

The Cost of Waiting for Long-Term Care: Findings from a Qualitative Study

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Introduction

In Ontario, more than 38,000 people are waiting for long-term care placement and the waitlist is growing (Ontario Government 2020). While waiting for long-term care, many families continue to provide crucial support to address the needs of their loved ones at home, retirement home, hospital, or other places. Delayed admission can lead to negative health consequences for those waiting for care and create uncertainty, anxiety, and stress for them and their family caregivers (Cressman et al. 2013; Kuluski et al. 2017).

The wait for long-term care can be just a day for some or more than several years for others. Wellesley Institute's previous studies (Um 2016; Um & Iveniuk 2020) found significant disparities in long-term care wait times across various population groups. The findings highlight that wait times varied by the individual's health status and urgency of long-term care admission, as well as where the person resides, which language one speaks, and whether the person was seeking specific cultural accommodation in long-term care. The wait was particularly long for those seeking placement in a religious, ethnic, or cultural home, such as Yee Hong and Mon Sheong Long-Term Care Centre for the Chinese-Canadian community, Suomi-Koti Nursing Home for the Finnish-Canadian community, and Belmont House for the Christian community in the Greater Toronto Area (GTA).

Building on the previous work, the research team conducted qualitative research to explore the reasons why some people choose to wait for long-term care homes with longer waitlists and to examine the experiences of family caregivers of older immigrants throughout their long-term care application and waiting journey.

This research paper presents the findings from focus groups and individual interviews with family caregivers of older immigrants from five different ethnocultural communities, waiting for long-term care placement in the GTA. It explores the considerations that influence caregivers' decision on pursuing long-term care and making a choice of long-term care homes for their loved ones. This paper provides insights into family caregivers' perceptions of key elements to consider when choosing homes and how they are similar or different across diverse ethnocultural groups. Also, this paper explores waiting experiences of family caregivers and the impact of waiting on the health and well-being of family caregivers and their loved ones. Research findings presented in this paper highlight some commonalities shared by family caregivers across ethnocultural groups as well as unique experiences presented by individual caregivers or different groups. Based on the research findings, this paper discusses identified issues and concerns about the current support system for those needing long-term care and their family caregivers.

Methods

A qualitative descriptive design was used for the study (Sandelowski 2000). The primary method used was focus group discussions and interviews with family caregivers looking after older immigrants (65 years+) currently or previously on long-term care home waitlists. The use of qualitative data collection allowed the research team to capture the breadth of participants' experiences as well as shared views on the challenges they experienced while waiting for long-term care. Data was collected from May to July 2019 through focus groups and individual interviews with family caregivers of older immigrants, representing the top five countries/regions of origin of older immigrants in the GTA.¹ To facilitate recruitment and discussions in community languages, one primary language was identified for each group through community consultations (English for the U.K. and the Caribbean, Punjabi for South Asian, Italian for Italian, and Cantonese for the Chinese communities).

¹ Italy, United Kingdom (U.K.), China, South Asia, and the Caribbean

Family caregivers were recruited across different regions as well as locations in the GTA (e.g., where their family members are waiting for LTC, such as hospitals, homes, retirement homes, etc.). Community collaborators, including various mainstream and ethnocultural service agencies and advocacy organizations serving older adults and their family caregivers, facilitated recruitment through posting ads in their newsletters, social media, and in their organizations, and the research team also posted flyers at common gathering places for each ethnocultural group.

Participants were recruited using a purposive sampling framework (Tongco 2007). Family caregivers interested in participating in the study were screened through a brief in-person or phone conversation to ensure they met the inclusion criteria: 18 years or older, caring for a family member who is 65 years or older, is waiting for/previously waited for a long-term care home, resides in the GTA,² and from one of the five selected ethnocultural communities. Participants also identified their language of preference for the discussion to be held in.

There was a total of three focus groups each about 90 minutes and seven interviews about 30 minutes in length. Both the focus group and interview guides used the same questions. These two different formats of data collection were used to accommodate participants' preferences, availabilities, residential locations, and health limitations. All participants completed a brief questionnaire about their own and their older family member's socio-demographic information (e.g., age, city of residence, country of birth, etc.) and some details about which home their family member is/was waiting for and what kind of support family caregivers provide. In the discussion, moderators or interviewers then asked participants, in their preferred language, about current care and living arrangement of their family members being cared for, their experiences of seeking and applying for long-term care, reasons for choosing the LTC home their family members are waiting for, ethnocultural needs and preferences, and their own and their family members' health status and any change in health since being placed on the waitlist.

All focus groups and interviews were audio-recorded, transcribed verbatim and translated into English. Each participant received an honorarium (i.e., \$40 for focus group and \$20 for interview). Any incurred caregiver expenses or travel costs were reimbursed. Ethics Approval was obtained from Ryerson University prior to the start of the study (REB 2019-111).

All transcribed data was analyzed using thematic analysis strategies (Braun & Clarke 2006). Three research team members reviewed the data individually first, and then discussed observations to establish a list of focused thematic codes. Based on these conversations, the thematic codes were applied across all transcripts during coding. Finally, the research team identified themes and patterns that reflect the commonalities and differences in participant experiences across the various discussions.

Findings

In total, 29 family caregivers participated in our study (22 females and seven males). Participants' age ranged from 44 to 81 with the average age of 62. Most participants were born abroad (83 per cent). At the time of the study, they had lived 34.3 years on average in Canada. Participants came from different parts of the GTA: Scarborough, Oakville, Georgetown, Brampton, Mississauga, Etobicoke, Central Toronto, North York, Markham, Richmond Hill, and Vaughan. Most participants reported living in the same municipality with the family members they were caring for (79 per cent). Further, 66 per cent of caregivers had power of attorney to make personal care decisions on behalf of the family member.

The age of older family members ranged from 72 to 96, with the average age of 86.4 years old (17 females and 12 males). Participants reported that the family members they were caring for arrived in Canada across different immigration periods: 1950-1969 (39 per cent), 1970-1989 (43 per cent), 1990-2009 (11 per cent), and 2010 to present (7 per cent). Those from the UK and Italy were relatively more established immigrants compared to those from South Asia, the Caribbean, and China. While all older family members from the UK and the Caribbean reported English as their mother tongue and preferred language, all from Italy, China, and South Asia reported non-English language as their mother tongue and preferred language.

² GTA represents the City of Toronto and four surrounding regional municipalities: Durham, Halton, Peel, and York.

Across the 29 participants, 30 per cent waited or were waiting for long-term care homes for less than one year, 33 per cent for one to two years, 19 per cent for three to four years and 18 per cent for five years or longer, with a range of two months to nine years. Just over half (52 per cent) of older adults were waiting or had previously waited for long-term care from home where they co-resided with family caregivers, another 28 per cent were living at own home independently, and 14 per cent were waiting from a retirement home.

Just over half (52 per cent) of family caregivers reported that on average they provided more than 40 hours of care to their older family member per week. Participants assisted their older family member with preparing meals (86 per cent), getting to appointments and running errands such as shopping for groceries (86 per cent), doing everyday housework (79 per cent), personal care such as washing, dressing, eating or taking medications (61 per cent), moving about inside the house and other facility (e.g., hospital or retirement home; 54 per cent) and looking after personal finances such as making bank transactions or paying bills (68 per cent).

Main Themes

Three primary themes were identified in the analysis of the focus group discussions and interviews: (1) family caregivers making a tough decision to apply for long-term care; (2) choosing the right home can be challenging; and (3) family caregivers' increasing stress and burden while waiting for long-term care. First, we explore how family caregivers described their family's decisions to apply for long-term care. For most family caregivers, seeking long-term care was their last resort strategy. While making the decision to apply for long-term care was difficult for all, we highlight that some experienced more challenges when there was no available long-term care option accommodating their loved one's culture. Second, we focus on family caregivers' long-term care application experiences, highlighting the key elements of care considered when choosing which homes to apply and wait for. Participants described the application process as a highly personalized one which required careful consideration of individual needs and a thorough analysis of which elements of care mattered more for their loved ones. Many family caregivers emphasized the importance of meeting the linguistic and cultural needs of their loved ones. Third, we explore the cost of waiting for long-term care from family caregivers' perspectives. We focus on the shared experiences of worsening health and well-being as family caregivers continued to bear the heavy burden of caring while their loved ones were waiting for long-term care. We also highlight how informal and formal support could help relieve some of the caregiver burden when it was available. Many caregivers, however, felt left with little or no support and expressed their desire to access more support while waiting for care.

1. Family caregivers making a tough decision to apply for long-term care - "We just can't do it anymore."

Making the decision to pursue long-term care was described as a difficult experience for family caregivers across all ethnocultural groups. Family caregivers strived to look after their loved ones at home or in the community for as long as possible until they reached a stage when their family member's needs exceeded their capacity to provide adequate care. As one daughter of an older immigrant from the UK stated, "we just did it - we wanted to keep him in his own home for as long as possible, which, I think...he was 94 [when we decided to pursue long-term care]." Another caregiver said,

"In fact we have been, like this gentleman here, procrastinating, . . . didn't want our parents to move in [to a long-term care home]. All our siblings agree to send them [our parents] to a home. We have been procrastinating until they are now 92 years old. We know that we cannot handle it." (family caregiver for older immigrants from China)

The decision to pursue long term care for loved ones is an emotional one. In part this reflects anxieties about whether family caregivers have done enough to care for them, as well as concerns about the level of care and support their loved one would receive in long-term care. The negative perceptions of the care provided at long-term care homes were shared by many caregivers. While describing her frustrating experience of deciding to pursue long-term care for her mother, one caregiver reported that media coverage and her own experience of caregiving for her mother in a hospital

had shaped her assumption about the care her mother would receive in long-term care:

“We tried to do it for as long as we could. The horror stories that we’ve heard about the nursing homes and because, of course, the nursing homes wouldn’t be accommodating what we would want. Because my mother spent quite some time in the hospital and we had to make sure we were there every day, that they took care of her the way that we wanted them to take care of her. So knowing this of the nursing home, we tried to do that for as long as we can, but now we just can’t anymore.”
(family caregiver for an older immigrant from Jamaica)

As her mother’s health deteriorated to a stage that her family could not handle, however, her family started questioning whether a long-term care home could be a better option for their loved one.

The majority of family caregivers agreed that home, whether their loved ones lived by themselves or with others, was no longer a safe place for their aging family members. In fact, several caregivers reported incidents of their parents gone missing, as described by one adult son who was looking after two parents, both waiting for long-term care placement:

“We are afraid that they may leave home and go outside, because Dad has left home and wandered outside before, and Mom has also left home and wandered outside before. Mom fell and got hurt. Dad was brought back by somebody. He was not properly clothed... in the winter. We were very worried.”
(family caregiver for older immigrants from China)

For other caregivers, concerns around fire safety were more prominent, especially around the increasing risk of accidental fires in and around the kitchen. One daughter of an older woman with dementia, for example, expressed her frustration over keeping her mother safe at home after an accidental fire caused by her mother while she was using the kitchen a few months ago: “So it’s like I have kids in the house. It’s a big stress on our family, and I just... I can’t anymore. I feel so awful” (family caregiver for an older immigrant from Italy).

While long-term care had not been considered as an ideal alternative at the beginning of their caregiving journey, for many family caregivers, it became a better, safer option to meet the increasing needs of their aging relatives. One adult daughter of an older immigrant waiting for long-term care from home said,

“It’s just that she [my mother] suffers from epilepsy, so she needs help every single moment. Someone has to be with her. So we have a button. . .so she can press it if she falls or something. But she’s very prone to falling as well, right? And she has weak bones. So just getting her all the care she really needs was getting harder and harder. So that’s why we thought that would be a good solution for her, because she’s always watched by someone there at the facility.” (family caregiver for an older immigrant from India)

A few family caregivers described their resistance to the idea of institutionalization of their family members, especially aging parents, due to the cultural notion of filial piety. As one daughter of an older immigrant from India noted, “personally, especially our Indian background, we really don’t want to send our parents to the nursing home.” While some caregivers mentioned the pressure from other siblings to keep their aging parents at home despite escalating health needs requiring more intensive care, most caregivers mentioned that their decision on applying for long-term care was made based on family consensus. Another daughter of an older immigrant from India described,

“So my brother, although I mean he’s not as involved in the care for my dad, but at the same time, he’s very supportive so whatever decision I make, he doesn’t interfere, he actually supports me a lot. He’s the one telling me you know “are you considering sending him to the nursing home now since his needs are getting more and more?” (family caregiver for an older immigrant from India)

However, when this caregiver started seeking long-term care for her father, she realized that not having a culturally appropriate long-term care option in her South Asian community made it even more challenging to make the decision to pursue long-term care. She eventually added her father to the waitlists of three long-term care homes, close to home, in Mississauga about a year ago. She shared her excitement about a new initiative of building a South Asian long-term care home in Mississauga. Without a current viable option for long-term care dedicated to providing culturally appropriate care for South Asians in her local community, however, pursuing long-term care for her father was a profound experience for her as his primary caregiver, accompanied with intense emotions and strong feelings of guilt. She noted,

“I just feel you know, as I said if Indus [a new initiative to build an ethno-specific long-term care home for South Asians] is there tomorrow, I would have sent him. It’s like Catch 22 for me. I wanted to send him because there’s a need for me to send him but at the same time you feel so guilty because somehow, it’s not balanced. If somehow, the need is tomorrow that I cannot take care of him, I don’t know what the situation is going to be with the catheter, maybe that need is going to go up and my emotion is going to go down right? Then I’ll be needing the help like okay I can’t handle it.”(family caregiver for an older immigrant from India)

Many family caregivers across the ethnocultural groups described long-term care as a last resort. Deciding on whether to apply for long-term care required careful consideration and was often accompanied with anxieties and feelings of guilt as they were balancing the social and cultural expectations on family caregiving against the stresses of managing care at home, often all by themselves. When family caregivers finally decided to seek long-term care, they faced new challenges of waiting and of finding the right homes that meet the needs of their family member. For some family caregivers, lack of options for cultural accommodation in existing long-term care homes exacerbated the challenges as they continued to carry the burden of caring as their and their family member’s health deteriorates.

2. Choosing the right home can be challenging: “There are many aspects to consider.”

When applying for long-term care, the system allows each applicant to choose up to five homes. Few family caregivers, however, reported that they chose five at the time of application. During the focus group discussions, when asked to list up to five of their chosen homes, a family caregiver of an older immigrant from China laughed at the question and said, “I am laughing because we only had three [homes]. There’s not a whole lot to choose from. There are only a few. That’s why I laughed.” Her parents-in-law were waiting for three ethno-specific homes for the Chinese-Canadian community in Scarborough, near their home. Among hundreds of long-term care homes to choose from across the GTA, family caregivers were finding it challenging to identify and choose the homes that can meet various aspects of the needs and preferences of their aging family members as well as of themselves as a family caregiver.

When choosing which homes to apply for, family caregivers were encouraged to visit different homes to compare and gather information from online and offline resources. Many caregivers reported largely relying on the information gathered from their informal networks such as friends and other family members who had relatives already living in long-term care homes. Yet, many family caregivers felt that they did not receive sufficient information to make the right decision.

Particularly, in seeking ethnocultural accommodation, several participants expressed their desire to make more informed decisions supported by health agencies (the Local Health Integration Networks or LHINs) or other organizations. For example, Chinese-Canadian family caregivers in our study raised their concern around the lack of information sharing about long-term care homes providing cultural accommodation. While all participants in the Chinese-Canadian focus group were waiting for ethno-specific homes, some also reported waiting for a few mainstream homes that have an ethnic cluster (e.g., many Chinese-Canadian residents reside on the same floor) and provide meal services and other support tailored to Chinese culture. These participants mentioned that they found these homes through word-of-mouth or by luck. They expressed their desire to know more about such options, as described by one Chinese-Canadian family caregiver:

“We may have the wrong impression that only these [ethno-specific] homes are Chinese-speaking. In fact, there are quite a number of them. The problem is, it seems that either the government or LHIN has not made that very clear in their descriptions. They didn’t explain very clearly which ones. . . support [Chinese culture], have Chinese staff members, or provide Chinese meals. If they can improve the presentation of the information, families will have more choices.” (family caregiver for an older immigrant from China)

While participants across the ethnocultural groups shared their challenges in finding the right home, some group differences were found when describing key elements to consider when choosing homes to apply for. For example, family caregivers of older immigrants from the U.K. identified location of the facility (i.e., close by to family) and quality of care as stronger consideration factors when choosing homes. While location and care quality were recognized as important factors, most caregivers from the other four ethnocultural groups reported additional considerations related to culture and/or language, and having specific ethnocultural needs made it even more challenging to find the ideal home for their family members. For many, mainstream homes were viewed as “programmed to European, North American, or whatever the case is,” as described by one caregiver of a Jamaican-origin immigrant.

Most family caregivers thought that the long-term care homes that provide culturally appropriate care for their own ethnocultural community would be the place where their aging family members “feel most comfortable. . . and supported in a way that they feel at home”, as described by a family caregiver for an older immigrant from Italy. And, cultural and linguistic accommodation was particularly important at this stage of their loved one’s life. One family caregiver whose mother had been waiting for two Italian-Canadian homes for the last two years noted, “we only put her in [the two homes] because of the heritage. There’s no point for my mother anywhere else.”

In fact, all participants from the Chinese-Canadian and Italian-Canadian communities – the two communities that have established long-term care homes dedicated to their own ethnic communities in the GTA - reported that their family members were waiting for ethno-specific homes. And, those waiting for the homes serving Chinese-Canadians reported a particularly longer wait – mostly two to seven years – than any other groups. When describing why they chose to apply for ethno-specific homes, despite their extremely long wait times, family caregivers emphasized the importance of being in an environment where their older family members can access their familiar food everyday, enjoy culturally-tailored programs, and communicate with other residents and staff in their mother tongue.

One family caregiver of an Indian-origin immigrant shared her view on mainstream services and wanted to see more cultural diversity in food and programming in mainstream homes, such as including Indian meal options in the weekly menu:

“So I find that if even though, it’s not totally catered to the Indian community, if it even, with the multicultural nursing home, it can have some kind of consideration, for you know “okay, one day a week we can have Indian food or something else or some kind of program that you know promotes my needs are met, not only Canadian culture only. You know we’re just going to give you fish and chips or meat and potato kind of thing. What about other communities?” (family caregiver for an older immigrant from India)

Without an option to apply for an ethno-specific home dedicated to South Asians within her local community, this caregiver expressed her concerns about meeting her father’s cultural needs in terms of having access to Indian food in long-term care. She described how important it is for her father to have Indian food, especially daal (Indian spiced lentils), every day. While waiting for long-term care, during the day, her father attended an adult day program for South Asians where he got served Indian meals which he really enjoyed. Upon his admission to one of the mainstream homes in the future, this family caregiver expected that she would have to “come up with creative ways” (e.g., making daal every week or so and bring it to him) “to make sure he’s not deprived of what he liked to do, or what he likes to eat.”

Many other family caregivers echoed the importance of having access to cultural meals in long-term care for the health and well-being of their loved ones. A South Asian caregiver whose mother got a placement in a mainstream long-term care home continued to take one homecooked meal every day for his mother to ensure her taste buds were satisfied.

Additionally, the need for older immigrants to be supported in their mother tongue in long-term care was highlighted by many family caregivers, especially by those looking after older immigrants who have low English proficiency. Communication barriers were perceived as an important health issue for people living in long-term care, as described by a family caregiver of her parents-in-law waiting only for ethno-specific homes:

“At least [in a Chinese-speaking home] they can tell somebody when they feel unwell. But if they move to an... English environment they may not be able to communicate. In fact both of them are suffering from very serious dementia. . . If the staff don’t understand them, and they don’t understand the staff, this is actually a big problem.” (family caregiver for older immigrants from China)

Linguistic accommodation was also viewed as important for some family caregivers even when their family member was fluent in English. Many family caregivers of Italian and South Asian-origin older immigrants reported that even though their parents speak and understand English well, they would feel most comfortable and included in the community when they could speak their mother tongue with other residents from the same ethnocultural background. This was echoed by another family caregiver for an older immigrant from India:

“I find my dad will feel at home he’s in between same community people. He loves to talk to people and maybe that way he’s not left alone with all his thoughts. He can still communicate in English also, he’s an educated man but at the same time I feel like he feels more at home with people of the same background.” (family caregiver for an older immigrant from South Asia)

While many participants described linguistic and cultural accommodation as one of the most important elements to care, a few family caregivers looking after aging parents with advanced dementia shared different views. For example, one family caregiver of her mother from China mentioned that while she had considered linguistic accommodation important at first, it was less important now because her “mother’s dementia has got to a stage where her ability to communicate is very low.” While waiting for long-term care, her mother was receiving home care support. She felt that her mother was very well cared for by one particular personal support worker: “one of the PSWs who come now. . . doesn’t know any Chinese, but she manages my mother very well. That’s why it very much depends on that particular worker.”

Across the five ethnocultural groups, participants shared their views on preferred homes: they would want their loved ones to live in facilities that are located near their and/or their loved one’s community and provide quality care in a welcoming and inclusive environment. However, such homes typically have long waitlists. Given that the wait times for a long-term care placement vary widely across different facilities in the GTA, choosing which home(s) to apply for can be a tricky and highly personalized process. In this process, participants described that their decisions were made based on their analysis of which home would best serve their loved ones considering not only their health needs but also their social, emotional, and cultural needs. This process also pushed families to consider, among so many elements to care, which elements matter more for their loved one. Meeting individual needs, such as linguistic and cultural needs as highlighted by many, was considered so important that people opted to wait much longer for certain homes of their choice while bearing the cost of waiting for the right home.

3. Family caregivers’ increasing stress and burden while waiting for a long-term care home: “It takes a big toll on me and my family.”

Once an application for a long-term care home is submitted, caregivers are generally advised that the wait times are unpredictable. Our participants reported wait times anywhere between two months to nine years. Consistently across all groups, participants felt frustrated and anxious about the uncertainty of how much longer they will have to wait for a placement. While waiting, most family caregivers received no regular update about their expected wait time.

Caregivers' frustration about wait times is compounded by concerns about whether they would be able to continue providing support until their loved one gets a placement. While waiting, caregivers find themselves in difficult predicaments, where they are struggling to meet the care needs of their older family members experiencing rapidly declining health and growing complex needs, as shared by a daughter of an older immigrant from China:

"We are currently waiting for these three top choices. We can't wait any longer. We have asked the case staff to expedite our case, to treat it as a... "crisis (case)", to admit my mother. Because we know that we cannot handle it. We have five siblings here, taking turns to help out, yet we feel that we cannot handle it. This has created a dangerous environment." (family caregiver for an older immigrant from China)

Long wait times have clear consequences for their loved ones who are oftentimes waiting without adequate support at home or in the community while their physical and mental health deteriorate. In providing care for their older family member, caregivers also reported an increasing impact over time on their physical and mental health, social life, and work. While acknowledging the need to continue to support their family members waiting for care, participants expressed a lot of concerns and feelings of guilt. In one case, a caregiver's family doctor even advised her to stop caregiving as it continued to pose a risk to her health. This caregiver said,

"And we've been on a list for six months. I'm very discouraged right now, hearing everyone's stories. But I can't do it anymore. Physically, I was told by the doctor I can't take care of her. So I don't know what's gonna happen – it's either me or her goes first." (family caregiver for an older immigrant from Italy)

Overwhelmingly caregivers felt a lot of guilt and reported worsening mental health due to limited or no support, increased caregiving load, lack of time for self-care, and burnout. Often, caregivers cited the cultural preference for kin-keeping and filial piety as strong determinants to continue providing care to their older family member, even as it continues to negatively impact their own well-being. For example, one participant said,

"I know I have put all these measures and checks in place but it's really stressful. . . I just feel that there isn't much support for me. And you feel guilty, if you don't do things for your dad, you feel that you know he's my dad. What will my mom think if she was still alive and I'm not taking care of him but at the same time it's really stressful. . . And although I feel that I love my dad, I feel that I get stressed with routine work, like I got to, I have no relaxing time. . . By the time, he's done, it's 8:30 and I'm exhausted. And it's okay for 1 day, 2 day, 3 day but it's ongoing for almost 2 years." (family caregiver for an older immigrant from South Asia)

Further, caregiving stress extends to the rest of the family as well. While the primary caregiver continues to bear the brunt of the caregiving load, their immediate family also experiences secondary impacts of the absent, tired, and overwhelmed primary caregiver. Some family caregivers discussed the challenges of fulfilling their family responsibilities without neglecting the care for their older family member.

"So it takes a big toll on both myself and him, and my family suffers because I live an hour away. So I hardly could go home. . . And I still have not come to terms yet to say, "Oh my gosh, I can stay home." This is for the first time in over a year I'm able to go home for more than three days and stay. So it's a big, big thing." (Family caregiver for an older immigrant from the Caribbean, who was temporarily placed in a nursing home in Jamaica)

Caregivers also felt immediate impacts on their employment, where some had to reduce the number of hours worked, miss work or leave the workforce temporarily or completely in order to support their older family member. Several caregivers expressed the lack of financial sustainability to provide informal, unpaid support to their loved ones. Participants also identified amplified costs to caregivers, which are associated with the time lost from not working coupled with the out-of-pocket expenses due to accessing caregiving supports.

The degree of stress amplifies when caregiving duties are not shared with other family members. Participants

discussed seeking support from their siblings, partner, children, or other family members as a strategy to manage their stress levels. However, some family caregivers had no other family member who was willing to share the caring responsibilities and they were left alone with little or no external support. They often felt overwhelmed and exhausted from being a sole caregiver for their aging relatives.

In contrast, the experiences of family caregivers with shared responsibilities seemed to have different impacts on their well-being and the quality of care the older adult received. In shared caregiving arrangements, caregivers reported being able to provide more comprehensive and frequent care. A more equitable division of labour allows for a better manageable caring load and ensures caregivers have each other to rely on for support, as one caregiver for her mother describes:

“And then we have five siblings here, taking turns, taking up one or two days each. Lunch is from 11 am to about 1 pm. And then we have hired a lady to prepare dinner from 3 to 5 pm. We have set up three check-points, actually. The one at 8 am was the one who discovered that my mother has fallen, gone missing. We have division of labour.” (family caregiver for an older immigrant from China)

When asked about their experiences of receiving formal support, many participants reported accessing home care services, adult day programs, or respite care. Several family caregivers expressed their appreciation about receiving support from their local ethnocultural community organizations, such as South Asian, Italian, and Chinese adult day programs.

Participants also discussed the importance of respite care as it relieves caregiver stress and burden. Having access to respite care allows caregivers to participate in social events and other household chores such as meal preparation, laundry, grocery shopping that normally would conflict with their caregiving duties. For example, one participant said having access to respite care allowed her to participate in this study’s focus group.

While appreciating the benefits of receiving support, participants identified the challenges associated with accessing home and community care, including the lengthy application process and the long wait times. Many participants also complained about lack of initiatives that proactively share information about available services and programs for family caregivers and their family members waiting for long-term care. Several family caregivers reported that they had not been given adequate information about existing services available for them at the time of applying, as well as while waiting for long-term care. For example, one family caregiver mentioned that she had not known about existing respite care options until her mother was admitted to a hospital where a LHIN coordinator finally connected her with respite care. Another participant also shared her experience of learning about much needed respite care only after reaching a crisis point:

“Nobody has come out and said, “Oh by the way, while you’re on the waiting list, this is available to you. No, you have to get to a crisis point. You have to start crying in the lobby – sorry, this was me in January. And then they’ll say, “Oh, put them in respite!” And then if they’re part of the day program, we pick them up, and we drop them off. But no one will tell you this.” (family caregiver for an older immigrant from Italy)

While it could relieve caregiver burden, accessing respite care was also perceived by family caregivers as an opportunity for their family members to build some familiarity with living in an institutional setting before finally moving into long-term care. Some participants expressed their desire to access respite care at the long-term care homes their loved ones were currently waiting for as this would help them make easier transitions into the long-term care home when they get a placement in the future.

Providing care for aging parents and other relatives takes a big toll on family caregivers. As the wait became unbearably long and unpredictable, many participants experienced worsening health and well-being across various aspects, including physical and mental health, as well as financial, social, and emotional well-being. For those looking after older adults waiting for long-term care, various formal support (e.g., respite care, home care services, and community care programs) and informal support from other family members could be a great help. Yet, across the ethnocultural groups, many family caregivers reported not receiving adequate support and as a result they felt increasing stress and burden.

Discussion

In our focus group discussions and interviews, we heard from 29 family caregivers of older immigrants waiting for long-term care admission about their experiences of waiting for long-term care in the GTA. Overall, the findings in this report presented the shared challenges of seeking, applying, and waiting for long-term care as family caregivers continued to bear the burden of informal caregiving, often without adequate support. The data in our study also highlighted some of the privilege and marginalization experienced by various ethnocultural communities in accessing long-term care homes across the GTA.

Consistent with existing literature (Caron et al. 2006; Penrod et al. 1998; Sussman & Dupuis 2012; Kong et al. 2010; Nolan & Dellasega 2000), our findings indicate that many family caregivers consider long-term care homes as a last resort, and often avoid addressing institutionalization for as long as possible. Participants across the ethnocultural groups cited their preference of taking care of older relatives at home if they were able to provide adequate care. Previous research suggests that this reluctance may rest on sentiments of loyalty and compassion towards their loved one, or even on the anticipation of feelings of guilt and shame with regards to the institutionalization of their kin (Nussbaum 1996). Family caregivers in our study also talked about their negative perceptions of long-term care which were largely informed by media, word-of-mouth, and personal experiences. Yet, as they reached the crisis point, families made highly emotional decisions to seek long-term care, often accompanied with feelings of guilt. Indeed, previous research on family caregivers described the process of deciding to seek long-term care for their loved ones as the most difficult care decision in their caregiving journey (Caron et al. 2006).

While all participants described their decision-making process as highly stressful, the stories we heard from family caregivers of older immigrants from South Asia and the Caribbean highlighted how lack of cultural accommodation in the current long-term care system acted as access barriers to long-term care and could exacerbate the caregiver stress in their journey of seeking care. With limited option for culturally appropriate long-term care, some families delayed their decisions on applying for long-term care even after they had realized urgent needs for institutionalization. While being on waitlists for mainstream homes, these families were continuously concerned about their loved ones' well-being in their future long-term care placement.

In fact, immigrants are underrepresented in the Canadian long-term care resident populations. A recent study found that immigrants who had arrived in Canada after 1985 comprised just 4.4 per cent of long-term care residents in Ontario, compared to 13.9 per cent in the general population (Jeong et al. 2020). Evidence from international literature indicates that people from ethnic minorities are more likely to delay institutionalization and are less likely to use long-term care than their counterparts (Stevens et al. 2004). Cooper et al. (2010)'s summary meta-analysis of ten studies, which tested whether ethnicity predicted entering a long-term care facility, found that people with dementia from minority ethnic groups were 40 per cent less likely to move to a long-term care facility than their white counterparts. While it may relate to cultural preferences, the authors also suggest potential barriers in accessing long-term care, such as a language barrier and a lack of cultural sensitivity, that may lead to lower use of long-term care by certain ethnic groups.

While waiting for the homes of their choice, family caregivers and their families live with the consequences of delayed admission. Our participants discussed that caregiving left them feeling frustrated, overwhelmed, and anxious at times, while putting strains on their physical and mental health, financial stability, employment, and other social relationships. The stories shared by our research participants are consistent with previous research findings. A report by the Change Foundation (2019) reported that while caregivers experience a strong sense of commitment to the person they care for, they also experience a decline in their well-being in terms of poor sleep, depression, and increased sense of loneliness. Previous studies also demonstrated greater risks of caregiver burden for immigrant family caregivers. A recent Ontario study (Qureshi et al. 2020) found that caregivers of recent immigrants who were admitted to long-term care were more likely to report symptoms of caregiver burnout and the inability to continue providing caregiving. Another Ontario study found that family caregivers looking after home care clients with need for an interpreter showed higher caregiver distress compared to those looking after home care clients with no need for an interpreter (Chang et al. 2015). In our previous qualitative study on immigrant family caregivers (Laher et al. 2019), we found that, due to the limited availability of linguistically and culturally appropriate home and community care, many family caregivers of older

immigrant women with limited English proficiency felt stretched to their limit while providing extensive support to meet their loved one's needs, especially linguistic and cultural needs, as a main caregiver, system navigator, and interpreter.

Our findings demonstrate a need for the health care system to offer better ways to support family caregivers when seeking, applying, and waiting for long-term care. For many family caregivers in our study, it was evident that the lack of support for system navigation added frustration and stress to their caregiving journey. Many family caregivers were not well informed about the long-term care wait times before their applications. They reported feeling unsupported when making highly emotional decisions on institutionalizing their loved ones. While waiting for a long-term care placement, the uncertainty about wait times often made family caregivers feel frustrated and anxious about their future. Previous research by Caldwell et al. (2014) noted that health care professionals' interventions to address family caregivers' concerns about long-term care placement could ease some of the fears affecting the decision and improve caregivers' experiences. This could be facilitated through highlighting positive aspects of living in a long-term care home, such as the professional care provided and the increased opportunities for social interactions. Also, providing better information about wait times and available options for long-term care and home and community care could help family caregivers make informed decisions and reduce some of the pressure from their caregiving role. In addition, the findings in this study support the recommendations of our previous work on home and community care (Um et al. 2019): there is a need to improve access to home and community care for those waiting for long-term care, and this care needs to provide effective care services and programs to address linguistic and cultural needs of older adults from diverse ethnocultural backgrounds.

In our study, we found that many family caregivers chose to wait longer to place their loved ones in a home of their choice. Understanding the factors that influence individual choice is important to ensure that the long-term care system provides adequate supply responsive to people's needs and preferences (OACCAC 2015). Our data shed a light onto some of the most important factors contributing to immigrant families' choice of long-term care homes. While individual preferences and needs vary widely, our findings highlighted caregivers' shared quest to find the long-term care homes with the elements that would make their family members "feel at home."

Among many elements of care needed for that home-like environment, many family caregivers in our study highlighted the importance of meeting linguistic and cultural needs in long-term care. In fact, all participants from the Italian-Canadian and Chinese-Canadian communities reported that their loved ones were waiting for ethno-specific long-term care homes. Those from the South Asian-Canadian and Caribbean-Canadian communities were looking forward to having the option to apply for ethno-specific homes. Despite the long waitlists, those waiting for ethno-specific homes chose to wait for these homes as they believed that their loved ones would feel at home in these homes where they would speak their mother tongue with other residents and staff, enjoy familiar meals, and engage in social programs designed to reflect their culture. In their study on an Iranian ethno-specific care home in Sweden, Antelius and Kiwi (2015) observed that placing loved ones in this setting also seemed to partially help in easing the feelings of guilt of family caregivers of not fulfilling cultural standards about filial piety.

Evidence from a growing body of international literature confirms the importance of meeting cultural and linguistic needs for the health and well-being of older adults living in long-term care. A scoping review of international literature by Martin et al. (2019) found that the presence of cultural and linguistic congruity in care homes was beneficial for residents with dementia as it boosted their sense of well-being, identity and belonging. On the other hand, the absence of linguistic congruity was found as a strong predictor for decreased well-being due to communication barriers causing misunderstanding, subsequent inappropriate care, and social isolation. A U.K. mixed-method study (Cooper et al. 2018) found that long-term care residents with dementia speaking English as a second language were more likely than those speaking English as a first language to experience agitation and overall neuropsychiatric symptoms. In this study, qualitative interviews with care staff found that residing in a care home where no peer residents or staff shared resident's culture or language could cause or worsen agitation for people with dementia. Another study from Australia (Runci et al. 2012) compared verbal communication and psychiatric medication use among Greek and Italian residents with dementia in ethno-specific versus mainstream care facilities. Researchers found that residents in ethno-specific care homes had a higher rate of resident-to-resident communication and a lower rate of prescribed antipsychotics than those in mainstream homes.

While language congruity in long-term care has been identified as strongly advantageous, research also suggests that a shared language is not the only source of, nor a guarantee for, creating common ground and understanding between residents and staff in long-term care (Strandroos & Antelius 2017). An Australian study by Xiao et al. (2017) highlights the importance of socially constructed cross-cultural communication in identifying and meeting residents' care needs. When staff demonstrate cultural humility, residents from culturally and linguistically diverse backgrounds are empowered to engage in effective communication. Recently, the Ontario Centres for Learning, Research and Innovation in Long-Term Care (CLRI) (2020) published a toolkit to support equitable and respectful care within Ontario's long-term care sector, *Embracing Diversity: A Toolkit for Supporting Inclusion in Long-Term Care Homes*. This toolkit presents various promising strategies to address language barriers, such as inclusive, accessible communication materials, communication cards, language student placement, and translation services, that can support linguistic needs of residents and families whose mother tongue is different from the dominant language of the care home.

While the preference may be for ethno-specific homes, findings in our study indicate that many family caregivers of older immigrants were willing to apply for mainstream homes if they offered better services to meet their loved one's linguistic and cultural needs. Some caregivers also emphasized the effectiveness of the care provided by respectful and reliable staff for their loved one even though they did not share the same culture or language. In order to meet the diverse needs of older immigrants and their family caregivers, further work needs to focus on the development and implementation of various strategies to provide a range of options across mainstream and ethno-specific homes.

Limitations

This qualitative study offers valuable insights into the lived experiences of 29 family caregivers of older immigrants waiting for a long-term care placement from five selected ethnocultural communities in the GTA. We understand the findings in this report may not represent the experiences and views of all family caregivers of older immigrants waiting for long-term care. First, as our participants were recruited largely through community-based organizations, we recognize that harder to reach family caregivers, such as those who are socially isolated and caregivers with intensive caregiving responsibilities, may have not been included in our research. Second, by limiting our study to selected ethnocultural and linguistic communities we recognize that we might have missed opportunities to speak to caregivers from other communities who may have different life experiences and views. Third, we also recognize that the location of our focus groups and interviews and targeted outreach of ethnocultural communities largely through established community organizations limited the geographical diversity among research participants in each ethnocultural group. Despite these limitations, the team believes that the consistencies in the caregiving experiences and the needs for better cultural and linguistic accommodation in long-term care we heard across focus group discussions and interviews are likely to span the larger GTA community.

Conclusion

Long wait times for a long-term care placement have been identified as one of the key challenges facing Ontario's health care system (Premier's Council 2019). Health Quality Ontario (2020) clearly states that "delayed admission can result in health complications for people waiting, as well as create stress for them, family members and other caregivers." While waiting for long-term care can affect all older adults and their family caregivers on the waitlists, our research highlights additional challenges faced by those seeking linguistic and cultural accommodation in long-term care.

With the increasing diversity in our aging population, it is imperative for the long-term care system to provide services and programs that reflect linguistic and ethnocultural diversity of the people it serves. Importantly, for those waiting for a long-term care placement, there should also be more home and community support provided to meet the diverse needs of older adults and their family caregivers. Enhanced home and community care supports could greatly help many older adults age in place.

Amid the COVID-19 pandemic, the Ontario government (2020) is committed to improving access to long-term care with a vision to build an integrated long-term care system that provides residents with "safe, high-quality, resident-centred care and a dignified place to call home." Clearly, with the experience of COVID-19, safety should be the priority in the government's agenda to rebuild the long-term care system. Yet, to improve health for all older Ontarians and their family caregivers, it is apparent that fulfilling the vision for a renewed long-term care system will require significant improvements in how the system delivers services and programs to meet the diverse needs of our aging population.

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