and answer some demographic questions, including your ethnic origin, and information about your family. You will then be asked open-ended questions that will focus on your experiences and views on caregiving responsibilities in the home for South Asian older adults. Lastly you will be asked to share your opinions on home care services in Ontario.

The interview will be audio recorded to ensure an accurate transcript. If the interview is conducted in English, Hindi, and Tamil, Krithika will be conducting the interviews. For other languages, expect the

ones mentioned, an interpreter, in the presence of the research, will be conducting the interviews. Furthermore, with your permission, anonymous quotations may be used in publications and/or presentations.

**Who may participate in this study?**

The participants are eligible for the interview if they satisfy the following criteria:

- South Asian Older adult OR
- Care partner to a South Asian older adult OR
- Community members/key-informants, members of South Asian communities, such as representatives of local community centres, leaders in cultural centres, spiritual leaders, as well as health care providers, social workers and personal support workers who work with South Asian communities and have ability to comment on these communities' perceptions about and attitudes towards home care services.
- Age 18 or above
- Reside in Ontario for at least three months
- Speak Tamil, Malayalam, Telugu, Hindi, Urdu, Gujarati, Bengali, or English.
- Able to provide informed consent.

II. **Your Rights as a Participant**

**Is this study voluntary?**

Your participation in this study is completely voluntary. During the interview, you may decline to answer any question(s) you prefer not to answer by requesting to skip a question. Following the interview session, you may completely withdraw from the study within two weeks from completion of the interview by contacting the researchers, Krithika or Elena Neiterman.

**Will my personal information remain confidential? Will I be identifiable?**

Your confidentiality is a priority throughout this research. Your verbal consent will be stored as a separate audio file and will be encrypted and stored on the researcher's password-protected laptop. With your permission, we will gather some of your demographic information, such as your gender, race, country of origin and the amount of years you have lived in Canada. To ensure the confidentiality of your data, you will be identified by a participant pseudonym, which you may choose.

With your permission, the interview will be audio-recorded to facilitate the accurate collection of information, and later transcribed for analysis. Within this audio-recording, your name will not be used, but your voice may be heard. The audio recording collected during this study will be destroyed immediately upon transcription (within two weeks of the interview) and only the anonymized transcript from the interview will be retained. All information that could identify you will be deleted from the interview transcript. Only the research team will know which data is from your participation, and any identifying information will be kept separate from the data. Only Krithika will have access to any study records.

Your interview transcript will be stored separately under an anonymous participant code, encrypted and stored on the password-protected laptop, which is only available to the researcher. Encryption of electronic files will be conducted according to University of Waterloo IST policy. Any paper data (i.e., researcher notes) will be stored in Krithika's personal laptop. We will keep your data for the period seven years following the date of the interview, after which it will be destroyed according to University of Waterloo policy.

**III. Questions, Comments, Concerns**

**Has the study received ethics clearance?**

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #44858). If you have any questions for the Board, please contact the Office of Research Ethics at (519) 888-4567 ext. 36005 or reb@uwaterloo.ca

**Who should I contact if I have questions about my participation in the study?**

For all other questions regarding this study, or if you would like additional information to assist you in reaching a decision about participating, please contact me by e-mail at ksubbiah@uwaterloo.ca You can also contact my supervisor, Dr. Elena Neiterman, at (519) 888-4567 ext. 38221 or email eneiterman@uwaterloo.ca.

Yours sincerely,

Krithika Subbiah

MSc Candidate

School of Public Health and Health Systems

University of Waterloo

ksubbiah@uwaterloo.ca

CONSENT FORM

I have read the information presented in the information letter about a study being conducted by Krithika Subbiah, under the supervision of Dr. Elena Neiterman. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details that I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that the excerpts from the interview may be included in the findings of this study with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time by advising the researchers.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #44858). I was informed that if I have any questions, I may contact the Office of Research Ethics at (519) 888-4567 ext. 36005 or reb@uwaterloo.ca

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

□ YES □ NO

I agree to have my interview audio recorded.

□ YES □ NO

I agree to the use of anonymous quotations in future research projects/publications developed from this project.

□ YES □ NO

I give Krithika Subbiah  permission to retain the transcript from my interview for up to seven years and use it for research purposes as long as it has no identifiable information that ties it to me.

□ YES  □ NO

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

Participant Name: _____________ (Please print)

Participant Signature: _____________

Witness Name: _____________ (Please print)

Witness Signature: _____________

Date: _____________

# APPENDIX C: Interview Guide

Interview Guide for **Care partners/Older Adults**

(My name is Krithika Subbiah and I am currently working on a research study for my Master's thesis at the University of Waterloo titled: How do South Asian communities perceive caring for older adults in the home.

The objective of this study is to explore how South Asians living in Ontario view caring for older adults in the home. Additionally, this study will be exploring the attitudes towards home care services among South Asian individuals living in Ontario and their recommendations for a culturally competent home care services. The study will ask to share your experiences with caregiving roles and responsibilities in a South Asian household. It will also ask about your views on home care services to South Asian communities. Lastly, I will ask for some suggestions and recommendations for the development and improvement of culturally sensitive home care services in Ontario. )

Could you tell me a little bit about yourself?

Probes:.

a.How long have you been in Canada?

b.Please tell me about your family? (no. Of children, older adults, etc)

c.What you do for a living?

d.What is your ancestry/ethnic origin?

e.Who do you care for and how old they are? / Who cares for you?

f.Does your parent/family member have any specific health care need(s)?/ Do you have any specific health care need(s)?

2. Who is more likely to take care of an older adults in a South Asian family?

a. In South Asian household, who would typically take on a role of a care partner for an older adult? How do you think this came about?

b. Are there any differences in who is providing care? (e.g. son, daughter, husband, wife)

3.[If relevant] How do you take care of your parents/older adults at home?

a.Can you describe some of the activities that you do to provide care?

b.Which one according to you is most important and why?

c.Did you ever feel like you need any help with supporting your parents?

[If relevant] Who helps you around the home/who takes care of you?

a.Can you describe some of the activities that you need help with?

b.Which one according to you is most important and why?

c.Do you have someone who can do it for you? Who is that person?

5.What are your views on seeking help from professional health and support services to provide care to aging parent at home?

a.What are some of the good sides of this arrangement?

b.What are some of the issues that may arise?

c.How would your parents/children/family feel about such arrangement?

6. What do you know (if anything) about home care services that are available to those who need them in Ontario?

a. Do you know whom to reach out if you need them?

b.Do you know anyone who is getting home care services?

c. Would you be willing to pay out-of-pocket for those services? If you do wish to use home care services, what else would you/your family do, in order to help you stay living at home?

7.If you do wish to use home care services, what else would you/your family do, in order to help you stay living at home?

8.What would good home care service look like for you/your family?

a.Cultural/language factors

b.Will PSW gender/ethnicity matter?

9. If there is anything we did not discuss that you think is important to mention?

**Key Informant:**

Interview Guide

1.Could you tell me a little bit about yourself?

Probes:

a.What you do for a living?

b.How long have you been involved with South Asian communities?

c. Could you tell me about your experiences working with SA communities in relation to the care of older adults in the home?

2.How do SA care partners take care of parents/older adults at home?

a.What daily activities or tasks do they do for older adults?

b.How often do they do them for?

c.Do they ever feel like they need any help with supporting their parents?

What do SA communities think about receiving professional health and support services at home?

a.Would you agree/disagree with the concept? Why?

b. How would SA parents/ Older adults react to this idea?

4.Thinking about the SA families that you know and work with, is there an awareness of home support/home care?

What do you think the SA communities needs for awareness for home care services?

5.. What other options would SA use if they preferred to remain in their own home?

- Any other alternative to home care?

6.What would good home care look like to SA?

a.Cultural/language factors

b.Will PSW gender/ethnicity matter?

7. If there is anything we did not discuss that you think is important to mention?

# Appendix D: Feedback Form

[Date]

Dear [Name],

I would like to thank you for your participation in this study titled titled: CARE IN THE HOME AND HOME CARE: How do South Asian communities perceive caring for older adults in the home.

As a reminder, the objective of this study is to explore how South Asians living in Ontario view caring for older adults in the home. Additionally, this study will be exploring the attitudes towards home care services among South Asian individuals living in Ontario and their recommendations for a culturally competent home care services.

Conducting this study, I hope to improve our understanding of South Asians' experiences with provision of care in the home for older adults and explore how South Asians view home care, to ultimately adapt to meet the cultural needs of South Asian communities. This research will contribute to the existing ethinic minority genorontological knowlege base to better under caregiving practices in the home.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #44858). If you have any questions for the Board, please contact the Office of Research Ethics at (519) 888-4567 ext. 36005 or reb@uwaterloo.ca For all other questions, please contact, Krithika Subbiah at ksubbiah@uwaterloo.ca

Please remember that any data pertaining to you as an individual participant will be kept confidential by the research team. The findings from this study may be shared through conferences, presentations, and journal articles. If you would like to receive the report from this study, please contact Krithika Subbiah ( ksubbiah@uwaterloo.ca) at the contact information above. The study will be complete in August 2023.

Yours sincerely,

Krithika Subbiah