

**Dementia Dastan: Understanding the Experiences of South Asian Canadians Living with
Dementia and their Care Partners**

by

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Author's Declaration

This thesis consists of material all of which I authored or co-authored: see Statement of Contributions included in the thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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

Statement of Contributions

I, Navjot Gill-Chawla, am the sole author of Chapters 1, 2, 3, and 7. These chapters were completed under the supervision of Dr. George Heckman and are not intended for publication. This thesis includes three manuscripts (Chapters 4-6) designed for publication. I acknowledge co-authors' contributions while I am the primary author of these chapters. As the primary author, I conceptualized the study design, conducted data collection and analysis, and drafted and submitted the manuscripts. My co-authors provided valuable theoretical and methodological guidance, offering insightful feedback on draft manuscripts. All co-authors have reviewed and approved the manuscripts for submission in their current form, understanding that they would be included in this doctoral dissertation.

The authorship for the three manuscripts requiring substantial intellectual input, including contribution to research processes and feedback on the final draft, is as follows:

Chapter 4: Gill-Chawla, N., Heckman, G., McAiney, C., Tong C. (2025). Navigating Dementia in South Asian Canadian Communities: From Understanding and Diagnosis to Accessing Care. Manuscript in preparation for submission

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Abstract

Introduction

As Canada faces the growing challenge of dementia, there is an urgent need to ensure that care and support systems are responsive to the country's increasingly diverse population. While Canada's multicultural landscape has shaped many aspects of healthcare, the specific needs of diverse communities, such as South Asian Canadians, remain insufficiently addressed. Cultural stigma, language barriers, and a lack of culturally tailored resources continue to delay dementia recognition, diagnosis, and access to appropriate care for many in this population. While some experiences of individuals living with dementia and their care partners, such as navigating healthcare systems and dealing with the emotional toll of caregiving, are common across communities, South Asian Canadians face additional culturally specific challenges. These include stigma rooted in cultural beliefs, language barriers, and limited access to services designed to align with their cultural values. Despite strong caregiving traditions within South Asian families, limited Canadian research examines both the shared and culturally specific aspects of their experiences. This thesis examines the lived experiences of individuals with dementia, their care partners, physicians diagnosing dementia, and employees of community support organizations to identify barriers, strengths, and strategies for improving culturally inclusive dementia care while highlighting universally shared experiences.

Methods

This research employs a qualitative, interpretive phenomenological approach through three interconnected studies conducted across Canada in Alberta, British Columbia and Ontario.

Study 1 examines the experiences of 16 participants (14 care partners and two individuals living with dementia) across the stages of recognizing symptoms, obtaining a diagnosis, and accessing services. Study 2 examines the perspectives of 13 physicians on diagnosing dementia in South Asian Canadians, while Study 3 gathers the insights of 14 employees from community support organizations that provide dementia services. Semi-structured interviews were conducted in English for Studies 2 and 3 and in English, Hindi, and Punjabi for Study 1. Reflexive thematic analysis was applied to identify recurring and distinct themes across participant groups.

Results

Key findings are organized into themes within each study. Study 1 identified barriers and stigma in recognizing dementia, challenges in obtaining a diagnosis, accessing services post-diagnosis, and transitioning to long-term care. Cultural beliefs often delay symptom recognition, while stigma prevents families from seeking early intervention. Limited familiarity with healthcare systems and a lack of culturally sensitive resources further complicates the care process. Study 2 revealed themes related to barriers to dementia diagnosis, cultural and generational influences, communication and disclosure, and the improvement of inclusivity and resources. Physicians highlighted language barriers, cultural sensitivities, and the absence of tailored diagnostic tools as significant challenges. Study 3 identified themes of cultural sensitivity in service delivery, engaging with South Asian communities, challenges in delivering services, and future directions. Community support employees emphasized the importance of cultural humility, trust-building, and partnerships with cultural organizations while noting systemic funding gaps.

Conclusion

This research demonstrates the critical need for integrating culturally sensitive care into dementia care practices and policies to address the unique barriers faced by South Asian Canadians. Findings underscore the importance of early and accurate diagnosis, community engagement, and the development of culturally and linguistically tailored resources to support families. Strong familial networks and caregiving traditions within South Asian communities can serve as foundations for interventions that enhance access to services and reduce stigma. Systemic changes, including increased funding for the development and implementation of culturally sensitive resources and programs, are essential to achieving equitable dementia care. By addressing cultural and systemic barriers, this thesis contributes actionable insights that aim to inform dementia care that meets the needs of Canada's increasingly diverse population.

Acknowledgements

As I stand at the end of this doctoral dissertation journey, my heart fills with gratitude for the warmth, guidance, and love that have been showered upon me by those who have been my pillars of strength over the past four years.

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Each of you has played a pivotal role in shaping this journey, and I am profoundly grateful for your support and encouragement.

Dedication

This doctoral dissertation is dedicated to my parents, grandparents, and all the immigrant parents who gave up their wings so their children could fly high. Every achievement we make is a testament to their sacrifices and struggles.

ਇਹ ਡਾਕਟਰੇਟ ਖੋਜ ਨਿਬੰਧ ਮੇਰੇ ਮਾਤਾ-ਪਿਤਾ, ਬੀਬੀ ਅਤੇ ਪਾਪਾ ਅਤੇ ਉਨ੍ਹਾਂ ਸਾਰੇ ਪ੍ਰਵਾਸੀ ਮਾਪਿਆਂ ਨੂੰ ਸਮਰਪਿਤ ਹੈ ਜਿਨ੍ਹਾਂ ਨੇ ਆਪਣਾ ਦੇਸ਼ ਛੱਡ ਦਿੱਤਾ ਤਾਂ ਕਿ ਉਨ੍ਹਾਂ ਦੇ ਬੱਚੇ ਇੱਕ ਬਿਹਤਰ ਜ਼ਿੰਦਗੀ ਜੀ ਸਕਣ। ਸਾਡੀ ਹਰ ਪ੍ਰਾਪਤੀ ਉਨ੍ਹਾਂ ਦੀਆਂ ਕੁਰਬਾਨੀਆਂ ਅਤੇ ਸੰਘਰਸ਼ਾਂ ਦਾ ਪ੍ਰਮਾਣ ਹੈ।

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ਧਨ ਪਿਰੁ ਏਹਿ ਨ ਆਖੀਅਨਿ ਬਹਨਿ ਇਕਠੇ ਹੋਇ ॥

ਏਕ ਜੋਤਿ ਦੁਇ ਮੂਰਤੀ ਧਨ ਪਿਰੁ ਕਹੀਐ ਸੋਇ ॥੩॥

ਸ੍ਰੀ ਗੁਰੂ ਗ੍ਰੰਥ ਸਾਹਿਬ - ਅੰਗ ੧੮੮

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Chapter One: Breaking the Silence on Dementia: Beyond "Old Age"

“ਕਿਸੇ ਦੀ ਦਾਸਤਾਨ ਸੁਣ ਕੇ ਉਸ ਦੇ ਅਨੁਭਵਾਂ ਨੂੰ ਸਮਝਣਾ ਆਸਾਨ ਹੋ ਜਾਂਦਾ ਹੈ।”

“Understanding someone's experiences becomes easier by listening to their story” – Punjabi Proverb

1.1 Introduction

Imagine a scenario in which forgetfulness starts creeping into your daily life, but you casually dismiss it as a by-product of aging. You laugh it off, attributing it to the passing years, until one day the realization hits you like a sudden storm, and you can no longer find your way home on a familiar evening walk. The moment is fleeting, and you manage to reach home, but when you share the incident with your family, their response is a nonchalant "old age."

As time goes on, these memory lapses become more frequent, and you struggle to recall simple things, like your grandchild's name, as they excitedly chat with you. Concerned, your family takes you to a physician, and after a series of tests and discussions, the unsettling word "dementia" is mentioned. You furrow your brow, asking, "What does that mean?" The doctor explains it as a condition involving memory loss and cognitive decline. You glance at your daughter, seeking reassurance, but she looks confused as well, echoing the pervasive sentiment of the family: "old age."

Determined to understand more, you search for a translated version of information about dementia. You catch glimpses of phrases like "forgetting things," but the familiar refrain of "old age" continues to echo in your mind. The language used feels distant, making it difficult to fully grasp the weight of what is happening. Unbeknownst to you, dementia is quietly taking away your cognitive abilities, turning once-familiar territory into an uncharted and confusing landscape.

Concerned, your grandchildren attempt to convey the severity of the situation, but a language barrier makes it challenging for you to understand the nuances of their explanations. Still, in these moments, seeing their smiles and hearing their laughter brings you comfort, even if the details escape you.

Your family, trying their best to ensure your well-being, suggests engaging in activities to stay connected and involved. However, you find yourself lost in the intricacies of games like bingo or discussions about Marilyn Monroe, unfamiliar and perplexing activities. Though you feel a growing sense of isolation, you find joy in the presence of your loved ones, even as you struggle to navigate a world that feels increasingly distant.

Amidst your children's efforts to provide care, a painful reality emerges: the resources available for dementia care are often not culturally or linguistically appropriate. The disconnect intensifies as your challenges remain unaddressed, leading to an unspoken sense of frustration. Despite their best intentions, your family struggles to find resources that align with your cultural background. The available support, although well-meaning, does not take into account the unique cultural nuances that could significantly impact your care. Their search for guidance becomes a journey marked by frustration, but it is not without hope. The family's realization that more culturally tailored resources are needed is the first step in seeking better care.

This is the reality for many South Asian Canadians living with dementia and their care partners. In 2021, more than 8.3 million people or almost one in four people (23.0%), were or have been landed immigrants or permanent residents in Canada (Statistics Canada, 2022). According to Statistics Canada (2021), 2,571,400 Canadians had South Asian geographical origins, constituting approximately 7.1% of the total population, making South Asians the largest visible minority in Canada. In 2021, most immigrants were born in Asia, with India being the

country of birth for close to one in five (18.6%) recent immigrants (Statistics Canada, 2022). Based on research from the United Kingdom, in South Asian communities, dementia is often stigmatized due to language, lack of awareness and attribution to religious or spiritual reasons (Hossain et al., 2020; Mukadam et al., 2011). This cultural perception can sometimes delay the recognition of dementia symptoms, as they may be overlooked or minimized within families (Mukadam et al., 2011). Consequently, pursuing medical care may be delayed, as cognitive decline is not always recognized as a medical condition immediately. This delay is significant because dementia, which is often not recognized early, can affect not only the individuals diagnosed but also their family and friends, care partners.

The prevalence of dementia in the South Asian community in Canada is not well-documented. However, research suggests that the number of individuals with Asian origins, including South Asian communities, diagnosed with dementia is expected to triple over the next 25 years (Alzheimer Society of Canada, 2024; Canadian Centre for Economic Analysis, 2022). According to the Alzheimer Society of Canada's Landmark Study (2024), by 2050, one in four people diagnosed with dementia will be of Asian descent. This highlights the growing South Asian diaspora in Canada, whose aging population will face increasing challenges related to dementia care. The caregiving burden will fall not only on the individuals diagnosed but also on their families, who traditionally play a central role in caregiving due to the cultural value placed on filial piety. Filial piety, the deep-rooted cultural expectation that children care for their aging parents, further complicates the recognition of dementia and the provision of care, as family members may be reluctant to seek external help, viewing it as a sign of failure to honour their elders (Zhang et al., 2020).

Dementia in South Asian communities is a topic that is often not discussed openly due to a lack of awareness and stigma. Studies have shown that people living with dementia and their care partners from South Asian communities have unique experiences, including challenges in managing their health conditions and accessing healthcare services (Hossain et al., 2020). South Asian communities have unique cultural beliefs and practices that influence their attitudes toward health and healthcare, which can impact their experiences with dementia (Hossain et al., 2020; Hossain et al., 2022; Mukadam et al., 2011). Moreover, research has shown a lack of awareness and understanding of dementia in South Asian communities, which can lead to delays in symptom recognition and diagnosis (Hossain et al., 2020; Hossain et al., 2022; Mukadam et al., 2011).

To address dementia effectively within diverse cultural contexts, it is crucial to consider and respect cultural beliefs, values, and practices. This includes understanding their experiences and addressing their dementia care-related needs in a culturally inclusive manner. However, the studies referenced in the preceding paragraph are primarily based in the United Kingdom, as there is a notable gap in Canadian literature concerning the experiences of South Asians living with dementia and their care partners. We understand that dementia is a sensitive topic amongst South Asian communities due to a lack of awareness and stigma. However, the experiences and knowledge shared by the studies above are not from the Canadian context.

It is essential to question the validity of generalizing research from countries with different healthcare systems, resources, and historical contexts. In particular, studies from the United Kingdom may not fully reflect the realities of South Asian Canadians, whose experiences of immigration, racism, and access to care differ significantly from those of South Asians in other countries. The challenges faced by the Canadian South Asian diaspora are shaped by

unique factors, such as Canada's distinct healthcare system and social dynamics. Therefore, relying on international research without considering these differences can lead to misinformed conclusions about the needs of South Asian Canadians living with dementia and their care partners. To ensure that these individuals feel heard, supported, and properly understood in their dementia journey, it is critical that we turn our focus to research conducted within Canada, which can more accurately capture the specific challenges and experiences of this community.

There is a noticeable gap when it comes to the experiences of South Asian Canadians living with dementia and their caregivers. To ensure they receive the proper support, it is crucial that we not only acknowledge their needs but actively listen to their experiences. While research from the United Kingdom offers a starting point for addressing dementia in Canada, it is only by hearing directly from South Asian Canadians that we can truly tailor our support to meet their specific requirements.

1.2 A Call for Inclusive Support

Imagine a scenario where, from the onset of dementia symptoms, individuals and families affected by the condition could easily access support that understands their unique needs. Envision a healthcare system where cultural and linguistic considerations are fully integrated into dementia care, enabling individuals to navigate the complexities of the disease more easily. While resources that address these needs could alleviate some of the burden on families, the core challenge lies in understanding the lived experiences of South Asian Canadians. Only by gaining a deeper understanding of these experiences can we design resources and systems that truly serve this demographic.

This dissertation, comprising three studies, was conducted to gain an understanding of the experiences of South Asian communities living with dementia. The overarching goal of this

research is to examine dementia care within South Asian communities in Canada. It aims to gather insights from individuals living with dementia, their care partners, physicians involved in diagnosis, and staff members of community support organizations. Through these perspectives, the research aims to identify challenges, gaps, and opportunities in dementia care, aiming to inform healthcare services and support systems that are culturally sensitive and tailored to the unique needs of South Asian Canadians.

1.3 Format

The dissertation will be presented as an integrated manuscript-based thesis. An integrated manuscript thesis is a format that combines multiple stand-alone research papers into a cohesive whole. Each manuscript represents a complete research study or a significant portion of the overall project structure for publication. This format allows the author to present their work in a way that resembles academic journal publications and demonstrates research productivity. Introductory and concluding chapters provide an overarching narrative and connect the individual studies. It offers a concise and alternative way to present research findings while adhering to academic standards and contributing to the field's knowledge.

This dissertation follows an integrated manuscript format, according to the University's guidelines. As such, Chapters 4, 5, and 6 are presented as stand-alone manuscripts, each of which includes a brief overview of relevant literature and methodological approach. While efforts have been made to minimize redundancy, some repetition, particularly of background information and methods, is necessary to ensure each chapter can be understood independently. This structure was chosen to facilitate publication and communicate the contributions of each individual study within the broader research thesis.

Chapter 01 will introduce the topic, followed by Chapter 02, which will provide a literature review. Chapter 03 will detail the research methodology. Chapters 04, 05, and 06 will each present stand-alone research papers that align with the project's objectives, as outlined below.

Study One: Objective 1: To understand the experiences of South Asian Canadians living with dementia and their care partners through the stages of recognizing symptoms, receiving a diagnosis, and accessing services. (Chapter 4)

Study Two: Objective 2: To understand physicians' experiences with South Asian communities during the dementia diagnosis process. (Chapter 5)

Study 3: Objective 3: To understand the experiences, perspectives, and insights of community support organization employees in providing support and services to South Asian communities following a diagnosis of dementia. (Chapter 6)

Chapter 07 will integrate discussions from all three studies, exploring how they build on and inform one another and highlighting the implications of the overall thesis.

The research findings are expected to contribute valuable insights into the experiences and perspectives of South Asian Canadians living with dementia and their care partners. By understanding the cultural nuances that influence dementia care, this research aims to inform the development of culturally sensitive approaches that enhance support and reduce the stigma associated with dementia. Moreover, understanding the experiences of physicians and the employees of community support organizations will potentially guide the development of tailored interventions to improve diagnosis and service delivery within South Asian communities. This research will contribute to the growing knowledge on dementia care from

diverse cultural perspectives. Ultimately, it is anticipated that the findings may help to improve dementia care outcomes and ensure equitable access to services for South Asian Canadians living with dementia and their families.

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Chapter Two: A Literature Review on Dementia Experiences within South Asian Communities

2.1 Introduction

This chapter examines the existing literature on dementia care, focusing on understanding its intersection with cultural contexts and the unique challenges faced by South Asian¹ communities. It begins by outlining the methods employed for the literature search, ensuring a systematic review of relevant studies. The chapter then delves into the global and cultural understanding of dementia, highlighting its complex nature and the barriers and challenges encountered in dementia care. The discussion examines how cultural beliefs and practices influence dementia experiences, with a specific emphasis on the South Asian diaspora.

The literature review process began with a preliminary search on Google Scholar using keywords such as “South Asian,” “dementia care,” and “culturally inclusive care.” This initial search helped identify key papers, including systematic reviews and a foundational textbook on dementia care in ethnic communities in the United Kingdom. Building on this foundation, multiple meetings were held with a librarian to refine the search strategy and develop a search string. The finalized search was conducted across major databases, including PubMed, Scopus, and PsycINFO, to locate literature focused on dementia care within South Asian communities, with a particular emphasis on Canadian studies. References from key papers were also hand-searched to uncover additional relevant studies.

2.1.1 What is Dementia?

¹ South Asians refer to individuals from South Asia, encompassing countries including India, Pakistan, Bangladesh, Nepal, Sri Lanka, Bhutan, Maldives, and Afghanistan (United Nations, 2021). They share cultural ties while maintaining distinct languages and traditions (Pew Research Center, 2014).

Dementia is a collective term for a set of symptoms caused by different underlying conditions, including Alzheimer's disease (Alzheimer's Association, 2024). It arises from abnormal changes in the brain that impair its normal functioning (Alzheimer's Association, 2024). These changes lead to progressive declines in cognitive skills such as memory, reasoning, and decision-making, eventually interfering with daily life and independence. Beyond cognitive difficulties, dementia can also affect emotions, behaviour, and relationships, creating significant challenges for both individuals and their families (Alzheimer's Association, 2024).

There are several types of dementia, with Alzheimer's dementia being the most common, accounting for 60–80% of cases. Alzheimer's dementia is thought to be caused by Alzheimer's disease, which is characterized by the accumulation of beta-amyloid plaques and tau tangles in the brain, resulting in cell death and brain atrophy (National Institute on Aging, 2023). Early symptoms include memory loss and difficulty with language and spatial reasoning, progressing to severe cognitive decline. Other types of dementia include vascular dementia, Lewy body dementia, frontotemporal dementia, and mixed dementia, where multiple types coexist. While the symptoms of these types vary, they all share an impact on cognitive and functional abilities, requiring nuanced approaches to care and support (National Institute on Aging, 2023).

Currently, more than 55 million people worldwide are living with dementia, and this number is expected to increase to 139 million by 2050 (World Health Organization, 2023). As of January 1st, 2024, the Alzheimer Society of Canada estimated that 733,040 people were living with dementia, and this number is expected to increase to nearly 1 million by 2030 (Alzheimer Society Canada, 2024).

2.2 Challenges in Dementia Care: A General Overview

Caring for individuals living with dementia involves a complex interplay of emotional, physical, and systemic challenges that profoundly affect both those living with the condition and their care partners. At the center of these difficulties is the progressive nature of dementia, which leads to the gradual deterioration of memory, cognitive functions, and physical capabilities (Alzheimer's Association, 2021). This decline often manifests as confusion, difficulties in communication, mood swings, and behavioural changes, requiring ever-increasing levels of care and support (Alzheimer's Association, 2021). For individuals living with dementia, these changes can result in frustration, loss of autonomy, and social isolation, further diminishing their overall quality of life. For care partners, the ongoing demands of caregiving often lead to emotional exhaustion, physical strain, and feelings of isolation as they balance caregiving responsibilities with their personal and professional lives.

A critical challenge in dementia care lies in accessing timely and adequate support. Delayed diagnosis is common, often due to a lack of awareness or the stigma associated with dementia, which can deter individuals and families from seeking medical attention (Parker et al., 2020). Once a diagnosis is made, navigating the healthcare system becomes another hurdle, as care partners often struggle to find appropriate services, manage care transitions, and coordinate among multiple providers (White et al., 2024). The financial burden of care, encompassing medical treatments, home modifications, and professional caregiving services, adds another layer of complexity, particularly for families with limited resources (Lee et al., 2019). For care partners, the emotional toll of witnessing their loved one's decline, coupled with the logistical and financial stressors of caregiving, frequently results in burnout and mental health challenges, such as anxiety and depression (Jeste et al., 2021). These challenges are compounded by a lack

of accessible respite care options, leaving care partners with little opportunity to recharge (Jeste et al., 2021).

While these issues are universal, cultural factors significantly influence the dementia care experience, particularly within ethno-racial communities². Cultural beliefs³ about aging and cognitive decline often shape how symptoms of dementia are perceived, delaying recognition and diagnosis (Siette et al., 2023). In some cultures, caregiving is seen as a deeply ingrained familial duty, making it less acceptable to seek external help or rely on formal care services. Language barriers, mistrust of healthcare systems, and the lack of culturally tailored support further complicate the dementia care journey for individuals and families from diverse backgrounds (Blinka et al., 2023).

Within South Asian communities, these cultural dimensions play a particularly prominent role. Many South Asian families view caregiving as a natural extension of filial piety, with strong expectations that family members, particularly women, will serve as primary care partners (Hossain et al., 2020). While fostering deep familial bonds, this cultural norm can also put immense pressure on care partners, often resulting in physical and emotional strain. Furthermore, the stigma surrounding dementia, coupled with a lack of awareness about the condition, frequently leads to delayed diagnosis and reluctance to seek formal support (Philip et al., 2024). Language barriers and the absence of culturally sensitive resources further isolate South Asian families, leaving many to navigate dementia care alone (Hossain et al., 2022). Exploring these

² Ethno-racial pertains to the fusion of ethnicity and race, acknowledging the interplay between cultural and physical attributes (Twine & Gallagher, 2008). It recognizes that individuals encounter societal treatment based on both ethnic and racial factors (Bowleg, 2012). This term underscores the intricate nature of identity, encompassing cultural heritage and physical traits that shape individuals' experiences (Phinney, 1992).

³ Culture refers to a group's shared beliefs, values, practices, and symbols (Kroeber & Kluckhohn, 1952). It encompasses customs, language, art, and more, shaping identity and behaviour (Samovar et al., 2016). This dynamic concept influences how individuals perceive and interact with their world (Hofstede, 1980).

cultural intersections is essential for understanding how to support South Asian individuals and families living with dementia.

Before delving deeper into the experiences of South Asians navigating dementia care, it is essential to understand their immigration history in Canada. South Asians have a rich and varied history that has profoundly shaped their identity and experiences within Canadian society. Examining this historical context provides critical insight into the cultural values, familial expectations, and systemic challenges that influence their approaches to caregiving and their interactions with healthcare systems.

2.3 South Asians in Canada

South Asians in Canada have a rich immigration history that has significantly contributed to the country's diverse cultural fabric. The diaspora primarily includes individuals from countries such as India, Pakistan, Bangladesh, Sri Lanka, and Nepal. Their immigration journey dates to the late 19th century, with the earliest arrivals often being labourers, mainly from Punjab, India. These labourers played vital roles in constructing railways and working in agriculture (Kalra et al., 2005). Different waves have marked the immigration history of South Asians in Canada, each reflecting distinct motivations and experiences. The 1960s and 1970s witnessed a significant increase in immigration, driven by shifts in Canadian immigration policies that prioritized skilled workers and professionals, attracting individuals from various South Asian countries (Kalra et al., 2005). These immigrants⁴ brought diverse skills, contributing to Canada's workforce and economic growth (Tran & Allard, 2005).

⁴ Immigrants are individuals who relocate to a different country for permanent residence (United Nations, 2021). They do so for reasons such as economic opportunities, family reunification, or seeking refuge (International Organization for Migration, 2021). Immigrants enrich host countries culturally and economically (Migrant Integration Policy Index, 2020).

The experiences of South Asian immigrants in Canada have been shaped by factors such as racial discrimination, efforts to preserve cultural identities, and the pursuit of social and economic integration. South Asians have faced instances of racial prejudice and discrimination, notably exemplified by the discriminatory policies of the early 20th century, including the infamous Komagata Maru incident in 1914. The Komagata Maru incident occurred in 1914 when a Japanese steamship carrying 376 passengers from India was denied entry into Canada due to restrictive immigration policies. The ship was forced to return to India, where many of the passengers faced arrest or violence upon disembarkation. This incident highlighted the discriminatory immigration laws of the time and has since become a significant event in Canadian history, symbolizing the struggles against racial exclusion and injustice. (Walton-Roberts, 2013).

The immigration history of South Asians in Canada has also influenced their health experiences, particularly in the context of older adults and their care partners. The "healthy immigrant effect" phenomenon has been observed among immigrants, wherein newcomers often arrive with better health than the host population due to selective migration (Lin, 2022). However, as these individuals spend more time in Canada, the initial health advantage may wane due to various factors such as acculturation, lifestyle changes, and exposure to new health risks.

The experiences of older South Asian immigrants and their care partners within the Canadian healthcare system have been shaped by various challenges. Reviews by Wang et al. (2019), and Lin (2022) highlight the barriers faced by older immigrants in accessing healthcare, including language barriers, cultural differences, and limited awareness of available services. South Asian immigrants, like other older immigrants, confront difficulties in navigating a complex healthcare system that may differ significantly from their countries of origin. They

frequently use health services less and face various barriers to access, such as language difficulties, cultural differences, health beliefs, cost, lack of health insurance, location (e.g., availability and distance), and socioeconomic status. (Wang et al., 2019). Cultural factors, immigration status, and generational shifts also significantly impact the healthcare experiences of South Asian Canadians.

In summary, South Asians in Canada are diverse (Table 1) with various immigration-related experiences and contribute significantly to the country's cultural tapestry. Facing challenges such as racial discrimination and efforts to maintain cultural identities, their experiences are shaped by distinct waves of immigration and integration efforts. Within the healthcare system, older South Asian immigrants and their care partners encounter barriers, including language and cultural differences and limited awareness of available services. As the "healthy immigrant effect" diminishes over time, there is a need for tailored interventions that consider factors like time since immigration and generational shifts.

Table 1a: Demographic and Cultural Diversity of South Asian Countries

Country	Religions	Languages	Traditions	Population
India	Hinduism, Islam, Christianity, Sikhism, Buddhism, Jainism, Zoroastrianism, Bahá'í Faith (Census of India, 2011)	Hindi, Bengali, Telugu, Marathi, Tamil, Urdu, Gujarati, Malayalam, Kannada, Oriya, Punjabi, Assamese, etc. (Census of India, 2011)	Diwali, Holi, Eid, Christmas, Baisakhi, Navratri, Pongal, Ganesh Chaturthi, etc. (Encyclopaedia Britannica, 2024)	1.4 billion (World Bank, 2023)
Pakistan	Islam, Christianity, Hinduism, Sikhism (Pew Research Center, 2012)	Urdu, Punjabi, Sindhi, Pashto, Balochi, English (Census of Pakistan, 2017)	Eid, Ramadan, Ashura, Basant, Independence Day, Nowruz (Encyclopaedia Britannica, 2024)	240 million (World Bank, 2023)

Bangladesh	Islam, Hinduism, Buddhism, Christianity (Pew Research Center, 2012)	Bengali, English (Census of Bangladesh, 2011)	Pohela Boishakh, Eid, Durga Puja, Nabanna, Bishwa Ijtema (Encyclopaedia Britannica, 2024)	165 million (World Bank, 2023)
Sri Lanka	Buddhism, Hinduism, Islam, Christianity (Pew Research Center, 2012)	Sinhala, Tamil, English (Census of Sri Lanka, 2012)	Vesak, Sinhala and Tamil New Year, Deepavali, Eid, Christmas (Encyclopaedia Britannica, 2024)	21 million (World Bank, 2023)
Nepal	Hinduism, Buddhism, Islam, Kirant, Christianity (Pew Research Center, 2012)	Nepali, Maithili, Bhojpuri, Tharu, Tamang, Newar, Magar, Awadhi, English (Census of Nepal, 2011)	Dashain, Tihar, Buddha Jayanti, Holi, Teej, Maghe Sankranti (Encyclopaedia Britannica, 2024)	30 million (World Bank, 2023)
Bhutan	Buddhism, Hinduism (Pew Research Center, 2012)	Dzongkha, Tshanglakha, Lhotshamkha, English (Census of Bhutan, 2017)	Tshechu, Losar, Thru Bab, Blessed Rainy Day (Encyclopaedia Britannica, 2024)	800,000 (World Bank, 2023)
Maldives	Islam (Pew Research Center, 2012)	Dhivehi, English (Census of Maldives, 2014)	Eid, Ramadan, National Day, Independence Day (Encyclopaedia Britannica, 2024)	540,000 (World Bank, 2023)
Afghanistan	Islam (Pew Research Center, 2012)	Pashto, Dari, Uzbek, Turkmen, English (Census of Afghanistan, 2010)	Eid, Nowruz, Ashura, Independence Day (Encyclopaedia Britannica, 2024)	38 million (World Bank, 2023)

Table 1 b: Prominent South Asian Origin Groups in Canada by Country of Origin (Statistics Canada, 2021)

Country of Origin	Population (2021)	% of Total South Asian Canadian¹
India	1,858,755	72.3 %
Pakistan	303,260	11.8 %
Sri Lanka	144,490	5.6 %
Bangladesh	75,425	2.9 %
Nepal	21,975	0.85 %
Bhutan	3,215	0.13 %
Other South Asia²	remainder of 2.57 M	~7.3 %
Total	2,571,400	100 %

2.4 The Three Phases of Dementia Care

Dementia care has been broadly categorized into three phases, each critical to managing and supporting individuals' dementia journey (Giebel, 2015). The first phase, **recognizing symptoms**, involves the individual and their family identifying changes in health that may indicate the onset of dementia, such as memory loss or difficulty with everyday tasks. Early recognition is crucial as it prompts timely medical consultation. In the second phase, **receiving a diagnosis**, the individual seeks or receives a formal diagnosis from a healthcare professional. This step is essential as it provides a clear understanding of the condition and allows for appropriate planning and intervention. The final phase, **accessing services**, occurs post-diagnosis and involves individuals utilizing various healthcare and support services designed to maintain and improve their quality of life. These services can include medical treatments, support groups, and community resources to provide care and assistance to the individual and their caregivers (Giebel, 2015). South Asian communities have unique experiences within each phase.

2.5 Main Challenges in Dementia Care for South Asian Communities

2.5.1 Cultural and Linguistic Barriers

Recognizing Symptoms

A lack of understanding and knowledge about dementia poses significant barriers for South Asian communities (Cheston et al., 2024). Limited proficiency in English and the absence of dementia-specific terms in South Asian languages exacerbate these challenges. Cultural and religious beliefs often shape perceptions of dementia, with symptoms such as memory loss being attributed to natural aging, mental health issues, or even spiritual causes (Philip et al., 2024). This perception delays diagnosis and fosters stigma, leading families to conceal symptoms rather

than seek help (Hossain et al., 2020; McCleary et al., 2012). Local terminologies, such as “sathiyana” in North Indian dialects or “chinnan” in Malayalam, further normalize dementia symptoms, framing them as typical signs of aging (Cohen, 1998; Iype et al., 2006).

Across South Asia, dementia is frequently seen as part of the normal aging process, with studies highlighting similar beliefs in countries like India, Pakistan, and Sri Lanka (Islam & Akter, 2023). This cultural framing delays the acknowledgment of cognitive decline as a medical condition, failing to seek timely intervention. Families often identify dementia symptoms only during a crisis, such as a hospital visit or significant behavioural changes, further delaying treatment and support. Religious and social norms may also lead families to attribute dementia to past wrongdoing or life events, reflecting cultural influences on how the condition is understood and addressed (Sagbakken et al., 2020; McCleary et al., 2012)

Receiving a Diagnosis

Obtaining a dementia diagnosis is fraught with challenges, including language barriers and reliance on family members as translators, which can result in miscommunications and incomplete assessments (McCleary et al., 2012). The stigma surrounding dementia further complicates the process, deterring families from pursuing a formal diagnosis until symptoms become severe or disruptive (McDermott et al., 2024; Mukadam et al., 2011). Families often resist the notion of incurability, seeking multiple medical opinions or alternative remedies to find a cure (Brijnath, 2022). Individuals have also attributed memory problems not only to aging but also to loneliness, stress, and spiritual explanations, such as past-life consequences or divine will (Mukadam et al., 2015).

Cultural expectations also influence the diagnostic journey. Many South Asian families view initial symptoms as part of natural aging, delaying recognition and professional consultation. Diagnostic tools and services often need more cultural sensitivity, further impeding the process. Cognitive assessments used in dementia diagnosis may underestimate the abilities of individuals from minority ethnic groups, leading to potential over- or underdiagnosis. The study by Nielsen et al. (2011) found that dementia tends to be underdiagnosed among ethnic minorities aged 60 and older, while overdiagnosis is more common among those under 60, suggesting that age, ethnicity, and potential cultural or systemic factors within healthcare settings may influence diagnostic disparities. Care partners frequently report frustration with hospital staff and medical systems that need to address their unique cultural and linguistic needs (Mukadam et al., 2011).

Accessing Services

Socio-cultural factors create additional barriers to accessing dementia-related services. South Asian cultural norms prioritize family caregiving, particularly by women, discouraging the use of external support services. This expectation, coupled with traditional gender roles, places significant emotional and physical stress on care partners, particularly daughters-in-law, who often juggle caregiving responsibilities with full-time jobs (Hossain et al., 2020).

The stigma surrounding dementia and seeking external help further complicates service utilization. Families express concerns about privacy, confidentiality, and the perception of failure to fulfill familial duties when engaging with outside care providers (Hansson et al., 2022). The limited availability of culturally sensitive resources, including information in South Asian languages, amplifies these challenges. Care partners also cite dissatisfaction with existing services, including hospitals' inability to meet the needs of individuals with dementia and perceived discrimination from service providers (Jutlla, 2011).

In addition, many families lack awareness of respite care and other support options, viewing them as invasive or shameful. This reluctance to engage with services often leads to burnout among care partners and unmet needs for individuals living with dementia. Addressing these barriers requires culturally tailored interventions, such as language-appropriate materials, culturally competent healthcare providers, and educational programs to reduce stigma and improve access to services.

2.5.2 Stigma and Its Impact on Dementia Care

Recognizing Symptoms

Stigma plays a critical role in how dementia is perceived and addressed in South Asian communities. Cultural beliefs frequently normalize cognitive decline as part of aging, delaying recognizing dementia symptoms (Wijesinghe & Mukaetova-Ladinska, 2024; Philip et al., 2024). This normalization is reinforced by terms like “sathiyana” and similar expressions in other South Asian languages, which frame dementia as a natural phase of aging rather than a medical condition requiring intervention (Cohen, 1998; Iype et al., 2006). The stigma associated with mental health issues often leads families to conceal symptoms, further delaying help-seeking and awareness within communities (Sun et al., 2019).

Receiving a Diagnosis

The fear of stigma also significantly hinders the pursuit of a diagnosis. Families often hesitate to consult healthcare professionals due to concerns about shame and judgment from their communities. Misattributions of symptoms to spiritual or moral failings are common, reflecting the influence of religious and cultural beliefs (Parveen et al., 2016; McCleary et al., 2012). Language barriers compound these issues, as reliance on untrained family members for

translation can result in miscommunication and inadequate assessments (Brijnath et al., 2022; Singh & Soble, 2021). Consequently, diagnoses are often delayed until symptoms become disruptive, hindering timely intervention and treatment.

Accessing Services

Stigma continues to affect service utilization, as families fear judgment for seeking external help, such as respite care or home-based services. Concerns about privacy, community perceptions, and the inadequacy of culturally sensitive services discourage families from accessing available resources (Jutlla, 2011). For many South Asian care partners, traditional caregiving roles and the expectation of keeping relatives at home intensify the challenges of managing dementia without external support.

Improving dementia care for South Asian communities requires addressing stigma at multiple levels. Culturally tailored education, increased availability of language-specific resources, and integration of cultural values into healthcare practices can help reduce stigma and improve access to services. By fostering open dialogue and providing culturally competent care, healthcare systems can better support individuals with dementia and their families, mitigating the impact of stigma and ensuring equitable care.

2.6 Other Challenges

2.6.1 The Communication of Diagnosis

Effective communication with patients and their care partners is critical to diagnosing dementia. The process often involves physical and psychiatric evaluations, behavioural observations, assessments of daily living activities, cognitive tests, blood samples, and brain scans (Neilson et al., 2011). However, despite these essential measures, healthcare professionals'

understanding of dementia and diagnostic procedures varies significantly across and within countries, leading to widespread underdiagnosis, particularly in the early stages (Prince et al., 2011; Eichler et al., 2014). Alarming, in high-income countries, only 50% of individuals with dementia receive a formal diagnosis, while in low- and middle-income countries, this figure drops to less than 10% (Prince et al., 2016).

Among ethno-racial communities, specific barriers hinder effective communication and diagnosis. These include the lack of culturally sensitive diagnostic tools, difficulties in securing language-appropriate interpreters, and cultural beliefs that normalize cognitive decline as a natural part of aging (Chejor et al., 2022). Additionally, patients may feel dismissed during medical consultations, perceiving that their symptoms are attributed to natural aging due to the 'brief and transactional nature of interactions' (Arora et al., 2018). This often results in reluctance to seek help or disengagement from healthcare services altogether (Arora et al., 2018).

Physicians play a crucial role in facilitating these conversations, yet research highlights that primary care providers often struggle with effectively communicating dementia diagnoses to patients from diverse cultural backgrounds. Language barriers and limited cultural competence frequently make clinicians feel hesitant and less confident in their diagnostic capabilities (Giezendanner et al., 2018; Tillmann et al., 2019). Navigating these conversations often involves interpreters or family members, further complicating the dynamics of trust and rapport between clinicians and patients (Sagbakken et al., 2018).

2.6.2 Physicians' Difficulty in Identifying Dementia

Diagnosing dementia presents unique challenges for physicians, mainly when working with ethno-racial communities. One significant hurdle is the need for more culturally sensitive

assessment tools, which can lead to both underdiagnosis and overdiagnosis (Neilson et al., 2011). The reliance on family members as interpreters, rather than trained professionals, can further distort diagnostic outcomes, as family members may omit or reframe information due to cultural biases or misunderstandings (Neilson et al., 2011; Flores, 2005). Even when professional interpreters are used, differences in phrasing or interpreting responses may compromise the validity of cognitive assessments (Plejert et al., 2015).

In South Asian communities, the diagnostic process is further complicated by cultural beliefs, language barriers, and family dynamics (Hossain et al., 2020). Cultural perceptions often regard cognitive impairments as a natural part of the aging process, thereby delaying recognition and diagnosis. For instance, terms like "sathiyana" in North Indian dialects exemplify the normalization of cognitive decline as a typical aspect of growing older (Brijnath, 2012).

Language barriers also play a significant role. Many South Asians prefer to communicate in their native languages, often relying on family members to translate during medical visits (Brijnath, 2022). This practice introduces potential inaccuracies and limits open discussions about symptoms and care options. Moreover, the stigma surrounding dementia, often tied to moral or spiritual failings, discourages families from seeking medical assistance, compounding delays in diagnosis (Hossain et al., 2022).

2.6.3 Diagnostic Tools

Screening for dementia is gaining importance for early detection, usually involving cognitive tests. There is a shortage of screening and diagnostic tools tailored explicitly for dementia in ethno-racial older individuals (Shah & MacKenzie, 2007). Research conducted in the United Kingdom found that screening instruments have been translated for some BME

(Black and Minority Ethnic) groups. The Abbreviated Mental Test Score (Qureshi & Hodkinson, 1984) has been translated into several Asian languages for use among South Asians and into English for use among older African Caribbean individuals in the United Kingdom (Rait et al., 2000a; Rait et al., 2000b; Rait et al., 1997). Similarly, the Mini-Mental State Examination (MMSE) (Folstein et al., 1975) has been translated into Gujarati, Bengali, Punjabi, Hindi, and Urdu (Rait et al., 2000a; Lindesay et al., 1997) for South Asians, and English for use in the African Caribbean group (Rait et al., 2000b) in the United Kingdom. There are concerns about the influence of education on MMSE scores, which have implications for individuals with limited formal education or those educated in different systems. As Nielsen et al. (2011) note, such factors may contribute to diagnostic inaccuracies among ethnic minority populations.

While translated assessment tools can support the diagnostic procedure for dementia, they may overlook cultural subtleties, potentially missing nuances that are crucial for an accurate evaluation (Oommen et al., 2009). Additionally, when relying solely on interpreters to deliver translated tools, there is a risk that clinicians may not directly interpret patients' responses, thus hindering their ability to grasp the extent of the evaluation fully (Oommen et al., 2009). The dependency on interpreters introduces a layer of interpretation that could distort or dilute the patient's intended meaning, impacting the overall quality and reliability of the assessment process. (Oommen et al., 2009).

Healthcare providers must prioritize culturally and linguistically sensitive approaches to address this issue. This may involve employing staff who speak the language of the individual with dementia or offering training on cultural sensitivity and communication strategies. A

supportive and inclusive environment that recognizes and accommodates diverse linguistic and cultural backgrounds is essential for person-centred care.

2.6.5 Long Term Care Homes

As dementia progresses, some individuals living with dementia may find it increasingly difficult to remain at home, leading to a transition into long-term care homes where they can receive the support they need (Canadian Institute for Health Information, 2024). For people under the age of 80 living with dementia, about one in three reside in long-term care homes, and this number increases to 42% for those aged 80 and older (Canadian Institute for Health Information, 2024). In South Asian communities, the transition to long-term care homes is often viewed with reluctance due to deeply ingrained cultural values emphasizing filial piety and the moral obligation to care for aging relatives at home (Arya & Tong, 2023)

As a result, there is a strong preference to keep elderly relatives at home, even in the face of severe cognitive, functional, and behavioural changes associated with dementia. This preference is supported by the belief that institutional care fails to meet the cultural and emotional needs of elderly family members and that placing them in long-term care facilities is a failure to fulfill familial duties (Arya & Tong, 2023). The stigma associated with dementia and the fear of community judgment further discourages families from seeking long-term residential care (Jutlla, 2011).

In Western countries, the caregiving journey often leads to a transition to a long-term care home due to social, financial, and emotional pressures exacerbating cognitive, functional, and behavioural challenges (Luppa et al., 2008; Banerjee et al., 2003). International policy movements advocate for dementia care primarily at home, supported by unpaid family care

partners and supplemented by governmental, non-governmental and paid caregiver assistance (Luppa et al., 2008). Strategies such as short-term respite care, day-care programs, and home care aides aim to alleviate the caregiving burden and enhance the well-being of individuals living with dementia.

However, communication barriers frequently arise in long-term care homes, particularly when residents require assistance with English. Criticisms include insensitivity toward accommodating language differences and a shortage of staff proficient in residents' languages, which impacts practical assessments of needs, mental capacity, and dementia care (Daker-White et al., 2002; Bowes et al., 2012; Manthorpe et al., 2010).

Research highlights the significance of culturally appropriate meals in long-term care homes. Preferences for traditional foods among care home residents underscore the importance of accommodating diverse culinary needs (Syed & Mann, 2020). However, inflexible mealtimes and menus dominated by "European" dishes often fail to address these needs, while instances of racism among staff compound cultural challenges (Warburton et al., 2009; Manthorpe et al., 2010).

Personal hygiene practices, such as bathing and toileting, are culturally defined and vary among individuals. Respecting specific religious rituals and cultural norms in care home settings is crucial. However, the lack of regular interaction with individuals from similar ethnic backgrounds can lead to isolation and loneliness (Daker-White et al., 2002; Bowes & Wilkinson, 2003). Racism and discrimination experienced by older individuals before entering care homes may persist post-admission, particularly in facilities with limited ethno-racial populations, contributing to mistreatment and reduced quality of life (Daker-White et al., 2002).

Limited research exists regarding family care partners' attitudes towards care home services for individuals with dementia in South Asian communities. Concerns about cultural suitability, language barriers, access to culturally appropriate food, and respect for cultural and religious beliefs contribute to hesitancy in seeking residential care (Jutlla, 2011; Adamson & Donovan, 2005). The discomfort with intimate care provided by care partners of the opposite sex further poses a barrier. Understanding and addressing these concerns is essential for improving the acceptance and effectiveness of long-term care services for South Asian individuals with dementia.

2.6.6 Discrimination and Racism

Social exclusion of South Asians as service users can be attributed, in part, to racism, fostering mistrust toward health and social care services, as highlighted by research from the United Kingdom (Jutlla, 2011; Patel et al., 1998). Additionally, Blakemore and Boneham (1994, p. 78) noted that "Asian people's social lives and priorities are often seen as 'too different' from majority norms, incomprehensible, and insufficiently adapted." Research involving Sikh care partners revealed that experiences of hostility and white racism upon arrival in the United Kingdom persisted over time, shaping their perceptions of health and social care services and linking them to past encounters with racism and exclusion (Jutlla, 2011). Consequently, migrant Sikh care partners drew upon the self-efficacy and resilience they had developed through their migration experiences to cope with and manage caregiving responsibilities.

For individuals who have faced discrimination and whose opportunities in life may have been hindered by structural inequalities like higher rates of poverty, unemployment, or poorer health, the development of a stigmatizing illness or condition could exacerbate these

disadvantages even further. Specifically, the shame associated with having or being associated with someone who has a stigmatizing disease (Liu et al., 2008; La Fontaine et al., 2007; Mackenzie, 2006) may deter individuals from seeking support within their communities, leading to significant isolation for people with dementia and their families. In cultures where arranged marriages are prevalent, individuals may refrain from disclosing that they have a relative with dementia, fearing it could diminish family members' prospects of securing a favourable marriage (Liu et al., 2008; Bowes & Wilkinson, 2002). Liu et al. (2008) also question whether stigma poses an additional risk for people with dementia in cultures where they are perceived as 'child-like,' as their autonomy and decision-making opportunities may be more likely to be undermined.

In conclusion, the communication of dementia diagnoses in South Asian communities presents significant challenges, often influenced by cultural norms that prioritize family unity and hope over individual awareness (Mukadam et al., 2011) Physicians typically communicate diagnoses to family members rather than directly to patients, aiming to shield them from distress. This practice aligns with broader cultural tendencies in South Asia, where families and doctors often withhold information about chronic or terminal illnesses to preserve the patient's optimism and hope. The chronic and degenerative nature of Alzheimer's disease further complicates communication, as medical interventions are limited, and families may react with disappointment, seeking second opinions and exploring alternative perspectives.

Identifying dementia during physician consultations is also fraught with difficulties. Low awareness, stigma, and different manifestations of symptoms in ethno-racial older individuals compared to their Caucasian counterparts contribute to the challenge. Additionally, there is a lack of comprehensive data on the clinical presentation of dementia in ethno-racial populations,

and individual physicians may have limited exposure to these groups. Language barriers, clinician bias, and family members withholding information further complicate the diagnostic process.

The shortage of culturally tailored diagnostic tools exacerbates these issues. While translated assessment tools exist, they may need to include cultural nuances, and reliance on interpreters can distort the patient's responses. Healthcare providers must prioritize cultural and linguistic competence, employing staff who speak the patient's language and offering training on cultural sensitivity.

Moreover, the uptake of dementia-related services is hindered by perceptions of dementia as a natural part of aging, leading to delayed support seeking. Negative connotations of dementia-related terms and the stigma associated with the condition contribute to this delay. Strategies to address this include campaigns to change negative terminology and straightforward explanations of dementia in relevant languages.

For South Asian families, the transition to long-term care homes is often viewed with reluctance due to cultural values emphasizing filial piety and caregiving at home. Communication barriers, culturally inappropriate meals, and personal hygiene practices in care homes further discourage their use. Concerns about cultural suitability, language barriers, and respect for cultural and religious beliefs add to the hesitancy.

In end-of-life and palliative care, limited awareness and conflicts between cultural traditions and care principles contribute to underutilization. Discrimination and racism experienced by ethno-racial individuals exacerbate these challenges, leading to mistrust towards

health and social care services. Addressing these issues requires culturally sensitive approaches, better communication, and increased awareness and education about dementia and available services.

2.7 Main Strengths

2.7.1 Cultural and Community Support

i) Recognizing Symptoms

South Asian communities demonstrate significant strengths in addressing dementia through cultural and community support systems, which can be harnessed effectively with the correct resources and services, such as increased awareness of the disease and community-specific resources. The communal nature of South Asian societies facilitates close-knit family structures, which can be advantageous in recognizing early signs of dementia. These communities often prioritize family involvement and care for the elderly, fostering an environment where behavioural and cognitive function changes can be more readily noticed. This familial vigilance helps bridge gaps in formal healthcare knowledge, as family members can support each other in understanding and addressing symptoms (McCleary et al., 2012; Seabrooke & Milne, 2004).

Cultural beliefs and practices also play a role in supporting dementia care. For instance, the concept of "sathiyana" or "gone sixtyish" in North Indian dialects (Cohen, 1998), while rooted in cultural interpretations of aging, can promote early recognition of cognitive changes. Similar expressions in other regional languages, like "chinnan" in Malayalam (Iype et al., 2006) and "nerva frakese" in Konkani (Patel & Prince, 2001), provide culturally relevant understanding that facilitates community understanding of dementia-related symptoms. These cultural

constructs, although varied, share common ground in recognizing and respecting the cognitive changes associated with aging.

Additionally, religious practices and community events provide platforms for social interaction, enabling families to observe and discuss health changes in a supportive environment. Religious leaders and community elders often play pivotal roles in raising awareness about dementia and encouraging families to seek medical advice when necessary. This community-centric approach facilitates early identification and intervention, thereby enhancing the overall care process.

Leveraging these inherent strengths and providing appropriate resources and services tailored to the community's needs, such as awareness programs and culturally specific support resources, can significantly improve the South Asian community's capacity to manage dementia.

ii) Receiving a Diagnosis

Community support significantly impacts the process of receiving a dementia diagnosis within South Asian communities. Family members often play a crucial role in seeking medical advice and facilitating communication with healthcare providers. This collective approach enables more effective navigation of the healthcare system, despite language barriers and other challenges (McCleary et al., 2012). Providing these families with the right resources and services, such as awareness programs and community-specific support, can harness their strengths to improve the diagnostic process.

The emphasis on family decision-making processes ensures that individuals with dementia receive comprehensive care, taking into account both medical and cultural perspectives. Family members often accompany their older relatives to medical appointments,

assist with interpreting medical information, and provide emotional support throughout the diagnostic process (Brijnath, 2022). This collaborative effort strengthens the overall care experience and helps mitigate the impact of linguistic and cultural barriers. Providing culturally humble healthcare services and interpreter support can further enhance this process.

Additionally, while challenging, South Asian families' resistance to incurability reflects a deeply rooted sense of duty and hope. This drive often leads families to seek multiple medical opinions and explore various treatment options, demonstrating resilience and a proactive approach to caregiving (Brijnath, 2022). This persistence can lead to a more comprehensive diagnostic process, ensuring individuals receive thorough evaluations and diverse perspectives on their condition. Supporting these efforts with clear information about dementia and available treatments can improve outcomes.

Furthermore, the role of community-based organizations and support networks must be considered. These entities often provide critical resources and advocacy, guiding families through the diagnostic journey and connecting them with healthcare professionals who understand their cultural context. This support enhances the diagnostic experience and promotes timely and accurate diagnoses. Strengthening these community organizations and integrating their services with formal healthcare systems can significantly improve the process of receiving a dementia diagnosis for South Asian families.

iii) Accessing Services

The preference for home-based care within South Asian communities highlights the robust cultural and familial support systems. Providing these communities with the correct

resources and services, such as awareness programs and culturally specific support, can harness their strengths to improve access to dementia care services.

Despite their significant challenges, these care partners exhibit remarkable resilience and commitment to their loved ones (Hossain et al., 2020). The cultural expectation of caring for older adults within the family unit fosters a supportive environment where the collective effort of Extended family members can help alleviate the caregiving burden. Offering support and resources tailored to these care partners' unique needs can amplify their strengths.

Moreover, community organizations and support groups within South Asian communities are vital in enhancing access to services. These groups often provide culturally tailored resources, support networks, and advocacy, helping families navigate the complexities of dementia care (Jutlla, 2011). This communal approach ensures that care partners and individuals with dementia receive the support they need, reinforcing the strengths of cultural and community support systems in managing dementia care effectively. Supporting these organizations can further enhance their impact.

Additionally, South Asian communities often have informal support networks that extend beyond immediate family members. Friends, neighbours, and community members frequently offer assistance through respite care, emotional support, or sharing caregiving responsibilities. This extended support network helps distribute the caregiving load, providing care partners with much-needed breaks and enhancing the overall care for individuals with dementia. Recognizing and integrating these informal networks into formal support systems can improve service access and caregiving experiences.

For example, culturally sensitive respite care services can enable primary care partners to take breaks while ensuring their loved ones are cared for in a manner that respects their cultural and religious practices. Community support groups can provide a platform for care partners to share their experiences, challenges, and solutions with others in similar situations, facilitated by trained professionals. Utilizing technology to provide virtual support and resources, such as online support groups and telehealth services, can also be beneficial.

In summary, the strengths of South Asian communities in dementia care are deeply rooted in their cultural values, communal support systems, and proactive approach to caregiving. These strengths facilitate early recognition of symptoms, comprehensive diagnostic processes, and enhanced access to necessary services, ensuring that individuals with dementia receive the care and support they need within a culturally appropriate framework. By leveraging these strengths with the right resources and services, the overall quality of dementia care in South Asian communities can be significantly improved.

2.8 Conclusion

This chapter has explored the complexities of dementia care, with a focus on the unique experiences of South Asian communities. The review highlighted key challenges faced by individuals living with dementia and their care partners, including barriers in recognizing symptoms, obtaining a diagnosis, and accessing culturally appropriate services. Cultural and linguistic barriers, stigma, and systemic inadequacies in healthcare provision exacerbate these challenges.

Cultural beliefs that normalize cognitive decline as part of aging often delay symptom recognition in South Asian communities. Combined with stigma and limited awareness of

dementia, families are frequently reluctant to seek medical attention. The diagnostic process is further complicated by language barriers, reliance on family members as interpreters, and a lack of culturally sensitive diagnostic tools. These issues, alongside the systemic challenges of accessing dementia services, such as the limited availability of culturally appropriate resources and services in multiple languages, hinder timely care and support.

Despite these challenges, South Asian communities also demonstrate significant strengths. Close-knit family structures, religious and cultural practices, and strong community networks provide a foundation for caregiving. Families are often vigilant about changes in behaviour and cognitive function, facilitating the early recognition of symptoms. Community-based organizations, religious leaders, and informal support networks provide emotional and practical support. These cultural and communal strengths reflect the resilience and resourcefulness of South Asian families in addressing dementia care within their cultural frameworks.

This review underscores the importance of addressing the unique needs of South Asian Canadians living with dementia and their care partners. Understanding these experiences is crucial for developing culturally tailored interventions that address stigma, enhance access to services, and promote more effective communication between families and healthcare providers. By leveraging the strengths of South Asian communities and addressing existing barriers, dementia care can be improved to ensure equitable and culturally appropriate support for individuals and families navigating this complex journey.

In this context, my research seeks to bridge these gaps by understanding the experiences of South Asian Canadians living with dementia and their care partners. By focusing on this population, this work aims to contribute to developing inclusive, person-centred care approaches

that recognize the cultural, linguistic, and systemic factors shaping the dementia care journey.

This understanding is critical to fostering equitable healthcare practices that respect and address the diverse needs of Canada's multicultural population.

2.9 References

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Chapter Three: Methods

3.1 Introduction

This chapter outlines the methodological approach used to explore the lived experiences of South Asian Canadians living with dementia, their care partners, physicians involved in the diagnosis, and employees of community support organizations delivering services.

Understanding these diverse perspectives is essential for identifying the strengths, challenges, gaps, and opportunities in dementia care within South Asian communities. The insights gained from this study will aim to inform the development of culturally sensitive healthcare services and support systems tailored to meet the unique needs of this demographic.

3.2 Objectives

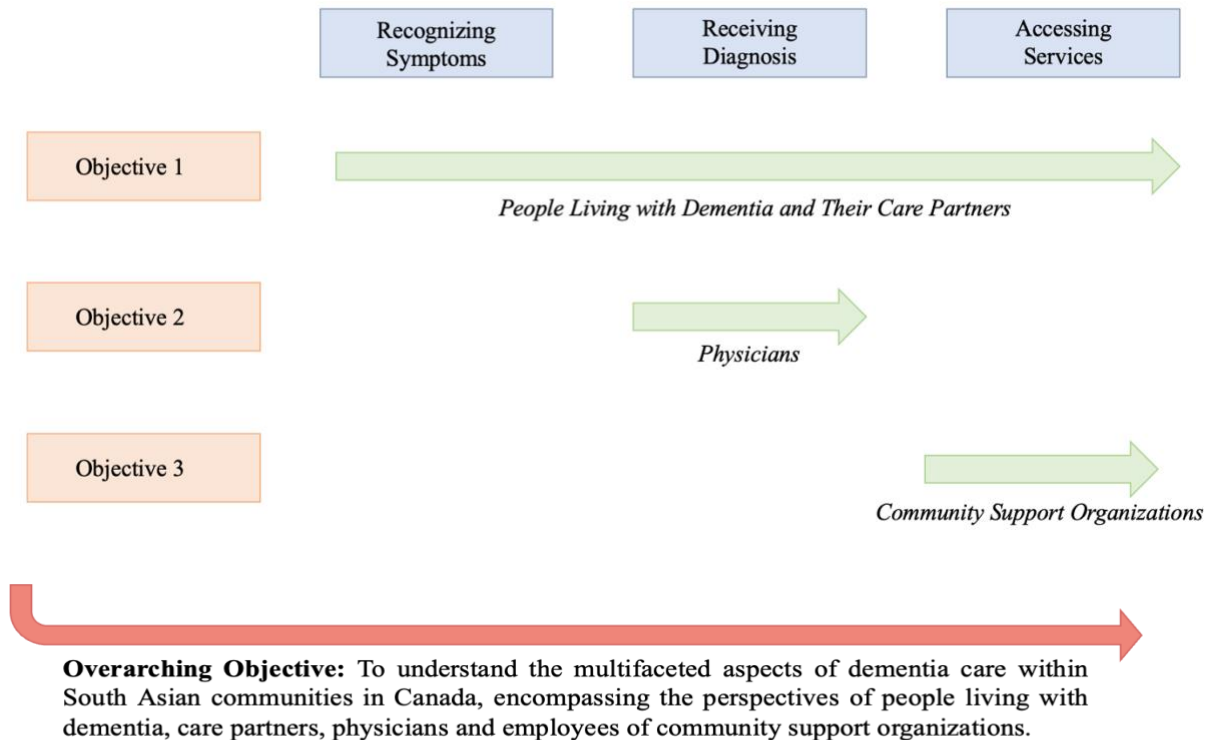
The overall goal is to understand the experiences of people living with dementia and their care partners, physicians and employees of community support organizations and identify strengths, challenges, gaps, and opportunities in dementia care within South Asian communities, aiming to inform and enhance culturally sensitive healthcare services, support systems, and strategies that address this demographic's unique needs and perspectives. The following three objectives (Figure 1) support the overarching goal:

Objective 1: To understand the experiences of South Asian Canadians living with dementia and their care partners through the stages of recognizing symptoms, receiving a diagnosis, and accessing services.

Objective 2: To understand physicians' experiences during the dementia diagnosis process with South Asian communities.

Objective 3: To understand the experiences, perspectives, and insights of employees of community support organizations during service delivery to South Asian communities.

Figure 1: Objectives of the study based on the three stages of dementia care.



3.3 Methodology

This research project used an interpretive phenomenological approach. This approach is well-suited to understanding the participants' subjective experiences and perspectives about their experiences with dementia. The interpretive process acknowledges the researcher's role in the study and recognizes that reality and knowledge are constructed through interactions and interpretations within the research context.

Interpretive phenomenology, also known as hermeneutic or existential phenomenology, came from Martin Heidegger's influence, tracing back to his work under Husserl (Frechette et al., 2020). This approach prioritizes interpreting and comprehending phenomena over merely describing them (Beck, 2013). Scholars within interpretive phenomenology acknowledge the inherent contextual nature of phenomena, which are shaped by historical, cultural, and social

factors (Beck, 2013). They acknowledge the collaborative nature of meaning-making between researchers and participants (Frechette et al., 2020). The primary goal of interpretive phenomenology is to unveil the underlying significance and ramifications of the phenomena by interpreting participants' narratives and the researcher's introspective engagement (Frechette et al., 2020). With the interpretive process, the researcher acknowledges that they are part of the research, interpret data, and cannot be separated from the study (O’Gorman & MacIntosh, 2015). Reality and knowledge are not objective, but rather are constructed by people within their environment (O’Gorman & MacIntosh, 2015).

3.3.1 Epistemological Positioning

Reflecting on one's epistemological stance before embarking on a research project is essential. Epistemology is the theory of knowledge and how it is gathered (Gray, 2014). One's epistemological perspective will influence how the study unfolds. Situating oneself before the onset will help guide the chosen methodology and the data analysis investigation.

The epistemology underlying interpretive phenomenology is rooted in constructivism. Constructivism emphasizes the active construction of knowledge by individuals through their subjective experiences, interpretations, and interactions with the world (Crotty, 1998). In interpretive phenomenology, knowledge is seen as a product of the interpretive process, where researchers aim to understand the meanings and essences of participants' lived experiences.

According to Smith et al. (2009), interpretive phenomenology aligns with constructivist epistemology. It recognizes that knowledge is not an objective truth waiting to be discovered. Instead, individuals construct knowledge through subjective interpretations and interactions with

the world. Interpretive phenomenology emphasizes the importance of understanding individuals' subjective perspectives and the meanings they attribute to their experiences.

Van Manen (2016) further emphasizes the constructivist nature of interpretive phenomenology, highlighting that knowledge is not pre-existing but emerges through the hermeneutic process of interpretation. Researchers engaging in interpretive phenomenology seek to uncover the meanings and essences that participants attribute to their experiences, recognizing that multiple interpretations may coexist.

This constructivist epistemology is closely linked to reflexivity, where researchers acknowledge their subjectivity and preconceptions and actively reflect on their role in the research process (Finlay, 2012). By recognizing their biases and assumptions, researchers can gain a deeper understanding of how their interpretations influence the construction of knowledge.

In summary, the epistemology of interpretive phenomenology is grounded in constructivism, which emphasizes the active construction of knowledge through subjective experiences, interpretations, and interactions with the world. By adopting a constructivist stance, interpretive phenomenology acknowledges the significance of understanding individuals' subjective perspectives in shaping their knowledge about their experiences.

3.3.2 Ontological Positioning

Ontology is the philosophical study of being. It refers to the view of reality and to what extent it exists 'out there,' to be captured through research (Moon & Blackman, 2017). The ontology of interpretive phenomenology is rooted in the belief that reality is socially constructed and subjective, emphasizing the importance of understanding individuals' lived experiences

within their unique contexts. As Smith et al. (2009) assert, interpretive phenomenology acknowledges the multiple realities that emerge through human interactions and interpretations, highlighting the inherently subjective nature of phenomena. This ontology suggests that no universal truths or objective realities are independent of human consciousness; individuals continually shape and interpret reality within their sociocultural environments.

Furthermore, interpretive phenomenology draws on the hermeneutic tradition, which emphasizes the interpretive nature of human understanding. According to Van Manen (2014), this approach recognizes that individuals actively make sense of their experiences through interpretation and reflection. Thus, interpretive phenomenology's ontology emphasizes the dynamic interplay between the researcher and the researched, as both contribute to the co-construction of meaning.

As a researcher from the South Asian community, my perspective on ontology has influenced my comprehension of reality and knowledge. In this study, I embraced a social constructionist viewpoint, positing that reality is socially shaped by language, culture, and interpersonal dynamics. Therefore, I interpret the experiences of South Asian Canadians living with dementia and their care partners, physicians and employees of community support organizations as phenomena constructed within social and cultural contexts. The ontological standpoint I have adhered to in this thesis asserts that external reality is nonexistent. Instead, reality emerges through the interplay between individuals' inner worlds, beliefs, understandings, and the external social environment they navigate.

In summary, the ontology of interpretive phenomenology posits that reality is subjective, socially constructed, and continually interpreted by individuals within their lived contexts. Interpretive phenomenology is the ideal methodology for this research, as it allows for an

understanding of the subjective experiences of South Asian Canadians living with dementia and their care partners. Rooted in constructivism, it recognizes that knowledge is actively constructed through personal experiences and interactions. Additionally, the researcher's reflexivity and reflective engagement with the data ensure that the findings are grounded in the participants' lived experiences.

3.3.3 Positionality Statement

As a 30-year-old South Asian woman born in Canada and raised both in Canada and India, my personal and cultural background significantly influences my research on the experiences of South Asian Canadians living with dementia and their care partners. Additionally, being familiar with the challenges faced by my own family, where both of my parents are care partners for my grandmother, who lives with dementia, further shapes my perspective. My position as a researcher is rooted in understanding the intricate dynamics within South Asian families and the unique cultural considerations that influence the lived experiences of individuals living with dementia. As a PhD candidate in Public Health specializing in aging, health, and well-being, my academic training equips me with critical research skills, theoretical grounding, and an understanding of broader health systems and social determinants that intersect with individual lived experiences. This dual perspective as both an insider to the community and a researcher enables me to approach the research with empathy, cultural insight, and analytical rigour.

Additionally, when conducting research within ethno-racial communities, it is essential to adopt a reflexive approach that extends beyond merely acknowledging one's positionality and actively reflecting on the constructed narratives. It is essential not only to focus on the deficits or challenges within these communities but also to recognize and celebrate their strengths. A

strengths-based approach deliberately centers resilience, cultural knowledge, and agency, countering deficit discourses that often dominate narratives about marginalized populations (Fogarty et al., 2018). This perspective aligns with approaches used in both social work and community-based psychological research, which emphasize the importance of engaging with communities as resourceful and capable rather than as passive recipients of intervention (Silverman et al., 2023). Strengths-based research emphasizes community assets, values lived experiences and seeks to build relationships founded on trust and reciprocity (Hamby, 2022). By embracing a strengths-based lens, researchers can ensure that the voices and experiences of these communities are accurately represented, fostering empowerment rather than reinforcing stereotypes or marginalization.

Therefore, it is crucial to let their stories, whether highlighting strengths or addressing challenges, guide the narrative without perpetuating a deficit-based perspective. By embracing a strengths-based approach, researchers can ensure that the voices and experiences of these communities are accurately represented, fostering empowerment rather than reinforcing stereotypes or marginalization.

In conclusion, as a researcher of South Asian descent immersed in Western culture, I recognize the inherent biases that shape my understanding of the experiences of individuals living with dementia within South Asian communities. Growing up in a Western context has undoubtedly influenced my perspectives, values, and assumptions, potentially affecting how I interpret and engage with the participants' narratives in my study. Moreover, as an educated woman of colour, I acknowledge my privilege and social standing within Western society, which may further influence my perceptions and interactions with research participants and their perceptions of me. I actively reflect on my positionality and how my background may intersect

with the experiences of those I seek to understand. I must remain vigilant about these biases and privileges to approach my research with humility, sensitivity, and openness.

3.4 Establishing Connections with the Community

Creating strong connections within the community is crucial when conducting research and advocating for dementia awareness and support, especially within South Asian communities where cultural nuances greatly influence perceptions and experiences related to the condition. This dual effort requires a delicate balance of raising awareness about dementia while respecting and addressing the cultural, linguistic, and social factors that shape these communities' understanding of the disease.

In my work, I have emphasized the importance of building trust and relationships within the community. I have gained valuable insights into their needs and concerns by actively engaging with community members. This understanding underscores the importance of cultivating meaningful connections as a foundation for research and advocacy efforts.

Working with South Asian communities on the sensitive topic of dementia necessitates a multifaceted approach. This includes collaborating with key organizations, practicing cultural humility, and delivering targeted presentations to care partner groups. These strategies enhance awareness and foster dialogue and understanding, cultivating a supportive environment where individuals feel empowered to seek help and support.

Ultimately, establishing connections within the community is more than just a strategic approach—it is a fundamental aspect of creating meaningful change (Han et al., 2021). By building trust and relationships, we can bridge gaps, reduce stigma, and ensure that support

services are accessible and tailored to the diverse needs of South Asian communities living with dementia.

3.4.1 Collaborating with Community Organizations

Partnering with organizations supporting individuals living with dementia and their care partners proved instrumental in recruitment efforts and gaining a deeper understanding of the urgent need for research. By collaborating closely with these organizations, I developed resources, delivered presentations, and established a vital bridge to the community. These connections were established through outreach on my part to explore opportunities for collaboration, as well as through invitations from organizations requesting presentations that were culturally and linguistically inclusive, with a focus on dementia care within South Asian communities.

Engaging with care partners and individuals living with dementia through these partnerships provided invaluable insights into their experiences, challenges, and needs. This firsthand understanding underscored the pressing demand for research initiatives aimed at addressing the complexities of dementia within South Asian communities. These collaborations also established connections for knowledge translation, allowing me to give back to the community by delivering workshops and presentations on various dementia-related topics. This exchange not only enriched the community's understanding of dementia but also ensured that the knowledge shared was both relevant and actionable.

Moreover, these connections facilitated the recruitment of participants for research studies. Building trust and rapport within the community through ongoing collaboration enabled me to effectively communicate the significance of research participation and garner enthusiasm

for involvement. As a result, the research benefited from a diverse pool of participants, ensuring the findings captured the diverse experiences.

In essence, these partnerships not only facilitated community engagement but also served as catalysts for advancing research objectives by illuminating the urgent need for support services tailored to the unique needs of South Asian individuals living with dementia.

3.4.2 Engaging with the Community

To advance dementia awareness and support within South Asian communities, an approach integrating various engagement strategies was employed, aligning with research and advocacy goals. Active participation in community events was a pivotal strategy, offering direct avenues for interaction with community members. These events included presentations on dementia-related topics, such as personal expressions and communication tips, for care partner groups, as well as participation in health fairs, facilitating informal discussions, and disseminating research outcomes. These opportunities emerged through both my own outreach to community organizations to explore collaboration, and through invitations from organizations requesting culturally and linguistically inclusive presentations on dementia care tailored to the needs of South Asian communities.

For instance, at the Health and Wellness Fair organized by Indus Community Support Services, I presented on dementia-related stigma prevalent in South Asian communities. At the same event, I was part of launching a dementia guidebook, which I co-developed with Indus Community Services, explicitly tailored for the community. This engagement provided valuable support and resources to the community, serving as a platform to highlight the research project.

Figure 2: Presentation for the community at the Health and Wellness Fair organized by Indus Community Support



In addition to organizing and participating in in-person engagements, I personally led digital outreach efforts to extend the impact of my work within South Asian communities. I wrote and published articles aimed at addressing common misconceptions about dementia and providing practical guidance for caregivers, such as *"Navigating Dementia Care in the South Asian Community: Overcoming Barriers and Stigma."* I also actively used platforms like LinkedIn to share these articles, promote research findings, and advance advocacy efforts. By taking a hands-on approach to digital engagement, I was able to amplify the reach of my

awareness campaigns, foster community connection, and contribute meaningfully to reshaping the conversation around dementia in South Asian contexts.

3.5 Methods

This section outlines the methods employed in the three studies. This chapter provides detailed information about the methods used. Abbreviated summaries of the methods are provided in the chapters that present the three studies in full (i.e., Chapters 4, 5 and 6). The participants, including eligibility criteria, recruitment strategies, and data collection processes, are unique to each study and presented separately. However, the analysis approach and ethical considerations were the same across all three studies and are described once.

3.5.1 Study 1: South Asian Canadians living with dementia and their care partners.

i) Objective: To understand the experiences of South Asian Canadians living with dementia and their care partners through the stages of recognizing symptoms, receiving a diagnosis, and accessing services.

ii) Setting, Context and Recruitment: I conducted recruitment for the study in Ontario, Alberta, and British Columbia using purposive and snowball sampling techniques. I began by identifying and reaching out to community support organizations that work with South Asian families affected by dementia. I introduced the purpose of the study and explored opportunities for collaboration. Once initial connections were established, I shared recruitment materials and study information with staff members and coordinators, who then distributed this information through their internal networks. These included email newsletters, bulletin boards, and direct referrals to potential participants. I also created electronic flyers (Appendix E) and social media posts, which I shared via my personal and professional networks, including LinkedIn. Flyers for

participant recruitment were developed drawing on my prior experience with community-based projects, where the significance of cultural representation and language accessibility was consistently emphasized. These materials were designed to reflect inclusive imagery and plain language to support engagement and trust-building within South Asian communities. The draft flyers were reviewed and refined in consultation with the supervisory committee to ensure clarity, cultural sensitivity, and alignment with ethical research practices. As part of the engagement strategy, I hosted care partner webinars where I introduced the study and invited attendees to participate.

Additionally, I shared information in person at events such as the Health and Wellness Fair hosted by Indus Community Services. Participants who joined the study were encouraged to refer others in their community who might be interested, facilitating snowball sampling. To ensure linguistic accessibility and cultural inclusivity, I prepared and distributed recruitment materials in Hindi, Punjabi, and English. At every stage of recruitment, I carefully maintained participant privacy and anonymity, following ethical research protocols.

Eligibility Criteria: To be eligible for the study, participants met the following criteria:

- Self-identify as a South Asian Canadian
- 18 years or older
- Living with dementia or caring for someone living with dementia. (Note: a diagnosis of dementia was not required for participation in the study; individuals could self-identify as having dementia.)
- Ability to provide consent or proxy for consent.

iii) Sample:

In phenomenological studies, the emphasis is on understanding the in-depth experiences and perspectives of a small number of participants rather than aiming for a large sample size (Creswell, 2007). Phenomenological research typically involves studying a small group of individuals who have experienced a specific phenomenon of interest (Creswell, 2007). The study aimed to recruit 5-7 people living with dementia and care partners. The study sample consisted of a total of 16 participants: 14 care partners and 2 individuals living with dementia.

v) Data Collection: Data were collected from February 13, 2024, to April 8, 2024, using semi-structured, in-depth interviews with care partners and individuals living with dementia.

Recruitment for the study was conducted in Ontario, Alberta, and British Columbia using purposive and snowball sampling techniques. I began by identifying and reaching out to community support organizations serving South Asian families impacted by dementia. I introduced the purpose of the study and invited them to support recruitment efforts by circulating information through their networks. These organizations agreed to share recruitment flyers via email newsletters, bulletin boards, and direct outreach to individuals who might be interested. Additionally, I created and posted digital flyers on social media platforms, such as LinkedIn, where individuals unaffiliated with the organization also saw the study details and reached out directly to express interest in participating.

When individuals expressed interest either through referrals or after seeing the flyer, I responded by providing them with a detailed information letter outlining the purpose of the study, what participation would involve, ethical considerations, and how their confidentiality would be protected. Participants were given time to review the letter and ask any questions. Informed verbal or written consent was obtained before the start of each interview, in accordance with the approved ethics protocol.

Participants were given the option to choose the interview format that was most comfortable and accessible to them: Zoom videoconferencing, telephone, or in-person (depending on their location and comfort level). Interviews were conducted in Hindi, Punjabi, or English, depending on the participant's preference and my fluency in all three languages, to ensure accessibility and inclusivity. A total of 14 interviews with care partners were conducted: 11 via Zoom, two over the phone, and one in person. Two interviews were conducted with individuals living with dementia: one in person and one via Zoom. Among care partners, 11 interviews were conducted in English, two in Hindi, and one in Punjabi. Both interviews with individuals living with dementia were conducted in Hindi.

Each interview lasted approximately 45 to 60 minutes. The semi-structured interview guide (see Appendix A) was developed based on the research objectives and reviewed by my supervisory committee. The questions focused on understanding participants' awareness of dementia symptoms, the process of obtaining a diagnosis, and their experiences with accessing services post-diagnosis. During the interview, participants were encouraged to speak freely and share their perspectives in detail. At the end of each interview, I collected demographic information, including age, gender, relationship to the person living with dementia (for care partners), and preferred language.

All interviews were audio-recorded with the participant's consent. English interviews were transcribed using Otter AI. However, Otter AI and Sonix were not able to accurately capture the audio for Hindi and Punjabi interviews. As a result, I manually transcribed these interviews by listening to the audio recordings, translating them into English, and typing the transcripts myself. All transcripts were anonymized, and pseudonyms were assigned to

participants to protect their identities. The final transcripts were then uploaded to NVivo 14 for data management and analysis.

Table 2: Sample Questions from the Care Partner Interview Guide

Sample Questions- Care Partner Interview Guide
<p><i>Awareness of Early Symptoms:</i></p> <ol style="list-style-type: none"> 1. Could you describe a situation when you first noticed changes in the behaviour or cognitive abilities of your [relative] with dementia? 2. What were the initial signs that made you suspect something was changing? <p><i>Diagnosis Process:</i></p> <ol style="list-style-type: none"> 1. Could you share your experiences with the diagnostic process? <ol style="list-style-type: none"> a. How did your [relative] react to this process? <p><i>Availability and Awareness of Services:</i></p> <p><i>Awareness of Services</i></p> <ol style="list-style-type: none"> 1. Were you initially aware of any dementia-related services in your community when your [relative] was diagnosed, or did you become aware of them as part of your care planning process?

3.5.2 Study 2: Physicians

i) Objective: To understand physicians' experiences during the dementia diagnosis process with South Asian communities.

ii) Recruitment: I carried out recruitment in Ontario, Alberta, and British Columbia with support from community support organizations in each province, including local branches of the Alzheimer's Society. I used purposive and snowball sampling techniques to identify and reach potential participants. To broaden the reach of recruitment efforts, I distributed both physical flyers and electronic materials, including emails and social media posts. I also leveraged my personal networks and those of my graduate supervisor to identify and contact eligible participants. My goal was to recruit physicians, both family doctors and specialists, from South Asian communities as well as other backgrounds to ensure a diversity of perspectives.

Eligibility Criteria: To be eligible for the study, participants met the following criteria:

- Had experience working with South Asian Canadians living with dementia and their care partners, specifically with a dementia diagnosis.
- Were able to provide informed consent to participate in the study.
- Were able to communicate fluently in English.

iii) Sample: Thirteen physicians participated in the study. Phenomenological research typically involves studying a small group of individuals who have experienced a specific phenomenon of interest (Creswell, 2007). The study aimed to recruit 5-7 people physicians.

v) Data Collection: I conducted data collection between February 12, 2024, and April 16, 2024. Recruitment took place in Ontario, Alberta, and British Columbia. To begin, I reached out to community support organizations, including local Alzheimer Societies and culturally specific community health organizations, to explain the purpose of the study and request their support in circulating recruitment materials. I created digital flyers that included information about the research and my contact details. Partner organizations shared these flyers through email newsletters, internal mailing lists, and social media platforms. I also shared the flyers via my professional networks and those of my graduate supervisor. In many cases, interested physicians contacted me directly after seeing the flyer. In other cases, community organizations referred individuals who met the inclusion criteria and had expressed interest in participating.

Once a potential participant expressed interest, I sent them a detailed information letter outlining the purpose of the study, what participation involved, the voluntary nature of participation, and measures in place to protect confidentiality. I allowed each participant to review the letter and ask questions before proceeding. Informed consent was obtained verbally before the start of each interview, in accordance with ethics approval.

I conducted all interviews virtually—twelve via Zoom and one by telephone—based on the participant’s preference and availability. Each interview lasted approximately 30 minutes. I used a semi-structured interview guide (Appendix B), which I developed based on the study objectives and reviewed by my supervisory committee. The interview questions explored physicians’ experiences diagnosing people living with dementia from South Asian communities, including the influence of stigma, cultural and generational factors, and systemic barriers. I also asked about strategies they found effective in navigating the diagnostic process.

All interviews were conducted in English and audio-recorded with the participant's consent. At the end of each interview, I collected basic demographic information such as participant role (e.g., family physician or specialist), years in practice, and practice setting (e.g., urban or rural), to contextualize their responses. I used Otter AI to transcribe the interviews. After transcription, I anonymized all data and assigned pseudonyms to protect participant identities. The finalized transcripts were uploaded into NVivo 14 for data management and thematic analysis.

Table 2: Sample Questions from the Physicians Interview Guide

Sample Questions- Physicians Interview Guide
<p><i>Communication of Diagnosis:</i></p> <ol style="list-style-type: none"> 1. What is your typical approach when communicating a dementia diagnosis to a patient and their family? Could you outline the usual information you share and how you convey it? 2. Was there anything you did differently or needed to consider in conveying the diagnosis because of the patient's background?

3.5.3 Study 3: Community Support Organizations⁵

i) Objective: To understand the experiences, perspectives, and insights of employees of Community support organizations during service delivery to South Asian communities.

ii) Setting, Context, and Recruitment: I conducted recruitment in Ontario, Alberta, and British Columbia, with support from various organizations in each province, including those with which I had previously established connections. I used both physical flyers and electronic media, such as emails and social media posts, to reach a broader audience. I applied purposive and snowball sampling techniques to identify and recruit participants. The individuals I recruited represented a range of community support organizations across the three provinces, all of which provide support services and advocacy for people living with dementia and their care partners.

iii) Sample: Fourteen community support organization employees participated in the study.

iv) Eligibility Criteria: To be eligible for the study, participants met the following criteria:

- Were an employee of a community support organization involved in service delivery, including South Asian communities.
- Were able to provide informed consent to participate in the study.

v) Data Collection: I conducted data collection between March 4, 2024, and April 9, 2024. To recruit participants, I first identified and contacted community support organizations across Ontario, Alberta, and British Columbia that offer services to individuals living with dementia

⁵ In the context of community support services, post-dementia diagnosis involves utilizing available non-medical resources within the local community (Alzheimer's Association, 2021). These services provide physical, mental, and social engagement for individuals with dementia and their care partners. This encompasses activities like art classes, exercise groups, memory cafes, and support groups (Alzheimer's Society, 2021). Community centers and similar establishments offer platforms for social interaction and cognitive stimulation (HealthinAging.org, 2021). The primary aim of accessing these services is to improve the overall well-being and quality of life of individuals with dementia while also providing valuable support for care partners (Alzheimer's Association, 2021).

and their care partners. I contacted these organizations directly via email, introduced the study, and requested their support in circulating recruitment materials. I also shared digital flyers containing study details and my contact information through professional networks and on social media platforms.

Many participants learned about the study through these organizational channels and contacted me directly after seeing the recruitment flyer. Once they expressed interest, I emailed them a detailed information letter explaining the study's purpose, procedures, voluntary nature of participation, and measures for ensuring confidentiality. I gave participants time to review the information and ask any questions they may have. Verbal informed consent was obtained before each interview, as outlined in the approved ethics protocol.

I conducted all interviews virtually using Zoom's videoconferencing platform. I used a semi-structured interview guide (Appendix C), which was informed by the study objectives and reviewed by my supervisory committee. The questions explored participants' experiences as employees of community support organizations in providing services to South Asian individuals living with dementia and their care partners. Participants were encouraged to reflect on challenges, successes, cultural considerations, and strategies used in their service delivery.

All interviews were conducted in English, lasted an average of 30 minutes, and were audio-recorded with the participant's consent. At the end of each interview, I collected basic demographic information, including job title, years of experience, type of organization, and province of practice. I transcribed the audio recordings using Otter AI, then anonymized the transcripts and assigned pseudonyms to each participant. The finalized transcripts were uploaded into NVivo 14 for data organization and thematic analysis.

Interviews were transcribed using Otter AI. The interviews were then anonymized, and pseudonyms were assigned to each participant. The transcripts were uploaded to NVivo 14 for analysis.

Table 3: Sample Questions from the Community Support Organization Employee Interview Guide

Sample Questions- Community Support Organization Employee Interview Guide
<p>IV. Challenges and Adaptations:</p> <p><i>Overcoming Stigma:</i></p> <ol style="list-style-type: none"> 1. Have you faced challenges, such as designing programs recruiting individuals related to the stigma associated with dementia within South Asian communities? How does the [organization] address this challenge? 2. Could you discuss strategies to raise awareness and reduce stigma within the South Asian communities effectively?

3.6 Data Analysis

The data from the three studies were analyzed using reflexive thematic analysis.

Thematic analysis is a qualitative approach widely utilized across various disciplines (Braun & Clarke, 2006; 2012; 2013). Initially lacking clear demarcation, it has evolved into a distinct method (Braun & Clarke, 2019). The thematic analysis aims to identify, analyze, and report themes within qualitative data, systematically organizing and interpreting data to uncover underlying patterns of meaning that address the research question (Braun & Clarke, 2006).

3.6.1 Types of Thematic Analysis

Thematic analysis encompasses various subtypes, each with its own approach and emphasis on different aspects of the analytical process.

- a. Reflexive Thematic Analysis:** This subtype takes an organic approach to analysis, emphasizing the interpretive nature of the research process and the researcher's role in

shaping the analysis outcomes. It falls under Big Q thematic analysis, allowing flexibility and independence from a specific theoretical framework (Braun & Clarke, 2019).

Reflexive thematic analysis prioritizes reflexivity and subjectivity, acknowledging the active role of the researcher in generating themes and interpreting the data.

- b. Codebook Thematic Analysis:** This type utilizes a structured coding process for analysis, providing a systematic approach to identifying and organizing themes within the data. It is classified as medium Q thematic analysis, emphasizing a more structured and predefined coding process (Braun & Clarke, 2019). Codebook thematic analysis involves developing a codebook or coding frame that guides the coding process, ensuring consistency and reliability in theme identification.
- c. Coding Reliability Thematic Analysis:** This subtype ensures the coding process's reliability and accuracy, emphasizing the coding outcomes' consistency and dependability. It is classified as a small q thematic analysis, highlighting the importance of coding reliability in the analysis process (Braun & Clarke, 2019). Coding reliability thematic analysis involves rigorous testing and validation of coding procedures to ensure that themes are accurately derived from the data and can be consistently applied by different coders.

Each type of thematic analysis offers distinct advantages and considerations, catering to different research contexts and objectives. Researchers may choose the most appropriate approach based on the nature of their data, research questions, and theoretical orientation. Regardless of the subtype, thematic analysis remains a versatile and widely used method for uncovering patterns and meanings within qualitative data.

3.6.2 Reflexive Thematic Analysis

Reflexivity is integral to refining thematic analysis methodologies (Braun & Clarke, 2006). Braun and Clarke developed thematic analysis as an inherently reflexive method, emphasizing subjectivity as a resource rather than a hindrance to knowledge production (Braun & Clarke, 2019). This led to "reflexive thematic analysis," highlighting the centrality of researcher subjectivity and reflexivity in the analytic process (Braun & Clarke, 2019).

3.6.3 Reflexive Thematic Analysis and Interpretive Phenomenology

Reflexive thematic analysis serves as a compatible and effective methodological approach within the framework of interpretive phenomenology, offering several key attributes that align with the epistemological and methodological principles of interpretive phenomenology.

- a. Epistemological Flexibility:* Reflexive thematic analysis allows for flexibility in epistemological perspectives, accommodating the interpretive nature of phenomenological research within interpretive phenomenology. Phenomenology values multiple perspectives and interpretations, emphasizing the importance of understanding individuals' lived experiences from diverse viewpoints (Braun & Clarke, 2019).
- b. Independence from Theory:* Unlike other qualitative analysis approaches, reflexive thematic analysis is independent of specific theoretical frameworks, which resonates well with the ethos of interpretive phenomenology. Interpretive phenomenology prioritizes understanding individuals' lived experiences without being constrained by preexisting theories, emphasizing the importance of open-minded inquiry and exploration (Braun & Clarke, 2019).

- c. *Subjectivity Acknowledgment:* Reflexive thematic analysis recognizes and values the researcher's subjectivity in the analysis process. This aligns with interpretive phenomenology, which emphasizes the researcher's role in interpreting and making sense of participants' experiences. In interpretive phenomenology, researchers are encouraged to engage reflexively with their perspectives and biases, recognizing their influence on the interpretation of qualitative data (Braun & Clarke, 2019).
- d. *Flexible Application:* Reflexive thematic analysis's broad applicability across different epistemologies, including essentialist and constructionist paradigms, makes it adaptable to the diverse methodological approaches within interpretive phenomenology. Whether researchers adopt an essentialist stance, seeking to uncover the universal essences of lived experiences, or a constructionist perspective, emphasizing the socially constructed nature of reality, reflexive thematic analysis can accommodate their analytical needs (Braun & Clarke, 2019).
- e. *Iterative Process:* Reflexive thematic analysis's iterative nature allows for ongoing reflection and refinement of themes, mirroring interpretive phenomenology's iterative and reflective nature. In interpretive phenomenology, researchers continually reflect and refine their interpretations, revisiting data and perspectives to deepen their understanding of participants' experiences. Reflexive thematic analysis supports this iterative process, providing a framework for dynamic and responsive analysis (Braun & Clarke, 2019).

In summary, reflexive thematic analysis offers a methodologically sound and flexible approach to conducting qualitative research within the framework of Interpretive Phenomenology. Its compatibility with interpretive phenomenology's epistemological principles

and methodological practices makes it a valuable tool for deeply exploring and understanding individuals' lived experiences.

3.6.4 Rationale for Using Reflexive Thematic Analysis

Reflexive thematic analysis offers a methodological avenue uniquely suited for exploring the multifaceted experiences of South Asian Canadians living with dementia and their care partners and delving into the perspectives of physicians and community support organizations involved in their care. Given the diversity of cultural values, familial dynamics, and societal expectations inherent within South Asian communities, reflexive thematic analysis is invaluable for understanding the complexities of dementia care within this cultural context.

Objective 1: Understanding the Experiences of South Asian Canadians Living with Dementia and Their Care Partners

Within South Asian communities, dementia care is often embedded within intricate familial structures and cultural norms. Reflexive thematic analysis enables researchers to navigate this complexity by immersing themselves in the lived experiences of individuals and families living with dementia. By adopting a reflexive lens, researchers can uncover the nuances of symptom recognition, diagnostic processes, and service utilization within South Asian households. This approach facilitates an exploration of cultural beliefs surrounding aging, mental health, and caregiving roles, shedding light on the intersecting factors that shape the dementia care journey for South Asian Canadians and their care partners.

Objective 2: Understanding Physicians' Experiences during the Dementia Diagnosis Process with South Asian Communities

Diagnosing dementia within South Asian communities requires physicians to navigate linguistic, cultural, and systemic barriers. Reflexive thematic analysis offers a means to elucidate physicians' experiences and challenges in this context. By embracing reflexivity, researchers can delve into physicians' perceptions of cultural competency, communication strategies, and decision-making processes during the diagnostic journey. This approach fosters a deeper understanding of how cultural norms, familial dynamics, and healthcare practices intersect to influence the diagnosis and management of dementia within South Asian populations.

Objective 3: Understanding the Experiences of Employees of Community Support Organizations during Service Delivery to South Asian Communities

Community support organizations are vital in supporting individuals and families living with dementia. Reflexive thematic analysis provides a robust framework for examining employees' experiences within these organizations. By engaging in a reflexive analysis process, researchers can uncover the cultural competencies, organizational challenges, and innovative practices employed in delivering dementia care services to South Asian communities. This approach facilitates the identification of culturally appropriate interventions, resource allocation strategies, and capacity-building initiatives aimed at addressing the unique needs of South Asian Canadians living with dementia and their families.

In summary, reflexive thematic analysis is a robust methodological approach for researching South Asian dementia care. By embracing reflexivity, subjectivity acknowledgment, and interpretive flexibility, researchers can gain profound insights into the lived experiences, healthcare practices, and service delivery dynamics shaping the dementia care landscape within South Asian communities. This comprehensive understanding can inform the development of

culturally responsive interventions and policies aimed at enhancing the quality of care and support for individuals living with dementia within this population.

3.6.5 Steps of Conducting Reflexive Thematic Analysis for South Asian Dementia Research

The following steps were followed for the analysis of all three studies included in this project:

1. **Familiarizing Myself with the Data:** I began the analysis by reading and re-reading the interview transcripts to gain a deeper understanding of the content and context. This initial immersion allowed me to gain a profound knowledge of the participants' experiences, perspectives, and insights. I paid close attention to the cultural, linguistic, and contextual factors shaping the dementia care landscape within South Asian communities. After each interview, I listened to the audio recording and took notes to capture initial impressions, noting timestamps for potential quotes and thought-provoking segments. Once the interviews were transcribed, I reviewed them again for accuracy and familiarity, followed by a third reading during the coding process. I referred to the audio recordings during coding to capture emotions and language use where relevant.
2. **Generating Codes:** I conducted initial coding using NVivo 14, identifying key concepts and ideas within the transcripts. I systematically labelled and categorized data segments based on their meaning and relevance to the research objectives. Throughout this process, I paid close attention to cultural and language nuances, as well as implicit meanings embedded in participants' narratives. After completing a first round of coding, I reviewed the initial codes, collapsed overlapping codes, and renamed others for clarity. I then revisited the coded segments to ensure they accurately reflected the revised code descriptions. The codes were along reviewed with the supervisory committee.

3. **Developing Themes:** I grouped and organized related codes to develop overarching themes that captured patterns and key concepts within the data. Using an iterative process of constant comparison and refinement, I identified themes that reflected the essence of participants' experiences. I looked for recurring patterns, cultural motifs, and contextual insights that illuminated the unique challenges and strengths in South Asian dementia care. I revisited transcripts regularly to check the coherence of themes and to ensure no relevant themes were overlooked. For example, in the first study involving care partners and people living with dementia, I initially identified nine themes. However, through repeated analysis and contextual review, I refined these into four final themes that best captured the depth and relevance of the data.
4. **Reviewing Potential Themes:** I critically reviewed each theme to ensure it was coherent, analytically sound, and aligned with the research objectives. I assessed whether each theme addressed the research questions and offered meaningful insight into the experiences of South Asian Canadians living with dementia, along with the perspectives of their care partners, physicians, and community support staff. When I encountered inconsistencies or discrepancies, I resolved them through further analysis and discussion with my supervisory committee. I also revisited the transcripts and pulled out illustrative quotes to support and enrich the themes.
5. **Defining and Naming Themes:** Once I finalized the themes, I developed clear definitions and descriptive labels that captured the core ideas and context of each theme. I ensured that the naming of themes was consistent and accurately reflected the data. This step helped me organize and present the findings in a coherent, accessible manner,

ensuring that the final analysis meaningfully conveyed participants' experiences and perspectives.

3.7 Enhancing Trustworthiness

Researchers should engage in reflexivity by acknowledging their biases, assumptions, and preconceptions to enhance the credibility of their findings (Braun & Clark, 2019). This process began by writing a positionality statement that acknowledged the researcher's background and assumptions. This process continued via reflection, captured in a journal, during the data collection and analysis. Reflexivity was practiced during various processes, including the examination of feelings and thoughts during the interviews, the evaluation of findings, and the consideration of potential study directions. A detailed description of the research context, participant characteristics, and data collection methods was provided to allow readers to assess the transferability of the findings to other contexts (Nowell et al., 2017). There was transparency about the sample in the study, highlighting their characteristics such as country, language, religion, and cultural identity to present various perspectives within South Asian communities.

3.8 Reflective Journal

A reflexive journal, also known as a reflective journal or research diary, can be a valuable tool. It allows researchers to document their thoughts, reflections, and insights throughout the research process, promoting self-awareness, critical thinking, and reflexivity. In reflexive journaling, researchers can reflect on their biases, assumptions, and preconceptions that may influence the research process and findings. It helps researchers recognize their subjective positionality and how it may shape data collection, interpretation, and analysis (Burns et al., 2022; Finlay & Gough, 2008). Additionally, a reflexive journal allows researchers to document

and reflect on the methodological decisions made throughout the study. It allows researchers to record their rationale for choosing specific research methods, sampling strategies, and analytical approaches, thus enhancing the transparency and trustworthiness of the research (Burns et al., 2022; Finlay & Gough, 2008).

Moreover, reflective journaling helps researchers navigate ethical dilemmas and challenges that may arise during the research process. It encourages researchers to critically examine their actions and decisions critically, ensuring ethical principles such as informed consent, confidentiality, and participant well-being are upheld (Burns et al., 2022; Nowell et al., 2017). Maintaining a reflexive journal enables researchers to monitor their personal growth and learning throughout the research project. It provides an opportunity for self-reflection and professional development, enhancing researchers' understanding of their roles, biases, and assumptions concerning the research topic (Burns et al., 2022; Finlay & Gough, 2003). Lastly, reflexive journaling facilitates researchers' examination of their interactions and dynamics with participants. It helps researchers identify how their presence and actions may influence participant responses and engagement, thus improving the quality of data collection and interpretation (Nowell et al., 2017).

My reflexive journal has been valuable throughout my research journey, capturing various moments of insight and self-reflection. For example, during a lecture on ethno-racial research language, I found myself challenged to reconsider the framing of my thesis. As the speaker delved into the nuanced implications of terminology, I realized that the title "Exploring the experiences..." did not fully encapsulate the depth of understanding I sought to achieve. Inspired by the emphasis on comprehension rather than mere exploration, I swiftly recognized the need to revise the title to "Understanding the Experiences...". This subtle yet significant

change reflected a shift in perspective and signalled a commitment to honouring the richness and complexity of the narratives I sought to uncover.

Furthermore, my interactions with care partners at various events and webinars provided invaluable insights into the lived realities of individuals living with dementia within their communities. During these engagements, I was struck by the pervasive stigma surrounding the condition, which manifested in various ways, from hesitancy to discuss diagnoses openly to the use of euphemistic language to avoid confronting the issue directly. Despite knowing that stigma existed, hearing it from care partners had weight. These encounters underscored the urgent need for advocacy and awareness initiatives to challenge misconceptions and foster a supportive environment for those living with dementia and their families.

Table 4: Sample Excerpt from Reflexive Journal

Sample excerpt from reflexive journal, dated July 11, 2023, after a conversation with a care partner
<ul style="list-style-type: none">• Had a chat with [name] Aunty• She told me why she didn't want to include her mom in the research.• Aunty is worried to bring up dementia with her mom – worried it might upset her or bring shame.• This made me think about the stigma around dementia in our South Asian community, it feels ?heavy somehow hearing it from an actual person vs reading it in papers.• So many families, like Aunty's, avoid talking about it openly, think it has happened with two other CPs now....? + all the literature• This avoidance not only impacts those with dementia but also stops us from creating better support systems.

The reflexive component was paramount during my research, particularly considering theoretical frameworks. While qualitative research within the interpretive paradigm prioritizes exploring experiences beyond pre-existing theories, it also prompts reflection on integrating theory without imposing preconceived interpretations. For my study on the experiences of South

Asian Canadians living with dementia and their care partners, refraining from established frameworks was a conscious choice to prioritize participant narratives. This decision, rooted in interpretive phenomenology principles, acknowledges the limitations of existing frameworks in capturing cultural nuances. By embracing reflexivity and abstaining from external frameworks, the study aims to authentically represent the diverse voices within the South Asian diaspora, reflecting a commitment to culturally sensitive research practices.

Moreover, reflections prompted by a webinar on public health disparities among South Asian communities prompted me to critically examine the potential impact of my research within this context. As the speaker highlighted systemic inequalities and the failure of mainstream public health initiatives to address the unique needs of diverse populations adequately, I felt a renewed sense of responsibility to ensure that my work contributed positively to the discourse. This entailed not only disseminating findings in accessible formats but also actively challenging deficit narratives and amplifying the strengths of the communities.

In conclusion, reflexivity has been instrumental in shaping my research trajectory, allowing me to navigate complex ethical and methodological considerations with greater insight and sensitivity. Through introspection and engagement with diverse perspectives, I have endeavoured to produce credible findings and contribute meaningfully to advancing knowledge in the field.

3.7 Ethical Considerations

As with any research involving human participants, ethical considerations must be considered. The study was conducted in accordance with the University of Waterloo's research ethics board, and clearance was received from the board, ORE # 45805 (Appendix D).

Participants for all three studies were provided with a “Letter of Information,” which provided detailed information about the study and contact information for the researchers in case they had any questions. Consent was obtained verbally at the beginning of the interview and was audio recorded. After the interview, the consent was recorded in the master sheet with the date the consent was obtained.

Including people living with dementia in research is of utmost importance as it ensures their perspectives and experiences are considered in understanding their experiences with dementia. Despite changes in cognitive capacity related to dementia, it should not be assumed that individuals living with dementia are unable to contribute meaningfully to research. In the present study, an adapted version of the "University of California San Diego-Assessing Consent to Participate in Research (UCSD)" protocol was utilized to assess participants' understanding of the study and obtain their consent (Jeste et al., 2007). If individuals living with dementia could comprehend and respond to the questions outlined in the protocol, they provided their consent and participated in the interview. In cases where they could not provide consent, proxy consent was sought from their care partners. The letter of information and consent form were shared with the care partner for themselves and the person living with dementia. For individuals living with dementia who were interested in participating, the UCSD was administered before the interview was conducted. One person living with dementia could provide consent, and proxy consent was obtained for the second participant living with dementia.

This approach acknowledges the agency of individuals living with dementia while recognizing the need for support and involvement of care partners in research participation. Importantly, the voices of people living with dementia from South Asian communities are largely

absent in research; making efforts to include them is crucial in giving voice to their experiences and ensuring cultural diversity in dementia research.

3.7.1 Conducting research with individuals from ethno-racial backgrounds

When conducting research with individuals from different ethno-racial backgrounds, it is crucial to address and uphold ethical considerations to ensure fairness, inclusivity, and the protection of participants' rights. The Belmont Report, which outlines principles of respect for persons, beneficence, and justice, can guide researchers in navigating these ethical considerations (Canadian Institutes for Health Research, 2022; National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979). Informed consent, a fundamental aspect of respect for persons, requires the researcher to obtain participants' voluntary and informed agreement to participate in the study (National Institutes of Health, 2020). This entails providing clear and comprehensive information about the study's purpose, procedures, risks, benefits, and the right to withdraw at any time. To address cultural sensitivity, researchers should be mindful of participants' cultural practices, values, and beliefs and avoid imposing Western-centric perspectives (National Institutes of Health, 2020).

Additionally, the researcher must ensure confidentiality and privacy, safeguard personal information, and comply with relevant data protection and privacy regulations (European Commission, 2018). To minimize bias and stereotypes, the researcher should strive for equitable representation, inclusivity, and the avoidance of perpetuating disparities or inequalities (American Psychological Association, 2017). By fostering community engagement and collaboration, researchers can involve community members in the research process, incorporate their perspectives, and build trust (National Institutes of Health, 2020). These ethical considerations, supported by frameworks such as the Belmont Report, enable researchers to

conduct studies that respect the rights and well-being of individuals from different ethno-racial backgrounds, leading to more meaningful and trustworthy research outcomes.

3.7.2 Conducting research with people living with dementia

Conducting ethical research with people living with dementia requires careful attention to inclusion, communication, autonomy, and well-being. The increasing involvement of individuals with dementia in qualitative research highlights the need for safe, respectful, and empowering methodologies (Novek & Wilkinson, 2019; McKeown et al., 2010). In this study, ethical considerations were guided by the principles of autonomy, beneficence, and justice, with a particular focus on how these principles apply to participants with cognitive impairments.

Informed consent was a foundational component of the research process, particularly given the sensitive nature of the study and the potential vulnerability of the participants. Strategies were implemented to support comprehension and voluntary participation, including the use of clear, plain language and the opportunity for participants to ask questions and reflect on their decisions. Where appropriate, family members or legal representatives were involved as proxy decision-makers. This aligns with Dewing's (2008) concept of "process consent," which emphasizes the ongoing and relational nature of consent in dementia research, supporting the idea that consent should be continuously revisited and affirmed throughout the research process.

Ensuring participant autonomy and active involvement was prioritized at every stage. Participants were encouraged to share their perspectives freely, and their preferences regarding the interview process, such as timing, location, or taking breaks, were respected. This approach aligns with the inclusive research practices advocated by Williams et al. (2020), who argue for valuing the lived experiences of people with dementia and enabling them to contribute

meaningfully to knowledge production. In line with McKeown et al. (2010), participants were regarded as active collaborators rather than passive subjects, with the researcher adopting a flexible and responsive posture throughout the study.

Privacy and confidentiality were maintained through secure handling of all personal data and the use of anonymization strategies to protect participants' identities. Consent was also obtained for the use of anonymized quotes or data in dissemination. As Novek and Wilkinson (2019) highlight, maintaining confidentiality is not only a procedural obligation but also a key component of building trust and demonstrating respect.

The research protocol was designed to be non-intrusive and sensitive to the potential for emotional distress. Interviews were conducted in a manner that was culturally and linguistically inclusive, and efforts were made to continuously assess and respond to participants' comfort levels. Supportive resources were offered when needed. These practices are consistent with recommendations for ethically grounded and inclusive research methodologies that prioritize participant safety and dignity (Dewing, 2008; Williams et al., 2020).

This research received ethics approval from the University of Waterloo's Research Ethics Board. By implementing inclusive and ethically rigorous practices, the study aimed to uphold the rights, dignity, and well-being of South Asian Canadians living with dementia and their care partners, while contributing meaningful insights to enhance culturally appropriate dementia care.

3.8 Knowledge Translation

In research, especially when working with ethno-racial communities such as South Asian Canadians living with dementia, it is paramount to recognize the importance of reciprocity and community engagement. Ethno-racial communities often share their valuable experiences and

knowledge with researchers, trusting that it will be utilized for their benefit (Liamputtong, 2007). Therefore, it is imperative to give back to these communities by presenting the research findings and aiming that the knowledge generated is potentially translated into tangible benefits for the community members (Minkler & Wallerstein, 2011). By implementing a robust knowledge translation plan, researchers aim to bridge the gap between research findings and community action to empower community members to make informed decisions about their health and well-being (Jull et al., 2017). This approach fosters trust, respect, and collaboration between researchers and communities, ultimately leading to more equitable and impactful research outcomes. As researchers, we must recognize our ethical obligation to reciprocate the generosity of the communities we study and actively work towards advancing their interests and addressing their needs. The following outline has been created for knowledge translation for the present project to be conducted after the completion of the project:

Simplified Summaries: Easy-to-understand summaries of the findings from each study will be developed. The summaries will be tailored for different audiences and will focus on practical implications that can be used to improve dementia care within South Asian communities. These summaries will be drafted, sent to the participants, and provided to different organizations supporting recruitment to distribute to their members. The findings will be available in English, Punjabi and Hindi.

For Study 1, participants will be invited to a webinar to present the findings. I will also partner with organizations such as Indus Community Services and Alzheimer's Societies to host presentations and provide written summaries for individuals unable to attend the presentations. With Studies 2 and 3, the goal would be to draft summaries to share with participants, physicians, and employees of community support organizations.

Online Presence: Establish a personal website and maintain an active presence on social media platforms to share short insights and research updates and engage with followers interested in dementia care and related issues. The website and social media handles have been created; once the dissertation submission is complete, infographics and short summaries of the research findings will be shared.

Community Workshops: Collaborate with local support groups and community centers to organize workshops where research findings are presented in a relatable manner. Engage in open discussions to gather real-world insights from care partners and people living with dementia. Meetings will be set up with various community support organizations to organize and deliver webinars or workshops in English, Hindi, and Punjabi, and the findings will be reported to the community.

Media Engagement: Leverage local media outlets such as newspapers, radio, and TV to share critical findings, emphasizing their relevance to South Asian communities. Offer interviews and commentary to establish as a credible source for dementia-related topics. The groundwork for media engagement was done through interviews with CBC, CTV, and TVO and written articles with The Conversation. Connections will be re-established to share the findings of the study as well.

Networking: Attend relevant events, conferences, and meetings related to dementia care, healthcare, and community engagement. Build connections with individuals and organizations to amplify the reach of the research findings.

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Chapter Four: Navigating Dementia in South Asian Canadian Communities: From Understanding and Diagnosis to Accessing Care

4.1 Introduction

Over 55 million people worldwide live with dementia (World Health Organization, 2023), and in Canada, by 2050, one in four individuals with dementia is projected to be of Asian descent (Alzheimer Society Canada, 2024). Managing dementia and accessing healthcare services pose significant challenges for individuals and their care partners, especially among ethno-racial communities (Hossain et al., 2020). Within these groups, South Asian communities—one of Canada's fastest-growing ethno-racial populations—face unique barriers that are influenced by cultural beliefs, language limitations, and social support structures. These barriers often result in delayed diagnosis and limited access to appropriate services (Hossain et al., 2020; Sagbakken et al., 2018).

Dementia care has been divided into three broad phases: recognizing symptoms, receiving a diagnosis, and accessing services (Giebel, 2015). The first phase, **recognizing symptoms**, involves the individual and their family identifying changes in health that may indicate the onset of dementia, such as memory loss or difficulty with everyday tasks. Early recognition is crucial as it prompts timely medical consultation and allows more time for future planning (Giebel, 2015). A recent literature review on early diagnosis emphasized that timely evaluation could identify underlying causes of memory issues, such as depression and anxiety, reducing insecurity for individuals and their families (Rasmussen & Langerman, 2019). It also enables people with cognitive impairment to make more informed and considered decisions about their future care, living arrangements, and legal matters, while allowing families to plan for their support. Without a diagnosis, individuals may be unable to access specialized dementia care, including dementia teams, daycare, and long-term care homes.

In the second phase, **receiving a diagnosis**, the individual receives a formal diagnosis from a healthcare professional (Giebel, 2015). This step is essential as it provides an opportunity for a clearer understanding of the condition and paves the way for appropriate care planning and intervention. The final phase, **accessing services**, occurs upon or after diagnosis. After that, individuals utilize various healthcare and support services intended to maintain or improve their quality of life (Giebel, 2015). These services can include medical treatments, support groups, and community resources that provide comprehensive care and assistance to the individual and their caregivers (Giebel, 2015). South Asian communities within Canada have unique experiences within each phase.

4.2 Recognizing Symptoms

Recognizing dementia symptoms in a member of a South Asian community can be complicated by language barriers, cultural beliefs, and limited awareness of the condition (Hossain et al., 2020; McCleary et al., 2012; Seabrooke & Milne, 2004). In many South Asian communities, dementia is often perceived as a natural part of aging, with regional languages lacking specific terms to describe it (Iype et al., 2006). Terms such as "sathiyana" or "gone sixtyish" are commonly used to describe symptoms such as memory loss, stubbornness, or paranoia, but these terms contribute to a lack of clarity and misinterpretation of the condition (Cohen, 1998; Iype et al., 2006; Patel & Prince, 2001).

For example, variations in linguistic expressions and the stigma surrounding dementia often lead to delayed recognition of symptoms and care-seeking behaviour (Philip et al., 2024; Sun et al., 2019). Furthermore, the limited awareness and understanding of dementia in these communities are compounded by the concealment of symptoms from fear of social judgment (Hossain et al., 2022).

4.3 Receiving a Diagnosis

Obtaining a dementia diagnosis is fraught with challenges, including language barriers and reliance on family members as translators, which can result in miscommunications and incomplete assessments (McCleary et al., 2012). The stigma surrounding dementia further complicates the process, deterring families from pursuing a formal diagnosis until symptoms become severe or disruptive (Mukadam et al., 2011). Families often resist the notion of incurability, seeking multiple medical opinions or alternative remedies to find a cure (Brijnath, 2022).

Cultural expectations also influence the diagnostic journey. Many South Asian families view initial symptoms as part of natural aging, delaying recognition and professional consultation. Diagnostic tools and services often lack cultural sensitivity, further impeding the process. For example, care partners frequently report frustration with hospital staff and medical systems that need to address their unique cultural and linguistic needs (Mukadam et al., 2011).

4.4 Accessing Services

Socio-cultural factors create additional barriers to accessing dementia-related services. South Asian cultural norms prioritize family caregiving, particularly by women, discouraging the use of external support services. This expectation, coupled with traditional gender roles, places significant emotional and physical stress on care partners, particularly daughters-in-law, who often juggle caregiving responsibilities with full-time jobs (Hossain et al., 2020).

The stigma surrounding dementia and seeking external help further complicates service utilization. Families express concerns about privacy, confidentiality, and the perception of failure to fulfill familial duties when engaging with outside care providers (Hansson et al., 2022). The

limited availability of culturally sensitive resources, including information in South Asian languages, amplifies these challenges. Care partners also cite dissatisfaction with existing services, including hospitals' inability to meet the needs of individuals with dementia and perceived discrimination from service providers (Mukadam et al., 2011; Juttila, 2011).

This research focuses on understanding the lived experiences of individuals with dementia and their care partners to address these gaps and provide a deeper understanding of the dementia journey within the South Asian Canadian community. By examining their unique experiences throughout the phases outlined above, this study aims to contribute to the development of culturally sensitive support systems and care. The objective of this study is to understand the experiences of South Asian Canadians living with dementia and their care partners during the phases of recognizing symptoms, receiving a diagnosis, and accessing services.

Much of the existing research on dementia in South Asian communities has been conducted outside of Canada, particularly in the United Kingdom. While these studies offer valuable insights, they fail to fully capture the unique socio-cultural and healthcare contexts that South Asian Canadians experience. The Canadian healthcare system differs significantly from that of the UK, and the immigration histories, as well as the social dynamics of the South Asian diaspora in Canada, shape dementia care experiences in distinct ways. Therefore, it is crucial to take a more nuanced approach to understanding the experiences of South Asian Canadians living with dementia and their care partners, one that accounts for the specific cultural, linguistic, and systemic factors influencing their care journey. This study is essential in bridging this gap, providing insights directly relevant to the Canadian context.

4.4 Methods

This research project adopted an interpretive phenomenological approach (Frechette et al., 2020). This approach acknowledges the active involvement of the researcher, emphasizing that reality and knowledge are not static entities but are co-constructed through interactions and interpretations within the research context (Frechette et al., 2020; Neubauer et al., 2019). South Asian Canadians navigate cultural norms, familial structures, migration contexts, and healthcare beliefs that shape their dementia experiences. Interpretive phenomenology offers a framework for understanding these experiences by examining the cultural, social, and emotional dimensions of recognizing symptoms, receiving a diagnosis, and accessing services. Rooted in the work of Smith et al. (2009), this approach enhances our understanding of the nuanced journey of South Asian Canadians living with dementia.

i) Setting, Context, and Recruitment: Recruitment took place in Ontario, Alberta, and British Columbia through care partner webinars, in-person presentations at community events, and community outreach, utilizing purposive sampling. Flyers and digital media (including emails and social media) were used, with materials available in Hindi, Punjabi, and English. Community support organizations focused on dementia care, advocacy, and home care played a key role in recruitment. Snowball sampling was also used to connect with other interested individual participants.

Eligibility Criteria: To be eligible for the study, participants met the following criteria:

- Self-identify as a South Asian Canadian
- 18 years or older

- Living with dementia or caring for someone living with dementia. (Note: a diagnosis of dementia was not required for participation in the study; individuals could self-identify as having dementia.)
- Ability to provide consent or proxy for consent.

ii) Sample: Fourteen care partners (Ontario: 12, British Columbia: 1, Alberta: 1) and two people living with dementia (both from Ontario) participated (Table 5). Their personal characteristics are presented in Table 5. The study aimed for 5-7 participants (Creswell, 2007).

Table 5: Sociodemographic Characteristics of Participants (People living with Dementia and Care Partners)

Characteristic	Care Partners (n=14)	People Living with Dementia (n=2)
Age	Mean: 60.4 (SD: 14.8) Min: 30, Max: 82	Mean: 71.5 (SD: 6.4) Min: 67, Max: 76
Gender		
Female	12 (85.7%)	2
Male	2 (14.3%)	-
Marital Status		
Married	10 (71.4%)	2
Single	2 (14.3%)	-
Widowed	2 (14.3%)	-
Education Level		
College	2 (14.35%)	1
High School	-	1
University	12 (85.7%)	-
Province of Residence		
AB	1 (7.1%)	-
BC	1 (7.1%)	-
ON	11 (78.6%)	2
Age of Diagnosis	-	Mean: 68.5 (SD: 6.4) Min: 64, Max: 73
Canadian Generation		
First Generation	14 (100%)	2
Citizenship Status		

Citizen	12 (85.7%)	1
Permanent Residency	2 (14.3%)	-
Other - Waiting Permanent Residency	-	1
Primary Language		
English	2 (14.3%)	-
Gujarati	4 (28.6%)	-
Hindi	2 (14.3%)	-
Punjabi	2 (14.3%)	-
Urdu	4 (28.6%)	2
Region of Origin		
India-Eastern	1 (7.1%)	-
India-Northern	4 (28.6%)	-
India-Western	3 (21.4%)	-
India-Western/Kenya	1 (7.1%)	-
India/East Africa	1 (7.1%)	-
India/Guyana	1 (7.1%)	-
Pakistan	3 (21.4%)	1
Pakistan/Bangladesh	-	1
Ethnicity		
Guyanese	1 (7.1%)	-
Indian-Gujarati	4 (28.6%)	-
Indian-Gujarati/East African	1 (7.1%)	-
Indian-Hyderabad	1 (7.1%)	-
Indian-Punjabi	2 (14.3%)	-
North Indian	2 (14.3%)	-
Pakistani	3 (21.4%)	2
Religion		
Hinduism	4 (28.6%)	-
Islam	6 (42.9%)	2
None	1 (7.1%)	-
Sikhism	3 (21.4%)	-
Employment Status		
Full-time	2 (14.3%)	-
Part-time	2 (14.3%)	-
Retired	7 (50%)	2
Self-employed	1 (7.1%)	-
Unemployed	2 (14.3%)	-

iv) Data Collection: Data were collected using semi-structured in-depth interviews. The interview guide for this study was developed based on the three phases of dementia care,

recognizing symptoms, receiving a diagnosis, and accessing services, and the study's objectives to understand the experiences of South Asian Canadians living with dementia and their care partners. The guide was shared with the supervisory committee for feedback and refined to ensure cultural relevance, clarity, and alignment with the study's goals. This iterative process helped ensure that the questions (Table 6) were sensitive to the participants' unique experiences.

Data were collected from February 13 to April 8, 2024, via Zoom, telephone, or in-person. Interviews, lasting 45-60 minutes, were semi-structured, focusing on symptom awareness, diagnosis, and accessing services. 14 interviews with care partners (11 in English, 2 in Hindi, 1 in Punjabi) and two interviews with people living with dementia (both in Hindi) were conducted. Interviews were audio-recorded.

English interviews were transcribed using Otter AI. Transcripts were reviewed to ensure accuracy. However, Otter AI was unsuccessful in the Punjabi and Hindi interviews conducted as part of the study, as the language was not appropriately captured in Otter AI or in an alternative software, Sonix. Consequently, the audio recordings of these interviews were listened to, translated into English and transcribed by NGC. Anonymized transcripts, with pseudonyms assigned, were uploaded to NVivo 14 for analysis.

Table 6: Sample Questions from the Care Partner Interview Guide

Sample Questions- Care Partner Interview Guide
<p><i>Awareness of Early Symptoms:</i></p> <ol style="list-style-type: none"> 3. Could you describe a situation when you first noticed changes in the behaviour or cognitive abilities of your [relative] with dementia? 4. What were the initial signs that made you suspect something was changing? <p><i>Diagnosis Process:</i></p> <ol style="list-style-type: none"> 1. Could you share your experiences with the diagnostic process? <ol style="list-style-type: none"> a. How did your [relative] react to this process? <p><i>Availability and Awareness of Services:</i></p>

Awareness of Services

2. Were you initially aware of any dementia-related services in your community when your [relative] was diagnosed, or did you become aware of them as part of your care planning process?

4.5 Data Analysis

Reflexive thematic analysis was used to analyze the data (Braun & Clarke, 2019). Reflexive thematic analysis aligns with the epistemological principles and methodological practices of interpretive phenomenology (Braun & Clarke, 2019), rendering it a valuable tool for exploring and understanding individuals' lived experiences. The following steps were followed for the reflexive analysis:

1. Familiarizing Oneself with the Data: Familiarizing with the data involved reading and re-reading transcripts to understand the content and context, helping to develop a nuanced understanding of cultural, linguistic, and contextual factors. Notes were made during and after listening to recordings to capture initial impressions. Transcripts were reviewed for accuracy and familiarity, with audio recordings referenced during coding to capture emotions and language nuances.

2. Coding: Initial coding was conducted using NVivo 14, identifying key concepts and ideas. This involved systematically labelling and categorizing data segments based on their meaning and relevance (Figure 3). Cultural and language nuances were given special attention. Codes were reviewed, collapsed, and renamed to ensure alignment with the data. Similarly, for Study 1, the code “Experiences with Healthcare” was changed to “Diagnosis Experience” because the coded section provided more information on the interaction with healthcare professionals during the diagnosis process, specifically regarding healthcare in general.

Figure 3: Sample of Codes from Study 1.

Name	Description	Sources	References
Accessing or Availability of Resources	Care partners navigating findings resources and programs after diagnosis	14	34
Lack of Awareness of Services	The CPs were not aware of certain services either after the diagnosis or didn't find out about certain services till later in the journey	2	2
Attributing Changes to Other Conditions or Reasons	The care partners attributed the changes to other issues and reasons such as <u>depression, or</u> getting old.	10	16
Duration	How long the person has been living with dementia	2	4
Emotional Toll	The emotions associated with watching their relative and themselves navigate the dementia journey	9	12
Experiences with Healthcare	Including first time interaction for diagnosis, general experience with healthcare system and physicians	11	18

3. Themes: Codes were grouped into overarching themes that captured patterns and concepts within the data. An iterative process of comparison and refinement led to the identification of themes, recurring patterns, cultural motifs, and contextual insights.

4. Reviewing Potential Themes: The themes were critically reviewed for coherence, relevance, and alignment with the research objectives. This involved assessing their ability to address research questions and provide meaningful insights. Discrepancies were resolved through further analysis and committee discussions, with transcripts reviewed again to extract relevant quotes.

5. Defining and Naming Themes: Finalized themes were clearly defined and labelled to capture their essence succinctly. Descriptive labels ensured consistency and clarity in presenting findings, facilitating the organization and presentation of themes in the final analysis.

4.6 Ethics

This study adhered to the University of Waterloo's ethics guidelines and received clearance. Participants received a "Letter of Information" detailing the study, and verbal consent was recorded at the start of each interview, followed by written documentation.

Recognizing the importance of including people living with dementia in research, the study used an adapted version of the "University of California San Diego-Assessing Consent to

Participate in Research (UCSD)" protocol (Jeste et al., 2007). If participants with dementia could understand and respond, they provided consent; otherwise, proxy consent was obtained from care partners. One participant offered direct consent, while proxy consent was used for the other.

4.7 Findings

The findings of this study highlight the experiences of both care partners and individuals living with dementia, focusing on the cultural, emotional, and systemic challenges they encountered. The results are organized into four main themes: 1) **Barriers and Stigma in Recognizing Dementia**; 2) **From Symptoms to Diagnosis – Challenges and Insights**; 3) **Forging a Path Forward – Accessing Services Post-Diagnosis**; and 4) **and Navigating Long-Term Care – Transitioning from Home to Facility**. These themes provide insight into the dementia journey experienced by the participants (Table 7).

Table 7: Information on Quoted Participants

Quoted Participants: Persons Living with Dementia	
Rashida	67-year-old female from Pakistan, living at home with her husband
Zara	76-year-old female, from Pakistan/Bangladesh, living at home with family.
Quoted Participants: Care Partners	
Aradhaya	65-year-old female from Northern India, care partner to her mother
Beant	57-year-old female from Northern India, care partner to her mother and father
Bharti	50-year-old female from Western India, care partner to her father
Karima	51-year-old female from Western India, care partner to her mother-in-law
Latifa	50-year-old female from Pakistan, care partner to her mother
Parkash	82-year-old male from Western India, care partner to his wife
Priya	73-year-old female from Western India/Africa, care partner to her mother-in-law
Samira	30-year-old from Eastern India, care partner to her grandmother
Sunita	67-year-old female from India/South America, care partner to her mother

4.7.1 Barriers and Stigma in Recognizing Dementia

The first theme highlights how participants initially struggled to understand dementia, with symptoms such as forgetfulness and disorientation often attributed to aging rather than a distinct medical condition. This theme explores how cultural beliefs, stigma, and misconceptions

about dementia as normal aging delayed recognition and care, leaving families isolated and struggling for support. It also notes a gradual increase in awareness within some communities. Within these families, cultural beliefs and norms heavily influenced the understanding of dementia. Participants frequently described how dementia was not recognized as an illness but instead dismissed as something expected with aging, delaying recognition and care in their community. This lack of understanding was compounded by the stigma surrounding dementia, which led to hesitation in discussing the condition openly, both within the family and in the community.

Participants frequently referred to the cultural barriers they faced, describing “you know how it is in our culture” as a common phrase when reflecting on their challenges. They explained that within their cultural setting, there was little understanding of what dementia truly was, and as a result, symptoms were often minimized. Zara, a person living with dementia, initially believed that her forgetfulness was simply part of growing older, a belief that delayed her access to care:

"I didn't realize in the beginning that this was dementia; I thought I was just getting old. I would forget things, but then I would stop, think, and often remember again. It wasn't until later that I understood it was dementia."- Zara, Person Living with Dementia

Bharti's father, for example, acknowledged his memory issues but did not grasp their full significance, highlighting a common reluctance to address cognitive decline as something beyond aging. Other participants, such as Aradhaya, expressed how even well-educated individuals within their families and social circles misinterpreted dementia symptoms as normal aging. The idea that memory loss or changes in behaviour are part of the natural aging process

was deeply ingrained, making it difficult for families to recognize the need for medical intervention.

The cultural stigma surrounding dementia was a significant factor, often leaving families to navigate these challenges alone. Participants noted how difficult it was to explain the condition to others, only to have their concerns dismissed. Aradhaya shared her frustrations with this, noting how people would claim to understand her mother's behaviour but still expected her to behave normally:

"Whenever I tried to explain my mom's behaviour, they'd say they knew, but then they still expected her to act normally." – Aradhaya, Care Partner.

These interactions left care partners feeling “frustrated” and “isolated” as they struggled to make others understand the complexities of living with dementia. Participants explained that the lack of empathy from those around them made it difficult for them to seek or provide adequate support. Rashida shared that she only learned of a relative's dementia diagnosis after their passing, which underscored the tendency to conceal the condition due to stigma. This concealment often meant that families could not access support from those who could have helped.

Despite these challenges, participants observed some positive shifts over time. They mentioned that while many still didn't fully understand dementia, there was an increasing awareness that it was more than just a mental illness or an inevitable aspect of aging. Although significant gaps in knowledge and empathy remained, particularly regarding prevention and care, some participants felt there was a slow change in how dementia was perceived, at least within their immediate circles.

4.7.2 From Symptoms to Diagnosis – Challenges and Insights

The journey to obtaining a diagnosis involves emotional, cultural, and systemic hurdles. Participants often experienced delays, misdiagnoses, and poor communication from healthcare professionals. This theme explores the emotional, cultural, and systemic barriers families face in obtaining a dementia diagnosis, including delays, misdiagnoses, and poor communication. It highlights the role of cultural beliefs, stigma, and the value of persistence and advocacy in navigating healthcare systems both in Canada and abroad.

For instance, Beant shared her frustration with the healthcare system's failure to capture the severity of her mother's symptoms, leading to a delayed diagnosis despite the family's early recognition of dementia.

"I remember taking her to the geriatrician, and they did a standard memory test. The doctor said, 'No, I think it's just age-related, maybe she's got too much on her plate.' But we knew something was wrong. It took a few more years before she was officially diagnosed, even though by then, we already knew it was dementia. – Beant, Care Partner

Bharti had a similar experience, discovering her father's diagnosis only after taking him to the doctor. Her father had initially been diagnosed during a routine visit, which he went to by himself. His family physician had referred him to a specialist, and he received an official diagnosis, but the family was not informed. It wasn't until six months later, when Bharti became concerned about her father's symptoms and took him to her family doctor, that they were informed of the diagnosis.

"The family doctor just said, 'Yes, these signs are common for dementia,' but we didn't know! My dad was sent home, still driving, and no one told us he had dementia."- Bharti, Care Partner.

Latifa shared a similar experience in navigating the healthcare system. She had taken her mother to the doctor twice in Canada, recognizing the symptoms of cognitive decline. Still, on both occasions, the doctors told her that her mother did not have dementia. Latifa felt frustrated by the lack of clarity despite the tests and the symptoms she observed. In Pakistan, she noted that dementia "is not commonly talked about," but she felt fortunate that the doctor in her home country could diagnose her mother. Latifa emphasized that her background in healthcare gave her the confidence to push for the diagnosis:

"I also pushed for it and was insistent, and I think having my experience in healthcare there, I was able to push for this [the diagnosis], something I don't think I could have done here [Canada]."- Latifa, Care Partner

Parkash similarly shared that his concerns about his wife's cognitive changes were not taken seriously by doctors in Canada. Despite expressing his concerns multiple times, it took him ten years to get a formal diagnosis. Frustrated, he eventually sought help in his home country, where his daughter, a doctor, helped him navigate the system and secure the diagnosis for his wife. Being familiar with the healthcare system and having connections in their home countries made both participants feel more equipped to advocate for their family members, something they found much more challenging in the Canadian healthcare system.

Accepting and adjusting to the diagnosis is a complex emotional process. Participants described adjustments to their daily lives and future planning. For instance, Zara found that

accepting her condition and keeping herself engaged helped her cope better. Similarly, despite her diagnosis, Rashida chose to stay positive and focus on the blessings in her life.

"I decided to stay positive. I still cook and do everything. I won't waste my remaining time being sad."- Rashida, Care Partner.

Barriers to recognizing dementia within South Asian communities are compounded by cultural beliefs that attribute symptoms to aging rather than a medical condition, alongside the stigma that prevents open discussions and timely interventions. However, participants noted a slow shift towards greater awareness of dementia, despite persistent gaps in understanding, support, and empathy within these communities.

4.7.3 Forging a Path Forward – Accessing Services Post-Diagnosis

After receiving a dementia diagnosis, participants and their families continued to face challenges in accessing appropriate resources and support services. Many care partners expressed frustration with the available services, finding them inadequate or not tailored to their cultural needs. This theme highlights the challenges families face in accessing dementia services after diagnosis, emphasizing the need for culturally and linguistically tailored resources and proactive support to navigate care effectively.

Beant described the lack of resources appropriate for her family, particularly regarding language and cultural relevance. She highlighted how this absence of culturally specific programs led to feelings of isolation and loneliness for her parents.

Latifa shared her experience as a translator for her mother, as no resources were available in her mother's language. She pointed out that this made it more difficult to ensure her mother received proper care and information:

*"When her condition progressed, I reached out to [organization], but no one there could talk in her language, so I acted as a translator. They gave me reading material and everything, but we had no place where she could talk and explain her condition; **you are the very first person who has spoken to her in her language since she was diagnosed.**"-*

Latifa, Care Partner.

Other participants, like Karima, underscored the importance of language-specific services. Her mother-in-law spoke limited English, and this created challenges in finding appropriate programs:

"At times, we did not find any social programs or anything for her culture that were appropriate for her. The language barrier was huge because she did not speak English. Other than 'hi' or 'hello,' she did not know much. So, we did not find any support."-

Karima, Care Partner.

Accessing dementia services required families first to be aware of the available resources, and one of the participants noted how this assisted them in accessing care. Bharti shared how she first called an organization she was familiar with, having grown up in the same city. Her long-standing relationship with this organization made it her primary source for guidance on navigating dementia care. The organization helped her understand what to expect, how the dementia journey would unfold, and how to find more information.

The need for culturally tailored programs was not the only challenge. Participants also faced logistical and systemic issues when accessing services as they were often not linguistically and culturally inclusive. Latifa highlighted her mother's challenge while waiting for permanent residency, which limited her access to essential healthcare services. Despite being cleared for

permanent residency (PR), Latifa's mother faced delays in receiving her PR card, which is required to enroll in provincial health coverage such as the Ontario Health Insurance Plan. Sunita suggested that having a coordinator to help pull together all available resources would have been beneficial. Many families, she noted, were left to navigate the system on their own with minimal guidance from healthcare professionals. Latifa also highlighted her mother's challenge while waiting for permanent residency, which was limiting her access to specific healthcare services.

Participants described how organizations made efforts to engage multicultural communities, offering awareness sessions and support groups. Samia appreciated these efforts but noted that more could be done to raise awareness of these services and improve their marketing. She proposed setting up adult day programs in community centers or mosques to provide a familiar and culturally safe environment for those living with dementia.

While participants encountered cultural, linguistic, and systemic challenges in accessing services post-diagnosis, many also found support through familiar organizations and community efforts.

4.7.4 Navigating Long-Term Care – Transitioning from Home to Facility

As dementia progresses, the need for specialized care often becomes unavoidable. The decision to move a relative into a long-term care home is mixed with emotional, cultural, and logistical challenges. This theme examines the experiences of families navigating the transition from home to long-term care, highlighting the complexities and cultural considerations involved.

The transition to long-term care is often necessitated by the growing challenges of managing dementia at home. Families struggle with this decision, weighing the need for professional care against cultural expectations and personal guilt. Beant, for instance, described the escalating

burden on her family, which ultimately led to the difficult decision to move her mother to a care home. Following her father's death, her mother's condition worsened, including losing the ability to use the washroom independently. This increase in care needs made the move to long-term care inevitable for Beant and her family.

“And it got to a point where Dad got diagnosed with dementia as well and could not look after two of them. And mom was getting to a point where she did not know where the bathroom was. I think that was the deciding factor, that you know, not knowing where to go to the bathroom, right? And then Dad passed away, and we put her on the list for a care home, but that was such a tough decision to put her in a care home.” -Beant, Care Partner.

Participants emphasized the stigma surrounding the decision to place a relative in a long-term care home, often facing judgment and criticism from relatives who viewed it as a failure to fulfill family responsibilities. Beant shared how her choice to move her mother into long-term care was met with disapproval from both relatives and friends. This stigma extended beyond individual families; Beant recalled a funeral where the priest commended the family for enabling the deceased to age and pass away at home, contrasting this with the increasing use of care facilities. Samira also noted that cultural beliefs heavily influenced perceptions of long-term care homes.

“You know, in our culture, this is not an option. I don't think that is an option. I do not think like it would go down really well if we were to bring it up.” Samira, Care Partner

For other participants, cultural considerations and personal preferences made long-term care homes a less viable option. Taking the food preferences and cultural aspects into consideration was important for family members when considering long-term care settings, often determining the comfort and acceptance of the place. Participants shared concerns about their

relatives' diets in care homes, which do not align with their lifelong dietary practices. Priya mentioned how her mother-in-law would complain about the food without butter or spices, ensuring Priya would bring home-cooked food when she visited and stated that “*so, she would eat, and she recalled the taste.*” Bharti explained that placing her father in a long-term care home was unsuitable due to cultural reasons and his specific needs and preferences, as the care home environment would not provide the familiarity and cultural comfort he needed.

For me, long-term care was not an option. I was only interested in knowing the costs to gauge private care expenses. I knew he would not receive adequate hygiene care, like regular diaper changes, and the food would not match our South Asian flavours and textures, which are important to us. His spirituality, including the smell of incense and sounds of prayer, would be missing, as well as the constant music he loved, from spiritual songs to Bollywood hits. The care home could not replicate the social environment and love from family and friends visiting and helping at all hours. These are the tangible and intangible reasons why long-term care was not right for my dad.- Bharti, Care Partner

Despite initial reservations, some families found that long-term care homes provided necessary and beneficial support for their relatives. Beant noted the positive impact on her mother's well-being after moving to a care home, where specialized care and social interaction improved her condition. She mentioned how her mother thrived with the specialized care, with her diet improving. Beant further elaborated that despite the home not being South Asian community-specific, the staff and management had done an excellent job creating an inclusive environment for her mother. Similarly, Priya shared that although food remained an issue, her mother-in-law's health significantly improved in the long-term care home, and she adapted well overall.

“It is not tailored for South Asian communities, but there is a lot of mixed staff. Many South Asian staff speak Punjabi, but even the non-South Asians, you know, call every Punjabi lady “Bibi” and Punjabi uncle “Baba.” So, it’s not tailored, but it feels like it’s tailored.” - Beant, Care Partner

The findings from this study illustrate the experiences of South Asian Canadians living with dementia and their care partners, revealing significant cultural, emotional, and systemic challenges throughout the dementia journey.

4.8 Discussion

This study aimed to understand the experiences of South Asian Canadians living with dementia and their care partners across the phases of recognizing symptoms, receiving a diagnosis, and accessing services. The findings highlight important cultural, systemic, and advocacy challenges, offering new insights while reinforcing some previously known barriers in dementia care.

One key finding that stands out is the broader understanding of dementia demonstrated by participants in this study. While previous literature suggested that dementia was uniformly misunderstood due to cultural and religious perspectives (Prince et al., 2003; Mukadam et al., 2011), participants in this study exhibited a more nuanced awareness of dementia post-diagnosis as a medical condition within South Asian families. This reflects a level of understanding that contrasts with findings from earlier studies. Although the initial recognition of dementia symptoms was often delayed due to beliefs around aging, some participants expressed that there was growing awareness within their immediate circles that dementia was more than just a normal

part of growing older. This indicates a slow but significant change in how dementia is perceived within these communities, reflecting broader shifts in awareness and education about dementia.

Another finding is that the participants obtained a dementia diagnosis in their home countries rather than in Canada. Participants, such as Latifa and Parkash, described feeling more empowered to advocate for their family members in their countries of origin, where they had stronger connections with the healthcare system and greater familiarity with its processes. This finding underscores the importance of personal networks and knowledge of healthcare systems in facilitating timely and effective diagnoses for dementia. Research has shown that immigrants often face challenges in navigating healthcare systems in their host countries, such as language barriers, lack of culturally appropriate services, and unfamiliarity with how the healthcare system operates (McCleary et al., 2012; Pandey et al., 2021). These barriers can lead to delays in seeking care, misdiagnoses, or reluctance to engage with the system altogether (Shamshi et al., 2020).

The systemic hurdle of accessing healthcare while waiting for permanent residency was identified as another issue in this study. Participants like Latifa expressed frustration over their inability to access essential healthcare services for their relatives with dementia due to immigration status. Latifa's mother, cleared for permanent residency, faced healthcare access challenges while waiting for her PR card, which is required for provincial health coverage such as the Ontario Health Insurance Plan (Government of Ontario, 2023). In Canada, individuals must present a valid PR card to enroll in provincial healthcare, meaning families often cover medical costs privately during this interim period (Government of Canada, 2024). This delay can significantly hinder timely access to care, especially for chronic conditions like dementia. This

specific challenge has not been widely addressed in the literature on dementia care in immigrant populations.

Although this study focused on the experiences of South Asian Canadians, discussions of race or racism were explicitly identified in participants' narratives. This absence should not be interpreted as an oversight but rather reflects the nature of the discussions during interviews. It is possible that experiences of racialization and systemic racism may have shaped participants' encounters with dementia care in more implicit ways or were less readily articulated in the interview setting. Future research could examine more directly how experiences of racism and racialization intersect with cultural identity, access to care, and perceptions of dementia within South Asian communities in Canada.

This study underscores the importance of staff efforts in fostering inclusivity within long-term care homes, even when these facilities are not specifically designed for South Asian residents. Beant's experience illustrates how small, meaningful gestures, such as staff learning common Punjabi phrases and addressing older adults with culturally respectful terms like "Bibi" and "Baba", can significantly enhance residents' comfort and sense of belonging. While existing literature often critiques the lack of culturally specific care options (Godfrey & Townsend, 2001), these findings highlight the potential for staff initiatives to bridge cultural gaps and improve the lived experience of residents. This suggests that while systemic changes are necessary, individual and organizational efforts can also be crucial in addressing cultural needs within care settings.

The findings on stigma and delays in recognizing dementia align with previous research that identifies cultural beliefs as barriers to early symptom recognition. Studies from the United

Kingdom and India have shown that dementia symptoms are often perceived as a natural part of aging in South Asian communities (Hossain et al., 2020; Patel & Prince, 2001; Sagbakken et al., 2019). This research reaffirms that deeply ingrained cultural norms influence how dementia is understood and addressed. The lack of early intervention is compounded by the stigma surrounding dementia, a finding echoed in prior studies (Philip et al., 2024; Mukadam et al., 2011; Seabrooke & Milne, 2004), where the reluctance to discuss cognitive decline openly leads to delays in seeking medical advice.

One of the cultural nuances that were identified, but warrants further consideration, is the use and understanding of the word '*dementia*' itself. In many South Asian languages, there is no direct or widely understood translation for the term. Where equivalents exist, they often carry negative or stigmatizing connotations (e.g., terms suggesting madness or loss of mind). As a result, families may avoid using the word altogether or rely on euphemisms such as “memory weakness” or “just aging,” which can obscure the seriousness of the condition and delay formal diagnosis or intervention. This linguistic gap is not merely a matter of semantics; it reflects a more profound cultural discomfort in naming and discussing cognitive decline, highlighting the need for culturally informed education that does not shy away from the term '*dementia*' but instead contextualizes it in meaningful, culturally resonant ways.

Gender also played an important, though sometimes implicit, role in the experiences shared by participants in this study. Most care partners interviewed were women, which reflects broader societal and cultural expectations around caregiving responsibilities in South Asian families. Prior research has shown that caregiving is often considered a moral and familial duty for women in South Asian households, with daughters, daughters-in-law, and wives frequently expected to take on this role (Hossain et al., 2020). These gender norms likely influenced not

only who assumed caregiving responsibilities but also who felt comfortable participating in the research. As caregiving roles are more visible and socially accepted for women, their experiences may be more readily accessed in studies such as this. In contrast, male caregivers often remain underrepresented in research, with limited exploration of the unique challenges they face in navigating caregiving roles within traditionally gendered expectations (Hossain et al., 2020). Future research could further explore the perspectives of male care partners and others whose caregiving contributions may be less recognized or expressed due to prevailing gender norms.

Similarly, the challenges participants faced in accessing dementia-related services post-diagnosis reflect existing concerns in the literature about the lack of culturally relevant resources (McCleary et al., 2012). Beant and other participants expressed frustration with the inadequacy of resources tailored to South Asian needs, particularly around language barriers and cultural sensitivity. These findings are consistent with research highlighting the limited availability of culturally specific programs for ethnocultural groups, which makes it more challenging for families to access appropriate support (Joo & Liu, 2021; Godfrey & Townsend, 2001).

While many of the barriers and experiences shared by participants reflected cultural beliefs, values, and practices such as stigma, caregiving expectations, and language preferences, others were shaped by the broader healthcare system itself. For example, delays in diagnosis or inadequate service access were not solely the result of cultural misunderstanding but also of structural challenges within the Canadian healthcare system, including a lack of culturally appropriate services, language-inaccessible resources, and bureaucratic hurdles around immigration status. This distinction is important because it underscores that cultural factors do not operate in isolation but often interact with systemic gaps, creating compounded barriers for South Asian families navigating dementia care.

In conclusion, this study offers new insights into how South Asian Canadians navigate dementia care. It highlights the evolving understanding of dementia within these communities and the role of advocacy, both within the Canadian healthcare system and in home countries. It also reaffirms the ongoing challenges related to stigma, language barriers, and access to culturally appropriate services. These findings underscore the importance of creating more inclusive and culturally tailored dementia care options to support South Asian families in better navigating the complexities of dementia care.

4.9 Future Research Implications

While this study provides valuable insights into the dementia care experiences of South Asian Canadians, further research is necessary to build upon these findings and address existing gaps. Future studies could adopt a more comprehensive sampling strategy to capture greater diversity within South Asian communities, including participants from different regions, linguistic groups, and faith backgrounds. Exploring the differences between first- and second-generation South Asian Canadians may also offer valuable insights into how acculturation, intergenerational dynamics, and familiarity with the healthcare system influence experiences of dementia care. In addition to qualitative inquiry, there is a need for intervention-based studies that test culturally adapted support programs, educational tools, and care navigation strategies tailored to South Asian families. Such work would provide not only a deeper understanding of community needs but also actionable approaches for improving culturally inclusive dementia care.

Research should highlight challenges such as language difficulties and cultural insensitivity to address barriers in diagnosis, inform policy changes, and improve clinical care. Healthcare providers should collaborate with community leaders to enhance awareness and

reduce stigma through educational programs and workshops, fostering better service access. Creating dementia-friendly spaces, increasing service accessibility, and improving healthcare navigation through community partnerships will help ensure equitable care for South Asian Canadians living with dementia.

4.10 Strengths and Limitations

This study's strengths include its ability to build trust within the South Asian community, enabling participants to share their experiences openly, and its inclusion of diverse South Asian backgrounds, adding depth to the findings. The researcher's shared cultural background facilitated rapport with participants, enhancing the richness of the data. However, the study is limited by its linguistic scope, as interviews were conducted only in Hindi, Punjabi, and English, excluding other major South Asian languages. Additionally, some regions like South India, Sri Lanka, and Afghanistan were not represented, and the focus on educated, English-speaking participants with healthcare experience may have influenced the perspectives shared. The researcher's role may have introduced social desirability bias, potentially shaping participants' responses.

4.11 Conclusion

This study examined the experiences of South Asian Canadians living with dementia and their care partners, focusing on symptom recognition, diagnosis, and service access. Key findings include a gradual shift in understanding dementia within families, the reliance on home country healthcare systems for diagnosis, and advocacy challenges in navigating Canadian healthcare. The research also identified barriers related to immigration status and highlighted efforts by long-term care staff to foster inclusivity despite cultural gaps. Overall, the study underscores the

need for culturally tailored dementia care and more accessible, inclusive services for South Asian communities in Canada.

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Chapter Five: “*There is a lot more later recognition of dementia rather than early on*”: Physicians' experiences of dementia diagnosis in South Asian communities in Canada

5.1 Introduction

This chapter delves into physicians' experiences of diagnosing dementia in South Asian Canadians and working with their care partners. The study aims to understand the intricate dynamics that influence the diagnostic process. The analysis is rooted in the broader context of cultural beliefs, language barriers, and the social stigma associated with dementia, which collectively impact the interactions between South Asian patients, their families, and healthcare providers.

5.1.1 Cultural and Language Barriers in Dementia Diagnosis

Effective communication with patients and their care partners is crucial for diagnosing dementia. Accurate assessments often include physical, neurocognitive, and psychiatric evaluations, behaviour observations, daily living activity assessments, cognitive tests, blood samples, and brain scans (Neilson et al., 2011). Effective communication with patients and their care partners is part of diagnosing dementia. Comprehensive assessments usually involve physical, neurocognitive, and psychiatric evaluations, behavioural observations, assessments of daily living activities, cognitive tests, blood samples and brain imaging. Recent Canadian guidelines emphasize a holistic approach, encouraging comprehensive evaluations to ensure accurate diagnoses (Alzheimer Society of Canada, 2024). Similarly, updated U.S. clinical guidelines from the Alzheimer's Association recommend detailed assessments, including medical history, physical and neurological exams, cognitive and functional evaluations, laboratory tests, and neuroimaging when appropriate (Atri et al., 2024).

Despite these measures, the level of understanding about dementia and appropriate diagnostic procedures among healthcare professionals varies significantly between and within

countries (Prince et al., 2011). This inconsistency contributes to the widespread underdiagnosis of dementia, particularly in its early stages (Eichler et al., 2014). Recent research using capture-recapture modelling found that individuals from South Asian backgrounds are significantly less likely to have their dementia formally diagnosed compared to their White counterparts in England (Mukadam et al., 2025). Alarming, even in high-income countries, only 50% of individuals with dementia receive a formal diagnosis, while in low- and middle-income countries, this figure drops to less than 10% (Prince et al., 2016).

Research has identified several barriers to the timely and accurate diagnosis of dementia among ethno-racial communities, including the lack of culturally sensitive services and diagnostic tools, difficulties in providing language-appropriate interpreters, and prevailing cultural beliefs about dementia (Chejor et al., 2022). Additionally, when individuals from ethno-racial communities' access healthcare services, they may feel overlooked due to the brief nature of consultations and the perception that their symptoms are dismissed as part of normal aging (Arora et al., 2018). These factors can result in a reluctance to seek help or complete disengagement from available services (Arora et al., 2018).

5.1.2 Diagnostic Challenges in Ethno-Racial Communities

While clinicians' viewpoints are vital, there is a gap in the literature examining this area. Research indicates that primary care physicians often express lower confidence in assessing dementia among ethno-racial communities, which is attributed to perceived knowledge gaps and difficulties in conveying diagnoses effectively (Giezendanner et al., 2018). Language barriers and insufficient cultural competence also contribute to a need for more confidence in diagnostic capabilities (Tillmann et al., 2019).

Qualitative research highlights that clinicians may struggle to navigate diagnostic conversations involving patients, family members, and interpreters (Sagbakken et al., 2018). Language difficulties can lead to hesitation and insecurity among clinicians, hindering their ability to establish rapport and trust with patients (Sagbakken et al., 2018). Understanding the factors behind clinicians' lower confidence, often due to inadequate cultural training, can provide insights into barriers to delivering quality care (Monsees et al., 2021).

Another significant challenge for ethno-racial communities is the absence of culturally sensitive assessment tools, which can result in both underdiagnosis and overdiagnosis of dementia (Canevelli et al., 2021; Neilson et al., 2011). While some well-known tools, such as the Mini-Mental State Examination (MMSE) and Montreal Cognitive Assessment (MoCA), are available in translated versions, they often fail to account for cultural nuances, such as differences in educational backgrounds, linguistic expressions, and cultural norms, which can impact the accuracy of assessments (Ng et al., 2018; Velu & Leathem, 2017). Additionally, using family members as interpreters instead of professionals can lead to distorted diagnoses (Neilson et al., 2011; Flores, 2005). Even when professional interpreters are available, the precision and validity of cognitive assessments may be compromised due to nuanced differences in question phrasing and the interpretation of responses (Plejert et al., 2015). This underscores the need for linguistically and culturally appropriate tools to ensure equitable and accurate dementia diagnoses.

Diagnosing dementia in South Asian communities poses unique challenges shaped by cultural beliefs, language barriers, and family dynamics (Hossain et al., 2020). Additionally, the stigma surrounding dementia can deter families from seeking timely medical assistance, as it associates cognitive decline with shame linked to moral or spiritual failings (Hossain et al.,

2022). Cultural perceptions of cognitive impairments are often viewed as a normal part of aging, delaying proper recognition and diagnosis; for instance, terms like "sathiyana" in North Indian dialects reflect this acceptance (Brijnath, 2012). Language barriers further complicate the process, as many South Asian Canadians prefer communicating in their native languages and often depend on family members as translators during medical visits (Brijnath, 2022). Considering these challenges, this study examines physicians' experiences diagnosing dementia in South Asian Canadians.

5.2 Methods

This study utilized an interpretive phenomenological approach to understand physicians' experiences diagnosing dementia within South Asian Canadian communities. This methodology is well-suited for examining the subjective and complex nature of these experiences, emphasizing how cultural beliefs, social dynamics, and personal interactions shape the diagnostic process (Frechette et al., 2020). Interpretive phenomenology allows a deep understanding of how physicians navigate cultural nuances, language barriers, and social stigma in their diagnostic practices (Frechette et al., 2020).

i) Setting, Context, and Recruitment: Recruitment took place in the following provinces: Ontario, Alberta, and British Columbia. Purposive sampling was used to identify physicians who have experience working with South Asian communities. Flyers were shared on social media platforms, including LinkedIn, and by Alzheimer's societies across the three provinces to assist with recruitment. NGC's graduate supervisor, GH, a geriatrician, assisted with recruitment by connecting with their network. Once contact was made with initial physicians, snowball sampling was used to connect with other physicians in their networks.

ii) Eligibility Criteria: Participants met the following criteria to be eligible for the study: participants were required to be licensed physicians. They had to have experience providing care for South Asian Canadians living with dementia and their care partners. Participants also needed to be capable of providing informed consent to participate in the study and must have been able to communicate fluently in English. Participants did not need to be from the South Asian community to be eligible.

iii) Sample: The study aimed for 5-7 participants (Creswell, 2007). 13 physicians were recruited: nine from Ontario, three from Alberta, and one from British Columbia (Table 8). Regarding specialization, ten geriatricians, two family physicians, and one internal medicine specialist participated in the study.

Table 8: Sociodemographic Characteristics of Participants (Physicians)

Characteristic	Physicians (n=13)	%
Gender		
Female	5	38.5%
Male	8	61.5%
Age		
30-39	8	61.5%
40-49	3	23.1%
50-59	1	7.7%
60-69	1	7.7%
Ethnicity		
South Asian	11	84.6%
Other	2	15.4%
Primary Language of Communicating When Communicating with Patients		
English	4	30.8%
English/Hindi	2	15.4%
English/Hindi/Urdu/Punjabi	2	15.4%
English/French	2	15.4%
English/Punjabi	2	15.4%
English/Gujarati/Hindi	1	7.7%

Province of Practice		
Ontario (ON)	9	69.2%
British Columbia (BC)	1	7.7%
Alberta (AB)	3	23.1%
Medical Specialty		
Geriatrician	10	76.9%
Family Physician	2	15.4%
Internal Medicine	1	7.7%
Years in Practice		
0-5	7	53.8%
6-10	2	15.4%
11-20	1	7.7%
21-30	2	15.4%
31+	1	7.7%
Primary Practice Setting		
Hospital	9	69.2%
Clinic	2	15.4%
Hospital/Clinic	2	15.4%

iv) Data Collection: Data collection occurred between February 12, 2024, and April 16, 2024.

The interviews were conducted virtually via the online videoconferencing platform Zoom or by telephone. Twelve interviews were conducted over Zoom, and one was conducted over the phone. Semi-structured in-depth interviews, lasting 30-40 mins, were conducted with participants, allowing them to share their thoughts, experiences, and perspectives regarding their experiences of diagnosing South Asian Canadians living with dementia. The interviews were conducted in English, audio recorded, and then transcribed using Otter AI, an online transcription software. Pseudonyms were assigned to participants based on their self-identified background and profession, with "MD-SA" followed by a numerical identifier used for South Asian participants and "MD-NSA" followed by a numerical identifier for non-South Asian participants. This system ensured anonymity while allowing for distinctions between participant groups in the analysis. Anonymized transcripts were uploaded to NVivo 14 for analysis.

5.3 Data Analysis

The data were analyzed using reflexive thematic analysis. Reflexivity is integral to refining thematic analysis methodologies (Braun & Clarke, 2006). Braun and Clarke developed thematic analysis as an inherently reflexive method, emphasizing subjectivity as a resource rather than a hindrance to knowledge production (Braun & Clarke, 2019). This led to "reflexive thematic analysis," highlighting the centrality of researcher subjectivity and reflexivity in the analytic process (Braun et al., 2019).

Steps of Conducting Reflexive Thematic Analysis

1. Familiarizing Oneself with the Data: Familiarizing oneself with the data involved reading and re-reading transcripts to understand the content and context. Notes were made during and after listening to recordings to capture initial impressions. Transcripts were reviewed for accuracy and familiarization, and audio recordings were referred to during coding to capture emotions or language nuances.

2. Coding: Initial coding was conducted using NVivo 14, identifying key concepts and ideas (Figure 4). This involved systematically labelling and categorizing data segments based on their meaning and relevance. Codes were reviewed, collapsed, and renamed to ensure alignment with the data. For example, the "Acceptance of Diagnosis" code was changed to "Reaction to Diagnosis" as the coded sections highlighted the different reactions of family members and patients as described by the physicians compared to the focus on acceptance of diagnosis.

Figure 4: Example of Codes from NVivo

Codes			
Name	Description	Sources	References
Accessing Home Care and Long Term	Physicians discussion with patients around home care and LTC	10	22
Delay in Diagnosis Seeking	Physician note a delay in diagnosis seeking for SA communities	5	5
Difficulty in Diagnosis	Challenges such as language, gender dynamics etc.	4	7
Disclosing Diagnosis	How physicians disclose diagnosis and the conversations they have with families at the time of diagnosis	11	20
Acceptance of Diagnosis	Family and PLWD reaction to diagnosis	3	4
Disclosing to PLWD	Discussion around disclosing the diagnosis to the PLWD; family potentially wanting to hide the diagnosis	4	5
Family Dynamics	How the family members communicate and work around the diagnosis, decision making as a unit versus individual	9	13
First Gen vs Second Gen	Understanding of dementia for first gen versus second gen SA	3	4
Improvements for inclusive care	Physicians discuss the potential improvements that can support the healthcare to be more inclusive and culturally sensitive.	10	10
Lessons Learned	What physicians have learned about providing diagnosis to SA communities	9	11
Minimization of Symptoms	Patient or family member downplay the symptoms and try to minimize the extent of symptoms	3	6
Process of Diagnosis	The steps physicians take for diagnosis.	13	29
Referred due to language	Physicians mentioned they would get patients referred because of language	1	1
Resources for South Asian Families	Physicians knowledge of resources for SA families, in general and what resources they use/refer patients to.	11	19

3. Themes: Codes were grouped into overarching themes that captured patterns and concepts within the data. An iterative comparison and refinement process identified themes, including recurring patterns, cultural motifs, and contextual insights.

4. Reviewing Potential Themes: Themes were critically reviewed for coherence, relevance, and alignment with the research objective. This involved assessing their ability to address research questions and provide meaningful insights. Discrepancies were resolved through further analysis and committee discussions, with transcripts reviewed again to extract relevant quotes.

5. Defining and Naming Themes: Finalized themes were clearly defined and labelled to capture their essence succinctly. Descriptive labels ensured consistency and clarity in presenting findings, facilitating the organization and presentation of themes in the final analysis.

5.4 Ethics

This study adhered to the University of Waterloo's ethics guidelines and received clearance (ORE #45805). Participants received a "Letter of Information" detailing the study, and verbal consent was recorded at the start of each interview, followed by written documentation.

5.5 Findings

Findings from the interviews with 13 physicians highlight the unique challenges faced by healthcare providers and illuminate the cultural, systemic, and practical barriers in dementia care. The findings are organized into four main themes: barriers and challenges in dementia diagnosis and care, cultural and generational influences, communication and disclosure, and improving inclusivity and resources. Each theme is discussed in detail to provide an understanding of the complexities in dementia care for South Asian Canadians.

5.5.1 Barriers and Challenges in Dementia Diagnosis and Care

The participants highlight the numerous barriers and challenges rooted in cultural expectations, systemic inadequacies, and practical constraints faced by their patients and their families from South Asian communities. A significant barrier is the delay in seeking a diagnosis due to cultural beliefs and a lack of awareness, leading to patients being diagnosed at more advanced stages. This delay often stems from attributing symptoms to normal aging, preventing timely medical intervention, and exacerbating the challenges in managing dementia effectively.

"I feel like there's a lot more later recognition in South Asian communities rather than early on." - MD-SA 01

Diagnosing dementia in South Asian patients is particularly challenging due to cultural and practical factors. Participants in the study noted that traditional gender roles could obscure symptoms in men who have not typically engaged in household tasks, making functional impairments less noticeable. For example, one physician explained that cultural roles within families can complicate the identification of functional impairments:

"So, depending on where they're from, and the specific values of the family that I'm speaking to, you find some of the time the cultural roles of the spouses make it such that it's difficult to tell when someone's functionally impaired."- MD-NSA01

Additionally, lower levels of education in some populations can confound the use of formal cognitive screening tests, particularly among individuals who have worked in manual labour without extensive formal education. This nuanced understanding is essential for accurately diagnosing dementia in this culturally diverse population.

"There's lower levels of education... a lot were farmers or manual laborers in their home country, or they were educated and then worked labor jobs when they moved here. So, I mean, those are some challenges with the lower level of education—especially when it comes to doing cognitive tests"- MD-SA 06

Minimization of symptoms by both patients and their families is another significant barrier. Symptoms of cognitive decline are often downplayed or attributed to normal aging, delaying medical intervention. This cultural tendency to minimize symptoms prevents timely diagnosis and intervention, exacerbating the challenges in managing dementia effectively.

"I've found a pattern of at least in my patients of minimizing a lot of the deficits that come with dementia and attributing it either to aging or just downplaying it altogether."- MD-SA 02

The need for culturally sensitive approaches often complicates the process of diagnosing dementia in South Asian patients. Standard diagnostic tools are not appropriate due to language barriers and different cultural understandings of cognitive decline.

"I don't feel comfortable doing a MoCA in Hindi or Punjabi, and that would not be a fair examination." – MD-SA 03.

Participants discussed significant barriers in accessing home care and long-term care services. They highlighted how cultural preferences for caring for loved ones at home often conflict with the practical realities of providing adequate care. Many participants noted that the limited availability of culturally appropriate care services and the high cost of private care further restrict options, making it challenging for families to manage dementia care effectively at home. As MD-SA04 shared, these challenges often lead to a cycle of hospital readmissions:

"Nine out of 10 times, these patients come right back to the hospital within a month because families realize that they just cannot manage."- MD-SA 04

These insights illustrate the complex interplay between cultural expectations, systemic gaps, and the practical demands of caregiving for individuals with dementia.

In summary, barriers to dementia diagnosis and care in South Asian communities include cultural beliefs that delay seeking help, a tendency to attribute cognitive decline to normal aging, and traditional gender roles that obscure symptoms. Additionally, lower educational levels complicate the use of formal assessments, while symptom minimization by families and limited access to culturally sensitive services further hinder effective care.

5.5.2 Cultural and Generational Influences

The participants discussed how family decision-making in South Asian communities often involves collective input rather than individual autonomy, complicating diagnostic and treatment processes. While this collective approach can streamline decision-making by designating a family spokesperson or primary care partner, it can also place a disproportionate

burden on that individual, leading to burnout, especially when external support is limited. One participant described how decision-making within families tends to happen quickly and collectively:

"In the patient's family, [...] the deferral of decision making happens a lot faster...it's a family decision making or like that spokesperson for the family."- MD-SA03

Another physician noted that families often designate a primary care partner early on, explaining:

"I find I don't chase as much when it comes to South Asian communities because that person has already taken on the mantle of the primary care partner."- MD-NSA02

Participants highlighted how this dynamic can simplify interactions with healthcare providers, as there is usually a clear point of contact. However, they also emphasized that this approach often results in the primary care partner bearing significant caregiving responsibilities, which can contribute to burnout without adequate support.

"Oftentimes, with other families, we're chasing down a collateral history, trying to find someone to provide transportation or coordinate care. But I find I don't have to chase as much when it comes to South Asian communities—because there's usually already someone who has taken on the mantle of primary care partner. For better or worse, that role is assumed early on. Sometimes it doesn't go well for them—it can be incredibly stressful, there's burnout, financial strain, and more."- MD-NSA 02

The participants also emphasized that generational differences have a significant impact on the approach to dementia care. First-generation immigrants maintain traditional practices, often living in multi-generational households, which can create a support system for dementia

care. In contrast, second-generation families often adopt Western practices, which can lead to challenges in providing in-home care. However, second-generation families are more aware of the condition and tend to seek diagnosis and resources.

"There's a lot more awareness among the second generation of wanting to seek out a diagnosis...they are more well-read; they do look for more resources." - MD-SA 05

The comprehension and acceptance of dementia vary widely. The participants discussed a lack of awareness and understanding of the progression and impact of dementia. Cultural perceptions of aging and cognitive decline can cloud the experience of dementia, requiring culturally sensitive explanations to bridge the gap between traditional beliefs and modern medical understanding.

Physicians noted that cultural and generational factors significantly influence dementia care among their patients. Family decision-making often involves collective input, which can complicate the diagnostic and treatment processes and potentially lead to caregiver burnout. First-generation patients tend to rely on traditional practices within multigenerational households, while second-generation patients often exhibit greater awareness of dementia and actively seek diagnoses and resources. Physicians emphasized that a limited understanding of dementia's progression is a challenge that requires culturally sensitive communication to bridge the gap between traditional beliefs and modern medical perspectives. While this challenge is not unique to South Asian communities and may be observed universally, physicians noted that culturally specific factors, such as traditional health beliefs and stigma, further complicate discussions about dementia within this population.

5.5.3 Communication and Disclosure

Effective communication and disclosure of a dementia diagnosis in South Asian patients pose unique challenges that intersect cultural, generational, and practical dimensions. Disclosing the diagnosis, accepting the diagnosis, and the approach to informing patients of these complexities shape the physician-patient interaction. The participants noted how their patients' families frequently prefer to shield their loved ones from the diagnosis. This necessitates a careful and nuanced approach to ensure that the ethical obligation to inform the patient is balanced with family wishes and the patient's capacity to understand.

"A lot of times, families do not want the diagnosis shared. So that is the biggest challenge that you face."- MD-SA 03

"Most of the time, they don't see the value of them [the patient] knowing. And they don't want to stress them out."- MD-SA 07

Acceptance of the diagnosis varies widely and is often influenced by the families' level of health literacy and previous exposure to dementia. In some cases, families may outright reject the diagnosis, potentially impacting the management and support the patient receives. For people living with dementia, understanding and accepting their diagnosis can be complicated by cognitive decline and cultural stigmas associated with dementia.

"I don't think patients have a good grasp of what this actually means when you first tell them that they have dementia or how this is going to impact the remainder of their life dramatically."- MD-SA 08

The approach to communicating a dementia diagnosis involves not only clarity but also cultural sensitivity. Simplifying the medical jargon and framing the conversation in relatable

terms is crucial. Despite these challenges, it is critical to ensure that people living with dementia and their families understand the diagnosis and its implications. Providing resources and support systems, such as connecting families with the Alzheimer Society, is a common practice among physicians to help families navigate the complexities of dementia care. MD-SA 04 uses the Global Deterioration Scale, a tool that categorizes the progression of dementia into seven stages, to provide a clear framework, explaining that since it is a numerical scale, it helps put the diagnosis in perspective.

"How do you articulate this diagnosis? So it takes a lot of going back and forth between Punjabi and English to find that balance to convey the diagnosis."- MD-SA 02

In summary, effective communication of a dementia diagnosis among South Asian patients presents unique challenges influenced by cultural and generational factors. Physicians noted that families often prefer to shield patients from the diagnosis, complicating the physician's ethical obligation to inform them. Participants discussed that acceptance of the diagnosis usually varies based on family health literacy and prior exposure to dementia. Participants shared that families with greater awareness or previous experience with the condition were more likely to accept the diagnosis. In contrast, others without such exposure struggled to come to terms with the diagnosis. Clear and culturally sensitive communication is essential, requiring simplification of medical jargon and relatable framing. Physicians often provide resources and support to help families navigate dementia care, utilizing tools like the Global Deterioration Scale for clarity.

5.5.4 Improving Inclusivity and Resources

Physicians emphasized the importance of culturally inclusive care and highlighted the limited resources available to their patients. During the interviews, they acknowledged the significance of culturally sensitive communication and tailored support.

“Sometimes, we just make recommendations for activities that can be good for cognition that relate to their culture. We might do something as simple as writing an actual prescription on a pad for social engagement as a way to legitimize the talking point.”-

MD-NSA 02

Practicing cultural humility for healthcare providers is crucial in this context. MD-SA 02 underscored the need for such training, suggesting that accessible and flexible formats like recorded lectures or conference sessions could enhance the practice of cultural humility of healthcare providers. This approach ensures that training is practical and can fit into the busy schedules of healthcare professionals.

“Realistically, what kind of training would be most accessible to people? It’s often like self, like lectures and stuff that are recorded, that you can access on your own time, or if it’s built into conferences.”- MD-SA 02

Additionally, some providers leverage personal connections and shared cultural backgrounds to foster rapport with patients, thereby significantly enhancing the patient experience. MD-SA 09, who speaks Hindi and Punjabi, shared their positive experiences of greeting the patients in their native language, highlighting the importance of linguistic and cultural familiarity in building trust and understanding: *“For me, you know, to even go in and*

greet them in their language and ask them how they are doing, you know, just right away creates rapport.”

Physicians' efforts to provide inclusive care have also yielded several key lessons. One significant insight is the importance of involving the entire family in the care process, recognizing their interconnectedness with the community to open avenues for resources and support. Participants highlight the importance of continuous follow-up and support, which are vital, allowing healthcare providers to address evolving needs and concerns.

“Treating the family as a whole, but also treating the family as a part of their community. Because ultimately, a lot of the times, I’m seeing they’re quite interconnected with the community.”- MD-NSA 01

MD-SA 05 emphasized the importance of regular follow-ups, noting that it takes time for patients and families to absorb the diagnosis and understand its implications. Regular interactions enable healthcare providers to address evolving needs and concerns, thereby reinforcing understanding and providing ongoing support.

“So I do try to follow people typically every three to six months to provide ongoing support and help them because it takes time to absorb the diagnosis understand what’s going on.”- MD-SA 05

Additionally, the role of non-medical interventions has been highlighted as vital. MD-NSA 02 shared how recommendations for activities, such as social engagement, can be legitimized through actual prescriptions.

Despite these efforts, a notable gap remains in culturally specific resources for South Asian families. Many providers rely on community resources and social workers to bridge this

gap, emphasizing the importance of connections with community agencies. As MD-SA03 noted, *"The organizations don't have a lot of culturally specific ones [programs],"* highlighting the need for more formal and widely recognized resources beyond mere translation to ensure South Asian families receive comprehensive care and assistance.

Participants mentioned that in certain provinces, there is a lack of South Asian-specific services, with reliance primarily on translated resources, such as pamphlets and informational documents, provided by local health organizations. MD-SA08 noted, *"I don't think I had anything that was culturally sensitive towards South Asians that I was aware of."* This highlights the need for culturally adapted services to meet the specific needs of South Asian families. Telling patients to seek support outside the home often fails, as many feel self-conscious about engaging in external activities. This highlights the importance of normalizing in-home care services and involving multiple family members in the care process to prevent caregiver burnout and maintain healthy family relationships.

5.6 Discussion

The findings of this study reveal that while some challenges in dementia diagnosis and care are universal across all communities, others are uniquely shaped by the cultural and social contexts of South Asian families. Challenges include delays in seeking a diagnosis due to the minimization of symptoms, difficulties accessing home care and long-term care services, and the emotional and logistical burdens placed on family caregivers. However, South Asian communities face additional culturally specific barriers, such as the stigma surrounding dementia, traditional gender roles that obscure symptoms, and a reliance on collective family decision-making that complicates diagnostic and care processes.

Another factor contributing to delays in recognizing dementia symptoms is the structure of multigenerational households, which are common in many South Asian families. In these settings, early lapses in memory or functional ability may go unnoticed or be compensated for by other family members. Others may take over tasks such as cooking, financial management, or phone communication without explicitly acknowledging the cognitive decline. As a result, the individual's loss of independence may not immediately disrupt household routines or raise concern, thereby masking early symptoms and delaying formal assessment and diagnosis. While these familial support structures offer many benefits, they can unintentionally obscure the early signs of dementia, contributing to diagnostic delays (Sagbakken et al., 2018; Jutlla, 2013; Hossain et al., 2020). These findings align with previous literature, suggesting that strong caregiving networks, while protective, can also complicate timely symptom recognition and access to care.

The experiences of physicians diagnosing dementia in South Asian Canadian families reveal several insights that enhance understanding of the unique experiences in this context. One particularly noteworthy finding is the difficulty in diagnosing dementia in men due to traditional cultural norms and roles. As the participants highlighted, traditional gender roles often prevent men from engaging in household tasks, making it challenging to identify functional impairments typical of dementia. This issue is compounded in populations where men primarily work in manual labour without extensive formal education, further complicating the diagnostic process previously discussed in the literature (Sagbakken et al., 2018). This underscores the necessity for physicians to adopt a nuanced approach, considering cultural roles and expectations to diagnose dementia in South Asian men accurately.

Another significant observation is the increased awareness and proactive approach to dementia among second-generation South Asian Canadians. Physicians noted that second-generation families are generally more informed about dementia and more likely to seek out diagnoses and resources compared to the first-generation. This aligns with the broader literature on second-generation immigrant communities, which often demonstrates a greater understanding and engagement with healthcare systems due to increased exposure to host-country education, resources, and health campaigns (Ng, 2010; Rishworth et al., 2022). This increased understanding among second-generation families may lead to earlier dementia diagnoses and improved management, ultimately enhancing patient and family outcomes.

The study also reveals a gap in understanding the progression of dementia from cognitive decline to behavioural symptoms among South Asian families. While there is a general awareness of dementia, families often fail to recognize the behavioural and psychological symptoms as part of the disease's progression. MD-SA 06 noted that many South Asian families manage initial symptoms of cognitive decline within the home, only seeking medical help when the cognitive and other behavioral symptoms worsen significantly. This finding aligns with the literature on normalizing dementia symptoms in South Asian communities (Brijnath, 2022). However, it also highlights the need for better education and support to help families understand and manage the full spectrum of dementia symptoms.

Physicians' lessons in this study emphasize the importance of culturally sensitive communication and continuous support, including cultural humility (Greene-Morton & Minkler, 2020). They also underscored the need for cultural humility training, suggesting flexible and accessible formats such as recorded lectures or conference sessions. This approach enables healthcare providers to accommodate busy schedules while fostering cultural humility.

Additionally, physicians' experience building rapport through linguistic and cultural familiarity highlights the importance of personalized care in improving patient trust and engagement.

Although the interview guide did not explicitly ask physicians whether they disclosed the dementia diagnosis to patients, some participants shared their general views on the matter. A few physicians expressed hesitation about disclosing the diagnosis directly to the person living with dementia, particularly when they believed it would cause distress or confusion without offering therapeutic benefit. This perspective was often framed in terms of the desire to protect the patient from emotional harm. In contrast, other physicians emphasized the ethical obligation to inform the individual, stating that patients have the right to know their diagnosis and participate in care decisions. These divergent views reflect broader debates in dementia care around autonomy, beneficence, and culturally sensitive communication, particularly in cases where families request that the diagnosis be withheld from the patient. Future research should investigate how physicians make these disclosure decisions in practice and how cultural expectations, family dynamics, and ethical obligations influence whether and how a diagnosis is communicated to individuals living with dementia.

Physicians' perspectives on the barriers and challenges in diagnosing and managing dementia in South Asian communities are consistent with findings from existing literature on the subject. The delay in seeking a diagnosis due to cultural beliefs and lack of awareness, as described in the study, is well-documented in the literature (McCleary et al., 2012; Mukadam et al., 2011). This delay is often exacerbated by the minimization of symptoms, as noted by physicians in this study, where cognitive decline is attributed to normal aging, preventing timely medical intervention (Hossain et al., 2020).

Language barriers and the reliance on family members as translators further complicate the diagnostic process. This issue aligns with findings by McCleary et al. (2012) and Neilsen et al. (2011), who noted that untrained family translators can lead to miscommunications and incomplete assessments. The need for culturally sensitive diagnostic tools is critical, as standard tools may not effectively capture the nuances of dementia symptoms in non-English-speaking populations (Canevelli et al., 2021; Neilsen et al., 2011).

In addition to language and education, cultural knowledge and context can significantly influence performance on standardized cognitive assessments such as the MMSE or MoCA. For example, items that rely on familiarity with Gregorian calendars, Western schooling references, or culturally specific orientation tasks may disadvantage individuals educated through non-Western systems, such as Koranic or oral learning traditions (Sagbakken et al., 2018). Individuals may score lower not due to cognitive impairment but because the tools fail to reflect their cultural and educational backgrounds. Research has highlighted the limitations of commonly used screening tools in multicultural settings, supporting the use of alternative assessments, such as the Rowland Universal Dementia Assessment Scale (RUDAS), which are designed to reduce cultural and educational bias (Naqvi et al., 2015). This highlights the need for culturally adapted or alternative assessment tools that more effectively account for diverse knowledge systems and lived experiences.

The stigma associated with dementia, which hinders effective communication and delays diagnosis, is another significant barrier identified in this study. As noted by Hossain et al. (2020) and Mukadam et al. (2011), the fear of social condemnation and the tendency to hide symptoms due to shame can prevent families from seeking timely medical help. This stigma is deeply

rooted in cultural and religious beliefs, which can lead to misattributions of dementia symptoms to other conditions or spiritual causes (Hossain et al., 2020; McCleary et al., 2012).

Physicians in this study described challenges in accessing home care and long-term care services and the stigma associated with utilizing these services. While access barriers such as wait times, cost, and availability are universal issues in Canada, participants highlighted unique cultural barriers in South Asian communities, including stigma and shame tied to placing a family member in long-term care (Canadian Institute for Health Information, 2023). This expectation to provide care within the family often conflicts with the practical realities of managing dementia. Studies have shown that many South Asian families view institutional care negatively, associating it with a lack of familial support and cultural disconnection (Canadian Family Physician, 2023). These findings emphasize the need for culturally sensitive care models that address both universal and community-specific challenges in dementia care.

These challenges are consistent with the literature on the practical and cultural constraints faced by South Asian families in managing dementia care at home (Giebel et al., 2015; Botsford et al., 2012). The preference for caring for loved ones at home often conflicts with the realities of providing adequate care, mainly due to the limited availability of culturally appropriate long-term care (LTC) homes and services in Canada. Arya and Tong (2023) highlight how South Asian seniors in a large Canadian city perceive institutional care negatively, associating it with cultural disconnection and a lack of familial support. This underscores the need for more affordable, culturally sensitive care models that meet the practical needs of families and align with their cultural expectations and values.

As is consistent with the broader literature on providing dementia care (Brodaty & Donkin, 2009; Livingston et al., 2017), the study also emphasizes the importance of continuous follow-up and support. Regular interactions allow healthcare providers to address evolving needs and concerns, reinforcing understanding and offering ongoing support. This approach is critical for managing the chronic and progressive nature of dementia, as highlighted by Brijnath (2022). The role of non-medical interventions, such as social engagement activities recommended by physicians in the study, also aligns with the literature on holistic dementia care, emphasizing the importance of addressing the social and emotional needs of patients and their families (Hackett et al., 2019; van Beek et al., 2011).

In conclusion, physicians' experiences diagnosing dementia in South Asian Canadian families provide valuable insights into the unique challenges and barriers in this context. These findings underscore the importance of culturally sensitive diagnostic practices, enhanced education and support for families, and ongoing follow-up and support from healthcare providers. Addressing these challenges is essential for improving the diagnostic experience and outcomes for South Asian Canadians living with dementia and their care partners.

5.7 Future Implications

This study highlights the need for further research into the diagnostic phase of dementia within South Asian communities. Future investigations should include physicians from diverse cultural backgrounds to capture a broader range of diagnostic experiences and conduct cross-cultural comparisons among South Asian subgroups. Longitudinal studies that track patients from symptom recognition to diagnosis will provide valuable insights into the challenges of dementia care.

Clinically, the findings emphasize the importance of cultural humility in healthcare. Training programs should incorporate cultural humility related to the specific challenges faced by South Asian patients. Developing culturally sensitive diagnostic tools and integrating community health workers can enhance understanding and support for families during the diagnostic process.

At the community level, increasing awareness and education about dementia is crucial. Initiatives such as workshops and support groups can help reduce stigma and promote early diagnosis. Collaborating with community leaders to provide resources for recognizing early symptoms and creating dementia-friendly spaces will further support individuals living with dementia and their families.

5.8 Strengths and Limitations

This study addresses a gap in the literature by examining the diagnosis phase of dementia within South Asian communities through physicians' experiences. It offers valuable insights into the unique cultural, systemic, and practical challenges faced in diagnosing dementia among South Asian Canadians. The study benefits from a diverse participant pool, including family physicians and geriatricians with varying experience levels and practice settings, enriching the findings and providing a comprehensive view of diagnostic challenges.

However, the study has limitations. Most participating physicians were from South Asian communities, which, while providing deep cultural insights, may have excluded perspectives from those of different cultural backgrounds. This limitation could result in a lack of broader experiences and challenges faced by all healthcare providers, as non-South Asian physicians might encounter different barriers or apply alternative diagnostic approaches not examined in this study.

5.9 Conclusion

In conclusion, this study sheds light on the experiences of physicians diagnosing dementia in South Asian Canadian families, highlighting the unique cultural, systemic, and practical challenges they face. The findings reveal significant barriers, including cultural beliefs that delay diagnosis, the impact of generational differences, and the complexities of communicating a dementia diagnosis. While the study contributes valuable insights, it also identifies the need for culturally sensitive practices and training to enhance understanding and support for families. Future research should examine the diverse physician experiences and implement community initiatives to raise awareness and reduce the stigma surrounding dementia, ultimately aiming to improve care for South Asian Canadians living with dementia.

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Chapter Six: "*Creating Awareness That Truly Resonates*": Experiences of Community Support Services Supporting South Asian Canadians Living with Dementia and Their Care Partners

6.1 Introduction

This study examines the experiences and perspectives of community support service employees as they deliver services to South Asian communities. Examining the unique challenges these service providers face aims to illuminate the complex dynamics influencing care delivery and support within this demographic. The analysis is situated within the broader context of cultural beliefs, language barriers, and the social stigma surrounding the need for support services, which collectively influence the interactions between South Asian clients, their families, and community support staff.

Community support services (CSS) play a crucial role in assisting individuals living with dementia and their care partners, particularly during the post-diagnosis stages when caregiving responsibilities intensify and non-clinical supports are required. In the context of CSS, post-dementia diagnosis involves utilizing available non-medical resources within the local community (Alzheimer's Association, 2021). These services provide physical, mental, and social engagement for individuals with dementia and their care partners. This encompasses activities like art classes, exercise groups, memory cafes, and support groups (Alzheimer's Society, 2021). Community centers and similar establishments offer platforms for social interaction and cognitive stimulation (HealthinAging.org, 2021). The primary aim of accessing these services is to improve the overall well-being and quality of life of individuals with dementia while also providing valuable support for care partners (Alzheimer's Association, 2021). Despite their critical role, CSS face considerable challenges in addressing the unique needs of South Asian

Canadians, a population often encountering socio-cultural barriers to accessing these services (Siette et al., 2023; Poole et al., 2021).

Caregiving in South Asian communities is traditionally rooted in cultural expectations and norms, with the responsibility often falling on family members. These caregiving roles are influenced by values of filial piety, where seeking external assistance may be perceived as failing to fulfill familial obligations (Botsford et al., 2011). The stigma surrounding dementia further compounds barriers to accessing CSS. Families may fear that engaging with these services could lead to gossip or negative perceptions within their community, deterring them from seeking much-needed support (Hossain et al., 2020; McCleary et al., 2012). Additionally, concerns about privacy, confidentiality, and cultural mismatches exacerbate these challenges, such as the lack of language-specific resources or services that cater to religious or dietary needs (Jutlla, 2011). While healthcare services are often perceived as essential and unavoidable, CSS may be viewed as less critical or optional, which can create further disparities in service utilization. Literature on healthcare services for South Asians has focused mainly on pre-diagnosis issues, such as barriers to dementia awareness and delays in diagnosis, leaving a notable gap in understanding the role of CSS in supporting families post-diagnosis (Blakemore et al., 2018; Islam & Akter, 2021; Hossain et al., 2020; McCleary et al., 2012).

Post-diagnosis care occupies a liminal space between healthcare and CSS, with the former addressing medical and diagnostic needs and the latter focusing on social and practical supports. While “post-diagnosis care” is often used interchangeably, this study situates CSS as the primary focus, given its role in providing non-clinical, community-based support.

Recognizing this distinction is crucial, as CSS is uniquely positioned to address the caregiving burden and improve the quality of life for individuals and families navigating dementia.

Despite the growing need for culturally relevant CSS, research on their availability and effectiveness for South Asian communities in Canada remains limited. Studies on dementia care often highlight systemic barriers, such as the lack of culturally tailored support and the underrepresentation of ethno-cultural perspectives in service planning and delivery. The Canadian Dementia Strategy, along with reports from the Alzheimer Society of Canada, has underscored the importance of addressing these gaps and advocating for inclusive, culturally relevant supports to ensure equitable access to care.

Given these gaps in the literature, this study aims to understand the experiences of community support organization employees as they deliver services to South Asian Canadians living with dementia. Examining how various socio-cultural factors shape these experiences aims to identify strategies that may enhance service delivery and potentially improve outcomes for people with dementia and their families.

6.2 Methods

This study utilized an interpretive phenomenological approach to understand the experiences of community support services employees providing services to South Asian Canadians living with dementia (Frechette et al., 2020). This methodology is well-suited for examining the subjective and complex nature of these experiences, emphasizing how cultural beliefs, social dynamics, and personal interactions influence service delivery. Interpretive phenomenology allows a deep understanding of how employees navigate cultural nuances,

language barriers, and social stigma (Frechette et al., 2020). It provides insights into the challenges they face and the strategies they employ to support this community.

i) *Setting, Context, and Recruitment:* Recruitment for this study took place in three Canadian provinces: Ontario, Alberta, and British Columbia. Purposive sampling was used to identify organizations that provided dementia-related services. The process was facilitated by collaboration with various organizations within each province and leveraging previously established connections with specific organizations. Recruitment methods included physical flyers and electronic media, such as emails and social media posts, to reach a broader audience. Snowball sampling was also used to further connect with community support services once connections were established with initial participants.

ii) *Eligibility Criteria:* To be eligible for participation in the study, individuals had to meet the following criteria:

- Be an employee of a community support organization involved in service delivery, including to South Asian communities.
- Be able to provide informed consent to participate in the study.

iii) *Sample:* The study aimed for 5-7 participants (Creswell, 2007). Fourteen employees from community support services participated in this study (Table 9). Ten participants were from Ontario, two from Alberta, and two from British Columbia. These participants represented a range of community support services across the three provinces, all providing support services and advocacy for people living with dementia and their care partners.

Table 9: Sociodemographic Characteristics of Participants (Employees of Community Support Services)

Characteristics	Employees of Community Support Services (n=14)	Percentage (%)
Gender		
Female	13	92.9
Male	1	7.1
Age		
20-29	2	14.3
30-39	5	35.7
40-49	3	21.4
50-59	4	28.6
Province		
Ontario	10	71.4
British Columbia	1	7.1
Alberta	2	14.3
Ethnicity		
South Asian	9	64.3
White	5	35.7
Primary Language of Communication with Clients		
English	14	100
Other Languages Spoken when working with Clients		
Hindi	6	42.9
Punjabi	7	50.0
Urdu	3	21.4
Gujarati	1	7.1
Years Employed with the Organization		
<1 year	1	7.1
1-4 years	5	35.7
5-9 years	4	28.6
10+ years	4	28.6

v) **Data Collection:** Data collection was conducted between March 4, 2024, and April 9, 2024.

Data was collected through semi-structured, in-depth interviews held virtually using the Zoom online videoconferencing platform. The interview questions focused on the experiences of community support organization employees in providing services to South Asians living with dementia and their care partners. All interviews were conducted in English, audio-recorded, and

lasted an average of 30 minutes. Interviews were transcribed using Otter AI. Transcripts were reviewed to ensure accuracy. Anonymized transcripts, with pseudonyms assigned, were then uploaded to NVivo 14 for analysis.

6.3 Data Analysis

The data were analyzed using reflexive thematic analysis. Reflexivity is integral to refining thematic analysis methodologies (Braun & Clarke, 2006). Braun and Clarke developed thematic analysis as an inherently reflexive method, emphasizing subjectivity as a resource rather than a hindrance to knowledge production (Braun & Clarke, 2019). This led to "reflexive thematic analysis," which highlights the centrality of the researcher's subjectivity and reflexivity in the analytic process (Braun et al., 2019).

Steps of Conducting Reflexive Thematic Analysis for South Asian Dementia Research

1. Familiarizing Oneself with the Data: Familiarizing oneself with the data involved reading and re-reading transcripts to understand the content and context. Notes were made during and after listening to recordings to capture initial impressions. Transcripts were reviewed for accuracy and familiarity, and audio recordings were referenced during coding to capture emotions and language nuances.

2. Coding: Initial coding was conducted using NVivo 14, identifying key concepts and ideas. This involved systematically labelling and categorizing data segments based on their meaning and relevance. Codes were reviewed, collapsed, and renamed to ensure alignment with the data (Figure 5). For example, the "Managing Services for SA Families" code was changed to "Navigating Care for SA Communities," as the coded sections highlighted the need to navigate the services with cultural nuances to ensure they were appropriately delivered to their clients.

Figure 5: Example of edits made to the codes to ensure they reflected the data

- ~~Managing Services for SA Families~~-Navigating Care for SA communities
- No Specific Services
- Planning for Inclusivity
- Recognizing the Gap
- Services for SA Communities
 - SA Awareness and Uptake of Services
- Services offered
- Successful Collabs or Participation
- ~~Stigma in Communities~~²-Understanding of Dementia
 - Difference in Understanding of Dementia 1st vs 2nd Gen
- Understanding the ~~Culture~~-Cultural Influence
 - Long Term Care
 - Role of Women in Caregiving

3. Themes: Codes were grouped into overarching themes that captured patterns and concepts within the data. An iterative process of comparison and refinement identified themes, including recurring patterns, cultural motifs, and contextual insights.

4. Reviewing Potential Themes: Themes were critically reviewed for coherence, relevance, and alignment with the research objective. This involved assessing their ability to address research questions and provide meaningful insights. Discrepancies were resolved through further analysis and committee discussions, with transcripts reviewed again to extract relevant quotes.

5. Defining and Naming Themes: Finalized themes were clearly defined and labelled to capture their essence succinctly. Descriptive labels ensured consistency and clarity in presenting findings, facilitating the organization and presentation of themes in the final analysis.

6.4 Ethics

This study adhered to the University of Waterloo's ethics guidelines and received clearance (ORE #45805). Participants received a "Letter of Information" detailing the study, and verbal consent was recorded at the start of each interview, followed by written documentation.

6.5 Findings

The findings of this study offer a nuanced understanding of the experiences and challenges faced by community support organization employees as they deliver dementia-related services to South Asian Canadians and their care partners across Ontario, British Columbia, and Alberta. The key themes that were identified—**Engaging with South Asian Communities**, **Cultural Sensitivity and Awareness in Service Delivery**, and **Challenges and Future Directions**—highlight the complexities of tailoring care to meet this population's cultural and linguistic needs of this population. These themes collectively present strategies, barriers, and opportunities for improving dementia care for South Asian communities.

6.5.1 *Engaging with South Asian Communities*

Participants emphasized the importance of proactive community engagement in raising awareness and improving service uptake. Strategies included collaborating with local organizations, leveraging ethnic media, and participating in cultural and religious events. These approaches fostered trust, built relationships, and connected with South Asian families in familiar and comfortable settings.

Collaborations with local organizations enabled the co-delivery of dementia education sessions in multiple languages, ensuring accessibility for diverse audiences. Participants described successful partnerships with South Asian media outlets, including radio stations and newspapers, to promote health fairs and events. These partnerships significantly increased

turnout and led to direct referrals to programs. For example, setting up booths at gurdwaras, temples, and community festivals provided opportunities to educate attendees in culturally appropriate ways.

“Engaging in community events and establishing partnerships with local agencies have significantly helped us in providing culturally sensitive services and raising awareness about dementia.” – Ratan, Community Support Organization Employee.

Some participants adopted informal outreach methods, such as mingling with attendees at community events while wearing their organization’s branding. This approach fostered personal connections and resulted in invitations to present at mosques and other venues. Tailored messaging also played a crucial role in overcoming stigma. Participants avoided using terms like "dementia" or "Alzheimer's" in outreach campaigns, opting instead for terms like "brain health" to encourage participation.

Interactive activities like making healthy salads or practicing finger yoga were also used to engage community members in less intimidating and more relatable ways. These innovative approaches made awareness sessions more accessible and meaningful to South Asian audiences.

“Through the Gurdwara [Sikh place of worship] booths, we collaborate with gurdwaras and other organizations to create awareness about dementia. This collaboration has been crucial in reaching out to the community effectively.” – Jaspreet, Community Support Organization Employee.

The feedback from these efforts was overwhelmingly positive. Initiatives such as monthly social cafes created supportive spaces where individuals living with dementia and their

care partners could connect and access support. Addressing practical barriers, such as providing bus tickets to facilitate participation, further enhanced engagement.

“I just walked around and was one of them, and I connected... that connection led to a mosque presentation with 70 attendees and now we run a monthly social café with community members. This is how community outreach has worked for me and the organization—we're seeing real changes, people are now coming to us for services.”-

Kadira, Community Support Organization Employee

6.5.2 Cultural Sensitivity and Awareness in Service Delivery

Cultural sensitivity was pivotal in delivering effective services. Participants emphasized the importance of adapting programs to reflect cultural practices, such as including holidays like Diwali and Ramadan instead of Christmas in educational materials. These culturally tailored approaches increased relevance and engagement with South Asian clients.

“Creating that awareness within the society is something that works for this mainstream population will not work for the South Asian population. For example, in education, I will change up the side so that they're more meaningful, like preparing for holidays education, which I changed up. So it's not surrounding Christmas and stuff, but rather Diwali and Ramadan.” – Jaspreet, Community Support Organization Employee.

Language barriers were frequently cited as a significant challenge. Participants shared how direct translations often led to misunderstandings. For example, the word “dementia” was inaccurately translated as “madness”, perpetuating stigma and confusion. Community consultations were critical for ensuring accurate and culturally appropriate translations.

“When we were translating the awareness documentation, we spoke about it. Because as you know, I mentioned earlier, it is like when we were looking at the translations, and I was looking at the Hindi version, I couldn’t understand myself being South Asian because for the word dementia, they were Google translation. Just showed dementia translated to madness.” – Kadira, Community Support Organization Employee.

Participants also emphasized the importance of culturally focused programs, such as weekly support groups that included celebrations of cultural events and activities conducted in clients’ first languages. These programs created a comfortable and familiar environment, reducing isolation and encouraging participation. Offering culturally appropriate meals further enhanced clients’ comfort, as one participant described how their organization ensured that clients received food they were accustomed to eating.

“We cater the food to be South Asian as well. I know that’s a concern for a lot of individuals when they put their parents into care that, you know, they’re sending them somewhere, especially in long-term care where there really isn’t a South Asian-focused one. So our day programs are able to provide them with food that they’re used to eating.” – Noor, Community Support Organization Employee.

Cultural representation among staff was also identified as a critical factor in fostering trust and facilitating communication. Clients reportedly felt more comfortable interacting with staff who shared their cultural background, as this connection fostered mutual understanding and trust.

“When clients see someone who speaks their language or understands their culture, it’s easier for them to open up and feel comfortable. That connection matters a lot.” –

Monica, Community Support Organization Employee.

6.5.3 Challenges and Future Directions

Despite significant progress, participants identified several persistent challenges in delivering dementia care to South Asian communities. Resource limitations, including insufficient funding and capacity, was identified as a central concern. Participants highlighted the lack of tailored services for South Asian families, instead relying on piecemeal adaptations of existing programs.

“No... They just didn’t have the capacity for it. So the answer is no, not specifically, of course, the program is available for anybody, but they haven’t had any targeted engagement with the South Asian community.” – Danielle, Community Support Organization Employee.

Participants described how, in the absence of specific programs, they personalized services to meet clients’ needs. This included conducting family sessions at clients' homes and allocating additional time for translations during interactions.

“We also do community presentations... We try to be as person-centred as we can, to allow people to help... So that’s kind of how we address our culturally diverse groups.” – Abigail, Community Support Organization Employee.

While these measures were helpful, they were often described as stop-gap solutions rather than structured, long-term initiatives. Transportation barriers and the limited frequency of

support groups were also noted as significant obstacles to service accessibility. Participants emphasized the need for systemic solutions, such as expanded transportation support and additional funding to sustain culturally relevant programs.

Participants reflected on the importance of relationship-building and cultural humility. Approaching clients with flexibility and respect for their unique needs was seen as essential for fostering trust and engagement. For instance, participants noted the value of building relationships before offering services.

“I think for me, what works the best is to have a relationship first... It’s important, like, I mean, yes, you have an agenda before you enter the door of a house, but you have to go with the agenda of people that are inside.” – Muskan, Community Support Organization Employee.

Ultimately, participants envisioned more inclusive and sustainable services. They advocated for increased collaboration with policymakers, other organizations, and cultural groups to expand programs and address gaps in language-specific and culturally relevant content. Creating linguistically accurate and culturally sensitive materials, as well as addressing practical barriers like transportation, were seen as critical steps toward achieving this goal.

6.6 Discussion

This study provides valuable insights into how community support services navigate delivering dementia-related care to South Asian Canadians, uncovering both shared challenges and culturally specific barriers. While resource limitations, accessibility constraints, and systemic underfunding remain pervasive across populations, the unique cultural and linguistic

needs of South Asian communities highlight the necessity for culturally sensitive and community-centred approaches. These findings raise critical questions about the intersection of cultural humility, systemic inequities, and the role of community organizations in addressing these challenges.

One of the prominent findings of this study is the importance of cultural sensitivity in service delivery. Participants emphasized the need not only to embrace but actively practice cultural sensitivity by tailoring programs to reflect South Asian traditions, languages, and dietary preferences. This aligns with existing literature on cultural adaptations, which emphasizes that interventions are most effective when they resonate with the cultural norms and values of the communities they serve (Netto et al., 2010; López et al., 2017). For instance, including culturally significant holidays like Diwali and Ramadan, rather than defaulting to Western-centric holidays such as Christmas, was viewed as an intentional strategy to foster trust and engagement. Such adaptations go beyond surface-level inclusivity; they demonstrate a deliberate effort to reduce stigma and enhance the relevance of services to the community. The findings reinforce that cultural alignment is essential for addressing the stigma associated with dementia in South Asian communities, where discussing cognitive decline is often taboo (Hossain et al., 2020; Philip et al., 2024)

This study also reveals the potential of culturally specific programming in addressing barriers. Participants highlighted the success of culturally tailored interventions, such as delivering first-language services, partnering with ethnic media, and offering culturally appropriate meals and activities. These efforts resonate with research showing that culturally adapted programs are often more effective than one-size-fits-all solutions in addressing health

disparities (Bernal et al., 2009; Joo & Liu, 2020). For example, participants recounted instances where poorly translated materials, such as rendering “dementia” as “madness,” perpetuated stigma and created barriers to care. This aligns with broader evidence that co-designing materials with the community and conducting culturally nuanced consultations are essential for effective health communication (Chahaun et al., 2021; Lakhan, 2024). The findings underscore the importance of engaging with communities to create materials that accurately reflect cultural and linguistic nuances.

The economic implications of culturally tailored services in dementia care was also identified as a critical consideration. Participants noted that these services improve engagement and support individuals and their care partners in the community. Research supports these observations, with studies demonstrating that non-pharmacological, community-based interventions, such as culturally adapted social cafes and support groups, are cost-effective in managing dementia symptoms and improving outcomes (Guzzon et al., 2023). By reducing caregiver burden and preventing premature institutionalization, culturally tailored CSS programs present a compelling economic case for policymakers and funders. Investments in these programs have been shown to yield long-term benefits, including reduced healthcare costs and improved quality of life for individuals and families (Parker et al., 2020). These findings suggest that culturally adapted services should be strategically reframed as essential investments rather than discretionary expenditures.

The findings also highlight the effectiveness of relational, non-Western approaches to community engagement. Participants shared how informal strategies, such as mingling at cultural events, engaging in casual conversations over tea, and attending religious gatherings, helped

foster trust and build rapport within the community. This aligns with Liamputtong's (2010) advocacy for non-Western engagement approaches, prioritizing relational over transactional interactions. For example, one participant described attending an Eid Mela without setting up a formal booth; instead, they connected with attendees informally while wearing the organization's branding. Such strategies resonate with South Asian cultural norms, where trust and familiarity often precede formal discussions of sensitive topics such as dementia. These relational methods offer valuable insights for service providers seeking to engage diverse communities more effectively.

Another finding concerns the role of cultural representation among staff in fostering trust and improving service uptake. Participants noted that clients felt more comfortable and understood when interacting with staff who shared their cultural backgrounds. However, achieving complete cultural representation among staff is neither feasible nor desirable. Instead, the findings highlight the importance of providing robust cultural sensitivity training to all staff, equipping them with the skills necessary to effectively navigate the diverse needs of their client populations. This dual approach—combining cultural representation with sensitivity training—has been widely advocated in the literature on cultural competence to strike a balance between inclusivity and feasibility (Jongen et al., 2018; Shepherd et al., 2019). Training programs should extend beyond surface-level awareness to encompass practical strategies, such as navigating language barriers, accommodating dietary preferences, and recognizing the importance of cultural and religious practices.

Despite these successes, the study highlights persistent systemic challenges, including transportation barriers, funding limitations, and the lack of targeted services for South Asian

families. Participants frequently cited transportation issues as a major obstacle, as many clients struggled to attend programs due to a lack of accessible options. Funding constraints were also a recurring concern, with participants expressing frustration over their inability to sustain culturally specific initiatives such as providing healthy meals during workshops. These findings reflect broader systemic inequities in the allocation of resources to ethno-racial communities (Clough et al., 2013; Lai & Surood, 2008; Scheppers et al., 2006). Addressing these barriers requires increased funding and more equitable policy frameworks that prioritize the unique needs of ethno-racial populations.

Lastly, the findings underscore the importance of fostering long-term client relationships built on trust and cultural humility. Participants emphasized that effective service delivery often requires flexibility and a willingness to “go with the agenda of the people inside the house,” as one participant put it. This relational approach aligns with the broader shift toward person-centred care, albeit with a strong emphasis on cultural specificity (Kelsall-Knight, 2022; Tham & Solomon, 2024).

In conclusion, this study underscores the imperative for community support services to integrate cultural sensitivity into dementia care for South Asian Canadians. By addressing universal challenges, such as systemic underfunding and accessibility issues, as well as culturally specific barriers, including language misunderstandings and dietary preferences, service providers can enhance the trust, engagement, and overall effectiveness of their interventions. Moreover, as highlighted in Liamputtong’s work, adopting non-Western approaches to engagement offers a valuable framework for building stronger connections with ethno-racial communities. These findings advocate for a dual focus on cultural humility and systemic

advocacy, ensuring that CSS programs meet immediate needs and contribute to broader systemic equity. Future research should continue to explore strategies that promote cultural humility and community-centred care, ensuring that CSS programs are equipped to serve the diverse needs of all populations effectively.

6.7 Future Implications

This study opens several avenues for future research, particularly in examining the experiences of community support services working with South Asian Canadians living with dementia. Further research should investigate organizations in rural and remote areas, as their challenges and resources may differ significantly from those in metropolitan regions.

Longitudinal studies could provide valuable insights into how these organizations adapt to evolving community needs amid demographic shifts and changes in healthcare policy.

Comparative research with other cultural communities may also help identify best practices that can be adapted across various settings.

The study highlights the vital role of community support services in bridging cultural gaps and delivering tailored services. Organizations should continue refining culturally specific programs that address their clients' unique needs. Increased collaboration among community organizations, healthcare providers, and policymakers is essential to ensure adequate funding and support for these services. Community outreach and engagement should build trust and reduce stigma through culturally appropriate communication and education. Ultimately, community organizations should advocate for the inclusion of diverse perspectives in dementia care policy development to ensure that all communities have access to the necessary support.

6.8 Strengths and Limitations

This study has several significant strengths. To the best of our knowledge, it is among the first to examine the experiences of community support services working with individuals living with dementia and their care partners in the Canadian context. It provides valuable insights into the unique challenges and strategies employed to support South Asian Canadians, a demographic that has been previously underrepresented in research. Participants were recruited from organizations across three provinces—British Columbia, Ontario, and Alberta—allowing for an understanding of experiences across different regions and capturing a broader range of perspectives and practices. Including interviews with employees from various organizations offering diverse services adds depth to the findings, reflecting the multifaceted nature of community support for individuals living with dementia and their care partners.

However, the study also has limitations. Many participating organizations were based in major metropolitan areas, which may not fully represent the experiences of those in rural or remote regions, where challenges and resources can differ significantly. Moreover, to protect participant confidentiality, the study maintained complete anonymity for the organizations, which limits the discussion of specific programs or initiatives and may restrict the ability to highlight unique or innovative practices that could serve as models for others.

6.9 Conclusion

This study provides valuable insights into the experiences of employees who offer community support services to South Asian Canadians with dementia-related needs across Ontario, British Columbia, and Alberta. It emphasizes the importance of cultural sensitivity, effective communication, and community engagement in addressing the unique challenges faced by this demographic. The findings underscore the need for tailored programs that reflect local

cultural practices and languages, the importance of community collaboration, and the effectiveness of feedback mechanisms in enhancing service delivery. While the study contributes significantly to understanding the support landscape for South Asian Canadians living with dementia, it also identifies gaps, such as the lack of targeted services for rural areas and the necessity for ongoing funding. By addressing these challenges and building on identified successes, community organizations may enhance their capacity to provide inclusive and culturally relevant care, potentially improving outcomes for individuals living with dementia and their families.

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Chapter Seven: Discussion

This chapter synthesizes the findings from the three studies, offering a perspective on dementia care within South Asian Canadian communities. Each study provides unique insights into the experiences of individuals living with dementia, their care partners, physicians, and employees of community support organizations. The combined findings reveal a complex, interwoven narrative that highlights the role of cultural, systemic, and practical factors shaping these experiences. This chapter integrates these insights, examining how each study informs and builds upon the others, and discusses implications for practice, policy, and future research.

Synthesis of Findings

The synthesis of findings from the three studies provides an understanding of the experiences of South Asian Canadians affected by dementia, incorporating the perspectives of care partners, physicians, and community support organization employees. The framework (Figure 6) was initially used to guide the design and focus of the three studies. It organized the dementia care journey into three key phases: recognizing symptoms, receiving a diagnosis, and accessing services. This structure enabled the examination of the challenges and opportunities faced within each phase.

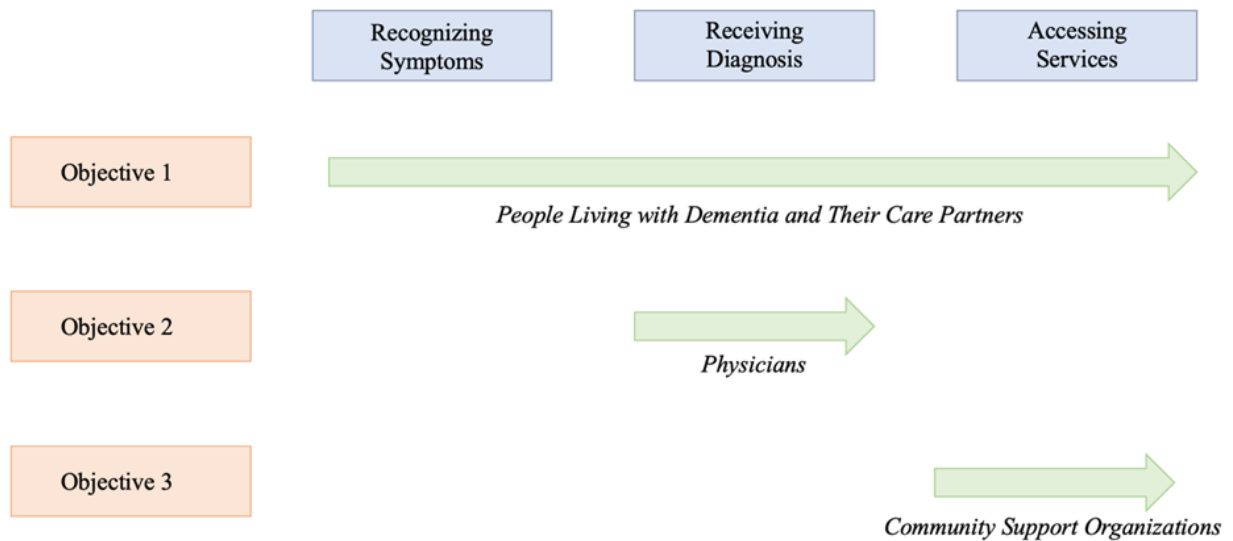
However, during the integration phase, it became apparent that the framework, while helpful in guiding the studies, was not the best fit for synthesizing the findings across the three stakeholder groups. The lived experiences of South Asian Canadians and the intersecting roles of physicians and community support organizations often cut across these predefined phases. For example, stigma, cultural beliefs, and systemic barriers were pervasive throughout the journey, influencing each stage in interconnected ways. These issues did not occur in isolation at a single

phase but instead shaped how individuals and families recognized symptoms, sought diagnoses, and accessed or navigated services. Furthermore, many participants moved back and forth between phases, such as revisiting earlier suspicions of dementia after receiving a formal diagnosis or struggling to access services long after diagnosis, highlighting the non-linear and dynamic nature of the dementia journey. Organizing the integrated findings strictly under the three headings in Figure 6 disrupted the narrative flow and overlooked the cross-cutting nature of these themes. It also risked fragmenting the experiences and obscuring how structural and cultural factors interplayed across time and contexts. A more thematic and fluid approach to integration enabled deeper insight into the persistent influences that shaped the dementia journey, providing a more holistic understanding of stakeholder perspectives and highlighting points of convergence and divergence among them.

Instead, this synthesis presents the findings in terms of overarching challenges and opportunities that span all phases of the dementia care journey. This approach enables a more cohesive and integrated understanding of how cultural beliefs, systemic gaps, and stigma collectively influence the experiences of South Asian Canadians.

This reframing underscores the importance of a culturally sensitive ecosystem of care that extends beyond the traditional linear progression of recognizing symptoms, receiving a diagnosis, and accessing services. By highlighting these intersections, the synthesis provides a more comprehensive view of the shared and distinct challenges faced by families, healthcare providers, and community organizations in supporting dementia care for South Asian Canadians.

Figure 6: Three stages of dementia care and study objectives



7.1.1 Stigma and Its Impact on Care Experiences

The stigma surrounding dementia is identified as a pervasive barrier to care across all three studies, shaping experiences and limiting support at every stage of the dementia journey. Stigma delays families from seeking treatment in the early stages, as symptoms are often minimized or hidden to avoid social judgment. Following a diagnosis, many families continue to conceal the condition, fearing damage to their reputation within the community. This ongoing secrecy isolates individuals living with dementia and their caregivers, preventing them from openly accessing external support. The emotional toll of managing dementia in secrecy is profound, leaving care partners feeling unsupported and overwhelmed by the demands of caregiving while navigating societal and familial expectations.

Physicians' perspectives further illuminate the impact of stigma, noting that families frequently resist disclosing dementia diagnoses to the individuals affected, preferring instead to

"shield" them from the knowledge of their condition. This practice aligns with findings in the literature, where family members often request that physicians withhold a diagnosis to protect their loved ones from perceived distress. According to a review by Peel (2010), cultural beliefs usually shape these decisions, as families may prioritize collective well-being and emotional protection over patient autonomy. Similarly, the Nuffield Council on Bioethics (2009) highlights that cultural considerations play a critical role in shaping family decisions around disclosure, with physicians often navigating ethical dilemmas between respecting patient rights and honouring family preferences. Challenges related to nondisclosure are further discussed by Werner et al. (2013), who note that these situations can complicate care planning and communication, particularly when individuals with dementia remain unaware of their condition and its progression. These findings suggest that stigma, cultural beliefs, and family dynamics influence how disclosure is managed, presenting unique challenges for physicians in delivering person-centred care.

Community support organization employees underscore the pervasive effects of stigma on service utilization, noting that culturally specific terminology or phrasing can exacerbate negative perceptions of dementia. For instance, employees describe cases in which translations of "dementia" into South Asian languages implied "madness," reinforcing stigma and deterring families from accessing services. This observation is supported by Giebel et al. (2015), who found that South Asian older adults experience difficulties in accessing services for memory impairment and dementia, partly due to linguistic and cultural barriers. Similarly, Siette et al. (2023) discuss how language barriers and cultural beliefs contribute to heightened dementia-related stigma within culturally and linguistically diverse communities, affecting help-seeking behaviours. Blakemore et al. (2018) further highlight that most South Asian languages lack a

direct equivalent for the term "dementia," often leading to descriptions that perpetuate stigma and misunderstanding.

Poole et al. (2021) emphasize that a lack of understanding and awareness of dementia in South Asian populations can lead to misconceptions and stigma, which can impact service utilization. These linguistic challenges add a layer of complexity to stigma, as families may feel further alienated from mainstream dementia care due to the language used to describe the condition. Community support organizations attempt to address this by rephrasing dementia-related concepts in less stigmatizing ways and that are more aligned with cultural sensitivities. However, this remains a challenging and ongoing process.

The combined findings reveal that stigma is not merely a cultural issue but is deeply intertwined with linguistic, systemic, and social factors that collectively reduce access to care. Addressing stigma requires a coordinated response that includes culturally sensitive language in educational materials, open dialogue about dementia within the community, and support for families navigating these complex dynamics. Each study highlights the multifaceted nature of stigma and its implications for care, underscoring the need for initiatives that promote an accurate understanding of dementia while respecting cultural identity.

7.1.2 Challenges in Diagnosis and Access to Care

Each study contributes a unique perspective on the myriad challenges involved in the diagnosis of dementia and access to care, constructing an integrated narrative of the pathways and barriers that South Asian Canadians navigate in their dementia care journey. Care partners and individuals with dementia describe a journey marked by emotional and systemic obstacles, often beginning with delayed symptom recognition due to cultural beliefs that frame dementia as

a natural consequence of aging, combined with the associated stigma of dementia. This belief delays family members' acknowledgment of symptoms as potentially serious, with many families only seeking a formal diagnosis when cognitive decline progresses to include behavioural symptoms.

The physicians' experiences provide a complementary perspective, highlighting the cultural and linguistic challenges that impede effective diagnosis and communication. Physicians report that families may minimize symptoms or resist acknowledging a dementia diagnosis, partly due to cultural stigma and a desire to avoid social judgment. The experiences align with existing literature, indicating that cultural stigma and linguistic challenges significantly hinder effective dementia diagnosis and communication. Tillmann et al. (2019) highlight that language barriers and cultural differences impede effective communication between physicians and patients from migrant backgrounds, complicating the diagnostic process. Furthermore, the World Alzheimer Report 2012 by Batsch and Mittelman emphasizes that cultural perceptions and stigma lead families to deny or conceal symptoms, delaying diagnosis and access to care.

Moreover, many physicians feel that current diagnostic tools are ill-suited for South Asian patients, particularly those with lower educational backgrounds, as these tools may not account for cultural differences in cognitive assessment. The concerns expressed by physicians regarding the suitability of current diagnostic tools for South Asian patients, especially those with lower educational backgrounds, are well-supported by existing literature. Naqvi et al. (2015) conducted a systematic review revealing that many cognitive assessment tools possess inherent cultural biases, rendering them less effective for ethnically diverse groups, including South Asians. Similarly, Tavares-Júnior et al. (2019) highlighted the challenges in accurately assessing cognitive impairment in individuals with limited education, as standard tools often lack

validation for this demographic, increasing the risk of misdiagnosis. While there are translated versions of validated tools, they are insufficient and require cultural adaptation (O'Donald & Calia, 2025; Khan et al., 2022). These studies collectively advocate for the development and implementation of culturally and educationally appropriate diagnostic tools to enhance the accuracy and effectiveness of cognitive assessments in diverse patient populations.

Physicians often find themselves struggling to balance the clinical need for accurate diagnosis with the cultural expectations of South Asian patients and their families, which can lead to compromised care and misunderstandings. These findings are supported by existing literature, as a study by Jin et al. (2002) discusses the significant impact of cultural beliefs and practices on diagnosis and treatment, emphasizing the need for healthcare providers to understand and navigate these cultural nuances to deliver effective care. Similarly, Vashisht et al. (2023) highlight the challenges physicians face during advanced care planning with South Asian patients, noting that cultural expectations and family dynamics often influence medical decision-making, resulting in misunderstandings and compromised care. These studies underscore the importance of cultural competence in healthcare to bridge the gap between clinical objectives and patients' cultural expectations, thereby improving patient outcomes and satisfaction.

Community support organization employees further add to this understanding by highlighting the logistical and structural barriers that South Asian families face when accessing services post-diagnosis. They noted that many CSS programs, such as adult day programs, support groups, and respite services, are often delivered exclusively in English and fail to reflect the cultural practices, food preferences, or social norms of South Asian communities. This lack of linguistic and cultural alignment discourages participation and limits the effectiveness of available support. Equity in care is often compromised for South Asian families due to linguistic

barriers and limited availability of culturally competent care, especially after diagnosis (James et al., 2024). The Fraser Health Authority (2017) similarly found that South Asian caregivers often perceive service providers as lacking cultural competence, leading to unmet needs and limited engagement with community-based supports. Khatri and Assefa (2022) further emphasize the scarcity of culturally tailored social care resources, which contributes to delays in seeking assistance and makes it difficult to navigate existing services. These challenges are compounded by the limited availability of staff who can speak South Asian languages or who are familiar with culturally appropriate care practices. As such, families often rely on informal networks for support, placing additional pressure on care partners to serve as cultural and linguistic mediators. These insights underscore the critical need for culturally inclusive CSS programming that goes beyond translation to meaningfully incorporate language, cultural values, and traditions into service delivery.

Integrating these perspectives reveals a continuum of challenges that extends from initial symptom recognition through diagnosis to ongoing access to care. Each stakeholder group, including individuals, care partners, physicians, and community support staff, faces unique yet interconnected challenges that underscore the need for an integrated approach grounded in cultural humility for dementia care. The findings suggest that overcoming these diagnostic and access barriers requires coordinated efforts that bridge cultural, linguistic, and systemic gaps, ensuring that South Asian Canadians can access timely and appropriate care at each stage of their dementia journey.

7.1.3 Cultural Awareness and Sensitivity

Cultural awareness was identified as a recurring theme across all three studies, emphasizing its significance to understanding how South Asian Canadian communities perceive

and approach dementia. These intrinsic cultural perceptions shape how dementia is understood and managed at the family and community levels, underscoring the need for greater awareness to address these barriers. In addition to cultural beliefs, gendered differences also influenced how dementia symptoms were assessed and recognized. Physicians in the study noted that it was often challenging to establish a functional baseline for male patients, particularly when they did not typically engage in household tasks such as meal preparation or laundry. As a result, changes in their ability to perform activities of daily living (ADLs) were less noticeable, potentially delaying diagnosis. These insights highlight the importance of considering both cultural and gender norms when interpreting symptoms and tailoring dementia care approaches.

Building on this, cultural sensitivity is vital in shaping how healthcare providers and community organizations engage with South Asian families. The lack of culturally sensitive diagnostic tools and communication practices creates significant challenges for physicians, as these tools may fail to account for cultural and gendered differences in functional roles. For instance, traditional gender roles within South Asian families can obscure symptoms in men, who may not engage in household tasks where cognitive impairments, such as difficulties with daily routines, are more noticeable. This gap highlights the need for diagnostic approaches that are attuned to cultural and gender dynamics to ensure accurate identification of dementia symptoms across diverse populations. Additionally, cognitive assessment tools that assume a certain level of formal education may not be effective for all segments of the South Asian community, leading to potential misdiagnoses or underdiagnoses (Rosli et al., 2015). Physicians highlighted the importance of tailoring these tools and their approach to align with their patients' cultural backgrounds and educational contexts.

Community support organization employees emphasized that cultural sensitivity extends beyond language translation to include cultural adaptation of programs and resources. For instance, translations of "dementia" in some South Asian languages can carry connotations of "madness," reinforcing stigma and deterring families from seeking help. Organizations have responded by creating materials and programs that align with cultural values and practices, such as celebrating South Asian festivals like Diwali or Ramadan and providing dietary accommodations to reflect traditional food preferences. These culturally tailored approaches may foster trust and familiarity, creating an environment where families feel understood and supported.

The interplay between cultural awareness and cultural sensitivity is essential for effective dementia care. Existing literature underscores that healthcare providers' understanding of individuals' cultural backgrounds and beliefs significantly influences the quality of care delivered. For instance, Vila-Castelar et al. (2022) emphasize the need to integrate cultural factors into clinical practices, noting that such integration can improve diagnosis accuracy and patient engagement. Moreover, the Alzheimer's Society (2024) highlights that people's backgrounds and beliefs inform their responses to diagnoses and interactions with healthcare services. This suggests that cultural sensitivity can enhance individual-provider relationships and care outcomes. Adapted dementia interventions like START for South Asian carers emphasize not just translation but deep cultural adaptation, including new examples, culturally resonant metaphors, and delivery in Urdu, to improve acceptability (Webster et al., 2023). These findings align with our study, which demonstrates that cultural awareness and sensitivity among healthcare providers and community organizations are crucial in addressing the unique challenges faced by South Asian Canadian families dealing with dementia. By acknowledging

and respecting cultural differences, care strategies can be more effectively tailored to meet the specific needs of diverse populations.

In summary, the synthesis of findings highlights the complex challenges South Asian Canadians face in dementia care, rooted in cultural beliefs, systemic barriers, and stigma. Cultural perceptions that frame dementia as a natural part of aging delay symptom recognition and intervention, emphasizing the need for culturally informed education and sensitivity in healthcare. Systemic barriers, such as language issues and inadequate diagnostic tools, hinder timely diagnosis and care, while stigma further isolates families, deterring them from seeking support. Addressing these challenges requires integrated care that is grounded in cultural humility, promotes early recognition, reduces stigma, and improves access to resources throughout the dementia care journey.

7.2 Connecting Findings to Existing Research

The findings from this research extend and deepen the existing body of literature on dementia care within ethno-racial communities, bringing particular focus to the unique experiences and needs of South Asian Canadians. Previous research has consistently highlighted how low awareness of dementia and pervasive stigma hinder timely access to care across diverse cultural groups (Mukadam et al., 2011; Mukadam et al., 2015; Brooke et al., 2018; Kovaleva et al., 2021). While some experiences, such as challenges posed by stigma and systemic barriers, are common across immigrant communities, others are uniquely shaped by the cultural norms and practices of South Asian families. This thesis builds upon these insights by examining how such issues uniquely manifest within South Asian communities, where cultural beliefs about

aging and cognitive health intertwine with systemic challenges to shape distinct patterns in dementia care-seeking behaviours, diagnosis, and support.

A recurring theme in the literature is the tendency within South Asian cultures to attribute cognitive decline to "normal aging" rather than to a medical condition that requires attention and intervention (Philip et al., 2024; Hossain et al., 2022; McCleary et al., 2012). The findings in this research reaffirm this concept but provide additional cultural specificity, illustrating how South Asian norms around aging, family roles, and mental health complicate the recognition and understanding of dementia symptoms.

This thesis confirms these patterns and offers new insights specific to the South Asian Canadian context, where concerns about family reputation, collective identity, and perceived honour exacerbate the reluctance to seek support. For example, stigma operates not only as an individual or familial response but as a community-wide phenomenon that perpetuates isolation and limits access to resources. These findings echo broader immigrant health research while underscoring the distinct pressures faced by South Asian families, who may view dementia as a "weakness" or cause for shame. Addressing this stigma requires community-level initiatives to foster open conversations, reduce stigma, and normalize dementia care.

Another key contribution of this thesis is its focus on the roles of community support organizations, an area that has been underrepresented in previous studies. While existing literature acknowledges barriers to accessing culturally appropriate care (Kenning et al., 2017; Botsford et al., 2012), there is limited exploration of how these organizations operationalize culturally meaningful engagement on the ground. This research fills that gap by illustrating how CSS act as cultural intermediaries (Kovaleva et al., 2021), bridging the disconnect between

mainstream healthcare systems and immigrant families. Through initiatives such as collaborating with faith leaders to reduce stigma, setting up informational booths at cultural events, and training bilingual staff to facilitate communication, these organizations demonstrate a deep commitment to inclusivity.

Importantly, their work often extends beyond translation to accurate cultural adaptation. For instance, community organizations have tailored materials to reflect South Asian cultural contexts, not only by referencing holidays like Diwali and Ramadan, but also by incorporating culturally resonant metaphors and proverbs to explain dementia in more accessible ways. These grassroots efforts are grounded in trust, familiarity, and relational care, reflecting a client-centred ethos that is responsive and community-driven.

However, the success of these initiatives is often despite, not because of, existing system-level support. Many community organizations operate with limited resources and staffing, yet continue to take on responsibilities that bridge systemic gaps in care. The findings of this study underscore that with proper investment, structural support, and long-term funding, these organizations could play an even more transformative role in delivering culturally safe, accessible dementia care. Supporting them is not just beneficial, it's essential for achieving equity in dementia services.

Language barriers, long recognized as a challenge in dementia care (Canevelli et al., 2021; Neilsen et al., 2011; Sharyn & FaLalaua, 2024), are another area where this research contributes nuanced insights. While the stigma associated with direct translations of "dementia" as "madness" has been documented by others (e.g., Brijnath et al., 2022, Brijnath et al., 2012; Hossain et al., 2022; Mukadam et al., 2011), this study reveals how linguistic mismatches in

South Asian languages further discourage care-seeking. For instance, terms used in translations often carry connotations that reinforce stigma and cause families to withdraw from support. This highlights the need for culturally sensitive translations that align linguistically and conceptually with community values (O'Donald & Calia, 2025; Khan et al., 2022). Collaborative efforts among community organizations, cultural navigators, and healthcare providers can address these challenges, although specialized training from linguistic experts may be necessary.

The findings from the study with physicians illuminate additional gaps in the healthcare system's responsiveness to South Asian Canadians, particularly regarding diagnostic practices. Prior studies have noted that standard diagnostic tools often disadvantage patients with limited formal education (Brooke et al., 2018). This research builds upon these findings by examining the intersection of language and education, highlighting how culturally and educationally inappropriate tools can lead to misdiagnoses or delays in care. Physicians expressed concerns about tools that rely on literacy-dependent tasks, which are incompatible with the educational experiences of many South Asian older adults. These findings highlight the need for culturally responsive diagnostic practices that integrate culturally validated tools to ensure equitable access to care.

Systemic inadequacies in Canadian healthcare compel some South Asian families to seek diagnoses in their countries of origin, where they perceive greater alignment with cultural values and norms in healthcare delivery. While immigrant health literature has broadly discussed challenges in navigating healthcare systems (Lin, 2022; Wood et al., 2023), this study uniquely examines how families resort to international options due to systemic shortcomings. This

highlights the urgency for culturally inclusive practices in Canadian healthcare to reduce reliance on external healthcare systems and associated disruptions.

Lastly, this research underscores the pivotal role of community organizations in bridging healthcare systems and immigrant families. Although literature emphasizes the importance of these organizations in diverse communities (Hossain et al., 2020), there is limited documentation of their culturally meaningful strategies. This study examines how organizations utilize ethnic media, religious gatherings, and local cultural leaders to foster trust and facilitate open discussions about dementia. These efforts normalize dementia care in familiar community contexts, offering a scalable model for addressing stigma and fostering engagement.

In summary, this thesis not only affirms existing literature on barriers to dementia care in ethno-racial communities but also advances understanding through its focus on South Asian Canadians. Incorporating perspectives from physicians, families, and community organizations provides a multi-layered view of dementia care challenges and opportunities. These findings emphasize the importance of culturally sensitive diagnostic tools, linguistically appropriate educational materials, and community organizations as cultural intermediaries, advocating for systemic reforms that ensure equitable care for diverse populations.

7.3 Methodological Implications

The methodological design of this thesis, rooted in building community connections using a multi-perspective approach, which was integral to capturing the nuanced and multifaceted experiences of dementia care within South Asian Canadian communities. By bridging the insights of care partners, individuals living with dementia, physicians, and community support organization employees, this approach provided a view of the systemic,

cultural, and emotional barriers encountered in recognizing symptoms, receiving a diagnosis, and accessing services throughout the care journey. Additionally, being a researcher from the same cultural background added unique layers to the research process, including enhanced participant trust as well as the analytical challenge of interpreting culturally implicit references made during interviews.

7.3.1 Community Connection Building as a Foundation for Trust

A crucial element of this research was the time and effort invested in building genuine connections within South Asian communities before the formal data collection process began. Establishing trust was essential to creating an environment where participants felt comfortable sharing deeply personal and, at times, stigmatized experiences related to dementia care. This period of community engagement involved attending community events, networking with local leaders, and openly discussing the purpose and goals of the research in culturally respectful ways. Through these activities, community members became familiar with both me as a researcher and the broader objectives of the study that would be taking place, helping to alleviate apprehensions about discussing sensitive topics.

This process of community connection-building was instrumental in fostering a safe and open environment for the community. With this groundwork established through these connections, it allowed for richer, more candid narratives for the individuals who eventually agreed to participate in the research, as they felt reassured by the trust and understanding built over time. This methodological approach underscores the importance of community-led engagement in research, mainly when working with ethno-racial communities where cultural sensitivity and relational trust are paramount (McAiney et al., 2024). In this context, the time invested in connection building was a preparatory step and a foundational element.

7.3.2 The Conundrum of “You Know”: Cultural Implicitness in Shared Identity

An unexpected yet illuminating aspect of this research was the frequent use of the phrase “you know” by participants. This shorthand assumed a shared cultural understanding between researcher and participant. As members of the same cultural community, participants often relied on “you know” to convey complex cultural dynamics, unspoken social expectations, and implicit beliefs about family roles and dementia. This simple phrase signalled a sense of trust and mutual recognition, allowing participants to speak freely without explaining every detail of their experiences. In these moments, participants trusted that I would “get it”, that I would understand the layers of meaning behind their words without requiring explicit explanations.

While this phrase of “you know” facilitated rapport during interviews, it presented a unique challenge during analysis. Due to the lack of detail provided in these instances, I needed to unpack the implicit references to make the findings accessible and understandable to readers outside South Asian communities, who might not inherently grasp the cultural nuances behind each “you know.” Each instance required me to interpret and articulate the cultural context that participants took for granted, translating this implicit knowledge into explicit descriptions for an external audience. When the context of a “you know” moment was unclear, I revisited the transcript and audio recording to understand the intended meaning better and ensure accurate interpretation during analysis. This interpretive process was complex, as it required balancing preserving cultural authenticity with making hidden assumptions visible and understandable for readers who may not share this cultural background. The “you know” phenomenon thus underscored the dual role I held as an insider with assumed cultural knowledge and an interpreter who had to make these nuances accessible to others.

This analytical task highlights an important methodological consideration for researchers working within their communities: the need to navigate and articulate implicit cultural understandings for an external audience. In this study, each “you know” moment reminded me of the shared cultural assumptions between myself and the participants, requiring careful reflection and the translation of these shared insights into clear, accessible narratives.

7.3.3 The Weight of Shared Experience: Empathy and Internalization

Conducting research within one’s cultural community also brings an added layer of emotional resonance. As a member of the South Asian community, the narratives shared by participants were not simply abstract data points but stories that resonated on a deeply personal level. Hearing care partners recount their struggles, frustrations, and fears invoked a personal and professional sense of empathy. Listening to participants speak in our shared languages, using phrases and expressions I recognized from my own life and community, imbued their experiences with a profound emotional weight. This linguistic familiarity allowed for a depth of expression that might not have been possible in English, as certain cultural concepts and emotions carry layers of meaning that are challenging to translate fully.

While empathy is a natural response to any participant’s story, the sense of “heaviness” was more acute when engaging with members of my community. The familiarity with cultural references, the use of colloquial language, and the raw emotion conveyed in the participants’ native languages intensified the impact of their experiences. It was as though each story held a mirror up to my understanding of family, care, and cultural responsibility. This deeper resonance did not compromise my objectivity but added a layer of emotional labour that is perhaps unique to researchers working with their communities. Unlike studies conducted with other communities, where empathy is tempered by some degree of professional distance, here, every

shared story felt like a collective experience, an echo of my own culture's struggles, strengths, and vulnerabilities. Scholars have noted this phenomenon, where insider researchers face the dual challenge of managing emotional proximity and maintaining professional distance (Dwyer & Buckle, 2009; Chavez, 2008). Insider status often amplifies the emotional stakes of qualitative research as researchers navigate the tension between relational approaches to participants and the analytical detachment necessary for rigorous interpretation (Berger, 2015).

This internalization of the participants' experiences required continuous self-reflection to ensure that my empathy and shared identity did not overshadow the analysis. It also highlighted the dual role of the researcher as both an insider and an interpreter, bridging personal resonance with the responsibility of translating these experiences into a format that an external audience can understand without diluting their emotional and cultural depth. This balance between personal connection and analytical distance is a methodological implication that merits consideration for any researcher working within their community, as it requires navigating the space between being a cultural insider and a researcher. As Dwyer and Buckle (2009) emphasize, insider researchers must continuously negotiate the duality of their position—being “one of them” and yet distinct.

7.3.4 Multi-Stakeholder Perspective as an Integrative Lens

The multi-perspective approach employed in this thesis, incorporating the voices of care partners, individuals living with dementia, physicians, and community support organization employees, served as an integrative lens to view the interconnected roles and challenges experienced by all stakeholders in the dementia care landscape. By juxtaposing these perspectives, the research reveals gaps in understanding and support at each level of the care journey, highlighting areas where more coordinated, culturally sensitive approaches are needed.

For instance, while care partners often grappled with the emotional and logistical challenges of providing care, they also expressed frustration with healthcare providers' limited understanding and empathy. On the other hand, physicians acknowledged these gaps but struggled with systemic constraints, such as the inadequacy of diagnostic tools tailored for culturally diverse populations. Community support organization employees bridged these perspectives, offering insights into the practical challenges of delivering culturally relevant programs and the need for more systemic support to meet the specific needs of South Asian families. Each stakeholder group provided a unique vantage point, yet their experiences converged around shared challenges related to cultural sensitivity, accessibility, and stigma.

This integrative approach highlights the need for an enhanced, holistic, and collaborative framework in dementia care that extends beyond isolated interventions. By illuminating the interconnected experiences of individuals, families, and professionals, this research demonstrates how systemic and cultural barriers are interwoven and require an inclusive care ecosystem at every level. The multi-stakeholder perspective, therefore, not only enriches the analysis but also highlights actionable insights for policy and practice, emphasizing the importance of coordinated efforts to address the multifaceted needs of South Asian Canadians living with dementia and their care partners.

7.4 Challenges and Opportunities for Improvement

The synthesis of findings from the three studies reveals a nuanced picture of the challenges and opportunities within dementia care for South Asian communities in Canada. These challenges are not isolated; they intersect and compound across cultural, systemic, and practical domains, creating a multifaceted barrier to culturally responsive dementia care. Using the framework that guided these studies, focused on the interconnected processes of recognizing

symptoms, receiving a diagnosis, and accessing services, the findings highlight distinct yet overlapping challenges faced by three key groups: people living with dementia and their care partners, physicians, and community support organizations. Each study provides unique insights into these phases, illustrating how they intersect to shape the overall dementia care experience. By viewing these challenges through this integrated lens, we also uncover potential pathways for meaningful change, underscoring the importance of collaborative, culturally attuned strategies that engage individuals, families, healthcare providers, and community organizations in unison.

7.4.1 Recognizing Symptoms

i) Cultural Beliefs and the Need for Culturally Informed Education

One of the most significant cultural challenges identified across all studies is the pervasive belief within South Asian communities that dementia-related symptoms are simply a part of aging rather than indicators of a specific medical condition. This belief, deeply rooted in cultural narratives around aging and mental health, often delays recognition and diagnosis, as cognitive decline is not immediately viewed as a condition requiring medical intervention. As seen in the experiences of care partners and individuals with dementia, this misperception can lead to missed opportunities for early support and intervention and further exacerbates the stigma associated with dementia.

This challenge presents a clear opportunity: developing culturally informed educational initiatives that reframe dementia as a medical condition that benefits from timely diagnosis and support. Community support organizations, which already act as trusted intermediaries, are well-positioned to lead these efforts, tailoring educational materials that resonate with South Asian cultural perspectives on aging. Education campaigns could involve culturally relevant

terminology, familiar analogies, and the active engagement of community leaders to normalize conversations around dementia. Leveraging respected figures in the community, such as religious leaders, health practitioners, and social influencers, could facilitate a shift in attitudes, encouraging families to seek support earlier in the dementia journey.

7.4.2 Receiving a Diagnosis

i) Systemic Barriers in Diagnosis and the Role of Cultural Humility

The pathway to diagnosis often has systemic barriers, as evidenced by the findings from physicians and care partners. Physicians reported struggling to provide accurate diagnoses due to a lack of culturally tailored assessment tools and communication challenges stemming from language barriers and differing cultural perspectives on health and cognitive function. Care partners, on the other hand, expressed frustration with delayed or missed diagnoses, feeling that their concerns were often downplayed or misunderstood by healthcare providers who lacked an understanding of cultural nuances.

Addressing these barriers requires a commitment to fostering cultural humility within healthcare systems, a stance advocated by leading professional organizations. For instance, the First Nations Health Authority (FNHA) emphasizes that "system-wide change begins with every individual that works in health by implementing the protocol of cultural safety and humility" (FNHA, 2017). Similarly, the Canadian Medical Association (CMA) has taken steps to promote cultural safety and humility among healthcare providers. In partnership with the FNHA, the CMA developed resources such as the *Cultural Safety & Humility Action Series*, which provides tools, resources, and skills related to cultural safety and humility (CMA, 2020). Promoting cultural humility among healthcare providers is essential to equip them with the mindset needed

to interpret symptoms within a cultural context and engage patients and families in a manner that respects their beliefs and values. This approach could include opportunities for reflection on culturally adapted assessment tools, understanding how traditional gender roles may influence symptom presentation, and strategies for effective communication with patients who speak limited English. Additionally, integrating community-based health navigators, individuals who understand the healthcare system and the cultural context of South Asian communities, could bridge the gap between patients and providers, ensuring that language and cultural subtleties are not lost in translation.

ii) Language Barriers and the Opportunity for Linguistically Inclusive Resources

Language barriers surfaced as a persistent challenge across the studies, affecting every stage of the dementia care process, from diagnosis to accessing services. Care partners frequently found themselves in the role of translator, a responsibility that added stress and sometimes led to misunderstandings, particularly when discussing sensitive medical details (Arya et al., 2024). Physicians and community support organizations echoed this concern, highlighting the limitations of sometimes relying on family members as interpreters and the inadequacy of healthcare materials that are often translated literally without considering cultural context or regional dialects.

This challenge underscores the urgent need for linguistically inclusive resources beyond direct translation. Healthcare providers and community organizations should collaborate to develop dementia education materials that are both linguistically and culturally sensitive, considering regional dialects and preferred terminologies within South Asian communities. Additionally, as Arya et al. (2024) noted, investing in professional interpreters trained in medical terminology and cultural nuances could reduce the burden on care partners and enhance

communication between patients and providers. Offering healthcare materials and workshops in South Asian languages tailored to the dialects spoken by the local population can create a more inclusive and supportive environment for individuals and families navigating dementia.

7.4.3 Accessing Community Support Services

i) Stigma as a Barrier and the Potential for Community-Led Awareness Initiatives

The stigma surrounding dementia was identified as a profound barrier that shapes every aspect of the care experience for South Asian families. This stigma, reinforced by cultural and religious beliefs, often leads families to conceal a dementia diagnosis, resulting in social isolation and a reluctance to seek help. Care partners reported feeling burdened by the expectation to “handle it alone” to avoid social judgment. At the same time, physicians noted that families sometimes resisted disclosing the diagnosis to the individual with dementia, fearing emotional distress or a perceived loss of dignity.

To counteract this stigma, community-led awareness initiatives are essential. These initiatives could include public education campaigns that frame dementia within a culturally respectful context, reducing the shame associated with cognitive decline and encouraging open discussion. For instance, holding dementia awareness workshops in familiar community spaces, such as cultural centers, gurdwaras, mosques, and temples, could foster a sense of belonging and normalize discussions about dementia within a safe environment. Similar approaches have been successfully used to promote other health issues within South Asian immigrant communities. For example, the practice of *langar* in Sikh gurdwaras has been utilized to promote health through its cultural and religious significance (Daffu-O'Reilly et al., 2024). Community health and lifestyle

interventions in temples have also successfully engaged South Asian communities in health promotion activities (Coe & Boardman, 2008).

Additionally, community cardiovascular health promotion programs involving paramedics and volunteers have demonstrated feasibility and effectiveness within South Asian populations (Agarwal et al., 2020). While these examples provide valuable insights, the unique nature of dementia may require tailored approaches that address the emotional and cultural sensitivities surrounding the condition. Furthermore, involving individuals who have experienced dementia in their families as advocates and speakers can personalize the issue, allowing community members to relate to these experiences and feel more comfortable discussing dementia openly.

ii) Practical Barriers to Service Access and the Opportunity for Systemic Support

Accessing dementia-related services post-diagnosis is a complex endeavour for South Asian families, complicated by barriers such as the lack of culturally relevant services and the expectation placed on family members to provide care at home. Care partners highlighted the difficulty of finding long-term care homes honouring dietary restrictions, religious practices, and cultural preferences, an issue documented in Ontario, where many study participants were situated. Reports from the Wellesley Institute indicate that applicants to ethno-specific long-term care homes often face longer wait times than those applying to mainstream dwellings, suggesting that the current system does not adequately meet residents' linguistic and cultural needs (Wellesley Institute, 2020).

Within Ontario, the introduction of Bill 7 in 2022, known as the More Beds, Better Care Act (Government of Ontario, 2022), has further complicated this landscape. The legislation allows hospital patients to be transferred to long-term care homes that are not their choosing, aiming to free up hospital beds. However, this has raised concerns about seniors being relocated to homes far from their families or unfamiliar cultural settings. Cultural long-term care homes have reported an increase in the number of residents who do not share the home's linguistic or cultural background, potentially undermining the culturally sensitive care these facilities aim to provide (Crawley, 2023).

Community support organizations also noted the challenges of sustaining culturally tailored programs amid funding constraints, which often limit the scope and reach of their services. The need for culturally appropriate care is pressing, as linguistic and ethnic-specific services have been shown to positively impact residents' physical and mental health, reducing isolation and depression (Family Councils Ontario, 2023). Addressing these challenges requires systemic changes, including increased funding for culturally specific long-term care homes and the development of policies that prioritize cultural matching in resident placement. Engaging with community organizations and stakeholders is essential to creating a more equitable and culturally sensitive long-term care system that respects the diverse needs of all residents.

iii) The Role of Community Support Organizations as Essential Connectors

Community support organizations play a pivotal role in bridging the gap between South Asian families and the broader healthcare system, as evidenced during the COVID-19 pandemic. For instance, the South Asian COVID-19 Task Force in Ontario effectively addressed unique challenges faced by the South Asian community through culturally tailored public engagement

strategies (Samina et al., 2024). Similarly, grassroots groups increased vaccine confidence by partnering with local community organizations to develop health messages considering new immigrants' different languages and cultures (Anand & Kandasamy, 2023).

The findings here highlight these organizations' essential role in offering culturally resonant resources and creating a sense of community for individuals. This research demonstrates that these organizations undertake culturally sensitive outreach efforts, adapt programs to reflect South Asian cultural practices, and offer a trusted space for care partners to seek advice and support. However, these organizations face significant challenges, including limited funding, staff shortages, and systemic barriers that restrict their ability to deliver comprehensive care.

Community support services organizations often operate with limited resources, which can impact service delivery. A systematic review identified that many third-sector organizations struggle to evaluate their activities following evidence-based practices due to limited resources and funding pressures (Bach-Mortensen & Montgomery, 2018; Tong et al., 2021). Additionally, inadequate staff resourcing, including staff shortages and high turnover, has been reported as a significant barrier to the sustainability of these organizations (Bach-Mortensen et al., 2020; Tong et al., 2021).

Systemic barriers also impede the effectiveness of these organizations. For example, during the pandemic, South Asian communities in the Greater Toronto Area were disproportionately affected by COVID-19, highlighting systemic inequities in healthcare access and delivery (Anand et al., 2022). These challenges underscore the need for systemic changes to support community organizations in delivering culturally appropriate care.

Recognizing the critical role of these organizations, there is a clear opportunity to strengthen their capacity through targeted funding and resource allocation. Policy initiatives that increase financial support for community organizations could allow them to expand their services, offer additional language-specific programs, and employ staff from similar cultural backgrounds who can connect with clients on a deeper level. Furthermore, fostering partnerships between healthcare systems and community support organizations can enhance the continuum of care, allowing these organizations to act as a bridge for families navigating complex healthcare processes. By bolstering the capacity of community support organizations, we can create a more resilient support system that addresses the unique needs of South Asian Canadians living with dementia.

7.4.4 Across All Three Stages of Dementia Care

i) Towards an Enhanced Holistic Model of Culturally Inclusive Dementia Care

The interconnected challenges identified in this research underscore the need to expand existing frameworks to adopt a more holistic, culturally inclusive model of dementia care that addresses medical, emotional, and social support dimensions. This perspective aligns with assertions made by other scholars and organizations. For instance, Goeman et al. (2016) developed an inclusive model of culturally sensitive support using a specialist dementia nurse to assist individuals from culturally and linguistically diverse communities, emphasizing the importance of culturally appropriate assessment tools and community-based care pathways. Additionally, the Alzheimer Society of Canada (2002) has recognized the need for culturally sensitive information and resources, ensuring that knowledge and care about dementia are accessible to people living with dementia and their caregivers in culturally diverse communities. Furthermore, the Yee Hong Centre for Geriatric Care (2023) has been recognized for its

continuum of culturally appropriate services and innovative care models, which support clients through culturally sensitive approaches that enhance person-centred care. These examples underscore a growing recognition of the crucial need for culturally inclusive dementia care models that effectively integrate diverse support dimensions to serve diverse populations. These models should be built on cultural humility, language inclusivity, and community engagement, ensuring that individuals living with dementia and their care partners can access services responsive to their cultural needs at every stage of the care journey. Such an approach would require collaboration between healthcare providers, policymakers, community organizations, and cultural leaders to create an adaptable, inclusive, and sustainable care ecosystem.

This integrated approach emphasizes that culturally inclusive dementia care is not solely the responsibility of individual providers or organizations; it requires systemic change at multiple levels. By addressing cultural beliefs through education, reducing stigma through community-led initiatives, enhancing language access, and supporting community organizations, there is potential to create a dementia care landscape that genuinely reflects Canada's multicultural population. In doing so, this research advocates for a shift from isolated interventions to a cohesive framework that places cultural inclusivity at the core of dementia care.

7.5 Recommendations and Implications

This section presents recommendations for enhancing dementia care within South Asian Canadian communities. Based on the findings from all three studies, these recommendations address key cultural, systemic, and practical gaps identified by care partners, physicians, and community organizations. They aim to create a more inclusive, supportive, and effective care environment. While these recommendations reflect the specific and unique needs of South Asian

families in Canada, they also echo broader calls for culturally inclusive dementia care across diverse communities, as highlighted by prior research and policy reports.

7.5.1 Develop and Expand Culturally Inclusive Educational Materials

The findings underscore the critical need for dementia education that extends beyond translation to embed cultural context and nuance, resonating effectively with South Asian communities. Prior studies have emphasized that culturally inclusive materials can dispel common misconceptions and reduce stigma in diverse communities (Mukadam et al., 2011; Alzheimer Society of Canada, 2024). Educational resources should address beliefs within South Asian communities, such as viewing dementia symptoms as a natural part of aging, by providing accessible explanations of symptoms, diagnoses, and care pathways through culturally familiar terms and examples.

Collaboration with cultural leaders and community members is essential to ensure these materials are relevant. Involving respected figures, such as community elders, religious leaders, and healthcare advocates, has been shown to enhance engagement and credibility (Goeman et al., 2016). Additionally, delivering materials in multiple South Asian languages and formats—such as informational videos, podcasts, and visual guides—can broaden accessibility and bridge generational gaps. This approach reflects evidence from other communities demonstrating the impact of multifaceted educational strategies on increasing awareness and early diagnosis. By integrating these strategies, culturally inclusive education can promote acceptance and timely care within South Asian Canadian families.

7.5.2 Promote Cultural Humility Among Healthcare Providers

The literature widely recognizes the need for cultural humility in dementia care (Jongen et al., 2018; Lekas et al., 2020; Robinson et al., 2021). Unlike cultural competence, cultural humility emphasizes ongoing reflection, learning, and mutual respect between healthcare providers and patients. This research highlights that South Asian families often experience care that lacks sensitivity to their cultural values, beliefs, and family dynamics, creating a barrier to trust and effective communication.

Healthcare institutions should implement reflective practices and training sessions to help providers explore cultural biases and develop effective communication strategies. Studies suggest workshops, case studies, and collaboration with cultural mediators can foster an understanding of how cultural beliefs and gender roles influence dementia care (Alzheimer Society of Canada, 2024). Employing community-based health navigators familiar with South Asian languages and healthcare systems can further bridge gaps between providers and patients. These strategies have been successfully implemented in other settings to enhance patient-provider relationships and improve health outcomes (Jongen et al., 2018).

7.5.3 Sustain and Expand Funding for Community Support Organizations

Community support organizations are vital in addressing cultural, linguistic, and systemic gaps in dementia care, particularly for South Asian families. However, as this research and prior studies have identified, these organizations often operate under significant resource constraints, limiting their ability to deliver comprehensive services (Bach-Mortensen & Montgomery, 2018).

For example, inconsistent funding limits hiring culturally and linguistically diverse staff and developing tailored programs.

Sustained funding is essential to enable community organizations to expand their services, such as developing culturally relevant educational materials and reaching underserved areas, including rural and remote regions (Goeman et al., 2016). Evidence demonstrates that stable funding improves outreach and enhances the capacity of community support organizations to foster culturally responsive care. Importantly, for South Asian communities, community support services often extend beyond formal agencies to include informal and faith-based organizations. Places of worship, such as gurdwaras, mosques, temples, and churches, play a central role in community life and have been used effectively in delivering health promotion initiatives (Coe & Boardman, 2008; Dhatt, Simpson, & MacDonald, 2012). These venues offer trusted and accessible spaces where stigma can be reduced and cultural practices respected. While there is growing evidence of their success in chronic disease management and lifestyle interventions, their potential in dementia-related outreach remains underexplored and underutilized. Given the heterogeneity within South Asian populations, culturally tailored efforts must reflect the diverse religious and cultural identities across these communities. Policymakers and funders should therefore consider broadening their support to include these grassroots and faith-based partners as integral components of a resilient, inclusive support network for South Asian families affected by dementia.

7.5.4 Policy Advocacy for Equitable Access to Dementia Care

The systemic barriers faced by South Asian families in accessing dementia care, such as immigration status, language barriers, and the lack of culturally tailored services, require urgent

policy action. These challenges align with broader findings emphasizing the need for equitable access to dementia care across diverse communities (Alzheimer Society of Canada, 2024). For instance, strengthening language access policies by mandating professional interpreters and culturally tailored materials can reduce reliance on family members as translators. This practice often leads to miscommunication and additional stress for care partners (Goeman et al., 2016).

Policy reforms should also focus on ensuring healthcare services are accessible to individuals awaiting permanent residency, preventing disruptions in care. Additionally, embedding cultural humility into healthcare practices through mandated education and training can improve the inclusivity of care delivery (Lekas et al., 2020). By advocating for these changes, policymakers can contribute to a healthcare landscape that prioritizes equity and culturally sensitive dementia care for South Asian Canadians.

Finally, policies that embed cultural humility into healthcare practices are needed. These policies should mandate ongoing education and support for providers to understand diverse communities better. By advocating for these changes, policymakers can contribute to a healthcare landscape that upholds equity, respects cultural diversity, and provides South Asian Canadians with the dignified and comprehensive dementia care they deserve.

7.6 Conclusion

This discussion synthesizes findings from three studies, highlighting the intersecting roles of cultural beliefs, systemic barriers, and stigma in shaping dementia care for South Asian Canadians. Through a multi-stakeholder approach, this thesis provides a nuanced understanding of how these factors collectively impact care, revealing the need for culturally informed, coordinated, and empathetic practices. The findings underscore that culturally sensitive dementia

care requires more than translation or basic adaptation; it calls for cultural humility, an approach where healthcare providers and community organizations continually learn from and adapt to the needs of their community.

This research extends the existing literature by incorporating insights from care partners, physicians, and community organization employees. It points to practical, policy-driven steps to foster a more inclusive dementia care environment. Recommendations emphasize the need for culturally contextualized education, sustainable community support, accessible healthcare, and a systemic commitment to cultural humility, guiding the path toward respectful and responsive dementia care.

In conclusion, this thesis highlights that enhancing dementia care within South Asian communities requires an integrated, empathetic approach that respects cultural nuances. By fostering partnerships across healthcare, community organizations, and policy domains, we can work toward a future where dementia care is accessible, dignified, and attuned to the unique needs of diverse populations.

7.7 References

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Appendix A

A.1 STUDY ONE: Interview Guide: Understanding the Experiences of South Asian Care Partners

**Care partner version*

Letter of Information and Verbal Consent

Introduction:

1. Welcome and thank the participant for their willingness to share their experiences.
2. Explain the purpose of the research project: to gain insight into the experiences of South Asian Canadians living with dementia and their care partners as they navigate through the stages of recognizing symptoms, receiving a diagnosis, and accessing services.
3. Emphasize that their input is valuable in improving the understanding of the unique challenges faced by this community.
4. Reiterate that participation is voluntary and confidential.

I. Background:

Let's begin by getting to know you and your relationship with your [relative] living with dementia.

1. Can you briefly introduce yourself and your relationship with the person with dementia?
2. Can you tell me a bit about your family and your family's move to Canada? This will help us understand when you came, where you came from, and who lives together in your household.

Probes for additional information:

1. When did your family make the move to Canada?
2. What was the place of origin for your family?
3. Who currently resides in your household?

II. Recognizing Symptoms and Seeking Help:

Now, I'd like to hear about your family's initial experiences with dementia.

Awareness of Early Symptoms:

5. Could you describe a situation when you first noticed changes in the behaviour or cognitive abilities of your [relative] with dementia?
6. What were the initial signs that made you suspect something was changing?
7. What was this experience like for your family?

Probes for: did anyone say anything? Did anyone express concern?

8. What do you think this experience was like for your [relative] living with dementia?

Cultural Perceptions and Beliefs:

1. Could you describe how you perceived the changes your [relative] was experiencing?
2. How do people from your [cultural community/country of origin] talk about dementia?
3. Do you think that your cultural/religious backgrounds shaped /informed your initial views and reactions to dementia?

Decision to Seek Help:

1. What factors or events led to seeking medical advice or professional help?
2. Were you worried about seeking help?
3. Was it challenging to seek help?
 - a. Probes: accessibility, language, transportation, the availability of a family doctor, or any other challenges you encountered during this process?

Interaction with Healthcare Professionals:

1. Does your [relative] with dementia have a family doctor? If so, how long have they been seeing that doctor? Does the doctor speak the same language as you and your loved one?
2. Can you communicate effectively with the doctor, and can your [relative] with dementia also share their needs?
3. Did you or your relative talk to the family doctor about the changes in your relative's behaviours or cognitive abilities? If so, what was this experience like? Was the family doctor helpful?
4. Were the healthcare professionals helpful in addressing your needs and concerns?

III. Receiving a Diagnosis:

Now, I would like to talk to you about receiving a diagnosis of dementia. A diagnosis is arrived at after a doctor or nurse practitioner asks you questions, performs a physical examination, conducts blood tests and x-rays, and finally identifies and names the specific health condition or illness that explains a person's symptoms. It helps in deciding the right treatment or care. In this case, it would be dementia.

Diagnosis Process:

1. Could you share your experiences with the diagnostic process?
 - a. How did your [relative] react to this process?
2. How was the diagnosis communicated?
 - a. Was your [relative] involved in the communication?
 - b. Were you given time to ask questions?
 - c. Were you given instructions for the next steps?
3. How did you react to the diagnosis?
4. How did your [relative] react to the diagnosis?

IV. Accessing Services:

Availability and Awareness of Services:

Awareness of Services

39. Were you initially aware of any dementia-related services in your community when your [relative] was diagnosed, or did you become aware of them as part of your care planning process?
 - a. How did you learn about these services if you were initially aware?
 - b. How were these services introduced during your care planning, such as through automatic referral or contact information?
40. Did you actively explore these services?
 - a. If not, what were the reasons for not pursuing them, and were any related to your cultural background?
 - b. If you did explore a service, can you share your experience in terms of comfort and cultural acceptance?
41. If you continued with a service, what factors influenced your decision to stick with it, such as feeling welcome and comfortable?
42. If you faced challenges but persisted, what improvements could enhance your experience?

Cultural Considerations in Service Utilization:

Inclusive Support and Ideal Programs:

1. Were there any dementia-related programs or supports where you felt your [relative] with dementia would feel included?
2. Were any services available in your language or culturally suitable to your needs?

Ideal Program Discussion:

1. Can you describe what the ideal program for your [relative] with dementia would look like? What features or elements would make it perfect for them?

Support Networks:

1. Who has helped you and your family through the dementia journey?
2. Were there any culturally specific sources of support that were particularly helpful? For example, how did your community, temple, mosque, South Asian Seniors group, etc., help you?

V. Coping Strategies:

In this section, we will explore your strategies to cope with the challenges posed by dementia and caregiving.

1. How have you, considering potential cultural influences, adapted to the changes brought about by dementia? Are there common strategies that helped and any specific to your cultural background?
2. What has helped you, taking into account cultural factors, maintain your well-being during this challenging time? Could you share specific actions or coping mechanisms that have been particularly effective in safeguarding your overall health and resilience?

VI. Reflection and Advice:

In this section, we will have questions to reflect on your experiences and provide insights for others going through a similar journey.

1. Looking back, what advice would you give to other South Asian Canadians who are in the early stages of recognizing symptoms or have recently received a diagnosis of dementia for a loved one?
2. Are there any changes you would suggest regarding healthcare services or community support to better address the needs of South Asian families dealing with dementia?

VII. Closing:

1. Express gratitude for the participant's openness and willingness to share their experiences.
2. Reiterate the importance of their contribution to the research.
3. Assure confidentiality and explain how the collected information will be used.

A.2 STUDY ONE: Interview Guide: Understanding the Experiences of South Asian Canadians with Dementia

***People living with dementia**

Letter of Information and Verbal Consent

Introduction:

1. Welcome and extend our sincere appreciation for your willingness to share your experiences.
2. Explain the purpose of the research project: to gain insight into the experiences of South Asian Canadians living with dementia as they navigate through recognizing symptoms, receiving a diagnosis, accessing services, and coping with challenges.
3. Emphasize that your input is invaluable and will contribute to a better understanding of the unique challenges faced by individuals living with dementia in this community.
4. Reiterate that your participation is voluntary, and we assure you that all information will be kept confidential.

I. Background:

Let's start by getting to know you and your experiences.

1. Please introduce yourself and share your journey, including your background and when you came to Canada.

Probes for additional information:

When did you immigrate to Canada?

What was your place of origin?

Who currently resides with you in your household?

II. Recognizing Symptoms:

Now, let's discuss your experiences related to dementia.

Awareness of Early Symptoms:

1. Can you describe your current experiences with changes in your thinking and memory?
 - a. What issues in your day-to-day activities are raising concerns for you, or have you noticed any recent challenges?
2. Considering the potential differences in insight or memory due to dementia, could you share what this experience is like for you now, in the present moment?
 - b. Can you provide insights into the type of dementia you have and how it might affect your awareness and memories of these changes?

Cultural Perceptions and Beliefs:

1. How did you personally perceive the changes in your behaviour or cognitive abilities?
2. What are your cultural perspectives on dementia, and how do people from your cultural community or country of origin typically discuss it?

The Decision to Seek Help:

1. What factors or events led you to seek medical advice or professional help?
2. Were there any challenges or concerns you faced when seeking help, such as accessibility, language, transportation, or finding a doctor?

Interaction with Healthcare Professionals:

1. Can you describe your experiences during these initial visits to healthcare professionals regarding dementia symptoms?
2. Were the healthcare professionals helpful in addressing your needs and concerns?
3. If you have a family doctor, how long have you been seeing that doctor, and do you find it easy to communicate your needs and concerns to them?

III. Receiving a Diagnosis:

Now, let's talk about receiving a diagnosis of dementia

Diagnosis Process:

1. Can you share your experiences during the diagnostic process? How was the diagnosis communicated to you?
2. How did you react to the diagnosis?
3. How did your family do it?

Emotional Impact:

1. How did you feel upon receiving the dementia diagnosis?
2. Can you describe your emotional responses and how you've coped with the diagnosis?
3. Were there any cultural influences, norms, or beliefs that impacted your emotional response and coping strategies regarding the diagnosis?

IV. Accessing Services:

Moving forward, let's discuss your journey in accessing services and support.

Awareness of Services:

1. Were you aware of any dementia-related services or support available in your community during diagnosis?

Seeking Services:

2. What services or resources did you use or attempt to use after the diagnosis? How did you go about seeking these services?
3. Did you ask your doctor or specialists for recommendations, consult with your community, or use specific sources like technology or word of mouth to find support?

Cultural Considerations in Service Utilization:

1. Were there any services where you felt a sense of inclusion?
2. Were any services available in your language or culturally suitable to your needs?

Ideal Program Discussion:

1. Can you describe what the ideal program or service for individuals living with dementia would look like to you? What features or elements would make it perfect for you?

Support Networks:

1. Who has been there to support you through your dementia journey?
2. Were there any culturally specific sources of support that were particularly helpful?

V. Coping Strategies:

Let's explore the strategies you've used to cope with the challenges posed by dementia.

1. How have you adapted to the changes brought about by dementia?
2. What coping mechanisms or strategies have you found most effective in maintaining your well-being?

VI. Reflection and Advice:

Now, I'd like you to reflect on your experiences and provide insights for others going through a similar journey.

1. Looking back, what advice would you give to other South Asian Canadians living with dementia who are in the early stages of recognition or have recently received a diagnosis?
2. Are there any changes you would suggest regarding healthcare services or community support to better address the needs of South Asian individuals dealing with dementia?

VII. Closing:

1. Express our heartfelt gratitude for your openness and willingness to share your experiences.
2. Reiterate how significant your contribution is to our research.
3. Assure confidentiality once more and explain how the collected information will be used.

Appendix B

B. 1 STUDY TWO: Interview Guide: Physicians' Experiences Diagnosing South Asian Canadians Living with Dementia

Letter of Information and Verbal Consent

Introduction

1. Welcome and express appreciation for the physician's willingness to participate in the research.
2. Briefly explain the research project's focus: to gain insights into physicians' experiences when diagnosing dementia in South Asian Canadians.
3. Emphasize the significance of their perspectives in enhancing the understanding of unique challenges and considerations in dementia diagnosis.
4. Reiterate that participation is voluntary and confidential.

I. Background:

Let's begin with general questions to gather some background information.

1. Can you introduce yourself and briefly describe your medical background?
2. Can you tell me about your experience in diagnosing dementia cases and how frequently you encounter South Asian families seeking a diagnosis? Is this a common occurrence in your practice?

II. Diagnostic Process:

Initial Observation and Symptoms:

1. Can you share an experience where you had to assess and identify symptoms of dementia in a patient? This case can be an example to help us explore and discuss the following questions.

Diagnostic Evaluation:

1. Could you describe the steps you took to confirm the diagnosis of dementia in the South Asian Canadian patient, and can you provide insights into the resources or tools you had access to in your office setting? Additionally, did you employ any specific approaches for patients of South Asian descent that differed from your standard practice?
2. Were there any challenges or considerations you needed to make in diagnosing these individuals because of their cultural background, and did you have access to resources or methods tailored to individuals of South Asian descent during this diagnostic evaluation?

Communication of Diagnosis:

3. What is your typical approach when communicating a dementia diagnosis to a patient and their family? Could you outline the usual information you share and how you convey it?
4. Was there anything you did differently or needed to consider in conveying the diagnosis because of the patient's background?

II. Cultural Considerations:

Cultural Perspectives on Dementia:

1. In your experience, have you observed any variations in how South Asian Canadian communities perceive and understand dementia, particularly in the context of interactions between the patient, their family, and the larger community?
2. How did these cultural perspectives impact your interactions with the patient and their family?

Family Involvement and Decision-Making:

1. Can you describe how you involved the patient's family in the diagnostic and decision-making process? Were any notable cultural aspects within South Asian Canadian families that influenced your approach?

IV. Challenges and Insights:

Now, I would like to discuss South Asian patients with dementia and their families more broadly.

Language Barriers:

1. Have you encountered language barriers when discussing dementia with South Asian Canadian patients and their families? How do you address these challenges?
2. Do language barriers affect the patient's understanding of the diagnosis or ability to access appropriate care and support?

Stigma and Cultural Norms:

1. Have you encountered instances where cultural norms or stigmas around dementia affected the diagnostic process or subsequent care? How do you manage these situations?

Resources and Support:

1. How do you guide South Asian Canadian patients and families to relevant resources and support services following the dementia diagnosis?
2. Are there any specific challenges in connecting them with culturally appropriate resources?

V. Personal Reflection:

In the following questions, reflect on your experiences and insights from diagnosing South Asian Canadian patients with dementia.

1. Based on your experiences, what have you learned or gained about providing effective diagnosis and support to this community?

VI. Future Improvements:

Now, let's discuss opportunities for improving the diagnostic process and care for South Asian Canadian individuals with dementia.

1. Could you tell us about any specific training you've received related to diagnosing dementia beyond medical school?
2. Would you like training in working with the South Asian community? If so, what would you like this training to look like?

VII. Closing:

1. Express gratitude for the physician's contribution and valuable insights.
2. Reiterate the importance of their input in advancing knowledge and care for South Asian Canadians with dementia.
3. Assure confidentiality and explain how the collected information will be used.

Appendix C

C.1 STUDY THREE: Interview Guide: Experiences of Employees of Community Organizations Providing Support Services to People Living With Dementia And Their Care Partners from South Asian Communities

Letter of Information and Verbal Consent

Introduction:

1. Welcome and express appreciation for the participant's involvement in the research.
2. Briefly outline the research's purpose: to gain insights into employees' experiences delivering services to South Asian communities.
3. Emphasize the participant's role in enhancing understanding and service effectiveness.
4. Reiterate that participation is voluntary and confidential.

I. Background:

Let's start with introductions and your role within the [organization]

1. Could you introduce yourself and describe your role within the [organization]?

II. Context and Approach:

Service Overview:

1. Please provide an overview of the services that the [organization] offers.
 - a. [if they have services specific to South Asian communities] How do these services support this demographic's needs and experiences?
2. How do these services cater to this demographic's specific needs and challenges?

Engagement and Outreach:

1. Does the [organization] engage with South Asian communities to raise awareness about dementia and available services?
Probe: If yes, how?
2. Can you share examples of successful strategies or initiatives that have encouraged community participation?

III. Community Interaction:

Partnerships and Collaborations:

1. Have you collaborated with other organizations or community leaders to enhance service delivery to South Asian communities?
2. How have these collaborations contributed to better outreach and support?

Cultural Aspects in Service Delivery:

1. Does the [organization] consider cultural aspects when designing and delivering services to South Asian communities?
2. Can you explain how cultural considerations have influenced service design or delivery?

IV. Challenges and Adaptations:

Overcoming Stigma:

3. Have you faced challenges, such as designing programs recruiting individuals related to the stigma associated with dementia within South Asian communities? How does the [organization] address this challenge?
4. Could you discuss strategies to raise awareness and reduce stigma within the South Asian communities effectively?

V. Impact and Success Stories:

Share positive experiences and outcomes from the [organization] service delivery efforts to South Asian communities.

1. Can you describe a success story where your services significantly benefited a South Asian family or individual living with dementia?
2. Does the [organization] assess the effectiveness and impact of its services within these communities? If so, how?

VI. Lessons Learned and Future Plans:

Discuss insights gained from the [organization] service delivery experiences and any plans for future enhancements.

1. Based on your experiences, what lessons have you learned about providing effective services to South Asian communities?
2. Are there specific future initiatives or improvements you are considering serving these communities?

VII. Closing:

1. Express gratitude for the participant's contribution and valuable insights.
2. Reiterate the importance of their perspective in shaping service delivery and advancing dementia care for South Asian communities.
3. Assure confidentiality and explain how the collected information will be used.

Appendix D

D.1 Letter of Ethics Clearance

UNIVERSITY OF WATERLOO

Notification of Ethics Clearance to Conduct Research with Human Participants

Principal Investigator: George Heckman

Student investigator: Navjot Gill

File #: 45805

Title: Dementia Dastan: Understanding the Experiences of South Asian Canadians Living with Dementia and their Care Partners.

The Human Research Ethics Board is pleased to inform you this study has been reviewed and given ethics clearance.

Initial Approval Date: 02/07/24 (m/d/y)

University of Waterloo Research Ethics Boards are composed in accordance with, and carry out their functions and operate in a manner consistent with, the institution's guidelines for research with human participants, the Tri-Council Policy Statement for the Ethical Conduct for Research Involving Humans (TCPS2 2022), the Ontario Personal Health Information Protection Act (PHIPA), and all laws and regulations of the province of Ontario (as applicable). Additionally, CREB operates in a manner consistent with the International Conference for Harmonization of Technical Requirements for Pharmaceuticals for Human Use (ICH) Guidance E6(R2): Good Clinical Practice, the International Organization for Standardization of Good Clinical Practices (GCP) as set out by ISO 14155 - Clinical investigation of medical devices for human subjects, Part C, Division 5 of the Food and Drug Regulations, Part 4 of the Natural Health Products Regulations, Part 3 of the Medical Devices Regulations. Both Boards are registered with the U.S. Department of Health and Human Services under the Federal Wide Assurance, FWA00021410, and IRB registration number IRB00002419 (HREB) and IRB00007409 (CREB).

Expiry Date: 02/08/25 (m/d/y)

Multi-year research must be renewed at least once every 12 months unless a more frequent review has otherwise been specified. Studies will only be renewed if the renewal report is received and approved before the expiry date. Failure to submit renewal reports will result in the investigators being notified ethics clearance has been suspended and Research Finance being notified the ethics clearance is no longer valid.

Level of review: Delegated Review

Signed on behalf of the Human Research Ethics Board



Asima Naeem, Ethics Advisor, a33naeem@uwaterloo.ca, 519-888-4567, ext. 41067

This above named study is to be conducted in accordance with the submitted application and the most recently approved versions of all supporting materials.

Appendix E

Recruitment Flyers

E.1 Care Partner/Person Living with Dementia English

Are you living with dementia
or a care partner within the
SOUTH ASIAN COMMUNITY?

Your experiences will be crucial
in understanding the
experiences of people living
with dementia and their care
partners in South Asian
communities.

**JOIN AN INTERVIEW
ONLINE OR BY PHONE
(APPROXIMATELY 60-90
MINUTES)**

INTERESTED OR HAVE QUESTIONS?

PLEASE CONTACT:

NAVJOT GILL



n35gill@uwaterloo.ca



289-887-1033



THE UNIVERSITY OF WATERLOO RESEARCH ETHICS BOARD
(ORE#) HAS REVIEWED AND APPROVED THIS RESEARCH
STUDY.



UNIVERSITY OF
WATERLOO

School of Public
Health Sciences

क्या आप साउथ एशियन कनाडाई हैं जो डिमेंशिया के साथ जी रहे हैं या देखभाल करने वाले साथी हैं?

एक शोध परियोजना के हिस्से के रूप में, आपकी अंतर्दृष्टि डिमेंशिया के साथ जी रहे व्यक्ति के अनुभवों को समझने या दक्षिण एशियाई समुदायों में देखभाल भागीदार होने के लिए महत्वपूर्ण होगी।

**ऑनलाइन या फ़ोन द्वारा
साक्षात्कार में भाग लें
(लगभग 60-90 मिनट)**

रुचि है या कोई प्रश्न है? कृपया संपर्क करें:

नवजोत गिल



n35gill@uwaterloo.ca



289-887-1033



इस अध्ययन की समीक्षा की गई है और इसे वाटरलू यूनिवर्सिटी रिसर्च एथिक्स बोर्ड के माध्यम से नैतिक मंजूरी प्राप्त हुई है।



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ਕੀ ਤੁਸੀਂ ਡਿਮੇਨਸ਼ੀਆ ਨਾਲ ਰਹਿ ਰਹੇ ਸਾਊਥ ਏਸ਼ੀਅਨ ਕੈਨੇਡੀਅਨ ਹੋ ਜਾਂ ਉਹਨਾਂ ਦੇ ਦੇਖਭਾਲ ਭਾਗੀਦਾਰ ਹੋ ?

ਇੱਕ ਖੋਜ ਪ੍ਰੋਜੈਕਟ ਦੇ ਹਿੱਸੇ ਵਜੋਂ ਦੱਖਣੀ
ਏਸ਼ੀਆਈ ਭਾਈਚਾਰਿਆਂ ਵਿੱਚ
ਡਿਮੈਂਸ਼ੀਆ ਨਾਲ ਰਹਿ ਰਹੇ ਲੋਕਾਂ ਅਤੇ
ਉਹਨਾਂ ਦੇ ਦੇਖਭਾਲ ਭਾਗੀਦਾਰਾਂ ਦੇ
ਅਨੁਭਵਾਂ ਨੂੰ ਸਮਝਣ ਵਿੱਚ ਤੁਹਾਡੇ ਅਨੁਭਵ
ਮਹੱਤਵਪੂਰਨ ਹੋਣਗੇ।

**ਔਨਲਾਈਨ ਜਾਂ ਫੋਨ ਦੁਆਰਾ
ਇੰਟਰਵਿਊ ਵਿੱਚ ਸ਼ਾਮਲ ਹੋਵੋ
(ਲਗਭਗ 60-90 ਮਿੰਟ)**

ਦਿਲਚਸਪੀ ਹੈ ਜਾਂ ਕੋਈ ਸਵਾਲ ਹਨ? ਕਿਰਪਾ
ਕਰਕੇ ਸੰਪਰਕ ਕਰੋ:

ਨਵਜੋਤ ਗਿੱਲ



n35gill@uwaterloo.ca



289-887-1033



ਇਸ ਅਧਿਐਨ ਦੀ ਸਮੀਖਿਆ ਕੀਤੀ ਗਈ ਹੈ ਅਤੇ ਵਾਟਰਲੂ ਖੋਜ ਨੈਤਿਕਤਾ ਬੋਰਡ ਦੀ
ਯੂਨੀਵਰਸਿਟੀ ਦੁਆਰਾ ਨੈਤਿਕਤਾ ਦੀ ਪ੍ਰਵਾਨਗੀ ਪ੍ਰਾਪਤ ਕੀਤੀ ਗਈ ਹੈ।



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Are you a physician specializing
in dementia care with the
SOUTH ASIAN COMMUNITY?

Your experiences are crucial
in understanding the
intricacies of the dementia
diagnosis process within this
context.

**JOIN AN INTERVIEW
ONLINE OR BY PHONE
(APPROXIMATELY 30-45
MINUTES)**

**INTERESTED OR HAVE QUESTIONS?
PLEASE CONTACT:
NAVJOT GILL**



n35gill@uwaterloo.ca



289-887-1033



THE UNIVERSITY OF WATERLOO RESEARCH ETHICS BOARD
(ORE#) HAS REVIEWED AND APPROVED THIS RESEARCH
STUDY.



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E.5 Community Support Organization Employee

Are you an employee of a community organization providing support services to People Living with Dementia and their Care Partners from the

SOUTH ASIAN COMMUNITY?

Your experiences and perspectives are vital in understanding the nuances of service delivery to individuals with dementia within these communities as part of a research project.

**JOIN AN INTERVIEW
ONLINE OR BY PHONE
(APPROXIMATELY 30-45
MINUTES)**

INTERESTED OR HAVE QUESTIONS?

PLEASE CONTACT:

NAVJOT GILL



n35gill@uwaterloo.ca



289-887-1033



THIS STUDY HAS BEEN REVIEWED AND RECEIVED ETHICS CLEARANCE THROUGH A UNIVERSITY OF WATERLOO RESEARCH ETHICS BOARD.



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WATERLOO | School of Public
Health Sciences

Glossary

Dementia: Dementia denotes condition that causes a progressive decline in cognitive function that affects memory, thinking, and daily activities (Alzheimer's Association, 2021). It encompasses various neurodegenerative diseases, such as Alzheimer's, Lewy body, frontotemporal, and vascular dementias (World Health Organization, 2017). Common symptoms include memory loss, confusion, language difficulties, and changes in personality (Mayo Clinic, 2021). According to the DSM-5, this condition is also called major neurocognitive disorder (American Psychiatric Association, 2013).

South Asians: South Asians refer to individuals from South Asia, encompassing countries including India, Pakistan, Bangladesh, Nepal, Sri Lanka, Bhutan, the Maldives, and Afghanistan (United Nations, 2021). They share cultural ties while maintaining distinct languages and traditions (Pew Research Center, 2014). This diverse group has a global presence due to migration and diaspora (Institute for South Asia Studies, UC Berkeley, n.d.).

Immigrants: Immigrants are individuals who relocate to a different country for permanent residence (United Nations, 2021). They do so for reasons such as economic opportunities, family reunification, or seeking refuge (International Organization for Migration, 2021). Immigrants enrich host countries culturally and economically (Migrant Integration Policy Index, 2020).

Culture: Culture refers to a group's shared beliefs, values, practices, and symbols (Kroeber & Kluckhohn, 1952). It encompasses customs, language, art, and more, shaping identity and behaviour (Samovar et al., 2016). This dynamic concept influences how individuals perceive and interact with their world (Hofstede, 1980).

Ethnicity: Ethnicity refers to a social group sharing cultural, linguistic, or ancestral traits. It shapes identity and interactions, with shared customs and heritage, often linked to a specific geographical origin (Cornell & Hartmann, 2014). This concept influences individuals' sense of belonging and relationships (Phinney, 1990). In contrast, culture encompasses broader shared beliefs, values, practices, and symbols within a group (Samovar et al., 2016), shaping how people perceive and interact with their world (Hofstede, 1980).

Race: Race is a social construct categorizing people based on physical features, not determined based on biological characteristics (American Anthropological Association, 1998). It has been used historically for social differentiation but lacks genetic validity (Yudell et al., 2016). Race, a cultural concept, influences social status and opportunities (Appiah & Gutmann, 1996).

Ethno-racial: Ethno-racial pertains to the fusion of ethnicity and race, acknowledging the interplay between cultural and physical attributes (Twine & Gallagher, 2008). It recognizes that individuals encounter societal treatment based on ethnic and racial factors (Bowleg, 2012). This term underscores the intricate nature of identity, encompassing cultural heritage and physical traits that shape individuals' experiences (Phinney, 1992).

Accessing community support services: In the context of community support services, post-dementia diagnosis involves utilizing available non-medical resources within the local community (Alzheimer's Association, 2021). These services provide physical, mental, and social engagement for individuals with dementia and their care partners. This encompasses activities like art classes, exercise groups, memory cafes, and support groups (Alzheimer's Society, 2021). Community centers and similar establishments offer platforms for social interaction and cognitive stimulation. The primary aim of accessing these services is to improve the overall well-being and quality of life of individuals with dementia while also providing valuable support for care partners (Alzheimer's Association, 2021).