

**Exploring the Factors that Influence Equitable Access to and Social
Participation in Dementia Care Programs by Foreign-born Population living
in Toronto and Durham Region**

By

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Access to dementia care and support and Foreign-born population in Canada

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The above committee determined that the thesis is acceptable in form and content and that a satisfactory knowledge of the field covered by the thesis was demonstrated by the candidate during an oral examination. A signed copy of the Certificate of Approval is available from the School of Graduate and Postdoctoral Studies.

Abstract

The purpose of this study was to explore the barriers that influence participation and utilization of dementia care and support programs by the foreign-born population. A qualitative interpretive study was conducted using one-on-one semi-structured interviews with the following three subgroups who are users and practitioners of dementia support programs: person with dementia, caregivers of PWD, and healthcare professionals. Themes associated with structure, processes, and outcomes related to barriers were identified. Structural barriers include: Homogenous composition of program cohort, lack of financial sensitivity in existing programs, and lack of linguistically diverse programs. Process barriers include barriers related to the process of care delivery (i.e., insufficient cultural and age sensitivity in program facilitation) and the process of implementation (i.e., strategies to protect cultural safety, impact of stigma and normalization of dementia symptoms). The study identifies the importance of raising awareness and culturally competent dementia care system to increase participation and access.

Keywords: Access, Dementia, Barriers, Immigrant, Canada

AUTHOR'S DECLARATION

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Statement of contribution

I hereby certify that I am the sole author of this thesis. I have used standard referencing practices to acknowledge ideas, research techniques, or other materials that belong to others. Furthermore, I hereby certify that I am the sole source of the creative works and/or inventive knowledge described in this thesis.

Participants for this research was recruited from Alzheimer Society Durham Region and Geriatric Assessment Intervention Network Clinic (Scarborough area). Part of the literature review described in Chapter 2 has been published as:

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Chapter 1: Introduction

Dementia has been identified as one of the leading health issues concerning the aging population (Alzheimer's Association, 2018). This makes the disease a global health crisis that must be addressed. The number of older Canadians living with Alzheimer's disease and other forms of dementia is increasing at an alarming rate (Alzheimer Society Canada, 2017).

Improving the diagnosis, treatment and care for Canadians living with dementia is becoming a key priority in Canada with a focus on adequately supporting the individuals with dementia and their caregivers to achieve the goal of living well with dementia.

1.1. Defining Dementia

Diagnostic Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013) classifies dementia as a neurocognitive disorder. Dementia is used as an overall term to describe a wide range of symptoms caused by disorders of brain. These symptoms are related to memory or cognitive functions, and are severe enough to impair a person's ability to perform everyday activities (Alzheimer Society of Canada, 2019; Sagbakken, Spilker, & Nielsen, 2018). Effects include (but are not limited to) memory loss and difficulty with thinking, problem-solving and language as well as changes in mood or behaviour (Alzheimer Society of Canada, 2019). Dementia can be a result of several disorders associated with brain abnormalities, including Alzheimer's disease (Alzheimer Society of Canada, 2019). In order to be diagnosed with dementia, one must meet certain criteria listed in the DSM-5 when determining major neurocognitive disorders, such as: (a) showing evidence of significant mental decline that interferes with usual daily routines, or for milder cases, (b) show signs of modest cognitive decline with only little interference of daily active living (Alzheimer's Association, 2018).

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Dementia is progressive which means that the symptoms worsen gradually as the damage in brain cells increases.

1.2. Demographics

The Aging Population. The population of Canada is going through a phase of rapid aging with an increasing number of seniors. Aging is defined as a natural progressive development of growing old (Shelby, Thompson, & Edward , 2016). In Canada, the term “Old Age” refers to a transitional period where older adults encounter changes in both their physical health and social roles (e.g., retirement) and “Senior” is defined as an individual who is over the age of 65 (Shelby, Thompson, & Edward , 2016). According to demographic projections by Statistics Canada, Canada’s senior population stood at 4.8 million as of 2010. From 2015 to 2021, the country’s senior population is estimated to outnumber the population of children between the ages 0 to 14 for the first time in history. (Statistics Canada, 2018). By 2036, the estimated proportion of seniors in the overall population will range somewhere between 23 to 25 per cent (Statistics Canada, 2018), making this age cohort the fastest growing population in Canada. This alarming rate of increase is attributed to the baby boom generation—Canada’s largest birth cohort between 1946 and 1965—who will turn into the age of 65 or older between 2011 and 2031 (Canadian Institute of Health Information, 2011).

Increasing number of aging populations leads to the emergence of age-related health issues. According to Statistics Canada, individuals aged 65 and older are more likely to have one or more chronic health conditions (Statistics Canada, 2018). In 2012, the Public Health Agency of Canada (2014) reported that 85% of older adults aged 65 to 79 and 90% of older adults above

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the age of 80 indicated that they have at least one chronic condition that influences their quality of life, such as the development of physical disability and cognitive impairment.

Foreign-Born Population. Canada is defined by its ethno-cultural diversity and migration. A significant proportion of the Canadian population is composed of foreign-born individuals, including both recent and non-recent migrants from various countries. Statistics Canada (2018) defines individuals immigrating to Canada in 2006 and later as recent immigrants. Those who immigrated to Canada earlier than 2006 are considered non-recent immigrants. Since 2011, Canada had a foreign-born population of about 6,775,800 people, encompassing 20.6% of the total population and 17.2% of this foreign-born population are recent immigrants between 2006-2011 (Statistics Canada, 2018). It is estimated that by 2031, visible minorities from multicultural backgrounds, majority of whom had lived in Canada for less than 15 years, will make up approximately 63% of the population in Toronto, the largest city in Canada (Koehn, Neysmith , Kobayashi, & Khamisa , 2013). The vast majority of the foreign-born population live mainly in four provinces: Ontario, British Columbia, Quebec and Alberta; and are primarily migrating from Asia (including the Middle East) followed by Africa, Caribbean, Central and South America (Statistics Canada, 2018).

Dementia & the Foreign-Born Population: Emerging Gaps. Along with the aging population and the growing foreign-born population in Canada, there are emerging challenges for the development of dementia care and support services that is in accordance with the specific needs of the foreign-born individuals with diverse linguistic and cultural background. The increasing number of foreign-born Canadians will lead to an increasing number of people with dementia who possess unique cultural needs. Cultural diversity encompasses the diverse socio-

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cultural characteristics of each migrated subgroup from different parts of the world. With the increasing number of individuals living with dementia and the migratory increase being the leading engine of population growth in Canada (Statistics Canada, 2017), it is crucial to identify the factors that may influence access to dementia care and support programs aimed at improving the quality of life for those living with dementia. The patterns in healthcare use are different between immigrant groups and the native majority population, where immigrant groups face different challenges when accessing health (Sagbakken, Spilker, & Nielsen, 2018). Research from across the world identified differences in the utilization of dementia care services among different ethnic groups as well as delays in access to diagnostic services for minority ethnic groups (Nielsen, Vogel, Phung, Gade, & Waldemar, 2010). Study conducted by Giebel, Zubair, Jolley, Bhui, and Challis (2014) identified reduced levels of participation in dementia care and support programs among immigrant population when compared to their non-immigrant counterparts. These trends are concerning and warrant further examination in order to develop a solid understanding of this phenomenon. Despite the availability of care and support, individuals living with dementia often experience social isolation and exclusion. This issue is particularly significant among migrants and refugees, for whom access to dementia care and support programs are found to be significantly less than non-immigrant Canadians (Sun, Biswas, Dacanay, & Zou, 2019).

1.2. Study Purpose

The purpose of this research was to identify the barriers and facilitating factors of access to dementia care by foreign born individuals, including immigrants and refugees. The following is this study's overarching research question to address the study purpose:

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“What are the factors that influence equitable access to and social participation in dementia care and support programs among foreign-born individuals including recent and non-recent immigrant and refugee population living in Toronto and Greater Toronto Area?”

1.3. Significance of study

Dementia is considered to be a key public health problem when it comes to the aging population in the global context. An estimated 47 million people worldwide are currently living with dementia and this number is projected to increase to 75 million by 2030 (World Health Organization, 2017). In fact, the number of cases of dementia is estimated to almost triple by 2050 (World Health Organization, 2017) with approximately 10 million emerging new cases every year (World Health Organization, 2017). This alarming increase in dementia cases is reflected in the Canadian population. Currently there are 564,000 Canadians living with dementia and the number is doubling every 20 years (Alzheimer Society Canada, 2017; Wong, Gilmour, & Ramage-Morin, 2016). The economic burden of dementia will increase from \$15 billion in 2008 to \$153 billion by 2038 (Parmer, et al., 2014). In addition to the rising number of people with dementia, there has been a shift in the age distribution of Canadian population, with an increasing number of population reaching the age of 65 and up, which is the most vulnerable stage of life with regards to the development of dementia (Wong, Gilmour, & Ramage-Morin, 2016). Moreover, migratory increase has been identified as the major driving force of population growth in Canada, which indicates a change in the composition of population with an increased cultural diversity (Statistics Canada, 2017). Identifying the barriers in participation and access to dementia care and support program will contribute to determining the gap in the existing programs to adequately meet the needs of foreign born individuals living with dementia.

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Identifying the gap will open an array of scope of improvement in the current program delivery to promote better access to support programs that would increase social participation by the foreign born individuals with dementia. Understanding the factors that influence access to dementia care and support programs will lead to the improvement of existing programs and make them more culturally inclusive for the marginalized immigrants and refugees living with dementia

Chapter 2: Literature Review

2.1. Chapter overview

This chapter presents a literature review of barriers influencing access to dementia care and support programs by foreign-born population. Sub-sections presented in this chapter include the descriptions of cultural groups and diversity in Canada, equitable access, migrants in Canada, dementia care and support services and key contributors of dementia care and support services in the Greater Toronto Areas. Specifically, this section presents the thematic findings from the literature review to identify the major barriers in influencing access and social participation in dementia care and support programs by foreign-born population in the global context.

Knowledge gap revealed by the literature review will be presented to provide recommendations for future research directions.

2.2. Defining the context

The Foreign Born Population. The target audiences of this research study are the foreign-born populations migrated to and living in Canada. According to Statistics Canada, Toronto had the largest share of foreign-born Canadians, encompassing 37.4% of all foreign-born in Canada (Statistics Canada, 2018). About 2,537,400 immigrants lived in Toronto in 2011, which made up 46.0% of Toronto's total population (Statistics Canada, 2018).

The four main categories of immigration to Canada are (1) economic immigrant, (2) immigrant sponsored by family, (3) refugee and (4) other immigrants who were granted permanent resident status under a program that does not fall in neither the economic immigrants, immigrants sponsored by family or refugee categories (Statistics Canada, 2019). Economic

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immigrants are selected for their ability to contribute to Canada's economy through their ability to meet labour market needs; to own, manage or build a business; to make a substantial investment, to create their own employment or to meet specific provincial or territorial labour market needs. Sponsored immigrants are individuals with Canadian citizenship or permanent residence status, which they received on the basis of their relationship (as the spouse, partner, grandparent, child, or other relatives) with a sponsor, who is also a Canadian citizen, (Statistics Canada, 2017).

The term "refugee" defines a person who meets certain eligibility criteria set out by international law. According to the Geneva Convention 1951 Article 1, a refugee is an individual who is "unable or unwilling to return to their country of origin owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion" (Holzer, 2012). Frequently, individuals entering Canada as refugees are those who meet the refugee definition in the 1951 Geneva Convention relating to the status of refugees or person in need of protection (i.e. a person who may not meet the Convention definition but is in a refugee-like situation defined in Canadian law) (Canadian Council for Refugees, 2019).

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Contextualizing Dementia

Overview. The number of individuals living with dementia across Canada is rising steadily, as is the number of challenges facing the healthcare systems. Once diagnosed, individuals affected by dementia can continue to live independently during the early stages of their disease, and with the appropriate support, can continue to live in their home until the later stages (Alzheimer Society of Canada, 2019). According to Canadian Institute for Health Information (CIHI) (2019), among the estimated 431,000 seniors living with dementia in Canada between 2015 to 2016, more than 261,000 (approximately 61%) were estimated to reside outside of publicly funded long-term care or nursing homes. Canadian Institute for Health Information (2019) identifies that one in five of this sub-population has severe cognitive impairment; one in four requires extensive assistance or are dependent for activities of daily living; while one in four exhibits at least one responsive behaviour and one in four have signs of depression. The Alzheimer Society of Canada (2019) identifies the importance of comprehensive home and community care as a way to maintain quality of life for people with dementia living at home.

Over the course of many years, individuals with dementia will no longer be able to live at home as they become unable to perform the activities of daily living such as dressing, eating, bathing, etc., and will often display behaviours that may be difficult for caregivers to manage. At this stage of progression, seniors may need to move into long-term care homes, often known as nursing homes, if they can no longer be supported at home. A change has been observed in the population in long-term care settings over the past five years with higher number of individuals experiencing moderate to severe dementia (Canadian Institute for Health Information, 2019). In addition to severe cognitive impairment (40% of residents with dementia), 31% had signs of depression and 82% required extensive assistance or were dependent for activities of daily living,

Access to dementia care and support and Foreign-born population in Canada making it challenging to provide care for residents with dementia in long-term care settings (Canadian Institute for Health Information, 2019).

Physiological and Psychological Aspects of Dementia. Being diagnosed with dementia impose a big impact on both the individual being diagnosed and their caregivers. Diagnosis of dementia may result in experience of a range of emotions including grief, loss, anger, shock, fear, and disbelief (Alzheimer's Association, 2018; Wong, Gilmour, & Ramage-Morin, 2016). The confirmation of a diagnosis may lead to depression and anxiety in some individuals (Alzheimer Society UK, 2019). PWD often experience changes in their emotional responses and find themselves having less control over their feelings, such as being irritable, prone to rapid mood changes, overreacting to things, appearing unusually uninterested in things or just being generally distant (Alzheimer Society UK, 2019). Moreover, experiencing dementia may cause individuals to feel insecure and lose confidence in themselves and their abilities (Giebel, Zubair, Jolley, Bhui, & Challis, 2014). Perceived experience of effects of stigma and social demotion such as not being treated the same way by people as a result of their diagnosis has also been observed (Mackenzie, 2006), leading to a negative impact on the person's self-esteem. As consequences of dementia symptoms, individuals experience loss at the physical and psychological level, including social roles, mobility, and living arrangements. This may lead to a decline in social relationships and an increase in isolation, posing a serious risk physical and emotional health (Biordi & Nicholson, 2010).

As dementia progresses, the PWD becomes more and more dependent on their caregivers. Due to the nature of symptoms, caring for a family member with dementia can become very stressful and can often lead to physical, emotional and psychological exhaustion

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among the informal caregivers. According to CIHI, family caregivers of individuals with dementia experience higher levels of stress, almost twice as much when compared with caregivers of seniors without dementia (Canadian Institute of Health Information, 2011). Caring for a family member with dementia and the associated level of stress and anxiety can lead to poor functionality in daily life as well as negatively impact the financial and health conditions of caregivers (Epstein-Lubow, Davis, Miller, & Tremont, 2008).

Caregiving in Dementia. Although during the earlier stages, the PWD may be able to take care of themselves, support from caregivers becomes crucial towards the later (moderate to late) stages of dementia. Wong, Gilmour, & Ramage-Morin (2017) indicate that among the Canadians living with dementia, 85% relied, at least in part, on family, friends or neighbours for assistance; 43% of those also received some formal assistance; the remaining 41% relied solely on informal assistance, while 15% of those with dementia received neither formal nor informal assistance (Wong, Gilmour, & Ramage-Morin, 2017). Sources of assistance may be influenced by the availability of caregivers, volunteer and paid services, as well as financial resources. PWD who chooses to stay at home during the moderate disease stage would require support from family members or external professionals to perform day-to-day activities. Most household residents with dementia receive formal or informal assistance. Homecare services are available as a type of formal assistance from licenced health professionals (e.g., nurses, social workers, physiotherapists, occupational therapists) and trained volunteers to allow a person with Alzheimer's or other forms of dementia to better perform daily activities, as well as staying in their own home with dignity, independence and quality of life (Alzheimer's Association, 2019; Gilmour, 2018).

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Informal caregivers include mainly family and friends of the PWD. In general, the primary type of informal caregiver for people with dementia is a spouse (46%) or an adult child (44%), often, a daughter (71%) (Wong, Gilmour, & Ramage-Morin, 2016). In very small number of cases, informal caregivers can also be other relatives, friends or neighbours (9%) (Wong, Gilmour, & Ramage-Morin, 2017). Most spouses and child caregivers live in the same household as the person with dementia and provide daily care while residing together (Wong, Gilmour, & Ramage-Morin, 2017).

Approaches to addressing dementia in Canada. There are 564,000 Canadians who are currently living with dementia and the number is doubling every 20 years (Alzheimer Society Canada, 2017; Wong, Gilmour, & Ramage-Morin, 2016). Without follow-up support, being diagnosed with dementia can lead to social isolation and depression (Senate Committee on Social Affairs, Science and Technology, 2016). Dementia initiatives primarily focus on prevention, delaying or slowing the progression of disease by early diagnosis, promoting healthy living and maintaining active cognitive functioning (Government of Canada, 2016). Currently no effective medication is available to cure or to stop the progression of dementia. Some forms of dementia present specific symptoms that can be treated or minimized with medications, however these do not reverse, slow down or stop the neurological damage within the brain (Senate Committee on Social Affairs, Science and Technology, 2016). In addition to the pharmaceutical approaches administered by the physicians, several non-pharmaceutical approaches have been and continue to be developed to stimulate the brain, provoke memories and induce calmness and peace (Senate Committee on Social Affairs, Science and Technology, 2016). Cognitive stimulation interventions for persons with dementia are adopted as means of a better quality of life through a range of enjoyable activities, such as providing general

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stimulation for thinking, concentration and memory, particularly in a small social group setting (Woods , Aguirre, Spector, & Orrel, 2012). Such interventions are being taken at the community and provincial level to promote living well with dementia. Persons with dementia and their caregivers require a complex combination of social and healthcare interventions that is tailored to the unique individual and cultural needs, preferences and priorities (Livingston, et al., 2017).

Day programs for individuals with dementia are offered across Toronto and Greater Toronto Areas by hospitals (such as Adult Day Program at Baycrest and indirectly via community partners), nursing homes and long term care homes, community health centers, and other non-profit and charitable organizations (Toronto Central Health Line, 2020). The goal of adult day programs are to provide stimulating activities and social opportunities for PWD in a group setting, under the supervision of professional and trained individuals while providing an opportunity of respite for caregivers (Aging Care, 2020).

The Alzheimer Society of Canada (ASC) is the leading nationwide health charity for people living with Alzheimer's disease and other dementias, including their caregivers and families. ASC is active in the communities across Canada and focuses mainly on four key areas: (1) providing information, support and education programs; (2) funding research to improve treatments and to find a cure; (3) promoting public awareness on dementia; and (4)influencing policy change for better dementia care and support (Team Alzlive, 2019). One of the most notable initiatives by ASC is First Link early intervention program offered across the country to provide information on how to live well with dementia to recently diagnosed PWD and their family, as well as connecting them to variety of support services within their respective communities (Senate Committee on Social Affairs, Science and Technology, 2016). Other

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initiatives by ASC include Memory Café, adopted in several provinces of Canada, aim to provide a safe, friendly space, often churches or community halls, for PWD and their caregivers to gather on a regular basis for social engagement while educating themselves on dementia related issues and topics through lectures and discussions (Senate Committee on Social Affairs, Science and Technology, 2016). ASC also offers Minds in Motion program to promote physical activity, intellectual stimulation and social engagement for people with early and mid-stage dementia along with their informal caregivers, or care partners (Alzheimer Society of Canada, 2019).

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Cultural competency and cultural safety. Cultural aspect of dementia care plays a key role in access to care by immigrant population. Cultural competency is recognized as a key contributor to improving the delivery of health care to racial/ethnic minority groups with the aim of reducing racial/ethnic health inequalities (Truong, Paradies, & Priest, 2014). Cultural competency in health care is often viewed as a set of compatible skills, communication strategies, and policies that function collectively in a system, organization, or among a group of professionals with an aim to facilitate effective delivery of services in cross-cultural situations (Khanna, Cheyney, & Engle, 2009). A culturally competent system understands the importance of social and cultural influences on patients' health beliefs and behaviours; considers the interactions of these factors at multiple levels of the health care delivery system; and, finally, develop interventions that accounts for these issues and ensure quality healthcare delivery to diverse patient populations (Betancourt J. R., Green, Carrillo, & Ananeh-Firempong, 2003). In this context, cultural sensitivity is often described as an awareness of the nuances of one's own and other cultures (Betancourt, Green, & Carrillo, 2002) as well as recognizing the importance of respecting cultural differences and diversity (Aboriginal Nurses Association of Canada, 2009). Cultural competency and cultural sensitivity increase cultural safety of healthcare (Ball, 2009). In addition to cultural awareness and acknowledgement of the difference, cultural safety allows us to understand the limitations of cultural competence, which focuses on skills, knowledge, and attitudes of organizations and professionals (Aboriginal Nurses Association of Canada, 2009). Culturally safe practice is defined as actions that recognize, respect and nurture the unique cultural identify of all cultural groups as well as recogniz their needs, expectations and rights (Smye, Josewski, & Kendall, 2010).

2.3. Findings from Literature

A literature review was conducted to explore the socio-cultural factors that are contributing to the access of dementia care and support programs among the migrants living with dementia. Analysis of the existing literature that explored the factors associated with the access to dementia support programs among immigrants and refugee populations has led to the emergence of the following four overarching themes, which are discussed below.

Literature Review Method

Inclusion and Exclusion. The search strategy for the literature review included journal articles that were published until May 2017. A preliminary search aimed to determine the scope of the existing literature revealed a lack of published research in the field of dementia care for immigrants and refugees. Therefore, no specific boundary on the date range of publication was used to broaden the scope of search about the topic of interest. Articles that were published in the English language were solely included in the search.

A set of keywords was determined to represent the search for dementia care and barriers experienced by migrated immigrants and refugee populations. The keywords related to barriers included: “Barriers”, “Social Barriers” and “Cultural Barriers”. “Immigrants”, “Refugees” and “Newcomers” were used for search terms for migrated populations which contains immigrants, newcomers and refugee subgroups. The review included literature regarding both dementia support programs and care services to incorporate a large spectrum of barriers faced by migrated individuals with dementia. The target population involved PWD, informal and formal caregivers (e.g., nurses, personal support workers and other service providers), and dementia program facilitators and coordinators. Exclusion criteria for the review involved literature exploring

Access to dementia care and support and Foreign-born population in Canada special subgroup, including Indigenous communities, because these subgroups are not considered migrants despite of their diverse cultural background.

Search Strategy and Data Analysis. An extensive search of the literature using the Ontario Tech University (UOIT) library databases was conducted, including the PubMed databases and Wiley Library using a predetermined set of inclusion and exclusion criteria. Only full text papers published in peer-reviewed journals and proceedings were selected for further review. Editorials, letters, and conceptual papers were excluded. All papers that addressed the keywords and search terms which were relevant to the research topic of interest were retrieved, regardless of their study design.

A total of 4451 research publications resulted from the key word search from both databases, which included peer reviewed journal articles, eBooks/books, dissertations/thesis and book chapters. A primary screening with title followed by secondary screening with abstracts were conducted. Research papers identified to be related to the research topic following abstract screening were kept and full-text papers were retrieved for further review. In the absence of an abstract, full-text papers were retrieved and reviewed for prospective inclusion. Reference lists of selected papers were examined to identify other relevant articles. There was a total of fifteen articles included in the final data using a thematic analysis method based on its relevance and scope of research for data extraction purposes. The findings were analyzed and synthesized to identify common themes and research gaps related to barriers influencing access to dementia care and support programs among migrated populations.

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Literature Review Themes. The literature review identified four major themes that act as the underlying factors associated with the access to dementia care programs among foreign-born populations from diverse cultural backgrounds. The themes are discussed below: (1) Stigma associated with disease condition; (2) Culturally preferred coping strategies; (3) Misconception regarding aging and dementia; (4) Challenges related to language barrier.

Stigma associated with disease condition. Stigma was identified to be the most common and impactful factor associated with the access to dementia care programs. Stigma influences willingness to seek diagnosis, to seek support once diagnosed and a lack of willingness to participate in research (*Swaffer, 2014*), even as far as being reluctant to “recognize the illness” (*Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007*). Fontaine et. al. (2007) reported that stigma often prevented person with dementia and caregivers from accessing the necessary information or support as “people would gossip about you if something went wrong” and “people don’t want to get branded as odd or weird” (*Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007*).

Giebel, Zubair, Jolley, Bhui, and Challis (2014) reported that in South Asian culture, a great deal of stigma appears to be associated with mental illnesses including dementia where open discussion of a relative’s mental health issues could cause the family to be stigmatized, with a reduced social standing that could affect later generations, such as interfering with marriage arrangements (Giebel, Zubair, Jolley, Bhui, & Challis, 2014). South Asian migrants often adopted “Concealment” mechanism to protect the reputation of the person with dementia and reputation of their family (Giebel, Zubair, Jolley, Bhui, & Challis, 2014; Mackenzie, 2006). Mackenzie (2006) indicated that the most common explanation for not using any support

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services among informal caregivers was the perception of “putting an already precarious balance between shame and inner pride in jeopardy” (Mackenzie, 2006). This phenomenon is also observed in the Eastern European cultures where stigma associated with dementia reinforced the tendency to “keep it in the family” instead of seeking support (Mackenzie, 2006) as “going public” is perceived to be linked with inviting condemnation from others in the community (Mackenzie, 2006). This reinforces the behavior of informal caregivers around providing support alone instead of seeking help from their social and community support networks.

Lee et. al. (2005) identified that anticipated stigmatization and resulting concealment had a significant impact on non-compliance with care-seeking behavior and avoidance of further interaction between the person with the illness and community members in an attempt to hide any shameful incidence (Lee, Lee, Chiu, & Kleinman, 2005). Liu et. al. (2008) reported that shame and “loss of face” contributed to stigmatization associated with dementia among Asian Americans such as Chinese and Vietnamese (Liu, Hinton, Tran, Hinton, & Barker , 2008). Concealment was adopted to deflect such situations (Yang & Klainman, 2008), resulting in delays and non-adherence to acquiring external care and support.

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Culturally preferred coping strategies. Religion and culturally preferred coping strategies were identified to be particularly important within South Asian communities (*Giebel, Zubair, Jolley, Bhui, & Challis, 2014*). Mackenzie (2006) reported that South Asian subgroups appear to prioritize on complying to family values where providing care for a family member is associated with the perception of responsibility and religious obligation regardless of the religion, where caring was perceived as “duty” or a way of “gaining blessings” or “repaying” the person with dementia for previous acts of kindness (*Mackenzie, 2006*). Thus, South Asians have been reported to prefer providing care for a family member with a mental illness rather than seeking medical care, social care or community support and assistance, thus leading to reduced engagement in dementia support programs (*Giebel, Zubair, Jolley, Bhui, & Challis, 2014*). Alternative coping strategies included practicing “faith” associated mental resilience and alleviation of stress experienced by people with mental illnesses such as dementia and their caregivers (*Giebel, Zubair, Jolley, Bhui, & Challis, 2014*). Other coping strategies included meditation and prayers.

The concept of “acculturation” appeared as an important concept in terms of implications for support services among migrants, meaning branching out from own cultural norms to adopt other norms. Acculturation varied depending on the length of stay in a migrated country and historical time of migration (Iiffe & Manthorpe, 2004; Kong, Deatruck, & Evans, 2010). Adoption of a foreign culture appears to be a selective process where fundamental values and beliefs appear to stay unchanged after immigration (Kong, Deatruck, & Evans, 2010). Reluctance to adopt the “foreign” culture can lead to the preservation of conventional norms and methods of practice in one’s culture when dealing with chronic diseases, such as the care and management of dementia.

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Misconception regarding aging and dementia. One of the widely shared beliefs in many cultures is “normalization” of functional and cognitive decline among older populations. Bunn et. al. (2012) reported that populations from some ethnic minorities are less likely to recognize symptoms of dementia, perceiving such symptoms as part of the aging process (***Bunn, et al., 2012***). Normalization is observed among Asian, African-Caribbean’s and Hispanic Americans where dementia symptoms such as memory loss, disorientation and loss of functional abilities were recognized but not conceptualized as an illness (Mukadam, Cooper, & Livingston, 2011; Liu, Hinton, Tran, Hinton, & Barker , 2008). Majority of the common symptoms of dementia are interpreted as “age-related cognitive and functional change” (***Liu, Hinton, Tran, Hinton, & Barker , 2008***). Interviews conducted with various subgroups originating from Chinese and Vietnamese cultures identified a culturally shaped metaphor that emphasized holism and the inevitability of deterioration in dementia (***Liu, Hinton, Tran, Hinton, & Barker , 2008***), reinforcing the lack of understanding regarding the necessity of accessing dementia care programs.

Fontaine and Colloques (2007) reported that South Asian subgroups residing in England has identified that their culture may recognize the symptoms associated with dementia but not conceptualize these as part of an illness even when they are severe (Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007). This reinforces the belief that individual and family efforts are enough to cope with dementia related symptoms. In many cases, dementia related symptoms including confusion, becoming quiet and sad, feelings of isolation and loneliness, and other mental health impairments that are considered to be the “negative” aspects of normal aging (Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007; Bunn, et al., 2012) among South Asian families. This leads to the conceptualization of not viewing dementia as an illness and therefore

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creating a significant barrier to accessing the external resources that support living well with dementia.

Challenges related to language barrier. One of the most significant factors associated with reduced access to dementia care was language barrier. Iliffe & Manthorpe (2004) reported that immigrants and refugees who do not speak the language of the host country might be at a greater disadvantage in accessing the healthcare system (*Iliffe & Manthorpe, 2004*). Difficulty with communication and changes in verbal language frequently appear in Alzheimer's disease and other neurodegenerative dementias, including word-finding difficulties, decreased verbal fluency, or difficulties with naming and comprehension (*McMurtagh, Saito, & Nakamoto, 2009*). McMurtagh and colleagues (2009) indicated that older adults who were bilinguals often relapse to a single language despite a lifetime of dual language use, losing the ability to speak the second language (*McMurtagh, Saito, & Nakamoto, 2009*), and thus leading to difficulty in communicating with the healthcare professionals and service providers (*Rosendahl, Soderman, & Mazaheri, 2016*). Bilingual individuals with dementia are often observed to incline towards asymmetrical language impairment with preferential preservation and use of the first acquired language (*Mendez, Perryman, Ponton, & Jeffery, 1999*). In addition, information and memory that are more remote are often relatively preserved over recently learned information, thus reinforcing the regression towards the predominant use of the language learnt earlier in life or the first language (McMurtagh, Saito, & Nakamoto, 2009; Mendz, Perryman, Ponton, & Jeffery, 1999).

Evidence obtained from the study of immigrants in Sweden suggested that immigrants with dementia noticeably preferred music and television programs that had more familiarity,

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such as programs in their native language (Rosendahl, Soderman, & Mazaheri, 2016). Interest to participation and level of engagement was higher in dementia care programs when immigrants could communicate in their native language (Ilfie & Manthorpe, 2004; McMurtay, Saito, & Nakamoto, 2009). Research evidence from Korean Americans with dementia suggested that treatment and intervention programs designed to promote living well with dementia were observed to be more effective when using a familiar language or the native language of the individual (Kim, Wood, & Phillips, 2014).

Based on this literature review, the most commonly shared barriers to accessing dementia care within the global context included stigma, culturally preferred coping strategy, misconception regarding aging and dementia, and language barriers. The literature review identifies the need for future research to explore the barriers faced by the Canadian immigrants and refugees with dementia in accessing timely and appropriate dementia care, as well as developing equitable programs and culturally sensitive services that adequately address their needs.

2.4. Knowledge Gap

Based on the literature review, knowledge gaps were identified in the literature, which highlighted the need for future research. In particular, there is a lack of empirical evidence obtained directly from persons living with dementia among the foreign-born populations. Moreover, most of the current research related to dementia with an ethno-cultural focus were conducted in Europe and Australia. Empirical evidence from North American settings focused primarily on American immigrants with dementia, while there is a lack of research about the influence of socio-cultural barriers on access to dementia care/support programs among the

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Canadian migrants. The literature review highlighted a lack of research focusing on identifying the cultural needs among the foreign-born population with dementia about equitable access to dementia care programs. These findings underscore the need to conduct research on Canadian immigrants with dementia to explore the challenges and barriers faced by this vulnerable population related to dementia care access and procurement, as well as identifying future recommendations to improve the existing services that appropriately meet their cultural needs to support living well with dementia.

Chapter 3: Methodology

3.1. Chapter Overview

This chapter provides a detailed description of the methodology of the current research including research design, recruitment process, data collection tools and procedure, and data analysis process. A description of the researcher and her relation to the subject along with the role of researcher in this study are presented in this chapter. This research study was approved by the Research Ethics Board (14689) at the Ontario Tech University.

3.2. Research Design

Research Method. This study adopted a qualitative method using an interpretive approach. Merriam (2002) proposes that qualitative inquiry can obtain rich description of the subject matter as this allows the researcher to understand the phenomenon from the perspectives of the study participants. Interpretive description is defined as an inductive analytic approach designed to create ways of understanding a phenomenon of interest that produce applications and implications (Thorne, Kirkham, & O'Flynn-Magee, 2004). The foundation of interpretive approach is the in-depth qualitative investigation of a phenomenon of interest for the purpose of capturing themes and patterns that lies within the subjective perceptions of participants to generate an interpretive description of the research phenomenon (Thorne, Kirkham, & O'Flynn-Magee, 2004). As the goal of this study was to explore the lived experiences of immigrants living with dementia, a qualitative interpretative study design was the chosen methodology that best fit the purpose of this research.

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Research Framework. The key purpose of this research was to evaluate the existing dementia support programs through exploring the influence of social and cultural factors related to program access by migrants. To achieve this purpose, the study was grounded in the conceptual framework by Donabedian's (1998) model of measuring quality of care.

Donabedian's Quality of Care model suggests that inferences can be drawn about the quality of healthcare, while services can be classified under three categories: structure, process, and outcome. This conceptual model describes that good structure increases the likelihood of good process, which in turn, good process increases the likelihood of a good outcome (Donabedian , 1988).

Structure refers to the characteristics of the settings in which the care takes place which includes characteristics of the organization, the physical setting and characteristics of the staff (Donabedian , 1988). Structural input is integral for the functionality of healthcare services. Process refers to what actually happened during giving and receiving of care such as actions of the patient or client as well as the actions of the healthcare professionals involved in care delivery (Donabedian , 1988). Outcome refers to the changes observed in a patient or client's condition as a result of the care that has been provided to them, which includes changes in patient/client knowledge, the management of symptoms, changes in health condition and patient satisfaction (Donabedian , 1988). Each of the three components is integral to ensure the quality of care services as without the proper infrastructure, services cannot be delivered. Similarly, without quality services, a satisfactory outcome would not be possible. In addition, infrastructure and service delivery cannot be improved without measuring the outcomes of impact.

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Donabedian's quality of care conceptual model was adopted for current study with the aim of exploring the following research question: "What is the role of socio-cultural factors that affects equitable access to and social participation in dementia care and support programs among recent and non-recent immigrants and refugee populations living in Toronto and Greater Toronto Area?" Specifically, I used the Donabedian model as a conceptual framework to guide the research process of my study. While developing the interview guide, I used the conceptual model to help generate relevant questions to examine the structure, process and outcome of impact regarding the current dementia care and support programs, as well as identifying barriers to access and social participation by migrants with dementia. This framework was used to help extract the collected data into the three levels of healthcare for data analysis and generation of qualitative themes.

3.3. Methodology

Study Sample. The target populations for this study were categorized into three main groups and the number of participants who were recruited in each group is shown in Figure 1. The included groups are: (1) Persons with dementia (PWD); (2) Informal caregivers of PWD; and (3) Formal healthcare professionals.

The target populations of this study were foreign born individuals with dementia and their caregivers. The inclusion criteria of main study sample were persons living with dementia (PWD) and their caregivers who have migrated to Canada from another country at one point of their life, currently residing in Toronto and Greater Toronto Area (GTA) and were involved with either one of the two recruitment locations: (1) Alzheimer Society of Durham Region (ASDR) and (2) Geriatric Assessment and Intervention Network (GAIN) Clinic. The Alzheimer Society

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acts as the leading contributor of support programs aimed at improving the lives of PWD and their caregivers in Canada. The GAIN clinics (located both in hospitals and the community) provide comprehensive geriatric assessments, care planning and delivery to address the complex needs of older adults, including individuals with dementia through inter-professional working in collaboration with Lakeridge Health Oshawa, Peterborough Regional Health Centre, Rouge Valley Health System (Centenary Site), The Scarborough Hospital (General Campus) and seven community-based organizations (Central East Health Line, 2019).

The specific inclusion criteria for PWD group was foreign-born individuals living with dementia who have migrated to Canada as an adult from another country and with English as a second language. Both recent and non-recent immigrants and refugees were included in the study to compare the differences in their perspectives. All participants were English-speaking adults who were able to provide informed consent. All participants in the PWD group were at the age of 65 or over. Since study participants were required to provide informed consent on their own, only people with dementia who had mild cognitive impairment were included in the study. Individuals with later stages of dementia were excluded from the study due to the challenges of their advanced cognitive impairment. Individuals who were unable to communicate in English were excluded from this study as no interpretation service could be provided in this study. Only informal caregivers (i.e. spouse, children or other family members) were included in the study as the focus of the study was to explore the perceptions of PWD and their family members to obtain an increased understanding of the phenomenon from a socio-cultural perspective. The inclusion of the healthcare professional group was guided by the following criteria: Individuals who directly or indirectly worked with PWD and their caregivers who were immigrants or refugees and were involved with the programs in ASDR or GAIN Clinic.

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Participant Recruitment. Prior to beginning of recruitment, staff members who were assigned by the organization to support the recruitment process were informed of the inclusion criteria to ensure eligible participants were recruited into the study. The recruitment of PWD and their caregivers from ASDR was conducted through the distribution of promotional flyers (Appendix A) within the ASDR programs, along with the word of mouth by the program facilitators. Furthermore, I attended the social recreational programs held at the organization in order to reach out to the target populations. During these programs, I clearly explained the study purpose, procedure, impact and significance of the study. The letter of information was distributed prior to the research briefing to facilitate informed consent by the potential study participants. Individuals who expressed interest during the recruitment efforts were requested to participate in the interview after the social recreational program on the same day, or they were offered the option to schedule an interview later at a time of their convenience. Recruitment of study participants from the GAIN clinic was facilitated by the program managers using the similar approach as the ASDR recruitment effort. Healthcare professional group was recruited through email communication by myself using the letter of information (part of consent form) that outlined the research purpose, procedure and study significance. Individuals who were interested in study participation were requested to schedule an interview at a mutually agreed upon time and location of preference. The script used for face-to-face and email recruitment is attached in Appendix B1 and B2.

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Sampling Strategy. Both PWD and informal caregiver groups were included in this research to explore their barriers experienced in the utilization of dementia care. The PWD group was chosen to directly gain an increased understanding of their lived experiences regarding their barriers with accessing dementia care, while the informal caregiver group was included to develop an understanding of their challenges to program access from the perspectives of informal caregiving.

The healthcare professional (HCP) group was included to develop an understanding of the barriers experienced in the areas of service delivery and utilization of dementia care. Two healthcare professionals were selected for their unique roles. HCP1 works with patients closely in person, hence able to provide us information from their one on one interactions with patients. HCP 2 has a managerial position who works with healthcare professionals in dementia care, hence able to provide higher level of understanding and insights about the program delivery of dementia care.

Since the goal of this research was to obtain insights into the lived experiences of the target populations, purposive sampling of study participants who can provide an in-depth understanding of the research phenomena was the most appropriate sampling strategy for this qualitative interpretive approach (Onwuegbuzie & Leech, 2007). Moreover, Crouch & Mackenzie (2006) suggests a sample size of less than 20 study participants in qualitative research is appropriate as this allows a close association of the researcher with the participants which would enhance the validity of in-depth inquiry while obtaining meaningful phenomenological data (Crouch & McKenzie, 2006). Thus, this study aimed to achieve a sample size of five to ten participants. The primary goal of the study was not to obtain data saturation, but rather to get an

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in-depth understanding of the lived experiences of each study participant about our phenomenon of interest.

Interview Guide. Data was collected through one-on-one, in-depth, semi-structured interviews using an interview guide (Appendix E). The interviews were facilitated using the interview guide to explore the perspectives and experiences regarding the socio-cultural barriers and facilitators that influence access to dementia care support programs by the recent and non-recent immigrants and refugees. The interview guide was developed based on the findings from the literature review which included the exploration of factors related to equitable access such as stigma, cultural attitudes, health beliefs and coping strategies, misconception regarding aging and dementia. Interview questions were developed by the graduate student with the guidance from her graduate supervisor. An interview guide previously used by the Alzheimer's Society of Durham Region to conduct research on persons with dementia and their caregivers (Appendix F) was adapted and used as a template to construct the interview questions to ensure the interview guide is appropriate for PWD and caregivers.

The language used in the interview guide were simplified by excluding the use of complicated words and sentences to ensure simplicity and readability, making the questions easier for PWD to understand and follow. Once the interview questions were developed, they were then reviewed by a research assistant who was not involved in the current project, and had previous experiences working with PWD to examine the readability and clarity of the interview questions. The revised questionnaire was reviewed by the members of the Graduate Thesis Committee prior to finalizing the interview guide. Along with the interview guide, this study used a brief quantitative survey to collect the demographic data of the PWD and their caregivers

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including: age; gender; residence location; living arrangement; stage of dementia; frequency of program attendance; changes related to level of confidence; stress level; sleeping pattern, appetite; loneliness and pleasure in life associated with program participation (See Appendix D1 for Demographic Form for PWD and Caregivers). Demographic data collected from healthcare professionals focused on the following areas: professional background, experience working with PWD and caregivers, location and organization of work, number of programs involved in, and program focus (See Appendix D2 for Demographic Form for Healthcare Professionals).

Data collection. Upon participants' expression of interest in the study and completion of informed consent, I scheduled an interview with each participant at a mutually agreed upon time and location. The interviews were conducted in dyads of PWD and their caregivers if they were family members. Dyad interviews were conducted as it was observed in previous research that PWD was able to communicate with increased confidence if their caregivers were present during the interview. One caregiver interview was conducted individually as the family member with dementia did not meet our inclusion criteria and was unable to participate in the interview. The interviews for PWD and caregivers were conducted in meeting rooms allocated by the recruitment site or at participant's home, depending on their preferences.

For those participant who preferred to have the interview at the recruitment site, I set up the interview space at the site where the participants attended the programs. The interview was held in a quiet meeting room to ensure completion of the interview without any interruption. Upon arrival of the participant at the scheduled interview, I thanked them for coming in, welcomed them to sit in the chair and introduced myself. In cases where the interview was held at the participant's house, I arrived at their residence and introduced myself when being greeted

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by the study participant. I carried my Ontario Tech University student identification card to ensure that the participants were comfortable with my identity and professional designation.

To establish rapport and alleviate any tension, I began by talking to the participants about general information, such as how they were feeling and how was their day. To build trust and comfort, I have shared with them my background as an immigrant. Once I perceived that the participants were comfortable, I proceeded by asking them for their permission to begin the interview. Upon their approval, I briefed each participant regarding the research which included study purpose, study involvement and procedure, information related to confidentiality and right to withdrawal, plan for study dissemination, as well as my contact information to access to the research findings following study completion. During the informed consent process, I answered all the questions from the participants related to any aspects of the research as well as their rights and protection of confidentiality. Each study participant was required to sign the consent form (Appendix C) approved by the Ontario Tech University Research Ethics Board and then followed by the completion of a demographic questionnaire (Appendix B). Once the demographic form was completed, I informed the participant that I would begin the audio-recording of the interview using the digital audio-recorder.

At the beginning of the audio, I stated the date, time and used a pseudonym to replace the participant's name; and obtained verbal consent from the participant. I asked each participant all the questions from the interview guide as stated. When required, I have used prompts to guide the study participants and to clarify meaning of questions during the interview process in order to make sure all the areas of interest are covered during the interview. To avoid challenges related to conversing with PWD, the caregiver was present during the interview of PWD. In addition,

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the caregiver was requested to explain the question to the PWD when needed or to ensure the PWD is comfortable and confident to converse.

The interviews lasted approximately 30-45 minutes and was guided by an interview guide consisting of a series of open-ended questions (Refer to Appendix D1 and D2 respectively for the Interview Guides of PWD and caregivers). Once all the interview questions were addressed, I asked each participant if there was anything else to add to the interview in relation to the research topic. Prior to the end of the interview, I let the participant know that they can access the findings of this research after the data has been analyzed and I will send an email invite to inquire their interest about the follow-up on study results. Upon the completion of the interview, I thanked the study participants again for their participation and their valuable input into this research.

Researcher's Background and Reflexivity. In qualitative interpretive research, it is crucial for the researcher to engage in reflexivity. This was achieved by examining the researcher's background and experiences, as well as reflecting on any personal biases and assumptions that may have influenced the research process. Reflexivity can ensure a clear examination of how any preconceptions may enter into the current study (Lopez & Willis, 2004). As a researcher, I have designed and conducted the study, facilitated the interviews, analyzed the collected data and developed the study report which may have been influenced by my background as a researcher and my past lived experiences.

I have immigrated to Canada as a child in 2008 from South Asia. Growing up in a South Asian culture, I observed how symptoms of dementia often being ignored and in many cases these symptoms were misread as signs of normal aging. In addition, I realized that many South

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Asian languages did not have a word that defined dementia which made it difficult to articulate the essence of the disease. Furthermore, I understand that caring for an elderly has been practiced as a social responsibility in South Asian culture as a way of receiving blessings and repaying for past favours. Thus, many families would choose not to seek external help for dementia and many frail elders would not have received the appropriate professional care for symptoms of dementia as required. This realization has contributed to my interest in conducting a research in addressing the barriers to accessing dementia care by migrants.

I have over four years of background experience working in non-profit organizations where I was involved in multiple projects focused on promoting better quality of life for elders and their caregivers. While I was working as a research assistant at ASDR, I noticed that the demographics of the program participants were not ethnically diverse despite the cultural diversity of the populations in Durham region. These past observations have led to my research interest in examining ways to promote equitable access and participation of dementia care programs by Canadian migrants.

Throughout the research process, I was mindful of the potential biases that may arise and kept my assumptions, feelings and perceptions in place. In order to achieve this, I engaged in reflexivity, which is a process of self-reflection that researchers practice in order to develop awareness about their actions, feelings and perceptions, which leads to improved transparency in the researcher's subjective role (Wesam, 2014). The reflexivity process is a way to help ensure the credibility of the study findings. Throughout every step of the research process, I have openly acknowledged my personal assumptions about the study topic. In addition, I pursued bracketing method to mitigate the potential effects of personal perceptions that may taint the research

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process and to ensure the process of data collection and analysis is data-driven (Wesam, 2014). For instance, I have bracketed my knowledge of previous findings from literature when asking the interview questions to ensure I did not impose my participant towards any pre-constructed assumptions. In addition, I have practiced bracketing when coding the qualitative interviews to make sure the thematic findings are solely based on the obtained data and not influenced by findings from the literature nor my perspectives based on my previous background and experiences. My background as an immigrant positively influenced facilitation of interview and data collection. It was observed that as I share similar background as the participants, the participants were able to open up to me without hesitation including their negative experiences, without concealing unpleasant experiences.

Data Analysis. The process of qualitative interpretative data analysis was grounded within Braun and Clarke's (2006) thematic analytical model. This model suggests six phases of thematic analysis as a step-by-step approach which include: 1) Familiarizing with collected research data, 2) Generating initial codes of data in a systematic fashion, 3) Collating codes into potential themes, 4) Reviewing generated themes, 5) Defining and naming themes, and 6) Producing the report (**Braun & Clarke, 2006**). An Inductive method was adopted to identify the themes related to the research question using a data-driven approach; thus the themes identified were established based on the collected data rather than matching with any existing coding frame or based on the researcher's frame of reference (Braun & Clarke, 2006).

For the demographic questionnaires, the data were entered in an Excel document to generate a descriptive data summary. The summary was then reviewed to analyze the characteristics of study participants regarding their age, gender, academic background,

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geographical location of participants, and length of stay in Canada and frequency of program participation. Specifically, the demographic questionnaires were coded for the length of stay in Canada (Recent migrants' vs non-recent migrants) and were cross-referenced to the interview data to examine the differences of how recent migrants perceived socio-cultural factors associated with dementia care access compared to their non-recent immigrant counterparts.

The qualitative interview data was analyzed using Braun and Clarke's (2006) thematic analytical model. Verbatim transcripts of each interview were done simultaneously while data collection process continued. In order to ensure consistency, each transcript was prepared and organized using a similar approach. Transcripts were compared with the corresponding recordings to ensure the details of the interview data were captured. To ensure anonymity, each transcript was numerically identified. All data audio and transcripts were stored securely in encrypted folders accessible only by the researchers.

As guided by Braun and Clarke (2006), I adopted the following six steps of data analysis process. The first step of data analysis was to begin by familiarizing myself with the data. Once the transcription was completed, each transcript was read and re-read individually in order to develop an in-depth understanding of the lived experiences of the participants.

Next, I generated initial codes from the interview data by reading and re-reading the transcripts. Initial coding was developed in the following two phases. In phase one, I reviewed the transcripts and assigned codes on each transcript. In phase two, I used a fresh copy of the transcript that did not contain any preliminary codes or memos from phase one to ensure the coding were not redundant and conflicting.

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Once the two phases of coding were completed, a codebook was developed to organize the codes, including the description of codes and direct quotes from the transcripts. I examined the contents of each code to examine if they can be combined to generate an overarching theme. The identified themes were collated where six major themes were identified and were categorized under the three systems evaluation categories proposed by the Donabedian framework (1988).

The identified themes were then reviewed to assess whether the themes work in relation to the coded extracts and the data set using a thematic map. As a result of the analytical process, six finalized themes were defined and described, accompanied by data extracts (quotes) to facilitate auditability of the study findings. The final step was to develop a comprehensive report of the study findings which is presented in Chapter Four.

3.4. Ethical Considerations

In addition to the REB approval from UOIT, a letter of permission was obtained from each organization to ensure the study method met the requirements of working with each target group. Each participant was briefed regarding the purpose, procedure and outcome of the research and interviews were conducted upon the completion of written consent by the study participants. Participants were expected only to answer the questions that they were comfortable with, and they were not obligated to provide any information that they don't want to share. Each participant was able to access the audio recording of their own interview and the study results upon request. All the collected data was anonymous using a coding method to protect participants' confidentiality. Participants were informed that they could withdraw from the interview at any time. All the collected information including demographic survey, consent

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forms and copies of interview transcripts were stored in a secure folder only accessible by the researchers. Interview audio and transcripts were stored in a password protected folder inside the personal computer of the researcher, accessible only by the researcher.

Chapter 4: Study Findings

3.5. Chapter Overview

This chapter presents the findings of the current study which includes the descriptive summary obtained from the demographic survey and key qualitative themes identified from the analysis of interview data. Using the Donabedian's Quality of Care Framework, interview data revealed seven overarching themes related to access and participation in dementia care programs by migrants, including three structural barriers, three process barriers and one outcome of impact as a result of barriers.

3.6. Demographic Information of Participants

This research recruited a final sample of seven participants: two people with dementia, three caregivers and two healthcare professionals (Summary of recruitment is presented in Figure1).

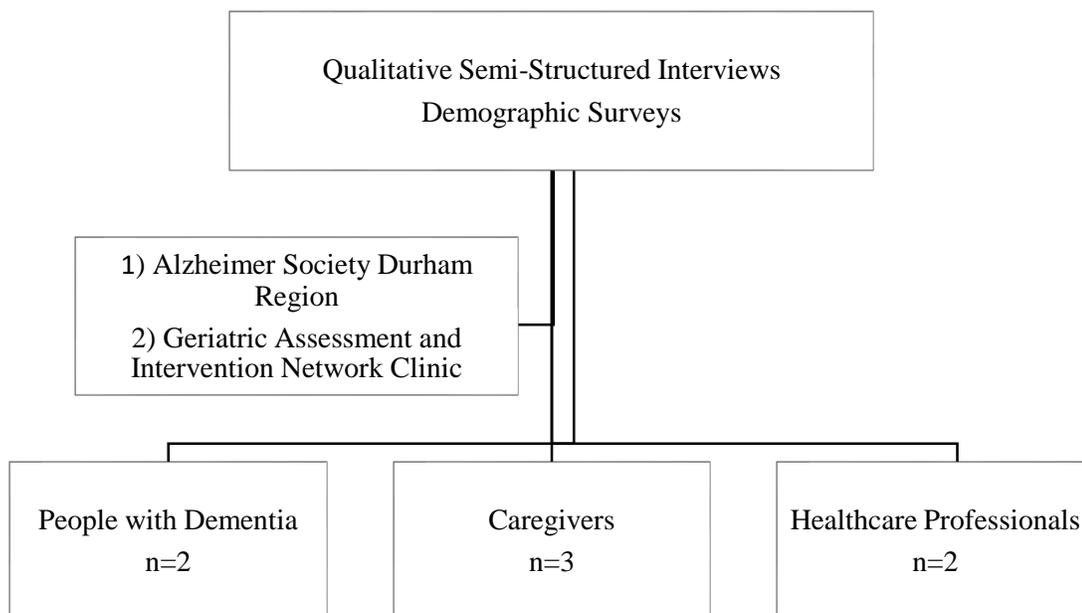


Figure1: List of organizations from which participants were recruited and number of participants in each subgroup.

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Demographic Summary of PWD and Caregivers. The final study sample included two subgroups who are receiving support from dementia programs, PWD (n=2) and caregivers (n=3). The age range of PWD and caregivers who participated in the research was from 75-79 years and 49-65 years respectively. All participants in the interview were women. Ethnic background revealed the diversity of study sample encompassing African (n=2), Middle Eastern (n=1) and South Asian (n=2) ethnicity. PWD and caregiver participants resided primarily in Toronto (n=3) followed by Durham Region (n=2). Living arrangement of PWD participants included living with a spouse (n=1) and living alone (n=1); and caregiver participants reported living with spouse (n=1), living with person with dementia (n=1) and living alone (n=1). All PWD participants were experiencing moderate stage of dementia and accessed to less than one dementia care service/support programs. All participants reported an overall positive change in perceived stigma, level of confidence, stress level, loneliness and fun and pleasure in life after accessing to or participating in dementia care services or support programs. A summary of demographic information obtained from PWD and caregivers is presented in Table 2.

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Table 2: Demographic Summary of PWD and Caregiver Participants

Participant	Age	Number of years in Canada	Ethnic Background	City of Residence	Living Arrangement	Stage of Dementia	Number of Dementia related program accessed
PWD1	79	55	Jamaican	Durham Region/Whitby	Living with spouse	Moderate	1
PWD2	75	46	South Asian	Toronto/Scarborough	Living alone	Moderate	1
Caregiver 1	51	48	Jamaican	Durham region/Whitby	Living alone	N/A	1
Caregiver 2	65	28	Middle Eastern	Toronto/North York	Living with family member (PWD)	N/A	1
Caregiver 3	49	46	South Asian	Toronto/Scarborough	Living with spouse	N/A	1

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Demographic Summary of Healthcare Professionals. The healthcare professional participants for this study involved a Clinical Program Lead (n=1) and an Executive Director of Regional Programs at Senior Care Network (n=1). Both healthcare professionals held over 25 years of experience working with seniors who are PWD and caregivers. Healthcare professional participants worked with several specialized geriatric programs with expertise in dementia care in Toronto.

3.7. Qualitative Thematic Findings

Analysis of the qualitative interview data revealed three structural barriers, three process barriers and one outcome relate to barriers which were associated with equitable access to and social participation in dementia care programs by migrants. Summary of qualitative findings is presented in the following thematic tree (Figure 2). This section will provide a description of future recommendations and suggestions for reducing barriers to program access among migrants with dementia.

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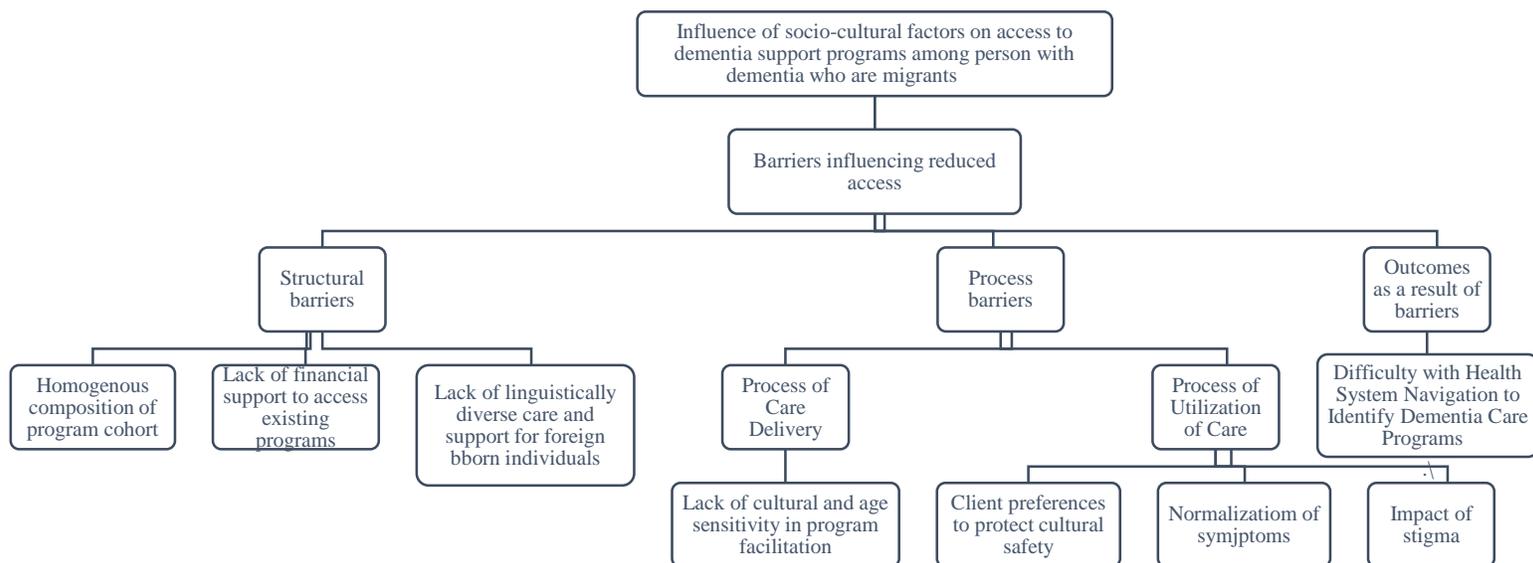


Figure 2: Thematic tree of structural and process barriers and outcome identified as a result of barriers

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Themes related to Structural Barriers. The three structural barriers associated with the lack of socio-cultural sensitivity of existing dementia care programs include: (1) homogenous composition of program cohort; (2) lack of financial support to access existing programs; and (3) lack of linguistically diverse care and support for the foreign-born individuals.

Homogeneous composition of program cohort. PWD and caregivers indicated that social participation in existing programs was influenced by the cultural composition of program cohort. One caregiver stated that the PWD was observed to be hesitant to freely express him/herself in front of other program users from varying culture, which is a barrier in program participation as the structure of many programs may not possess the element of cultural diversity. The interview data identified that being an ethnic minority in a dementia program where majority of the participants were coming from another culture has led to the increased hesitation in program participation. In addition, one caregiver indicate that the PWD is often observed to be more comfortable speaking with other program users who are able to communicate in his/her native language, as reflected in the following quote by the caregiver: “I would like to have her be amongst people she feels comfortable, or people with whom she can speak Hindi and Bengali.” (CG3).

HCP interviews also identified that participation was influenced by the cultural diversity of program cohort. One HCP identified that some clients were observed being uncomfortable socializing or interacting with people from other cultures while exhibiting a higher tendency of socializing with other program users sharing similar cultural background. In addition, some dementia care programs were comprised of homogenous cohort of similar age group rather than diverse age groups interacting together. Healthcare professionals working with PWD emphasized

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on the importance of having more inter-generational interactions within the program where younger age groups would have the opportunity to interact with the older generation. This was reflected in the following quote by a HCP, *“Lots of our programs are designed around age cohort, so the people in the day programs may all be elderlies. There may not be any children/younger adult which is not consistent with the way those people (older adults) might typically live their life. So, I do think there are some cultural barriers where things will not feel necessarily like home for the person living with dementia which is particularly problematic because dementia takes you back to your youth.”* (HCP2).

Lack of financial support for immigrants and refugees. Financial support was identified as a key factor contributing to the level of access to dementia care. Healthcare professional’s interviews identified financial constraint as a leading factor to reduced program participation and loss of follow-up. In many cases, participation in dementia support program was not free of cost and it involved a fee for participating in each program/session. Fee-for-service payment acted as a barrier, particularly among new-comer populations as this would interfere with paying for the expenses of other essential priorities. One healthcare professional highlighted this issue in her interview, *“Programs are paid and require 20 dollars to attend. Given this specific group, not everyone is willing to pay 20 dollars for each program due to financial constraints and having to take care of other priorities... In many cases participants are recently moved immigrants, they do not have a lot of money to spare to attend these programs and paying 20 dollars a day is a big expense for them.”* (HCP1).

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Lack of linguistically diverse care and support for the foreign-born individuals. One of the most prominent and widely shared challenges related to program access by immigrants and refugees living with dementia is language barrier. The PWD, caregivers and healthcare professionals identified that unavailability of programs in their native language was one of the most significant factors leading to inequitable access and reduced program participation. Deterioration in the capability of speaking a second language is a commonly observed phenomenon among migrants with dementia. This concern was raised by both the caregivers and healthcare professional, as reflected in one of the caregiver interviews: “I have noticed that her (PWD) English is not as good as it used to be. She sometimes starts speaking Bengali to my children who doesn’t understand Bengali.” (CG3).

The interviews suggested that although many of the PWD were accessing programs facilitated in English, facilitators and caregivers observed a lack of active participation by the PWD due to language barrier. One caregiver further described this concern as indicated in the following quote: “*I know she wants (PWD) to be around English-speaking people, but I think she is more comfortable around Punjabi and Bengali speaking people because she can express herself better. I see her talking a lot more to her peers who are Bengali...She goes to the programs, but I am not sure how much she participates (due to language barrier).*” (CG3)

Healthcare professionals also recognized that language barrier and the lack of existing programs in diverse languages as key challenges in influencing equitable participation. Analysis of interviews identified that program facilitators in some dementia support programs and services were able to speak in languages other than English, including Punjabi, Hindi, Tamil, Cantonese, and Mandarin. However, availability of such support is geographically limited to the urban

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centres such as the City of Toronto and Scarborough area only. In addition, a limited number of programs and services (e.g., Adult day programs, Meals on Wheels) are available in languages other than English in Toronto, which may not adequately meet the needs of the large ethnic groups of PWD and caregivers. The concern about language barrier is described in the following quote by a healthcare professional: *“There are some services particularly in Scarborough that might be offered in Tamil, like the Day program. For the Meals on Wheels, these kinds of services may be offered in some Asian languages. But not everything might be offered, there is no guarantee that every home care worker comes to assist a person (PWD) is able to provide the services in their language for example.”* (HCP2).

Themes related to Process Barriers

Two categories of process barriers were identified: (1) Process of care delivery which included lack of cultural and age sensitivity in program facilitation; and (2) Process of care utilization, including client preferences to protect cultural safety; normalization of symptoms and impact of stigma.

Process barrier in care delivery: Lack of cultural and age sensitivity in program facilitation and program components. Analysis of the interviews revealed a lack of cultural sensitivity in the existing dementia care programs. Both PWD and caregivers reported that they have experienced insufficient cultural sensitivity from their program facilitators. One PWD reported that she did not feel welcome in the program as she perceived of being treated differently by the facilitator for being an ethnic minority, as reflected in the following quote, *“She (the facilitator) spoke to me differently because I was from South Asia or I don’t know English and I did not speak like them”* (PWD2). One caregiver reported that the facilitators of

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one program did not exhibit the professionalism and appropriate skills required to work with people with dementia who were visible minority. Caregivers felt that program facilitation revealed ageism toward participants from all ethnic background, and it did not create a supportive and encouraging environment for optimal participation by the PWD of different age groups. This barrier was reflected in the following quote, “It (the program) was terrible! It was the facilitator. I couldn’t believe it. Everyone that went there had a horrible experience... You know I think they were not that patient or kind to the elderly people... And when I told them (program facilitators) that she (PWD) wasn’t coming back, these guys (program facilitators) were very abusive, and they were rude to me.” (CG3).

In addition, components of programs influenced the active participation by immigrants and refugees with dementia. Analysis of interview data identified a gap in ensuring culturally sensitive program components where many existing programs were not designed in a way that facilitated the approaches of bringing different cultures together to embrace diversity in the community. One healthcare professional identified that the meals provided within many programs were not inclusive of the dietary preferences and restrictions of PWD from diverse culture, as indicated in the following quote by a healthcare provider: “*Meals in our programs did not necessarily reflect the diet of people (PWD).*” (HCP2). Lack of culturally appropriate program components including dietary considerations were considered to be a major barrier that influenced PWD’s access to and participation in dementia programs.

Process of care utilization: Coping strategies to protect cultural safety. Coping strategy for people with dementia varies in different cultures while interview data identified that reduced

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access to dementia care programs was observed to be associated with their coping strategies to protect cultural safety.

Current study identifies that there were many cultural beliefs and preferences regarding coping strategies to protect cultural safety. One healthcare professional provided some examples: *“South Asians don’t associate dementia with something they need to seek help on, and they would rather take care of themselves instead of asking for help. South Asian is a very tight community and they are willing to help each other”*. Most caregivers indicated that they prioritize to ensure the PWD can practice the culturally preferred coping strategies, thus allowing the PWD to cope with the symptoms in a culturally safe environment. Analysis of interview data identified that priority was given for the PWD to manage the symptoms of dementia at home instead of relocating into a nursing home. This is because in most culture, elders prefer to be around their family while family members prefer to look after their loved ones themselves. In addition, having access to cultural food based on PWD’s preferences, and being able to socialize with family members and friends from earlier life were identified as a priority to protect cultural safety. This theme was reflected in the following quote by one caregiver, *“In Jamaica, the elderly would stay with the younger family members and we don’t have nursing homes, not as much as North America. The culture is to take care of the elders in your home. That’s why she (my mom) is still in her home. I make sure she eats foods that she likes which is Jamaican food. If a Jamaican person is not eating, you know something is wrong. For the most part, Jamaicans like to socialize and be with their family and friends which she (my mom) also does and it has helped her a lot” (CG1)*.

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In addition, PWDs were observed to practice culturally-based coping strategies in order to stay mentally active for better health and well-being. Culturally preferred activities included prayers and meditation, reading books and listening to music of native language, as well as socializing with family members to engage in intergenerational activities.

Process of care utilization: Normalization of Symptoms of Dementia. The most prominent and widely shared factor contributing to reduced access to dementia care programs by the migrants was normalization of dementia symptoms as part of normal aging process. Both person with dementia and their caregivers identified that the leading reason for delaying access to support services was their inability to recognize the symptoms of dementia. This is because the symptoms were often masked as signs of aging or depression where family members of PWD or the PWD themselves did not perceive the necessity to seek professional help. This theme was reflected in the following quote by one caregiver: “When it comes to mental health, no one talks about it.... (people confuse the symptoms with) aging, depression/dementia, oh just old people acting this way”. (CG3)

Similarly, healthcare professionals acknowledged that one of the leading challenges with program participation is that many cultures do not associate the symptoms of dementia with a disorder. Normalization of symptoms lead to family members of PWD and the PWD him/herself believing that seeking external help is not required, as indicated by one healthcare professional “*South Asians don’t associate dementia with something they need to seek help on, and they would rather take care themselves instead of looking for help*”(HCP1). In most cases, PWD and caregivers were found to not seeking care from the physicians regarding their dementia

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symptoms, and the PWD was not diagnosed until they visited the physicians for other health concerns such as post-stroke complications, or injury due to falls etc.

Process of care utilization: Perceived stigma towards dementia. The impact of stigma towards dementia and mental health was found to be a commonly shared phenomenon in many cultures which acted as a key barrier in seeking for external support for the management of dementia. Stigma acts as a barrier in acknowledging dementia, as well as delaying diagnoses and accessing to dementia care programs. Healthcare professional interviews indicated stigma as a major factor contributing to reduced access and utilization of dementia care by migrants despite the availability of accessible support and services. One healthcare professional indicated that in some cultures, identification of having mental illness and cognitive impairment may not be openly accepted by the community, and therefore migrants do not necessarily seek treatment for dementia care. Healthcare professionals also indicated that, due to the stigma associated with mental health concerns, there may be a large number of Canadians who are living with dementia without being properly diagnosed or accessing timely support for the management of dementia. This concern was highlighted in the following quote by a healthcare professional:

*“In some culture, identification of concerns like mental health and cognition might be normalized, where these are not something people would seek treatment for. There are some significant proportion of population who are living with dementia that are not diagnosed, and this number is higher in cultural groups where the desire to get diagnosed may not be there
“(HCP2)*

In many cultures, including South Asian and Middle Eastern cultures, although people openly speak about their physical concerns or diseases, opening up about mental health concerns

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is extremely rare and no one prefers to talk about it. PWD2 stated that she did not access dementia care programs because she preferred to keep her mental health concerns to herself as revealing such concerns to the community were often associated with the fear of being stigmatized and discriminated. PWD2 also indicated that revealing her dementia diagnosis to the community would lead to “gossiping” and “judging” regarding the unfortunate events in her life, hence she would conceal the diagnosis from her family and friends to avoid being judged by others. One caregiver also identified that avoiding negative judgements from the community was one of the key reasons why migrants with dementia did not reveal his/her diagnosis of dementia to their loved ones , leading to the delay in seeking timely dementia care and support. The negative impact of stigma was described in the following quotes by PWD and caregiver,

“You know how some people in our culture enjoys gossiping. They would try to get information on the unfortunate events in your life and talk about it with others and be very judgemental. Which is why I did not want to tell anyone (about my dementia diagnosis), not even my family” (PWD2).

“...she (PWD) was worried about being discriminated (due to her dementia condition), which happens very often in our circle. They focus on the negatives and they would call out on it. My brother and I have grown out of it. But my mother still has that culture in her” (CG3).

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Outcome as a Result of Barriers

Difficulty with Health System Navigation to Identify Dementia Care Programs.

Navigating the healthcare system to identify appropriate dementia care programs has been identified as an ongoing challenge by foreign born individuals living with dementia, particularly among the immigrant and refugee populations. Analysis of the interview data acknowledged that PWD's delayed access to dementia care programs was related to the difficulty in health system navigation.

In particular, the interview data revealed a gap between the time of diagnosis and time of access to services as PWD were unaware of how to find an appropriate dementia care programs that would meet their cultural needs. Healthcare professionals indicated that most of the PWD and their caregivers had access to the dementia care support primarily through referral from family physicians or other healthcare professionals. Self-initiated access to programs by family members of PWD is a rare phenomenon due to the lack of knowledge about the suitability of existing programs, as well as the challenges with navigating the complexity of health services to find their ways to the programs of their choice. This challenge was described by one healthcare professional: *"I have recently spoken to a few caregivers in Scarborough and they told me that they didn't know about our GAIN (Geriatric Assessment Intervention Network) team. So, I still think we have work to do to make sure people (PWD and caregivers) know that we are out there...I don't have numbers to back up but I suspect that it would be more challenging for newcomers and immigrants to find their ways to services."* (HCP 2).

Challenges with finding the ways to the dementia care program is more prominent among the immigrants and refugees. For example, one PWD highlighted the difficulties of recent

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immigrants and refugees might face in finding their ways to services compared to non-recent immigrants: *“To be quite honest, I didn’t know what (services) were out there. Like if you are new to a country, you rely on somebody to come to you and tell you what is available.”* (PWD 1). In addition, finding out existing dementia care programs was identified as a key challenge for both recent and non-recent immigrants living in smaller, rural communities. Analysis of interview data identified that those living outside of urban areas such as foreign-born individuals from Durham region faced greater challenges in finding their ways to the dementia care programs than those living in the urban centres such as Toronto. This challenge was described by one caregiver: *“If I am in a city, I can sort of figure out (what was available). But in Durham, I didn’t know what was available. We found out more information through the Alzheimer Society...”* (CG1)

Recommendations and Suggestions for Reducing Barriers to Access. The interviews identified several recommendations suggested by PWD, caregivers and healthcare professionals to address the barriers experienced by program participants. Increasing focus on developing culturally sensitive components within the dementia care delivery and support programs was identified to be the main priority recommended by the study participants. Language barrier was identified as one of the key barriers leading to reduced access and insufficient social participation in dementia care and support services, and the study participants suggested that developing effective communication strategies to address the linguistic diversity in dementia care delivery will help facilitate increased social participation from migrants living with dementia.

Study participants suggested that developing dementia care evaluation tools in diverse languages will allow immigrants and refugees to contribute their feedback into the future

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improvement of dementia care programs that will meet their cultural needs. Healthcare professionals suggested that greater efforts must be made to reach out to immigrants and refugees in their communities to help raise awareness about the increased understanding of dementia such as identifying the differences between normal aging and dementia, as well as strategies to overcome stigma associated with mental health concerns. PWD and caregiver participants also suggested that the increased availability of programs involving ethnically diverse program participants will help promote social participation by generating a greater sense of belonging. Moreover, as migrants tend to enjoy being around people of their own cultural descent, increasing familiar faces such as attending the program activities with a family member or friend may contribute to increased willingness of participation by the PWD. Finally, interview data highlighted that future recommendations must incorporate the implementation of increased culturally relevant activities such as sewing, knitting, movies, walking program and day trips to places enjoyed by migrants to enhance their willingness to access and participate in the social recreational programs that demonstrate respect for cultural safety.

Chapter 5: Discussion and Conclusion

5.1. Chapter Overview

The purpose of this chapter is to present a discussion of the study findings. Findings from the research focuses on the lived experiences of five PWD and their caregivers as well as observations of healthcare providers to identify their barriers in equitably accessing and actively participating in the current dementia care programs. This chapter focuses on presenting the comparison of current study findings with the existing literature as well as a discussion about the study limitations and recommendations for future research.

5.2. Discussion of Study Results

The analysis of the existing literature revealed a lack of research that focused on the examination of barriers faced by immigrant and refugee populations and their access to dementia care and support. To the researcher's knowledge, the current study is the first study that explored the process and structural barriers associated with equitable access to dementia programs by recent and non-recent migrants residing in Toronto and Durham region in Ontario, Canada.

The analysis of data collected through in-depth, one-on-one semi-structured interviews generated themes about three structural and three process barriers associated with the current dementia care programs. The structural barriers include: (1) homogenous composition of program cohort; (2) lack of financial support to access the existing programs; and (3) lack of linguistically diverse program to meet the cultural needs. Meanwhile, the process barriers associated with the current dementia care services include: (1) lack of cultural sensitivity in program facilitation; (2) difficulty with health system navigation; and (3) client preferences towards protecting culturally preferred coping strategy. The thematic findings suggest that

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barriers experienced by the target population leads to two key consequences: reduced access to existing programs (e.g., navigating the existing programs, awareness, reaching out etc.) and reduced participation in an already enrolled program. Barriers associated with financial support to attend programs, navigation, and client preference towards protecting culturally preferred coping strategies lead to reduced access. Homogenous composition of program cohort and inadequate cultural safety in program facilitation leads to reduced level of program participation and noncompliance. Lack of linguistically diverse programs and stigma towards dementia lead to both reduced access to existing programs as well as reduced level of program participation .

Through qualitative interpretation, the study participants were able to share their perceptions and experiences with the utilization of dementia care programs, including the perspectives of both program users (PWD and caregivers) and program facilitators (healthcare providers). Not only did the current study created an opportunity for the participants to share their experiences, it also gave the participants a platform to share their specific needs from a cultural perspective while providing recommendations and suggestions for future program improvement.

The study findings revealed that the qualitative interpretation design was appropriate, as it provided an exploratory lens into the examination of study phenomenon that addressed the research questions. The qualitative interpretation design was an effective way to investigate a new body of knowledge by providing the researcher with an increased understanding about the migrant's perception of barriers to access and participation in dementia care programs within the Canadian context.

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Varying access to dementia care in urban vs suburban areas. One of the key findings from this current study was the varying levels of access to dementia care in urban vs suburban areas of Toronto and Greater Toronto Area. It was observed that, although difficulty in navigating the healthcare system to find an appropriate program was a common phenomenon across Toronto and greater Toronto area, it was more challenging for individuals to find programs in the Durham region. One caregiver participant indicated that living in a city would definitely be an advantage in terms of finding the right programs for dementia care as it is easier to navigate. On the other hand, it was challenging for her to identify the programs in Durham as she was unsure of where to find the programs while the most practical way of finding potential programs was through online. This finding indicated that timely access to healthcare is more challenging in sub-urban areas than cities. Existing research identified that limited diagnostic services and under-servicing of special-needs groups, such as seniors, are areas of concern for sub-urban/rural, remote, northern, and Aboriginal communities in Canada (Morgan, et al., 2014). Studies exploring dementia care in rural Canada reported that limited availability of formal services and supports, long distance to access services, and transportation difficulties (Forbes, 2006; Morgan, 2002) can lead to challenges for users in identifying the appropriate community-based programs to attend.

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Identification of social and cultural barriers experienced by immigrants and refugees. Antelius and Plejert (2016) describes dementia as a multidimensional phenomenon that requires de-medicalized research in order to comprehend dementia as a lived experience rather than just a biological fact (Antelius & Plejert, 2016). In addition, earlier research studies highlighted the influence of socio/ethno-cultural settings in shaping the experience and meaning of both aging and dementia as well as on health-maintenance and health-seeking behavior (Antelius & Plejert, 2016; Iliffe & Manthorpe, 2004). In the present study, dementia was explored as a culturally and socially shaped phenomenon through understanding the lived experiences of PWD, as well as how social and cultural barriers may influence their coping with dementia, accessing external care and support seeking behaviors.

Previous studies identified that structural barriers such as language barrier influenced reduced level of participation by immigrants and refugees in comparison to non-immigrants (Pinquart & Sorensen, 2005). Additionally, PWD with an immigrant background generally faced more barriers in accessing health services than their non-immigrant counterparts, and this concern was even more prominent in PWD who are older adults due to their vulnerabilities such as additional disabilities, and loss of social roles etc. (Sagbakken, Spilker, & Nielsen, 2018). These barriers could be the consequences of other social, cultural and economic factors such as health illiteracy, lack of interpretation services, communication problems, different health beliefs, negative experiences with healthcare services, or high levels of direct or indirect costs of services (Scheppers, Van Dongen, Dekker, Geertzen, & Dekker, 2006). This phenomenon was validated by the interview data which identified PWD's difficulty with health system navigation as one key factor leading to the delay in receiving care and support of dementia care. In addition, healthcare professionals identified that the financial implications related to the cost

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involved with accessing care and participating in the programs underscored the need to develop more affordable dementia care delivery model.

Stigma alters external help seeking behaviour which highlights the need for raising awareness. Although public awareness and understanding of dementia is improving, there are still specific knowledge gaps. Our study findings indicated that stigma associated with dementia alters help seeking behaviour among immigrants living with dementia. Mukadam (2013) identified that barriers relating to stigma associated with dementia, as well as concerns of being called out as not caring for one's own family members can be addressed by raising awareness about dementia care. Canadian Academy of Health Sciences (2019) recognizes the importance of public awareness to address the stigma and fear, to show how it is possible to live well with dementia and to empower persons with dementia and their caregivers. Increased public awareness and understanding contribute to reducing the stigma associated with dementia, thus encouraging persons with dementia and their caregivers to access services in a timely manner (Nova Scotia Health Research Foundation, 2014). Increasing the understanding and awareness of personal biases and pre-conceived notions can contribute in reducing negative connotations about dementia care, leading to greater societal empathy, and reduced fear of being labeled with dementia. (Batsch & Mittelman, 2012).

Cultural competency is a key element to enhance equitable access and participation.

The study findings identified that cultural competency of dementia care and support programs is vital to enhancing increased equitable access and social participation by the immigrant and refugee populations. Cultural competency is defined by the ability of individuals to provide care to patients or clients with diverse values, beliefs, and behaviors which includes tailoring delivery to meet the social, cultural, and linguistic needs of the care/service users

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(Betancourt, Green, & Carrillo, 2002). Mendes (2018) identifies that cultural competency can be accomplished by ensuring effective delivery of services that meet the unique needs of the ethnic minorities. Current study findings identified both structural and process barriers associated with addressing the social, cultural and linguistic needs of program participants. Giebel et al. (2014) identified that linguistic barriers and lack of cultural sensitivity in the program delivery are key challenges to deliver appropriate dementia assessment and intervention which resonated with our study findings. Current study indicated that many program activities and facilitation process lacked efforts in protecting cultural competency and inclusiveness. For example, the interview data identified that many programs did not provide a variety of spoken languages, activities or dietary alternatives preferred by PWD from diverse ethno-cultural background. Literature highlighted that it is important to implement context specific care and service design tailored to the cultural needs of PWD in order to remove the barriers to achieve linguistic and cultural competency (Giebel, Zubair, Jolley, Bhui, & Challis, 2014).

The present study identified that lack of cultural sensitivity in program facilitation was one of the leading causes of low participation in the dementia care programs because PWD did not perceive the program facilitators were welcoming and friendly. Sagbakken, Spilker, & Nielsen, (2018) indicated that the lack of cultural sensitivity in dementia care was the result of healthcare professionals who lacked the experiences in working with migrants living with dementia (Sagbakken, Spilker, & Nielsen, 2018). Limited expertise and experiences of healthcare professional combined with language barriers can contribute to the feelings of insecurity and lack of confidence when engaging PWD in program activities. There is an urgent need for educating healthcare professionals to develop increased cultural competence in responding to the unique needs of migrants with dementia.

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Reduced program access is influenced by the cultural values and norms of participants. Our study revealed that participants' preference towards culturally relevant coping strategies in their program participation demonstrated the concepts of *familism* and *filial piety* (Sagbakken, Spilker, & Nielsen, 2018). McCleary and Blain (2013) stated that familism is a strong identification and solidarity with family members, and involves strong normative feelings of attachment, responsibility, and reciprocity (McCleary & Blain, 2013). Filial piety refers to a fundamental value in Confucian (Chinese) ethics that reflect respect for parents and older people and placing families' needs over individuals' needs (Sagbakken, Spilker, & Nielsen, 2018). Although filial piety is a key value in Asian cultures, similar ethical values and norms are observed in many other cultures and religions such as South Asian and Middle Eastern cultures (Mackenzie, 2006) (Sagbakken, Spilker, & Nielsen, 2018). These perspectives helped understand the study findings where PWD's belief in seeking help from the outside was considered disrespectful of a person's autonomy/dignity, as well as reflecting failure to fulfil one's familial obligations, which can lead to reduced or delayed access to dementia care and support by migrants.

5.3. Significance of Study Findings

Our study addressed the gap in the existing literature that explored the factors that influenced equitable access to dementia care by immigrants and refugee population in Canada. Sagbakken, Spilker and Nielsen (2018) indicated that patterns in healthcare use differs between immigrant groups and the non-immigrant counterparts where immigrant populations face unique challenges when accessing healthcare services due to their socio-cultural background. Existing literature revealed the ethnic differences in the utilization of dementia care services, as well as delay in access to diagnostic services for minority ethnic groups (Sagbakken, Spilker, & Nielsen,

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2018). Our research addresses the knowledge gap identified in the literature by adding new knowledge about the facilitating factors and challenges that influenced timely access to dementia care and support by immigrants and refugees in Canada. The exploration of perspectives from the healthcare professionals, PWD and caregivers enriched our understanding of the limitations and areas for improvement within the structures and processes of dementia care programs that would lead to better outcomes for the migrants.

5.4. Implications of Study Findings

Mendes (2018) indicates that improvements should be made to incorporate the fundamental cultural safety components to the current dementia programs to ensure they are more appropriate for the diverse ethnic population, and will meet the social, cultural and linguistic needs of migrants with dementia. Current study suggests that although dementia care and support programs are available across Toronto and Durham region, the lack of cultural competency within the existing programs and services was identified to be a significant barrier. Future improvements in existing program components and delivery need to focus on making dementia care programs more culturally appropriate to meet the client's needs. Findings from this study sheds light on the importance of cultivating increased cultural competency of program facilitators in the delivery of dementia care services. One of the key findings observed from the interview data revealed the lack of participation in program activities among persons with dementia from varying culture. Incorporating artistic and cultural activities in dementia care programs that are common and universal to all cultures such as sewing, cooking, and music will help promote a sense of appreciation and belonging from migrants in all walks of life, which will ultimately increase their willingness for future program participation. For instance, Clair (2002) identifies the benefit of music therapy and music-based interventions in increasing

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engagement and participation in dementia programs. Mathews, Clair and Kosloski (2001) identifies that incorporating rhythmic music during exercise activities increases PWD's level of motivation and participation in program activities. Finally, providing cultural competency training opportunities for individuals implementing dementia care will help better prepare and equip a future workforce capable of providing culturally appropriate dementia care and support for migrants in the future .

5.5. Limitations

The current research adopted an exploratory qualitative study with the aim of understanding the lived experiences and perspectives of migrants living with dementia who participated in dementia care programs. As this study focused on marginalized population, recruiting a large sample size was a challenge. Because of the lack of ethnic diversity in the existing programs, this study was unable to recruit a large sample which may limit the extent of generalizability. In addition, the study recruited participants from two locations, one in Toronto and one in Durham Region due to time restriction and feasibility. Future studies should aim to recruit participants from multiple locations with broader geographical areas in an attempt to increase sample size and heterogeneity of sample.

Another study limitation is that our current sample was comprised of foreign born individuals with dementia who were already accessing dementia care and support. Therefore, our study findings may not have been able to capture a complete picture of the socio-cultural barriers faced by those migrants who were non-users of dementia care programs. Study bias may come from the participants who were active users of the dementia care programs and they may be experiencing different types of challenges than those who were non-users. Future studies should

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attempt to interview both program users and non-users to develop a greater understanding of the differences observed among the user and non-user group in regards to barriers to access.

Additionally, participants for this study were recruited from Alzheimer Society Durham Region and Geriatric Access and Intervention Network clinic, thus creating a homogenous sample. The homogenous nature of the study sample may not be representative of the general foreign born population living with dementia in Canada. All participants in the study were non-recent immigrants who has lived in Canada for over 28 years. Therefore, the findings from this study represented barriers faced by non-recent immigrants who may have already transitioned into the Canadian culture, and may report lower levels of challenges than the recent immigrant counterparts.

The study participants only included female PWD and caregivers, hence the study findings may not be representative of their male counterparts. Studies found that male individuals are more likely to accept barriers to access in relation to mental health issues and usefulness of health care services (Slaunwhite, 2015), thereby potentially reducing their interest and desire to participate in a research study about access to care. Evidence also suggest that females are more likely to be in a caregiving role for a family member than a male (Wong, Gilmour, & Ramage-Morin, 2016).

Moreover, since this study adopted a qualitative approach using face to face interviews with the study participants, social desirability bias may have influenced their reports of personal experiences. Research involving survey, questionnaire, or interview to collect data about private or sensitive topics have the tendency to be affected by external bias caused by social desirability or approval (Althubaiti, 2016). The current study explored sensitive topics regarding the cultural

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experiences of migrants which may have triggered positive compliance from the participants in order to be viewed positively and more favorable by the researcher.

The current study has taken the necessary steps to maintain credibility of the research through reflexivity and structural coherence, that is to ensure that there are no unexplained inconsistencies between the data and their interpretations (Krefting, 1991; Anney, 2015). In order to improve credibility and validity of research findings through structural coherence, member-checking was conducted with the healthcare professional participants. This was done by returning the interview data obtained from the healthcare professional group to check for accuracy and interpretation of meaning.

To reduce the risk of assessment bias, I did not attend any of the dementia care or support programs. I also reflected on my personal reflexivity as a researcher and practiced bracketing my own underlying assumptions throughout the course of the research process. In order to assess the usability of the interview guide, peer-debriefing method was adopted. The interview guide was reviewed by an external volunteer (research assistant who is not part of the current study) and was revised accordingly to ensure the interview questions were presented in simple language and easy to understand by the study participants, especially the PWD. To facilitate the interview process, I have incorporated sub-questions and many prompts during the interview to ensure the study participants clearly understood the interview questions. Following transcription of the audio file, the interview transcripts were carefully cross-referenced with the interview audio, where all themes were developed and supported by data extracts including transcripts and field notes. The codebook summarized the observed codes, definition of each code as well as all relevant quotes obtained from the interviews and themes were derived solely based on the data

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extracts. Although data saturation was not observed in all the participant groups., the primary purpose of this study was to obtain an in depth understanding of the lived experiences of each study participant using a qualitative interpretation lens.

5.6. Future Research Directions

Findings from this research call for the necessity of future research and action to implement educational programs and training for healthcare professionals in developing more culturally competent dementia care programs within Ontario, Canada and beyond. According to the knowledge gap observed in our literature review, there was a lack of research evidence that explored access to dementia care programs by immigrants and refugees within the Canadian context. Therefore, further research on this topic is important to ensure the development of quality dementia care and services that will adequately address the social and cultural needs of the migrant populations. The current study was able to develop a greater understanding of the barriers faced by non-recent immigrants and refugees with regards to equitable access and social participation in dementia care in Toronto and Greater Toronto Area. Future research should focus on identifying the barriers faced by recent immigrants and refugees who may experience greater challenges due to their difficulties in transitioning into the Canadian culture. This study included the perceptions of workers who are health care professionals. Given the nature of current programs where volunteers play a key role in program delivery and providing support, future research should focus on exploring the perspectives from volunteers working in dementia care services . Finally, our study explored the experiences of individuals who are currently participating in dementia care programs. Further research should be conducted to explore the lived experiences of those migrants with dementia who are non-program users to help uncover the underlying reasons and barriers for non-utilization of services.

5.7. Conclusion

As suggested by the findings of our study, foreign-born individuals living with dementia experience a great deal of process and structural barriers in accessing the dementia care programs. In order to address these barriers, it is crucial to develop needs-based dementia care plan to evaluate the quality of the existing programs and services. Evaluating the existing dementia care programs to identify how well the programs are serving the foreign-born migrants and incorporating approaches to address process and structural barriers at the planning stage of future programs are urgently needed . Our study suggests that incorporating culturally inclusive activity components that involve cognitive stimulation and rehabilitation interventions will cultivate interest in program participation by individuals from various ethno-cultural background. Training healthcare professionals in communication skills may help build competence and confidence when working with people from different cultural and linguistic backgrounds. In order to prevent normalization of symptoms and promote timely access to dementia care, it is important to focus on generating increased awareness and acknowledgement of dementia as an illness rather than a normal part of aging or a stigmatized condition . This can promote more openness and willingness from migrants with dementia and their family members to seek the required help and support in a timely manner.

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Chapter 7: Appendices

Appendix A

Recruitment Flyer

Participant Needed!

Are you a foreign born individual living with dementia or caring for a family member with dementia?

Are you facing socio-cultural barriers that prevent you from participating in dementia support programs?

We want to hear about your experience of living with dementia as an immigrant in Canada. We want to know about any stigma, coping strategy, misconception and any other barriers that prevents you from participating in support programs. We want to establish programs that are more suitable to your needs.

We cordially invite you to participate in a short face-to-face interview discussion for you to share your experiences and needs. Please share your thoughts and help us meet your need to address socio-cultural barriers and increase social participation in support programs.




Don't be shy-Tell us what acts as barrier for you to access to support programs.

Let us know how we can increase your participation in dementia support programs!

Requirement

- Person with Dementia or informal caregiver who has immigrated to Canada as an adult, currently living in Durham region
- >18 years old and English-speaking

If you want to participate, please contact:
Srija Biswas
BSC, MHSc (Candidate)
University of Ontario Institute of Technology

Phone: 647-773-2782
Email: srija.biswas@uoit.ca

Appendix B1

Recruitment Script

Face to face Recruitment Script

(Distribute a flyer to everyone, pass around a consent form)

Hello everyone,

My name is Srija Biswas and I am a graduate student and Ontario Tech University. I am currently working on my Thesis research for which I will be exploring the influence of socio-cultural factors in equitable access to and reduced participation in dementia support programs among migrated subpopulation living in Durham Region. I am here to invite you to participate in the study I am conducting as part of my thesis research so that you can contribute in developing support programs appropriate for migrated subpopulation.

For the study purpose I will be speaking with you individually in an interview format and it will take up to 40 minutes. You will be asked to complete a short demographic questionnaire and participate in discussing a series of open-ended questions regarding your experience of living with dementia or caring for someone with dementia as a migrant in Canada.

The goal of this research is to contribute to developing dementia support programs that are more appropriate to meeting your needs. From the information provided by you, we will identify the key socio-cultural barriers that migrated subpopulation face regarding access to and participation in dementia support programs. The study aims at increasing our understanding of the influence of stigma, culturally preferred coping strategies and other socio-cultural barriers such as language, cultural attitudes and cultural/religious beliefs in relation to the access and participation to support programs among Canadian immigrants. From the result of this study, we will identify the needs of migrants living with dementia and their caregivers, and the existing gap of current support programs to open up scope of improvement in support program delivery making them more appropriate to the needs of migrants to increase participation.

I have passed around a copy of consent form for further details. If you are willing to participate, you can come in and speak with me now so that we can set up a time that works for you the best. Or you can email me later to schedule. My contact information is in the flyer provided.

Appendix B2: Email recruitment script

Project Title: Exploring the influence of Socio-cultural factors on equitable access to and social participation in Dementia Support Programs among Immigrant Population living in Durham Region

You are invited to participate in a study that is exploring the influence of socio-cultural factors on access to and participation in Dementia Support Programs among migrated population, conducted by Ontario Tech University.

Purpose and Process:

The purpose of this study is to explore the influence of socio-cultural factors on access to and participation in Dementia Support Programs among migrant population living with dementia and their informal caregivers. The study will take up to one and half hour and will be conducted as a focus group discussion session involving 4-5 participants with a researcher. You will be asked to complete a short demographic questionnaire and participate in discussing a series of open-ended questions regarding your experience of living with dementia or caring for someone with dementia as a migrant in Canada.

Potential Benefits:

The goal of this research is to contribute to developing dementia support programs that are more appropriate to meeting your needs. From the information provided by you, we will identify the key socio-cultural barriers that migrated subpopulation face regarding access to and participation in dementia support programs. The study aims at increasing our understanding of the influence of stigma, culturally preferred coping strategies and other socio-cultural barriers such as language, cultural attitudes and cultural/religious beliefs in relation to the access and participation to support programs among Canadian immigrants. From the result of this study, we will identify the needs of migrants living with dementia and their caregivers, and the existing gap of current support programs to open up scope of improvement in support program delivery making them more appropriate to the needs of migrants to increase participation.

Attached is a consent form for further details. If you are interested to participate, please contact:

Researcher:

Graduate Student: Srija Biswas

Departmental and institutional affiliation(s): Faculty of Health Sciences at UOIT

Contact number/email: 646-773-2782; srija.biswas@uoit.ca

Appendix C



RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

Consent Form

PARTICIPANT CONSENT FORM – Person with Dementia

Title of Research Study: Exploring the influence of socio-cultural factors on equitable access to and social participation in Dementia Support Programs among Migrant Population

You are invited to participate in a study exploring the influence of socio-cultural factors on equitable access to and social participation in Dementia Support Programs among Migrant Population, conducted by UOIT. Please read this consent form carefully, and feel free to ask the Researcher any questions that you might have about the study. If you have any questions about your rights as a participant in this study, please contact the Research Ethics Coordinator at 905 721 8668 ext. 3693 or researchethics@uoit.ca.

Researcher(s):

Principal Investigator: Dr. Winnie Sun

Graduate Student Lead: Srija Biswas

Departmental and institutional affiliation(s): Faculty of Health Sciences at UOIT

Contact number(s)/email: winnie.sun@uoit.ca; srija.biswas@uoit.net

Purpose and Procedure:

The purpose of this study is to explore the influence of socio-cultural factors on equitable access to and social participation in Dementia Support Programs among Migrant Population living with dementia.

In this study we primarily will be using individual in-depth interviews lasting approximately 30-45 minutes each to collect data. We will also be using a short questionnaire to collect some information about you to assist us with a better understanding of the data. You will participate in one interview with the researcher and complete a brief demographics questionnaire

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with the interviewer prior to the start of interview. During this interview, you will answer a series of open-ended questions regarding your experiences as a migrant/refugee living with dementia. Interviews will be audio-recorded and you may choose to review a verbatim transcript of the interview once it has been completed.

Potential Benefits:

Analysis of the interviews and demographic data will help identify key cultural barriers associated with migrant's equitable access to and participation in dementia support programs. The study aims at increasing our understanding of the influence of stigma, culturally preferred coping strategies and other socio-cultural barriers such as language, cultural attitudes and cultural/religious beliefs on access and participation to support programs among Canadian migrants. The study will identify needs of migrants living with dementia and the existing gap of the current support programs to address these needs to open up an array of scope of improvement in healthcare service delivery to increase participation in social programs among migrants living with dementia.

Potential Risk or Discomforts:

There are minimal risks associated with the kinds of questions we will be asking in this study. You will be asked questions related to your experience as a migrant/refugee living with dementia which might create some discomfort, however, the interview is not expected to create this effect. You can stop the interview process at any time and do not need to answer any questions that you do not wish to answer.

Storage of Data:

All data collected will be stored in a personal, password-protected laptop kept in a secure location, accessible only to the researchers named above. You will be assigned a pseudonym that will be used to identify your data. Once a pseudonym has been assigned, any direct identifiers will be destroyed and all data you have provided will not be traceable back to you. This non-identifiable and strictly confidential data may be kept beyond the length of this study, in the event that it could be used in pursuance of a future study surrounding the same or similar phenomenon of interest.

The results of this study may be published in a scientific journal and/or presented at a conference. Any information that would identify you will NOT appear in these publications.

Confidentiality:

Before you participate in an interview, you will be asked to complete a demographic questionnaire with the interviewer. You will be asked to indicate your age, gender, educational level, ethnic background, and information on program participation. This information will be paired with your interview to allow the researcher to better understand the interview data. After a

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pseudonym has been developed for this data, any direct identifiers will be destroyed. Throughout the study, this information will only be accessed by the researchers named above.

To safeguard your rights to confidentiality and anonymity, both verbal and written information about the objectives of this study will be available to you throughout the study period. You will be asked to provide explicit signed informed consent before participating in this study, and you will be provided with a copy of this consent form. As mentioned above, this study has received ethics approval from UOIT's Research Ethics Board. You will be notified of the use of an audio recorder during the interview and a verbatim transcript of your answers will be provided to you for review upon request. Pseudonyms will be used to preserve your anonymity, and the data will be kept in a secure, password-protected location at all times, accessible only by the researchers named above.

Your privacy shall be respected. No information about your identity will be shared or published without your permission, unless required by law.

Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct. Please note that confidentiality cannot be guaranteed while data are in transit over the Internet.

Right to Withdraw:

Your participation is voluntary, and you are asked to answer only those questions that you are comfortable with answering. The information that is shared will be held in strict confidence and discussed only with the research team. You will be given information that is relevant to your decision to continue or withdraw from participation.

You may withdraw from the study at any time without any consequences. You are not obliged to provide a reason for your withdrawal. If you choose to withdraw from the study before your information has been anonymized, any data that you have provided will be promptly removed from the study and destroyed thereafter. Please note it is not feasible to withdraw your results once your data has been anonymized and aggregated as it will be impossible to trace it back to you after the elimination of direct identifiers. It will also be difficult, if not impossible, to withdraw results once they have been published or otherwise disseminated.

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Conflict of Interest:

There are no conflicts of interest present in this study.

Compensation

There is no compensation for participating in this study. However, it is expected that people with dementia and informal caregivers will benefit from this study through the betterment of the Alzheimer Society programming as a result of feedback from the study.

Debriefing and Dissemination of Results:

The results from this study will be used to inform the further development of Alzheimer Society of Durham Region programs designed to decrease social isolation for the migrants living with dementia and their informal caregivers. If you wish to be informed of the results of this study, please feel free to contact the researchers named above at the given email addresses up to 6 months after the interview.

Participant Concerns and Reporting:

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the researcher **Srija Biswas** at srija.biswas@uoit.net. Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Research Ethics Coordinator – researchethics@uoit.ca or 905.721.8668 x. 3693.

By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Consent to Participate:

1. I have read the consent form and understand the study being described.
2. I have had an opportunity to ask questions and my questions have been answered. I am free to ask questions about the study in the future.
3. I freely consent to participate in the research study, understanding that I may discontinue participation at any time without penalty.

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- 4. A copy of this Consent Form will be made available to me.
- 5. I allow myself to be audio recorded during the interview.

I would like to meet a second time to review a transcript of my interview.

Yes No

(Name of Participant)

(Date)

(Signature of Participant)

(Signature of Researcher)



RESEARCH ETHICS BOARD
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PARTICIPANT CONSENT FORM – Informal Caregiver

Title of Research Study: Exploring the influence of socio-cultural factors on equitable access to and social participation in Dementia Support Programs among Migrant Population

You are invited to participate in a study exploring the influence of socio-cultural factors on equitable access to and social participation in Dementia Support Programs among Migrant Population, conducted by UOIT. Please read this consent form carefully, and feel free to ask the Researcher any questions that you might have about the study. If you have any questions about your rights as a participant in this study, please contact the Research Ethics Coordinator at 905 721 8668 ext. 3693 or researchethics@uoit.ca.

Researcher(s):

Principal Investigator: Dr. Winnie Sun

Graduate Student Lead: Srija Biswas

Departmental and institutional affiliation(s): Faculty of Health Sciences at UOIT

Contact number(s)/email: winnie.sun@uoit.ca; srija.biswas@uoit.net

Purpose and Procedure:

The purpose of this study is to explore the influence of socio-cultural factors on equitable access to and social participation in Dementia Support Programs among Migrant Population living with dementia and informal caregivers.

In this study we primarily will be using individual in-depth interviews lasting approximately 30-45 minutes each to collect data. We will also be using a short questionnaire to collect some information about you to assist us with a better understanding of the data. You will participate in one interview with the researcher and complete a brief demographics questionnaire with the interviewer prior to the start of interview. During this interview, you will answer a series of open-ended questions regarding your experiences as a migrant/refugee living with dementia.

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Interviews will be audio-recorded and you may choose to review a verbatim transcript of the interview once it has been completed.

Potential Benefits:

Analysis of the focus group discussion and demographic data will help identify key cultural barriers associated with migrant's equitable access to and participation in dementia support programs. The study aims at increasing our understanding of the influence of stigma, culturally preferred coping strategies and other socio-cultural barriers such as language, cultural attitudes and cultural/religious beliefs on access and participation to support programs among Canadian migrants. The study will identify needs of migrants living with dementia and their caregivers, and the existing gap of the current support programs to address these needs to open up an array of scope of improvement in healthcare service delivery to increase participation in social programs. The goal of this research is to contribute to developing dementia support programs that are appropriate to meeting your needs.

Potential Risk or Discomforts:

There are minimal risks associated with the kinds of questions we will be asking in this study. You will be asked questions related to your experience as a migrant/refugee living with dementia which might create some discomfort, however, the discussion session is not expected to create this effect. You can stop participating in the process at any time and do not need to answer any questions that you do not wish to answer.

Storage of Data:

All data collected will be stored in a personal, password-protected laptop kept in a secure location, accessible only to the researchers named above. You will be assigned a pseudonym that will be used to identify your data. Once a pseudonym has been assigned, any direct identifiers will be destroyed and all data you have provided will not be traceable back to you. This non-identifiable and strictly confidential data may be kept beyond the length of this study, in the event that it could be used in pursuance of a future study surrounding the same or similar phenomenon of interest.

The results of this study may be published in a scientific journal and/or presented at a conference. Any information that would identify you will NOT appear in these publications.

Confidentiality:

Before you participate in the session, you will be asked to complete a demographic questionnaire with the researcher. You will be asked to indicate your age, gender, education level

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etc. This information will be paired with your focus group discussion data to allow the researcher to better understand the focus group discussion data. After a pseudonym has been developed for this data, any direct identifiers will be destroyed. Throughout the study, this information will only be accessed by the researchers named above.

To safeguard your rights to confidentiality and anonymity, both verbal and written information about the objectives of this study will be available to you throughout the study period. You will be asked to provide explicit signed informed consent before participating in this study, and you will be provided with a copy of this consent form. As mentioned above, this study has received ethics approval from UOIT's Research Ethics Board. You will be notified of the use of an audio recorder during the discussion session and a verbatim transcript of your answers will be provided to you for review. Pseudonyms will be used to preserve your anonymity, and the data will be kept in a secure, password-protected location at all times, accessible only by the researchers named above.

Your privacy shall be respected. No information about your identity will be shared or published without your permission, unless required by law.

Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct. Please note that confidentiality cannot be guaranteed while data are in transit over the Internet.

Right to Withdraw:

Your participation is voluntary, and you are asked to answer only those questions that you are comfortable with answering. The information that is shared will be held in strict confidence and discussed only with the research team. You will be given information that is relevant to your decision to continue or withdraw from participation.

You may withdraw from the study at any time without any consequences. You are not obliged to provide a reason for your withdrawal. If you choose to withdraw from the study before your information has been anonymized, any data that you have provided will be promptly removed from the study and destroyed thereafter. Please note it is not feasible to withdraw your results once your data has been anonymized and aggregated as it will be impossible to trace it back to you after the elimination of direct identifiers. It will also be difficult, if not impossible, to withdraw results once they have been published or otherwise disseminated.

Conflict of Interest:

There are no conflicts of interest present in this study.

Compensation

There is no compensation for participating in this study. However, it is expected that people with dementia and informal caregivers will benefit from this study through the betterment of the Alzheimer Society programming as a result of feedback from the study.

Debriefing and Dissemination of Results:

The results from this study will be used to inform the further development of Alzheimer Society of Durham Region programs designed to decrease social isolation for the migrants living with dementia and their informal caregivers. If you wish to be informed of the results of this study, please feel free to contact the researchers named above at the given email addresses up to 6 months after the focus group discussion session.

Participant Concerns and Reporting:

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the researcher **Srija Biswas** at srija.biswas@uoit.net. Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Research Ethics Coordinator – researchethics@uoit.ca or 905.721.8668 x. 3693.

By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Consent to Participate:

1. I have read the consent form and understand the study being described.
2. I have had an opportunity to ask questions and my questions have been answered. I am free to ask questions about the study in the future.
3. I freely consent to participate in the research study, understanding that I may discontinue participation at any time without penalty.
4. A copy of this Consent Form will be made available to me.
5. I allow myself to be audio recorded during the session.

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I would like to meet a second time to review a transcript of my session.

Yes

No

(Name of Participant)

(Date)

(Signature of Participant)

(Signature of Researcher)



RESEARCH ETHICS BOARD
OFFICE OF RESEARCH SERVICES

PARTICIPANT CONSENT FORM – Healthcare Professional

Title of Research Study: Exploring the influence of socio-cultural factors on equitable access to and social participation in Dementia Support Programs among Migrant Population

You are invited to participate in a study exploring the influence of socio-cultural factors on equitable access to and social participation in Dementia Support Programs among Migrant Population, conducted by UOIT. Please read this consent form carefully, and feel free to ask the Researcher any questions that you might have about the study. If you have any questions about your rights as a participant in this study, please contact the Research Ethics Coordinator at 905 721 8668 ext. 3693 or researchethics@uoit.ca.

Researcher(s):

Principal Investigator: Dr. Winnie Sun

Graduate Student Lead: Srija Biswas

Departmental and institutional affiliation(s): Faculty of Health Sciences at UOIT

Contact number(s)/email: winnie.sun@uoit.ca; srija.biswas@uoit.net

Purpose and Procedure:

The purpose of this study is to explore the influence of socio-cultural factors on equitable access to and social participation in Dementia Support Programs among Migrant Population living with dementia and informal caregivers.

In this study we primarily will be conducting individual in-depth interviews lasting approximately 30-45 minutes each to collect data. We will also be using a short questionnaire to collect some information about your opinions and experiences with person living with dementia to assist us with a better understanding of the data. You will participate in one interview with the researcher and complete a brief demographics questionnaire with the interviewer prior to the start of interview. During this interview, you will answer a series of open-ended questions regarding

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your experiences as Healthcare professional working with migrant/refugee living with dementia, what are the current status of participation in programs and what can increase participation in the dementia support programs. The interview will be audio-recorded and you may choose to review a verbatim transcript of the session once it has been completed.

Potential Benefits:

Analysis of the interviews and demographic data will help identify key cultural barriers associated with migrant's equitable access to and participation in dementia support programs. The study aims at increasing our understanding of the influence of stigma, culturally preferred coping strategies and other socio-cultural barriers such as language, cultural attitudes and cultural/religious beliefs on access and participation to support programs among Canadian migrants. The study will identify needs of migrants living with dementia and their caregivers, and the existing gap of the current support programs to address these needs to open up an array of scope of improvement in healthcare service delivery to increase participation in social programs. The goal of this research is to contribute to developing dementia support programs that are appropriate to meeting your needs.

Potential Risk or Discomforts:

There are minimal risks associated with the kinds of questions we will be asking in this study. You will be asked questions related to your experience as a Healthcare professional working with migrant/refugee living with dementia. You can stop participating in the process at any time and do not need to answer any questions that you do not wish to answer. If there is any emotional distress speaking about any client's experience or your experience working with a client, we will take a break from the interview and will only resume the interview if you indicate that you wish to continue.

Storage of Data:

All data collected will be stored in a personal, password-protected laptop kept in a secure location, accessible only to the researchers named above. You will be assigned a pseudonym that will be used to identify your data. Once a pseudonym has been assigned, any direct identifiers will be destroyed and all data you have provided will not be traceable back to you. This non-identifiable and strictly confidential data may be kept beyond the length of this study, in the event that it could be used in pursuance of a future study surrounding the same or similar phenomenon of interest.

The results of this study may be published in a scientific journal and/or presented at a conference. Any information that would identify you will NOT appear in these publications.

Confidentiality:

Before you participate in the session, you will be asked to complete a demographic questionnaire with the researcher. You will be asked to indicate your age, gender, education level etc. This information will be paired with your interview to allow the researcher to better understand the interview data. After a pseudonym has been developed for this data, any direct identifiers will be destroyed. Throughout the study, this information will only be accessed by the researchers named above.

To safeguard your rights to confidentiality and anonymity, both verbal and written information about the objectives of this study will be available to you throughout the study period. You will be asked to provide explicit signed informed consent before participating in this study, and you will be provided with a copy of this consent form. As mentioned above, this study has received ethics approval from UOIT's Research Ethics Board. You will be notified of the use of an audio recorder during the interview and a verbatim transcript of your answers will be provided to you for review. Pseudonyms will be used to preserve your anonymity, and the data will be kept in a secure, password-protected location at all times, accessible only by the researchers named above.

Your privacy shall be respected. No information about your identity will be shared or published without your permission, unless required by law.

Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct. Please note that confidentiality cannot be guaranteed while data are in transit over the Internet.

Right to Withdraw:

Your participation is voluntary, and you are asked to answer only those questions that you are comfortable with answering. The information that is shared will be held in strict confidence and discussed only with the research team. You will be given information that is relevant to your decision to continue or withdraw from participation.

You may withdraw from the study at any time without any consequences. You are not obliged to provide a reason for your withdrawal. If you choose to withdraw from the study before your information has been anonymized, any data that you have provided will be promptly removed from the study and destroyed thereafter. Please note it is not feasible to withdraw your results once your data has been anonymized and aggregated as it will be impossible to trace it back to you after the elimination of direct identifiers. It will also be difficult, if not impossible, to withdraw results once they have been published or otherwise disseminated.

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Conflict of Interest:

There are no conflicts of interest present in this study.

Compensation

There is no compensation for participating in this study. However, it is expected that people with dementia and informal caregivers will benefit from this study through the betterment of the Alzheimer Society programming as a result of feedback from the study.

Debriefing and Dissemination of Results:

The results from this study will be used to inform the further development of Alzheimer Society of Durham Region programs designed to decrease social isolation for the migrants living with dementia and their informal caregivers. If you wish to be informed of the results of this study, please feel free to contact the researchers named above at the given email addresses up to 6 months after the time of the interviews.

Participant Concerns and Reporting:

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the researcher **Srija Biswas** at srija.biswas@uoit.net. Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Research Ethics Coordinator – researchethics@uoit.ca or 905.721.8668 x. 3693.

By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Consent to Participate:

1. I have read the consent form and understand the study being described.
2. I have had an opportunity to ask questions and my questions have been answered. I am free to ask questions about the study in the future.
3. I freely consent to participate in the research study, understanding that I may discontinue participation at any time without penalty.
4. A copy of this Consent Form will be made available to me.
5. I allow myself to be audio recorded during the session.

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I would like to meet a second time to review a transcript of my session.

Yes

No

(Name of Participant)

(Date)

(Signature of Participant)

(Signature of Researcher)

Appendix D1

Demographic Questionnaire

Dementia in Migrants

Demographic and Well-being Questionnaire

Please tell us the following information about yourself:

1. Please check one of the following categories that applies to you

I am a person living with dementia caregiver

2. What is your age: _____

3. What is your gender: Male Female

4. How long have you been living in Canada for? _____

5. What is your ethnic background?

- a. Eastern European
- b. South Asian
- c. East Asian
- d. Middle eastern

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e. Hispanic

6. In which city or town do you live? _____

7. What is your educational level?

No formal education

Grade school

High school

College /University

8. What is your marital status?

Married/ common-law

Separated/ divorced

Widowed

Never married

9. What is your current living arrangement?

I live alone

I live with my spouse

I live with other family member(s)

I live in a Retirement Home

I live in a Nursing Home

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10. If you are a person with dementia, including Alzheimer's disease, what is the severity of your disease?

Mild Moderate Severe

11. Are you currently participating in any support programs to promote living well with dementia?

Yes

How many programs are you attending? -----

No

12. After the participation in the program activities, did you experience any changes in

Perceived stigma	positive change <input type="checkbox"/>	negative change <input type="checkbox"/>	no change <input type="checkbox"/>
level of confidence	positive change <input type="checkbox"/>	negative change <input type="checkbox"/>	no change <input type="checkbox"/>
stress level	positive change <input type="checkbox"/>	negative change <input type="checkbox"/>	no change <input type="checkbox"/>
sleeping pattern	positive change <input type="checkbox"/>	negative change <input type="checkbox"/>	no change <input type="checkbox"/>
appetite	positive change <input type="checkbox"/>	negative change <input type="checkbox"/>	no change <input type="checkbox"/>
loneliness	positive change <input type="checkbox"/>	negative change <input type="checkbox"/>	no change <input type="checkbox"/>
fun and pleasure in life	positive change <input type="checkbox"/>	negative change <input type="checkbox"/>	no change <input type="checkbox"/>

Thank you very much for your time.

Appendix D2

Demographic Questionnaire-Healthcare Professionals

Please tell us the following information about yourself:

1. What is your profession working with people with dementia and caregivers (i.e. Physician, Program facilitator, volunteer)
2. How long have you been working with person with dementia and caregivers?
3. In which city or town do you work? _____
4. What organization do you work with? _____
5. What is your educational level?

No formal education

Grade school

High school

College /University

6. Are you currently working in any support programs to promote living well with dementia?

Yes No

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7. How many programs are you working with? -----

8. What is the focus of these programs?

9. Which subgroup are you working with?

Person with Dementia

Caregiver

Other Please specify

10. After the participation of the person with dementia and caregivers in the program activities, did they exhibit changes in

Perceived stigma positive change negative change no change

Level of confidence positive change negative change no change

Stress level positive change negative change no change

Sleeping pattern positive change negative change no change

Appetite positive change negative change no change

Loneliness positive change negative change no change

Fun and pleasure in life positive change negative change no change

Thank you very much for your time.

Appendix E

Interview Guide

Dementia Support Program Users

Interview Guide (People living with Dementia)

Introduction

Thank you for meeting with me today. My name is Srija, and I would like to talk to you about your experiences of living with dementia as migrant with particular focus on how you have used dementia care and support services in the past. The interview should take about approximately 45 minutes. With your permission, I will be audio recording the session so I don't miss out on any of your answers to the questions. Even though I'll be taking notes during the interview, I won't be able to write everything down. Because we'll be audio recorded, please make sure to speak up so we don't miss anything when we are putting your responses onto the paper copy. Your answers will be kept confidential. They only will be shared with research team members and we will make sure that whatever information we include in our report does not identify you in any way. You do not have to talk about anything you don't want to and you may end the interview at any time. Here is a consent form that provides the details of the study. I will read through each part of this consent with you to ensure you understand before you sign this form. You will be provided a copy of this signed consent form. If you have any questions, please feel free to ask me at any time.

Before we begin the interview, I am going to ask you a few questions to assist us understand your experience better (Demographic Questionnaire). The information provided here will help us identify relevant background information and other barriers such as geographical barrier faced in accessing to support programs. Please only answer the questions you are comfortable to provide information about.

(Completion of Demographic questionnaire) Thank you. We will begin the interview.

Interview Prompt Questions

1. Tell me a little bit about your story of coming to Canada as a new migrant.
(What was it like to settle down in a new country? What was your experience with adjusting to new changes?)

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2. As a new migrant, how was your experience in terms of participating in community activities? Were there any challenges affected your involvement with the community?
3. How did you first find out your diagnosis of having Dementia?
4. Tell me a little about how you became aware of the dementia care and support services.
5. What programs are you accessing now?
6. When and how did your access to those programs begin?
7. What are those factors that enable you to access and participate in these dementia care and support program(s)?
8. What kind of coping strategies did you follow from your culture to cope with dementia before participating in these programs?
9. Before you started participating in the programs, did you face any cultural barriers that prevented you from participating in these support programs? For example misconception regarding dementia symptoms and aging, unaware of how to manage symptoms, language barrier etc.
10. How if at all, did stigma affect your willingness to participate in these support programs? By stigma I mean any negative attribute that you may have perceived such as discrimination, hate or disgrace you faced from family, friends or society as a whole due to having dementia.
11. Are you still facing any barriers in participating in these programs at this moment? If so, what are they?
12. What programs or aspects of the program(s) have you found most culturally appropriate for you and why?
13. What programs or aspects of the program(s) have you found least culturally appropriate for you and why?
14. What would you add or remove from the programs to increase your willingness to participate?
15. If you were to give one piece of advice to a new migrant about accessing and participating in the dementia care and support program, what would this be?

Conclusion:

(End audio recording.) Okay, I'll be making this audio recording into a printed record, which I will review with you to ensure we were able to record your answers accurately (if you would like to do this). This data will be used to develop a report on the research findings. If you're interested in remaining updated with this study, feel free to get in touch with me using the contact information provided. We are keeping a list of people who are interested and will present the findings to them.

Thank you so much for your time. I very much appreciate you sharing your experiences and suggestions.

Care Partners of Dementia Support Program Users

Interview Guide

Introduction

Thank you for meeting with me today. My name is Srija, and I would like to talk to you about your experiences of living with dementia as migrant from another country, and your perspectives about the care and support services for people with dementia. The interview should take about 45 minutes. With your permission, I will be audio recording the session so I don't miss out on any of your answers to the questions. Even though I'll be taking notes during the interview, I won't be able to write everything down. Because we'll be audio recorded, please make sure to speak up so we don't miss anything when we are putting your responses onto the paper copy. Your answers will be kept confidential. They only will be shared with research team members and we will make sure that whatever information we include in our report does not identify you in any way. You do not have to talk about anything you don't want to and you may end the interview at any time. Here is a consent form that provides the details of the study. I will read through each part of this consent with you to ensure you understand before you sign this form. You will be provided a copy of this signed consent form. If you have any questions, please feel free to ask me at any time.

Before we begin the interview, I request you to kindly fill out a few questions to assist us better understand you and person who you care for. (Demographic Questionnaire). The information provided here will help us identify relevant background information and other barriers such as geographical barrier faced in accessing to support programs. Please only answer the questions you are comfortable to provide information about.

(Completion of Demographic questionnaire) Thank you. We will begin the interview.

Interview Questions

1. Tell me a little bit about your story of coming to Canada as a new migrant. (What was it like to settle down in a new country? What was your experiencing with adjusting to new changes?)

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2. As a new migrant, how was your experience in terms of participating in the into community activities? Were there any challenges that prevented you from engaging with the community?
3. How did you first find out about the diagnosis of your family member of having Dementia?
4. Tell me a little about how you and your family member you care for became aware of the dementia care and support services.
5. What programs are your family member currently accessing for dementia care and support?
6. When and how did his/her access to those programs begin?
7. Did you and your loved one face any cultural factors acting as a barrier that prevented you and your family member from participating in these support programs? For example misconception regarding dementia symptoms and aging, unaware of how to manage dementia symptoms, language barrier etc.
8. How if at all stigma affected your willingness to encourage your loved one to participate in support programs? By stigma I mean any negative attribute that you perceived such as discrimination, hate or disgrace you faced from family, friends or society as a whole due to having dementia.
9. What kind of cultural coping strategies did your loved ones follow to cope with dementia before participating in these programs?
10. Do you think the family member you care for is still facing any barriers in participating these programs at this moment? If so, what are they?
11. What programs or aspects of the program(s) have you found most culturally appropriate and why?
12. What programs or aspects of the program(s) have you found least culturally appropriate and why?
13. What would you add or remove from the programs to increase your willingness to support your loved ones to continue their participation in these programs?
14. If you were to give one piece of advice to a new migrant about accessing and participating in the dementia care and support program, what would this be?

Conclusion:

(End audio recording.) Okay, I'll be making this audio recording into a printed record, which I will review with you to ensure we were able to record your answers accurately (if you would like to do this). This data will be used to develop a report on the research findings. If you're interested in remaining updated with this study, feel free to get in touch with me using the contact information provided. We are keeping a list of people who are interested and will present the findings to them.

Thank you so much for your time. I very much appreciate you sharing your experiences and suggestions.

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Please use same introduction as previous interview guide.

Healthcare Professional Interview Questions

1. Tell me a little bit about your experience working with PWD and caregivers from immigrant or refugee subpopulation or from varying culture.
2. How do the PWD and caregivers get access to the support program?
3. How would you describe program participation among PWD and caregivers from immigrant/refugee population with regards to frequency of participation, level of interaction and interest in participation?
4. Did you observe any difference in participation between immigrant/refugees and non-immigrant participants? If so, could you describe what differences did you observe?
5. Do you think there are any socio-cultural factors makes it difficult for immigrants to participate? If so, what are they? What are some of the barriers they are facing (Example language barrier, coping strategy, communication)
6. How do you think socio-cultural factors that challenge participant's level of participation?
7. How do healthcare providers overcome the challenges of stigma, cultural beliefs, language barriers faced by migrants and their caregivers when delivering care/support?
8. In there anything you suggest to reduce barriers and increase participation for this subgroup? If so, what do you suggest (i.e. facilitating factors to program participation)

Appendix F

Alzheimer Society Durham Region Interview Template

Interview Guide (Persons living with Dementia)

Introduction

Thank you for meeting with me today. My name is XXX, and I would like to talk to you about your experiences of the Alzheimer Society of Durham Region programs. The interview should take about an hour. With your permission, I will be audio recording the session so I don't miss out on any of your answers to the questions. Even though I'll be taking notes during the interview, I won't be able to write everything down. Because we'll be audio recorded, please make sure to speak up so we don't miss anything when we are putting your responses onto the paper copy. Your answers will be kept confidential. They only will be shared with research team members and we will make sure that whatever information we include in our report does not identify you in any way. You do not have to talk about anything you don't want to and you may end the interview at any time. Here is a consent form that provides the details of the study. I will read through each part of this consent with you to ensure you understand before you sign this form. You will be provided a copy of this signed consent form. If you have any questions, please feel free to ask me at any time.

Before we begin the interview, I am going to ask you a few questions to assist us with understanding who you are and what brings you to the Alzheimer Society programs (Demographic Questionnaire).

Interview Prompt Questions

1. Tell me little about why you agreed to this interview.
2. Tell me how you became aware of the Alzheimer Society programs.
3. What programs are you attending at the Alzheimer Society?
4. Prior to coming to the program(s), what did your social life look like and what does it look like now (ask about connection to others, resources etc.)?
5. What part of the program did you enjoy the most (find most helpful) and why?
6. What part of the program did you least enjoy (was least helpful) and why?
7. Is there anything that makes it difficult to attend the program(s) at the Alzheimer Society?
8. Is there anything that makes it easier to attend the program(s) at the Alzheimer Society?
9. How has the program changed your life, if at all? (e.g., with partners, friends, other family, community)

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10. Is there anything that you might change about the programs – e.g., take out or add?
11. Is there anything else you would like to say that I haven't asked about?

Conclusion:

(End audio recording.) Okay, I'll be making this audio recording into a printed record, which I will review with you to ensure we were able to record your answers accurately (if you would like to do this). This data will be used to develop a report on the research findings. If you're interested in remaining updated with this study, feel free to get in touch with me using the contact information provided. We are keeping a list of people who are interested and will present the findings to them.

Thank you so much for your time.

Interview Guide (Informal Caregiver)

Introduction

Thank you for meeting with me today. My name is XXX, and I would like to talk to you about your experiences of the Alzheimer Society of Durham Region programs. The interview should take about an hour. With your permission, I will be audio recording the session so I don't miss out on any of your responses. Even though I'll be taking notes during the interview, I won't be able to write everything down. Because we'll be audio recorded, please make sure to speak up so we don't miss anything when transcribing your responses. Your responses will be kept confidential. Your responses will only be shared with research team members and we will make sure that whatever information we include in our report does not identify you in any way. You do not have to talk about anything you don't want to and you may end the interview at any time. Here is a consent form that elaborates on the details of the study. Please read through it carefully and sign at the bottom for your free informed consent to participate in this study. You will be provided a copy of this signed consent form. If you have any questions, please feel free to ask me.

Before we begin the interview, I am going to ask you a few questions to assist us with understanding who you are and what brings the person you provide care for (or yourself) to the Alzheimer Society programs.

Interview Prompt Questions

1. Tell me a little about what prompted you to agree to this interview.
2. Tell me a little about how you became aware of the Alzheimer Society programs.
3. What program(s) are you **or** the person you provide care for attending at the Alzheimer Society and when did begin to attend those programs begin? (could be one program or more)
4. Prior to attending the program(s), what did your social life look like and what does it look like now (ask about connection to others and resources etc.)?
5. What program(s) or aspects of the program(s) have you found most helpful and why?
6. What program(s) or aspects of the program(s) have you found least helpful and why?
7. What are those factors that challenge the ability for the person you provide care for and/or yourself to attend the program(s) at the Alzheimer Society? (e.g., timing of the program, location, transportation, cost etc.)
8. What are those factors that make it easier for you to access the program(s) at the Alzheimer Society?
9. How has the program impacted your life in relation to connection to others and/or resources, if at all? (1) your relationship with your partner and/or extended family and friends was improved after participating in the program; (2) forming friendships; (3) mutual peer support from group members; (4) feeling inclined to participate in other community activities?
10. Is there anything that prevents you from using these programs?
11. Is there anything that you might change about the programs – additions, deletions etc.?
12. If at all, in what ways have the program volunteers enhanced your participation experience?
13. Can you tell me about your experience with mobile devices; which ones do you use and in what way do you use them? How would you describe your ability to be connected to resources and others through the use of these devices? If you don't use devices, can you tell me what keeps you from doing so.
14. Is there anything else you would like to add that I haven't asked about?

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Conclusion:

(End audio recording.) Okay, I'll be transcribing this audio recording into a verbatim transcript, which I will let you review to ensure we captured your responses accurately. Thereafter, this data will be used to develop a report on the research findings. If you're interested in remaining updated with this study, feel free to get in touch with me using the contact information provided. We are keeping a list of those who wish to see the study results so we can present them.

Thank you so much for your time.