



**The Experiences of
Marginalized Canadian
Family Caregivers**

Discussion Paper 2022/2023

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About the Author

Reemal Shahbaz, BSc, MSc

I, Reemal Shahbaz, identify as an able-bodied, cis-gendered female, of Pakistani descent. I immigrated to Canada with my parents and siblings when I was nine years old in March, 2010. I have a Bachelor of Science in Honours Life Sciences and have recently completed my Master of Science in Global Health from McMaster University in Hamilton, Ontario. Further, I belong to the Canadian marginalized family caregivers community as a Muslim woman who engages in caregiving for my two sisters, diagnosed with Cerebral palsy; a motor and cognitive illness. I also provide emotional and financial transnational caregiving to loved ones in my country of origin. I have grown up to believe that it is my religious obligation and a cultural expectation to care for my parents, siblings, extended family members, and those who are in need.



Executive Summary

In October 2023, three virtual roundtable discussions brought together caregiving experts such as researchers, professors, caregivers, and executive members of Canadian caregiving organizations to discuss the experiences of marginalized family caregivers across the country. These discussions aimed to delve into the complex intersectional barriers encountered by marginalized family caregivers.

The roundtable conversations were facilitated by Dr. Adriana Shnall, program director at the Koschitzky Centre for Innovations in Caregiving at Baycrest and an Assistant Professor (Status-Only) at the Factor-Inwentash Faculty of Social Work at the University of Toronto. The collaborative dialogue provided an open and safe space for panelists with diverse backgrounds and specialties to provide insights into the unique challenges of caregiving with the intersection of factors such as culture, socioeconomic, and gender among marginalized populations in the Canadian context. This paper sheds light on the three main themes that emerged from the discourse of the cross-sectoral caregiving experts: nuances in the socioeconomic challenges of caregiving, inaccessibility of caregiver education and support programs, and the invisibility of family caregivers. It is our intent that this paper is used to further highlight the needs of marginalized caregivers, and that it serves as guidance in the field of caregiving within Canada.

THE GUIDING QUESTIONS THAT INFORMED THE ROUNDTABLE SESSIONS WERE:

- I. What are some of the shared challenges that marginalized family caregivers face?***
- II. What changes do we need to make to address these barriers?***





1. Introduction

1.1 Definitions

Marginalized groups are individuals or communities who are being excluded from or face barriers in accessing services and support based on characteristics such as their race, religion, sex, gender, or other identity.¹ This marginalization is caused by fundamental societal inequities and exclusion leading to disparities that impact economic, physical, and emotional well-being. Marginalized groups in Canada are more likely to experience difficulties in care accessibility, receive lower-quality services, face different treatment from healthcare providers, and report being less satisfied with the healthcare system compared to the general population.¹ Marginalized communities include but are not limited to residents of remote regions, 2SLGBTQI+ people, low-income families, immigrants, refugees, Indigenous communities, the homeless, seniors, and members of ethnocultural, Black, and other racialized populations.²

We define a family caregiver as someone who provides unpaid long-term or episodic assistance to a family member, friend, or loved one who is experiencing a significant mental or physical health challenge.³ Care responsibilities can include but are not limited to tasks such as personal care, mobility assistance, and medical care management, practical support such as managing doctor appointments or providing financial aid, and emotional support.⁴ Family caregiving is inclusive and applies to chosen family, as well as traditional or extended family definitions. Terminology such as caregiver, carer, and family caregiver are synonymously used and do not incorporate parenting, child care, or care of loved ones with a short-term illness.³



Caregiving tends to be complex, unpredictable, and can last for years, having a significant impact on the economic, physical, and mental well-being of family caregivers.

1.2 Background

Caregiving is a critical issue in the Canadian landscape. Already an estimated 28% of Canadians engage in unpaid caregiving obligations.^{4,5} In the coming years, this number will continue to increase, especially as the Canadian population ages, leading to a higher number of Canadians bearing caregiving responsibilities.^{6,7,8} **Caregiving tends to be complex, unpredictable, and can last for years, having a significant impact on the economic, physical, and mental well-being of family caregivers.**^{9,10,11}

Although there is clear evidence that family caregivers in Canada face economic, mental, and physical health impacts, **there is a significant lack of data on the intersectional challenges and unique experiences of marginalized caregivers in Canada.**^{9,10,12} This scarcity of research makes it difficult to develop and provide equitable support systems and policies for these caregivers, despite the evident need. While marginalized caregivers share many of the same challenges that all family caregivers face, it is vital to recognize that in comparison to non-marginalized family caregivers, individuals from marginalized communities who are providing unpaid caregiving carry an additional burden stemming from systemic inequalities, historical injustices, and cultural nuances.¹ These challenges are further exacerbated by the

intersection of their identity markers, such as race, gender, and socioeconomic status (SES), making their caregiving experiences more complex.

In an effort to address this, Petro-Canada CareMakers Foundation hosted a series of three roundtable discussions designed to discuss the intersectional challenges that family caregivers within marginalized populations in Canada face and to identify the different opportunities to support them. This discussion paper highlights the themes and conversations shared by a broad range of stakeholders, centering the perspectives and needs of marginalized family caregivers in the discussion.

The needs and experiences of every individual within marginalized communities are unique. This paper may not voice the challenges observed by every member of marginalized groups, however, **it addresses the need for family caregivers from under-served populations to be given the space to lead as the landscape of informal caregiving in Canada continues to develop.** It is only through this that we will be able to build an inclusive and supportive space for marginalized family caregivers to access the services they need.



2. Challenges

The purpose of the roundtable discussions was to better understand the barriers to care faced by marginalized caregivers in Canada. Participants were from a wide spectrum of backgrounds including those from different racial and ethnic communities, genders, and individuals with disabilities. The diversity in the roundtable discussions provided a more robust understanding of shared experiences and common challenges, which will form a starting point for further research and action. A thematic analysis of the three roundtable discussions generated the following three themes: i) nuances in the socioeconomic challenges of caregiving, ii) inaccessibility of caregiver education and support programs, and iii) invisibility of family caregivers.



A key theme from the roundtables was that many marginalized family caregivers do not self-identify as a “caregiver”.

2.1 Nuances in the Socioeconomic Challenges of Caregiving

2.1.1 The Health Needs of Caregivers

Formal employment and unpaid caregiving responsibilities together have a significant impact on the physical and psychological well-being of carers.¹³ One of the most frequently mentioned challenges cited by roundtable participants was the need for caregivers to provide for their own mental and physical health needs on top of providing caregiving requirements for their care recipients. Mental health needs in particular are significant, as many family caregivers struggle with stress and anxiety over their situation. Many participants noted that amongst many marginalized populations, mental health care is overlooked as a priority, and due to the often-additional out-of-pocket expense of these services, they often fall to the wayside. Depending on the frequency and duration of sessions, therapy can be costly and generate additional economic burden on caregivers, especially those who are already grappling with the expenses related to the medical needs of their care recipients while having a low SES.¹³

A key theme from the roundtables was that **many marginalized family caregivers do not self-identify as a “caregiver”**. Participants mentioned that this is often due to cultural norms, and the expectation that marginalized family caregivers will provide care for their family members. Research supports these discussions - in particular, immigrant

caregivers in Canada of Pakistani, African, South American, and Syrian origin report that caregiving is a cultural and religious obligation and that they are expected to take care of their elderly and those in need.²⁶ Individuals from these and other cultures may not self-describe as marginalized family caregivers, but rather as fulfilling their familial duties and abiding by their traditional values.²⁶ In such cases, **caregiver needs often go overlooked as they are not able to see themselves as someone who fulfils the role of a “caregiver”**. Prolonged disregard for their role as a caregiver may propagate poor emotional and physical health, further hindering the financial well-being of marginalized family carers.^{14,15}





Approximately 600,000 young Canadians aged 15 to 19 are family caregivers.



2.1.2 Personal Expenses on Medical Necessities

The economic cost of family caregiving in Canada is massive and poses a significant challenge to many family caregivers. The Conference Board of Canada determined that family caregivers of aging adults spend an average of \$5,800 annually out-of-pocket to provide caregiving for their loved ones.¹⁶ Participants emphasized that marginalized family caregivers often incur additional out-of-pocket expenses beyond that amount. These costs can be substantial and place financial strain on family caregivers who are already facing financial hardships. Participants expressed that even if caregivers are making a decent earning, much of their income is spent on medical equipment, respite care services, and other costs related to treatments for their care recipients. According to the most recent Census in 2021, marginalized groups in Canada such as Indigenous peoples and those who are visible minorities had disproportionately low levels of income.¹⁷ The intersection of increased household expenses, inflexible employment, and limited access to services can create a cycle of poverty for marginalized family caregivers.

Roundtable participants emphasized several specific populations for whom the personal expenses of caregiving may prove to be an extreme burden. In particular, participants touched on the greater impact on Black family caregivers, and other racialized populations who due to historic discrimination, have a lower annual household income in Canada relative to the general population.¹⁸ These levels of income inequality create disproportionately high economic hardships when purchasing care supplies and making home modifications to accommodate the needs of their care recipients.^{19,20} Participants also alluded to the significant burden young caregivers face by simultaneously managing their school life and caregiving obligations which

can have a lasting impact on their educational attainment and long-term financial success. **Approximately 600,000 young Canadians aged 15 to 19 are family caregivers.**²³ Young caregivers report falling asleep in class, having a hard time focusing on their education, and receiving poor grades as a result of caregiving. Many leave school early or delay further education to work and provide for the financial needs of themselves and their care recipients. This places future job prospects in danger and can drain their savings accounts.²¹

Marginalized family caregivers and their care recipients can face added expenses that are rooted in cultural or societal expectations that may differ from the general caregiving population. Many roundtable participants mentioned that in particular newcomers to Canada often feel that because certain health services are free, they should not question the care they are offered. Participants said because of cultural norms, newcomers avoid complaining and try to adjust to what they are being offered. Participants in the roundtables also pointed out that the perception that the Canadian healthcare system is “free” is often not true for family caregivers. While many services are covered by provincial health care systems, there are many other necessary or specialty services such as prescription medication, home care support, dental or vision care, and more that require out-of-pocket spending.²² Experts in the roundtable discussions voiced that many care recipients require multiple assistive devices, accessible home upgrades, and other supports to function in their daily lives. In particular, hearing aids, visual aids, and communication devices, along with the costs of stair lifts, walk-in showers, and Hoyer lifts can add up and put marginalized caregivers in profound financial difficulties.²²



Afolasade Fakolade, PhD
Assistant Professor
Queen's University

“ My caregiving journey began with my mother’s cancer diagnosis. Even as a healthcare provider, I was unprepared for the overwhelming physical, emotional and economic strain of balancing work and caregiving. Despite my healthcare background, advocating for her proved challenging, underscoring the difficulty of caring for oneself while supporting others. My subsequent research on the impact of disability, particularly multiple sclerosis, highlighted the interdependence between care recipient and caregiver well-being.

Through stories shared with me in my work, I’ve seen the vulnerability of marginalized caregivers, and the inequities they experience navigating healthcare. Culturally care is vital for family caregivers to access necessary services. Without this nuance, many will not be able to access the services they need. The current system must evolve to prioritize family-centered care, acknowledging the unique needs of marginalized caregivers. Without integrating caregivers into care provision, especially for marginalized individuals, we risk perpetuating failures in supporting both caregivers and those in their care.

“[Caregivers] are already overwhelmed with all caregiving work. So part of our job as health and social care providers is to signpost them. Like, hey, this is available. I really think that you’d benefit from this.”

2.1.3 Balancing Caregiving and Employment

One common theme expressed by roundtable participants was the impact of balancing paid employment and unpaid caregiving responsibilities. Many expressed that the lack of caregiver-friendly workplace policies in Canada causes marginalized family caregivers to reduce work hours or take unpaid leave to fulfil caregiving responsibilities. **Caregiving responsibilities such as assisted transportation and attending doctor appointments often coincide with traditional working hours, which result in absenteeism, financial stress, and loss of necessary income.**^{2,23} This lack of flexibility in work arrangements makes it hard for family caregivers to manage their care and employment responsibilities without negative effect on their income.²³ Research consistently shows that **caregivers, especially those from racialized backgrounds, often end up retiring early, changing their occupations, or decreasing work hours.**⁷ They are more likely to accept a job at a reduced income or stop working to balance care responsibilities.^{7,24} Insufficient inclusion policies in places of employment can exacerbate challenges for marginalized family caregivers, leaving them in financial instability.²³

Marginalized populations are significantly underrepresented and undervalued in the Canadian labour market. Marginalized family caregivers such as those from racialized communities, youth, and people with disabilities, face additional obstacles to equal employment due to race-based discrimination, wage inequality, lack of recognition of foreign credentials, and more.^{10,25,26} Due to this, many are underemployed, or have precarious employment, making them even more vulnerable to job-loss. Roundtable participants shared that family caregiving responsibilities often lead to additional barriers to finding adequate employment that can provide the paid leave or flexibility their situation requires. This in turn provides yet another impediment to building lasting economic stability such as saving for their futures, affecting the economic and emotional well-being of the caregiver and their family members. Marginalized populations are at risk of experiencing higher economic impact as a lack of caregiver-friendly workplace policies can lead them to quit their jobs and in return observe economic losses such as a decreased pension, problems re-entering the labour market, and poverty in the long run.^{8,16,17}



Olivia Wilks

Family Navigator
Family Navigation Project at
Sunnybrook Health Sciences Centre

“ My journey as a navigator at Sunnybrook’s Family Navigation Project is deeply rooted in personal and professional connections to family caregiving. Witnessing my own mother, a single parent from the West Indies, navigate complex systems to ensure her daughters had the support they needed, instilled in me the value of being a voice and an advocate for one’s family. This experience became the driving force behind my work helping family caregivers access crucial resources.

Discussing the challenges faced by marginalized caregivers is crucial because their voices have been excluded, and there exists a historical lack of trust with those in positions of power. The fragmented system leaves many of the families I work with, especially from marginalized communities, struggling with extended wait times, high staff turnover, and service eligibility issues. We need to empower marginalized caregivers, create safe communities, increase resource accessibility, and reduce geographic and institutional barriers. Caregiving is not a one-size-fits-all situation; every family’s caregiving journey is unique, and they deserve the support and empowerment to navigate it successfully.

“Many marginalized caregivers feel invalidated or dismissed by service providers. As a navigator, bridging that connection reinforces the fact that families do matter, especially for marginalized communities. They matter, they’re important. They deserve care just like anyone else.”

2.2 Inaccessibility of Caregiver Education and Support Programs

2.2.1 Lack of Awareness about Available Services

Existing research shows that **the majority of caregivers in Canada lack access to caregiver-friendly information such as financial and emotional support services that could facilitate them in managing their caregiving responsibilities.**^{9,10,12} Many roundtable participants identified that the complex environment of care provision in Canada makes understanding what is available almost as challenging as accessing the care itself, in particular for caregivers who may not have a comprehensive understanding of the healthcare system, or technology. Participants referenced a variety of intersectional challenges that take up the limited time and resources of marginalized caregivers, thereby contributing to a lack of awareness of available services. These challenges include many already mentioned here, such as employment struggles, food insecurity, language barriers, geographic distance, time poverty, and more. Consequently, caregivers are simply not aware of the resources that they could receive. Many caregivers struggle to know where they can easily identify what services they might qualify for, or benefit from. Participants emphasized that a

significant barrier to accessing services for marginalized family caregivers is a lack of awareness of not only generally accessible services but particularly those that are designed specifically for the needs of different marginalized populations.

Participants at the roundtables highlighted the need for greater outreach from service provision organizations to increase caregiver awareness, however, there are challenges in enacting this solution. Particularly for under-resourced community organizations providing culturally appropriate and specific care, the time and cost of community outreach may not be possible. The representatives of service provision organizations at the roundtables pointed out that the funding and resources necessary to provide this intensive outreach were simply not available, noting how this creates an additional barrier to awareness and access. The challenge of outreach in culturally, linguistically, or community-focused ways is a major barrier to family caregivers’ awareness of services designed to build comfort, which in turn leads to reduced access.²⁷

2.2.2 Language Barriers

Participants of the roundtables discussed that many marginalized populations, in particular allophones and newcomers to Canada, face language barriers in accessing relevant services. They noted that a lack of English or French proficiency significantly impedes caregivers' ability to receive appropriate healthcare resources for themselves or their care recipients. **As of the 2021 census, more than 4.6 million Canadians speak a language other than English or French at home, and 6.8% of newcomers speak neither language at all.**²⁸ These individuals experience significant barriers when seeking medical care from health professionals who are not proficient in the first language of either the marginalized caregiver or the care recipient.²⁸ This prevents carers from easily navigating the health system and accessing appropriate care.²⁸ Of particular issue is the use of highly specific medical terminology employed by healthcare providers, which makes it challenging for allophones to understand and question the services they are receiving, or even advocate for their needs as effectively.²⁹

Many participants in the roundtable discussions cited the additional burden that many marginalized family carers face when translating for the person they are providing care for. Participants explained that in particular young caregivers from immigrant households often have to be present at all appointments to provide translation for their loved ones.³⁰ **Acting as a translator can place additional burdens on young caregivers as they feel that they must accurately translate information from the health professionals to their family members.**^{30,31} Translation of medical diagnoses and terminologies can be complicated as young carers may not comprehend medical jargon which can potentially cause miscommunication between the care-recipients and the health professionals. Young caregivers can feel anxiety and stress for being given the responsibility of linguistically translating for family members who do not speak English.³⁰

One roundtable discussion used the example of the challenges deaf caregivers face in accessing appropriate services. Participants said that as with many other marginalized family caregivers, deaf carers may struggle to convey their concerns or understand medical instructions. Previous research displays that many deaf caregivers and care recipients are vulnerable to increased health disparities and a worsened quality of life.³² **The longstanding history of inequitable access to accommodations such as sign language interpreters and video relay services in the medical settings are systematic challenges in the Canadian healthcare system, that place barriers to accessing equitable care.**³³ These communication barriers prevent deaf caregivers from adequately conveying or understanding medical information which hinders their ability to access health services for themselves and their care recipients.³²





Marginalized carers such as older adults and individuals from low-income families can experience difficulties travelling to hospitals and clinics when they accompany their care recipients, making accessibility of care stressful and time-consuming.

2.2.3 Rural vs. Urban Settings

Carers residing in regions that are classified as rural and remote often have less favourable social determinants of health such as low income and reduced educational background.³³ In rural settings of Canada, resources are scarce, such as fewer doctors, nurses, and home support personnel, and less healthcare infrastructure in comparison to urban centres. This makes it challenging for marginalized caregivers to receive specialized care for their unique psychosocial needs. Roundtable participants pointed out that living in rural areas creates an additional intersectional dimension for marginalized family caregivers. Caregivers in these hard-to-reach communities can feel isolated and stressed due to social and geographic isolation, and distance from quality care.³³ This makes it hard for caregivers to secure timely care and medical attention for themselves and their care recipients.^{33,34} Remote regions also have a lack of public transportation that inhibits the ability of marginalized carers to access care facilities and can lead to missed appointments.³³

While urban areas in Canada generally have more services, experts from the roundtable discussions underscored that marginalized family caregivers may still face hardships in

accessing services. Participants discussed that the siloed nature of caregiver and care recipient resources often requires frequent transit between distant neighbourhoods where specific services are available. This is in addition to rigid access requirements that prevent some from accessing the services geographically closest to them, due to a technicality.^{35,36} Participants explained that specifically for marginalized caregivers, time poverty, or the lack of free time to spend accessing services is frequently compounded with lack of affordable and accessible transportation. Urbanized regions in Canada frequently have transportation problems such as heavy traffic congestion and limited parking options, and over a million Canadians suffer from limited access to available transit.^{35,36}

Marginalized carers such as older adults and individuals from low-income families can experience difficulties travelling to hospitals and clinics when they accompany their care recipients, making accessibility of care stressful and time-consuming.³⁷ Metropolitan areas can additionally have overcrowded facilities leading to marginalized caregivers experiencing long wait times for doctor appointments which can ultimately delay diagnosis and treatments.^{37,38}

2.3 Invisibility of Family Caregivers

2.3.1 Care without the Caregiver

The Canadian healthcare system has traditionally placed an emphasis on task-centered care delivery, rather than person-centered holistic care, failing to address the essential role that family caregivers play in the well-being of care recipients.³⁸ **Many individual care providers and healthcare organizations do not perceive marginalized caregivers as part of the care team and do not treat their input as valuable or important.** As a result, the care recipient may not receive comprehensive and effective care.³⁸ Roundtable discussions highlighted that the healthcare system excludes caregivers in its efforts to prioritize the needs of the care recipient, and emphasized that there is a need for healthcare providers to recognize that all family caregivers are a vital part of the caregiving team. In particular caregivers from marginalized populations, many of whom have unique cultural and familial relationships to caregiving, play a critical role. The participants discussed how greater acceptance and involvement of caregivers in care would build trust in individual and institutional service providers, and enable caregivers to provide more informed care. Research shows that the absence of service provider training on the importance of caregivers and the part that they play in the health journey of patients is preventing a more holistic approach to care delivery which can lead to better health outcomes and lower costs for the patients and their caregivers.^{38,39}

Participants of the roundtable discussions noted that marginalized carers play the role of “cultural experts”, who understand the culturally appropriate needs of the care recipient. They further emphasized that family caregivers are the individuals who are often most knowledgeable about the needs of care recipients, as they are providing personal support on a day-to-day basis. Research shows that caregivers

from marginalized communities have the familial dynamics and cultural understandings that are crucial in the caregiving process of a patient.^{40,41} Participants explained that this is overlooked by the healthcare system, and as a result, it hinders the visibility of marginalized caregivers as they do not receive the attention and care they deserve. **The Canadian healthcare system does not prioritize and value the cultural expertise of visible minority family carers while providing care to individuals from these ethnocultural minorities.**^{41,42} The lack of acknowledgement of marginalized caregivers as cultural experts and advocates is a significant obstacle in achieving tailored patient-centered care which values and considers the opinions of the caregivers which can lead to improved care services for the patient.^{40,41}



2.3.2 The Normative Design of the Healthcare System



All three virtual roundtable conversations highlighted that there is a need for the healthcare system to recognize the “non-normative” and offer sensitive services that understand the unique needs of marginalized populations. This ranges from services that address the medical demands of those with disabilities, to culturally specific care that recognizes historical trauma and medical mistrust. Participants expressed that when these needs are not understood, it creates a feeling of invisibility for marginalized caregivers, and alienates them further from the healthcare system. Research shows that **the Canadian healthcare system predominantly caters to the general population rather than to those with additional or outlying needs.**⁴³ Marginalized family caregivers and their loved ones, however, are considered “non-normative” in care systems. As a result, **health professionals are ill-equipped to deal with the unique challenges that caregivers from marginalized communities face.**^{42,43} Healthcare providers do not receive adequate training and education on the distinct health requirements that carers from various intersectional identities have historically encountered. The Association of Faculties of Medicine of Canada has recently stated that Canadian medical training lacks diverse learning contexts that can support marginalized communities like low-income families and minority cultures and religions.⁴³ This ultimately causes a lack of support and understanding from medical professionals into the unique ways that marginalized caregivers and care recipients can be assisted.^{42,43}

Culturally competent medical care means that healthcare providers and systems understand and incorporate cultural intelligence into delivering healthcare services.⁴⁴ Roundtable participants mentioned that there is a lack of culturally competent care available for marginalized family caregivers in Canada. One particular example was that some immigrant families fear getting a diagnosis from physicians. One roundtable participant mentioned that many immigrant parents are afraid that their children may not get jobs in the future if they are diagnosed with a mental health condition as a result of their caregiving duties. In Canada, as a result of immigration, many patients have diverse behaviours and values that are shaped due to intersectionality factors such as gender, ethnicity, race, religion, sexual orientation, and SES.⁴⁴ The goal of cultural sensitivity in healthcare is to ensure that patients obtain quality care, regardless of their ethnic, racial, or religious backgrounds.⁴⁴ However, many marginalized communities in Canada still do not receive culturally competent care, and as a result of this, individuals within these groups avoid seeking care.^{45,46,47} In addition, Canadian medical institutions lack diversity and representation from marginalized communities. As a result, few service providers are taught about or have lived experience regarding cultural traditions, community values, or specific needs when caregivers and their care recipients require medical attention.^{47,48} **Since marginalized caregivers have difficulty finding health professionals who relate to them, many do not feel comfortable seeking care.**^{45,47,48}



“ As a Black disabled woman, and a caregiver for family members who also have disabilities, I experience first-hand the complexities of navigating the caregiving space. The strong Black women stereotype, and societal expectation that Black women will take on caregiving roles, further compounded by systemic issues of anti-Black racism, ableism, gender biases, and historical trauma, means we do not have access to equitable or culturally- responsive resources. There is an image of what health and disability look like for Black people, but it’s based on white, male, institutionalized studies, completely overlooking the Black experience. Instead, there is an expectation by society that we will carry on, silently, in a system where there is no care for the caregiver.

This lack of support for Black caregivers leads to not only exclusion, but invisibility. When Black caregivers’ voices are silenced, it makes caregiving even more challenging, especially when our voices are seen as a problem. Advocacy and research are the first steps towards making sure caregivers feel seen. We must problematize Black gendered stereotypes, and create space for all people’s voices.

“Caregiving is not resilience, it’s resistance”

– **Liza Arnason**, Founder

ASE Community Foundation for Black Canadians with Disabilities

2.3.3 Medical Mistrust

Medical mistrust is when individuals have a lack of trust in healthcare providers and organizations stemming from historical and contemporary trauma and discrimination that marginalized caregivers and their communities have experienced.⁴⁹ Roundtable participants noted that marginalized family caregivers, particularly within Black or Indigenous communities, face or worry about facing racism from healthcare providers. Participants shed light on how marginalized caregivers have trouble trusting a system that has historically neglected and overlooked them. **Discrimination, bias, and unethical standards of healthcare that Black family caregivers and other racialized populations have been subjected to by the healthcare system have left a lasting legacy of trauma** in Black individuals.⁵⁰ For example, Black communities in Canada experience disproportionate health disparities such as increased rates of long-term illnesses and shorter life expectancies. This shows that there is a lack of effective care that meets the needs of this marginalized population which further leads to caregivers avoiding care.^{49,50,51}

Roundtable participants emphasized that this mistrust and concern around stigma from service providers is reflected across many historically marginalized communities. Participants referenced that members of the 2SLGBTQI+ community who are family caregivers also have medical mistrust in the healthcare

professionals because they too have observed long-standing mistreatment and discrimination in the care systems. Participants talked about how healthcare providers are not adequately trained to recognize the unique health needs of sexual minorities. Research reveals that healthcare institutions lack gender-affirming care and educational programs that reduce disparities and make individuals from a broad range of sexual orientations comfortable trusting healthcare providers.^{52,53}





There is a lack of race-based data and research in Canada that can provide quantifiable evidence about the stark racism and discriminatory practices faced by marginalized caregivers accessing the healthcare system.

2.3.4 Data Issues

There is a lack of race-based data and research in Canada that can provide quantifiable evidence about the stark racism and discriminatory practices faced by marginalized caregivers accessing the healthcare system.^{54,55,56} Roundtable participants discussed that there is a lack of evidence into the experiences of caregivers with intersecting identity markers such as race, religion, gender, and sex. Participants talked about the importance of understanding the needs of vulnerable marginalized populations but noted that there is no significant body of research or collection of data specifically focused on this outcome. The insufficient data surrounding marginalized caregivers can hinder policymakers, service providers, and researchers from developing tailored resources to meet the needs of these underserved communities.

Roundtable participants strongly felt that there is a need to create major systemic change in the Canadian healthcare system, to ensure that all people living in Canada receive adequate and appropriate care. They emphasized that one important step towards achieving this goal for marginalized caregivers is the collection and sharing of data showing the extent of the inequities and disparities faced by marginalized individuals, and the challenges they face when navigating

the healthcare system. Disaggregated race-based data which further breaks down into more specific components such as First Nations, South Asian, and Black Caribbean **could provide an additional robust comprehension of the realities that different groups of marginalized caregivers face.**⁵⁴ Within the Canadian context, the lack of standardized collection, distribution, and analysis of disaggregated race-based data prevents the generation of efficient educational programmes and public health strategies that could help improve the health outcomes of marginalized family caregivers.^{54,55}





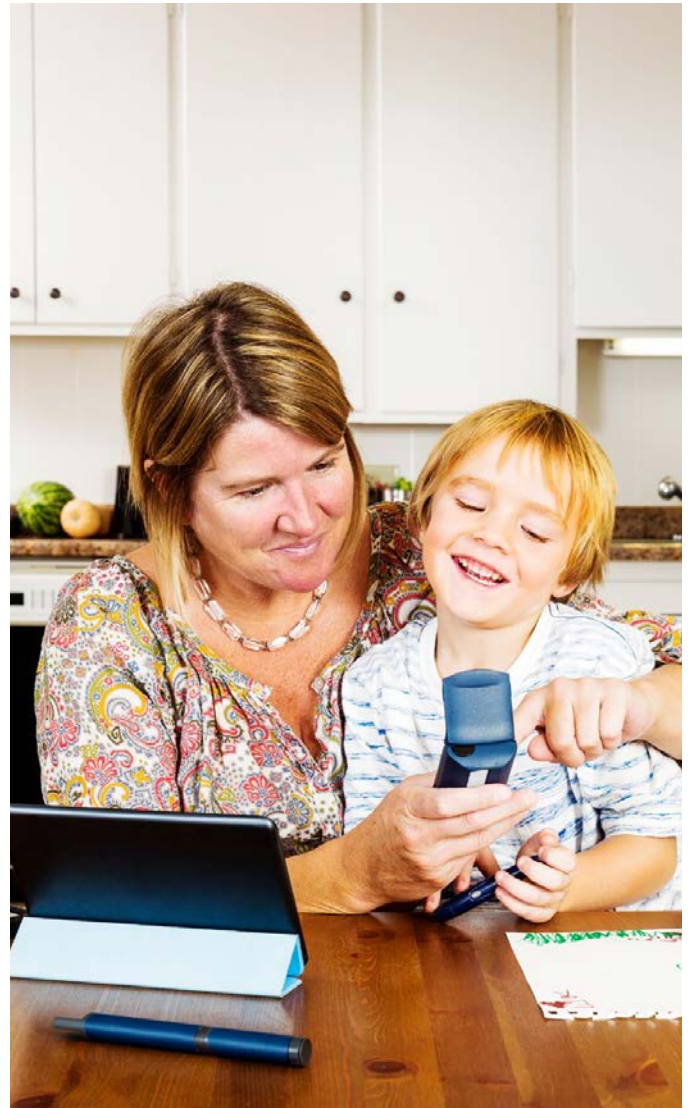
3. Moving Forward

Alongside the intersectional challenges faced by marginalized family caregivers, roundtable participants identified several areas of focus for potential solutions to create change and address the highlighted barriers. These solutions were targeted toward affordable healthcare services, improved accessibility of care systems, and the placement of marginalized family caregivers at the forefront of decision-making processes.

3.1 Affordable Services

Roundtable participants identified the crucial need to develop strategies that prioritize sustainable funding for support services geared toward marginalized caregivers. Participants stated that as a result of unstable funding, **caregiver service providers face issues such as high staff turnover rates, increased costs for clients, program discontinuation, or a reduction in the quality of service provision.** Sustainable funding can allow service-providing organizations to offer supports to marginalized communities at more affordable prices or even free of cost.⁵⁷ When funding is stable, care providers are more likely to subsidize costs, and in the process alleviate some of the economic and emotional burden on carers.^{57,58} Making services such as mental health counselling and respite care lower in cost or even free will reduce the out-of-pocket expenses of marginalized caregivers, which can, in turn, decrease caregiver burnout and stress.⁵⁹

To have long-term funding available for service organizations that aim to offer assistance to marginalized family caregivers, **there must first be recognition by healthcare stakeholders and the government of the vital role that family carers play in the overall well-being of a patient.**⁵⁸ Advocacy, collaboration, and coordination of expertise among caregivers, healthcare institutions, and the government can ensure that there are more caregiver-friendly programs and that they are funded and capable of adapting to the changing demographic patterns of Canada.^{58,59}





Public awareness campaigns can decrease health disparities by enhancing awareness of available support resources for marginalized communities, leading to more equitable access to healthcare.

3.2 Improved Accessibility

Participants from the roundtables stated that there is an immediate need for public awareness campaigns, community programs, and a more accessible flow of information about resources to marginalized caregivers. Participants stated that through this, caregivers who have been historically underserved may be able to better identify and utilize resources such as social services, respite care options, and financial assistance programs. **Public awareness campaigns can decrease health disparities by enhancing awareness of available support resources for marginalized communities, leading to more equitable access to healthcare.**^{60,61} The implementation of policies and practices focused on increasing awareness about support services among marginalized family caregivers can result in less emotional distress, better psychological health, and an overall greater quality of life.^{61,62} In addition, participants expressed the need for cultural or community navigators, to facilitate the challenging process of navigating the health care system for marginalized caregivers. These navigators would increase awareness of relevant services, and improve the ability of caregivers to “speak the language” of the system to access these resources more effectively.

Roundtable conversations also underscored the need for community-based safe spaces that can provide support to marginalized caregivers. Participants suggested networks like community hubs would allow marginalized caregivers to share information on important resources such as culturally relevant services, or existing supports. **Stronger community networks and awareness initiatives for marginalized family caregivers can lead to decreased isolation and increased support for caregivers**, thereby reducing financial, emotional, and physical burdens.⁶²





Involving marginalized family caregivers in advocacy and policy-making decisions can improve the cultural competency of the healthcare system, ultimately enhancing the quality of care for members of underserved communities.

3.3 Marginalized Communities at the Forefront

Participants from the roundtable discussions stated that representation is critical for caregivers. They mentioned that marginalized family caregivers need to be central in advocacy, the design of caregiver support services, and discussions around caregiving in general. **Involving marginalized family caregivers in advocacy and policy-making decisions can improve the cultural competency of the healthcare system, ultimately enhancing the quality of care for members of underserved communities.**^{63,64,65,66} By giving marginalized caregivers a seat at the table, there will be increased awareness about culturally appropriate care and their other needs.

In addition to this, participants suggested changes to the education of service providers such as doctors and nurses. They felt that training that highlights cultural awareness, the importance of family caregivers, and the unique needs of marginalized populations is vital to the prioritization of their needs. When combined with policy changes, the resulting **culturally sensitive care can be the first step towards building trust with healthcare service providers and professionals**, increasing adherence to seeking treatment plans, and an overall more effective delivery of care that is aligned with the preferences of underserved communities.^{65,66}

Participants of the roundtables also stated that to increase the visibility of caregivers with intersectional needs in the healthcare system, there needs to be a significant increase in available data on marginalized populations. More nuanced data that acknowledges the different needs of all people living in Canada will allow service providers, organizations, and the Canadian government to explicitly address these needs. There is a growing movement in Canada for the collection of more diverse and representative race-based data. This **data can shed more light on social inequities, validate the lived experiences of marginalized individuals, and hold public institutions accountable for developing frameworks that address systemic injustices from an intersectional lens.**⁵⁴





4. Conclusion

Marginalized family caregivers living in Canada face a variety of intersectional challenges that create barriers to appropriate, accessible, and dignified care for their loved ones. From the perspectives of a diverse group of researchers, professors, caregivers with lived experiences, and service-providing organizations, these three virtual roundtable dialogues emphasized the importance of prioritizing the needs and voices of underserved individuals in the caregiver space.

By understanding the different intersectional barriers that marginalized family caregivers face, there may be greater initiatives geared toward inclusive and equitable care systems. Implementation of gender-sensitive and caregiver-friendly policies in establishments can enhance the quality of life of marginalized caregivers and the welfare of broader Canadian society. It is essential to normalize discussions on the experiences of marginalized caregivers so that there can be greater advocacy for expanding resources to address the unique needs of communities that are historically overlooked and excluded.

We at the Petro-Canada CareMakers Foundation, alongside the organizations we partner with, are committed to empowering the voices of these populations and shedding light on their experiences. By bringing these crucial issues to the forefront, we aim to foster an understanding of the daily challenges faced by these caregivers. This paper serves as a valuable resource, providing insights for those seeking to understand the complexities of marginalized family caregiving. Moreover, we hope it offers a glimpse into the importance of the cause, and why our Foundation has chosen to focus its efforts in this space.

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