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Stress Among Immigrant Tamil Canadian Caregivers: a Qualitative Study

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Stress Among Immigrant Tamil Canadian Caregivers: a Qualitative Study

Abstract

The purpose of this study was to understand the impacts of caregiving on immigrant Tamil family caregivers of Patients Living with Dementia, identify the factors influencing caregiver stress, and barriers and facilitators to accessing support services.

This study used qualitative descriptive design. Family caregivers and health care professionals were recruited using purposive sampling in the Greater Toronto Area (GTA), Ontario, Canada. Virtual, semi-structured interviews and focus groups were conducted from May to August 2022. Kingston Caregiver Stress Scale (KCSS) was used to assess caregiver burden. Recordings were transcribed, translated as needed, coded using an inductive and deductive approach and thematically analyzed using the Braun and Clarke method; descriptive statistics summarized KCSS scores and demographics.

Among fifteen caregivers, two thirds were women, Caregivers' ages ranged from 31 to 80 years; the most common age group were 41 to 50 years. Mean KCSS score was 25.4, which indicated severe caregiver stress. Seven Tamil speaking health care providers were interviewed. Four primary themes emerged: motivations for family caregiving, allocation of caregiving responsibilities, daily caregiver stressors and associated impact on caregiver's life, and access to care- barriers and mitigation strategies. In addition to the fragmented dementia care, this study identified the influence of war, immigration and sociocultural norms on the delayed support-seeking behaviors of immigrant Tamils. It proposes to address the unique needs of this population by facilitating community relations, caregiver education, and culturally tailored care at all levels, to reduce caregiver stress. Urgent action is needed to develop coordinated, culturally safe care models that address layered inequities and improve outcomes for diverse communities.

Introduction

The prevalence of dementia in Canada is rising, with the number of persons living with dementia (PLWD) projected to increase by more than 187% between 2020 and 2050. Family caregivers (FCGs) provide an average of 26 hours of care weekly, totaling over 470 million hours of unpaid support each year (Alzheimer Society of Canada, 2024). According to the Public Health Agency of Canada (2023), one in three Canadians supported a relative with dementia in daily activities over the past five years. Family caregivers of PLWD , tend to feel overburdened financially, emotionally, physically, and psychologically (Ahmad et al., 2022, Black et al., 2019, Guo et al., 2019, and Springate et al., 2014). According to Black et al. (2019), these caregivers show the largest increase in depression scores and exacerbation of physical health. Factors that contribute to caregiver stress include the need to provide around-the-clock care, safety concerns, and worsening of behavioral and psychological symptoms of dementia (Sörensen & Conwell, 2011).

Cultural diversity of patients adds complexity to dementia care. Foreign-born patients have more unmet needs than their Canadian-born counterparts (Ahmad et al., 2022 and Yang et al., 2021). For example, dementia-specific studies report that Chinese older adults rely heavily on their adult children and extended family members for primary support (Wong et al., 2024 and Springate et al., 2014). This reliance is partly shaped by structural gaps on an individual-level (e.g., knowledge and communication difficulties), community-level (e.g., provider time constraints), and societal-level (e.g., mental health stigma) (Berg et al., 2025). However, there are also cultural preferences to caregiving such as filial duty (Wang et al., 2023). Foreign-born caregivers face higher stress due to barriers accessing timely, language-concordant services (Schaffler et al., 2019). Caregiver demographics such as length of stay in the country of settlement, education, income, age, gender, and cultural expectations inform their awareness and willingness to seek support in a timely manner (Williams et al., 2016).

According to the 2021 Canadian census, approximately there are 237,890 Tamil speaking individuals in Canada, within a global Tamil diaspora estimated around 5 million (Statistics Canada, 2022). Caregiver stress is often overlooked in the Tamil community. Particularly, immigrant Sri Lankan Tamil family caregivers are uniquely vulnerable to additional stressors associated with experiencing war and forced migration (Guruge et al., 2021, George et al., 2001, and Morton et al., 2003). A pilot quantitative study using Kingston Caregiver Stress Scale (KCSS) revealed a high degree of caregiver stress in Canadian Sri Lankans providing care to a loved one with dementia (Vickneaswaran et al., 2024). This study explored caregiver stress in this population using caregiver and provider perspectives. The study aimed to examine the impact of dementia caregiving on the lives of Tamil family caregivers, including their real-world experiences, perceptions, available supports, knowledge of resources, and the barriers and facilitators influencing service access. The findings will inform development of culturally appropriate strategies to better support Tamil immigrant caregivers.

Methods

Given the limited literature on Tamil immigrant dementia caregiving experience, this study used a qualitative descriptive design to explore participants' perspectives, an approach suited to providing a rich summary of experiences in participants' own terms (Colorafi & Evans, 2016; Neergaard et al., 2009; Sandelowski, 2000, 2010). The study was informed by a pragmatic qualitative approach. The study team consisted of four Tamil Canadian women, a second-year medical student with qualitative research experience, an international medical graduate with prior experience as a medical assistant in a geriatric clinic, a master's student in global health systems and an experienced academic geriatrician. The Geriatrician provided clinical care to PLWD and was familiar with some family caregivers; all other researchers had no prior relationship with study participants.

Family caregivers (FCGs) were recruited from two geriatric clinics in the Greater Toronto Area (GTA), using purposive sampling (Tongco, 2007). Tamil Caregivers of patients with a dementia diagnosis within the senior author's medical practice were contacted by telephone. To avoid any undue influence, the senior author had no role in recruitment or consent. Caregiver participant identification numbers reflect

their position in the sampling list, therefore some identifiers exceed the final sample size of 15. Tamil-speaking health care providers (HCPs) who provided care to Tamil Canadian patients with dementia and had regular interactions with FCGs were recruited from GTA through email invitations or telephone calls using publicly available contact information. Participation for all individuals was voluntary.

Data was collected from May to August 2022. FCGs participated in a 40-60-minute semi-structured interview conducted virtually in either Tamil or English based on participant preference, Caregivers provided brief sociodemographic information about themselves and their family members as well as details regarding their caregiving role. During the interviews, participants described the current care and living arrangements of the family member with dementia, their experiences providing and coordinating care, their use or non-use of external supports, ethno cultural needs and preferences, and their own and their family member's health status, including any changes since the dementia diagnosis. KCSS, previously identified as a preferred measure for this population was administered to provide contextual information regarding participants' perceived burden. The scale also served as a prompt to support reflection during interviews, as caregivers may not always explicitly acknowledge or articulate their own stress. Data collection continued until the research team agreed that data saturation had been achieved, defined as the point at which no new codes emerged from independently conducted interviews by the two interviewers. To ensure that emerging concepts were not overlooked, recordings were reviewed at multiple time points throughout data collection, consistent with recommendations by (Guest et al., 2006). Patient information was obtained through a retrospective chart review of electronic medical records, providing demographic details such as age, gender, and documented diagnoses. HCPs participated in either individual interviews or focus groups. Focus groups were conducted with providers who practiced at the same location or within the same specialty; otherwise, individual interviews were arranged. Sessions lasted 30 to 60 minutes. An online survey was used to collect relevant practice-related information from the HCPs.

A single interview guide was used for all HCPs interviews and focus groups, and a separate guide was utilized for caregivers. All interviews, focus groups, and KCSS administrations were conducted by first and/or second authors, without the presence of any non-participants. Interviews were audio-recorded, transcribed verbatim in the language used during the session, and translated into English as needed. Student

volunteers assisted with transcription and translation. All transcripts were verified against the audio recordings for accuracy, and audio files, transcripts, and KCSS scores were de-identified prior to analysis.

Descriptive statistics were used to summarize demographic characteristics and KCSS scores. Data were analyzed using reflexive thematic analysis as described by Virginia Braun and Victoria Clarke. Analysis followed the six phases of thematic analysis, with codes and themes developed inductively from the data at a primarily semantic level to remain close to participants' accounts. Coding and theme development were conducted iteratively, with regular team discussions to refine interpretations. All team members reviewed transcripts for familiarization, and additionally the senior author reviewed random selection of a few audio recordings. First and second authors independently generated initial codes in Microsoft Word, which were compared and consolidated into a shared coding framework through discussions between both. Code, theme, and subtheme development occurred iteratively through repeated reviews of the transcripts, codes, multiple team meetings and collaborative refinement of shared Microsoft documents. These processes supported reflexivity and enhanced the credibility of the findings.

Final themes were constructed to capture commonalities and variations in participant experiences. Member checking was not conducted due to practical constraints, the sensitive nature of the discussions. Ethics approval was obtained from the Academic Health Sciences Network Research Ethics Board (REB #22-13).

Results

Participant Characteristics

Family Caregivers: Fifteen FCGs included ten women and five men. Half of the women were daughters of PLWD (Table 1). To maintain the utmost anonymity of caregiver participants, only aggregate data are presented here. Ages of the participants ranged between 31 to 80 years. A third were between 71 and 80 years, the most common age group was 41 to 50 (40%). Participants came from different parts of the GTA: Scarborough, Markham, New Market, Vaughan, Ajax, Pickering, and Central Toronto. Most participants reported living in the same municipality of the family members they were caring for.

Participants reported a mean KCSS total score of 25.40 (SD 11.19), which correlates to severe stress levels. The minimum calculated score was 14/50, and the maximum was 49/50. Seven participants (46.7%) had total scores above 24 with a mean score of 34.29 (SD 9.83), which correlates to severe stress levels.

Patients: patients being cared for by the FCGs participants consisted of 10 women and 5 men. Age ranged between 56-95 years, most (73%) in the 76-85 bracket. The majority had Alzheimer's disease or mixed dementia.

Health care providers (HCPs): Seven Tamil-speaking HCPs (5 women, 2 men) participated, including: two family physicians (Family Medicine Focus Group, FMFG); one geriatrician and one medical student in a geriatrics clinic (Geriatrics Focus Group, GeriFG); and three social service professionals: a home care caseworker (HCW), a social worker (SW) from a healthcare organization, and a community support worker (CSW) from the local health network. Over 60% of the clients served were immigrants, with the majority being Tamils. The family physicians reported around 20% were older adults and less than 20% were people with dementia. Social workers primarily served older adults (over 60%) and reported 21-40% of their clients had dementia.

Main Themes

Four primary themes and their corresponding subthemes (table 2) were identified in the analysis of interviews with caregivers and HCPs. The main themes included: 1) motivations for family caregiving, 2) allocation of caregiving responsibilities, 3) daily caregiver stressors and associated impact on caregiver's life, and 4) Access to care: barriers and mitigation strategies.

Theme 1: Motivations for Family Caregiving.

Caregivers' motivation to provide home-based care include a sense of filial duty, a sense of love or reciprocity, spiritual fulfillment, societal pressures to provide care, guilt, and in some instances, financial constraints.

Subtheme1: Filial Duty. The concept of filial duty is rooted in collectivist communities, where care is best provided by kin. Several participants indicated it is their duty to look after family members.

"What's hard [about caregiving]? We will absolutely do it because it's our duty. I'm only telling you this because you're asking. Other than that, I don't complain about anything to anyone." FCG-19.

Subtheme 2: Fulfilment in Caregiving. Those who were motivated by love and reciprocity expressed a sense of satisfaction and confidence in providing care. It was noted that caregivers who identified more beneficial components of their role experienced less burden, better health and relationships, and greater social support.

"I don't feel like it's a forced thing to have to take care of your parents. It is something that gives me satisfaction." FCG-01

Subtheme 3: Cultural and Societal Expectations. Social pressures arise from cultural expectations to provide care. Such beliefs are further exacerbated by the model minority belief held strongly in many immigrant communities, which motivates families to not overburden the government and be self-sufficient. As a result, seeking external support for caregiving was a last resort.

"Tamil people don't send them [to LTC]. You know, our heritage or our feelings that we grew up with..." FCG-16.1

Caregivers who are motivated by guilt, and societal stigma often made oblique references to resentment in caregiving responsibilities and reported greater psychological distress compared to their counterparts who had more positive motivations.

"I feel pity for my father which is why I take care of him. He does not have anyone." FCG-04

There are generational differences in caregiving attitudes, one healthcare provider stated

"It's often the grandchildren, not the children, who want to give proper care. "SW

Subtheme 4: Financial Constraints. HCPs talked about financial interdependence as another critical motivation to keeping patients living with dementia at home.

"The financial aspect [of] relying on the money that comes for the PLWD… I know a number of families that [are] reliant on that money." (CSW)

Another participant echoes how his family's financial circumstance has crumbled due to his health.

"Now we both don't go to work due to our health conditions. So, I feel it would be helpful if we had some extra income through my mother-in-law." FCG-03

On the other hand, some families continue to take care of their older family members at home due to immigration status.

Theme 2: Allocation of caregiving responsibilities.

The care provider designation was influenced by factors such as patient preference, circumstantial obligations, gender and access to social resources. More than half the caregivers provided hands-on care whereas other caregivers were care managers who arranged others to provide care. Most caregivers had difficulty identifying an objective number of hours of care provided, but felt they worked around the clock with caregiving duties.

Subtheme 1: Patient Preference. Patient preference was based on cultural unfamiliarity and unease of having external support person help with basic activities of daily living. This often led to PLWD refusing external support and family assuming more responsibilities.

"When I tried to arrange [home support] for my father-in-law, he got really mad and didn't want anyone new coming and giving him a bath. And we stopped it" FCG-01

Subtheme 2: Circumstantial Obligation. Circumstantial obligation emerged from several intersecting factors. The unplanned nature of migration among immigrant Tamil families has often led to their dispersion across different countries, thereby reducing the pool of individuals available to share caregiving responsibilities.

Some participants noted that care "back home" was shared in intergenerational households, reducing strain on the primary caregiver. In contrast, the lack of availability, willingness, or capacity of other family members here often compels certain individuals to take on caregiving roles alone.

"One of her sons hurt his head resulting in memory problems, another son passed away, and the youngest son lives in Norway. So, they are not that involved. And my wife is the only daughter, so she takes care of her." FCG-03

When care providers reached out for support, often it was from their adult children or siblings with other competing commitments and had limited capacity.

"There is no time for people to take care of other families here in Canada. So, not enough time. They also have kids; they have to take care of them. They also have their work. We shouldn't give them stress." FCG-10.2

Systemic limitations also played a role when needs of PLWD exceeded the available formal support. Some caregivers described their role as care managers, due to the limited availability of PSW support and the lack of control over scheduling, they often had to step in and provide direct care.

Subtheme 3: Gender based roles. There is a cultural expectation of gender roles within the Tamil immigrant community. Family-based care is typically provided by women.

"I told my wife that she is the one that should take care of her mother. No one else would take care of her like you." FCG-03

When it comes to providing intimate care, the importance of matching caregivers and care recipients by gender was also very strongly emphasized.

"I was hesitant to give him a bath because I am a woman, and he might not be comfortable with it." FCG-01.

Another participant clarified that " Since my mother is a woman, you know there are a lot of private things…when it comes to dressing and other things, it's uncomfortable and also, it's not normal in our culture and where I come from" FCG- 05

Subtheme 4: Access to social support. Social support provides a buffer against caregiver burden and stress for caregivers by increasing the resources available to cope with caregiver stress. Often when

respite is required caregivers requested help from immediate family members, as opposed to looking into formal programs. One caregiver reported that a relative from Europe came to provide respite.

Caregivers who had family members to provide social support recognized it as a positive impact in their lives. “To truly help me, I have a cousin. Ever since I came to Toronto he does the shopping for me. ” FCG 14

As a result of having minimal publicly funded services that meet the unique needs of this community, some participants talked about relying on privately run Tamil retirement homes in the GTA to use a respite bed on a short-term basis. However, access to these supports is dependent on the financial capacity of the caregiver.

Theme 3: Burden and Impacts of Caregiving.

Caregivers face multiple responsibilities including daily stressors of providing care, addressing safety concerns, behavioral symptoms, competing demands from their personal lives and the emotional burden of witnessing the decline of their loved one. In addition, caregiving exerts a significant impact on their physical and mental health, socialization, employment, income and overall wellbeing.

Subtheme 1: Daily stressors of care. Safety concerns such as kitchen safety, falls risk, wandering risk, medication safety and managing behavioral symptoms such as paranoia, verbal aggression and mood changes were more stressful to the caregivers compared to managing basic and instrumental activities of daily living. “This is too much stress, because I need to spend all 24 hours with him. Both my son and daughter are also stressed due to him. He speaks to them carelessly, cursing them.” FCG-16.2

Caregiver’s perception of quality of life for PLWD adds to the stress. “He is not happy, when he doesn’t enjoy his present life, I feel stressed” FCG 14

“There were a few occasions when my mom tried to cook and she would forget and would burn the food. That was kind of scary for us.” FCG-05

Subtheme 2: Competing demands. The other contribution to caregiver stress is secondary role strains from competing duties. Most had to balance employment, child-rearing and other competing household responsibilities leading to time scarcity.

"Everything was getting too much. My mom started going down this year. Last year my son was diagnosed with autism. So, I quit my job last year. I cannot manage going to work and I have to manage my son and my mom." FCG-08

Subtheme 3: Emotional toll of dementia progression. As dementia progresses, patients often become distant, apathetic, and may forget loved ones, placing an emotional toll on caregivers. Across interviews, caregivers consistently described feeling "empty" in interactions and distressed by their loved ones' withdrawal.

"He doesn't even ask if any of us have eaten yet. He used to ask everyone this, but ever since he was diagnosed with dementia, it seems he is very self-centered" – FCG 01.

These combined traits have made caregivers feel as if they have "lost" or "will eventually lose" their loved one due to dementia. One caregiver spoke about the loss of quality time with PWD due to being completely occupied with daily chores.

In families, where the PWD offered support, their functional decline left profound deficits on the family and contributed to caregiver stress.

"He used to drive; we were able to go everywhere. But the past 2 years, we haven't gone anywhere because he doesn't have his license anymore."- FCG 2

Subtheme 4: Impacts on Caregivers' Lifestyle and Wellbeing. Caregivers described significant impacts on their health, social life, relationships, leisure time and work life balance. There is a considerable amount of manual labor leading to physical exhaustion and worsening of physical and mental health.

"I feel so much pressure and tension. Sometimes my chest hurts. When others trouble me it's hard to cope with it at my age. When he acts like this I make mistakes even while cooking." FCG-16.2

Most caregivers' had their own health issues. Physicians discussed the high prevalence of diabetes, cardiovascular diseases and multi-morbidity amongst the caregivers.

Caregivers reported reducing work hours, missing work, or leaving the workforce, while facing increased out-of-pocket costs and lost income, leaving many financially strained in supporting their loved ones.

One participant discussed seeking financial support through the government but did not receive any aid.

"I applied through the government for caregiving compensation. They did not give it"- FCG 16.1

HCPs noted challenges in caring for dementia patients who are sponsored visitors and lack of Ontario Health Insurance coverage. Caregivers reported reduced social contact due to homebound caregiving duties, sacrificing leisure activities and time with extended family and friends. Safety concerns and patient behaviors often led to social isolation.

"Now, I can't leave him alone at home. If left by himself he won't know what to do and I can't be peaceful at the place I go." FCG-14.

Even simple pleasures have been lost according to participants.

"I never go out. I can't even go on a walk. Say that I want to go to a store, I can't go. It feels like I am arrested" FCG 16-2.

"Sometimes I don't even have time to speak to my husband." FCG-01

Theme 4: Access to Care: Barriers and Mitigation Strategies.

All participants noted that Tamil caregivers and care recipients face barriers to timely, culturally appropriate dementia care due to knowledge gaps, stigma, and limited access to language-concordant, trauma-informed services. The lasting impact of war and forced migration also shapes dementia care in the Tamil diaspora.

Subtheme 1: Knowledge Gaps and Lack of Awareness of Available Supports. Caregivers spoke about knowledge gaps and lack of understanding of dementia related symptoms, which impacted their ability to seek support.

"Everybody has to have a workshop to educate normal ordinary people. All of a sudden, someone like me faces this, it is very hurtful and confusing. Not knowing something may hurt your decisions, you and your loved ones" FCG-05

All HCPs identified poor health literacy and lack of awareness adding to the challenges. Misidentification of the symptoms of dementia as part of normal aging, misinterpretation of changes in behavior and personality also delayed diagnosis and access to support.

"Many have had devastated lives because of war and immigration. When they come here, there's confusion in diagnosis—whether it's dementia or depression. They talk about trauma and PTSD symptoms."GeriFG1

Very few of our caregivers were aware of available dementia support.

"I never asked for help. I thought I should do it myself." – FCG-16.1

We found that 80% of our participants were not connected to the Alzheimer's Society. Our HCPs discussed how lack of awareness further exacerbates the burden of care felt in the Tamil community, including increased isolation, stigma, and delays in seeking a diagnosis.

"There are senior Tamil associations, they have good resources [that] are discussed in those [meetings], not everyone participates, some are at home, and not taking part in any of the community events and so awareness is not reaching everyone". FMFG

The language barrier further exacerbates the knowledge gap. A community worker noted that even Tamil-fluent HCPs and interpreters struggle to find the right terminology during education sessions, raising concerns that the information may not be conveyed to the clients.

Physicians spoke about caregivers not receiving support due to lack of awareness.

"First they will say 'no I don't want any home care' because they don't understand what it is." Geri FG.

Subtheme 2: Societal Expectation and Stigma. Societal expectation and stigma related to fear or shame within families and communities can create barriers to seeking support because they want to preserve the dignity of their loved one and there is a cultural expectation for the family to provide for the needs of patients living with dementia.

I have never requested it (formal support) as my mother is there. My mother will take care or I will" FCG-16.1

Family caregivers strived to look after their loved ones at home until they reached a stage where needs of PWD exceeded caregivers' capacity.

There is a stigma around discussing certain topics, even in public education sessions. "I was told not to talk about abuse at a Tamil seniors' workshop—it could cause family conflict."- CSW

Similarly, this participant recounted the normalization of abuse in some families stating "one client mentioned 'it's my mom's money, why can't I use it?' "- CSW

Stigma also reduces conversations about caregiver stress and dementia diagnosis, making caregivers further wary of asking for help. Most of our caregivers shared diagnosis only with immediate family members.

"[Extended] family members learned about her dementia when they came to visit her and when I spoke about the challenges of caregiving, they advised not to [talk ill about the situation]. It's like nobody wants to know about these things." FCG-05

HCPs expressed that even when help is offered to the caregivers, they are hesitant to accept.

"Patients or caregivers are often hesitant. They'll say, 'no doctor, we don't need it.' Compared to other communities, ours seems more hesitant, maybe out of reluctance or lack of trust in letting new people into the home." FMFG 2

Subtheme 3: Lack of Linguistically and Culturally Appropriate Resources. A major systemic barrier to seeking support is the lack of culturally and linguistically appropriate formal care options. Patients are reluctant to accept care when PSWs do not share their culture.

"The support workers prior to the current one were of different cultures and different languages. I found a new caregiver, and within a couple of days my mom and new lady clicked. The culture and language are very important. Especially in the case of a patient with Alzheimer's." FCG 05.

Participants discussed relying on home care supports like PSWs and community nurses, but raised concerns about lack of rapport, fragmented hours, and frequent changes in staff.

"If new people come, she will not cooperate at all. During that time, it's really hard." FCG-19

Culturally, people often start their day with taking a bath. "Tamil patients, in particular, may prefer services early in the morning—around 7 or 8 o'clock—but PSWs are often unable to accommodate that time" FMFG2. As a result, patients may decline the service.

HCPs noted a shortage of Tamil-speaking professionals in medical offices and adult day programs, making it hard for older adults to access dementia services or communicate with providers. Finding appropriate programs was also challenging. "This man can do yoga for over half an hour, to this kind of person when they say tap your legs, raise your hands, it is like some game, and it does not feel useful." FCG06

Due to limited publicly funded, culturally appropriate services, some participants relied on private Tamil retirement homes in the GTA for short-term respite care.

"The care may not be great, but they use it because they can speak the language and receive Sri Lankan food." FMFG

Further, caregivers can be strongly influenced by structural barriers such as systemic discrimination, mistrust in authority from previous trauma, difficulty navigating health services that are not culturally appropriate, and lack of resources in the language of choice that cause hesitancy to engage with the healthcare system.

Subtheme 4: Delay in Diagnosis and Access to Services. Primary care physicians play a key role, but HCPs observed reluctance to diagnose or disclose dementia, especially with patients who face language barriers, low literacy, or limited education. Some physicians assume certain ethnic groups will provide family care and do not need formal services. Cultural differences in expressing distress also pose challenges.

"They don't express their issues directly. Even when they see a doctor, they struggle to explain what's really happening. Trauma clients often don't share their feelings openly, so as mental health workers, it's hard to identify their needs—they don't put their emotions into our language." SW

Practical constraints also add to the delay in diagnosis. "Caregivers are a sandwich generation—…. Taking time off to bring parents to medical appointments becomes a major challenge" Geri FG

Language barriers often contribute to the delay. "[PLWD] depends on children or someone else to interpret. There should be more accessible interpretation services for patients at a specialist office." HCW "Every time a different person may take them to appointments and (interpret), there is no continuity." SW

Knowledge gap and stigma also precludes these patients presenting to physicians early. "They wait until the patient develops behavioral symptoms." FMFG

Additionally, prior trauma, a lack of trust in authorities and model minority beliefs, may deter individuals from accessing services until such access becomes absolutely necessary.

"As long as she is able to walk, I can figure out the bath. If she is going to be bedridden it'll be hard. If she's bedridden she would (still) be with me. For that I would need a PSW." FCG-08

Subtheme 5: Possible Mitigation Strategies. Caregivers emphasized the importance of having language-concordant, consistent PSWs, Tamil day programs, respite beds, long-term care facilities, and educational resources. HCPs highlighted the need for community education, centralized resource repositories, patient education materials, and capacity building for primary care providers in dementia diagnosis, disclosure, referrals, and culturally responsive, trauma-informed care. They also noted the need for early specialist access, culturally appropriate day programs, affordable transportation, and long-term care homes.

Discussion

Care provision within Tamil communities has traditionally relied on extended family structures and interconnected social networks, allowing for natural respite for caregivers. However, unplanned migration has significantly disrupted these traditional systems. Tamil families are now dispersed globally, leading to the erosion of extended family support. Consequently, caregiving responsibilities often fall on one or two individuals. This shift is compounded by language barriers, which limit their ability to navigate care systems. For immigrant caregivers, the challenge is intensified by competing demands: establishing their own households, raising children, and attempting to uphold cultural traditions that may no longer be feasible in the new sociocultural context.

Despite these pressures, stigma surrounding formal care remains prevalent. Seeking external support is often perceived as neglect or a failure to fulfill familial obligations, this reluctance is compounded by the limited linguistically and culturally appropriate resources within a highly fragmented Canadian dementia care model. . Many caregivers sacrifice personal well-being, career progression, and social engagement in an effort to balance caregiving with other responsibilities. COVID 19 pandemic further contributed to social isolation and cessation of their formal supports out of fear, resulting in increased stress.

Research findings presented here explore both shared and unique experiences of family caregivers. This study takes a comprehensive approach in combining local, cultural knowledge from family caregivers and health care providers in the Tamil community. It provides a nuanced understanding of the lived experiences of immigrant Tamil family caregivers navigating the complex landscape of dementia care in the GTA with an intersectional lens. Through the voices of caregivers and service providers, four interconnected themes emerged, illuminating the multifaceted challenges they face. This is the first qualitative study in this visible minority population.

We explored the deep commitment to caregiving in this community, grounded in cultural values and moral obligations. Dementia care was framed as an extension of filial duty and respect for older adults, often reinforced by religious beliefs and cultural norms. While caregiving was described as an act of love, it

was also accompanied by personal sacrifices and hidden emotional costs, revealing the duality of pride and burden embedded in the caregiving experience. The caregiving journey was marked by progressive and compounding stressors. As dementia symptoms worsened, caregivers faced significant disruptions to daily life. Many caregivers were isolated, navigating complex family dynamics and gendered expectations with limited social or institutional support. HCPs echoed these sentiments, highlighting the systemic gaps that exacerbate caregiver fatigue and emotional burnout. They also identified the after effects of war as a significant contributor to the current state.

Significant barriers to accessing culturally and linguistically appropriate dementia care were identified. Delayed help-seeking was driven by stigma, misinformation, and misinterpretation of symptoms. This community faced challenges with obtaining a timely diagnosis due to language barriers and limited cultural awareness among healthcare providers. Systemically, formal home care options were often mismatched with cultural needs, and limited services were available in Tamil. While caregiver burden is well documented, our study highlights missed opportunities for targeted caregiver support within the Tamil community. Formal supports such as home care, respite, adult day programs, and long-term care does help but do not reduce mental load when not culturally tailored. Multi-modal public education, capacity-building for physicians, and early involvement of social workers and legal teams are needed to support caregivers and facilitate timely discussions while the person with dementia can express their wishes. While this study focused on the Tamil population, its findings are relevant to broader South Asian communities, other immigrant groups, and dementia caregivers in general.

There are limitations inherent to purposive sampling. The small caregiver sample size was determined by data saturation in our interviews. To increase generalizability, efforts were taken to obtain participants from multiple cities across GTA. These caregiver participants had already accepted the dementia diagnosis, were connected to a geriatric clinic, and had some access to resources, introducing potential bias. Including caregivers who deny the diagnosis, decline help, or have low health literacy may experience different stress levels, was not feasible. Reaching out to people with fear of contact with institutions was not feasible. Those experiencing severe stress may have declined participation. The study reflects the Greater Toronto Area, which has more resources and a large Tamil population, rural caregivers

are not represented. All participants and researchers were from the same ethnic community, which may have influenced responses due to cultural stigma, though efforts were made to build rapport. Many participants valued the involvement of a culturally and linguistically aligned specialist; however, these reflections, shared post-interview, were not included in the thematic analysis.

Most participants expressed appreciation for the interview. The conversation provided an opportunity for caregivers to acknowledge their caregiver stress. Some even described the interview as having a therapeutic effect. These responses highlight the value of conversations of caregiver stress within primary care settings and involving integrating interprofessional team members within medical clinics to address caregiver stress.

Caregivers and patients with dementia often do not share the same healthcare provider. Caregiver support is frequently suggested by the specialist caring for the PLWD, but education and resources may be better received from the family physician, who is familiar with the caregiver's context. Ideally, caregivers should be screened for caregiver stress and receive ongoing education and resources, much like chronic disease management within a primary care team setting. System-level support for this process could include permitting billable time for caregiver education and counselling within primary care. Incentives to educate Tamil-speaking PSWs would also help address a system need.

Conclusion

Collectively, the findings of this study underscore the urgent need for a dementia care model that is culturally responsive, linguistically inclusive, and grounded in the lived realities of racialized communities. This also emphasizes the importance of trauma informed and culturally safe caregiver interventions. Increased education and awareness on dementia, efforts on de-stigmatization, to the general Tamil population is necessary to further encourage future planning and decrease caregiver stress. This will affirm the cultural expectations of caregivers, validate their feelings and support persons living with dementia in a formal space where additional care can be provided without hindering kin-based care. A

one-size-fits-all approach to care cannot be implemented due to unique circumstances and challenges each community faces.

Policies and services must recognize caregiving as both a cultural strength and a source of vulnerability and address the structural inequities that limit access to timely, respectful, and appropriate care. Without systemic changes, Tamil caregivers will continue to carry disproportionate burdens in silence. This study highlights the urgent need for effective, efficient and coordinated dementia care models that are culturally safe and trauma informed.

Abbreviations

Community support worker (CSW)

Family caregivers (FCGs)

Family medicine focus group (FMFG)

Geriatrics focus group (GeriFG)

Greater Toronto Area (GTA)

Health care providers (HCPs)

Home care caseworker (HCW)

Kingston Caregiver Stress Scale (KCSS)

Patients Living with Dementia (PLWD)

Social worker (SW)

TABLE 1

Caregiver and patient demographic information

Caregiver Variables (n=15)[1]	**Value (%)**
Age	
21-30	1 (6.7%)
31-40	1 (6.7%)
41-50	6 (40.0%)
51-60	2 (13.3%)
61-70	1 (6.7%)
71-80	5 (33.3%)
Sex	
Male	5 (33.3%)
Female	10 (66.7%)
Relationship to Patient	
Daughter	5 (33.3%)
Wife	3 (20.0%)
Daughter-in-law	2 (13.3%)
Grand Daughter	1 (6.7%)
Son	3 (20.0%)
Son-in-Law	1 (6.7%)
Husband	1 (6.7%)
Kingston caregiver stress scale	
Total score range (10-50)	14-49
Mean	25.4
SD	11.2
Patient Variables (n=15)*	**Value (%)**
Age	
56-65	1 (6.7%)
76-85	11 (73.3%)
85-95	3 (20.0%)
Sex	
Male	5 (33.3%)
Female	10 (66.7%)
Clinical Diagnosis	

[1] Values include one patient with >1 caregiver and two patients with one caregiver but had different relationship to patients.

Alzheimer's Disease	7 (46.7%)
Mixed Dementia	7 (46.7%)
Vascular Dementia	1 (6.7%)

TABLE 2

Caregiver stress: Themes, Subthemes and Sample quotes

Major themes	Subthemes/codes	Sample quotes
1.Motivations for Family Caregiving	Filial duty	"As long as I am able to do (it), I need to do it properly...I need to take care. That is my thing..." FCG-14
	Fulfillment in caregiving	"I am happy to take care of her" FCG19
	Cultural and societal expectation and stigma	"So, our relatives know that he has dementia. They usually say that I'm taking care of him very well. I usually don't tell them that it's hard or anything like that." FCG-02
	Financial Constraints	"We sponsored them to Canada and we have to look after them for 10 years." FCG-01
2.Division of Caregiving Duties	Patient Preference	"I don't want a personal support worker (PSW); she might not want anyone to help her." – FC-08
	Circumstantial obligations	"I'll say the truth, mostly, I don't want to keep him here, but I don't have the means to go and keep him elsewhere. FCG-16.2
	Gender based roles	"She can't tell me that she is going to the bathroom. It's a shy thing that is common in our community." FCG-03
	Access to social supports	"Sometimes, for me, we leave my father at my younger brother's place". FCG-16.1
3. Burden and Impacts of Caregiving	Daily stressors of dementia care -behaviors - safety concerns -bADLS & IADLS	Sometimes she removes her incontinence briefs and leaves it around, we do not know where it is, and we'll find stool all over the floor. It gets very stressful. Giving her food and taking her to the bathroom is okay" FCG 07 "She won't eat sometimes; she causes struggles when we try to get her to eat. Sometimes she would throw things. Sometimes when we take her to the washroom, she would refuse, hit my hand and do stuff like that." FC-19 "I have to cook for my father. If I'm by myself, I do not have to do things this way or that way." FCG-04 "[Caregivers] are going through the same struggle regardless of the education they have, I would say the stress level is the same. But if they have higher education, they may have [more disposable income to pay out of pocket for] fee for service [home care supports] on top of what [home care] provides." HCW
	Competing roles	"By 7:30 I have to give him dinner. So right before 7, he will ask, is it 7 yet? Over and over, in the meantime I have to give dinner to my kids and husband. – FCG 01

Major themes	Subthemes/codes	Sample quotes
	Emotional toll of dementia progression	"The man who did so well is now... He is like this... It makes me sad" FCG-14
	Impacts to lifestyle and wellbeing -health - social isolation -employment - finances	"By the time I take her to change her incontinence brief, I am out of breath. We have to hold her properly or else sometimes she goes down" FCG-19 "If by accident my mother-in-law falls down, I won't be able to lift her up because then I would need someone to lift me up." FCG-03 "I couldn't go back to work even after my kids started schooling because I have to look after my father-in-law and mother. FCG01 "I used to phone people and talk a lot, but now I avoid it." FCG-19 "So, the economic status affect [their care]. Certain medications are not covered and some of our patients are newcomers, and they came within [the last] ten years, so they don't have any income, pension, or anything. So, all the burden goes to the caregiver." FMFG 2
4. Challenges in Accessing Formal Dementia Supports	Knowledge gaps and lack of awareness of available supports	"I was stressed, once my brother-in-law(psychiatrist) explained, I understood the behaviors…. felt better" FCG01 "I was thinking even if they have some kind of a program for seniors with transportation; pick them up and go to their community center. And then spend one hour or two doing some activity and then come back." FCG-06
	Stigma	"Caregivers often don't recognize their own stress until it reaches burnout. Even when they do, stigma prevents them from seeking help or using support programs. Many Tamil caregivers also worry about family reputation, so they avoid sending loved ones to day programs or long-term care, choosing to manage at home until they themselves are overwhelmed." SW
	Lack of linguistically and culturally appropriate resources	"The patient doesn't want to go there and talk to people they don't know. The family will think there will be a language barrier. They want to be at home and watch their Tamil drama." CCW
	Delay in diagnosis and referrals	"I have seen patients saying 'we were going around 5 years here and there, we don't have a diagnosis'" GeriFG
	Mitigation strategies	"If they give more PSW hours, it will be useful. The time they come for lunch is the time I take to take my lunch." FCG19 "If there are Tamil day programs nearby, I will send him" FCG06

References

Ahmad, M., van den Broeke, J., Saharso, S., & Tonkens, E. (2022). Dementia care-sharing and migration: An intersectional exploration of family carers' experiences. *Journal of Aging Studies, 60*, 100996. https://doi.org/10.1016/j.jaging.2021.100996

Alzheimer Society of Canada. (2024, January 22). *The Landmark Study: The many faces of dementia in Canada (Report #2).* https://alzheimer.ca/en/the-many-faces-of-dementia-in-canada-landmark-study-volume-2

Berg, A., Issakainen, M., Ervasti, K., Montonen, T., Solje, E., & Mäki-Petäjä-Leinonen, A. (2025). Barriers to accessing care and support services for older immigrants and immigrants with dementia in Finland: Perspectives of professional social and health care providers. *Journal of Cross-Cultural Gerontology, 40*(1), 49–76. https://doi.org/10.1007/s10823-025-09523-2

Black, B. S., Johnston, D., Leoutsakos, J., Reuland, M., Kelly, J., Amjad, H., Davis, K., Willink, A., Sloan, D., Lyketsos, C., & Samus, Q. M. (2019). Unmet needs in community-living persons with dementia are common, often non-medical and related to patient and caregiver characteristics. *International Psychogeriatrics, 31*(11), 1643–1654. https://doi.org/10.1017/S1041610218002296

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

Colorafi, K. J., & Evans, B. (2016). Qualitative descriptive methods in health science research. *HERD: Health Environments Research & Design Journal, 9*(4), 16–25. https://doi.org/10.1177/1937586715614171

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? *Field Methods, 18*(1), 59–82. https://doi.org/10.1177/1525822X05279903

Guo, M., Kim, S., & Dong, X. (2019). Sense of filial obligation and caregiving burdens among Chinese immigrants in the United States. *Journal of the American Geriatrics Society, 67*(S3). https://doi.org/10.1111/jgs.15735

Guruge, S., Sidani, S., Man, G., Matsuoka, A., Kanthasamy, P., & Leung, E. (2021). Elder abuse risk factors: Perceptions among older Chinese, Korean, Punjabi, and Tamil immigrants in Toronto. *Journal of Migration and Health, 4*, 100059. https://doi.org/10.1016/j.jmh.2021.100059

Health Quality Ontario. 2024. .https://www.hqontario.ca/Evidence-to-Improve-Care/Quality-Standards/View-all-Quality-Standards/Dementia/The-Quality-Standard-In-Brief

KC, S., Clarke, K., & Seppänen, M. (2023). A scoping review on ageing migrants in Finland through the lens of intersectionality and vulnerability. *Nordic Journal of Migration Research, 13*(3), 2. https://doi.org/10.33134/njmr.561

Morton Beiser, Laura Simich, Nalini Pandalangat (2003) Community in Distress: Mental Health Needs and Help-seekingin the Tamil Community in Toronto. International Migration. https://doi.org/10.1111/j.0020-7985.2003.00268.x

Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description – the poor cousin of health research? *BMC Medical Research Methodology, 9*, 52. https://doi.org/10.1186/1471-2288-9-52

Public Health Agency of Canada. (2023). *Stigma related to dementia in Canada* (Catalogue No. H14-461/2023E-PDF). Government of Canada. https://publications.gc.ca/collections/collection_2023/aspc-phac/H14-461-2023-1-eng.pdf

Robert W. Hopkins, Lindy A. Kilik. Kingston caregiver stress scale. https://nebula.wsimg.com/979c665ffd41f5c5a0f8987c3817d273?AccessKeyId=954A289F7CDF75707C10&disposition=0&alloworigin=1

Sadak, T., Korpak, A., Wright, J. D., Lee, M. K., Noel, M., Buckwalter, K., & Borson, S. (2017). Psychometric Evaluation of Kingston Caregiver Stress Scale. *Clinical Gerontologist*, DOI:10.1080/07317115.2017.1313349

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*(4), 334–340. https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 33*(1), 77–84. https://doi.org/10.1002/nur.20362

Schaffler, J. L., Tremblay, S., Laizner, A. M., & Lambert, S. (2019). Developing education materials for caregivers of culturally and linguistically diverse patients: Insights from a qualitative analysis of caregivers' needs, access and understanding of information. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, *22*(3), 444–456. https://doi.org/10.1111/hex.12867

Sörensen S, Conwell Y. Issues in dementia caregiving: effects on mental and physical health, intervention strategies, and research needs. Am J Geriatr Psychiatry. 2011 Jun; 19(6):491-6. doi: 10.1097/JGP.0b013e31821c0e6e. PMID: 21502853; PMCID: PMC3774150.

Springate, B. A., & Tremont, G. (2014). Dimensions of caregiver burden in dementia: Impact of demographic, mood, and care recipient variables. *The American Journal of Geriatric Psychiatry, 22*(3), 294–300. https://doi.org/10.1016/j.jagp.2012.09.006

Statistics Canada. (2022, November 30). *Census profile, 2021 Census of Population.* Government of Canada. https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/index.cfm

Tongco, M. D. C. (2007). Purposive sampling as a tool for informant selection. *Ethnobotany Research and Applications*, *5*, 147. https://doi.org/10.17348/era.5.0.147-158

Vickneaswaran, A., Shanmuganathan, T., Sriharan, S., & Yogaparan, T. (2024). A pilot study on caregiver stress in immigrant Tamil Canadian family caregivers of persons with dementia. In P. Subramaniam (Ed.), *Book of abstracts of the 5th International Conference on Gerontology and Geriatric Medicine (SilverAge 2024)* (p. 1). SilverAge Conference.

Wang, Q., Xiao, X., Zhang, J., Jiang, D., Wilson, A., Qian, B., Song, P., & Yang, Q. (2023). The experiences of East Asian dementia caregivers in filial culture: a systematic review and meta-analysis. *Frontiers in Psychiatry*, *14*. https://doi.org/10.3389/fpsyt.2023.1173755

Wong, K. L., Johnson, G., & O'Connor, D. (2024). Living with dementia: Exploring the intersections of culture, race, and dementia stigma. *Dementia, 23*(6), 1001–1020. https://doi.org/10.1177/14713012241249796

Williams, A., Sethi, B., Duggleby, W., Ploeg, J., Markle-Reid, M., Peacock, S., & Ghosh, S. (2016). A Canadian qualitative study exploring the diversity of the experience of family caregivers of older adults with multiple chronic

conditions using a social location perspective. *International Journal for Equity in Health*, *15*(1). https://doi.org/10.1186/s12939-016-0328-6

Yang, X. Q., Vedel, I., & Khanassov, V. (2021). The cultural diversity of dementia patients and caregivers in primary care case management: A pilot mixed methods study. *Canadian Geriatrics Journal, 24*(3), 184–194. https://doi.org/10.5770/cgj.24.490

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Data Availability

Due to the sensitive nature of the qualitative data and the potential risk of participant identification, the data are not publicly available but may be available from the corresponding author upon reasonable request and with appropriate ethical approvals.