The Changing Face of Home and Community Care:

Findings from Focus Groups with Family Caregivers of Older Women from Diverse Ethnocultural Communities in the GTA

Nazeefah Laher, Seong-gee Um, & Brenda Roche

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Wellesley Institute works in research and policy to improve health and health equity in the GTA through action on the social determinants of health.

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Statement on Acknowledgement of Traditional Land
We would like to acknowledge this sacred land on which the Wellesley Institute operates. It has been a site of human activity for 15,000 years. This land is the territory of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. The territory was the subject of the Dish With One Spoon Wampum Belt Covenant, an agreement between the Iroquois Confederacy and Confederacy of the Ojibwe and allied nations to peaceably share and care for the resources around the Great Lakes.

Today, the meeting place of Toronto is still the home to many Indigenous people from across Turtle Island and we are grateful to have the opportunity to work in the community, on this territory.

Revised by the Elders Circle (Council of Aboriginal Initiatives) on November 6, 2014

10 Alcorn Ave, Suite 300
Toronto, ON, Canada M4V 3B2
416.972.1010
contact@wellesleyinstitute.com

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Introduction

Families are the primary source of care for older adults across all cultures.[1] Family caregivers play a critical role in supporting aging in place as they provide a wide range of care and support while navigating the complex health and social care system for their aging family members. In Ontario, an estimated 3.3 million people, 29 percent of the provincial population, are providing care and support to their family members or friends. Many families reported looking after those experiencing aging-related health problems.[2] While taking care of their loved ones, family caregivers report challenges in accessing the current support system – often inconsistent and hard to navigate – for themselves as well as their family members. They also express difficulties in fulfilling family and work responsibilities and face increasing financial hardship, stress, and emotional challenges.[2,3]

While the caregiving expectations and challenges are widely shared among families across diverse ethno-cultural communities, evidence suggests that some ethno-cultural groups of older adults and their family caregivers may experience additional challenges while accessing and receiving/providing care.[2,4]

Wellesley Institute's previous quantitative research on home care access[5] found existing disparities in the use of home care among older adults from ethnically and linguistically diverse immigrant communities in the GTA. While receiving less publicly-funded home care, immigrant older adults were more likely than non-immigrant older adults to report receiving support from informal caregivers – mostly family members. Older adults whose mother tongue[6] was not English were nearly twice as likely as those whose mother tongue was English to receive home care from informal caregivers. The higher rates of informal care received by older adults with immigrant and non-English mother tongue backgrounds may result in higher rates of caregiver stress for their families.

Building on this previous work, we conducted a follow-up qualitative study. In this study, we sought to understand why these disparities in accessing publicly-funded home and community care exist and how older women and their family caregivers perceive their needs and unmet needs for support in the current home and community care system, similarly and differently across the diverse ethno-cultural communities. With research findings from focus groups with older women[7] and family caregivers, our aim is to develop community-informed policy recommendations to improve access to home and community care for older adults and their family caregivers from diverse ethno-cultural communities in the GTA.

In this study, we examine:

1. the nature of older women's needs to age in place from the perspective of family caregivers;
2. the experiences of family caregivers seeking home and community care and support for their aging family members; and
3. the needs and unmet needs for family caregiver support

This research paper presents the findings from our focus groups with family caregivers who provide support to their aging family members – mothers, grandmothers, spouses, sisters, and aunts – from diverse ethno-cultural communities across the GTA. Our results point to some common experiences shared among our research participants while highlighting the experiences that were found to be unique to certain groups. Based on our presented data, we discuss the ways to move forward to address the challenges we heard from our focus groups to improve access to home and community care for diverse ethnocultural communities.

Methods

This qualitative study used focus group discussions to capture the breadth of participant's experiences of providing and accessing support for their aging family members as well as their shared views on the needs and unmet needs for older women and family caregivers. In March and April 2017, five focus groups were conducted with family caregivers of women 65 years and older from five different countries/regions of origin: UK, Italy, China, India, and the Caribbean. The previous quantitative study identified the selected ethno-cultural groups as the largest older immigrant groups in the GTA by country of origin.[8] To facilitate focus groups in community languages, we identified one main language for each group through community consultations, with two bilingual focus groups (English for UK and Caribbean, Punjabi and English for Indian, Italian and English for Italian, and Cantonese for Chinese focus group).

Participants were recruited through community-based organizations that serve diverse populations, home and community care service providers, newsletters, flyers, and word of mouth. Recruitment strategies were designed to cater to each ethnic community. Family caregivers interested in participating in the study were screened through a brief phone conversation to ensure that participants met our selected criteria: caring for a family member who is a woman of age 65 years and older, resident of the GTA, with support needs for home and community care, and first or second-generation from one of the five selected ethno-cultural communities. To participate, family caregivers were also required to speak either the selected language of the ethno-cultural group or English.

Each focus group was about 90 minutes in length. Before the discussions, each participant was asked to fill out a short survey including questions on some of their and their family member's socio-demographic information (i.e., age and the city of residence) and the support

needed by and provided to their family members. Moderators then asked participants about current care arrangements for their family members, details of the type of support or care their family members needed to age in place and the support or care they received, their familiarity with and experience of accessing Community Care Access Centres (CCACs) and the conditions of home and community care support their family member received as well as any caregiver support they received, and their preferred care arrangements. Focus groups were held in libraries, older adults' centres, cultural centres, offices, and community buildings across the GTA, including North York, Brampton, Scarborough, and Central Toronto. All focus group discussions were recorded and later transcribed and translated into English (when needed). All participants received a $30 honorarium and were compensated for transportation expenses. For those who needed caregiver services for their family members while participating in the focus group, caregiving expenses were compensated. Ethics Approval was obtained from Ryerson University prior to start of the study (REB 2016-403).

A thematic analysis was undertaken to analyze transcriptions of focus group data.[9] Transcripts were reviewed by project team members (NL, SU, BR) individually and then observations were discussed to determine an open coding framework to be applied to the transcribed data. Data was coded separately by two research team members and then compared and consolidated to identify a set of coherent and consistent themes throughout the data. Once all transcripts were coded, team members reviewed and established a list of refined and focused thematic codes that were then applied across the transcripts. Working from coded transcripts, the central themes and patterns were identified in the analysis, paying attention to how concepts were framed and described by the participants across the focus group data.

Findings

In total, 40 family caregivers participated in five focus groups: 35 female and 5 male participants. Participants came from different parts of the GTA: Scarborough, Oakville, Brampton, Etobicoke, Central Toronto, Markham, Aurora, Vaughan, and Ajax. Most participants (34 participants) reported living in the same municipality with their family members they were caring for.

The family caregivers in our focus groups reported providing care for their family members who were older women between 65 and 97 years of age with a mean age of 84 years. Nearly three in five family caregiver participants looking after older women reported providing support to their mothers, while others care for their mothers-in-law, spouses, grandmothers, and aunts. All participants reported their family members having difficulties with activities of daily living due to mobility issues, chronic health conditions, and/or cognitive impairment. Some participants also mentioned their family members' needs for support due to their limited English proficiency. According to the short survey conducted before focus group

discussions, participants assisted their aging family members with a wide range of activities, including preparing meals (78 percent), getting to appointments or running errands (85 percent), doing everyday housework (68 percent), helping with personal care such as washing, dressing, eating, or taking medication (68 percent), moving about inside the home (43 percent), and looking after personal finances (75 percent). Other support reported include assistance with mobility, transportation, language interpretation, emotional support, entertainment, long-term planning, and end of life decisions.

Two central themes emerged in the analysis of the focus group discussions: (1) older women's needs and unmet needs for home and community care from the perspective of family caregivers, and (2) challenges of family caregiving. First, we explore how family caregivers described the needs and unmet needs of older women for home care and community care. Playing a vital role in their loved one's care, family caregivers provided a unique perspective into the needs and unmet needs of their love one. While we observed commonalities and consistencies in the perceived needs and unmet needs for home and community care across the focus groups, we also found that, as in our focus groups with older women, linguistic needs added another layer of complexity to the provision of care. Second, we explore some of the challenges family caregivers shared across the focus groups. We describe family caregivers' multiple roles throughout their caregiving journey as care providers, advocates, system navigators, knowledge brokers, and in many cases as interpreters. We also highlight their experiences of caregiver stress and guilt while performing their roles to meet a wide range of needs for older women, often with no or little formal support.

Older Women's Needs and Unmet Needs for Home and Community Care from Family Caregivers' Perspectives

When describing the needs and unmet needs for home and community care, family caregivers emphasized the importance of addressing older women's needs from a comprehensive understanding of health and well-being, including social, physical, psychological, emotional, and linguistic and ethno-cultural aspects. Family caregivers expressed their concerns around the limited availability of home and community care support to meet a wide range of older women's support needs across the care continuum.

Needs for Better Home Care Support

Family caregivers across the focus groups were asked to share their views on what kind of support older women needed to age in place. Participants perceived that their aging family members needed help with a wide range of in-home support. To address older women's needs, participants in our focus groups described supporting older women with many activities of daily living such as medication supervision, cleaning, cooking, getting to/from appointments, and more. Participants also mentioned that older women's needs often

fluctuate according to their health conditions. To respond to older women experiencing health decline as they age, families had to arrange and re-arrange home and community care support, from themselves and any other available resources, to make sure that their loved ones were well cared for.

> *"My mum was a type that she would never get out of the house. She was staying at the house, do things, by herself, and not get out and talk to the neighbour or anything. So finally, I started to taking her [to a program]. She has a mild Alzheimer, she needs help because she takes a lot of medications. And we already had an incident, that one day she took enough for 2 days. All at once. That scared us. Her Alzheimer's looks like every day is different, is getting worse and worse, sometimes she is asking for daddy when she gets home, even though he passed away in 2013."* [Family caregiver for an Italian-origin woman]

For many of the women whom family caregivers were caring for, aging-related health challenges placed restrictions on their ability to self care. Formal bathing support was identified as one of the most important supports needed to address older women's personal care needs. Many participants were assisting their mothers or other family members with bathing as their safety was compromised when bathing alone. One family caregiver noted how formal assistance with showering and bathing would offer great help in caring for her mother by relieving some of the stress and strain that could occur within families as they navigate caregiving:

> *"Well for me, uh I have to do most of the taking care of my mom and that puts a strain on me, because the other siblings are not really helping, they always have an excuse, and they're tired, and this or that, and I'm tired too but you know, what they can overlook I can't like, I have to help my mom, the week gone by, I have to shower her, I can't leave her for three weeks, but they could easily do that because it's like – I can't be bothered and you know and that's affecting me, and my kids you know, oh they saying "oh mom it's not only one daughter, you know she has –" but I say, "yeah but I [am] not gonna leave her you know – yeah they're supposed to chip in and do their part but they're not doing it so I'm trying to get help now, a PSW to come in and help shower her and somebody to help look after her feet."* [Family Caregiver for a Caribbean-origin women]

One male participant also spoke about the value of that formal bathing support could offer for this mother. As a male caregiver, he found this aspect of caring for his mother challenging; wanting to balance her need for privacy but worried for her safety:

"that's [bathing support is] all I need for my mom – is probably an hour or so, um she – she showers herself, but I'm still, scared when she goes in the shower. I stand outside the door while she showers, but I, I'm a man, you know – and she's a Western Trinidad woman, and she has still that [other participants agreeing] and she still has that – you know, stuff, you know, and you know, so all I really want from them is come give me an hour, just be for her when she has a shower what have you. You know she does have a – I'm sure you know about Sun Downers, so she does notice – sort of from now, around now it starts right? All the different things (other participants agreeing)" [Family caregiver for a Caribbean-origin woman]

In our focus group discussions, many family caregivers shared their views on formal homecare support provided to their family members. As described by one participant, and echoed by many others, home care support offers great assistance with personal care needs of older women while allowing some time for family caregivers to help with other domestic tasks:

"So...I care for my mom. . .my mom is, she's 94, she has ailments, like she has dementia and other things, arthritis, mobility issues and that, so but mom gets home care, so the personal stuff I don't do for her, cause home care comes in to do that for her, but I do the other stuff like around the home, to be there with her, . . .you know get her meals out, meal preparation, and other things in the home, like medication, that sort of thing." [Family Caregiver for a Caribbean-origin women]

While appreciating the support received, many participants raised concerns around inconsistent care provision, with frequent changes in home care staff. As one family caregiver in the UK-origin focus group described, "the PSW gets attached to the senior, the senior gets attached to the PSW, and then the reason, because of work situations or the lack of hours, or funding, they go. And so it, it does change, and that is a big um, a big problem." Family caregivers highlighted the importance of receiving consistent care from the same home care providers as this would build trust and comfort between older women and their formal caregivers. This was particularly important for women with a cognitive impairment such as dementia or Alzheimer's.

"With people who have cognitive deterioration you have to send the same person, you cannot keep sending different person all the time because they need to establish trust, and that's not happening." [Family caregiver for an Italian-origin woman]

"...mum can't deal with change and [we] requested the same worker and basically said that if the same worker couldn't attend, then we didn't want

a person in the home anymore. Because it created too much confusion and anxiety for mum." [Family caregiver for an Italian-origin woman]

Language added another layer of complexity to meeting the home care needs of older women with limited English proficiency. Family caregivers described significant implications of language barriers on the quality of care and the relationships between older women and their formal caregivers when receiving home care services.

> *"But my mom doesn't speak English. If you are not there, there is no way they can communicate at all. In fact people may have good intentions … "I would like to do this for you now" … But she doesn't understand what she is saying. She thinks people are trying to push her for no reason. Just like that."* [Family Caregiver for a Chinese-origin woman]

Some participants who provided support to those with a form of cognitive impairment such as Alzheimer's or dementia observed that their family member lost their ability to speak English and reverted back to their mother tongue, even after having been bilingual for most of their life. This made the need for language supports even more critical.

> *"I personally find that everything is complicated because my mother's English is obviously not fluent like mine is. Plus, with Alzheimer's, advancing Alzheimer's, they begin to lose more of that acquired language and they want to revert more back to their own language"* [Family caregiver for an Italian-origin woman]

> *"the other thing is that [my mother] stopped speaking English. She speaks, she is gone back to the language of her birth, so she really forgot. So, my husband is not Italian and she was able to communicate with him and now it's just a word here and there, whatever, a gesture whatever, but it's not like it was before when she was able to communicate."* [Family caregiver for an Italian-origin woman]

Without adequate support to meet the individual's linguistic needs, formal care services alone could not meet the home care needs of older women with limited English proficiency. In addition to their commitment to providing a wide range of home care support, family caregivers often had to step in to provide needed interpretation support between care providers and their family members even when formal support was received.

Needs for Better Community Care Support

Across the five ethno-cultural groups, family caregivers noted the importance of social connectedness for older women who age in place and the need for more social programming, like adult day programs, ethno-specific programs, social programs, and exercise programs, to engage older adults in their communities and to reduce their social isolation and loneliness.

Without such connections in place, participants across the focus groups expressed concerns about isolation and loneliness experienced by their family members.

> *"She [My grandmother] would and because we are also in Oakville, most of her friends live in like Brampton, Mississauga, you know like far out that it's not always feasible for even us to be driving her in to see people, like that kind of thing. Yeah I mean, I don't know what that looks like, I don't know what that kind of support looks like but I think loneliness is a pretty common feature and more support around that would just lessen the burden on caregivers and on that individual."* [Family Caregiver for a women of Indian Origin]

Some family caregivers described that their loved ones were actively seeking social interaction through participating in community programs, talking to friends over the phone, and visiting friends or families. One participant explained how his grandmother used her waiting time at her doctor's office as an opportunity for social interaction:

> *"I, what I just tend to do, when I make her doctor's appointment, like I either want the first appointment or the last appointment. The first appointment because like I don't have to like, when you go in, when they open, we are the first patients, or we are the last patients, and my grandma doesn't like that because my grandma likes to go and sit there and…she meets someone she'll talk because she doesn't go out."* [Family caregiver for an Indian-origin woman]

Linguistically and culturally appropriate programming was noted as particularly beneficial for the health and well-being of older women and their family caregivers. Many family caregivers whose family members had specific linguistic and ethno-cultural needs highly appreciated the current programs offered by their local ethnic communities as they noticed positive changes on their mothers' health and quality of life. Those programs allowed family caregivers to take much needed time to look after themselves and fulfill other daily responsibilities. Many, however, also noted long waitlists and limited availability of such programs, often inconsistent across ethno-cultural groups, regions, and service providers.

> *"Our application [for a Chinese adult day program] was approved at the beginning of February. It took a while. My mom was very happy. . .it was just for one day. But it was great. I highly recommend it. For our entire family, it felt like discovering a gold mine! It was because mom did not have to be lying in bed all day at home. She already felt better. . .We can leave her so we can relax for a few hours. From 9.30 am to 2.30 pm I can go grocery shopping and it won't be a headache. Forget about other luxuries. You can do. . .the most basic things. Otherwise it would be very stressful."* [Family caregiver for a Chinese-origin woman]

Family caregivers perceived transportation as one of the most essential supports for older women to age in place while staying connected with other important programs and services.

The lack of accessible and reliable transportation services was noted as a considerable gap in the current system. Further, the lack of linguistical sensitivity in transportation services created an additional barrier for many older adults, as described by Italian family caregivers:

> *"I mean, my concern right now is transportation... We have some [community] programs, but we are having a difficult time getting them [my parents] there with the appropriate transportation. Ehm that's a big concern."* [Family Caregiver for an Italian-origin woman]

> *"We actually pick up my mother and bring her the day program and then we come back and pick her up again and take her home. . .You know why, I'll tell you why, because we tried the transportation service and number one, they don't always come at the same time uhm there are different drivers. My mother literally went to the door, said I don't know who you are, bang and slammed the door. And so, you know, and she is alone. So anyway, transportation is an issue because there are obviously. . .we used to have our own [Italian-speaking driver from the centre]"* (Family caregiver for an Italian-origin woman)

Italian family caregivers mentioned that their family members and other older adults in their community used to feel more reliable and comfortable when served by Italian-speaking drivers in the past. Recent changes in the local transportation system made it difficult for many older adults in this community to receive transportation services in their language. Families had to constantly provide support with transportation so that their family members could attend community care programs.

Challenges of Family Caregiving

Family caregivers across the five focus groups reported playing a vital role in the lives of the older women they were caring for. While family caregiving took diverse forms based on each family's context, there were shared observations and experiences of supporting older women living in the community. Family caregivers act as advocates, knowledge brokers, and interpreters to support older adults as they navigate home and community care services. Within the limited public support system, family caregivers make best efforts to addressing older women' needs in a wide array of home and community care and ensuring their health and well-being. And, this often led to their experience of caregiver stress and guilt. Additional burden seemed to appear for those looking after family members with limited English proficiency and little knowledge of the local health and social system.

Family Caregivers as Advocates, Knowledge Brokers, and Interpreters

Family caregivers in our focus groups emphasized their roles as advocates, knowledge brokers, and/or interpreters as a critical part of their caregiving responsibilities. Their role

extended beyond ensuring the functional health and safety of their loved one around home. As knowledge brokers, family caregivers became the main interface between their aging family members and the formal care system.

> *"I um just wanna say…in getting help for your parents or whoever it is you're – you have to be an advocate…you have to be advocate to get services, you really have to know the system and be an advocate, that's how you get things done, you know, if they come into your home, they do your assessment, like when will I hear back from you, you don't hear back from them, you call. They're not answering you, you go to the manager, you go up, like you really have to advocate, you really have to be that advocate."* [Family caregiver for a Caribbean-origin woman]

Again, language added another complexity into family caregiving. Older womens' limited English proficiency, often compounded by limited knowledge of the local system, resulted in family caregivers' extended, often intensive support to assist older women with most of their daily activities such as booking taxi rides, paying bills, supporting with transportation, making appointments, banking, and more.

> *"You have to do the banking for them, to have to pay their bills for them, … and of course, because we are talking about women who don't speak English that well. They can communicate in English, I don't know if all of your mums could do that. They can communicate in English, but it's not their first language, so that is a further complication which is why they need us [emphasis] to constantly advocate for them, you know, they don't know necessarily well."* [Family caregiver for an Italian-origin woman]

Throughout their family caregiving journey, from seeking to receiving support for their loved ones, family caregivers caring for a family member with limited English proficiency often had to provide additional support as an interpreter. Even when receiving formal home care, families were expected to stay with the women in order to offer interpretation to facilitate the communication between their loved one and the person providing care.

> *"Well, language is very important. Take my mom, for example. She is 86. She is bedridden. She needs others' help for sure. So like, like this morning, or every Sunday, CCAC would send some PSW … two times on the same day, morning and night. Of course, my mom doesn't know any English…If the person being sent is [of a different culture of background or doesn't speak Cantonese], she would be shaking in shock. She would say, "I don't know how to communicate with them. Don't leave. You have to sit here." Alright, that means even if they come they can't be of any help to me. I still have to sit there the whole time."* [Family caregiver for a Chinese-origin woman]

Participants highly appreciated the provision of home care services in their language as they were so important for the health and well-being of older women and their family caregivers. Family caregivers reported positive impacts of the services provided in the language their family member could understand, as described by a family caregiver in the Chinese focus group: "whenever the Cantonese speaking one [personal support worker] comes over she [my mother] would be very happy. While she would keep talking about her own story, the worker would be working and laughing at the same time. This is just natural." Such care also significantly benefits family caregivers as it provides much needed time to take care of themselves and other tasks. Yet, many family caregivers acknowledged the limited availability of care workers who speak their community language in the home and community care sector.

Family Caregiver Stress and Guilt

In addition to sharing the experiences they had helping their family member navigate systems of care and support, most family caregivers also spoke of the challenges they faced as primary caregivers. Often, family caregivers found themselves providing support on their own. While fulfilling their family responsibilities and completing other tasks as primary caregiver for their loved ones, many participants expressed the lack of time for self-care, high caregiver stress, and burnout.

Family caregivers also shared their experiences of feeling guilt constantly as they were unable to meet all the needs of their family member. Some participants described their guilty feeling from a perspective of second-generation immigrants looking after aging parents:

> *"I think one of the things that complicates it for people of my generation, and I can tell you this from all of my friends that are going through this. We are a very uniquely, ehmm …we are a unique generation, because we have these parents who made all these sacrifices to get us through school, to give us the life we have, and now, so guilt is a huge motivating force for us."* [Family caregiver for an Italian-origin woman]

Emotional support was frequently noted as one of the areas of unmet needs for older women. Recognizing the importance of providing social and emotional support for older women to stay socially engaged and connected, many family caregivers felt guilty as they could not adequately provide the needed social support for their loved ones.

> *"In the morning she's good, like she could go alone, if me and my mom have to go groceries or anything. But at night, if it's like 6 [or] 7 o'clock, my grandma when we come home, she'll be like "oh it's getting dark, you guys are late, my heart was sinking. I was home all alone" and stuff like that. So it's always like we can't leave her alone for a long period of time and it's just I think that limits*

you from a lot of things too and at the same time, you kind of have to do what you gotta do right?" [Family caregiver for an Indian-origin woman]

"yeah, I think it [the gap in the care provided by family] is around the emotional support. Just like them being alone a lot and like you feeling guilty that you're not providing that for them either." [Family Caregiver for an Indian-origin woman]

While most families were stretched between the demands of care, work, and other tasks, participants in our focus groups spoke of no adequate support for family caregivers. Some participants had knowledge of existing resources for family caregivers and shared the information during and after the focus groups with other participants, including caregiver support groups, educational workshops, counselling services, and compassionate care benefits from the government. A couple of participants also reported receiving formal respite care, for example up to 20 hours per month, which was a great help for family caregivers. Yet, participants across the focus groups shared significant challenges of family caregiving: families had to juggle competing family caregiving demands with other demands of life and work while experiencing financial, physical, and emotional stress.

Discussion

In our focus group discussions, we heard from 40 family caregivers of older women from diverse ethno-cultural backgrounds. This report complements our research report on findings from focus groups with older women from diverse ethno-cultural communities.[6] It provides additional insights on the unmet needs of older women in the GTA, specifically, from the perspectives of their family caregivers who play a vital role in supporting them at home. While the older women in our focus groups were a relatively younger and healthier group of older women, we were able to hear from family caregiver participants about their experiences of caring for women who were older and with higher care needs. This allowed us to hear about a range of experiences and needs for home and community care as women age.

Family caregivers shared their views on the range of needs of older women to age in place in a very comprehensive way that spans across home and community care. Our findings emphasize the importance of understanding the social, physical, psychological, emotional, and linguistic and ethno-cultural needs of older women in home and community care planning and delivery. Yet, family caregivers expressed their frustrations over the inadequate support available in the current system, with the narrow focus on medical and functional health needs, to meet the wide range of needs of their aging family members.

For home care, among a wide range of activities of daily living, support with personal care such as bathing was identified as an area of needs which family caregivers felt their family members most needed but often left unmet. The safety and privacy concerns associated

with bathing alone was often shared among family caregivers across the ethno-cultural groups. Many of the family caregivers in our focus groups reported that their family members received some formal home care support including support with bathing, personal care, and medications. While appreciating the support from nurses and personal support workers, they raised concerns around frequent changes in home care staff. For older adults, particularly for those with Alzheimer's and dementia, family caregivers emphasized the importance of consistency in care provision to building trust and rapport in the person providing care.

For community care, our focus group discussions centred heavily around their concerns on social isolation and demands for more programming to improve social connectedness for older women. There is strong evidence on the importance of social connectedness on older adults' health[10]; Canadian Community Health Survey data shows that older adults who reported a strong sense of belonging were 62 percent more likely to report good health than those who reported a weak sense of belonging.[11,12]

Many family caregivers also acknowledged the benefits of participating in adult day programs and various other community programs for older women: it fostered social connectedness and helped reduce social isolation and loneliness. Particularly, ethno-cultural programs were noted by many family caregivers as important for the health and well-being of their family members from diverse ethno-cultural communities. Such programs, however, had long waitlists, up to two years for an Italian adult day program, for example. Existing research suggests that immigrant seniors may experience an increased risk of social isolation due to factors associated with settling in a new country, decreased network size, and ethnocultural and linguistic barriers.[13,14] Better access to linguistically and culturally appropriate programs, through greater availability and proactive outreach programming, will improve social connectedness for older adults from diverse ethno-cultural communities.

Family caregivers viewed transportation as a core component of community care. This view was largely shared by older women participants. Access to transportation services allowed older adults to attend community programs independently; this also relieved a lot of the pressure on family caregivers. We also learned from the Italian family caregiver focus group that accommodating linguistic needs is so important for older adults with limited English proficiency to access community programs and for family caregivers to relieve their caregiver stress.

It was evident that across ethno-cultural groups families were expected to and currently played an important role in providing care, navigating the system, and advocating for their aging family members. While many perceived it as part of their familial commitment, the demand of caregiving often went beyond what family members could fulfill and it had significant impacts on the health and well-being of family caregivers. Family caregivers shared their feelings of caregiving stress and guilt without adequate formal support. Our findings are consistent with existing literature on family caregivers. The Change Foundation

and the Health Quality Ontario's work on Ontario's family caregivers report the shared experiences of caregiver stress and burnout.[2,3] While family caregivers play a vital role, there is a lack of recognition of their contribution and limited formal support for family caregivers in the health and social care system.[15]

Our findings suggest additional risks for caregiver stress, as described by the family caregivers looking after aging family members with limited English proficiency and little knowledge of the local system. These family caregivers felt stretched to their limit while providing extensive support to meet their needs, especially linguistic needs, across a wide range of support. We observed that while family caregiving affects all families it may have different health consequences on diverse ethnocultural communities. Previous studies found higher caregiver stress among immigrant family caregivers and those looking after persons with limited English proficiency. Using the General Social Survey data, a Canadian study by Suwal[16] found that immigrant family caregivers were three times more likely than non-immigrants to report a negative health consequence as a result of caregiving. The author also found that feeling of reciprocity played a major role in their health impact. Feeling of giving back as a child of immigrant family was also shared among some of our focus group participants. Chang and Hirdes' Ontario study,[17] based on the analysis of the Resident Assessment Instrument-Home Care data, 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.

Language barriers have significant health implications on both older women and family caregivers. English proficiency can impact the quality and quantity of home and community care programs and services older women could access to. Further, when there is limited availability of linguistically-appropriate home and community care, family caregivers play a greater role in meeting the needs of older women: families provide extended, often intensive, care and support to meet the women's needs across a wide range of support. We heard from many family caregivers that even when personal support workers or nurses attended to care for their family members they had to be present to provide interpretation support between care providers and their family members. Linguistic diversity is growing in older populations. More than one in three Ontario older adults[18] and more than half of Toronto older adults[19] reported having a mother tongue that is not English. Enhanced accommodation of diverse linguistic needs can significantly improve the access to home and community care programs and services for all older adults. This can consequently relieve some of the pressure on family caregivers looking after their loved ones with limited English proficiency.

Limitations

This qualitative study offers a glimpse into the experiences of family caregivers of older women from different ethnocultural groups. Building on our previous work,[11] this study

reflects the experiences of family caregivers of older women from the five largest older immigrant groups by country of origin across the GTA. We aimed to capture the experiences of a diverse range of family caregivers of older women from diverse ethnocultural groups. When conducting each focus group, we strived to offer culturally and linguistically appropriate environment so that participants felt comfortable sharing their own stories and perspectives without linguistic and cultural barriers. By limiting our study to family caregivers of older women from the selected ethnocultural and linguistic communities, however, we recognize that we might have missed the opportunity to hear from family caregivers from other communities with vastly different life experiences and views on home and community care. While limited in our selection criteria, the consistencies in the needs, challenges, and concerns we heard across the groups are likely to span the larger GTA community.

Additionally, the location of the focus group and targeted outreach of ethno-specific communities limited the geographical diversity among participants in each focus group (e.g., Brampton for the Indian focus group and North York for Chinese focus group). We also understand that harder to reach family caregivers, potentially given their intensive caregiving, may have been less likely to come forward or may be socially isolated and therefore may be difficult to include. Despite the limitations noted, we believe that this data offers valuable insights into home and community care access from the perspectives of family caregivers of older women from diverse ethnocultural communities across the GTA.

Conclusion

Family caregiving has received increasing attention recently. Reports by Canadian Institute for Health Information, Health Quality Ontario, The Change Foundation, and others have highlighted the important role of family caregiving and its consequences on the health and well-being of family caregivers looking after aging family members.[2,3,20] Although still limited, there has been important policy development by federal and provincial governments to enhance support for family caregivers through better financial, educational, emotional, and other support to relieve family caregiver burden.[21,22]

While there is growing recognition of family caregiving in research and policy, there is a gap in our understanding of experiences of family caregiving within diverse ethnocultural communities across the GTA. Some of the stories presented in this report add important aspects of family caregiving from voices of family caregivers of older women with different immigration histories, linguistic, and cultural backgrounds. In addition to documenting the shared experiences and challenges of family caregiving, this report sheds light on some of the added challenges that some family caregivers and their aging family members experience while accessing home and community care.

To ensure access for all older adults, regardless of their backgrounds, our research identifies the importance of providing linguistically and culturally appropriate care across a care

continuum. The implications of such programming would be significant on the health and well-being of both older adults and their family caregivers. Based on what we heard from family caregivers, and from older women from diverse ethnocultural communities as presented in our companion research report[6], our policy brief[23] provides community-informed policy recommendations to improve access to home and community for all older adults in the GTA.

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