

TAMIL CANADIANS CAREGIVING EXPERIENCES CARING FOR OLDER ADULTS
WITH DEMENTIA AT HOME

A Thesis Submitted to the Committee on Graduate Studies in Partial Fulfillment of the
Requirements for the Degree of Master of Science in the Faculty of Arts and Science

TRENT UNIVERSITY

Peterborough, Ontario, Canada

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Nursing, Professional Practice Leadership M.Sc. Graduate Program

January 2025

Abstract

Tamil Canadians Caregiving Experiences Caring for Older Adults with Dementia at Home

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This study examines the experiences of Tamil Canadian caregivers providing home care for older adults with dementia, highlighting their unique challenges. Grounded in a social constructivist and phenomenological approach, the qualitative research explores the influence of social, cultural, and familial expectations on caregiving roles. Semi-structured interviews with ten Tamil Canadian caregivers revealed difficulties in accessing healthcare, managing complex care needs, and balancing personal well-being with caregiving responsibilities. Language barriers and limited awareness of available health and social services further exacerbated emotional, financial, and physical burdens. Caregivers expressed a strong need for educational resources to enhance their skills and support their roles. Despite these challenges, participants reported emotional rewards, such as strengthened family bonds and a profound sense of duty. The study underscores the importance of tailored interventions, advocating for culturally responsive services, language support, and caregiver education to better address the needs of Tamil Canadian caregivers.

Keywords: Tamil Canadian caregivers, dementia caregiving, caregiver burden, cultural barriers, cultural values in caregiving, language barriers, caregiver support systems, healthcare access, family caregiving, caregiver education, self-care for caregivers.

Acknowledgements

First and foremost, I bow in reverence to the almighty Lord Muruga, whose divine light has illuminated my path, providing clarity and direction. With utmost humility, I offer my deepest pranams to Bhagwan for His boundless grace, divine guidance, and strength throughout this journey. It is through His wisdom and blessings that I have been able to persevere and complete this work. I am sincerely thankful for the support, and guidance provided by my supervisor, Dr. Abeer Omar, and my research committee. Their expertise and dedication have been invaluable in shaping the course of this project. I deeply appreciate their perseverance, thoughtful feedback, and unwavering support, which have significantly enhanced the quality of this work.

I would also like to extend my heartfelt thanks to everyone who participated in this project. Their willingness to share their time, energy, and experiences through the survey has enriched this research, making it more meaningful and impactful.

To my loved ones, I offer my deepest gratitude. Your unwavering support, compassion, and endless encouragement have been my anchor throughout this journey. Your love, patience, and steadfast belief in me have given me the strength to keep moving forward, even during the most difficult times. Words cannot fully capture how profoundly you have inspired and uplifted me. Finally, working on this thesis has been an immensely rewarding experience, both intellectually and personally. I am deeply grateful for the knowledge gained, the challenges overcome, and the fresh perspectives developed along the way.

Table of Contents

Abstract.....	ii
Acknowledgements.....	iii
Chapter 1: Introduction	1
Background	1
Problem Statement	2
Definitions	4
Chapter 2: Literature Review	6
Cultural Values in Caregiving	6
Caregiving Burden	8
Language barrier	8
Social stigma	10
Stress	11
Caregivers Educational Needs	12
Caregivers Self-Care and Social Support	13
Self-care	13
Social support	14
Positive Aspects of Caregiving	15
Chapter 3: Research Methods	17
Research Questions	17
Research design	18
Theoretical Framework.....	19
Role of the researcher	21

Sampling and setting	23
Recruitment	24
Data Collection	27
Data Analysis	30
Compilation and Transcription	30
Interpretive Description	31
Thematic Analysis Framework	32
Data Analysis Process.....	33
Trustworthiness	35
Triangulation.....	35
Reflexivity.....	38
Ethical Procedures	40
Chapter 4: Findings	42
Demographic Data	43
Theme 1: Lack of Knowledge	46
Limited awareness of available supports.....	46
The Need for Education	48
Theme 2: Caregiver Burden	50
Language Barrier.....	50
Financial Burden	54
Limited Family Support	56
Lack of Self-Care	58
Family Responsibility.....	60

Theme 3: Culturally Supported Values.....	61
Duty to Reciprocate Care	61
Cultural Caregiving Responsibility	61
Emotional and Physical	62
Theme 4: Positive Experiences of Caregiving	63
Sense of Luck and Gratitude	64
Emotional Connection and Happiness	64
Positive Impact on Family Dynamics.....	64
Achieving Data Saturation.....	67
Chapter 5: Discussion	69
Lack of Knowledge.....	69
Caregiver Burden.....	71
Language Barrier.....	72
Financial Burden.....	74
Limited Family Support.....	75
Lack of Self-Care.....	76
Family Responsibility.....	77
Culturally influenced caregiving	77
Duty to Reciprocate Care.....	77
Cultural Caregiving Responsibility.....	78
Emotional and Physical.....	79
Positive experiences of caregiving.....	79

Sense of Luck and Gratitude.....	80
Emotional Connection and Happiness.....	80
Positive Impact on Family Dynamics.....	81
Study Limitation.....	81
Implications for Nursing Practice.....	82
Recommendations for Supporting Tamil Canadian Caregivers.....	83
Empowering Caregivers through Education and Awareness of Available Services.....	83
Improving Cultural Competency and Communication for Tamil Canadian Caregivers...85	
Health Support Systems and Financial Resources.....	86
Promotion of Self-Care Practices.....	87
Training Program for Tamil Canadian Caregivers.....	87
Conclusion.....	89
References	91
Appendix A.....	101
Appendix B.....	102
Appendix C.....	105
Appendix D.....	106
Appendix E.....	107

List of Tables

Table 1: Demographic data	43
Table 2: Organization of Themes and Sub-themes	45
Table 3. Sub-theme: Limited Awareness.....	46
Table 4. Sub-theme: The Need for Education.....	49
Table 5. Sub-theme: Language Barrier.....	52
Table 6. Sub-theme: Financial Burden.....	55
Table 7. Sub-theme: Limited Family Support.....	56
Table 8. Sub-theme: Lack of Self-Care.....	58
Table 9. Sub theme: Family Responsibility.....	60
Table 10. Theme: Culturally Supported Values.....	62
Table 11 Theme: Positive Experiences of Caregiving.....	65

Chapter 1: Introduction

Caregiving for older adults, particularly those living with dementia, is a critical yet often overlooked aspect of the healthcare system. Family caregivers play an essential role in providing care to their loved ones, often at great personal cost. In the Tamil Canadian community, cultural and language barriers can significantly complicate access to healthcare and support services. This study aims to explore the unique experiences of Tamil Canadian caregivers caring for older adults with dementia at home and the support systems needed to alleviate the demands of caregiving for those living with dementia.

Background

Caregiving is a multifaceted phenomenon that entails a broad spectrum of activities including personal care, meal preparation and financial management. The 2022 annual Ontario Caregiver Report estimates that around four million caregivers in Ontario provide physical and emotional support to individuals, with 49% of care recipients residing with their caregivers (Ontario Caregiver Report, 2022). The findings of a survey conducted on 820 self-reported caregivers in Ontario indicate that they provide unpaid care to a family member (Ontario Caregivers, 2022). Despite the critical role that family caregivers play in the healthcare system, their caregiver status often comes at a personal cost, resulting in emotional distress, anger, or depression about their caregiving role or their inability to continue in that role.

According to the Alzheimer Society of Ontario, there are approximately 255,000 people living with dementia in Ontario in 2021, and this number is expected to increase to 328,000 by 2028. It is estimated that about 12% of Ontarians aged 65 and older have dementia, and this percentage increases with age, with 35% of Ontarians aged 85 and older living with dementia and needing a caregiver to manage their care at home.

Dementia can be a challenging condition for both the person living with dementia and their caregivers. Caring for older adults with dementia can be challenging, for family caregivers who provide care at home. Caregivers of older adults with dementia may often experience high levels of stress, depression, and anxiety, as they may be responsible for managing complex care needs, navigating the healthcare system, and dealing with challenging behaviors (Alzheimer Society of Canada, 2021). In a survey done by the Alzheimer Society of Canada in 2021, 72% of caregivers reported experiencing depression, 66% reported anxiety, and 42% reported high levels of stress. These statistics highlight the significant burden that caregivers of older adults with dementia face and the urgent need for targeted interventions to support these caregivers. Caregivers with a limited understanding of dementia overestimate the abilities of those they care for, which can lead to increased feelings of anger, frustration, and depression. Without adequate knowledge of the challenges associated with dementia, caregivers might develop unrealistic expectations, further intensifying their emotional strain (Ala et al., 2005).

Problem Statement

Caregiving for older adults with dementia is a critical yet often underappreciated aspect of the healthcare system. Family caregivers play a pivotal role in providing care, often at a significant personal cost. Within the Tamil Canadian community, cultural expectations, language barriers, and limited access to resources create unique challenges that amplify the caregiving burden. Despite the growing Tamil Canadian population, particularly in cities like Toronto, their experiences as caregivers remain largely unexplored in the existing literature.

The caregiving experience is influenced by numerous internal and external factors, including cultural beliefs, the nature of the care recipient's needs, and the complexity and duration of care. Toronto, one of the most culturally diverse cities in Canada, is home to a

significant Tamil Canadian community, representing approximately 4.4% of the city's population, or about 300,000 individuals (Census of Population Canada, 2021). Tamil Canadian caregivers face unique challenges, particularly in accessing and navigating the healthcare system, due to language barriers, cultural differences, and a lack of awareness of available resources. Research by Kneebone and Martin (2003) has shown that there is limited knowledge about the caregiving experiences of caregivers from specific ethnic backgrounds, further complicating their ability to receive appropriate support.

The limited research on ethnic-specific caregiving experiences leaves a significant gap in understanding the unique needs of Tamil Canadian caregivers. These caregivers navigate their roles through a cultural lens that shapes their approach to caregiving, while simultaneously contending with systemic barriers in accessing healthcare and social support. For many, linguistic challenges hinder effective communication with healthcare providers, complicating their ability to advocate for their loved ones. Additionally, cultural stigmas around dementia and the lack of culturally informed support systems further isolate caregivers, leaving them without adequate assistance or education on managing their caregiving responsibilities.

This study aims to address these gaps by examining how cultural and linguistic factors influence caregiving practices within the Tamil Canadian community. By focusing on their lived experiences, the research seeks to shed light on the barriers they face and identify the support systems necessary to alleviate their caregiving burden. Ultimately, understanding these dynamics can inform the development of inclusive, culturally informed, and linguistically accessible interventions to better support Tamil Canadian caregivers.

Definitions

Caregiver: An individual, who provides personal care, meal preparation and financial management to someone unable to care for themselves due to age and illness (Wolff et al., 2016).

Informal and Formal Caregivers: Caregiving is broadly categorized into two types: informal and formal caregivers. Informal caregivers are typically family members, friends, or neighbors who provide unpaid assistance to individuals with chronic illnesses, disabilities, or age-related conditions. Their responsibilities often include helping with daily activities such as bathing, feeding, medication management, and emotional support. Informal caregiving is deeply rooted in personal relationships and a sense of familial or social obligation. While this type of caregiving can foster close bonds between the caregiver and care recipient, it often comes with significant emotional, physical, and financial burdens for the caregiver. In contrast, formal caregivers are trained professionals who provide paid caregiving services in various settings, including home care, nursing facilities, or hospitals. Formal caregiving typically involves structured schedules, professional boundaries, and specialized training in areas such as dementia care or medical assistance. These caregivers are an integral part of the healthcare system, offering expertise and relieving some of the stress and responsibilities borne by informal caregivers. Tamil Canadian caregivers predominantly fall into the category of informal caregivers.

Dementia: A general term used to describe a decline in cognitive function severe enough to interfere with daily life. This includes conditions such as Alzheimer's disease and other forms of memory loss, affecting thinking, behavior, and the ability to perform everyday activities (Alzheimer Society of Canada, 2021).

Tamil Canadian Community: Refers to individuals of Tamil ethnic origin residing in Canada, The community primarily originates from Sri Lanka, with Tamil as their native language.

Caregiver Burden: The adverse effects that caregiving has on caregivers' emotional, social, financial, and physical functioning, impacting their well-being and leading to stress, social isolation, financial strain, and physical exhaustion (Zarit et al., 1980).

Culture: A complex framework of shared beliefs, values, practices, and social norms that shape individuals' perceptions, behaviors, and interactions. In this study, culture is understood as a dynamic influence that frames caregiving attitudes, expectations, and practices within the Tamil Canadian community, encompassing traditions, familial roles, religious beliefs, and community dynamics.

Caregiving Burden: The physical, emotional, social, and financial stressors associated with providing care to individuals with complex health needs, such as dementia. Cultural expectations, gendered caregiving roles, and systemic barriers, including limited access to linguistically or culturally aligned resources, can exacerbate this burden.

Chapter 2: Literature Review

This study aimed to explore the caregiving experiences of Tamil Canadian caregivers who provide care for older adults with dementia at home. While extensive research has been conducted on the experiences and stressors of caregivers from various ethnic backgrounds, Tamil Canadians have been notably underrepresented in the literature. This study will address this gap by examining the unique caregiving experiences of Tamil Canadian caregivers.

The review of the literature was conducted to gain a comprehensive understanding of existing research on this topic. Multiple studies on caring for loved ones with dementia have shown that caregivers face significant challenges when caring for individuals with dementia and similar illnesses. This literature review covers various aspects, including cultural values in caregiving, the need for caregiver education, caregiving burden, caregivers' educational needs, caregivers' self-care and social support, as well as the positive aspects of caregiving.

Cultural Values in Caregiving

Maintaining values and customs during caregiving can contribute to caregivers' satisfaction (Wakefield et al., 2012). Caregivers gain caregiving knowledge and awareness through their experience. Couto et al. (2016) conducted a study with Brazilian caregivers and found that caregiving experiences help preserve emotional bonds between caregivers and the care recipients. Positive caregiving experiences, including affection, solidarity, pleasure, gratitude, commitment, and well-being, can hold great value and meaning (Couto et al., 2016). Brazilian caregivers bring their family values and customs into their caregiving role, which can be highly valued and satisfying for both the caregiver and the care recipient. The role of solidarity is recognized by these caregivers, as they aspire to continue caring for other dependents voluntarily later in life (Couto et al., 2016).

Botsford et al. (2011) discussed the significance of cultural values in shaping how family members perceive and respond to caregiving responsibilities. This study revealed that Caribbean and Asian people living in England extend family care beyond the individuals who are directly involved and are deeply intertwined within broader family networks, including friends, all influenced by cultural factors. Decisions about care, such as how, when, where, why, and by whom such care should be provided, and support for older adults are collective family undertakings. Andruske & O'Connor (2020) explored family care across three different ethnic groups which are Chinese, South Asian, and Latin American in Canada-further supporting a similar understanding of family care within culturally diverse contexts, recognizing that it occurs within broader networks of family and friends, often influenced by culture. Williams et al.'s (2016) study provided valuable insights into the role of gender in caregiving, emphasizing the importance of understanding how gender, particularly within specific ethnicities, plays a significant part in determining caregiving responsibilities. These studies reinforce the importance of cultural values in shaping family caregiving dynamics and highlight the collective decision-making process within families regarding caregiving responsibilities. Culturally sensitive policies and practices are needed to accommodate diverse approaches to family care. It is necessary to adapt policies and practices to different ways of providing care, considering the diverse cultural perspectives and approaches to caregiving.

In Tamil culture, caregiving for elders is viewed as a sacred duty rooted within the family. Adult children, especially daughters and daughters-in-law, are often expected to assume primary caregiving roles. This cultural norm can create significant emotional and physical strain, as caregivers frequently prioritize familial responsibilities over their own well-being. The collectivist nature of Tamil culture amplifies these pressures, as caregiving is seen as a collective

family effort. However, for Tamil immigrant families in Canada, where nuclear family structures are more common, conflicts may arise in balancing individual needs with collective expectations.

Caregiving Burden

Caring for older adults with dementia presents distinct challenges for caregivers from diverse populations. Caregiver burden is defined as a multidimensional response to the physical, psychological, emotional, social, and financial stressors linked to the caregiving experience (Kasuya et al., 2000). Objective caregiver burden refers to the time spent on caregiving and the specific tasks carried out, while subjective burden pertains to the caregivers' personal experiences with these tasks, including the physical, psychological, emotional, social, and financial effects of caregiving (Cao & Yang, 2020).

Dening et al. (2012) conducted a qualitative study that examined the barriers faced by caregivers of older adults with dementia, uncovering the challenges in providing appropriate care, which led to increased caregiver burden. Similarly, Garand et al. (2005) examined the caregiving burden experienced by spouses caring for individuals with cognitive impairment, highlighting the significant burden these caregivers face. These studies enhance our comprehension of the challenges related to caregiving and offer valuable insights into the burdens faced by caregivers. However, it is important to note that these studies were not specifically conducted with particular ethnic groups. The researcher anticipates the necessity of conducting more studies that focus on specific ethnicities to gain a better understanding of their unique needs.

Language barrier

Navigating the healthcare system can be particularly challenging for caregivers with language barriers. As caregivers take on the responsibility of caring for loved ones, they often

encounter difficulties communicating effectively with healthcare providers due to language differences. Language barriers in healthcare can lead to miscommunication between medical professionals and caregivers, reducing satisfaction for both parties and decreasing the quality of healthcare delivery (Al Shamsi et al., 2020). Caregivers and patients who do not speak the local language encounter significant disadvantages when accessing healthcare services (Floyd & Sakellariou, 2017). This communication barrier can hinder caregivers' ability to advocate for their loved ones' health needs, understand medical information, and participate effectively in care planning. Multiple studies have indicated that individuals facing language barriers tend to experience poorer health outcomes compared to those who are proficient in the local language (Divi et al., 2007).

Addressing language barriers is crucial to ensuring that caregivers can access and utilize healthcare services comprehensively. By improving language access in healthcare settings, caregivers can better navigate the complexities of caregiving and advocate more effectively for the health and well-being of their loved ones. This, in turn, contributes to better health outcomes and enhances the overall caregiving experience. A systematic review by Lindeza et al. (2020) of family caregivers' perceptions of caregiving discussed the challenges that can arise from factors such as language barriers. Latino caregivers face language challenges that affect their ability to communicate medical needs and navigate the healthcare system effectively (Martinez et al., 2024). Language barriers can lead to misunderstandings during medical consultations, potentially affecting the quality of care provided to their loved ones. The absence of formal support can lead to feelings of isolation among caregivers, who express a sense of being left to manage their responsibilities alone (Livingston et al., 2010). Moreover, caregivers may struggle to access

necessary support services, such as educational resources or caregiver support groups, if these are unavailable in their preferred language.

Language barriers are a significant obstacle for many Tamil caregivers, particularly first-generation immigrants with limited English proficiency. These challenges hinder effective communication with healthcare providers, complicating navigation of the healthcare system and access to necessary resources. Even when interpreters are available, differences in communication styles, such as Tamil caregivers' tendency toward indirect expressions or deference to authority can lead to misunderstandings.

Social stigma

Caregiving experiences for individuals looking after older adults with dementia often involve a significant emotional burden, encompassing negative emotions such as sadness, frustration, and guilt (Lindeza et al., 2020). Caregivers are emotionally burdened by the stigma surrounding dementia in certain cultures (Lindeza et al., 2020). Caregivers from diverse populations may face additional stressors, including stigma and discrimination (Lee & Kim, 2019).

In Asian households, a dementia diagnosis is frequently associated with shame, which affects the entire family dynamic (Jang et al., 2018). This shame often leads to social stigma, causing families to feel embarrassed and opt for isolation instead of seeking support (Jang et al., 2018; Uppal et al., 2014). Moreover, caregivers may experience social isolation due to cultural differences or a lack of adequate support from their social network, including family and friends (Lindeza et al., 2020). Cultural misconceptions about dementia often result in stigma within Tamil communities. Symptoms of dementia are sometimes attributed to spiritual disturbances, supernatural causes, or moral failings, which discourages families from seeking professional

help. This stigma delays diagnoses and interventions, leaving caregivers to manage challenges privately. Social norms emphasizing family dignity can further isolate caregivers, who may avoid discussing their struggles openly.

Stress

Caring for older adults with dementia presents significant challenges and stress for caregivers. Dementia progressively affects cognitive functions like memory and communication, necessitating specialized caregiving. The demands of caring for dementia patients often lead to heightened caregiver stress. Brodaty and Luscombe (1998) observed a link between caregivers' psychological difficulties and the severity of dementia in their loved ones in a study involving 193 caregivers. Similarly, Battista et al. (2004) highlighted that cognitive and behavioral issues in dementia patients contribute to increased caregiver stress.

Sorensen and Conwell (2011) noted increased risks of depressive symptoms and health problems among Latino and Asian caregivers. Ranney and Aranda (2001) found moderate levels of depression in 97 Latino familial caregivers, describing these depression levels as clinically significant and disruptive to daily functioning. Bertrand et al. (2006) identified elevated stress levels as a significant psychological effect of caregiving in their study involving 349 caregivers. They observed higher stress levels among caregivers of individuals with dementia compared to those caring for individuals without dementia.

The research underscores the need for more studies focusing on minority caregivers, emphasizing the importance of using diverse samples in caregiving research. Studies consistently show elevated stress levels among caregivers of dementia patients, particularly affecting minority caregivers such as Latinos and Asians. Addressing these challenges requires tailored support and interventions that consider the unique needs of caregivers from diverse backgrounds.

Many Tamil Canadians arrived as refugees' migrants, bringing additional stressors related to resettlement. Financial insecurity, employment challenges, and the demands of adapting to a new cultural environment compound the difficulties of caregiving. These migration-related factors exacerbate caregivers' struggles to balance the demands of caregiving with their own integration into Canadian society. Further research using diverse samples is crucial to better understand and effectively support caregivers across different cultural and ethnic groups.

Caregivers Educational Needs

New caregivers often face difficulties adjusting to the demands and new routines of caregiving. Research conducted by Couto et al. (2019) among Brazilian caregivers found that the lack of knowledge and experience in caregiving leads them to actively seek support and education. Caring for a dependent older adult often exceeds caregivers' capacity, leaving them uncertain about the adequacy of their care and causing feelings of insecurity and emotional distress. Consequently, caregivers recognize the need for education, assistance, and monitoring, as evidenced by their utilization of social networks and health services to cope with the emotional impact they experience.

Providing education to caregivers has proven beneficial across various studies. Sorensen and Conwell (2011) and Holley and Mast (2009) reported that education is an effective approach for enhancing caregiver knowledge and alleviating high levels of burden. Additionally, Haley et al. (2003) found that early enhanced caregiver support leads to significant improvements. Burns et al. (2003), in their study involving 167 caregivers, demonstrated the effectiveness of educational materials in managing stress and coping for caregivers and care recipients with dementia. These interventions significantly reduced caregivers' feelings of burden by providing valuable knowledge and coping strategies. The study underscored the importance of offering

targeted educational resources to support caregivers and alleviate the stress associated with caring for individuals with dementia.

Caregivers Self-Care and Social Support

Self-care

Caregivers frequently express a strong need for attention, support, and care due to the overwhelming physical exhaustion and emotional distress they endure while caring for elderly individuals at home (Couto et al., 2016). Negative experiences often arise when caregivers neglect their own self-care as they prioritize providing uninterrupted care for older adults. An exclusive focus on caregiving responsibilities can lead to significant physical and psychological strain on the caregivers' well-being. They may find themselves sacrificing their social lives and struggling to engage in activities they once enjoyed, as their primary focus is fulfilling their caregiving duties (Couto et al., 2016). Morgan et al. (2002) suggest that caregivers frequently experience social isolation due to a lack of support from their families, which significantly affect their personal and social lives. The limited availability of leisure time and self-care among caregivers results in a noticeable decline in social connectedness (Morgan et al., 2002). It is essential to provide comprehensive support services tailored to the unique needs of caregivers to mitigate the adverse consequences associated with their caregiving roles.

Caregivers often prioritize the needs of their loved ones over their own health and physical well-being. Duplantier and Williamson (2023) found that caregivers frequently neglected important aspects of self-care, such as eating well, exercising, and getting sufficient sleep. Although the physical demands of caregiving were significant, caregivers generally did not focus on these challenges (Duplantier & Williamson, 2023).

Social support

The level of social connectedness significantly influences the caregiving experience of Korean caregivers, particularly those caring for older adults with dementia (Hong & Kim, 2008). Research has shown a strong negative correlation between depression and social support, indicating that caregivers lacking a social support network are more prone to experiencing depressive symptoms. Caregivers with higher levels of social support generally report greater well-being and overall better health (Hong & Kim, 2008).

In general, caregiving has shown that caregivers with a strong social support network are more likely to find satisfaction in their caregiving role and maintain positive attitudes toward caring for individuals with dementia (Wakefield et al., 2012). Caregivers can find a sense of purpose and meaning in their caregiving experiences, further highlighting the significant impact of social support on their overall well-being and their ability to navigate the challenges associated with caregiving.

Kontrimiene et al. (2021) conducted a qualitative study in Lithuania that explored the experiences of Lithuanian informal caregivers caring for older adults with dementia. The researchers highlighted that informal caregivers acquire their caregiving knowledge primarily through social networks within their culture and personal experience, receiving limited guidance from healthcare professionals. However, this reliance on personal experience and social networks may lead to shortcomings in their competence, negatively affecting the quality of care provided. Caregivers' fear of incompetence and lack of knowledge about available care resources can also contribute to psychological distress.

Positive Aspects of Caregiving

Although much of the caregiving research emphasizes its negative effects, there is evidence suggesting that caregiving can also lead to positive personal growth and enrichment. For instance, Ott et al. (2007) highlighted positive outcomes, such as caregivers experiencing personal growth and engaging in meaningful self-reflection. Caregivers frequently report positive aspects of their caregiving roles, including a sense of fulfillment, satisfaction, and an increase in self-esteem (Cohen et al., 2002; Harmell et al., 2011).

A study by the National Opinion Research Center found that 83% of caregivers in the United States viewed their caregiving experience as positive and believed it strengthened their relationship with the care recipient, even though it also introduced some stress within the household (National Opinion Research Center, 2014). This suggests that while caregiving can be demanding, it often brings meaningful emotional and relational gains that contribute to the caregiver's overall well-being. Similarly, a study of Asian family caregivers of dementia patients in Singapore found that receiving encouragement significantly boosted caregivers' sense of gain. The research also indicated that spirituality and religion indirectly contributed to this positive outcome by fostering encouragement (Lim et al., 2011). These findings highlight that caregiving can be rewarding and fulfilling, improving caregivers' psychological health and helping to counterbalance negative effects (Haley et al., 2003).

In another study, Jervis et al. (2010) found that American Indian caregivers perceived caregiving for older adults as rewarding rather than burdensome. This highlights the importance of exploring different aspects of the caregiving experience, particularly in cultures where caregiving is viewed as a reciprocal exchange of familial support. In American Indian culture, for instance, caregiving represents a longstanding relationship where elders have significantly

contributed to the caregivers' lives, with family members sharing caregiving responsibilities to alleviate the burden.

However, the previously mentioned studies generally lack a focus on specific ethnic groups, such as Tamil Canadians. By incorporating the existing knowledge and perspectives from other researchers, this study aims to better define the experiences of caregivers in this community, explore their recommendations for improving health and social services for themselves and their loved ones with dementia, and suggest further research as needed. The current study attempts to understand the unique barriers and challenges that Canadian Tamil caregivers face when caring for people with dementia, which are shaped by their specific cultural context.

Chapter 3: Research Methods

This chapter outlines the methodology employed in this study, beginning with the research questions, design, and rationale, followed by a discussion of the researcher's role. It then details the study's methodology, including participant selection, recruitment procedures, instrumentation, data collection, and data analysis plans. The chapter concludes with a discussion of the study's validity and trustworthiness, ensuring the rigor and credibility of the research findings.

The utilization of qualitative interviews with Tamil Canadian caregivers was crucial for identifying the current stressors and needs specific to this population. Through an in-depth exploration of their experiences, the research uncovered potential gaps in resources and necessities that are unique to Tamil Canadian caregivers. This lack of targeted information indicates that community health and home care professionals may not be adequately equipped to provide the required level of support. Consequently, research on the stressors faced by Tamil Canadian caregivers can offer valuable insights for developing more effective support strategies.

Research questions

The purpose of this study is to explore the caregiving experiences of Tamil Canadian caregivers who care for older adults with dementia at home. The current study asks the following research questions about Tamil caregivers' population:

RQ1: How do Tamil Canadian caregivers perceive the positive and negative experiences of caring for their loved ones with dementia?

RQ2: What are the barriers Tamil Canadian caregivers face when accessing health and social support for their care recipients?

RQ3: How do the Tamil Canadian caregivers' cultural background influence their caregiving experiences?

The researcher used the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool to define the key elements of the research since it is suitable for searching for qualitative research papers (Cooke, Smith & Booth, 2012). Please refer to Appendix A, which demonstrates how the SPIDER tool is used for the research question.

The decision to explore caregiving experiences among Tamil Canadian caregivers stems from the need to investigate a topic where existing data is limited. The experiences of Tamil Canadian caregivers have not been studied, necessitating an exploratory investigation to capture the authentic essence of this phenomenon.

Research design

Given the exploratory nature of this study, a qualitative approach was deemed most suitable. The choice between qualitative and quantitative approaches depends on the research questions being addressed. Qualitative research is particularly useful for answering research questions through naturalistic data collection techniques such as interviews, case studies, and observations (Creswell, 2009). While findings from qualitative research are often specific to a particular population, they can also inform future quantitative studies. This study's qualitative design allowed for an in-depth exploration of participants' unique experiences through personal interviews.

Qualitative research facilitates the collection of data from a smaller number of participants in a natural setting, enabling a detailed understanding of individual experiences. By conducting face-to-face interviews with a select group of individuals, the researcher was able to delve deeply into the participants' perspectives on the caregiving phenomenon. This approach

captured the true essence of lived experiences through interviews and direct observation of participants and their surroundings, providing a rich and nuanced understanding of their caregiving experiences.

Theoretical Framework

This study employs existential phenomenology as its theoretical framework to explore the lived experiences of Tamil Canadian caregivers caring for older adults with dementia. Existential phenomenology focuses on understanding human experiences through their subjective manifestations, as individuals assign personal meaning to their realities. This approach is particularly suited for this study, as it enables the researcher to gain profound insights into the unique and personal struggles of caregivers, capturing the complexity of their emotions, relationships, and cultural contexts (Sokolowski, 2000; Creswell, 2009). By focusing on individual experiences, phenomenology provides a robust method for exploring how caregivers perceive their roles and navigate their responsibilities within a specific cultural and social framework (Laverty, 2003).

Existential phenomenology delves into how individuals engage with and make sense of the world around them. This approach examines the essential structures that shape a person's ability to interpret their environment and the reflective processes that help individuals understand their emotions and interactions. In the case of Tamil Canadian caregivers, this method allows the study to explore how they balance their personal challenges with cultural expectations and how these roles evolve in response to caregiving (Von Eckartsberg, 1986; Cooper, 2008). It is particularly useful for investigating changes in caregivers' embodied experiences, shifts in relationships with themselves, their care recipients, and their broader sense of identity, as they manage the demands of dementia care (Bogard, 2010).

Additionally, this study incorporates a social constructivist perspective, which asserts that knowledge is created through social interactions and shared experiences. This philosophical lens allows the researcher to understand caregiving not just as an individual experience but as one deeply shaped by cultural, historical, and social contexts (Burr, 1998). Social constructivism emphasizes the subjective nature of reality, shaped by caregivers' interactions within their unique environments. This framework is crucial for examining the caregiving experience in Tamil Canadian communities, where caregiving practices are influenced by cultural values, family expectations, and collective norms. By focusing on how caregivers' beliefs, values, and cultural norms shape their caregiving roles, this paradigm offers a comprehensive understanding of the interplay between individual experiences and broader societal structures.

The study combines existential phenomenology and social constructivism to uncover the dynamics that shape the caregiving reality for Tamil Canadians. This dual approach allows for an in-depth exploration of the emotional, cultural, and relational aspects of caregiving, revealing how caregivers navigate feelings of duty, love and frustration while balancing personal and societal expectations. These insights are crucial for understanding the unique challenges Tamil Canadian caregivers face and providing culturally relevant recommendations for healthcare providers and policymakers.

To analyze the data, the study employs interpretive descriptive phenomenology, which is particularly suited for nursing research. This method emphasizes generating actionable insights from rich, detailed descriptions of lived experiences, going beyond mere description to uncover the deeper meanings and patterns underlying participants' experiences. It enables the researcher to interpret the caregivers' stories within their cultural and social contexts, ensuring the findings have practical relevance for healthcare practices. The study's iterative and dynamic approach to

analysis, based on Braun and Clarke's six-phase thematic analysis framework, ensures that the emerging themes and patterns are grounded in the caregivers' narratives. This method balances the description of caregivers' lived realities with an interpretation of the underlying structures and meanings that shape their experiences.

By combining existential phenomenology, social constructivism, and interpretive descriptive phenomenology, the study offers a comprehensive framework for exploring Tamil Canadian caregivers' experiences, revealing the deeper cultural, emotional, and relational dimensions that influence their caregiving practices.

Role of the researcher

In conducting this study, it is imperative to acknowledge and disclose the researcher's biases and experiences concerning the topic. Reflexivity, as outlined by Alvesson et al. (2022), involves an awareness that the researcher and the subject of study mutually influence each other throughout the research process. Drawing on ten years of experience as a care coordinator for home care services within the Tamil Canadian community, the researcher has consistently engaged with caregivers, addressing their specific needs. The researcher's primary focus has been on mitigating the 'physical' burnout experienced by caregivers, through enhanced in-home care support aimed at alleviating their burdens. However, there has been limited opportunity for the researcher to delve deeply into discussions about the emotional aspects of caregiving, given their role primarily centered on creating care plans for older adults rather than for caregivers themselves. This study emerges from a commitment to thoroughly explore the experiences of Tamil Canadian caregivers who care for older adults with dementia at home.

Hibbert et al. (2010) emphasize that reflexivity involves reflecting on our experiences and critically questioning our methods. Alvesson et al. (2022) suggest that researchers must be

conscious of the preconceptions they bring to their research topics. The researcher, who is a caregiver and cared for her elderly parents for over a decade, believes that she can internalize participants' experiences and bring a nuanced understanding to the study. Throughout the research process, she has reflected on how her intellectual, cultural, and traditional backgrounds influence the interpretation of the data. The researcher carefully considered how her ontological and social perspective influenced her decisions regarding research questions, methodologies, and outcomes. To ensure clarity and objectivity, she continually asked herself questions such as, "How am I connected to the research emotionally, and what effect will this have on my approach?" The answers to these questions helped her identify aspects that needed to be bracketed, allowing her to perceive participants' lived experiences from their perspectives.

Building a strong rapport with participants was essential for establishing a research relationship that allowed access to their stories (Ceglowski, 2000). As a researcher deeply interested in understanding caregivers' experiences, the researcher aimed to foster a researcher-participant relationship grounded in trust and openness. Although the researcher initially planned to share her caregiving experiences to build trust and create a safe space for self-disclosure, the researcher found that participants were very open in discussing their experiences without requiring her to share her own story.

Reflexivity guided the researcher's data analysis process. It provided the lens through which the researcher critically engaged with her own assumptions, emotional responses, and prior experiences, recognizing that these elements contribute to the interpretation of the caregivers' narratives. Reflexivity ensured transparency and enriched the analysis by acknowledging the researcher's subjective role in shaping the research process. Unlike bracketing, which attempts to set aside personal biases, reflexivity encouraged the researcher to

actively engage with her perspectives and reflect on how background, cultural knowledge, and caregiving experiences influence the data interpretation. In practice, reflexivity allowed the researcher to remain open to emerging themes within the data and reflect on how her personal caregiving experiences aligned or diverged from the participants' narratives. It also informed the iterative process of data analysis, where the researcher continually revisited interpretations in light of new insights.

Conducting qualitative research on sensitive topics can significantly impact the researcher. Maykut and Morehouse (1994) advocate for strategies that promote reflective thinking in qualitative researchers. Wincup (2001) recommends peer discussion as a valuable tool, providing reassurance and helping researchers overcome feelings of isolation by recognizing that their emotional experiences are not unique. The researcher is fortunate to have professional colleagues who have agreed to participate in weekly peer debriefing meetings. These meetings offer an opportunity to discuss the emotional challenges encountered during the interview sessions, ensuring a supportive environment that fosters reflective thinking and emotional resilience.

Sampling and setting

In this study, purposeful sampling was employed to select individuals with relevant experience and knowledge about the phenomenon being studied, specifically the experience of caregiving (Creswell & Poth, 2018). Purposeful sampling targets a population that meets specific criteria pertinent to answering the research questions (Ravitch & Carl, 2016). The participants for this study consist of caregivers who meet the following inclusion criteria: individuals aged 50 or older. The rationale for selecting caregivers of age 50 and above is that these caregivers are born outside of Canada and have a strong sense of culture and ethnic-specific values in caregiving. The

other inclusion criteria included caregivers who are fluent in Tamil, and currently providing care to older adults aged 65 or older with a diagnosis of dementia for a duration of less than six months within their home setting. The selection of spouses or children as the primary caregivers is based on their recognition as informal caregivers within the Tamil Canadian culture. The criterion of caregiving duration of less than six months is intended to capture the novice experiences of caregiving among Tamil Canadians. The exclusion criteria encompass caregivers below the age of 50, those who do not speak Tamil, and caregivers providing care for a duration exceeding six months within their home environment.

In qualitative research, the sample size is often determined by the principle of data saturation, which occurs when no new information or themes emerge from the data (Ravitch & Carl, 2016). For this study, a saturation sampling strategy was employed, with the sample size based on when saturation was reached (Ravitch & Carl, 2016). The recommended sample size for individual interviews are typically between seven to twelve participants, and for this study, ten participants were interviewed until data saturation was achieved. This approach ensured that the data collected was comprehensive, with no new insights emerging. The study was conducted in Toronto, a city known for its diverse population, where the Tamil community comprises 4.4% of the total population (Statistics Canada, 2021). Participants were recruited from caregivers of older adults with dementia who were receiving home care services through Ontario Health in Toronto.

Recruitment

The researcher recruited caregivers of older adults with dementia who were receiving home care services from Ontario Health in Toronto. The recruitment process began with the researcher, who is employed as a care coordinator at Ontario Health, reaching out to other care coordinators face to face within the team to explain the research objectives and methodology.

Four care coordinators, serving as the recruiters for this study, played an essential role in identifying and recruiting participants. The recruitment process began with the care coordinators (recruiters) reviewing a list of caregivers of older adults with dementia who were receiving home care services through Ontario Health in Toronto. Potential participants were selected based on their eligibility for the study, and this was communicated to them through an initial phone call.

During the phone call, the recruiters introduced the study and explained its purpose, which was to explore caregivers' lived experiences and the challenges they face while caring for dementia patients. The recruiters also provided an overview of the study's scope, including details about the nature of the interviews, the estimated time commitment, and how the data would be utilized. The recruiters emphasized that participation was voluntary and assured the caregivers that their identities and personal information would remain confidential.

After thoroughly explaining the study, the recruiters provided the participants with the researcher's contact information and invited them to reach out directly if they were interested in participating or had any additional questions. Participants were informed they could contact the researcher by phone to learn more or to schedule an interview. Following this, the researcher reached out to those who expressed interest to confirm their participation and provide further details about the interview process.

This recruitment process ensured that potential participants were fully informed about the study and could make an informed decision about their involvement. Additionally, the recruiters maintained patient privacy and confidentiality by informing participants about the study without disclosing any personal information to the researcher. This method protected participant anonymity and adhered to ethical standards throughout the recruitment process.

The researcher conducted individual information sessions with caregivers who had expressed interest in participating through phone calls. During these sessions, a comprehensive overview of the study was provided, including its aims, procedures, and expectations. Caregivers were then screened for eligibility based on the pre-defined criteria. Those who met the eligibility requirements and were willing to participate provided verbal consent. To ensure participants were fully informed, an informed consent form was provided (see Appendix B). The consent form detailed the voluntary nature of participation, the right to withdraw at any time, the study's purpose, benefits, procedures, and the plan for disseminating results. Additionally, it outlined the time commitment and compensation, offered participants the opportunity to ask questions, and explained how confidentiality would be maintained, as described in the data integrity and confidentiality section of the data analysis plan. Participants were assured that their decision to participate was voluntary and that their involvement in the study would not affect the care their families were receiving from Ontario Health in any way. Furthermore, participants had the freedom to withdraw from the study at any point if they chose to do so. By ensuring a thorough and respectful recruitment process, the researcher aimed to foster trust and openness among the participants, thereby facilitating the collection of rich, meaningful data on the caregiving experiences of Tamil Canadian caregivers.

Addressing Potential Biases

To mitigate potential biases introduced by the involvement of other care coordinators in the recruitment process, several strategies were implemented. A standardized recruitment protocol was established to ensure uniformity in how caregivers were approached, minimizing the likelihood of selective recruitment. Care coordinators were instructed to contact a broad range of caregivers, representing diverse experiences and levels of access to services. To further

reduce potential influence, recruitment materials were also provided by the researcher, ensuring impartial communication of the study's purpose and reassurances that participation would not affect the quality of care or the relationship with the coordinator.

The informed consent process emphasized the voluntary nature of participation, clearly stating that caregivers could decline or withdraw at any time without consequences. This approach aimed to alleviate any perceived obligation stemming from the caregivers' trust in their coordinators. Additionally, the researcher maintained reflexive awareness throughout the process, keeping a reflective journal to monitor how recruitment dynamics might shape participant responses and outcomes. These steps ensured a more balanced and representative dataset while upholding ethical research practices.

Data Collection

The researcher collected demographic information from all participants, including age, gender, level of education, and duration of caregiving experience and so on. The caregiving experience encompassed personal care, meal preparation, and financial management. The demographic data was essential as it could influence participants' responses during data collection (Steward, Shamdasani & Brook, 2007). Descriptive analysis was employed to analyze the socio-demographic data, providing a comprehensive summary of participants' characteristics. Following Mills (2006) perspective, the researcher approached data collection without preconceived ideas or beliefs, utilizing an inductive data collection approach. The researcher was aware of the mutual influence between herself and the participants. Since the researcher has ten years of experience as a care coordinator, in developing care plans for older adults, it was important to reflect on how this might shape assumptions and biases during the research process. To maintain objectivity, the researcher engaged in reflective practice, by asking herself

critical questions such as, 'How am I emotionally connected to this research?' This practice allowed the researcher to view the participants' experiences clearly, without imposing her own interpretations. To maintain privacy and confidentiality, the data is stored in a locked cupboard at George Brown College within the secure office of the study supervisor.

Semi-structured interviews were conducted, treating participants' responses as narratives (Cruickshank, 2012). These narratives illustrated the experiences of Tamil Canadian caregivers as perceived by the interviewees. To maintain focus and facilitate meaningful responses from research participants (Rubin & Rubin, 2012), an interview guide was developed; please refer to Appendix C for the interview guide developed for this study. This guide served as a valuable tool for the researcher, providing a structured framework during the interviews while allowing flexibility for deeper exploration.

The guide comprised a combination of general and probing questions designed to obtain comprehensive and insightful responses from participants. The interview questions aimed to clarify participants' perspectives and gain a deeper understanding of their experiences. By utilizing open-ended questions, the researcher minimized biases and provided participants with the opportunity to freely express their thoughts, feelings, experiences, and perspectives (Rubin & Rubin, 2012). Each semi-structured interview session lasted approximately 30 to 40 minutes, allowing for in-depth discussions while respecting participants' time commitments. The wording of the interview questions was carefully crafted to encourage participants to provide detailed descriptions of their personal experiences. As a result, the interview guide ensured methodological rigor and enhanced the credibility and reliability of the research findings. The interview questions consisted of open-ended questions to gather in-depth information on

participants' lived experiences. These questions, provided in Appendix C, were linked with and supported the study's research questions.

The study was conducted in the participants' homes to observe the caregiving phenomenon in its natural environment. This approach allowed for a deeper understanding of the lived experiences of the caregivers. To protect the confidentiality and anonymity of the participants, codenames such as TAM 01, TAM 02, and so on were used throughout the study. Throughout the interview process, the researcher actively employed effective listening skills to facilitate maximum participant engagement and encourage the sharing of participants' intimate caregiving experiences (Rubin & Rubin, 2012). By actively listening, the researcher aimed to establish rapport with participants, ensuring their comfort and willingness to share their caregiving experiences. To ensure accuracy and preserve the richness of the data, the interview sessions were recorded. Additionally, the researcher took detailed notes during the interviews, capturing participants' nonverbal expressions, observations of family dynamics, and environmental factors that might influence the caregiving experience. These supplementary notes contributed to a comprehensive understanding of the context and nuances surrounding participants' narratives. The in-depth interviews provided rich and detailed information regarding the researched phenomena (Rubin & Rubin, 2005). Each participant participated in one interview. Follow-up interviews were not necessary for clarification on any topics, the first interviews were in-depth to gather extensive information on participants' past and present experiences.

Data Analysis

Compilation and Transcription

The data analysis plan for this study involved a rigorous and systematic approach to ensure the authenticity and integrity of the participants' experiences. The researcher meticulously compiled all acquired information in a timely manner, transcribing interview responses verbatim after expanding the interview notes. This method preserved the participants' exact words and nuances, maintaining the integrity of the original data and providing a reliable foundation for subsequent analysis.

The researcher recorded and transcribed all interviews manually using Microsoft Word. The audio and transcribed data were stored and organized in a password-protected OneDrive file at Trent University. Data storage, organization, and confidentiality are discussed in detail in the subsequent section. Interview recordings will be listened to only by the researcher and will be deleted after data analysis is completed. The data will be stored in a password-protected OneDrive file at Trent University and only the researcher will have access to the data. All data will be destroyed after five years.

The process of transcribing and translating interviews from Tamil to English involved several careful steps to ensure both linguistic and contextual accuracy. The researcher personally carried out both the transcription and translation of the interviews conducted in Tamil. This process began with the researcher listening to the audio recordings and transcribing the content verbatim in Tamil. After completing the transcription, the researcher translated the text into English. To ensure the accuracy and trustworthiness of the translation, the researcher implemented a thorough verification process. This included reviewing the translated text to

ensure it remained consistent with the original Tamil, paying close attention to meaning, context, and cultural nuances.

Additionally, one of the recruiters, who was fluent in both Tamil and English, volunteered to assist with the verification. This recruiter reviewed the English translations for consistency with the Tamil transcripts and conducted a back-translation, where the English version was retranslated into Tamil to check for discrepancies. This collaborative and multi-step process ensured that the original meaning, context, and nuances from the interviews were accurately preserved in the final English transcripts. By combining the researcher's firsthand involvement with the validation provided by a fluent participant recruiter, the integrity and reliability of the qualitative data were maintained, ensuring its authenticity for comprehensive data analysis.

Interpretive Description

The researcher used an interpretive descriptive method to analyse the data. Interpretive description, according to Thorne, et.al. (1998), is an inductive analytical method crafted to generate insights into clinical phenomena that have practical applications. This methodology is particularly suited to the goals of nursing research, as it aims to produce actionable knowledge that can directly inform and improve health practice. Furthermore, Interpretive descriptive is an appropriate methodological alternative for nursing research, as it can address complex experiential questions while producing practical outcomes. It allows for the advancement of knowledge without sacrificing the methodological integrity that long-established qualitative approaches provide.

Thematic Analysis Framework

The researcher used thematic analysis for its versatility in obtaining and interpreting information from individuals' thoughts, feelings, and actions (Joffe, 2012). Thematic analysis is valuable for gaining insights and interpreting phenomena by exploring participants' subjective experiences (Joffe, 2012). It aligned well with the phenomenological approach, enabling the researcher to focus on the lived experiences of the participants. By employing the thematic analysis method described by Braun and Clarke (2006), the researcher aimed to identify and evaluate recurring themes within the data, facilitating the discovery of meaningful patterns. The thematic analysis included discussing relationships, similarities, and differences within the data (Ravitch & Carl, 2016). Themes were identified by grouping participants' quotes into sections of meanings, which were then organized into themes (Moustakas, 1994). The researcher explored the true essence of descriptions that signified each participant's meaning and experience, combining individual descriptions to develop a collective description for the entire group. Thematic analysis was deemed an appropriate analytical method for this study, as it enables a comprehensive understanding of the participants' experiences and provides rich qualitative data that aligns with the research objectives.

The data analysis involved identifying themes using an inductive approach. By adopting this method, the themes derived from the analysis were closely tied to the data itself (Patton, 1990). This approach allowed the researcher to code the data without fitting it into a pre-existing coding frame, enabling themes to arise naturally from the data. Consequently, the thematic analysis was driven by the data, facilitating a comprehensive exploration of the participants' experiences and perspectives. The researcher utilized Braun and Clarke's (2006) six phases of thematic analysis as a framework to guide the data analysis process. This approach involves the

identification, analysis, and reporting of themes derived from the data. By employing this method, the researcher identified themes or concepts present throughout the qualitative data, allowing for a comprehensive examination of the participants' experiences (Rubin & Rubin, 2012).

By integrating interpretive description and thematic analysis as the data analysis methods, this study aims to generate meaningful insights. Following a structured yet flexible analytical approach ensured that the research produced findings directly applicable to nursing practice, enhancing the understanding and supported the research questions.

Data Analysis Process

The data analysis process began with the researcher familiarizing herself with the gathered data. This involved repeatedly listening to the audio recordings, reading the interview transcripts, and carefully reviewing the data to develop a deep and comprehensive understanding of the information. During this initial phase, the researcher made notes on emerging thoughts and impressions that would later guide the analysis. Special attention was paid to non-verbal responses, family dynamics, and the overall interview environment, as these elements provided further insights and contextual understanding beyond the verbal content of the interviews.

The next phase involved generating codes from the data. Key phrases and relevant segments were organized into meaningful codes, serving as the foundation for identifying potential themes. As the analysis progressed, additional data were incorporated into these codes, enriching their depth and breadth. Open coding was used during this process to break the data into smaller, significant segments. Descriptive codes were assigned to capture the core ideas and concepts present in the interviews, ensuring that no important details were overlooked.

Once the initial codes were generated, the researcher began the process of searching for themes. The codes were organized into broader potential themes, and where necessary, more complex themes with diverse data were broken down into sub-themes to maintain clarity. Constant comparison was used throughout this stage, allowing the researcher to refine codes and develop broader categories by comparing data across different participants and sources. This approach helped to identify patterns and similarities, further strengthening the thematic structure.

Following this, the identified themes were thoroughly reviewed to ensure they accurately represented the data. The coherence of each theme was assessed to ensure that it captured the essence of the participants' experiences. To further organize and highlight relationships and patterns between the themes and categories, color-coding was employed, providing a visual structure that aided in the analysis process.

In the next stage, each theme was clearly defined and named to capture its core essence. The researcher refined the themes by comparing them against the original data and ensuring they were well supported by participant quotes. This iterative process ensured that the themes remained closely tied to the actual data, preserving the authenticity of the participants' voices.

The trustworthiness of the thematic analysis was reinforced by engaging in discussions with the principal investigator and the research committee to ensure that the emerging themes accurately reflected the participants' lived experiences and cultural context. This review process allowed for cross-checking of the findings, offering multiple perspectives on the themes and reducing the potential for researcher bias. The process of reviewing the results also included ensuring that all relevant data from the transcripts was accounted for and that no important themes were overlooked.

Finally, the researcher produced a scholarly narrative based on the identified themes. This report added depth and richness to the data analysis by providing a structured interpretation of the findings. The narrative was focused on generating practical and actionable insights relevant to clinical practice and medical education, ensuring the results were both meaningful and applicable in real-world contexts.

Trustworthiness

In qualitative research, trustworthiness and validity are pivotal concepts that ensure the credibility, accuracy, transferability, and dependability of study findings (Ravitch & Carl, 2016). Validity, specifically in qualitative contexts, concerns the researcher's ability to faithfully capture and communicate participants' authentic experiences.

To strengthen credibility and maintain the rigor of this study, the researcher employed member checking and triangulation. Member checking involved participants reviewing various facets of the research process, including data interpretations, to validate the accuracy and authenticity of their experiences (Ravitch & Carl, 2016). The researcher invited participants to review the textural-structural descriptions of their interview responses. This debriefing process aimed to ensure that the researcher had accurately captured the true essence of their experiences. Additionally, the researcher requested other care coordinators to participate in peer debriefing to gather alternative viewpoints and insights. This approach aimed to strengthen the study's credibility by considering diverse perspectives and ensuring robustness in the interpretation of findings.

Triangulation

Triangulation is a key strategy in qualitative research used to enhance the validity, credibility, and dependability of findings by incorporating multiple data sources and perspectives

(Ravitch & Carl, 2016). In this study, triangulation was achieved through a combination of interview transcripts, field notes, reflective journaling, and peer debriefing, ensuring a comprehensive understanding of the participants' experiences. The researcher also interacted with caregivers and their family members to verify their caregiving roles, further strengthening the triangulation process.

Field notes taken during interviews played a critical role in triangulation by capturing non-verbal cues, participant body language, and contextual observations not readily available through transcribed dialogue alone. These notes offered additional layers of meaning to the verbal content of the interviews, helping to provide a more nuanced understanding of the caregivers' experiences. For example, when participants expressed frustration or distress, these emotions were often reflected in their body language, tone of voice, or pauses, which might not have been fully conveyed through their words alone. By capturing these non-verbal cues, the researcher was able to cross-reference them with the verbal data in the transcripts, gaining deeper insight into the emotional context behind participants' words. This integration of verbal and non-verbal data allowed for a more holistic view of the caregiving experience and supported more accurate interpretations of participants' lived realities.

Additionally, the researcher used field notes to track emerging patterns and ideas throughout the interviews. These notes were reviewed alongside the interview transcriptions during the analysis phase to ensure consistency and to identify key themes that might not have been immediately apparent in the transcripts alone. By documenting initial thoughts, emotional reactions, and possible themes, the researcher was able to refine and focus the analysis, resulting in a more precise identification of the key themes and sub-themes in the data.

Triangulation was further enhanced through reflective journaling, where the researcher actively engaged in reflexivity by journaling her thoughts, emotional responses, and personal biases throughout the data collection and analysis process. This reflective practice allowed the researcher to track how her perspectives influenced the analysis and interpretation of the data. By revisiting the field notes, interview transcripts, and journal entries, the researcher ensured that the interpretations aligned with the participants' perspectives and were not overly shaped by personal experiences or preconceptions.

Peer debriefing was another important aspect of the triangulation process. Colleagues and research team members reviewed portions of the notes and analysis to offer alternative perspectives, providing external validation and helping to ensure that the data analysis was comprehensive, objective, and trustworthy. This external validation, combined with the researcher's ongoing self-reflection, ensured a rigorous approach to data analysis.

To further enhance the study's credibility and dependability, an audit trail was maintained to document all aspects of the research process, including decisions made and any modifications to the methodology. This audit trail ensured transparency and accountability, contributing to the study's methodological integrity. Triangulation was also achieved by integrating various data sources, which helped to confirm the findings through multiple perspectives, including those of caregivers, family members, and research team members.

For dependability and confirmability, the researcher took steps to maintain data integrity and confidentiality. Interview recordings were stored in a password-protected OneDrive account, and handwritten notes were kept in a locked file cabinet. Participants' informed consent forms were securely stored, and pseudonyms were used in the study to protect participants' identities. All data will be destroyed after five years to ensure compliance with ethical guidelines.

Reflective journaling was a key strategy in ensuring the trustworthiness of the study. This practice allowed the researcher to continuously document and critically examine her thoughts, emotions, and experiences throughout the research process, ensuring transparency and helping to prevent any undue influence on the data analysis. Reflexivity, through the process of epoche, also played an integral role. The researcher actively engaged in self-reflection, setting aside prejudgments and bracketing personal experiences (Moustakas, 1994), allowing for a more objective and nuanced understanding of the participants' lived experiences.

Reflexivity

Reflexivity played a critical role in the data analysis process, ensuring that the research was conducted with transparency, self-awareness, and a constant acknowledgment of the researcher's positionality. Reflexivity involves the researcher actively reflecting on how their personal experiences, values, cultural background, and professional knowledge shape the research process, from data collection to analysis. In this study, the researcher's dual role as both a care coordinator within the Tamil Canadian community and a caregiver for family members created a unique lens through which the data was interpreted.

During the analysis phase, the researcher continually reflected on her own experiences and how these might influence her interpretation of the caregivers' narratives. This process involved critically considering how personal biases, emotional responses, and cultural assumptions could shape the identification of themes and the understanding of the caregivers' lived experiences. For instance, as a researcher familiar with the cultural dynamics of Tamil families and the challenges they face in caregiving, it was essential to be aware of the potential for personal empathy to influence interpretations. The researcher worked actively to remain

conscious of these biases, documenting them in a reflective journal to track and question how they might be impacting the analysis.

To address reflexivity in the data analysis process, the researcher engaged in ongoing reflection and self-questioning while analyzing the interview transcripts and field notes. This included considering questions such as: “How does my understanding of Tamil culture influence my interpretation of the data?” or “How might my personal caregiving experiences shape my views on the burden expressed by participants?” These reflective practices allowed the researcher to better understand the dynamic between personal experiences and academic analysis, ensuring that the themes identified were grounded in the participants' actual experiences, not just influenced by the researcher's perspective.

Moreover, the researcher's reflective journaling was a crucial tool in maintaining reflexivity. Throughout the data analysis, the researcher documented their thoughts, emotional reactions, and the process of interpreting the caregivers' accounts. This allowed for transparency in the research process and helped the researcher recognize any emotional responses or biases that might surface. This journaling also facilitated deeper engagement with the data, allowing the researcher to revisit their interpretations regularly and make necessary adjustments to ensure they remained closely tied to the caregivers' narratives.

By incorporating reflexivity into the data analysis process, the researcher was able to enrich the interpretation of the data, ensuring that the findings were both rigorous and empathetic. Reflexivity ensured that the study not only acknowledged the researcher's subjective position but actively used that position to gain deeper insights into the caregiving experiences of Tamil Canadians. This process of ongoing self-reflection and adjustment helped to maintain a

balance between the researcher's personal perspectives and the authentic voices of the participants.

This approach allowed for a more nuanced and holistic interpretation of the data, ensuring that the study's findings reflected the true experiences of Tamil Canadian caregivers while being mindful of the researcher's influence on the analysis.

Ethical Procedures

This study adhered to ethical guidelines established by the Trent University Research Ethics Board (REB), emphasizing voluntary participation and informed consent. Participants were comprehensively briefed on study objectives, procedures, confidentiality measures, and potential risks. Ethical considerations also included providing support resources for participants experiencing emotional distress during or after interviews.

The participants in this study were not classified as a vulnerable population. The informed consent form comprehensively detailed the potential risks and benefits associated with participation. A potential risk identified was the discussion of sensitive topics, which could induce distressing emotions during or after the interview. To address this risk, participants were provided with contact information for the mobile crisis assessment team, ensuring access to support if needed. These precautions guaranteed that participants were fully informed and had access to necessary resources, thereby upholding ethical standards throughout the research process. Following the completion of the thematic analysis, the researcher conducted member checking by reviewing the textural and structural descriptions with the participants, as previously addressed in the trustworthiness and validity section. To facilitate ongoing communication, the researcher provided her email address and phone number to all participants for any questions during the research process. Additionally, the informed consent form included the phone number

for Trent University's Research Ethics Board (REB) Advocate, ensuring participants had access to further ethical oversight if needed.

Chapter 4: Findings

This chapter provides a detailed overview of the demographic data of the participants and the study's findings based on their responses. Following these findings, a discussion of the findings and their implications will be provided in subsequent sections.

The data collection process involved conducting semi-structured face-to-face interviews in the participants' homes. This method was chosen to enable the researcher to gather comprehensive verbal and nonverbal information, including participants' facial expressions and other non-verbal cues. The face-to-face interactions helped the researcher to foster personal connections and build rapport with the participants, thereby enriching the quality of the data collected. To ensure confidentiality and protect their identities, participants were assigned code names ranging from TAM01 to TAM10. During the interviews, participants shared their awareness of the available health and social supports. They elaborated on the various barriers they encounter when attempting to access these services as caregivers. Participants also provided in-depth descriptions of their experiences with stress, highlighting the specific factors that contribute to their stress levels.

In addition to discussing the challenges they face, participants recounted positive experiences related to caring for their loved ones at home. These responses offered valuable insights into the emotional and practical aspects of caregiving. Participants also reflected on how their roles as caregivers can contribute to their personal growth, particularly in terms of developing the knowledge and skills necessary for caregiving. Furthermore, participants offered recommendations for improving healthcare services. These suggestions were based on their firsthand experiences and were aimed at addressing the gaps they have encountered as caregivers.

Each topic covered in this chapter will include a detailed discussion of the major themes and sub-themes identified among the participants. These themes will provide a comprehensive understanding of the participants' perspectives and experiences.

Demographic Data

In qualitative research, understanding the demographic characteristics of participants is crucial because this data provides insights into the backgrounds and contexts of the participants, which can influence their experiences, perceptions, and responses. Table 1 presents an overview of the demographic profiles of the participants.

Table 1. Demographic data

Participant	Age	Gender	Employment	Education	Marital Status	Children	Years in Canada	Relation with care recipient	Daily caregiving hours
TAM01	52	F	Unemployed	High School	M	5	5	Mother	12
TAM02	64	F	Unemployed	High School	M	2	9	Father	10
TAM03	52	M	Employed	Less than High School	M	3	3	Mother	10
TAM04	53	M	Employed	High School	M	4	5	Mother	14
TAM05	54	F	Employed	High School	M	3	3	Mother	6
TAM06	56	F	Employed	High School	M	3	6	Father	10
TAM07	62	F	Employed	Less than High School	UM	0	9	Mother	7
TAM08	64	F	Employed	Less than High School	M	4	9	Father	7

TAM09	53	F	Employed	High School	M	2	5	Father	9
TAM10	60	F	Employed	High School	M	2	7	Mother	7

The demographic data of the 10 participants were analyzed across several key variables, including age, gender, employment status, education, marital status, number of children, years residing in Canada, relationship with the care recipient, and daily caregiving hours. Participants' ages ranged from 52 to 64 years, with an average age of 57, suggesting that most are in the later stages of middle adulthood, a phase typically linked with increased caregiving responsibilities. The sample was predominantly female, with 70% of participants being women, which is consistent with existing literature indicating that caregiving roles are often assumed by women. Employment status showed that 70% of participants were employed and 30% were unemployed, indicating potential differences in the amount of time they could allocate to caregiving tasks. Educationally, 60% of participants had completed high school, while 30% had less than a high school education, factors that may influence access to caregiving resources and support systems.

Marital status also played a significant role, with 90% of participants being married, which may impact caregiving dynamics by providing additional support from spouses. The number of children reported ranged from zero to five, potentially influencing both caregiving responsibilities and the level of support received from family members. Participants had resided in Canada for periods ranging from three to nine years, with the length of residency possibly affecting their familiarity with caregiving resources and services. In terms of their caregiving roles, 60% of participants were caring for their mothers, while 40% were caring for their fathers. The daily caregiving hours ranged from 6 to 14 hours, with an average of 9.2 hours per day, reflecting the significant time commitment involved in caregiving. These demographic findings

provide valuable insights into the participants' backgrounds and contribute to a better understanding of the factors shaping their caregiving experiences.

Overall, this demographic analysis provided a rich understanding of the participants' backgrounds and caregiving contexts, crucial for interpreting their perspectives and experiences as caregivers.

Themes

The study examined the diverse experiences of caregivers, emphasizing both the challenges and rewards inherent in their roles. The researcher utilized an interpretive descriptive approach, a qualitative method designed to generate practical insights into the phenomena being explored. Through an inductive analysis, themes and sub-themes were identified. Table 2 provides an overview of the identified themes and sub themes that emerged from the study. These themes provide valuable insights into the key dimensions of the study's findings, shedding light on the central aspects that addressed the research questions.

Table 2. Organization of Themes and Sub-themes

Theme 1	Theme 2	Theme 3	Theme 4
Lack Of Knowledge	Caregiver Burden	Culturally Supported Values	Positive experiences of caregiving
Sub-theme	Sub-theme	Sub-theme	Sub-theme
<ul style="list-style-type: none"> • Limited Awareness • Need for Education 	<ul style="list-style-type: none"> • Language Barrier • Financial Burden • Limited Family Support • Lack of Self-Care • Family Responsibility 	<ul style="list-style-type: none"> • Duty to Reciprocate Care • Cultural Caregiving Responsibility • Emotional and Physical Burden 	<ul style="list-style-type: none"> • Sense of Luck and Gratitude • Emotional Connection and Happiness • Positive Impact on Family Dynamics

Theme 1: Lack of Knowledge

The first theme identified was the caregivers' lack of knowledge about the health and social support services available for those caring for older adults with dementia at home. This theme captured both the verbal and non-verbal expressions of participants. Caregivers conveyed feelings of frustration and being overwhelmed, not only through their words but also through subtle non-verbal signals, such as deep sighs, prolonged pauses, and tense body language during the interviews. These cues underscored the emotional burden they experienced while navigating unfamiliar support systems. The researcher categorized this theme into two sub-themes, which are, limited awareness of available supports and the need for education.

Limited awareness of available supports

Participants consistently expressed a limited awareness about the health and social support services available to caregivers. This theme was evident from nine participants' responses (see Table 3). This confirms that limited awareness about health and social support services is a common issue among caregivers. 40% of participants indicated uncertainty about where to seek, whom to ask or how to access health and social support services. All participants were aware only of the current home support services provided to the care recipients. They had limited knowledge of any additional health and social support services available.

Table 3. Sub-theme: Limited Awareness

Participant Code	Quotation
TAM01	"I don't know what services are available". "I only know about the help from home care service my mother is getting". "I know a lady who comes from the government three times a week and helps my mother".

TAM02	<p>“I don’t know really know about everything but there is a lady who comes to our home in the morning to shower my father... She comes 7 days in a week to shower him.. I don’t know much about it”.</p> <p>“I know that the lady that helps my father in the morning is a service that my father gets. I do not know more than that”.</p>
TAM03	<p>“I know a little about this”.</p> <p>“My mother is getting home care help with showers in the morning. This is what I know about homecare health support ”.</p> <p>“My mother is getting some help with home care services that is what I think dementia people like my mother is helped. Beyond this help, I don’t know where and how to get services... where to ask about this... I am not sure...”</p>
TAM04	<p>“Currently my mother is receiving help 3 times per week for bathing. Beyond that I don't know about what services the government might provide and what kind of services they have”.</p> <p>“I don't know who to ask about available services. My mother is getting help with showers 3 times a week. But beyond that I don't know what services are there and I don't know whom to ask about this...”</p>
TAM05	<p>“I don't know about that... Aah mmm... I have to ask someone.”</p> <p>“I don’t know any other services except for the help my mother is getting...”</p>
TAM06	<p>“The support that my father is getting right now was arranged by family doctor... But beyond the services that my father is getting, I have no idea about it”.</p> <p>“He is getting help from the government... He is getting some help. He is getting daily visits for showers”.</p> <p>“People like me do not know what are the community support services are provided by the government for people like my father and for caregivers like me...”</p>
TAM07	<p>“I am unable to find out about what are the services available and where to get support”.</p> <p>“I only get help 3 days a week to help with showers for my mother. That is the only kind of help that I know of...”</p>

TAM08	<p>“...we did not know whether there was health support that was available for us and we are unable to ask anyone about the availability of these kinds of services”.</p> <p>“I don’t really know...My father is getting support 5 times a week. That’s all”.</p>
TAM09	<p>“I don’t really know much...”</p> <p>“My father gets some help at home to shower him, change his clothes... Other than that I don’t know what other community support there is”.</p>
TAM10	<p>“In our family there is no one who had this sort of sickness... this is the first time. So I don’t know... I don't know what kind of services there are for people like my mother here...”</p> <p>“There is a personal support worker who comes 3 times a week to help my mother with showers”.</p>

The Need for Education

The second sub-theme that emerged is the need for education (see Table 4). Many participants expressed a strong desire to learn new skills to improve their personal care techniques, aiming to provide competent care for their loved ones at home. They often compared their methods of care to the formal support their care recipients were receiving and expressed a wish to possess similar knowledge to better care for their loved ones.

Several participants specifically mentioned their desire to learn more about managing their care recipients' dementia conditions; in addition to improving their personal care skills. One participant wished for someone to explain the effects of his mother's medication. Two out of ten participants admired the formal caregivers' ability to calm their parents and expressed a strong desire to learn these techniques themselves. Furthermore, one participant inquired about therapy for her mother's cognitive function and expressed a wish to learn how to administer that therapy. This highlights the participants' recognition of the gap in their knowledge and their eagerness to bridge this gap to provide better care for their loved ones at home.

Table 4. Sub-theme: The Need for Education

Participant Code	Quotation
TAM01	<p>“When the workers come to care for my mother, they are very skillful. They are very fast when they help my mother. For example, when they change my mother’s diapers, give my mother a shower... whatever that they do for my mother ... she does it competently. The same things that I do for my mother take 2 hours to finish but the workers complete it in 15 minutes.</p> <p>“The workers are experienced, for me this is something new that I am doing. I must learn to do like the workers...”</p>
TAM02	<p>“In the morning, the worker comes and does personal care for my father and leaves. At times, I observe her changing diapers for my father. Even though I care for my father all day, I am not skillful enough like the worker...”</p> <p>“It is hard for me to do personal care for my father because I am not skillful...”</p>
TAM03	<p>“Since my mother has dementia, I know a little about the types medication she is taking. I know sometimes how to calm her... I learn all this with my own observation”.</p> <p>“It will be great if someone can teach me...”</p>
TAM04	<p>“Nobody has taught me how to take care of my mother. Like... it is hard to change the bedsheet with my mother on the bed...”</p> <p>“Sometimes my mother shouts without a reason, no one has taught me how to calm down my mother when she does that...”</p>
TAM05	<p>“Maybe there is something to help her cognition, like playing a mind game to test her memory ...”</p> <p>“If I have that knowledge, I will do that for my mother”.</p>
TAM06	<p>“When I want to take my dad for a shower, he refuses, he gives excuses for not bathing. But he doesn't refuse with the workers. I wish I can learn the technique of persuading my father like that...”</p> <p>“I always see that the workers change my father’s diaper with a certain technique on the bed ... I cannot do that, I don't know how... I wish they can teach me that too...”</p>

TAM 07	<p>“It is hard for me to change diapers for my mother. The workers are so skillful in their work. It is hard to change my mother's diapers in the bed. I would like to have that skill like the workers”.</p> <p>“I have to use my strength to transfer her and I experience back ache... but I see that the workers do it easily, maybe if I can have that kind of skill too... it will greatly help me to care for my mother better without physically straining myself”.</p>
TAM 08	<p>“You know... The workers that come to help my father are able to prop my father easily in bed before feeding him. I wish someone can teach me to prop my father like that”.</p>
TAM 09	<p>“I wish someone could teach me how to handle him at home. For example, sometimes he gets angry. I know it's because he has dementia”.</p> <p>“I wish someone could teach me some psychological techniques to handle my father at home”.</p>
TAM 10	<p>“The same things that I do for my mother take 2 hours to finish but the workers complete it in 15 minutes”.</p> <p>“The workers are experienced, for me this is something new that I am doing. I must learn to do like the workers”.</p>

Theme 2: Caregiver Burden

The researcher identified caregiver burden as the most significant finding from the interview sessions. All participants described experiencing various aspects of caregiver burden. The researcher categorized these aspects into sub-themes to analyze each response in depth. The sub-themes that emerged are language barrier, financial burden, limited family support, self-care and family responsibility.

Language Barrier

All participants expressed that the language barrier is a significant burden, especially when home care workers assist their care recipients at home (see Table 5). Participants reported

that, since English is not their first language, communicating with home care workers in English is challenging. This issue becomes especially critical when their parents are hospitalized.

Participants find it difficult to communicate and understand health professionals about their parents' health conditions. Two participants specifically mentioned feeling embarrassed by their lack of fluency in English, which prevents them from asking questions and causes stress in them. Participants mentioned that their father does not cooperate and becomes agitated with formal caregivers due to the combined challenges of the language barrier and dementia, requiring their constant presence during personal care, which further increases their stress.

One participant reported feeling stressed because she cannot effectively explain her father's needs to non-Tamil speaking home care workers. Misunderstandings and repeated instructions arise because the home workers do not understand her English, adding to her stress. Similarly, another participant highlighted that one of her major stressors is her inability to speak English. Neither she nor her mother can communicate in English, making the home care workers' assistance more of a burden than a help. She noted that the home care workers' visits often do not reduce her responsibilities but instead require her to translate and facilitate communication, which defeats the purpose of having formal support. When taking her mother to the hospital, a caregiver reported difficulty understanding medical discussions and instructions, attributing this to the language barrier. She also felt that healthcare professionals look down on them because they do not speak English. This feeling of being judged adds to her stress and exacerbates the burden of caregiving.

Table 5. Sub-theme: Language Barrier

Participant Code	Quotation
TAM01	<p>“My family came to Canada as refugees’ years ago. I don't know English well and it is difficult for me to speak and answer in English”.</p> <p>“There was one time my mother was admitted to the hospital, and I had so much difficulty in answering questions and asking any question because I don't know English well”.</p> <p>“I get some help from home care service. But my mother only speaks Tamil, so even when the home care worker comes to help my mother, I have to be there with my mother”.</p> <p>“There is no point getting homecare help if I must be with my mother when they provide care”.</p>
TAM02	<p>“...when I came from Sri Lanka ... when I came as a refugee, language was a problem”.</p> <p>“I did not know enough English and when my father was admitted in the hospital, it was very hard for me. It was truly embarrassing for me to speak and ask. Not knowing the language is a big problem for me...”</p> <p>“I cannot explain to the worker what we need... When a worker who don't speak Tamil visits my father. I don't understand the English she speaks...”</p> <p>“Sometimes, the worker tells something in English but I do something else and the worker keep repeating... I feel stress with this”.</p>
TAM03	<p>“I finished my education in Tamil language. I experience language barrier in this country”.</p> <p>“Language barrier... I don't speak English...so it is hard for me... My mother gets help with shower 4 days in a week...The workers that come are from different countries...”</p>
TAM04	<p>“First problem is language ... To whom I should ask... I don't know...”</p> <p>“More than that I feel shy that I don't know English well”.</p>
TAM05	<p>“The greater barrier is language. I cannot speak English”.</p> <p>“...but I can't speak English. My mother does not speak English. The support workers that my mother is getting is not support, it is more of a burden for me”.</p>

	<p>“When I take my mother to hospital, I don't understand ... this is all language barrier. And also I feel like they look down upon us, because we don't speak English”.</p>
TAM06	<p>“Firstly for us...language is a barrier, we need to converse in English and that is hard. It is hard for me, my mother and my father”.</p> <p>“... my parents don't speak English. I am not good in English. When the worker comes in the morning to shower my father, my mother cannot communicate with the worker to tell her my father's routines...”</p> <p>“My mother calls me... but I don't speak English too...”</p>
TAM07	<p>“I was unable to ask the doctor about my mother's condition even though I had so many questions. This is because I don't know English well”.</p> <p>“And also my mother has questions too and she is unable to ask...”</p>
TAM08	<p>“Importantly language barrier. As I said, I have not been taught to communicate in English. In Sri Lanka English was only a subject. We don't have the opportunity to speak in English there. I feel sad when I think about this...”</p> <p>“...the community support worker has a language barrier and due to this my father does not cooperate with them”.</p> <p>“...because of language barrier, for the whole 1 hour I must help the workers to provide care”.</p>
TAM09	<p>“Since I came to Canada, language is challenging. When I go to hospital with my father and when the doctor explains test result, I don't really understand due to my limited English comprehension”.</p> <p>“I can't even ask about what other services there is for my father , even if I ask they don't understand me..”</p> <p>“Language barrier... my father has dementia and doesn't understand when the workers communicate with him. He doesn't understand that the workers are coming to help him, he gets agitated. So, I must be there with the workers when they help my father”.</p>
TAM10	<p>“Firstly, it is the language barrier”.</p> <p>“I cannot communicate about my mother's condition with the workers. My mother doesn't know English too...”</p> <p>“Language barrier is another issue for me ... I am unable to find out what community services are there for my mother and myself”.</p>

All participants identified the language barrier as a significant burden, particularly when interacting with home care workers (see Table 5). These caregivers, whose first language is not English, face challenges communicating effectively with home care workers. This issue becomes especially critical during hospitalizations, where caregivers struggle to understand health professionals and convey their parents' health conditions. Overall, the language barrier significantly impacts caregivers' ability to effectively utilize home care services and support their loved ones.

Financial Burden

The financial burden is a significant challenge for caregivers, as evidenced by the experiences shared by six out of ten participants. The financial pressure of maintaining a household while providing care is a significant source of burden. The quotations in Table 6 highlight the nature of this burden and its impact on their caregiving responsibilities.

Participants briefly summarized that they have financial burden, one participant illustrated the desperate need for even minimal financial resources and the necessity to work despite personal challenges when he expressed that sometimes he does not have money for transport. Balancing employment with caregiving responsibilities presents a significant challenge for several participants. In Canada, the high cost of living necessitates caregivers to have two incomes. Some participants highlighted the struggle of balancing work and caregiving, combined with insufficient single income. Participants expressed financial constraints to hire private caregivers, who could help alleviate some of their caregiving burden.

Table 6. Sub-theme: Financial Burden

Participant Code	Quotation
TAM02	“...financial is a burden, my husband works two jobs, to look after the family expenses. I cannot go to work because my father is home with us”.
TAM03	“For me, finance is a burden right now”.
TAM04	“I need like \$3 for transport and sometimes I don’t even have \$3”. “I have to go to work. If I don’t go to work , there is no money. My wife is not working so I have to work to feed my family”.
TAM05	“In this country we have to work to earn money, me and my husband have to work to survive, so I have to work, look after my mother and children alone... it is hard”. “I have to work too. Just with my husband’s earnings we cannot survive in this country”.
TAM07	“I must go to work... Even if I want to have a private caregiver to help my mother, I need money for that, I cannot afford that... ” “Now in Canada everything is so expensive... I cannot manage financially... ”
TAM10	“In this country, we must work hard, otherwise we cannot pay rent, or do grocery shopping”. “It is very expensive to live here. I have to do both... look after my mother and work... and it's stressful for me... ”

The financial burden faced by caregivers is a critical issue that significantly impacts their ability to provide care and maintain their own well-being.

Limited Family Support

The majority of participants reported feeling burdened due to limited or no family support in caregiving for their loved ones at home. One participant shared that her relatives do not help her because they assume that caring for her mother is easy since she is a homemaker. She also confirmed that she feels stressed because her relatives believe she is solely responsible for her mother's care, being the only child. Another participant indicated that his siblings are not supportive because they lack the space in their homes to provide caregiving.

Participants mentioned that they have relatives in Canada, but these relatives are unable to help because they are also busy with their own families. One participant reported difficulties in understanding information due to limited English comprehension and highlighted the absence of family members to assist her, underscoring the significant challenge of accessing necessary support and information. Another participant added that his wife does not assist in caring for his mother due to family conflicts. Several participants stated that their siblings and relatives are in Sri Lanka, leaving them with no support in Canada. Participants compared their caregiving experience in Canada to that in Sri Lanka, noting that they would receive enough support from siblings and relatives if they were in Sri Lanka.

Table 7. Sub-theme: Limited Family Support

Participant Code	Quotation
TAM01	<p>“My relatives think that, just because I am a housewife , it is easy for me to take care of my mother... there is no one to help me. I tried to get relatives to help me but none of them help”.</p> <p>“I have no support from my relatives. My relatives say that it is my responsibility to take care because I am the only child but I am much stressed”.</p>

TAM02	“My siblings are not able to care for my father. They don’t have available room in their homes to care for my father like me”.
TAM03	“...my relatives do not help much in any way...”
TAM04	“...my uncle in Canada doesn’t help. Everything that needs to be done for my mother I do it”. “My wife does not care for my mother, when my mother was younger, she used to argue with my wife...My wife told me that she will not help to care for my mother. When I think about it, I am sad too, because my wife doesn't care for my mother... ”
TAM05	“I don't have my siblings and relatives like back home to help”. “I am alone in this country...I don't have any help from my siblings and relatives physically. They are all back home”.
TAM07	“My relatives are all in Sri Lanka. I don't have any help here”. “I don't have any relatives to help me when I need”.
TAM09	“My husband goes to work very early in the morning and comes back at night, he can't help me...” “I don't have anyone to help me. I have a brother, but he lives far from me, and he has a family too. I have no relatives to help too”.
TAM10	“All my siblings are in Sri Lanka”.

The findings highlight that limited or no family support significantly burdens caregivers, leading to increased stress and emotional strain. Cultural expectations, physical constraints, and family conflicts further exacerbate the lack of available assistance. Caregivers with relatives abroad or preoccupied family members in Canada face significant challenges in managing caregiving responsibilities alone.

Lack of Self-Care

Some participants expressed that there is a lack in self-care because they devote their time to caregiving for their loved ones at home. Participants are caught between caregiving, work and family responsibilities which leads them to knowingly neglect their own needs (See Table 8)

Several participants explicitly stated that they often feel like crying because there is no leisure time for themselves. This burden is the direct result of their inability to take breaks and engage in activities that they enjoy. Additionally, a participant mentioned that he has no time to rest or take a break because all his time is utilized to care for his mother. One participant described that she has declined in her health due to a lack of sleep.

Table 8. Sub-theme: Lack of Self-Care

Participant Code	Quotation
TAM01	“Sometimes I feel like crying. Because I have a lot of work and no leisure”.
TAM04	“I do exercise, it reduces my stress... but even to do my exercises, I need to have more time, all my time is spent to help my mother. I don't even have any time to do my exercises”. “Because I have to care for my mother, I have no time to do other things that, I like to do...”
TAM08	“I have a lack of sleep, and due to this I suffer from headaches and feel unwell”.
TAM09	“I feel so sad and feel like crying. I don't have anyone at home whom I can talk to. I like to take a walk, but I can only take a walk when there is someone home with my father. So I can't simply take a walk”.

The findings indicate that caregivers often neglect self-care due to their extensive caregiving responsibilities. The strain of constant caregiving without adequate rest or personal time highlights the critical issue of self-care among caregivers. Balancing caregiving, work, and family duties leaves little time for personal care, leading to emotional distress and health decline.

Family Responsibility

The findings indicate that participants are significantly burdened by simultaneously managing family responsibilities and caring for their parents with dementia (see Table 9). One participant reported feeling overwhelmed by the need to take care of her mother while also caring for her own family. Similarly, another participant emphasized the difficulty of balancing care for her father with her responsibilities towards her own family, stating that it is challenging to look after both simultaneously.

Participants expressed the strain of juggling work, caring for their parents, and looking after their own families. The frustration of these competing demands was echoed by one participant who highlighted the difficulty of managing work, family obligations, and caregiving, noting the need to divide time between her parents and her three children. A participant expressed stress from the inability to help her own children when needed, such as driving them to college, because she must be home with her father. Similarly, another caregiver mentioned the challenges of cooking for her kids and taking them to college while also managing caregiving duties.

Table 9. Sub theme: Family Responsibility

Participant Code	Quotation
TAM01	“...I also have a family. At the same time, I have to take care of my mother”.
TAM02	“I have my family too.. I have to care for them too”. “...it is hard to look after my father and my family at the same time”.
TAM03	“I have to look after my mother... aaa... I have to go to work, I have to look after my family”.
TAM04	“I am quite upset. I have to work, look after my family, and also look after my mother”.
TAM05	“I have to work, look after my mother and also look after my children... cooking...”
TAM06	“I am working, I also have a family of my own, I have 3 children and I have to do things for them too”. “I need to try to divide my time between my parents especially my father and my children”. “My father is not well. My mother is also old. My children need help too. I am also working”.
TAM08	“I am taking care of them 24 hours. My family... my husband and children...” “My children... I am unable to help them when they ask me to... for example, I am unable to drive them to college, when they ask me to drive them”. “This causes me stress too, as I cannot help my children when they ask me because I must be home with my father”.
TAM09	“I have kids... I have to cook for them, drop them off at the college.”

The findings underscore the burden on caregivers who must manage their caregiving duties and their own family responsibilities simultaneously. Participants reported feeling overwhelmed, stressed, and frustrated by the demands of balancing work, family obligations, and caregiving tasks. This dual or triple responsibility creates a challenging situation, resulting in caregivers feeling significantly burdened.

Theme 3: Culturally Supported Values

The responses from seven participants underscored the notable impact of culturally supported values on caregiving responsibilities. Refer to Table 10 for participants' detailed responses. Participants expressed a strong sense of duty to care for their parents, which often leads to increased stress. The researcher categorized this theme into three sub-themes to facilitate the analysis. The sub-themes are duty to reciprocate care, cultural caregiving and responsibility and emotional and physical burden.

Duty to Reciprocate Care

Majority of participants felt that since their parents looked after them when they were young, they must now look after their parents. These participants emphasized the cultural expectation of caring for their parents because their parents had previously cared for them. They believe it is their duty as children to reciprocate that care.

Cultural Caregiving Responsibility

Several participants highlighted the broader cultural expectation that children must care for their parents. Several participants stated that, according to their culture, it is mandatory to look after one's parents, viewing it as a fundamental responsibility. Participants reported feeling burdened because they are the only child and thus solely responsible for their parents' care.

One participant explained that he initially cared for his father alongside his mother, but after her passing, he now feels solely obligated to continue this care. Similarly, another caregiver observed his mother caring for his grandparents in Sri Lanka, which reinforced his belief in maintaining this cultural practice. A participant mentioned that his mother had cared for his grandparents' very well when they were old, and he feels compelled to do the same, highlighting the emotional burden of continuing this cultural tradition.

Emotional and Physical

The cultural expectations of caregiving have led to significant emotional and physical burdens for the caregivers. One participant expressed stress related to caring for her parents, acknowledging the difficulty of managing these responsibilities despite cultural norms. She questioned whether it is acceptable to feel stressed, given that they are her parents.

Table 10. Theme: Culturally Supported Values

Participant Code	Quotation
TAM01	<p>“My relatives say that it is my responsibility to take care because I am the only child”.</p> <p>“My mother looked after me when I was a child it is my turn to look after her now, It is my responsibility to care for her...”</p>
TAM02	<p>“According to our culture, we must look after our parents”.</p> <p>“My parents looked after me when I was young... My mother passed away... Now I am responsible to care for my father”.</p>
TAM03	<p>“I am her only child and I have to do her personal care because my mother looked after me when I was a child. So, I must look after her as much as I can”.</p> <p>“My mother looked after my grandparents very well when they were old. I saw her caring for my grandparents when I was a child in Sri Lanka and I must do the same, it is how we are...”</p>

TAM04	“When I was small, she looked after me. So I have to look after her”. “This is our culture... this is my responsibility, I must look after her...”
TAM05	“...with our culture. Generally, it is the responsibility of the children to look after our parents”.
TAM08	“Firstly, taking care of my parents is stressful to me. I am not sure if it is okay to say this because they are my parents”.
TAM09	“In our culture, children must look after their parents. We must look after our parents”.

These findings demonstrate that culturally supported values significantly influence caregivers' sense of duty and responsibility towards their parents. The cultural expectation to reciprocate care, along with the general obligation to care for aging parents, places substantial emotional and physical burdens on caregivers, adding to the stress and challenges they encounter.

Theme 4: Positive Experiences of Caregiving

The responses from participants highlight the positive aspects of caregiving, revealing shared feelings of happiness, satisfaction, and fulfillment (see Table 11). The researcher divided this theme into three sub themes to streamline the analysis and for an accurate interpretation of the data. The sub themes are sense of luck and gratitude, emotional connection and happiness and positive impact on family dynamics.

Sense of Luck and Gratitude

Several participants expressed a sense of luck and gratitude for the opportunity to care for their parents. They mentioned feeling fortunate to provide care, emphasizing the unique chance to reciprocate the love and care they received as children.

Emotional Connection and Happiness

Majority participants described the joy and emotional connection they experience through caregiving interactions. 40% of participants reported feeling happy and fulfilled when their parents show affection, such as holding hands, hugging, and kissing. These moments of physical affection reinforce their sense of purpose and the bond they share with their parents.

Additionally, participants found joy in the caregiving routine itself. Participants mentioned the satisfaction of knowing they are providing well for their parents. One participant described contentment in fulfilling his caregiving role and the emotional rewards that come with it.

Participants also found happiness in seeing their parents content and smiling. Several participants highlighted the joy they feel when their parents are happy and recognize them, despite having dementia. One participant specifically mentioned feeling blessed when her father shows appreciation through gestures like touching her head as a blessing.

Positive Impact on Family Dynamics

The positive impact on family dynamics was also noted. A participant expressed happiness that her children can spend time with their grandfather and hear his stories, creating cherished family memories and reinforcing cultural values.

Table 11 Theme: Positive Experiences of Care giving

Participant Code	Quotation
TAM01	<p>“I feel very lucky that that I have a chance to care for my mother. I have a strong bond with my mother”.</p> <p>“Sometimes when I give my mother a shower, she will hold my hand tightly, and I know that she is content that I am looking after her”.</p>
TAM02	<p>“... sometimes when my father behaves like a child , I laugh...”</p>
TAM03	<p>“When I see the happiness on her face, I am happy too”.</p> <p>“As a son, I am lucky that I get to feed her, not everyone is as lucky as I am. Not everyone gets an opportunity to care for their parents, but I am lucky...”</p>
TAM04	<p>“... I feel happy”.</p> <p>“I feel that I have looked her after well”.</p>
TAM 05	<p>“I feel satisfied that I am looking after my mother by myself. My siblings who are back home are not as lucky as I am”.</p> <p>“I feel satisfied that I am looking after my mother by myself. My siblings who are back home are not as lucky as I am”.</p> <p>“I think my mother is happy that she is staying with me. I am happy to see my mother happy”.</p>
TAM 06	<p>“When I am taking care of him, it gives me happiness”.</p> <p>“... even though he has dementia.. Sometimes he recognizes me as his daughter. When I am with him I see that he is happy... This is a pleasant experience for me caring for my father”.</p>
TAM 07	<p>“...to look after my mother is a blessing... I am happy taking care of her”.</p> <p>“She hugs me and kisses me when I am feeding her, I know that she is happy that I am caring for her. And I am happy that she is happy”.</p>
TAM 08	<p>“I am happy and contended providing care for my father”.</p> <p>“I feel the happiness and satisfaction of my father when I care for him</p>

	...even though my father has dementia... my father smiles when I feed him”. “I know he is happy. When I put socks for my father, he touched my head, I know that he is blessing me”.
TAM 09	“I am happy to look after my father. I am so happy that my children have a chance to spend time with my father. “Even though my father has dementia, I am happy when my father recognizes my children. I feel happy that my children get to hear his stories”.
TAM 10	“I am lucky and happy to look after my mother. To have the opportunity to look after my mother ... I am thankful to God...” “When I am looking after my mother, sometimes she kisses me... And she hugs me”.

This findings demonstrate that caregiving, despite its challenges, brings significant positive experiences. Caregivers reported feelings of happiness, satisfaction, and a sense of fulfillment from caring for their loved ones. Participants felt a deep sense of luck and gratitude for the opportunity to care for their parents, which strengthened emotional connections. Additionally, caregiving positively impacted family dynamics by creating cherished memories. These positive experiences significantly enhanced caregivers' emotional well-being, helping to balance the stresses and demands of caregiving.

The researcher has thoroughly analyzed the demographic data and findings from the study. The demographic overview reveals the varied contexts of caregiving, shaped by factors such as age, gender, education level, employment status, and others. Through careful analysis, several themes and sub themes emerged, providing a detailed understanding of the complex nature of caregiving.

The researcher identified significant issues, including the lack of awareness about available health and social support services, the heavy burden on caregivers, the influence of culturally supported values, and the positive aspects of caregiving. The study highlighted specific

challenges such as language barriers, financial difficulties, limited family support, and neglect of self-care, underscoring the complex pressures caregivers face. Despite these challenges, caregivers reported experiencing deep emotional connections and moments of happiness, illustrating the rewarding nature of their roles.

Achieving Data Saturation

Data saturation in this study was achieved through a systematic process of data collection and analysis. The research began with semi-structured interviews conducted with Tamil Canadian caregivers, which allowed the researcher to explore caregiving experiences, challenges associated with dementia care, and the support systems available to caregivers. As interviews progressed, thematic coding was conducted iteratively, enabling the researcher to identify emerging patterns and refine the focus of subsequent interviews. While the early interviews aimed to capture broad caregiving experiences, later interviews delved deeper into specific themes.

A key indicator of saturation was the repetition of themes across interviews. As data collection continued, participants consistently highlighted similar issues and challenges, suggesting that further interviews would have been unlikely to yield significantly new insights. For instance, themes related to language barriers, the influence of cultural beliefs on caregiving, and the awareness of healthcare services were echoed by multiple participants. This repetition reinforced the centrality of these issues within the caregiving experiences of Tamil Canadians.

The researcher also employed the technique of constant comparison throughout the data analysis process. By systematically comparing data from different interviews, the researcher ensured that the emerging themes were representative of the broader caregiving experience. This approach refined the thematic framework and confirmed that the core themes were consistent

across the sample. To further validate the findings, member checking was conducted.

Participants were invited to review and provide feedback on the preliminary results, ensuring that the identified themes accurately reflected their lived experiences. Feedback from participants confirmed that the interpretations resonated with their perspectives, and no new significant ideas or concepts emerged during this validation process. This additional layer of analysis reinforced the conclusion that data saturation had been achieved.

By the time the final interviews were completed, the themes identified early in the study were consistently repeated and fully explored. No new major themes or perspectives emerged, indicating that additional interviews were unlikely to provide novel insights or significantly alter the findings. The comprehensive exploration of all significant aspects of caregiving within the Tamil Canadian community supported the conclusion that the research questions had been adequately addressed with the existing sample size.

Reaching data saturation ensured that the study's findings were thorough and reflective of the caregiving experiences of Tamil Canadians. The iterative process of data collection, thematic analysis, and participant validation demonstrated that the sample size was sufficient to capture the full breadth of caregiving challenges and insights within this community. By achieving saturation, the study provided a robust foundation for understanding the unique experiences of Tamil caregivers and addressing their needs effectively.

Chapter 5: Discussion

The findings highlight the urgent need to improve support systems and resources for caregivers. In this chapter, the researcher will delve deeper into these findings, emphasizing the necessity for policy and practice changes. By gaining a deeper understanding of the nuanced experiences of Tamil Canadian caregivers, more effective strategies can be developed to ensure their well-being and improve their caregiving capabilities.

The journey of caregiving, particularly within the Tamil Canadian community, is rich with cultural variances, personal sacrifices, and complex emotional dynamics. This chapter synthesizes the findings from this study, providing a comprehensive discussion that connects these experiences to existing literature. In this chapter, the researcher will explore the diverse experiences of Tamil Canadian caregivers who are caring for older adults with dementia at home. Additionally, the researcher will discuss recommendations aimed at supporting caregivers, improving their quality of life, and informing policy and practice in homecare services. Through this discussion, the researcher aims to highlight the unique challenges and strengths of Tamil Canadian caregivers and propose strategies to enhance their caregiving experience.

Lack of Knowledge

Caregivers consistently showed limited understanding of the health and social support services available to them as well as the need for education to improve their caregiving. This finding is consistent with existing literature, which highlighted that new caregivers often struggle significantly due to their lack of experience and knowledge. As noted by Couto et al. (2019), caregivers often feel inadequate and distressed because they do not fully understand caregiving requirements. This theme is evident in the uncertainty expressed by participants regarding where to seek help and how to access necessary services.

The responses of nine participants highlighted their limited awareness of the health and social support services available to caregivers. This finding aligns with the study conducted by Couto et al. (2019), which indicated that caregivers often struggle to navigate and access the support services available to them. Couto et al. (2019) found that Brazilian caregivers frequently lack the knowledge and experience necessary to access support, leading them to actively seek education and assistance. This lack of awareness often leaves caregivers feeling uncertain about the adequacy of their care, causing feelings of insecurity and emotional distress.

A notable 40% of participants expressed uncertainty about where to seek, whom to ask, or how to access health and social support services. Despite being aware of the home support services provided to care recipients, participants had limited knowledge of any additional support services available. This gap in awareness highlights the need for better information dissemination for caregivers, echoing the findings of Couto et al. (2019) that caregivers recognize the need for education.

Caregivers expressed a strong desire for education to enhance their caregiving skills. Many participants expressed a wish to learn new skills to provide competent care for their loved ones at home. Similarly, Sorensen and Conwell (2011) acknowledges the benefits of providing educational resources to caregivers. Sorensen and Conwell (2011); Holley and Mast (2009) report that education effectively enhances caregiver knowledge and alleviates burden. Similarly, Haley et al. (2003) found that caregiver support leads to significant improvements in caregiver well-being.

Caregivers expressed the need to gain more knowledge about managing dementia and to enhance their personal care skills to better cope with caring for their loved ones and to understand the effects of medications and to learn techniques used by formal caregivers to calm

their care recipients. This mirrors the findings of Burns et al. (2003), who demonstrated the effectiveness of educational materials in managing stress and providing coping strategies for caregivers of individuals with dementia. The provision of targeted educational resources significantly reduced caregivers' feelings of burden and improved their ability to care for their loved ones (Burns et al., 2003). One participant asked about therapy for her mother's cognitive function and expressed a desire to learn how to administer it, highlighting a clear recognition of knowledge gaps among caregivers. This eagerness to bridge the knowledge gap underscores the importance of education and training for caregivers. Providing education not only improves caregivers' skills but also reduces the emotional and physical burdens associated with caregiving.

The findings in this study are consistent with existing literature on the challenges faced by caregivers and the benefits of providing education and support. Participants' limited awareness of available support services and their strong desire for education have been identified in several studies (Couto et al., 2019; Sorensen & Conwell, 2011; Holley & Mast, 2009; Haley et al., 2003; Burns et al., 2003). These studies collectively highlight the need for comprehensive support systems and educational resources to help caregivers manage their responsibilities effectively. The findings highlight the critical need to develop strategies that increase caregivers' awareness of available support services and provide them with the necessary education to enhance their caregiving skills. The researcher believes that addressing these gaps will provide better support to caregivers and alleviate the challenges they face as caregivers.

Caregiver Burden

The dual stress of caregiving and adapting to a new cultural environment adds another layer of complexity for Tamil Canadian caregivers. Many caregivers, as recent immigrants,

struggled to navigate Canadian healthcare systems and community resources while managing their caregiving responsibilities. This dual burden left caregivers feeling disconnected from both their home culture and their new environment. The findings highlight the need for targeted support services that address the unique challenges of immigrant caregivers, including culturally tailored healthcare navigation programs and community support networks.

Caregiver burden, according to Cao and Yang (2020), encompasses both the time and specific tasks involved in caregiving, known as the objective burden, as well as the personal experiences and impacts on caregivers, referred to as the subjective burden. Dementia presents unique challenges for caregivers from diverse backgrounds. According to Kasuya et al. (2000), caregiver burden is associated with the physical, psychological, emotional, social, and financial stressors linked to the caregiving experience. Dening et al. (2012) and Garand et al. (2005) identified significant barriers and challenges faced by caregivers, leading to increased caregiver burden. These findings are consistent with the current study, which also highlights the immense burden faced by caregivers. This study found that caregivers experience burdens due to language barriers, financial strain, limited family support, lack of self-care, and family responsibilities.

Language Barrier

Language barriers emerged as a significant challenge for Tamil caregivers, particularly among older generations with limited English proficiency. This issue hindered their ability to communicate effectively with healthcare providers and navigate complex healthcare systems. Caregivers often found themselves acting as intermediaries, translating medical information and instructions for their loved ones. While interpretation services are available, caregivers expressed frustration over the lack of Tamil-speaking professionals, which added to their stress and further isolated them from critical healthcare support. These findings highlight the need for more

accessible healthcare services, including increased availability of Tamil-speaking professionals and culturally informed healthcare practices.

This study revealed that caregivers consistently reported difficulties communicating with healthcare providers, which hindered their ability to advocate for their loved ones, understand medical information, and participate effectively in care planning. Navigating the healthcare system can be particularly challenging for caregivers who face language barriers. These findings are consistent with the research by Lindeza et al. (2020) and Martinez et al. (2024), who noted that language barriers significantly impact caregivers' ability to navigate the healthcare system and communicate medical needs effectively.

All participants in this study expressed that the language barrier is a significant burden, especially when home care workers assist their care recipients at home. Participants reported that, since English is not their first language, communicating with home care workers in English is challenging. This issue becomes especially critical when their parents are hospitalized. Participants find it difficult to communicate with and understand health professionals about their parents' health conditions. A few participants mentioned feeling embarrassed by their lack of fluency in English, which prevents them from asking questions and causes stress.

Several participants reported challenges with communication, particularly when interacting with formal caregivers or healthcare professionals. This barrier not only affected communication but also heightened the emotional and physical burden of caregiving. Participants described feeling overwhelmed by the need to translate and explain their family members' needs, which often led to misunderstandings and repeated instructions. For all participants, the inability to speak English effectively made it challenging to access or benefit from formal support services, as the workers' visits required more effort in communication than

actual relief from caregiving duties. Additionally, some participants reported feeling judged or marginalized by healthcare professionals due to their limited English proficiency, further exacerbating their stress and sense of isolation in their caregiving role. These findings emphasize the impact of language barriers on the caregiving experience and highlight the need for culturally and linguistically appropriate support services.

The researcher connected this to the participants' demographic data, noting that all participants were educated in Sri Lanka, where Tamil is the first language. They had limited opportunities to converse in English, as it was just another subject in school. As immigrants in Canada, they felt more comfortable speaking with other immigrants who spoke Tamil and did not prioritize learning English. Their primary focus was on survival in a new country, which was more important to them than learning to speak a foreign language.

Financial Burden

The financial burden emerged as a significant challenge for 60% of participants in this study. Maintaining a household while providing care imposes significant financial strain. Most participants reported that balancing employment with caregiving responsibilities is particularly challenging due to the high cost of living, often requiring dual incomes. Participants reported experiencing financial pressure, with some expressing a more urgent need for financial support, often struggling to cover basic expenses such as transportation. Several participants emphasized the struggle of balancing work and caregiving with insufficient income. These findings align with the study by Haddock et al. (2006), in which caregiving impacts a caregiver's work and family finances, including the challenge of balancing employment with providing care for family members. This highlights the necessity for financial support and resources to alleviate the financial strain on caregivers.

Limited Family Support

The majority of participants reported feeling burdened due to limited or no family support in caring for their loved ones with dementia at home. This lack of support leads to increased stress and emotional strain. Cultural expectations, physical constraints, and family conflicts further exacerbate the lack of available assistance. Some participants shared that relatives assumed caregiving was easier for them due to their roles or circumstances, while others mentioned that family members were unable to help due to space constraints or their own family commitments. Several participants mentioned having relatives in Canada who are unable to help due to their own family commitments. Additionally, several participants noted that their siblings and relatives are in Sri Lanka, leaving them with no support in Canada. These findings align with Morgan et al. (2002), who emphasized the importance of comprehensive support for caregivers. Moreover, caregivers may experience social isolation due to cultural disparities or inadequate support from their immediate social circle, including family and friends (Lindeza et al., 2020).

The collectivist nature of Tamil family structures, where caregiving responsibilities are often shared among extended family members, provides both strengths and challenges. While family networks can offer emotional support, they also create tensions when caregiving responsibilities are not equitably distributed. The study revealed that caregivers often faced internalized pressure to meet collective family expectations, which discouraged seeking external professional help. This reluctance to rely on outside services reflects deep-rooted cultural values surrounding family responsibility and underscores the importance of creating community-based support systems that align with these cultural norms.

Lack of Self-Care

Caregivers in this study expressed that they often neglect self-care due to their caregiving responsibilities. The strain of constant caregiving without adequate rest or personal time leads to significant physical and psychological stress. The findings of this study are consistent with studies conducted by Couto et al. (2016) and Connell & Gallant (1998), who observed that caregivers often sacrifice their own health and well-being to prioritize caregiving duties, leading to emotional distress and a decline in health. Some participants explicitly stated feeling like crying due to the lack of leisure time. Several participants mentioned having no time to rest, and expressed a decline in health due to lack of sleep, lack of leisure time and opportunities for self-care among caregivers leads to a significant reduction in their social connectedness (Morgan et al., 2002). . Balancing caregiving, work, and family duties leaves little time for personal care, leading to emotional distress and health decline.

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Family Responsibility

Caregiving affects family life because it reduces the caregiver's time with their family and friends (Parrish & Adams, 2003). Participants reported feeling overwhelmed by the need to balance caregiving, work, and family obligations. This dual responsibility creates a challenging situation, resulting in increased stress and frustration. The findings underscore the burden on caregivers who must manage both their caregiving duties and family responsibilities simultaneously. Several participants reported feeling overwhelmed by the challenge of balancing caregiving responsibilities with family duties. In addition to caring for their loved ones with dementia, many also faced the difficulty of managing their own households. 60% of participants highlighted the strain of juggling work, caregiving, and family obligations, which added to their overall stress and burden.

Culturally influenced caregiving

The responses from seven participants in this study highlighted the significant influence of culturally supported values on caregiving responsibilities. These responses mainly emphasized Duty to Reciprocate Care, Cultural Caregiving Responsibility, and Emotional and Physical Burden.

Duty to Reciprocate Care

A significant 70% of participants expressed that, since their parents had cared for them during childhood, it is now their responsibility to care for their parents. This cultural expectation of reciprocating care is deeply ingrained, and participants believe it is their duty as children to reciprocate that care. This finding is consistent with Botsford et al. (2011), who noted that caregiving responsibilities often influenced by cultural factors.

Cultural Caregiving Responsibility

Several participants highlighted the broader cultural expectation that children must care for their parents. For instance, participants stated that it is mandatory to look after one's parents according to their culture, viewing it not just as a choice but also as a fundamental responsibility. The sense of duty was especially challenging for participants who were the sole caregivers as the only child in the family. They expressed feeling overwhelmed by the responsibility, with no siblings to help share the caregiving tasks.

Participants described how the cultural practice of caregiving was reinforced by their family experiences. One participant explained that he initially cared for his father alongside his mother, but after her passing, he now feels solely obligated to continue this care, which has significantly intensified the caregiving burden. Another participant reflected on childhood memories of watching their mother care for grandparents in Sri Lanka, which strongly shaped their belief in upholding this cultural tradition. This family history deepened their sense of duty, compelling them to continue the caregiving role, despite the significant emotional and physical burden. These findings align with Couto et al. (2016), who emphasized the role of cultural values in caregiving and the emotional significance attached to these responsibilities.

A defining characteristic of caregiving within the Tamil community is the strong cultural expectation of moral obligation to care for their aging parents. Rooted in traditional values, caregiving is seen not merely as a personal task but as an essential aspect of one's familial and moral duties. This expectation places significant pressure on adult children, who are often expected to assume primary caregiving responsibilities. Unlike in other cultures where caregiving roles may be shared or flexible, Tamil families emphasize the child's responsibility, creating a sense of duty that deeply connects caregivers to their roles. However, this connection

often leads to feelings of exhaustion, isolation, and, in some cases, resentment as caregivers struggle to balance caregiving with personal and professional commitments. These findings reinforce the need for culturally sensitive interventions that respect these values while addressing the emotional and physical toll on caregivers.

Emotional and Physical

The cultural expectations of caregiving have led to significant emotional and physical burdens for the caregivers. Participant expressed stress related to caring for her parents, acknowledging the difficulty of managing these responsibilities despite cultural norms. She questioned whether it is acceptable to feel stressed, given that they are her parents. Andruske & O'Connor (2020) examined family caregiving across three different ethnic groups in Canada: Chinese, South Asian, and Latin American. Their research supports the understanding that caregiving practices are significantly influenced by cultural factors, leading to emotional and physical strains faced by caregivers within these diverse cultural contexts.

Positive experiences of caregiving

This study found that caregiving led to positive personal experiences. Caregivers felt a sense of luck and gratitude while providing care to their loved ones. All the participants confirmed experiencing emotional connection and happiness, as well as noting a positive impact on family dynamics. Ott et al. (2007) highlighted similar positive outcomes in their research, observing that caregivers often experience personal growth and engage in meaningful self-reflection. This aligns with the findings of this study, where caregivers reported various positive aspects associated with their roles.

Sense of Luck and Gratitude

Several participants expressed a profound sense of luck and gratitude for the opportunity to care for their parents. For instance, participants felt fortunate to provide care, highlighting the unique chance to reciprocate the love and care they received as children. This sense of gratitude underscores the emotional rewards that caregivers can experience and reflects a deeper appreciation for the caregiving role.

Emotional Connection and Happiness

Many participants described the joy and emotional connection they experience through caregiving interactions. Four out of ten caregivers reported feeling happy and fulfilled when their parents showed affection through holding hands, hugging, and kissing. These moments of physical affection strengthened their sense of purpose and deepened the bond they share with their parents. Additionally, participants found joy in the caregiving routine itself. For example, several participants mentioned the satisfaction of knowing they are providing well for their parents. Others described the emotional rewards and sense of contentment that came with fulfilling their caregiving role.

Participants also found happiness in seeing their parents content and smiling. Several noted the joy they experienced when their parents recognized them and appeared happy, even in cases where dementia affected their loved ones. Some caregivers specifically mentioned feeling blessed when their parents showed appreciation through affectionate gestures. This positive emotional connection is consistent with findings from Jervis et al. (2010), who reported that American Indian caregivers often perceive caregiving to older adults as rewarding rather than burdensome. This underscores the importance of exploring different aspects of the caregiving

experience, reflecting the belief that caregiving represents a longstanding relationship where elders have significantly contributed to the caregivers' lives.

Positive Impact on Family Dynamics

The study also highlighted the positive impact of caregiving on family dynamics. Some participants noted that caregiving allowed family members, especially younger generations, to spend meaningful time with their elders, creating cherished memories and reinforcing cultural values. This finding aligns with the literature, such as Horse (1980), who emphasized that caregiving for elders embodies mutual support and demonstrates respect for the elders' wisdom.

Study Limitation

This study provides valuable insights into the caregiving experiences of Tamil Canadian caregivers, yet several limitations must be acknowledged to contextualize its findings. One notable limitation is the sample composition. Participants were recruited exclusively from caregivers receiving homecare services through Ontario Health. While this ensured access to a group with active engagement in caregiving, it inherently introduced a selection bias. These caregivers may have different levels of access to resources, knowledge, and support compared to those without formal caregiving assistance. Consequently, the findings may not fully represent the broader spectrum of Tamil Canadian caregivers, particularly those navigating the caregiving landscape without external support.

The reliance on caregivers already receiving formal support might have influenced the study results. Caregivers with access to homecare services likely experience slightly reduced stress or have more resources to manage their caregiving roles compared to those who are unsupported. For example, challenges such as navigating the healthcare system independently, addressing severe caregiving burdens, or coping with extreme social isolation may be more

pronounced in caregivers not included in the study's scope. These nuances suggest that the study's findings may not comprehensively capture the experiences of Tamil caregivers facing more extreme caregiving hardships.

Implications for Nursing Practice

The findings of this study offer insights into how nursing practice can better support caregivers, particularly those caring for loved ones with dementia. It is critical for nurses to be fully aware of the unique challenges caregivers face, including the need for education, emotional support, and guidance in navigating health and social services.

The primary implications for nursing practice is the development and delivery of targeted educational programs and resources. By equipping caregivers with the skills and knowledge necessary to provide effective care, nurses can significantly reduce caregiver burden and enhance care outcomes. Offering accessible training on topics such as dementia management, medication use, and personal care techniques will not only improve caregivers' confidence but also the overall well-being of the care recipients.

Cultural competence is another crucial area of focus in nursing practice. The study highlights the need for nurses to understand and address the cultural values and expectations that shape caregiving, particularly for groups such as Tamil Canadian caregivers, who often view caregiving as a deeply ingrained cultural duty. Incorporating culturally sensitive care models and offering bilingual or culturally relevant educational materials and services will help bridge communication gaps. Nurses can foster a supportive environment by ensuring that caregivers feel respected, understood, and supported in their roles.

Additionally, the study underscores the necessity for nurses to advocate for comprehensive support systems, including financial assistance, emotional support, and respite

care options. These resources are vital in relieving caregiver stress, preventing burnout, and ensuring caregivers maintain their own health and well-being. Nurses can promote self-care practices by providing resources for workshops on stress management and encouraging caregivers to prioritize their physical and mental health.

By integrating these findings into nursing practice, nurses can contribute to a more supportive and effective caregiving environment. Advocacy for caregiver support, cultural sensitivity, and a focus on education and self-care will enhance the quality of care and improve both caregiver and recipient well-being.

Recommendations for Supporting Tamil Canadian Caregivers

The findings from this study highlight several critical challenges faced by Tamil Canadian caregivers of older adults with dementia. These challenges underscore the urgent need for comprehensive support and targeted interventions to enhance the caregiving experience. The following recommendations aim to address these challenges and improve the quality of life for caregivers, ensuring they are better equipped to provide effective care for their loved ones at home.

Empowering Caregivers through Education and Awareness of Available Services

The Tamil community's unique perceptions of dementia, often viewed as a moral issue rather than a medical condition, underscore the need for culturally tailored interventions. Effective programs must bridge the gap between traditional beliefs and medical understanding while respecting and integrating cultural values. Key recommendations for such interventions include education, family-centered care, culturally competent healthcare, and community-based support systems.

Culturally competent care is essential for addressing the specific needs of diverse caregiver populations (Andruske & O'Connor, 2020). Raising awareness through culturally sensitive education is a critical first step. Educational programs should address the medical aspects of dementia while engaging with the cultural beliefs that shape caregiving practices. Involving religious leaders, who are trusted figures within the Tamil community, can help dispel misconceptions by framing dementia as a medical condition that can be managed with appropriate care. These leaders can provide foster trust and acceptance. Community workshops and seminars in accessible spaces, such as cultural centers, can further reinforce this message. These workshops should explain dementia symptoms and the importance of early medical intervention, emphasizing how medical treatments and cultural practices can work together to enhance care. Additionally, multilingual resources in Tamil, using culturally appropriate metaphors and examples, are essential to address stigma and ensure that caregivers understand the importance of early diagnosis and professional care.

Interventions should also adopt family-centered care approaches, reflecting the Tamil community's strong emphasis on familial responsibility in caregiving. Providing educational resources and counseling for the entire family can reduce stigma, encourage open discussions, and foster shared caregiving responsibilities. This approach can alleviate the burden on primary caregivers, by involving extended family members in caregiving tasks. Programs should facilitate strategies for collaborative caregiving, ensuring that responsibilities are distributed more equitably across the family network. This support helps to balance the cultural expectation of family-centered care while addressing the practical challenges caregivers face. By addressing the unique challenges faced by Tamil caregivers, such programs can improve caregiving experiences and outcomes while respecting the values and beliefs of the Tamil community.

Improving Cultural Competency and Communication for Tamil Canadian Caregivers

Training healthcare providers in cultural competency is vital to ensuring that Tamil caregivers receive appropriate and respectful care. Healthcare providers should understand the influence of cultural beliefs on caregiving practices and offer guidance that aligns with these values while delivering evidence-based care. Health providers must also build trust with Tamil caregivers through non-judgmental and respectful communication. Acknowledging the role of culture in caregiving can make caregivers feel more comfortable seeking and following professional advice. Tailored healthcare services that respect cultural and spiritual traditions are critical to improving the caregiving experience for Tamil families.

Additionally, addressing language barriers is crucial. Offering translation services, bilingual healthcare professionals, and educational materials in Tamil can help caregivers better understand medical information, advocate for their loved ones, and effectively participate in care planning. Research shows that language barriers significantly impact caregivers' ability to navigate the healthcare system and communicate medical needs effectively (Lindeza et al., 2020; Martinez et al., 2024). By improving communication resources, caregivers can be more confident and competent in managing their caregiving responsibilities.

Building trust between caregivers and healthcare providers is crucial for encouraging Tamil families to seek external support. Healthcare professionals should receive training to approach Tamil caregivers with cultural sensitivity and empathy, recognizing their strong sense of family duty. Providers should develop strategies for effective communication, including offering guidance in Tamil and addressing concerns about external services in a culturally

respectful manner. By establishing trust, healthcare providers can motivate caregivers to access services such as homecare, respite care, or counseling without feeling they are compromising their family values.

Health Support Systems and Financial Resources

Establishing comprehensive health support systems that address both the emotional and practical needs of caregivers is crucial. This includes creating support groups, offering counseling services, and providing respite care options. Such systems can help caregivers manage stress, reduce feelings of isolation, and promote their overall well-being. The significance of comprehensive support for caregivers has been emphasized in various studies, demonstrating its positive impact on caregivers' mental and physical health (Morgan et al., 2002; Haley et al., 2003). Establishing support from peer groups is another essential component of effective interventions. The perception of dementia as a private family matter often isolates caregivers, making it important to create spaces where they can connect and share experiences. Caregiver support groups conducted in Tamil provide an opportunity for caregivers to learn from one another and reduce feelings of isolation. These groups can integrate cultural perspectives, offering ways to address caregiving challenges. Additionally, community-based support networks, such as volunteer programs or cultural events focused on caregiving, can strengthen social connections and provide caregivers with much-needed assistance.

In addition to emotional and practical support, implementing financial support programs is essential to alleviate the economic burden on caregivers. This could include subsidies, tax breaks, or direct financial assistance to help cover caregiving costs and compensate for lost income due to caregiving responsibilities. Financial strain is a common issue among caregivers, and providing financial support can significantly reduce their burden and stress (Haddock et al.,

2006). By combining these comprehensive support systems with financial resources, caregivers can receive the holistic support they need to effectively manage their responsibilities and maintain their well-being.

Promotion of Self-Care Practices

Encouraging caregivers to prioritize self-care by providing workshops and resources on stress management, time management, and self-care techniques is essential. Emphasizing the importance of self-care can help prevent burnout and ensure that caregivers maintain their health and well-being. Previous research indicates that caregivers often neglect their own health, resulting in emotional and physical decline (Couto et al., 2016; Connell & Gallant, 1998).

Implementing these recommendations can greatly enhance the quality of life for Tamil Canadian caregivers and improve the effectiveness of their caregiving. By addressing the identified gaps and offering comprehensive support, we can foster a more supportive environment for Tamil Canadian caregivers and their loved ones.

Training Programs Tamil Canadian Caregivers

Understanding the Tamil community's perceptions of dementia is essential for developing effective training programs for caregivers and healthcare providers. The unique cultural beliefs held by Tamil caregivers significantly shape their caregiving practices and attitudes toward medical interventions. Therefore, it is crucial to design programs that respect these beliefs while providing evidence-based knowledge and tools to improve caregiving outcomes. By incorporating culturally sensitive education, addressing stigma, fostering trust between caregivers and healthcare professionals, and engaging family members, these training initiatives can empower caregivers, enhance the quality of care for older adults with dementia, and reduce caregiver burden.

Training programs for Tamil caregivers and healthcare providers must consider cultural perceptions to ensure effectiveness and community acceptance. One of the most critical aspects is integrating cultural sensitivity into dementia care training. Caregivers should feel that their beliefs are respected, and programs should demonstrate how medical interventions can complement cultural practices. For example, healthcare providers can discuss dementia in a way that acknowledges cultural beliefs while explaining its medical basis. Additionally, training should guide caregivers on integrating cultural rituals alongside memory care techniques or addressing spiritual distress in their loved ones.

Given the collective nature of caregiving in Tamil families, training programs should adopt family-centered approaches. Engaging not only primary caregivers but also extended family members ensures shared understanding and responsibilities. These programs should educate families on navigating the emotional and practical challenges of dementia care and supporting primary caregivers in reducing stress and preventing burnout. Encouraging the involvement of extended family members can create a more balanced caregiving approach, which aligns with the Tamil community's emphasis on family support.

Reducing stigma around dementia is another essential focus for training programs. Misconceptions that dementia is a punishment or moral failing must be countered with evidence-based information about its biological and neurological causes. Educational initiatives should emphasize that seeking professional medical help is not a sign of failure but an essential step in improving the quality of life for both caregivers and care recipients. By normalizing dementia care and encouraging the use of medical and community-based services, these programs can help caregivers make proactive and positive choices.

Conclusion

This study provides important insights into the multifaceted challenges experienced by Tamil Canadian caregivers of older adults with dementia, employing an existential phenomenological approach to thoroughly examine their lived experiences. This approach allowed the researcher to focus on the subjective emotional, physical, and psychological burdens caregivers face, as well as the personal meaning they derive from their caregiving roles.

The findings revealed that caregivers often struggle due to limited knowledge of available health and social support services, financial strain, language barriers, and insufficient family support. These challenges are compounded by cultural expectations, where caregiving is seen as a deeply ingrained responsibility to reciprocate the care received from parents. In addition, many caregivers reported neglecting their own self-care, leading to physical and emotional distress, which further amplifies their burden.

The study underscores the critical need for culturally sensitive and comprehensive support systems tailored to the unique needs of Tamil Canadian caregivers. Key areas for improvement include providing targeted education and training on caregiving, financial assistance, language support, and mental health resources. Addressing these gaps would equip caregivers to better manage their responsibilities, reduce their stress, and improve the overall quality of care for their loved ones.

Despite the challenges, the study also highlighted the positive aspects of caregiving, including emotional fulfillment, gratitude, and strengthened family bonds. Many caregivers found joy in their personal connection with their loved ones and took pride in fulfilling their caregiving roles, highlighting the dual nature of caregiving as both a burden and a rewarding experience.

The findings of this study emphasize the urgent need for systemic changes in healthcare and social services to better support caregivers. By implementing the study's recommendations, healthcare providers, policymakers, and community organizations can enhance the caregiving experience for Tamil Canadian caregivers and ensure that both caregivers and care recipients receive the necessary support for a more sustainable and compassionate care system. The researcher hopes that these recommendations will lead to significant improvements in caregiver support and effectiveness, particularly within the Tamil Canadian community, better preparing caregivers to handle their responsibilities.

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Appendix A

The SPIDER tool applied to the research question.

S	Sample	Caregiver
P	Phenomenon of Interest	Enhance caregivers capacity to care for the elderly
I		
D	Design	Lived experiences
E	Evaluation	Caregiver experiences
R	Research	Qualitative

Appendix B

CONSENT TO PARTICIPATE IN RESEARCH.



Research title: The Experience of Tamil caregivers who care for older adults with Dementia

Researcher: Sumathi Parama Thayanithi, 1600 W Bank Dr, Peterborough, ON K9L 0G2.

Telephone number: 9057819307. Email: sparamathayanithi@trentu.ca

Research Supervisor: Dr Abeer Omar, George Brown College, 51 Dockside Dr, Toronto, ON M5A 0B6. Telephone number: 416-415-5000 x 2077. Email: abeeromar@trentu.ca

Study Code:

PLEASE READ THIS CONSENT AGREEMENT CAREFULLY BEFORE YOU DECIDE TO PARTICIPATE IN THIS RESEARCH.

BACKGROUND INFORMATION:

You are invited to take part in a research conducted by Sumathi Parama Thayanithi to explore the experience of Tamil caregivers who care for older adults with dementia. The purpose of this study is to gain an in-depth understanding of the caregiving experiences of Tamil Canadians caring for older adults with dementia at home. The results of this study will provide insights into the development of interventions to support caregivers. This study has been reviewed for ethical compliance by the Trent University Ethics Board. The researcher will read through this consent form with you and answer any questions you may have.

DETAILS OF THE STUDY:

The purpose of this research is to gain an in-depth understanding of the caregiving experiences of Tamil Canadians caring for older adults with dementia at home. The results of this study will provide insights into the development of interventions to support Tamil Canadian caregivers caring for older adults with dementia at home. If you are interested in participating, you will be contacted by the researcher by phone to schedule an interview session at your home.

WHAT YOU WILL NEED TO DO IN THE STUDY:

Upon consenting to participate in the research, you will be asked to complete a questionnaire about your demographics. After completing this demographic questions, in-person interview session will start. The interview will consist of six open-ended questions asked by the researcher. These questions will inquire about your experience with caring for a family member with dementia and the health and social services provided to you, feelings, and recommendations to improve the services. The demographic questionnaire will require up to 5 to 10 minutes to complete. If you

agree to participate in the interview, it will take from 60 to 75 minutes of your time in which you will discuss and answer the seven open-ended questions.

The interview session will be audio-recorded and transcribed for data analysis.

RISKS:

There are no anticipated major risks to participating in this study. Additionally, the care received from Ontario Health for your mother/father/spouse at home will not be affected in any way when you participate in this research. However, there may be a minor risk of emotional discomfort when discussing your experience of caring.

BENEFITS:

There are no direct benefits to you by participating in this research. However, the research findings will help in developing future health and social support/services to improve the experience of Tamil caregivers and to provide quality care to older adults with dementia at home

CONFIDENTIALITY:

Any identifying information that is gathered by this study will remain confidential and will not be shared with anyone. The information in the informed consent will be saved separately from your responses in the demographic questionnaire and will not be linked in any way. If you provide your name and phone number to schedule the interview, it will be used only to schedule the interview place and time. The researcher will use the last three letters of your name as a code name for the interviews to maintain anonymity. Only the researcher and the researcher's supervisor will have access to the data. The data will be stored in a locked cabinet in the researcher's supervisor's office in George Brown College for 5 years after data collection takes place. All data will be destroyed using paper shredder by the researcher after 5 years.

VOLUNTARY PARTICIPATION:

Participation in this study is entirely voluntary. There are no consequences if you decide not to participate or withdraw from this study.

RIGHT TO WITHDRAW FROM THE STUDY:

You have the right to withdraw from the research at any time without any consequences. You may withdraw from the research at any time and during or after your interview session. If you would like to withdraw after your data has been submitted, please contact Sumathi Parama Thayanithi at telephone number 9057819307 or email: sparamathayanithi@trentu.ca within 3 months after your interview session. All collected data will be deleted upon withdrawal.

COMPENSATION:

As compensation for participating in the interview, participants will each be given a \$25 Tim Hortons gift card as a thank you for your time.

FEEDBACK ON THE RESULTS OF THIS STUDY TO YOU:

The results of the current study will be published in scientific journals and conference meetings. A copy of the published manuscript can be sent to you if you are interested.

If you have any questions about your rights as a participant please contact: Anna Kisiala
Coordinator, Research Conduct and Reporting Office of Research and Innovation.

Email: annakisiala@trentu.ca

This study, with file number # 28637 has been granted clearance according to the recommended principles of Canadian ethics guidelines, and policies at the Trent University.

IF YOU WISH TO PARTICIPATE IN THE RESEARCH, PLEASE SIGN BELOW.

Signing this informed consent demonstrate that I voluntarily participate in this study. Also, I understood the study procedure and all my questions were answered by the researcher/interviewer.

Participant name:

Signature of participant:

Date:

Signature of researcher:

Date:

Appendix C

Interview Questions	
1.	<p>Can you tell me about your awareness of the available health and social support/services provided to you as a caregiver for older adults with dementia?</p> <p>1.1 How do you perceive the availability of services to caregivers for persons with dementia?</p>
2.	<p>How do you perceive the barriers to accessing health and social/support services as a caregiver to older adults with dementia?</p>
3.	<p>Can you explain to me your experience of stress?</p> <p>3.1 Can you tell me what you do if you are stressful</p>
4.	<p>According to your experience, what factors contribute to your stress as a caregiver?</p> <p>4.1 Can you tell me internal factors e.g. emotional, cultural, family, financial</p> <p>4.2 Can you tell me external factors e.g. community services, racism, language barrier</p>
5.	<p>How do you feel are positive experiences of caring for your loved one?</p> <p>5.1 Tell me about what makes you think you have positive experience caring for you loved one?</p>
6.	<p>How do you perceive about growing of your knowledge and skills when looking after your mother/father/spouse at home?</p>
7.	<p>What is your recommendations to improve the health care services provided to the caregivers of people with dementia in the Tamil Community</p> <p>7.1 What are the additional health and social support/services might improve the quality of your care?</p>

Appendix D

Interview Guide

Hello and thank you for participating in this interview today. My name is Sumathi Parama Thayanithi, and I am a graduate student at Trent University, currently enrolled in the Master of Science in nursing program. My research focuses on the experiences of Tamil Canadian caregivers who are caring for older adults with dementia at home. Your insights, feelings, and experiences are incredibly valuable, and I believe they deserve to be heard and shared.

This interview will take approximately 40 minutes of your time. There is no time limit for answering each question, so please feel free to take your time. I encourage you to provide as much detail as possible and share personal examples where relevant, as this will help me better understand your experiences.

There are no right or wrong answers; please respond honestly and to the best of your ability. If at any point you feel uncomfortable with a question, you are free to skip it, and we can move on to the next one.

For accuracy, I will be using an audio recorder to capture this interview. The recording will be securely stored and used only for transcription purposes. Once the transcription is completed, the audio file will be permanently deleted. Your personal information will remain strictly confidential, and no identifying details will be shared. In the reporting of any direct quotes, you will be referred to by a pseudonym to ensure your anonymity.

During the interview, I will also be taking notes to document your responses.

Do you have any questions before we start? If not, we can begin the interview.

Appendix E
REB Approval



October 16, 2023

File #: 28637

Title: Tamil Canadians caregiving experiences caring for older adults with dementia at home.

Dear Ms. Parama Thayanithi,

The Research Ethics Board (REB) has given approval to your proposal entitled "Tamil Canadians caregiving experiences caring for older adults with dementia at home".

When a project is approved by the REB, it is an Institutional approval. It is not to be used in place of any other ethics process.

To maintain its compliance with this approval, the REB must receive via ROMEO:

An Annual Update for each calendar year research is active;

A Study Renewal should the research extend beyond its approved end date of November 01, 2024;

A Study Closure Form at the end of active research.

This project has the following reporting milestones set:

Annual progress report-2023/12/31

Renewal Due-2024/11/01

To complete these milestones, click the Events tab in your ROMEO protocol to locate and submit the relevant form.

If an amendments to the protocol is required, you must submit an Amendment Form, available in the Events tab in your ROMEO protocol, for approval by the REB prior to implementation.

Any questions regarding the submission of reports or Event forms in ROMEO can be directed to Anna Kisiala, Coordinator, Research Conduct and Reporting, at annakisiala@trentu.ca

On behalf of the Trent Research Ethics Board, I wish you success with your research.

Best Wishes,

Dr. Liana Brown

REB Chair

Phone: (705) 748-1011 ext. 7238

Email: lianabrown@trentu.ca

c.c.: Anna Kisiala

Coordinator, Research Conduct and Reporting