

# The Changing Face of Home and Community Care:

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

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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



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## Introduction

The face of aging in the Greater Toronto Area (GTA) is changing as our older population becomes more linguistically and ethnically diverse. With the rapidly growing diversity in the GTA's older population (65 years and older), the need for linguistically and culturally appropriate care is increasing across the continuum of care.<sup>1,2</sup>

Wellesley Institute's previous quantitative research on home care access<sup>3</sup> highlighted existing disparities in accessing publicly-funded home care for older adults from diverse ethnocultural communities in the GTA. Using the Canadian Community Health Survey data, Um and Lightman found significant disparities in home care use among different older population groups based on sex, immigration status, country of origin, length of time in Canada, mother tongue, and racialized identity. Older women reported higher rates of unmet needs for home care than older men. Immigrant older adults were less likely than non-immigrant older adults to receive publicly-funded home care services, while they were more likely to receive home care only from family caregivers and more likely to report unmet needs for home care. Immigrants who had lived in Canada for less than 30 years were less likely than non-immigrants to receive publicly-funded home care. Racialized older adults and those whose mother tongue was not English were less likely to receive publicly-funded home care than non-racialized older adults and those whose mother tongue was English, respectively.

Building on this previous work, we conducted a qualitative study 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, similarly and differently across the diverse ethnocultural communities. With research findings from focus groups with older women and family caregivers<sup>4</sup>, 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 ethnocultural communities in the GTA.

In this study, we examine:

1. the nature of the needs of women who want to be cared for at home and in their communities;
2. women's experiences accessing, or trying to access home and community care services; and
3. the barriers and challenges these women face accessing these services.

This research paper presents what we heard from our focus groups with older women across the GTA. Our findings summarize the common experiences shared among our research participants from diverse ethnocultural communities while highlighting the experiences that were found 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 groups to capture the breadth of participant's experiences trying to access home and community care as well as their shared views on challenges in meeting the needs for home and community care within the current care system. In March and April 2017, five focus groups were conducted with older women from five different countries/regions of origin: United Kingdom (UK), Italy, China, India, and Caribbean. The previous quantitative study identified the selected ethnocultural groups as the largest older immigrant groups in the GTA by country of origin.<sup>5</sup> To facilitate focus groups in community languages, we identified one main language for each group through community consultations (English for UK and Caribbean, Punjabi for Indian, Italian for Italian, and Cantonese for the Chinese focus group).

Participants were recruited through a variety of methods: community-based organizations that serve diverse older populations, home and community care service providers, newsletters, flyers, and word of mouth. Recruitment strategies were designed to cater to each ethnic community. Women interested in participating in the study were screened through a brief phone conversation to ensure that participants met our selected criteria: women 65 years and older, residents of the GTA who expressed needs for home and community care or were receiving home and community care from either formal caregivers or family caregivers and were first or second-generation from one of the five selected ethnocultural communities. To participate, women were also required to speak the selected language of their identified ethnocultural group.

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 socio-demographic information (i.e., age and the city of residence) and the support needed. Moderators asked participants about their current living situation, details of the type of support or care they needed and received, their familiarity with and experience of accessing Community Care Access Centres (CCACs) and the conditions of home and community care support they received. Focus groups were held in libraries, centres for older adults, cultural centres, and community buildings across the GTA, including North York, Brampton, East York, 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 had limited mobility, escorted transportation was arranged and provided. 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.<sup>6</sup> Transcripts were reviewed by project team members (NL, SU, BR) individually and then individual observations were discussed by the team 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, paying attention to how concepts were framed and described by the women across the focus group data.

## Findings

In total, 41 older women participated in the five focus groups. Our research participants ranged in age from 65 to 91 years with a mean age of 77 years. The majority of women (73 per cent) reported receiving some kind of support from family caregivers: most commonly from a daughter (44 per cent) or a son (39 per cent), but also from daughters-in-law, grandchildren, friends, neighbours, and others. While most women received care from one or more of their family members, a small number of participants reported receiving formal care. Seven participants (three Italian-origin, two UK-origin, one Indian-origin, and one Caribbean-origin participant) used private, paid services to receive a range of support such as gardening and house cleaning. Only six participants (three Italian-origin, two UK-origin, and one Indian-origin participant) reported receiving formal care by personal support workers or nurses from their local CCACs. Many women in the focus groups reported using other community support programs such as Wheel-Trans for transportation and social and cultural programs for older adults.

Two central themes emerged from the focus group discussions: (1) needs and unmet needs for home and community care and (2) challenges related to accessing home and community care. First, we explore how women described their core areas of need to age in place, and how their current support system was responding to their perceived needs. When the women expressed their needs for home and community care across a wide range of supports and from multiple perspectives, they shared frustration and disappointment over how the current system was failing to fully meet their needs. Second, we focus on some of the structural and systemic barriers experienced by the women in accessing home and community care. While the women who participated in our focus groups were from diverse ethnocultural backgrounds and life trajectories, our data present commonalities and consistencies in

their struggles in navigating and accessing the current home and community care system. Importantly, however, we found significant differences across the focus groups. Most notably, language – English proficiency – was identified as a significant facilitator or barrier to accessing existing services across a continuum of care. Also, limited linguistically and culturally appropriate care programs and targeted outreach efforts discourage women from certain ethnocultural backgrounds from accessing publicly-funded programs and services.

## Needs and Unmet Needs for Home and Community Care

Women across ethnocultural groups shared that to age in place they need support along a broad continuum of care, ranging from support with activities of daily living such as housework, shopping, and transportation, to community programming to allow for active engagement in social activities, to more conventionally-defined health services by nurses, physiotherapists, doctors, and other health professionals. Yet, women expressed their frustration over the limited resources available for them to meet their needs across the full spectrum. Further, many women shared their struggles over accessing and receiving some of the available services when needed.

### Needs for Better Home Care Support

The women's perceived care needs speak to a broad sense and understanding of needs for home and community care that allows them to maintain their independence and health as they age. With aging, women experience a decline of certain life skills, particularly around activities of daily living. Support with activities of daily living was discussed as a critical need across the five focus groups. Participants shared that managing everyday personal care and household tasks was increasingly challenging aspects of their daily lives. Without adequate supports, many spoke of the challenges of trying to complete everyday tasks such as washing dishes, bathing, and doing laundry on their own.

*“I can't wash dishes at all. It's very hard for me because of my arthritis.”(Indian-origin older woman)*

Even women who were more independent expressed anxiety about future needs in their everyday personal and household tasks as they see people close to them face added challenges as they decline due to age. Among the women there was a strong recognition that while they might require less support today, their needs could rapidly change tomorrow.

*“Somebody who could come in and maybe if you need it give you a shower in the morning and maybe do a little house work - I'm not saying a lot. I can do everything right now, but I know somebody who can't do laundry, I know somebody who can't do the floors.” (UK-origin older woman)*

Across the groups, many women reported that their needs for support with bathing and other personal care were not adequately addressed. While bathing was one of the most commonly cited home care services they needed or received, participants noted that the existing services were not sufficient to meet their needs - often just one bath a week was offered (when eligible). While those women who were eligible expressed that they were grateful for the help they received, many felt that one bath a week was not sufficient to meet their needs.

For others, requesting support was made even more difficult when providers failed to recognize or even assess their needs, despite their request to do so. Many women shared frustrations and disappointments about the limited availability of existing services for home care support. For example, one participant mentioned that, after she had surgery, her family had called to request help with bathing, but the request was ignored: “no one came from outside. We did call the hospital, my son did too but no one came” (Indian-origin older woman). In other cases, women and their families were told that they were deemed ineligible for the service when they needed support.

*“I had some problems in the beginning too. I have a urine infection, so I was quite sick and I wasn’t able to get up. And when my daughter-in-law called to ask for someone who can help me with showering, they said I should be able to do it myself. They never sent anyone.”* (Indian-origin older woman)

Ultimately, families often had to fill this gap. In some cases, a primary family caregiver looked after their loved ones. In other cases, family members took turns to provide support with daily activities. Even among the women receiving formal care, it was common to receive significant support from family to supplement personal care and other health care received.

*“Because I really needed help. Now I do worse instead of getting better Friday my daughter-in-law came, and she went to do the groceries, and she went to the bank. Saturday the other one came. That one comes to clean. But the other one has three kids. . . I cannot demand that she comes. But otherwise during the week, I get by. Perhaps I spend from 8am when I wake up to 11am on the sofa without moving, not even drinking a glass of water because I can’t stand up.”* (Italian-origin older woman)

*“[The nurse] comes because I have the bag [colostomy bag]. It has to be changed always, because otherwise I can get infections right away. I have to be careful. She measures my blood pressure. She does a few things. After, there is my sister who helps me, without her how would I manage?”* (Italian-origin older woman)

Having to rely heavily on family for additional support, women were very candid about challenges their families face in trying to help with competing demands for their own family and busy work schedules.



*“The children have a difficult time...All of them have to work. All of them have families. So if somebody who can help me with cooking and cleaning on a daily basis...whatever I need...they can help me”* (Chinese-origin older woman)

*“See, our kids also have kids. So that’s another problem for them. And on top of that, we have also become kids. We have to tell our problems to our kids. They’re stuck in the middle...”* (Indian-origin older woman)

For the women with limited English proficiency, the language barrier was described as an additional burden for their family caregivers to act as an interpreter between them and their formal caregivers. One Indian-origin participant who had an experience of receiving home care from both Punjabi-speaking and non-Punjabi-speaking nurses expressed her appreciation of being cared for by someone who spoke her native language. She described the Punjabi-speaking nurse as *“someone from my own family taking care of me.”* While the other nurse also provided adequate care to meet her medical needs, there was a communication issue: *“when I had to explain something to her, or she wouldn’t get what I was saying, I would call my daughter-in-law and she would explain it.”* In the absence of linguistically-appropriate care, family caregivers are often expected to be present to support their family members with communication even when they are cared for by formal homecare staff.

## **Needs for Better Community Care Support**

Among a wide range of community supports available for older adults, transportation was cited as one of the most received and needed supports for the women to age in place. Having access to transportation offers women a sense of freedom and independence, enables them to get to and from medical appointments, grocery shopping, and other trips they need to make in their daily lives. Transportation also connected women to the community and allowed them to participate in community programs and other social activities. Publicly-funded transportation support, such as Wheel-Trans in Toronto and TransHelp in Peel, was often greatly appreciated by many participants who use the services.

*“Wheel-Trans is a godsend to so many people. Having Wheel-Trans has allowed older adults to belong to social groups, to go to medical appointments. Without it, most older adults would be home-bound. Long live Wheel-Trans!”* (UK-origin older woman)

From the women we spoke with, we learned about notable variations that existed in the accessibility and availability of community care services and programs across the jurisdictions, which effectively increased disparities in women’s experiences. The participants who resided within or close to Toronto Central reported more frequent use of public transit or transportation services and highly valued the services as it provided them a sense of freedom and independence. However, the participants living outside of Toronto showed very limited or no use of public transportation and heavier reliance on their family

members for transportation. The limited or no access to public transportation services posed a significant barrier for the women to fulfil their needs across a continuum of care.

The importance of transportation was clear, and women expressed that where access to transportation services were unavailable they felt there was a gap in the care they received. Transportation needs cut across multiple areas of care, from providing a way for women to manage outpatient care and medical appointments, to providing access to social activities or contact with family and friends.

*“I’d like some assistance because. . .for transportation to go where I want to go, like to the doctors and my son isn’t there. Or to look at my eyes and my dentures, I’d like to have that.”* (Caribbean-origin older woman)

Across the five ethnocultural groups, women frequently had to ask their family members’ help with getting to or from where they had to go. For many participants with health and mobility issues, limited access to transportation was a challenge to perform their daily activities such as grocery shopping. While many women said their family helped them with rides to supermarkets, meal delivery, and home cooking, they noted that their independence could be enhanced with additional support from innovative services from community agencies and local businesses, such as low-fee grocery delivery services and regular bus ride to supermarkets.

*“But it’s [grocery] shopping. That’s the big thing. I do go to [a local supermarket] that, by the way they deliver. . .but they’re expensive. I have a granddaughter who occasionally takes me in her car. She’s the only one with a car. But she’s going to move to England.”* (UK-origin older woman)

The impact of limited transportation weighed most heavily on recent immigrants who had limited English proficiency, no driver’s licence, and were unfamiliar with the health and other local systems. Many newcomer participants mentioned that they had to entirely rely on their children for transportation, getting to friends’ places, booking/getting to appointments, booking taxi rides, and other trips. For example, a Punjabi-speaking woman mentioned that she could only attend medical appointments when her children had the time to take her to the doctor. As she was reluctant to attend a doctor’s appointment by public transit in the winter without her children, she had to delay her doctor’s visit:

*“I also keep thinking about when the weather will be nicer, and then I tell my children to drop me off because going on the bus can be hard. . .I had some problem with my heart and I told the doctor to wait for 2 months. He said “why?” and I said “the weather is not good”. The nurse said to me “are you after the weather or your health, what’s more important?”. And I said to them “sorry, sorry, sorry”. . .I told “this is going to be a problem for my children”. It was December then and I asked for an appointment two months later. They*

*told me “if something happens to you in the two months, then what?” So then I apologized.”(Indian-origin older woman)*

Many women in the focus groups reported participating in social, cultural, and exercise programs targeting older adults in general and/or older adults from particular ethnocultural groups. Participants acknowledged that social programs in their community make a huge difference in their quality of life and reduces social isolation and loneliness.

*“I really feel alone. That’s why I need something to do all the time. You know, go to like one of these things, Lunch Bunch Tuesday, even [ESL] or whatever I do, I just need something.”(UK older woman)*

*“Sometimes I’m known at [my community centre] from 10 until 5. I enjoy being there. Because otherwise I would be locked up home alone. And we exercise, and we do little handwork like making beads because I’ve done – already I’m making earrings and – you know, we learned and enjoy yourselves together. And we do exercise and it’s therapeutic.”(Caribbean older woman)*

While recognizing the benefits of existing community programs to their health and well-being, participants expressed the desire to see more social programs available for older adults in their communities. In the focus group with Indian-origin older women, we heard that the women enjoyed attending ethnocultural programs for Punjabi-speaking older adults, offered two or three times a week by their local South Asian community organizations. On the other days when there were no programs, people stayed home from morning to evening, all alone while their family was out for work and school. Women acknowledged that on those days they “just have to get through” and “it does get lonely”. Women across the focus groups noted that there were many people in their communities who stay home without going out and experience depression because of the lack of social connectedness.

## **Challenges in Accessing Home and Community Care**

As the women described their unmet needs for home and community care, several issues were highlighted related to what makes it difficult for them to access available home and community care services and programs. Common themes emerged across the five focus groups related to navigational barriers and financial barriers. Additionally, for older women from certain ethnocultural groups, limited English proficiency and recent immigration status made it even more challenging to meet their needs for home and community care.

### **Navigational Barriers**

When asked about how familiar they were with the current home and community care system, many women, especially those from the Punjabi- and Cantonese-speaking focus groups, showed little or no knowledge of CCACs and/or how to access existing publicly-

funded services and programs. Those who learned about available programs and services for the first time during the discussions showed interest in learning more about how to access them.

Navigating the system was not an easy process for those who knew about the services and programs offered by CCACs or other community organizations. The lack of care coordination within the health and home and community care sector was a concern raised by many participants who experienced having to access multiple avenues in order to receive home and community care services. Also, as expressed by one participant, online services were not easily accessed by older adults with limited computer literacy.

*“Before I got [in touch with a service provider], I had to do so many calls. Because more than once you need to use a computer. But [it would work okay for those] who had the opportunity to use a computer because [they are] younger or studied more. But a senior like me...”* (Italian-origin older woman)

Language added another significant challenge for older women and their family caregivers in navigating the system. There was a shared understanding that with limited English proficiency “you don’t go anywhere” (Italian-origin older woman). Language barriers not only limited what women could access, but also made them completely dependent of family caregivers who often had to serve as interpreters and knowledge brokers.

*“But I think that if someone or a senior does not know a little bit of English it is difficult for everything. You have to depend on your family, and if they are busy with their family, it is a bother for them. Not that they don’t do it gladly, sons and family members, but...it is too much for them. And then we have to solve it on our own. But...it is not possible to have the thing that we are entitled to.”* (Italian-origin older woman)

Those participants with limited English proficiency reported feeling frustrated when information was given in English only, as described by one of the Cantonese-speaking participants: “I have been given a telephone number, but they speak English on the other side. . .it would be great to have more services for Chinese. . .It would be great if somebody can understand what I say when I call.”

In addition, many participants requested more targeted outreach so that older adults from their ethnocultural communities can learn more about available home and community care programs and services. During the focus group with women of Indian-origin, we heard from a participant who first learned about local ethnocultural community programs only after she had surgery. Hospital had encouraged her to make use of existing ethno-specific programs as a way to be more active and engage in social activities. While acknowledging the benefits of participating in these programs, she noted that it would have been beneficial to have known that information earlier.

*“Doctors only tell us these things if we have surgeries. . .they only tell those who are really sick or can’t move much. . .they [family doctors] should have some flyers or something in their offices with information on them right? that you can go and pick up and bring home with you?”* (Indian-origin older woman)

More proactive information sharing was suggested across the five focus groups. Many participants did not know about the programs and services already available for them and did not know how to access such information. Family doctor’s office was mentioned frequently as a place where the information about available home and community care programs and services could be shared effectively among older adults. Our focus group participants also emphasized the importance of linguistically and culturally appropriate outreach efforts to address their needs in navigating the system.

## **Financial Barriers**

As the current system offers only limited publicly-funded home and community care support, some women in our focus groups had to seek support from private sources to fill the gap in care-related services. While a few participants, often with their family’s financial support, could receive support with their daily activities from paid service providers, these services were beyond the reach for most participants as they lived on low or no retirement income.

*“Because someone who gets a small pension, what can he or she do? One pays all the expenses, one cannot pay the people who help. I looked for one, 28 dollars an hour, how can I pay 28! I get 900 dollars a month, how can you pay a person 28 dollars [an hour].”* (Italian-origin older woman)

More recent immigrant women, who were participants in the Indian-origin, Chinese-origin, and Caribbean-origin focus groups, expressed more financial concerns due to their limited or no access to government pensions. As immigrants sponsored by their adult children and not eligible for government pensions during the 10-year sponsorship period, newcomer women in our focus groups reported relying heavily on their children financially as well as with other aspects of everyday support. Many of these women were living in multi-generational households while looking after their grandchildren. They shared some levels of challenges and family tensions in providing care for their grandchildren. One woman described her sense of financial dependence on her son and daughter-in-law. This was shared by many other newcomer participants with no access to government pensions:

*“I live with my son and I really am wholly dependent on him, son and daughter[-in-law] because I came up here, ever since I came here. So, I have no income of my own. . .Well, I have to depend on them to give me money [to get out and to go to different places].”* (Caribbean older woman)

This woman helped her son's family by providing daily housework and caregiving to her school-age grandchildren. Despite her contributions to the household, she felt constrained financially and felt a lack of independence. Likewise, being financially dependent on her children, one Indian-origin woman felt obliged to care for her grandchildren in exchange for financial support from her child. However other women in her focus group responded that "every family is different".

In other cases where participants had access to pensions or other income sources, some women still had to rely on children to manage their finances. With limited knowledge of local banking practices, several women had to ask their children to arrange daily activities for them such as booking and paying for taxi rides.

Regardless of the length of their residency in Canada, we observed that many women across focus groups expressed their fear and uncertainty about how they could afford future expenses that would meet their health needs as they age.

*"The only thing I worry about, if you want to call it worry, if anything happens, I cannot afford to go to one of these retirement residences. I couldn't afford it even if I was working."* (UK-origin older woman)

*"One senior cannot get by. . . Thanks God. . . I am still alive, my kids are there. Okay it works. . . I don't have a set there to pay people to stay with me or to pay somebody to come, here, there, the other way around, I can't! So that scares me. Sometimes I feel sick even to worry about tomorrow."* (Italian-origin older woman)

For many women across the ethnocultural groups, the limited availability and accessibility of publicly-funded home and community care, together with the unaffordability of private care services, contributed to their shared experiences of stress and anxiety for the future.

## Discussion

In our focus group discussions, we heard from 41 older women with diverse ethnocultural backgrounds about their perceived needs for home and community care and their experiences in accessing and receiving the supports they needed to age in place. This report presents some of the commonly shared experiences among older women across the groups. It also highlights additional challenges some participants experienced, particularly as they struggled to meet their linguistic and ethnocultural needs while trying to navigate and access the current home and community care system.

Overall, women face substantial barriers accessing home and community care across the GTA. The stories shared in the focus groups confirm the existing inequities in accessing home and community care and help us understand to some extent why certain groups of older



women from diverse ethnocultural communities experience more difficulties in getting the support they need to age in place. Most notably, language barriers intersect with other access barriers and exacerbate inequities further.

English proficiency could facilitate or impede a women's ability to maintain health and independence as in most cases the ability to communicate in English was key to getting access to existing services and programs. In addition, recent immigrants, with limited knowledge of the local system and no access to government pensions, found it extremely challenging to navigate the system and receive the support they need. The current system is not delivering adequate support to not only meet their functional and personal care needs, but also to meet linguistic and ethnocultural needs.

Across ethnocultural groups, women spoke about their unmet needs for support across the care continuum. Women shared their frustrations over the limited availability and accessibility of existing services to meet their needs that go far beyond one bath a week. Personal care such as bathing was identified as an essential element of personal care as it serves not only a physiological purpose of cleaning but also a social purpose of upholding an acceptable standard of cleanliness and dignity.<sup>7</sup> Assistance with household tasks such as cooking, cleaning, and doing laundry was also identified as necessary to enable older women to stay independently at home and in their communities. Women also desired better community support. Public transportation services, affordable housing, and ethnocultural programming were identified as important supports for older women to maintain and improve health, independence, and social connectedness as they age.

Among many supports needed for people to age in place, transportation was viewed as an indispensable element of independence and access to essential services and programs. Our findings presented how transportation fosters social connectedness while reducing social isolation and loneliness among older adults. As noted in a study by Statistics Canada, a lack of access to appropriate transit negatively impacts an older adult's daily life by limiting the ability to maintain independence, move around, participate in volunteer work, and engage in the community.<sup>8</sup> Through our focus groups we identified jurisdictional barriers around access to reliable transportation services across the GTA. Compared to those living in Toronto who reported more frequent use of public transportation, the participants living in suburbs showed little or no access to public transportation while expressing frustrations over having to rely on their family members to go anywhere. The limited access to transportation significantly restricted their ability to make doctor's appointments and perform daily activities to maintain and improve their health and well-being.

The current system narrowly focuses on the medial and functional health needs, normally provided by short visits from nurses and personal support workers, while failing to acknowledge the other aspects of support critically needed for older adults to age in place. What we heard from the focus group discussions largely echoes previous research findings.

In her qualitative study on older women's experiences of disability and health decline in Montreal, Grenier<sup>9</sup> found that women's understanding of needs were related to their social contexts broader than functional limitations of their bodies. As the health and social care system mainly focused on the medical and functional understandings of bodies in decline, she argues that assessment and intervention practices often failed to address broader social determinants of health issues, such as transportation and housing, that were closely connected with older women's experience of disability and decline. As also noted in a UK study by Reed & Clarke,<sup>10</sup> needs assessments often fail to capture the complexities of people's lives, leaving a wide continuum of care needs for older adults unrecognized.

Older adults and their families find Ontario's home and community care services inconsistent and hard to navigate.<sup>11,12</sup> Many women in our focus groups also confirmed a limited knowledge of existing services and programs and expressed a strong desire to see more coordinated efforts within and between systems across the care continuum. For those with limited English proficiency and limited familiarity with the local system, this requires more proactive community outreach programs in multiple languages, targeting older adults across diverse ethnocultural communities.

In addition to the navigation barriers, our participants shared financial concerns, although at varying degrees, around whether they could afford the services they need to stay home as they age. More established immigrant participants, mostly from UK and Italian-focus groups, spoke of their inadequate retirement resources, often despite years of work in Canada, to afford private care services to fill the gap between the support they needed to stay home and the support they were currently receiving from various formal and informal sources. More recent immigrant participants expressed their deep concerns about their financial dependence on children as they had no access to full or partial government pensions. Typically, recent immigrants are not eligible for full or partial benefits from the Canada Pension Plan, which requires at least 40 years of work to receive the maximum amount, or Old Age Security, which has a 10 to 20-year residency requirement for sponsored older immigrants. The gendered income and poverty in old age has been well documented. In Ontario, while women outlive men on average, older women have an annual income approximately 32 percent less than their male counterparts.<sup>13</sup> Older women are also twice as likely to live in poverty compared to older men.<sup>14</sup> We also see that people who immigrate to Canada after age 50 have a higher risk of having a lower retirement income and the older a person is when they immigrate, the more likely they are to live in poverty.<sup>15,16</sup> Consequently, when gender intersects with immigration status and language, our findings showed that older immigrant women experienced stress and anxiety as they could not afford the private support, with limited or no public support, to meet their home and community care needs.

Our findings also highlighted the significant role of family caregiving to support older women to age in place, as also documented in other studies in Ontario.<sup>10,11,17</sup> While our participants expressed their appreciation of existing support programs and services as



they improved their health and well-being, the limited support in place led many women to rely on informal caregiving to fill the gap in meeting their everyday needs. Older women in our focus groups shared their experiences of feeling burdensome to their families who had to juggle the caregiving commitment with their own family and work responsibilities. Our focus group discussions also revealed a considerable burden on families, who offered support as caregivers, interpreters, mediators and system navigators to older women with limited English proficiency and little knowledge of the local health and social system. In our companion research paper, we explore further the role of family caregiving from the perspectives of family caregivers of older women from the five ethnocultural communities.

## Limitations

This qualitative study offers a glimpse into the experiences of older women from different ethnocultural groups trying to access home and community care. Building on our previous work,<sup>11</sup> our study reflects the experiences of the 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 older women from diverse ethnocultural groups. When conducting each focus group, we strived to offer culturally and linguistically appropriate environment so that women felt comfortable sharing their own stories and perspectives without linguistic and cultural barriers. By limiting our study to older women from the selected ethnocultural and linguistic communities, however, we recognize that we might have missed the opportunity to hear from women 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 Indian-origin women and Toronto for UK-origin women). While we worked to ensure the diversity within each focus group, our participants were also from relatively healthy and active groups of older adults as they could come out and attend our lengthy group discussions. We also understand that harder to reach older women may have been less likely to come forward or may be socially isolated and therefore may be difficult to include. In our focus groups with family caregivers, which are presented in our companion research paper, we were able to capture some of the experiences of older women with higher care needs from their family caregivers' perspective. Despite the limitations noted, we believe that this data offers valuable insights into home and community care access from the perspectives of older women from diverse ethnocultural communities across the GTA.

## Conclusion

Our research creates a platform for older women from diverse ethnocultural communities to use their own voices to share their experiences and views on home and community care. While acknowledging the commonality and consistency shared by older women across the ethnocultural groups, this report sheds light on some of the unique vulnerabilities that some older women experience, leading to inequities in access to home and community care. The additional barriers – language, recent immigrant status, and limited knowledge of the local system – exacerbates the challenges that older women face in meeting their needs to age in place within the existing home and community system.

Ontario is committed to improving access to home and community care.<sup>18</sup> In recent years, we have seen enhanced support for home care clients and their family caregivers. Yet, the needs of older adults from diverse ethnocultural and linguistic backgrounds are not fully addressed in the current policy discussions. To improve home and community care access for all Ontarians, it is critical for the publicly-funded home and community care system to address and remove access barriers for certain groups of people currently experiencing challenges in getting the right care that accommodate their needs. Based on what we heard from older women from diverse ethnocultural communities, and from their caregivers as presented in our companion research report<sup>4</sup>, our policy brief<sup>19</sup> provides community-informed policy recommendations to improve access to home and community for older adults from diverse ethnocultural communities.

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