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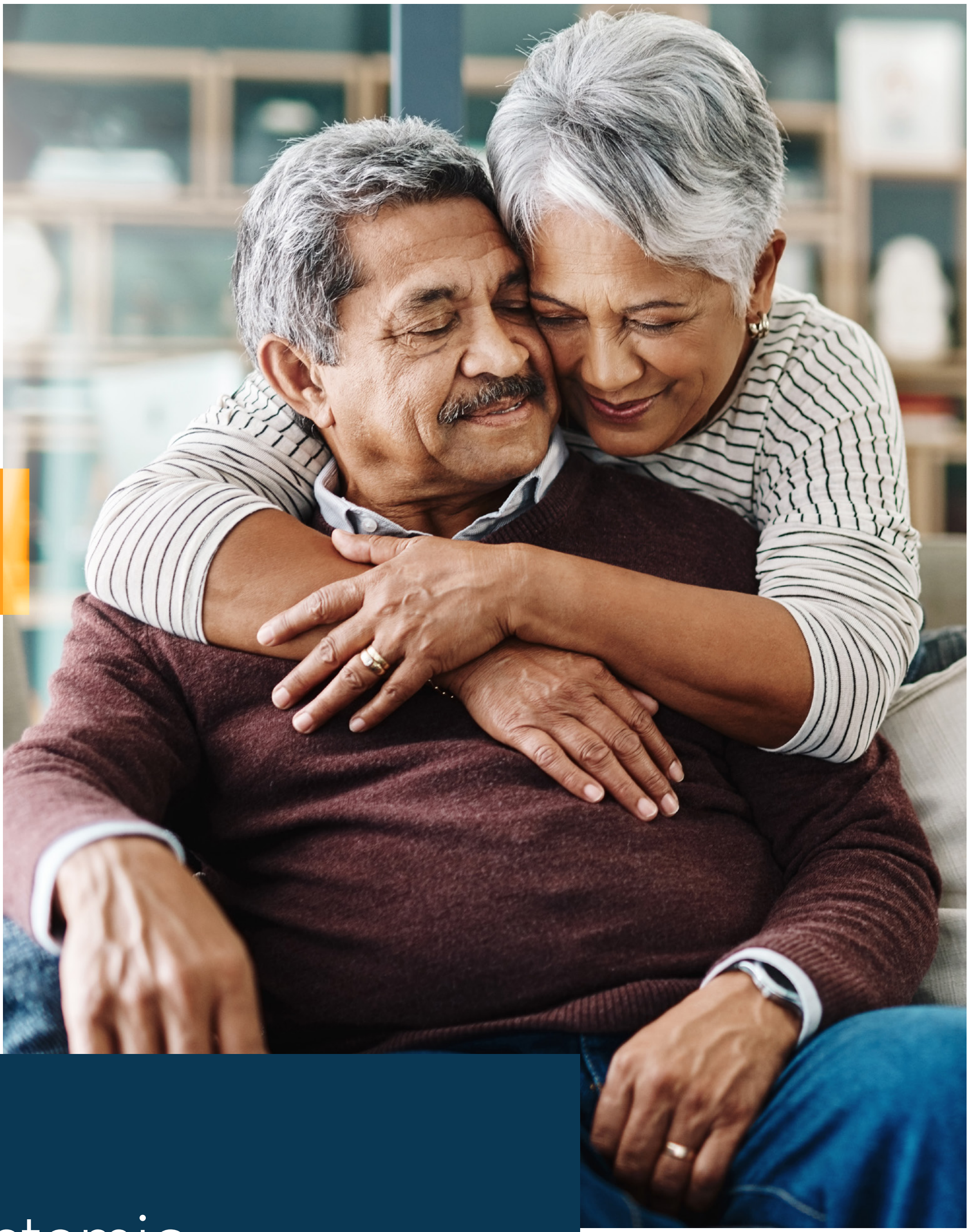
FAMILY CAREGIVING
IN CANADA



Addressing Systemic Challenges and Identifying Opportunities for Action

DISCUSSION PAPER —— 2021 / 2022

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Acknowledgements

In October 2021, a diverse group of caregiving thought leaders, practitioners and caregivers with lived experiences met virtually to explore systemic challenges impacting caregivers and discuss opportunities to increase awareness of the importance of caregiving and better address the needs of caregivers. The sessions provided valuable insights and helped us develop a more nuanced appreciation of the varied and complex issues in the caregiving space. It further clarified the potential role for charitable organizations to partner with other agents of change to overcome them.

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Executive Summary

Petro-Canada has identified family caregiving as a national priority and has made a long-term commitment to this important social issue through the establishment of a charitable organization called the Petro-Canada CareMakers Foundation/ Fondation proches aimants Petro-Canada. Established in November 2019, it is one of only a select few organizations in Canada focused exclusively on caregiving. The Foundation's goal is to support family caregivers, while inspiring the rest of Canada to do the same, and aims to achieve this goal through four pillars: grant making; raising awareness; thought leadership; and fundraising. Furthermore, the Foundation believes that supporting carers is a societal responsibility which should be taken up by the public, non-profit/charitable and private sectors.

This paper was developed based on a series of virtual roundtable conversations, with a cross-sectoral group of caregiving experts, including healthcare professionals, service providers, researchers, employers, non-profit organizations, charitable institutions and caregivers with lived experience. Stakeholders provided insight and recommendations on a range of challenges and opportunities facing Canadian caregivers.

The roundtables were facilitated by Dr. Adriana Shnall, Program Director of the Koschitzky Centre for Innovations in Caregiving at Baycrest Health Sciences Centre, and Assistant Professor (Status Only) at the Factor-Inwentash Faculty of Social Work and the Institute of Life Course and Aging at the University of Toronto.

THE GUIDING QUESTIONS FOR THE ROUNDTABLE DISCUSSIONS WERE:

- *What are the important systemic challenges impacting caregivers at the micro, meso and macro levels?*
- *What are the opportunities for change and action?*
- *What is the role of charitable organizations, in partnership with others, in addressing these?*

This paper synthesizes the challenges and proposed opportunities for action identified by roundtable participants. This paper also builds upon the caregiving literature; the important work of Canadian organizations specializing in caregiving, including the Canadian Caregiver Coalition, the Vanier Institute, the Change Foundation and Carers Canada; and finally, the inaugural Petro-Canada CareMakers Foundation report published in 2020, entitled "Caregiving in Canada: Challenges and opportunities shaping a national conversation." This paper also begins to explore the role of the Petro-Canada CareMakers Foundation/ Fondation proches aimants Petro-Canada in improving the lives of caregivers in Canada, with the understanding that supporting carers is a societal responsibility with a role for public, non-profit/charitable and private sectors to play. It is our intent that this paper will be used to generate awareness of challenges faced by caregivers and their advocates, highlight opportunities for change and action at multiple system levels and serve as a roadmap for action and change for caregiving in Canada.

Introduction

At some point in our lives, we will all be caregivers to a family member or friend with a long-term health condition, physical or mental disability, or problem related to aging, or need a caregiver ourselves.[1]

> Until you have experienced what it is like to care for a child with a disability, a spouse with dementia, or a parent with mental illness, it is difficult to wholly and adequately capture what it means to be a caregiver.

It can be an intensely rewarding experience but for many it also involves practical and profound challenges across multiple dimensions of well-being, including physical health, emotional well-being, financial health, relationships and role functioning.[2,3,4]

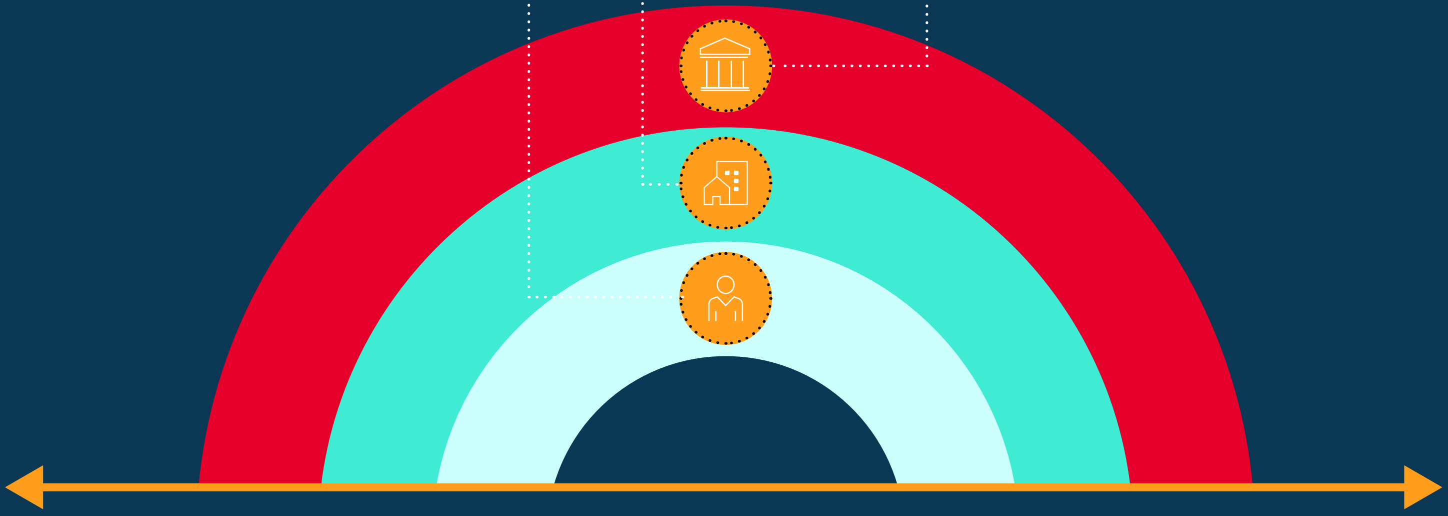
Social and financial supports and other forms of assistance can mitigate some of the potential negative impacts associated with caregiving; but to date, the issue of family caregiving has gone largely ignored by governments, policy makers, healthcare professionals and the general public alike. Additionally, our health and social care systems are designed around acute care needs and fare less well in dealing with chronic and aging-related conditions.[5] The burden has thus fallen to informal networks to make up for social and systemic gaps.

The COVID-19 pandemic has increased awareness of the challenges faced by Canada's eight million caregivers (or 25% of Canadians aged 15 and up),[6] and has created an environment that is more receptive to addressing caregiving issues. Given that caregiving will only grow in importance as Canadians continue to age with more health conditions, it is imperative to focus on what we can do as a collective to improve the lives of caregivers, both present and future.

Across multiple levels (micro, meso, macro), this paper presents the challenges and potential solutions to issues impacting caregivers in Canada. The ideas presented here were identified and discussed by a diverse group of caregiving experts, who participated in a series of roundtable discussions convened by the Petro Canada CareMakers Foundation in October 2021. This paper concludes with a discussion on the evolving role of the CareMakers Foundation and other grant makers working in the caregiver space.

Definitions:

We define a family caregiver as someone who provides unpaid assistance to a relative, partner, friend, or neighbour with a long-term health condition, a physical or mental disability, or problems related to aging.[7,8]
By assistance, we refer to tasks or activities such as providing personal care (e.g., assistance with bathing, toileting and dressing), medical care (e.g., assistance with medication management or wound care), practical support (e.g. assisting with finances, transportation, meal preparation, house cleaning, home maintenance or scheduling or coordinating care-related tasks), and emotional support.[9] We use the terms caregiver and family caregiver synonymously and take an inclusive approach in defining family to include chosen family as well as traditional family relationships. We note that caregiving does not include childcare, parenting, or care for individuals with minor short-term illnesses.[10] We refer to the person who is receiving care as a "care recipient."



MICRO

Age/life stage
Physical & emotional health
Financial health
Support network
Knowledge, skills, training
Self-identification as caregiver
Language
Culture
Relationship to care recipient

MESO

Community resources
Caregiver workplaces
Educational settings
Healthcare institutions

MACRO

Social norms and cultural norms
Political forces
Public media
Public policy
Healthcare and social services
Public programs
Legislative and legal factors
Macroeconomic forces

FACTORS INFLUENCING FAMILY CAREGIVING

(The arrow extending across the three levels suggests that factors or barriers extend into and interact across various levels.)

> We group challenges and opportunities according to different levels of analysis- micro, meso and macro.

We define micro as pertaining to individuals, families, and their one-on-one interactions with others, such as individual interactions with healthcare providers. We define meso as relating to specific groups, communities, or organizations within society, such as workplaces, educational settings, and neighbourhoods. We define macro as broader system-level forces that shape our society, including economic, political, legal, cultural, and social factors. In reality, there are complex interconnections between and across these levels of analysis; we use the categories as a framework to organize our thinking. The ultimate foci are to better understand how caregiving issues and caregiving experiences are influenced by individual interactions, and how these are shaped by broader social forces, to highlight opportunities for collaboration across these levels and ultimately achieve better outcomes for caregivers.

Challenges

A deeper understanding of the various challenges faced by caregivers is critical to inform the design and implementation of solutions. The following challenges were identified by roundtable participants as important barriers for caregivers, and those working to support them.

Challenges at the Micro Level:

SELF-IDENTIFICATION AS CAREGIVER

A commonly cited challenge among roundtable participants was that many caregivers do not recognize themselves as caregivers. Many do not feel like they have a choice in assuming a caregiver role, viewing it instead as a familiar or cultural expectation or natural progression in their role as adult child, partner, or parent. Indeed, some cultures do not have a word for "caregiver." Similarly, shifting into a caregiver role may be a long and gradual process for some, and one without a clear starting point. Until care becomes more intensive, frequent, or specialized, or until the caregiver is in crisis, it is less likely for them to recognize themselves as such and/or seek help and additional resources.[11] There may also be a natural resistance to viewing oneself as a caregiver as it can be an emotionally laden term, and a marker that things are changing. Participants highlighted that this challenge can make it more difficult for caregivers to acknowledge and validate their own distress, can influence the likelihood in accessing supports for themselves, and can also make it more difficult for agencies to reach them.

> *In Canada, it is estimated that 75% of care is provided by unpaid caregivers.*

LACK OF TRAINING/NEED FOR UPSKILLING

In Canada, it is estimated that 75% of care is provided by unpaid caregivers.[12] Yet as highlighted by several roundtable discussants, caregivers lack access to hands-on training and support for complex medical and personal care tasks, such as home dialysis, respiratory monitoring, gastrointestinal tube feeding, and injections, traditionally only performed by regulated health care professionals. In addition to contributing to concerns regarding the quality of care, it also reinforces a lack of acknowledgement and validation of the skill required of caregivers and is a factor in poorer outcomes for caregivers themselves.[13] Participants discussed how these kinds of care tasks can be experienced as overwhelming and even distressing to some caregivers who feel ill-equipped to take on this level of care. Given that medical needs of homecare recipients are becoming more and more complex, the ongoing lack of training and support was highlighted as a major challenge faced by caregivers daily.

CHALLENGES IN **CARE COORDINATION**

A main caregiving task is care coordination on behalf of care recipients, which involves navigating complex and fragmented health and social systems, scheduling appointments, treatments and services, communicating with a multitude of agencies and healthcare providers, and negotiating and advocating on behalf of the care recipient.[14] It was highlighted that this aspect of caregiving often goes unrecognized as an important challenge faced by caregivers despite evidence suggesting that this constitutes a significant portion of caregiver time and stress.[15] Roundtable participants discussed multiple factors at the micro, meso and macro levels that contribute to challenges in care coordination, ranging from language barriers, care literacy and access to information and technology, to confusing eligibility criteria for programs and benefits and disjointed services. It was discussed that caregivers require support in this role because challenges in care coordination ultimately pose barriers to accessing services, resulting in care recipients and caregivers not getting the services they need.

LACK OF INFORMATION

The majority of Canadian caregivers report that they lack access to other forms of caregiver-specific information, including information related to financial and emotional aspects of caregiving and finding appropriate services and support.[16] Not having access to important information impedes caregivers' abilities to plan for the present and prepare for the future. This challenge was framed as an issue among healthcare providers, with participants noting that discussions tend to focus on a diagnosis or treatment plan, rather than other post-diagnostic processes, logistical concerns, or psychosocial issues. As discussed by roundtable participants, this could be attributed in part to a lack of medical training in psychosocial aspects of illness, including caregiving issues, or as suggested by others, may be related to low levels of confidence among healthcare professionals in addressing these type of issues.[17]

The majority of Canadian caregivers report that they lack access to other forms of caregiver-specific information.

PHYSICAL/EMOTIONAL HEALTH

Caregiving results in chronic stress for many, with important negative effects on caregivers' physical and psychological well-being.[18,19,20,21] Research has consistently demonstrated that caregivers have worse physical health and mental health than non-caregiver comparisons, including higher rates of mortality.[22] The extensive evidence on the negative consequences to caregivers' health has prompted some to view caregiving as a public health issue.[23] Roundtable participants noted that many caregivers do not seek care for themselves and are also less likely to engage in preventive healthcare, citing barriers such as being too overwhelmed with caregiving duties to focus on themselves, being unsure of where to find the supports, or not feeling entitled to supports for themselves.[24,25] It was highlighted that at present, there is an insufficient response to this alarming issue, with experts citing poor health outcomes as one of the greatest challenges faced by caregivers.

FINANCIAL WELL-BEING

In Canada, the economic consequences of caregiving pose immense challenges. Financial support is the most significant need identified by Canadian caregivers and is also reported to be the greatest barrier to caregivers accessing a variety of supports.[26,27] In fact, a 2019 Change Foundation Report found that one-third of Canadian caregivers faced financial hardships in the preceding 12 months due to caregiving responsibilities.[28] In Canada, the majority of caregivers are employed in the labour force, and many see their work lives impacted, with financial implications for some.

According to Carers Canada, 15% of caregivers reduce their work hours, 40% miss days of work, 26% take a leave of absence, 10% turn down job opportunities and 6% eventually exit the labour force.[29]

Participants highlighted the long-term financial implications of these impacts on carers' career trajectories.

Participants also underscored that some caregivers were more vulnerable than others, for example those working precarious jobs, earning hourly wages, or those without access to sick pay or vacation pay. In addition to impacts on employment, discussants also focused on out-of-pocket expenditures shouldered by caregivers including costs related to transportation, medical supplies and professional services (e.g., personal support workers).[30] The financial impact for caregivers has also notably increased during the Covid-19 pandemic: according to a recent survey completed by the Ontario Caregiver Coalition, 40% of caregivers surveyed reported incurring higher costs for caregiving and have to use more of their personal finances to pay for costs due to Covid-19.[31]

Challenges at the Meso Level:

WORKPLACE AND EDUCATIONAL SETTINGS

Caregivers now make up one-third of the Canadian workforce.[32] While Canada's human rights laws extend protections to individuals based on their family status,[33] including a person's caregiving status, workplace accommodations for caregivers are often discretionary, and the duty to accommodate only goes so far. Furthermore, as highlighted by one roundtable participant, individuals in precarious or hourly-waged jobs may be unable or unwilling to disclose that they are caregivers or take time off, pitting them in even more vulnerable positions.

> Many roundtable participants discussed the **urgent need for caregiver-friendly and flexible workplace policies**, to complement the protections that are already in place for childcare.

We are also seeing an increase in the number of young caregivers (children and youth aged 24 and under), with estimates ranging from 12-28%.[34] Educational institutions (among other organizations and institutions) have important roles to play in identifying and supporting young caregivers, to help protect against a myriad of health, social and educational costs, including lower rates of school completion, higher rates of school absenteeism and lower rates of employment participation.[35,36] Given the potential lifelong implications of this trajectory, it is critical that educational institutions make concerted efforts to identify and support the needs of students who must balance their education with caregiving responsibilities.

CAREGIVERS GO UNRECOGNIZED IN HEALTHCARE SETTINGS

Patient-centered care has been championed in healthcare institutions across the country. Despite its inclusive philosophy, caregivers in practice are not routinely included as part of the healthcare 'team' nor as part of the unit of care that includes the care recipient. In fact, less than half of caregivers believe that healthcare providers view them as being caregivers.[37]

The participants of the roundtable discussions noted that there had been a significant shift in the context of the Covid-19 pandemic to include caregivers as "essential care partners," after the consequences of caregiver bans and visitor restrictions in healthcare and other residential settings demonstrated the detrimental impacts on patients and caregivers, healthcare providers, and healthcare systems, and spoke with a tone of cautious optimism of the potential for positive change in light of this important learning. It was also noted that some contexts such as palliative care are more inclusive of caregivers and routinely conceptualize the dyad and family as the unit of care, as grief and bereavement in this context is widely recognized.[38] However, we do not fare as well in situations where the role of the caregiver is more chronic, and where the result may be burnout.

Challenges at the Macro Level:

SOCIAL/CULTURAL NORMS

An important macro-level challenge impacting caregiving are social and cultural norms around age, gender, sexual orientation, ethnicity, language, socioeconomic status, immigration status, geographic setting, among others, that affect access to caregiving services, and expectations on individual caregivers.

Culture is an important and often overlooked consideration in caregiving, especially when it comes to culture specific approaches to who, where, how, and by whom care is provided. Termed "familialism," the assumption that family members such as parents, children or partners should assume responsibility for care provision conceptualizes caregivers as commodities, devalues the importance of their contribution and de-politicizes the importance of the issue of caregiving.[39,40] A homecare expert highlighted that cultural assessments are not routinely conducted prior to services being implemented, which would be an important step toward greater cultural sensitivity. Familialism also assumes a narrow definition of family based on blood or legal ties without accommodating chosen families including friends and neighbours or others who are not recognized under the law, such as same-sex couples who are not married.

Participants shared other important insights related to familialism, such as the implications for resource allocation. 'Chosen' family members are often not afforded the same rights as blood relatives and may not be able to access patient information or have the right to discuss health concerns. Furthermore, the responsibility for providing care is transferred from the public domain to the private household. Social changes in Canada, including more women in the workforce, higher divorce rates, lower birthrates, greater life expectancies and an aging population will reduce the number and proximity of family members available to care, and will increase care demands on those providing care.[41] Indeed, projections indicate there will be about 30% fewer close family members – namely spouses and adult children – that would potentially be available to provide unpaid care, which will create more burden for the fewer family caregivers available. [42]

Finally, discussants also highlighted that familialism has important impacts on how caregivers are viewed in formal systems: assessments, services and supports are often tailored to the care recipients; the needs of caregivers go unrecognized; and we lack the instinct and accountability at systems levels to do things differently. These trends may very well contribute to the challenge of caregiver self-identification; if not identified by healthcare teams and other professionals, it is no wonder that self-identification remains an ongoing issue.

HEALTH CARE INFRASTRUCTURE AND FORMAL SERVICES

Home care is an increasingly important component of health care systems across Canada.[43] Home care consists of a range of services such as assistance with personal care, medical care, safety assessments and is delivered across a range of settings, including in people's personal homes as well as in other community settings, such as retirement homes or group homes.[44] There are for-profit and non-profit companies that deliver homecare, however the roundtable discussions focused on services funded by provincial healthcare systems. By and large, people would prefer to be cared for at home and indeed, the vast majority of care occurs in home and community settings, with one homecare expert noting that only 6% of seniors in Canada live in long-term care settings. Yet home and community care networks across the country are plagued with problems with significant impacts on caregivers.

Alone and in combination, participants described homecare issues as foundational challenges with many reverberating effects on the caregiver, often resulting in high levels of stress due to having to take on a greater share of caregiving tasks and associated financial costs. Indeed, the challenges can make organizing, financing, and sustaining care at home too great to manage, resulting in institutionalization for the care recipient and even the caregiver if they are older adults themselves. [50,51] Addressing this challenge is crucial in advancing the interests and needs of caregivers.

THE MOST CITED ISSUES IN HOME CARE INCLUDE:

- **Financial Constraints Resulting in Service Shortages:** Insufficient funding for home care results in service shortages. Less than 20% of spending on personal care services is allocated to home care, with the remaining funds funneled into institutional settings such as long-term care.[45]
- **Language Barriers:** Canada is one of the world's most ethnically diverse countries, and yet as pointed out by panelists, most caregiving services are provided in English or French and are not ethno-specific. Medical and paramedical professionals rarely offer language-specific services; ethno-specific agencies in the community are a minority; and even federal institutions intended to serve all Canadians such as Service Canada do not consistently offer interpretations services, posing a huge barrier that significantly impacts accessibility for many groups.
- **Staffing Shortages and Working Conditions:** Funding shortages contribute to staffing shortages, making it more difficult to recruit and retain staff, and impact homecare workers' working conditions.[46] Some provincial governments (e.g., Ontario) tried to rectify this at the height of the COVID-19 pandemic by introducing wage enhancements for community personal support workers. However, payments have been slow to flow to agencies, further cash-strapping these organizations.
- **Lack of Continuity of Care:** Participants expressed concern regarding inconsistent and unreliable homecare and discussed impacts on continuity and quality of care. Some of the most common issues noted included last-minute cancellations, and a varying roster of workers providing care, which makes it difficult to establish rapport and trust.
- **A Narrow Focus on Care Recipient Medical Needs:** Publicly funded services are extremely barebones and focus on medical needs of care recipients only. This results in very limited funding for assistance with essential tasks such as food preparation and housekeeping. Furthermore, roundtable participants pointed out that even when services are provided, for example assistance with laundry or assistance in making a sandwich, it is usually only for the care recipient, and questioned how this might be helpful (or not) for the caregiver.
- **Insufficient Respite:** Respite care is often cited as the most important form of caregiver support to alleviate stress and burnout.[47] Respite can take many forms, ranging from practical assistance with meals or transportation, to in-home respite, facility-based respite, or day programs. Demand is increasing for respite services, particularly in-home respite, but as discussed above, there are shortages due to insufficient public funds for homecare. [48] Roundtable participants also pointed out that most of the publicly funded respite options offer 'replacement care' even though caregivers may primarily need a break from the caregiving tasks and responsibilities, not the relationship itself.
- **A Lack of Choice:** Care recipients should be given a choice regarding the care tasks they receive, and caregivers should be given a choice in terms of which tasks they would like to assume. At present, there is an expectation that caregivers help with all types of care, including performing complicated healthcare interventions, often with little training and support. The system will also continuously load the care onto the caregiver with little option to object or negotiate. Finally, given the unique needs of caregivers based on individual characteristics and circumstances, choice is needed, as one size does not fit all.
- **Barriers of Bureaucracy:** Home and community care systems are complex, fragmented, and bureaucratic and pose structural burdens to caregivers. Participants underscored that this is a known significant contributor to caregiving burden.[49]

POLITICAL WILL

Roundtable participants raised the important issue of political will in furthering interests of caregivers, noting that political will and leadership are crucial in establishing caregiver-friendly policy and legislation, and attracting more resources to address the multiple issues. Some participants expressed a sense of hope that caregiving will finally get the political attention it deserves because the pandemic has highlighted how essential caregivers are to society's functioning;[52] however, others pointed out that Canada's major political parties have yet to make a commitment to address the caregiving crisis.

FINANCIAL

Nearly all roundtable participants spoke about financial challenges experienced by caregivers including macro-level forces impacting upon the financial resources available to caregivers. As discussed, the absence of sustained political will and recognition of caregivers' significant contributions has had profound impacts on public resource allocation for caregivers. Not only are publicly funded supports chronically underfunded, financial supports for caregivers in the form of income replacement programs and tax credits do little to ease the burden.

> Results from Statistics Canada's 2018 General Social Survey on Caregiving showed that only 6% of caregivers received money from government programs, while only 8% accessed tax credits.[53]

Participants agreed that income security is a critical issue faced by caregivers. Caregivers in Canada are not paid for their work, though estimates indicate that if paid, the care they provide would total $9 billion for 2019 alone.[54] The majority of caregivers do not qualify for old age pensions and are ineligible for income replacement programs, including the Family Caregiver Benefit and the Compassionate Care Benefit. These programs are designed for caregivers who require a short-term leave from work to provide care for someone who is critically or terminally ill and are available to those who have paid sufficient premiums into the programs. Participants highlighted that this may exclude caregivers who had to take significant time away from work due to caregiving demands.[55,56] The Canada Revenue Agency briefly instituted the emergency Canada Recovery Caregiving Benefit during the pandemic, a step in the right direction in recognizing the importance of financial benefits for caregivers who could not work due to Covid-19-related caregiving responsibilities.[57] This program ended in November 2021 and has not been extended.

The most common form of financial support for caregivers are tax credits offered by provincial, territorial, and federal governments.[58] Some credits are refundable, however participants commented that most are non-refundable, thus limiting their effectiveness particularly among low-income earners.[59] In addition, discussants pointed out that financial eligibility for tax credits are tied to the care recipient's financial situation rather than that of the caregiver, excluding some who may otherwise meet low-income eligibility criteria. Participants emphasized that the low uptake of tax credits speaks to the need to inform the public about the availability of such credits, simplify the processes by which they can be accessed, remove overly restrictive and narrow eligibility requirements, and importantly, make them refundable credits so that low-income caregivers can actually make use of the benefit.[60,61,62,63]

Priorities for Action

Priority 1: Increase Collaboration and Coordination

Roundtable participants identified an urgent need for strong, cross-sectoral, interprovincial, and national collaborations to address rapidly growing caregiver needs now and in the future. Participants identified that this could be best achieved through adopting a collective impact approach to amplify the voices of those who care about caregivers, create new opportunities for organized action, promote synergy and collaboration, and act as a single unified voice to strengthen advocacy, generate greater public awareness and ultimately influence public policy and attract greater resources.

Participants noted that caregiving organizations from across the country, along with researchers, professional service providers, and caregivers have already come together to form the Canadian Caregiver Coalition. The Coalition is a national advocacy body, currently operating without funding, that represents caregiver needs and promotes their interests within communities and governments.[64] Participants highlighted that some provinces, such as Alberta, have developed a Caregiver Coalition with a core platform, enabling cross-ministerial cooperation. However, Canada still lacks a national caregiving strategy and a funded national body to guide caregiver initiatives. A collective impact approach could help us to build on the growing momentum and see us through to the creation of a cohesive pan-Canadian caregiving strategy.

Participants of the roundtables identified a need to create the right mechanisms to enable cooperation and sharing. They discussed that a critical piece of infrastructure could include the creation of a national inventory: a centralized place for caregivers, healthcare professionals and organizations alike to access information and resources. The platform could also serve as a place to exchange best practices, which would encourage the replication and scaling of successful programs. It was suggested that the creation of an inventory could reduce silos and duplication by focusing on commonalities across caregiving experiences and activities, and by centralizing resources that are typically separated into disease-specific silos. Participants also reflected on how a centralized inventory could improve caregivers' and healthcare providers' access to information and resources and simplify system navigation issues faced by many caregivers.

Participants also stressed the importance of broadening the conversation to include a range of perspectives, such as policy makers, and highlighted the importance of finding different ways of bringing everyone together. Stakeholder meetings, conferences, and other opportunities were suggested as opportunities to bring together a range of cross-sectoral actors to amplify the voices of caregivers and their advocates and increase collaboration and coordination.

Finally, discussants highlighted that a collective impact model would create opportunity for a coordinated, strategic and innovative national research program, focused on interventions with demonstrated impact. Participants highlighted that interventional studies would be important to evaluate the feasibility and effectiveness of current support models (e.g. peer support, the most widely studied) as well as innovative models of support, including virtual, and identified the value of including international perspectives to help inform best practices.

ROUNDTABLE DISCUSSIONS YIELDED SIX MAIN PRIORITIES THAT ADDRESS THE CHALLENGES AND BARRIERS DISCUSSED ABOVE:

1. Increase Collaboration and Coordination
2. Increase Awareness and value of caregivers
3. Increase employment, income and financial security
4. Ensure care systems support caregivers
5. Ensure Canadians are prepared to be caregivers
6. Establish local communities as first responders

Priority 2: Increase Awareness and Value of Caregivers

Participants stressed that building awareness and acknowledgement are crucial priorities, noting that without it, we are less powerful to make change. Some sub-groups within the caregiving population need and deserve special consideration, such as young caregivers whose voices and unique needs have been missing from national conversations.[65]

Finally, participants noted that the way we value care also has important implications on caregiver awareness and recognition. Care is a basic social infrastructure: without it, we could not function as a society. Using this lens could help shift government policy toward greater recognition of caregiving as an essential social function, with more financial resources, protections, services and supports provided in turn. This would have trickle down effects to meso and micro levels and could address the common challenges. And as highlighted by participants, it would also contribute to a shift in predominant cultural norms toward a greater awareness and recognition of caregivers and their needs.

PARTICIPANTS DISCUSSED WAYS TO BUILD GREATER AWARENESS AND RECOGNITION:

MACRO

Public awareness campaigns were identified as an effective strategy to build public recognition about caregiving. For example, participants shared that the national television commercials produced by Petro Canada to announce the creation of the CareMakers Foundation generated public discussion, public interest and greater awareness on caregiving.

MESO

Information could be targeted to specific communities and institutions, for example:

Information on caregiver supports, be it financial, emotional or respite, could be targeted to healthcare professionals to encourage more offers of support to caregivers, and generate more referrals. Information on young caregivers could also be distributed within education and other community settings, along with toolkits to support professionals in identifying and supporting them.

Employers could be provided with tools to help create caregiver friendly policies; generate solutions for accommodations; and develop business cases demonstrating the value of supporting caregivers, among others.

Caregiver identification can be implemented across institutions as a means of formal acknowledgment of their role. This can take many forms such as caregiver passports or caregiver IDs, as exemplified by the work of the Ontario Caregiver Organization: **https://ontariocaregiver.ca/caregiver-id-formal-recognition-of-the-caregiving-role/**.

Community led initiatives, organized through neighbourhood groups, and formal and informal networks are also powerful ways of generating awareness and recognition at the meso level. Several examples of this emerged during the Covid-19 pandemic such as households putting hearts in their windows to thank frontline workers; communities also came together via social media to offer support to those impacted by pandemic restrictions.

MICRO

A shift in focus toward recognizing caregivers' needs and providing them with support of their own would be a powerful way to promote caregiver self-identification. This could take the form of a validating and supportive conversation, a referral for additional support, or printed materials that are targeted to the caregiver. Additionally, simple checklists, self-assessments or brief questionnaires could also help individuals to identify as caregivers, and could help direct them to additional information or resources as needed.

Priority 3: Increase Employment, Income and Financial Security

Roundtable participants identified caregiver-friendly workplaces as a crucial priority, highlighting the need to closely examine how to improve workplace benefits and employment policies to enhance job security for the 6.1 million caregivers balancing work and care.[66] Organizations including the Vanier Institute and Carers Canada are researching and advocating for the adoption of caregiver-friendly policies and programs. The global pandemic has also set up the conditions for employers to look at things differently and could include introducing (or sustaining) opportunities to work remotely, more flexibility in scheduling and access to improved technologies that enable work from home. Participants urged that now is the time for caregiving advocacy groups to provide tools for employers to help bring about change, for example by building out business cases, developing standards or other organizational policies that could be adopted, and championing employers supporting caregivers. Other proposed suggestions included government incentives for employers through tax levers of various kinds and other incentives, as well as caregiver-friendly policy and legislation.

BELOW ARE LINKS TO ADDITIONAL READING MATERIALS FROM THE SECTOR:

NATIONAL SENIORS STRATEGY
nationalseniorsstrategy.ca/the-four-pillars/pillar-4/caregivers-older-adults-workforce/#_edn7

CANADIAN HOME CARE ASSOCIATION
cdnhomecare.ca/shaping-future-workplaces/

THE ONTARIO CAREGIVER ORGANIZATION
ontariocaregiver.ca/wp-content/uploads/2020/06/Employer-Action-Steps-COVID19-Impact-on-Working-Caregivers-2.pdf

It was emphasized that urgent action and significant resources are required to improve caregivers' financial security through a multi-pronged response. First and foremost, participants felt strongly that caregivers need and deserve to be compensated for their work. Discussants pointed out that other countries, such as the U.K., Australia, Norway, and Sweden, provide direct compensation to caregivers.

Participants collectively agreed on the need to improve access to existing financial supports through increased information, simplified where possible, about available resources, eligibility criteria, application support, etc.[67] It was underscored that barriers must be removed for low-income caregivers, which could be accomplished by basing financial eligibility on the caregiver's circumstances rather than on those of the care recipient, or by changing non-refundable tax credits to refundable, to benefit the most financially disadvantaged.[68] Participants highlighted a need to expand access to income replacement programs and other financial supports as too many caregivers do not qualify for existing programs. Other forms of financial benefits, such as subsidies or supplements for out-of-pocket expenses were also discussed, which could also provide meaningful financial relief to caregivers.

Finally, it was highlighted that the public and private sectors must work together to offer additional financial supports and benefits for caregivers. There are many opportunities, like offering discounts or other financial or in-kind benefits, for corporations to support caregivers. But first, for-profit corporations must be made aware of the financial implications of caregiving to help mobilize them to action.

Priority 4: Ensure Care Systems Support

Participants expressed that an important priority lay in ensuring that care systems better support caregivers. It was discussed that healthcare settings must shift towards an acknowledgement of the role of caregivers as experts, while also recognizing their need for support. Some participants discussed how relationship-centred care approaches that recognize the centrality of caregivers in the care of patients could be adopted across health institutions.

Participants discussed that healthcare providers require more training in how to better support caregivers. In addition to training, it was suggested that other mechanisms such as caregiver competency frameworks, caregiver assessments, caregiver care pathways, or caregiver-specific order sets and billing codes could be implemented to support such a change.

Participants also emphasized important changes that are needed in homecare, noting that issues at this level are major drivers of stress, burnout and institutionalization. Participants highlighted that despite governments having aging in place strategies, existing home and community supports are wholly inadequate to address the ever-increasing care and support needs of care recipients, with the vast majority of care falling on caregivers (to be sure, supports in hospitals and long-term care settings are also insufficient).[69,70] The Canadian Home Care Association has advocated for a national action plan for more and better home care and has called for inter-governmental collaboration, necessary resource allocation and strong leadership to drive change.[71] The Covid-19 pandemic has also underscored the need for better home care options, after exposing the precarious living conditions of Canada's long-term care homes which saw the highest Covid-19 fatality rates among other wealthy countries during the first wave of the pandemic (March to August 2020).[72,73] Participants felt strongly that governments must act now and invest sufficiently in home care as a requirement to improve the conditions of caregivers.

> *…healthcare settings must shift towards an acknowledgement of the role of caregivers as experts, while also recognizing their need for support.*

Priority 5: Ensure Canadians are Prepared to be Caregivers

Discussants highlighted that in Canada, people are not adequately prepared to become caregivers, and as a society, the challenges of caregiving tend to be underplayed. It was discussed how this can make it more difficult for caregivers to feel entitled to help and support. Multiple participants advocated for a shift toward a more proactive approach (where possible), citing the potential downstream benefits such as earlier intervention, higher uptake of supports, protection against burnout, and reduced social isolation, among other positive outcomes.

> Some discussants highlighted an opportunity to include the topic of **caregiving in school curriculums,** emphasizing once more the high rate of young careers in Canada and the importance of early education on this prevalent social issue.

Participants also discussed that existing services are typically only accessed when caregivers are in near-crisis situations and underscored a great need for more education as to what services are available as well as more funding to increase supports earlier on in the caregiving trajectory. Finally, participants highlighted that better preparation could help to upskill, capacitate and empower caregivers, while simultaneously also shifting formal systems toward greater recognition and earlier support for caregivers.

Priority 6: Establish Local Communities as First Responders

Community supporting community emerged as the final priority. Roundtable participants with expertise in community change advocated for a focus on community development approaches to bring forth new solutions in caregiving by focusing on underrecognized yet powerful community assets, such as dynamic and resilient informal support networks, to better support those who care for others.

Participants highlighted that communities are often the "first responders" in times of need, stepping in well before formal systems can respond (case in point: caregivers!).[74] However, much of the dialogue on supporting caregivers has focused on 'formal' systems such as publicly funded healthcare institutions.[75] Participants discussed solutions like the creation of 'caring communities' and how these could be nurtured at both local and national levels through grassroot efforts or 'care commitments challenges' similar to the United States where activities are spearheaded by the Caring Across Generations organization. Participants emphasized that we could build on the lessons learned through the pandemic: despite physical distancing and other pandemic protocols, Covid-19 has taught us the importance of communities coming together to support others in times of need.

Evolving the Role of the CareMakers Foundation and Other Grantmakers

Since the launch of the Petro-Canada CareMakers Foundation a year ago, we have started making great strides in our commitment to creating awareness on caregiving, understanding the issues of caregiving and inspiring Canadians to give. We have successfully raised funds and collaborated with five charitable partners across Canada whose work centres around meeting the immediate needs of caregivers at a time when families were experiencing uncertainties due to Covid-19.

In 2022, we intend to increase our reach and impact by funding charities with innovative ideas that can bring about solutions to the systemic challenges family caregivers face while amplifying some of the opportunities outlined in this paper. We will partner with more charitable organizations to deliver key programs focused on the development and launch of caregiving resources and support across the board.

We will work towards this goal by championing a national conversation around caregiving, addressing the needs of a diverse group of family caregivers with unique needs, and continuing to raise funds through various channels. We recognize that our work is just beginning and will continue to evolve through further discussion and learnings from experts and those with lived experience in family caregiving.

Conclusion

> As one roundtable participant put it, **"you don't know until you know"** what it means to be a family caregiver.

So long as caregiving remains a problem only for those directly affected by it, caregiving will not become a national priority. We at the Petro-Canada CareMakers Foundation, alongside other organizations dedicated to family caregiving, are working to fulfill our vision of a country where family caregivers are valued, recognized and supported. We are grateful to all of the participants of the roundtables, for sharing their thoughts, learnings and lived experience. We look forward to continuing our conversation together.

References

[1] Statistics Canada. (2020). The Daily – Caregivers in Canada, 2018. Retrieved from: https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm

[2] Law, S., Ormel, I., Babinski, S., Kuluski, K., & Quesnel-Vallée, A. (2021). "Caregiving is like on the job training but nobody has the manual": Canadian caregivers' perceptions of their roles within the healthcare system. BMC geriatrics, 21(1), 1-11. Retrieved from: https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-021-02354-z

[3] Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. Journal of Social Work Education, 44(sup3), 105-113. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2791523/

[4] Schulz, R., Eden, J., & National Academies of Sciences, Engineering, and Medicine. (2016). Economic impact of family caregiving. In Families Caring for an Aging America. National Academies Press (US). Retrieved from: https://www.ncbi.nlm.nih.gov/books/NBK396402/

[5] Brodhead, T. (2011). In a world of unpredictable change, what Canada needs most is resiliece. The J.W. McConnell Family Foundation. Retrieved from: https://mcconnellfoundation.ca/wp-content/uploads/2017/07/Resilience.pdf

[6] Statistics Canada. (2020). The Daily – Caregivers in Canada, 2018. Retrieved from: https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm

[7] Family Caregiver Alliance. (2021). Definitions. Retrieved from: https://www.caregiver.org/definitions-0

[8] Turcotte, M. (2013). Family caregiving: What are the consequences?. Retrieved from: https://www150.statcan.gc.ca/n1/pub/75-006-x/2013001/article/11858/sources-eng.htm

[9] Hango, D. (2020). Support Received by Caregivers in Canada: Statistics Canada. Retrieved from: https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00001-eng.htm#n1

[10] Canada. Employer Panel for Caregivers. (2015). When work and caregiving collide: How employers can support their employees who are caregivers. Government of Canada, Employment and Social Development Canada. Retrieved from: https://publications.gc.ca/site/eng/478070/publication.html

[11] Law, S., Ormel, I., Babinski, S., Kuluski, K., & Quesnel-Vallée, A. (2021). "Caregiving is like on the job training but nobody has the manual": Canadian caregivers' perceptions of their roles within the healthcare system. BMC geriatrics, 21(1), 1-11. Retrieved from: https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-021-02354-z

[12] Stall, N. (2019). We should care more about caregivers. Canadian Medical Association Journal, 191, E245-E246. Retrieved from: https://www.cmaj.ca/content/191/9/E245

[13] Flood, Colleen M., Deirdre DeJean, Lorraine Frisina Doetter, Amélie Quesnel-Vallée, and Erik Schut. 2021. Assessing Cash-For-Care Benefits to Support Aging at Home in Canada. IRPP Study 83. Montreal: Institute for Research on Public Policy. Accessed online: https://irpp.org/wp-content/uploads/2021/04/Assessing-Cash-for-Care-Benefits-to-Support-Aging-at-Home-in-Canada.pdf

[14] Taylor, M. G., & Quesnel-Vallee, A. (2017). The structural burden of caregiving: Shared challenges in the United States and Canada. The Gerontologist, 57(1), 19-25. Retrieved from: https://academic.oup.com/gerontologist/article/57/1/19/2631992

[15] Taylor, M. G., & Quesnel-Vallee, A. (2017). The structural burden of caregiving: Shared challenges in the United States and Canada. The Gerontologist, 57(1), 19-25. Retrieved from: https://academic.oup.com/gerontologist/article/57/1/19/2631992

[16] National Institute on Ageing. (2018). Why Canada Needs to Better Care for Its Working Caregivers. Toronto, ON: National Institute on Ageing White Paper. Available at: https://www.ryerson.ca/nia/commentary/caring-for-working-caregivers

[17] The Change Foundation. (2019). Spotlight on Ontario's Caregivers report 2019. Retrieved from: https://ontariocaregiver.ca/publications/spotlight-report-2019/

[18] Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. Journal of Social Work Education, 44(sup3), 105-113. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2791523/

[19] Vanier Institute (2017). A snapshot of family caregiving and work in Canada. Retrieved from: http://vanierinstitute.ca/snapshot-family-caregiving-work-canada/

[20] Hango, D. (2020). Support Received by Caregivers in Canada: Statistics Canada. Retrieved from: https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00001-eng.htm#n1

[21] Stall, N. (2019). We should care more about caregivers. Canadian Medical Association Journal, 191, E245-E246. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6400651/#b3-191e245

[22] Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. Jama, 282(23), 2215-2219. Retrieved from: https://pubmed.ncbi.nlm.nih.gov/10605972/

[23] Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. Journal of Social Work Education, 44(sup3), 105-113. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2791523/

[24] Law, S., Ormel, I., Babinski, S., Kuluski, K., & Quesnel-Vallée, A. (2021). "Caregiving is like on the job training but nobody has the manual": Canadian caregivers' perceptions of their roles within the healthcare system. BMC geriatrics, 21(1), 1-11. Retrieved from: https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-021-02354-z

[25] Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: a clinical review. Jama, 311(10), 1052-1060. Retrieved from: https://jamanetwork.com/journals/jama/fullarticle/1840211

[26] Hango, D. (2020). Support Received by Caregivers in Canada: Statistics Canada. Retrieved from: https://www150.statcan.gc.ca/n1/pub/75-006-x/2020001/article/00001-eng.htm#n140-41

[27] The Change Foundation. (2019). Spotlight on Ontario's Caregivers report 2019. Retrieved from: https://changefoundation.ca/spotlight-on-caregivers-report/

[28] The Change Foundation. (2019). Spotlight on Ontario's Caregivers report 2019. Retrieved from: https://changefoundation.ca/spotlight-on-caregivers-report/

[29] National Institute on Ageing. (2020). An Evidence Informed National Seniors Strategy for Canada - Third Edition. Toronto, ON: National Institute on Ageing. Retrieved from: https://nationalseniorsstrategy.ca/the-four-pillars/pillar-4/financial-support-caregivers/

[30] Fast, J., Eales, J. & Keating, N. (2018). Informal Caregiving: What Are the Financial Costs for Caregivers? CRDCN Synthesis Series. Retrieved from: https://crdcn.org/sites/default/files/financial_costs_of_family_caregiving.pdf

[31] Ontario Caregiver Organization. (2020). 3rd Annual Spotlight on Ontario's Caregivers: COVID-19 Edition. Retrieved from: https://ontariocaregiver.ca/wp-content/uploads/2020/12/OCO-Spotlight-report-English-Dec10.pdf

[32] Fast, J. (2016). We Need to Start Caring For Family Caregivers. Institute for Research on Public Policy. Retrieved from: https://irpp.org/op-ed/we-need-to-start-caring-for-caregivers/

[33] Canadian Human Rights Commission. (2014). A guide to balancing work and caregiving obligations: Collaborative approaches for a supportive and well-performing workplace. Retrieved from: https://www.chrc-ccdp.gc.ca/sites/default/files/2020-07/a_guide_to_balancing_work.pdf

[34] Lakman, Y., Chalmers, H., & Sexton, C. (2017). Young carers' educational experiences and support: A roadmap for the development of school policies to foster their academic success. Alberta Journal of Educational Research, 63(1), 63-74. Retrieved from: https://cdm.ucalgary.ca/index.php/ajer/article/view/56226

[35] Ca Cass, B., Smith, C., Hill, T., Blaxland, M., & Hamilton, M. (2009). Young carers in Australia: understanding the advantages and disadvantages of their care giving. FaHCSIA Social Policy Research Paper, (38). Retrieved from: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1703262.

[36] Stamatopoulos, V. (2015). One million and counting: The hidden army of young carers in Canada. Journal of Youth Studies, 18(6), 809-822. Retrieved from: https://www.tandfonline.com/doi/abs/10.1080/13676261.2014.992329

[37] The Change Foundation. (2019). Spotlight on Ontario's Caregivers Report 2019. Retrieved from: https://ontariocaregiver.ca/publications/spotlight-report-2019/

[38] Law, S., Ormel, I., Babinski, S., Kuluski, K., & Quesnel-Vallée, A. (2021). "Caregiving is like on the job training but nobody has the manual": Canadian caregivers' perceptions of their roles within the healthcare system. BMC geriatrics, 21(1), 1-11. Retrieved from: https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-021-02354-z

[39] Law, S., Ormel, I., Babinski, S., Kuluski, K., & Quesnel-Vallée, A. (2021). "Caregiving is like on the job training but nobody has the manual": Canadian caregivers' perceptions of their roles within the healthcare system. BMC geriatrics, 21(1), 1-11. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8243301/

[40] Fast, J., Keating, N., Eales, J., Kim, C., & Lee, Y. (2021). Trajectories of family care over the lifecourse: evidence from Canada. Ageing & Society, 41(5), 1145-1162. Retrieved from: https://www.cambridge.org/core/journals/ageing-and-society/article/trajectories-of-family-care-over-the-lifecourse-evidence-from-canada/55DD2050516D929AE809362A086640EE

[41] Law, S., Ormel, I., Babinski, S., Kuluski, K., & Quesnel-Vallée, A. (2021). "Caregiving is like on the job training but nobody has the manual": Canadian caregivers' perceptions of their roles within the healthcare system. BMC geriatrics, 21(1), 1-11. Retrieved from: https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-021-02354-z

[42] Stats Can, 2015: NIA, 2019

[43] Dunbrack, J. (2003). Respite for family caregivers: An environmental scan of publicly-funded programs in Canada. Health Canada. Retrieved from: https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/home-continuing-care/respite-family-caregivers-environmental-scan-publicly-funded-programs-canada.html

[44] Canadian Home Care Association (CHCA). (2016). Better home care in Canada: A national plan. Retrieved from http://www.thehomecareplan.ca/wp-content/uploads/2016/10/BetterHome-Care-Report-Oct-web.pdf.

[45] Grignon, M., & Spencer, B. (2018). The Funding of Long-Term Care in Canada: What Do We Know, What Should We Know? Canadian Journal on Aging / La Revue Canadienne Du Vieillissement, 37(2), 110-120. doi:10.1017/S0714980818000028. Retrieved from: https://policyoptions.irpp.org/fr/magazines/may-2020/the-case-for-public-long-term-care-insurance/

[46] Keefe, J. (2011). Supporting caregivers and caregiving in an aging Canada. Institute for Research on Public Policy. Retrieved from: https://irpp.org/research-studies/supporting-caregivers-and-caregiving-in-an-aging-canada/

[47] https://www.oecd.org/els/health-systems/47884889.pdf

[48] Dunbrack, J. (2003). Respite for family caregivers: An environmental scan of publicly-funded programs in Canada. Health Canada. Retrieved from: https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/home-continuing-care/respite-family-caregivers-environmental-scan-publicly-funded-programs-canada.html

[49] https://academic.oup.com/gerontologist/article/57/1/19/2631992

[50] Flood, Colleen M., Deirdre DeJean, Lorraine Frisina Doetter, Amélie Quesnel-Vallée, and Erik Schut. 2021. Assessing Cash-For-Care Benefits to Support Aging at Home in Canada. IRPP Study 83. Montreal: Institute for Research on Public Policy. Accessed online: https://irpp.org/wp-content/uploads/2021/04/Assessing-Cash-for-Care-Benefits-to-Support-Aging-at-Home-in-Canada.pdf

[51] Brodhead, T. (2011). In a world of unpredictable change, what Canada needs most is resiliece. The J.W. McConnell Family Foundation. Retrieved from: https://mcconnellfoundation.ca/wp-content/uploads/2017/07/Resilience.pdf

[52] Law, S., Ormel, I., Babinski, S., Kuluski, K., & Quesnel-Vallée, A. (2021). "Caregiving is like on the job training but nobody has the manual": Canadian caregivers' perceptions of their roles within the healthcare system. BMC geriatrics, 21(1), 1-11. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8243301/

[53] Statistics Canada. (2020). The Daily – Caregivers in Canada, 2018. Retrieved from: https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm

[54] MacDonald, B.J., Wolfson, M., and Hirdes, J. (2019). The Future Co$t of Long-Term Care in Canada. National Institute on Ageing, Ryerson University. Retrieved from: https://bc.healthyagingcore.ca/sites/default/files/2020-05/The%2BFuture%2BCost%2Bof%2BLong-Term%2BCare%2Bin%2BCanada.pdf

[55] The Change Foundation. (2019). Spotlight on Ontario's Caregivers report 2019. Retrieved from: https://changefoundation.ca/spotlight-on-caregivers-report

[56] Government of Canada. (2021). EI Caregiving Benefits. Retrieved from: https://www.canada.ca/en/services/benefits/ei/caregiving.html

[57] Government of Canada. (2021). Canada Recovery Caregiving Benefit (CRCB). Retrieved from: https://www.canada.ca/en/revenue-agency/services/benefits/recovery-caregiving-benefit.html

[58] National Institute on Ageing. (2020). An Evidence Informed National Seniors Strategy for Canada - Third Edition. Toronto, ON: National Institute on Ageing. Retrieved from: https://nationalseniorsstrategy.ca/the-four-pillars/pillar-4/financial-support-caregivers/

[59] National Institute on Ageing. (2020). An Evidence Informed National Seniors Strategy for Canada - Third Edition. Toronto, ON: National Institute on Ageing. Retrieved from: https://nationalseniorsstrategy.ca/the-four-pillars/pillar-4/financial-support-caregivers/

[60] National Institute on Ageing. (2020). An Evidence Informed National Seniors Strategy for Canada - Third Edition. Toronto, ON: National Institute on Ageing. Retrieved from: https://nationalseniorsstrategy.ca/the-four-pillars/pillar-4/financial-support-caregivers/

[61] Stall, N. (2019). We should care more about caregivers. Canadian Medical Association Journal, 191(9), E245-E246. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6400651/#b3-191e2454344

[62] National Institute on Ageing. (2018). Why Canada Needs to Better Care for Its Working Caregivers. Toronto, ON: National Institute on Ageing White Paper. Available at: https://www.ryerson.ca/nia/commentary/caring-for-working-caregivers/

[63] Canadian Centre for Elder Law. (2010). Chapter Five — Indirect Compensation of Caregivers through the Tax System. Retrieved from: https://www.bcli.org/elder-law-resources/execsum/chapter5

[64] Coalition, C. C. (2013). A Canadian caregiver strategy: A Canada that recognizes, respects and supports the integral role of family caregivers in society. Retrieved from: https://www.carerscanada.ca/wp-content/uploads/2021/03/CCC-Sttrategy-Renewal_web-pages.pdf

[65] Charles, G., Stainton, T., & Marshall, S. (2012). Young carers in Canada: The hidden costs and benefits of young caregiving. Ottawa, ON: The Vanier Institute of the Family. Retrieved from: http://vanierinstitute.ca/wp-content/uploads/2015/12/CFT_2012-07-00_EN.pdf

[66] Carers Canada. (2021). Supporting Working Caregivers: Shaping Future Workplaces. Retrieved from: https://www.carerscanada.ca/supporting-working-caregivers/

[67] National Institute on Ageing. (2020). An Evidence Informed National Seniors Strategy for Canada - Third Edition. Toronto, ON: National Institute on Ageing. Retrieved from: https://nationalseniorsstrategy.ca/the-four-pillars/pillar-4/financial-support-caregivers/

[68] National Institute on Ageing. (2020). An Evidence Informed National Seniors Strategy for Canada - Third Edition. Toronto, ON: National Institute on Ageing. Retrieved from: https://nationalseniorsstrategy.ca/the-four-pillars/pillar-4/financial-support-caregivers/

[69] Canadian Home Care Association (CHCA). (2016). Better home care in Canada: A national plan. Retrieved from http://www.thehomecareplan.ca/wp-content/uploads/2016/10/BetterHome-Care-Report-Oct-web.pdf

[70] Flood, Colleen M., Deirdre DeJean, Lorraine Frisina Doetter, Amélie Quesnel-Vallée, and Erik Schut. 2021. Assessing Cash-For-Care Benefits to Support Aging at Home in Canada. IRPP Study 83. Montreal: Institute for Research on Public Policy. Accessed online: https://irpp.org/wp-content/uploads/2021/04/Assessing-Cash-for-Care-Benefits-to-Support-Aging-at-Home-in-Canada.pdf

[71] Canadian Home Care Association. (2017). Strategic Plan. Retrieved from: https://cdnhomecare.ca/strategic-plan/

[72] Leroux, M-L., Achou, B., Glenzer, F., Lee, M., De Donder, P. (2021). Opinion: Canadians want home care, not long-term care facilities, after COVID-19. National Post. Retrieved from: https://nationalpost.com/news/canada/canadians-want-home-care-not-long-term-care-facilities-after-covid-19-2

[73] Howlett, K. (2021). Canadians died of COVID-19 in long-term care by the thousands. So why are there so few coroners' reports?. The Globe and Mail. Retrieved from: https://www.theglobeandmail.com/canada/article-canadians-died-of-covid-19-in-long-term-care-by-the-thousands-so-why/

[74] Brodhead, T. (2011). In a world of unpredictable change, what Canada needs most is resilience. The J.W. McConnell Family Foundation. Retrieved from: https://mcconnellfoundation.ca/wp-content/uploads/2017/07/Resilience.pdf

[75] Brodhead, T. (2011). In a world of unpredictable change, what Canada needs most is resilience. The J.W. McConnell Family Foundation. Retrieved from: https://mcconnellfoundation.ca/wp-content/uploads/2017/07/Resilience.pdf

[76] Joint SDG Fund. (n.d.). Goal 3: Good health and well-being. Retrieved December 20, 2021, from https://www.jointsdgfund.org/sustainable-development-goals/goal-3-good-health-and-well-being